ERASMUS+ PROJECT

SYNERGISTIC EDUCATION OF PARENTS WITH CHILDREN WITH SPECIAL NEEDS - SYNERGYED

GUIDELINES FOR PARENTING CHILDREN WITH DEVELOPMENTAL DIFFICULTIES/DISABILITIES

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Introduction

Welcome to the comprehensive guide on parenting children with developmental difficulties or disabilities. Parenting is a rewarding yet challenging journey, and navigating this path with a child who has unique needs requires additional understanding, compassion, and specialized strategies. This guide is designed to provide you with valuable insights, practical advice, and empathetic support as you embark on the journey of nurturing and empowering your child with developmental difficulties.

Every child is unique, and those with developmental difficulties or disabilities possess their own set of strengths, abilities, and potential. The guidelines presented here are rooted in a holistic approach that recognizes the importance of addressing the challenges your child may face and fostering their growth, independence, and self-esteem. By understanding their individuality and embracing their differences, you can create a nurturing environment enabling them to flourish and contribute positively to their lives and society.

This guide will delve into various aspects of parenting children with developmental difficulties. From early intervention and effective communication strategies to advocating for your child's needs within educational systems and promoting their social and emotional well-being, we aim to equip you with practical tools and emotional support.

It is important to acknowledge that this journey may have moments of uncertainty and adversity. However, remember that you are not alone. Many parents, caregivers, and professionals have walked a similar path and have valuable insights to share. By connecting with a supportive community, seeking professional guidance, and arming yourself with knowledge, you can navigate challenges and celebrate the unique milestones your child achieves.

Above all, this guide emphasizes the importance of unconditional love, patience, and empathy. Your role as a parent is paramount in shaping your child's sense of self and their place in the world. By embracing their journey and providing the proper support, you can empower your child to thrive, succeed, and lead a fulfilling life.

So, let us embark on this journey together: a journey filled with learning, growth, and a deep appreciation for the incredible individuals our children are and the remarkable potential they hold**.**

SynergyEd team

Defining and terminological aspects of disability

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Most important messages:

- Words are powerful. The language that society uses about disability shapes beliefs and ideas about persons with disabilities.
- The use of offensive or inappropriate speech can constitute discrimination and violation of human rights.
- Children with disabilities should fully enjoy all human rights and basic freedoms on an equal basis with other children.
- Use language that emphasizes the person first.
- Avoid labels and stereotypes.
- Disability is not a disease, nor a problem.

Defining disability

All over the world, throughout history, different terminologies and meanings have been attributed to the differences found in humans in modern Western countries known as disabilities. Words are powerful. The language society uses about disability shapes beliefs and ideas about people with disabilities. Outdated, inaccurate, and inappropriate descriptions reinforce and support negative stereotypes and attitudes. Conversely, the use of appropriate terminology can encourage positive attitudes towards persons with disabilities. The language we use has an undeniable influence, as it shapes our perception of the world.

Terminology has evolved over time, and expressions that were in everyday use until a few years ago are no longer acceptable. Therefore, it is important to increase awareness of appropriate terminology when speaking to or about persons with disabilities. Using offensive and inappropriate speech can constitute discrimination and a violation of human rights, which can cause a feeling of exclusion that can be an obstacle to their full inclusion in social life.

A cursory glance in most dictionaries reveals definitions of disability that include inability, loss, and deficiency, especially physical or mental impairment that limits standard achievement, something that hinders, disables, or disqualifies.

In the United Nations (UN) Convention on the Rights of Persons with Disabilities, disability is defined as "a developmental concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers...", and persons with disabilities are identified as "persons who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, can hinder their full and successful participation in society, on an equal basis with others" (1). According to the same Convention "children with disabilities should fully enjoy all human rights and fundamental freedoms on an equal basis with other children..." and recognizing that "women and girls with disabilities are often at greater risk (inside and outside the home) from violence, injuries and abuses...", emphasizing "the need to incorporate the gender perspective in all efforts to promote the full enjoyment of human rights and basic freedoms of persons with disabilities".

Another legal act in the USA (the Americans with Disabilities Act, ADA) considers a person to have a disability: "if he has a physical or mental impairment that significantly limits one or more of his/her basic life functions; if there is a record of such damage; or if she herself considers that she has such damage" (2). According to the last two parts of that definition, even "in the absence of substantial, substantially limiting impairment, people still may be discriminated "(2). For example, this may be the case when someone has a dysmorphic face, i.e. has or is suspected of having AIDS/HIV or mental illness.

In the international classifications of the World Health Organization (WHO), health conditions (diseases, disorders, injuries, etc.) are classified primarily in the International Classification of Diseases, Tenth Revision (ICD-10), which provides an etiological framework of these conditions. WHO recognizes that the very terms used in classification can, despite everyone's best efforts, stigmatize and label. In response to this concern, the decision was made to drop the term "handicap" entirely because of its pejorative connotation in the English language and that the term "disability" be retained as a general, inclusive term.

According to The International Classification of Functioning, Disability and Health (ICF), the handicap is a general term for damages, limitation of activity and limitations of participation (3). It denotes the negative aspects of the interaction between an individual (with an affected health condition) and that individual's contextual factors (environmental and individual factors). In the revision process of the ICF, since the beginning, the comments of persons with disabilities and their organizations have been included and used. Thus, there is a significant contribution to the revision of the ICF from the international NGO Disabled People International (Disabled People International, DPI). The ICF uses the term "disability" to denote the multidimensional phenomenon that results from the interaction between people and their physical and social environment. For various reasons, when naming persons, some prefer the term "persons with disabilities", while others prefer "disabled persons". In terms of this divergence, there is no universal practice that the WHO has adopted, instead affirming the important principle that people have the right to be called what they choose. The ICF is not a classification of people, but a classification of people's health characteristics in the context of their individual life circumstances and environmental influences. In fact, it is the interaction between health characteristics and contextual factors that produces disability (3). In doing so, individuals must not be reduced to or characterized solely in terms of their disability, activity limitation, or participation limitation (e.g., instead of being called a ``mentally disabled person", the classification uses the term ``person with problems" in learning"). The categories in the ICF are expressed in a neutral way to avoid disparagement, stigmatization, and inappropriate connotations. The negative attributes of a health condition and how other people react to it are independent of the terms used to define the condition. The categories in the ICF are expressed in a neutral way in order to avoid disparagement, stigmatization and inappropriate connotations. The negative attributes of a health condition and how other people react to it are independent of the terms used to define the condition. The categories in the ICF are expressed in a neutral way in order to avoid disparagement, stigmatization, and inappropriate connotations. The negative attributes of a health condition and how other people react to it are independent of the terms used to define the condition.

However, whatever the disability is called, it exists regardless of the labels. Disability is complex, dynamic, multidimensional, and contested. The problem is not only a matter of language but mainly a matter of the attitudes of other individuals and society towards disability.

Several conceptual models are proposed to understand and explain disability and the functioning of persons with disabilities. They can be expressed in the dialectic between the "medical model" versus the "social model". With the medical model, disability is observed as a person's problem directly caused by illness, trauma, or some other health condition that requires medical care through individual treatment by professionals. Managing disability aims to cure, adjust, and change the individual's behavior. In short, the medicalization of disability treats human diversity as a deviation from the norm, as a pathological condition, as a deficit, and, significantly, as an individual burden and personal tragedy. With society agreeing to prescribe a medical meaning to disability, it also conspires to keep this issue in the domain of the medical establishment, to keep disability as a personal matter, to "treat" the condition and the person with the condition, rather than "treating" the social processes and policies that limit the lives of people with disabilities. Disability studies and disability rights movements are critical of the dominance of the medical definition and see it as a major stumbling block when it comes to reinterpreting disability as a political category.

On the other hand, with the social model, the problem is observed mainly as a socially created problem and, basically, as a matter of full integration of individuals in society. Disability is not a trait of the individual but a complex set of conditions, many of which are the product of the social environment. Hence, solving the problem requires social action, which means the collective responsibility of society to make environmental modifications necessary for the full participation of persons with disabilities in all spheres of social life. Moreover, for this model, disability is a political issue, as human rights issues are affected.

The shift from an individual, medical perspective to a structural, social perspective has been described as a shift from a "medical model" to a "social model" in which people are seen as disabled by social circumstances rather than their bodies. Based on basic human rights principles, the "human rights model" recognizes that disability is a natural part of human diversity that must be respected and supported in all its manifestations. People with disabilities have the same rights as everyone else, and disability must not be used as an excuse to deny or limit people's rights.

Clarification of some terms found in international disability classifications and strategies

Bodily functions are the physiological functions of body systems, including mental functions. The term "body" refers to the human organism as a whole, including the nervous system (with the central nervous system, brain and the spinal cord). Hence, mental (or psychic) functions are subsumed under bodily functions.

Body structures are the structural/anatomical parts of the body, such as organs, limbs, and their components, classified by body systems.

Damage/Disturbance is a loss or abnormality of body structure or physiological function (including mental function).

Activity is the performance of a task or procedure by an individual. It represents an individual perspective on functioning. Everyday activities can be divided into three groups, including self-care activities (taking care of oneself, hygiene), productivity activities (for adults, this is work, a source of income; for children, it is play; for schoolchildren and students, it is learning) and leisure activities (hobbies, watching television, reading a book).

Limitation of activity (an expression with which they replace the term "disability" used in the 1980 version of the ICF) are the difficulties an individual may have in performing activities. Activity limitation can vary from slight to severe deviation in terms of the quality or quantity of activity performance, in the manner and to the extent expected of persons who do not have an affected health condition (persons without disabilities).

Participation is the person's involvement in life situations. It represents the social perspective of functioning.

Restrictions on Participation (an expression which replaces the term "handicap" used in the 1980 version of the ICF) are the problems that an individual may experience when engaging in life situations. The presence of a "participation limitation" is determined by comparing the individual's participation to that expected of an individual without a disability in that society.

Contextual factors are the factors that together constitute the full context of an individual's life and, in particular, the background against which health conditions are classified in the ICF. There are two components of contextual factors: environmental factors and individual factors.

- *Environmental factors* are a component of the ICF and refer to all aspects of the external world that form the context of an individual's life and, as such, have an impact on that person's functioning. Environmental factors include the natural physical world and its features, the human-made physical world, other people in various relationships and roles, attitudes and values, social systems and services, and policies, rules, and laws.
- *Individual factors* are the contextual factors relating to the individual, such as age, gender, social status, life experiences and so on, which are not currently classified in the ICF, but which users may include in their application of the classification (3).

Facilitating factors are the factors in the person's environment that, through their absence or presence, improve functioning and reduce disability. These include aspects such as an accessible physical environment, availability of relevant assistive technology, and positive attitudes of people towards disability, as well as services, systems, and policies aimed at increasing the inclusion of all people with an affected health condition in all areas of life. The absence of some factors can also be a mitigating circumstance, such as the absence of stigma and negative attitudes. Facilitating factors can prevent an impairment or "activity limitation" from becoming a "participation limitation" because the actual performance of activities improves despite the problem the person has with their capacity.

Barriers are the factors in the person's environment that, through their absence or presence, limit functioning and create disability. These include aspects such as an inaccessible physical environment, – examples are environment that is not argonomically adjusted, lack of ramps for disabled, missing or out-of-function elevators, restaurants without toilets adjusted for disabled, entry into the public transport, etc. Furthermore, barriers include a lack of relevant assistive technology, and negative attitudes of people towards disability, as well as services, systems, and policies that either do not exist or that hinder the participation of all people with an affected health condition in all areas of life (3).

Types of disability

Disability is an umbrella term for impairments, activity limitations, and participation restrictions and refers to the negative aspects of the interaction between a person (with their health condition) and that person's contextual factors (environmental and personal factors).

Physical disability refers to various conditions that can be congenital, acquired, or chronic. Physical disabilities include congenital conditions (e.g., spina bifida or CP), conditions associated with trauma (e.g., spinal cord injury), and conditions associated with medical intervention (e.g., amputation as a result of disease, such as a malignant disease).

Neurological and developmental disabilities include conditions occurring in the fetal period (e.g., microcephaly), at birth (e.g., anoxia), and conditions caused by exposure to toxic substances (e.g., alcohol, lead). Other disabilities include autism spectrum disorders (autism and pervasive developmental disabilities) and intellectual disabilities.

Intellectual disabilities include limitations in both general mental abilities and adaptive behavior, such as many everyday social and practical skills.

Sensory disabilities include conditions related to the senses. They can include individual senses or a combination of multiple senses or all sensory systems (sight, hearing, tactile system, vestibular and proprioceptive).

It is estimated that 1.3 billion people, 16% of the world's population or 1 in 6 people worldwide, experience some kind of disability during their lifetime. There are persons with disabilities in every age group and all genders. There are considerable differences in the prevalence of disability between men and women in both developing and developed countries: the male disability prevalence rate is 12%, while the female disability prevalence rate is 19.2%. The number of people experiencing disability is increasing due to the rise of chronic health conditions and an aging population. It is estimated that 30% of families live with an immediate family member who has a disability. 75 million people need a wheelchair, and only 5-15% have access to it (4).

Language and terminology

The UN Convention on the Rights of Persons with Disabilities sets the standard we must follow in terms of disability language and terminology (1, 5):

- **Use language that puts the person first.** "Person first" is the most widely accepted language when talking about people with disabilities. It is also the language used in the UN Convention on the Rights of Persons with Disabilities. The language "person first" emphasizes the person, not the disability, referring primarily to the person or group before the disability. For example, we can use expressions like "children with albinism", "students with dyslexia", "women with intellectual disabilities" and, of course, "persons with disabilities". However, there are certain exceptions where the "person first" rule does not always apply to all types of disabilities. Thus, when talking about persons who are blind, we can say either "blind persons" or "persons who are blind", and the same applies to the case of "deaf persons" or "blind and deaf persons". People with disabilities are not a homogeneous group and can self-identify in different ways. These identities should be respected and recognized. Therefore, if you are not sure, you should ask the person (or group) how they identify themselves.
- **Avoid labels and stereotypes.** Disability is a part of life and reflects the diversity of people, not something to be dramatized or sensationalized. Therefore, people with disabilities should not be portrayed as inspirational or "superheroes". Such language implies that it is unusual for people with disabilities to be productive and lead happy and fulfilling lives. Describing a person with a disability as "bold" or "brave" or that they have "overcome" their disability is patronizing, degrading, belittling and should be avoided. Regarding talents and abilities, people with disabilities are the same as everyone else. Focus on skills or prerequisites, and mention the person's disability only if it clarifies things or provides useful information. For example, if you are discussing Braille documents, you can say that the person/child "uses braille" or "reads braille" instead of saying the person is blind. The disability is not relevant; the fact that the person has the necessary skills is relevant. Always use this kind of positive and encouraging language. On the other hand, disability

should not be invisible. You should openly and respectfully discuss disability issues and make disability inclusion a priority.

- **Do not use derogatory euphemisms.** We should not use terms such as "differently abled", "all-abled", "differently abled", "disabled" or "persons with diversity", as these are all euphemisms that can be considered derogatory or offensive. For example, "differently abled" is a problematic term because we are all differently abled. In fact, euphemisms are a denial of reality and an avoidance of conversation about disability. "Persons with disabilities" is a more neutral term than "differently abled". The term "special" is usually dismissed when used for people with disabilities and is considered offensive and derogatory, as it euphemistically stigmatizes the different. This term should not be used to describe persons with disabilities, including in terms such as "special needs" or "special assistance", "special education". We recommend more neutral or positive language when possible (eg, "adequate assistance"). The term "special education" is widely used to refer to school programs, but the term carries negative connotations because it often refers to segregated education. Although dictionaries insist that specials are reserved for things that go beyond the ordinary, that are different from others of their kind, that are characteristic of a particular person, that have a limited or specific function, that is arranged for a particular purpose or occasion, yet experience teaches us that the term especially when applied to education or to children, has a different meaning. Calling children with disabilities and education that "is designed for students whose learning needs cannot be met by the standard school curriculum" (American Heritage Dictionary 1992) as special can only be understood as a euphemism, obscuring the reality that neither children nor education are considered desirable and that they are not thought to "go beyond what is common" (6).
- **Disability is not a disease nor a problem**. According to the medical model of disability, disability is a health condition that needs to be "fixed" or treated. According to this model, persons with disabilities are not seen as holders of rights. Similarly, the charitable model sees disability as a "burden" or "problem" that must be solved by non-disabled people. This approach portrays people with disabilities as targets of pity and pity, which reinforces negative attitudes and stereotypes. People with disabilities should not be referred to as patients unless they are under medical care and only in that context. Also, labeling people with disabilities according to their diagnoses (eg 'dyslexic') should be avoided, as this reflects the medical model of disability. Instead, use language that puts "the person first" (e.g. Expressions such as "suffering from", "affected by" or "bound to" are inappropriate. They suggest constant pain and powerlessness and imply that people with disabilities have a low quality of life. Instead, you can simply say that the person "has (disability)" or "is (blind/deaf/deaf and blind)". The term "victim" should not be used unless strictly relevant. For example, it is inappropriate to say that a person is a "victim of CP". CP does not turn a person into a "victim" (a victim is a person who has been injured in a crime or subjected to human rights violations). Avoid talking about a person trapped "in" the disability (for example, "the man in the paralyzed body") or "over" the disability (for example, "she overcame her disability"). Our bodies and minds cannot be separated from who we are.
- **Use appropriate language in oral and informal speech.** Most people with disabilities are comfortable with the words used in everyday life. You can say "let's go for a walk" to a person who uses a wheelchair or write "did you hear what happened?" to a person who is deaf. However, phrases such as "blind as a bat" or "deaf as a cannon" are unacceptable and must never be used, even in informal contexts. You should also be careful with metaphors, such as "blind to criticism" and "turn a deaf ear". Misused terminology can be both inappropriate and hurtful, so don't say, for

example, "they're paranoid." when some people are overly distrustful. Never use disability-related terms to insult someone or express criticism.

Disability Inclusive Language

Inclusive language is a key tool in the fight against "ableism" and its entrenched manifestations. The term ableism(eng. ableism) has recently been included in a dictionary (Readers Digest Oxford Wordfinder, Tulloch, 1993), where it is defined as "discrimination in favor of the physically able" (6).

Ableism implies discrimination and social prejudices against persons with disabilities or persons who are considered to have some form of disability. According to ableism, people are defined by their abilities, and people with disabilities are considered less valuable than people without disabilities. It is a misguided and biased understanding of disability that leads to the assumption that the lives of people with disabilities are not valuable. Ableism takes a wide range of discriminatory forms, including offensive language. For example, ableism is when you say that someone does not look like a person with a disability and expect it to be taken as a compliment. Ableism is when you assume that someone is automatically a strong and courageous person just because they have a disability.

In Table 1, in addition to the recommended terminology, terms that are considered inappropriate (language to be avoided) are given (5).

Table 1. List of recommended terms and terms to be avoided

Recommended language	Language to be avoided
person with disability person with [type of impairment] persons with disabilities people with disabilities (only in Easy Read documents, informal text and oral speech)	disabled person, handicapped, person with special needs, handicapable, atypical, person living with a disability, differently abled, people of all abilities, people of determination, person living with a disability
person without disability the rest of the population	normal, healthy, able-bodied, typical, whole, of sound body/mind
have [disability/impairment/condition]	suffer from, afflicted by, stricken by, troubled with
person with an intellectual disability person with an intellectual impairment	retarded, simple, slow, afflicted, brain-damaged, intellectually challenged, subnormal, of unsound mind, feeble-minded, mentally handicapped
person with a psychosocial disability	insane, crazy, maniac, psycho, hypersensitive, lunatic, demented, panicked, agitated, mentally deranged, mentally ill
deaf person person who is deaf person with a hearing disability person with a hearing impairment person with hearing loss hard-of-hearing person deafblind person	the deaf, hearing impaired, deaf and dumb, deaf and mute
blind person person who is blind person with a vision/visual disability person with a vision/visual impairment person with low vision deafblind person	the blind, partially-sighted
person with a physical disability person with a physical impairment	crippled, invalid, deformed, lame, handicapped, physically challenged, person with physical limitations, limp
wheelchair user person who uses a wheelchair person with a mobility disability person with a mobility impairment person using a mobility device	confined/restricted to a wheelchair wheelchair-bound
person of short stature little person person with achondroplasia (only if the person has this condition)	midget, dwarf, stunted
person with Down syndrome person with trisomy-21	mongoloid, special person, Down
person with albinism	albino
person affected by leprosy	leper, leprosy patient
person who uses a communication device person who uses an alternative method of communication	non-verbal, can't talk
accessible parking parking reserved for persons with disabilities accessible bathroom	disabled/handicapped parking handicapped bathroom

Terms that require additional explanations from a linguistic perspective

- Approach vs accessibility - Access means the opportunity or right to do something or enter a place. Accessibility refers to the design of products, devices, services, or environments suitable for use by persons with and without disabilities. Accessibility also includes information and communications. Physical accessibility includes creating barrier-free environments where people with disabilities can move freely (e.g., you can have access to the premises of a healthcare facility, but you don't have access if there are physical barriers, such as stairs or heavy doors. Although you may have access to the required documents/information in print or digital format, those documents are not accessible to users unless they are available in the required format (such as Braille or easy to read). Sometimes access is provided, but accessibility is not, so these terms are not equivalent and should be used in the right context. Universal design should be mentioned here. The universal design is design of products and environments that eneables them to be as accessible as possible to all individuals without the need for additional adjustments or the use of specialized design.
- Braille - is a system of raised dots for tactile perception with the fingers used by blind or visually impaired people. But not all blind people can read Braille; those who can are called Braille users. The process of converting printed text into Braille is called "transcription" (not "translation"). The process of "printing" is called "embossing".
- Transcript Captions vs. Subtitles - Transcript captions and subtitles are not identical, although both appear as text at the bottom of the screen and represent speech. Transcript subtitles are especially useful for the hearing impaired, as they contain information about background noises, speaker identification, music description, and other relevant details. Subtitles assume that viewers can hear but do not understand the language of the video (e.g., foreign-language films) and include only dialogue. Transcript captions come in two forms: open and closed captions. The viewer can turn off closed captions, while open captions are embedded in the video and cannot be turned off. Live captioning (synchronized or real-time) is provided at accessible meetings.
- Deaf and Blind - Deaf and blind people are a heterogeneous group of people who have significant sensory impairment, including blindness and deafness. In the United Nations, the form "deaf-blind" is preferred to "deaf-blind" (5).
- Statement and disclosure - Persons with disabilities have the right to share or not share information about their disability status. Also, the phrase "identifying as a person with a disability" should be avoided as it relates to issues of identity and belonging. Someone can have a disability and yet not identify as a person with a disability. The simple phrase "chooses to share information about their disability" is appropriate when talking about people's choices about their disability or specific requirements.
- Disabled person - In some states, the preferred term is "disabled person". This term must be retained when referring to their laws, policies, or authorities, as it reflects the reality in the country or is a deliberate choice of the author. Quotation marks can be used if necessary. However, on UH websites, documents, and speeches, we recommend using the language "person first" with the term "person with a disability" (1, 5).
- Easy readable format - it is an accessible format primarily intended for people with intellectual disabilities or for people who have difficulty understanding written text.

The process of converting/preparing a "readable" version of a document is called "adaptation", not translation. A "readable" document written in one language can be translated into any other language, in which case we can call the result a translation.

- Help, support, assistance - The terms "help", "support" and "assistance" have different connotations and are not interchangeable. The term "help" is not recommended, as it portrays people with disabilities as helpless and dependent. "Support" and "assistance" are better and more appropriate terms and can be used in expressions such as "participants in need of assistance" or "measures to support persons with disabilities".
- Impairment vs. disability-impairment refers to “any loss or abnormality of a physical, physiological or anatomical structure or function,” according to the WHO (3), while disability “is the result of the interaction between persons with disabilities and the attitudinal and environmental barriers that limit their full and effective participation in society on an equal basis with others" (1).
- Integration vs inclusion - There is a significant difference between integration and inclusion. Integration is the process of adapting and fitting a person into society, while inclusion refers to the process of changing society in the sense of including everyone, regardless of the state of their disability. When talking about people with disabilities, the connotations of "inclusion" are positive, while those of "integration" are negative. Therefore, these terms are not interchangeable.
- Needs vs. conditions - Some UN bodies and experts prefer the term "conditions" to "needs" (1). This is consistent with a human rights approach to disability, which recognizes that persons with disabilities are rights holders. The term 'needs' is thought to spread the stereotype that people with disabilities have needs or are a burden, especially when talking about 'needs for care'. An example that illustrates this approach is that schools must provide Braille materials for students with visual disabilities not because they need them but simply because they have the right to quality education on an equal basis with other students.
- Organizations for and organization of persons with disabilities - Organizations "of" persons with disabilities should be distinguished from organizations "for" persons with disabilities. Organizations of persons with disabilities are led and managed by persons with disabilities themselves. They represent the legitimate rights and interests of their members. On the other hand, organizations for persons with disabilities provide services or advocacy on behalf of persons with disabilities, but persons with disabilities do not necessarily participate in the management and activities of such organizations.
- Plain language - Plain language is communication the audience can understand the first time they hear or read it. Complex language and jargon are avoided, and various other principles are applied, such as using short sentences or avoiding passive sentences. It can also be called simple writing or clear writing.
- Reasonable accommodation - the term "accommodation", often used in the expression "reasonable accommodation", refers to the necessary and appropriate modifications and adjustments that ensure that persons with disabilities enjoy all human rights and fundamental freedoms. Other options can be used when talking about a place of residence, such as a house, apartment, or place of residence.
- Service animals for persons with disabilities - Service animals for persons with disabilities are trained to perform certain specific tasks. This includes animals that

assist the movement of blind and visually impaired people and animals that pull a cart or carry fallen objects. Example of such animals are therapeutic dogs and horses. Other animals can also be used. For example, capuchin monkeys can be trained to assist people with physical disabilities in performing daily tasks. Other animals can be trained or used for some kind of support (e.g., emotional support) to people with disabilities, such as parrots and ferrets.

- Sign language and international signs - Sign languages around the world differ from each other. Some countries (e.g., Canada) have multiple sign languages. There is no international sign language, but there is something called an international sign. International Sign is a form of signing based on a series of agreed signs used when deaf people from around the world meet at events. That is why the United Nations is said to provide interpretation with international signs, but we do not call it a language.
- Visual impairment or visual impairment vs. blindness - The term "visual impairment," "visual impairment," or "visual impairment" encompasses a wide variety of vision loss situations, of which blindness is just one situation. Therefore, these terms are not synonymous.

Very often, people with disabilities encounter barriers, stigmatization, and discrimination when accessing health services and information. Most of these barriers are due to the ignorance and attitudes of society and individuals, including health care providers, rather than the disabilities themselves. The skills and capacities of health care providers are even twice as likely to prove inadequate. Persons with disabilities experience unequal treatment, various forms of violation of their rights, and denial of their autonomy. Existing services could easily be adapted to the needs of persons with disabilities, and the first and most important step for this is to increase awareness. By providing accurate information and tailored, affordable services, health professionals have an important role in supporting people with disabilities. They should better understand the health care needs of persons with disabilities and be equipped with appropriate knowledge and skills to provide them with quality health care, treating them in appropriate facilities and with the same respect as persons without disabilities. According to the recommendations of UN Convention (1), it is necessary to use campaigns, education, media involvement and programs to raise awareness of the rights, abilities and contributions of persons with disabilities, as well as challenge stereotypes and prejudices relating to these persons.

Literature

1. UN Convention on the Rights of Persons with Disabilities; United Nations Organization,2007. https://nsiom.org.mk/konvencija
2. Americans with Disabilities Act of 1990. from https://www.upcounsel.com/list-of-disabilities-covered-under-ada
3. International Classification of Functioning, Disability and Health (ICF), Skopje: UNICEF, 2017. https://www.unicef.org/northmacedonia/media/3881/file/MK_ICF_Report_MK.pdf
4. Manual for sexual and reproductive health of persons with disabilities; UNFPA, 2023.
5. Disability-Inclusive-Language-Guidelines; https://www.ungeneva.org/sites/default/files/2021-01/Disability-Inclusive-Language-Guidelines.pdf
6. American Heritage Dictionary; Boston: Houghton Mifflin, 3rd ed. 1992.
7. National Strategy for the Rights of Persons with Disabilities 2023–2030 with Action Plan 2023–2026
8. Rulebook for functional assessment of children and youth with disabilities, Skopje: UNICEF, 2023.

9. World Health Organization & United Nations Population Fund. (2009). Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note. World Health Organization (https://apps.who.int/iris/handle/10665/44207).
10. Income and Living Conditions Survey, State Statistical Office,2017.
11. Law on prevention and protection against discrimination. "Official Gazette of RSM" no. 258/2020.
12. Sexuality, sexual and reproductive health of persons with intellectual disabilities, Handbook for professionals and parents/guardians; Skopje, X.E.R.A. Association for Health Education and Research, 2012.
13. Data collection on child disability–auxiliary professional brochure; United Nations Children's Fund 2014. https://www.unicef.org/northmacedonia/media/3986/file/MKInclusiveCollectingDataDisability_Report_MK.pdf
14. Longmore, P.K. 1987. Uncovering the hidden history of people with disabilities. Reviews in American History 15 (3) (September): 355–364.
15. Puberty & Sexuality for Children and Young People with a Learning Disability A supporting document for National Curriculum objectives) - The Children's Learning Disability Nursing Team, Leeds January 2009.
16. Simi Linton, Claiming Disability: Knowledge and Identity. New York: New York University Press, 1998.
17. Steadman's Medical Dictionary; Baltimore: Williams and Wilkins; 1987.

Alternative medicine will not help your child

Prof. Livia Puljak, MD, PhD

Most important messages:

- Citizens spend millions on alternative and complementary medicine products, fake therapies advertised with unfounded health claims.
- Patients usually turn their attention to alternative medicine when conventional medicine cannot help them at all, or it cannot help them as quickly as one would like.
- Alternative medicine is aggressively advertised and makes claims that are not based on medical research.
- There are no specializations in alternative medicine; they claim to cure all possible diseases.
- Official medicine is guided by evidence from scientific research, unlike alternative medicine.
- Alternative medicine is a huge business; alternative medicine “healers” are not altruists who just want to help you.

Every year, gullible, desperate patients spend millions on drug users and fake products advertised in the media. Patients usually turn their attention to alternative medicine when standard medicine cannot help them at all, or it cannot help them as quickly as one would like. Sadly, many unscrupulous individuals are willing to take advantage of the despair of a person who wants to help themselves or their family to solve a health problem. It is, therefore, essential to raise awareness about the problem of quackery and alternative medicine and to learn how to identify fraudsters.

What is alternative and complementary medicine?

Alternative and complementary medicine is a name for medical devices and practices that are not part of standard medical care. People often use such therapies because they feel that they are doing something to help their own efforts to treat or cure a condition (1).

Conventional medicine is a system in which healthcare professionals, including physicians, nurses, and pharmacists, treat symptoms and diseases with medicines, radiation, or surgery. It is also referred to as allopathic medicine, biomedicine, Western, or orthodox medicine. **Standard medical care** is a therapy that medical professionals accept as correct for a particular type of disease and is widely used by healthcare professionals. It is also referred to as best practice and standard of care (1).

Integrative medicine is an approach to medical care that combines conventional medicine with alternative and complementary medicine practices (1).

Complementary medicine is used with standard medical treatment but is not considered standard of care in itself. One example is the use of acupuncture to reduce side effects of a particular type of treatment. For most types of complementary medicine, fewer studies were conducted compared to therapies used in standard medicine (1).

Alternative medicine is used instead of standard treatment. One example is the use of a special type of diet to treat cancer instead of cancer medicines prescribed by an oncologist. For most types of alternative medicine, less research, of poor quality, was carried out (1).

Who is a quack?

A quack is a person pretending to have medical education and, in some way, empowered to diagnose or treat a patient with a health problem. Quacks seduce people to trust them with their health and then deceive the patient into selling (or at least trying to sell) a product or service that allegedly heals the patient.

Aggressive advertising of alternative medicine and miraculous therapies

In the media, there are many commercials and advertisements for products that are claimed to help us improve our health or cure various diseases that sound too good to be true. Those advertisements offer various solutions that are supposed to cure everything, from the common cold to incurable diseases to standard medicine, including various devices, products for boosting the immune system, magical slimming preparations, various magnetic devices, etc.

Various therapists without any medical education offer therapies with exotic names. Some of these quacks offer even treatment only by eye gazing. For such "healers", it is claimed that it is sufficient if they look at you and you will get well. Such healers, who allegedly help by eye gazing, can also supposedly help you remotely. It is claimed that it is enough for you to look at a video of such a healer to recover. Unfortunately, anything that sounds too good to be true usually is not true. If there really were people who could heal others by eye gaze and even do so remotely, then we would not need the health system as we know it today at all. It would be enough for those miracle healers to watch us via television and the Internet, and no one would be sick.

It is worth asking yourself how it is possible with all these miracle workers and healers that many people are still sick or have problems that we do not necessarily consider a disease, but people would rather not have them. Each of us knows people who are overweight, who have lost their hair, who suffer from various long-term incurable diseases such as diabetes or arthritis, diseases such as cancer, etc. So, think about it: how is it possible that these people still have these problems, given the fact that alternative medicine offers a bunch of solutions that are supposed to solve these problems quickly, efficiently, and completely safely? The answer is simple: these problems still exist because alternative medicine has no solution for them. Alternative medicine is a fraud.

Alternative medicine and quacks offer magical, simple solutions to a range of diseases

In standard medicine, there are a number of specialisations and sub-specialisations that physicians undergo in order to have as much knowledge and skills as possible to treat a specific narrow area. If you have a heart condition, you go to a cardiologist. If you have kidney problems, you go to a nephrologist. If you have eye problems, you need an ophthalmologist. A gynecologist solves problems with the female sexual system. However, there is no such thing in alternative medicine. Quacks claim to cure all possible unrelated diseases. Among alternative medicine healers, everyone knows everything and heals everything. They often use pseudoscientific terminology to make it sound better and to deceive people more effectively.

Alternative medicine practitioners offer quick and simple solutions

Anyone who has ever needed official medical services knows well how slow and gloomy this system can sometimes be, especially when it comes to the treatment of long-term illnesses. In addition, medicinal products and various therapies prescribed by official medicine may have a number of adverse effects, along with their positive effects. For example, if someone has cancer, takes treatments that will make their hair fall off, destroys various cells in the body, can cause nausea and vomiting, and many other harmful effects of therapy that further impair the patient's condition.

On the contrary, this is not the case in alternative medicine. No blood is extracted there, and no urine or other bodily fluids are taken. They scan you with various miraculous devices that do not require any needles. For example, with some alternative medicine healers, you just need to hold some kind of probe in your hand for 10 seconds, which is connected to a computer, and the computer then shows a complete list of diseases that have afflicted you. And, of course, they will tell you that you urgently need to solve those problems with their products.

Alternative medicine therapies often claim that their treatments are all natural, without "chemistry", patients are made to feel comfortable, and healers engage in long conversations with a patient, providing them with a lot of attention. Because of the large number of patients in standard medicine practices, physicians and nurses often do not have much time to talk to the patient. General practitioners usually see more than 100 patients a day, so they simply cannot devote much time to each one of them. But for alternative medicine healers, this is different because they count on people wanting to be paid attention to and listened to.

If alternative medicine does not help you, these "therapists" will usually blame you for treatment therapy. Failure of alternative medicine is never the fault of those healers, and it is never because it's not effective. Those healers will tell you that it's the fault of a patient who didn't believe enough, who wasn't taking the therapy properly, who wasn't taking enough therapy, etc.

Alternative medicine healers advertise natural products that do not poison you

Standard medicine is guided by evidence from scientific research. In alternative medicine, there is generally no scientific evidence that a treatment is effective and safe. Alternative healers expect that clients will trust their rich experience and their anecdotes about something helping a number of their other clients. The alternative healers gladly dismiss the standard medicine, saying that standard medicine poisons people, that the solution is in nature. They offer products that allegedly contain natural ingredients, often some medicinal plants that have supposedly helped people for thousands of years.

However, let's ask ourselves if nature really offers solutions to all our health problems. These medicinal plants have been around us in nature for thousands of years, and humans have really traditionally used different natural products to treat illness. However, only in the last 100 years have we seen progress in human health and the extension of life expectancy. This is due to the progress of science, technology, and better living conditions. Some 150 years ago, we were equally surrounded by nature and so-called natural remedies, but our average life expectancy was 40 years, children were mostly dying of pneumonia, and many women and children were dying during childbirth. One wonders why these natural remedies did not help us to live better and longer in those previous centuries.

Alternative medicine is a huge business; they are not altruists who just want to help you

There is insufficient talk about alternative medicine being a huge business, generating enormous profits, without any regulation or obligation to prove that their product is effective and safe. This business has no mercy for the sick and mostly no scientific evidence.

According to the MarketWatch website, the global market's value for complementary and alternative medicine was estimated at USD **132 billion** over the 2021/2022 period and is expected to reach USD 435 billion by 2030 (2).

The alternative medicine healers gladly diss standard medicine about the alleged corruption, claiming that the pharmaceutical industry is only interested in money, not people. They ignore, of course, the fact that the pharmaceutical industry is regulated. No medicine or medical device can come on the market today without conducting scientific experiments that regulatory agencies are checking in line with the highest scientific standards.

It is estimated that the cost of developing a new medicine today is more than 2 billion USD (3). This price is so high because many studies must be conducted in laboratories, on experimental animals, and in humans to prove that the medicine is safe and effective. It is strictly stipulated which studies should be carried out by the pharmaceutical industry to demonstrate the efficacy and safety of the medicinal product. Many of the medicines being investigated fail to pass this rigorous assessment and Regulation. On the other hand, when it comes to alternative healers, you only have their word that their product or service is effective or safe. Investing in a good advertisement is their only investment in proving the efficacy and safety of the product or service.

Parents of children with developmental disabilities are particularly vulnerable to quacks and false therapies

Most important messages:

- Parents of children with developmental disabilities are particularly susceptible to fake healers and false therapies.
- 27% to 88% of families of children with autism spectrum disorders say they use alternative and complementary medicine treatments.
- It is very important to educate parents and carers so that they do not waste time and money on treatments that will not help the child.

Parents of children with developmental disabilities are a sensitive group often targeted by alternative medicine quacks and fraudulent “solutions” to their child's problems. These parents are also often ashamed because they have not tried alternative drugs. Parents and carers of these children may be inclined to take alternative and complementary therapies because standard medicine does not offer them a solution to their child's condition.

For example, despite years of effort, there is no medicine to cure the autism spectrum disorder (ASD) or solve the underlying symptoms of this disorder. The only medicines approved by some medicines’ regulators are risperidone and aripiprazole for agitation and irritability in ASD, but not for underlying symptoms. Although they effectively reduce irritability/violence, they also cause problematic side effects, including metabolic syndrome, elevated liver enzymes, and movement disorders such as uncontrolled or unwanted movements, twitching, shaking, and muscle contractions. It is, therefore, not surprising that many families of children with ASD turn to alternative and complementary treatments, including diet, vitamins, and immunomodulatory therapies (4).

According to recent studies, 27% to 88% of families of children with ASD say they use alternative and complementary medical treatments. Research shows that many parents perceive natural and complementary therapies as natural and safe treatments compared to therapies offered by standard medicine. Most often, parents use multivitamins, an elimination diet (certain ingredients are removed from the diet), and methyl B12 injections for their children with ASD. Professionals working with parents and carers of children with developmental disabilities should improve their knowledge of alternative and complementary medicine in order to be able to advise parents and carers on these therapies for which we have limited or poor-quality data (4). It is also important to educate parents and carers so that they do not waste time and money on treatments that will not help the child.

How to protect yourself from alternative medicine fraud

Most important messages:
- Be careful if any therapy outside standard medicine uses pseudo-scientific terminology. Talk with your physician about these alleged scientific claims.
- Beware of therapies/treatments that treat everything. That's just not possible.
- Doubt testimony, anecdotes, or personal stories about how something from the alternative medicine repertoire has helped someone
- Watch out for false advertising text and fuzzy phrases used
- Beware of conspiracy theories
- Beware of therapies that have secret ingredients and effects
- Be aware that there is a placebo effect, which cannot cure conditions and is short-lived
- Natural therapies with herbal “medicines” are not necessarily effective and safe
- Be careful if someone invites you to “think for yourself” instead of trusting standard medicine
- Critically review the “evidence” offered by alternative medicine

Tip to help you recognize fraudulent therapies

We often hear about some new alternative and complementary treatment that is not offered by standard medicine, and we wonder if it can be an answer that will help you or someone you love to feel better. Is that a safe, healthy option, or is it a fraud? Quackery is the promotion or sale of health products that sound good but actually do not help and can even be harmful. These tips can help you avoid being misled by the false products, treatments, or people:

1. Does advertising/promotion use pseudo-scientific terminology?

Just because something sounds scientific, it is not necessarily based on scientific evidence. Quacks will often use scientific terms and name (or misquote) scientific sources when promoting their products and services. Some of the practitioners of alternative medicine may have medical or scientific education, but they have left a reputable scientific community. Talk to your physician about those alleged scientific claims.

2. Beware of therapies/treatments that treat all

Beware of therapies, procedures, or dietary supplements that are supposedly able to cure everything. Although some diseases are related to diet, most are not. Do not listen to “healers” who say, for example, that the wrong diet causes disease and that their dietary supplement will cure you. Do not seduce yourself into buying products that say they can cure many unrelated diseases. Unfortunately, there is no such product. If there were, we would all be healthy.

3. Doubt testimony, anecdotes, or personal stories about how something helped someone

If someone claims to have been helped by unusual treatment, ask your physician if there is any other explanation. Some diseases may have periods of improvement and periods without symptoms. Usually, along with alternative treatment, some people have used traditional medicine but credit alternative therapy for their improvement, disregarding the fact that they also used standard therapies. Perhaps these people did not have the correct diagnosis and never had the disease they were talking about. Some therapies, for example, are advertised as having helped to cure a child with autism. Unfortunately, autism is not currently treatable, so such claims cannot be true. Also, some people who advertise how much they have benefited from a certain alternative medicine product or procedure can be paid actors and are likely not telling the truth about their healing and healing.

4. Watch out for false advertising text and fuzzy phrases used

In the text of the alternative therapy ads, quacks often promise “detox” of your body or that their therapy will “balance” your body chemistry, “bring it into harmony” with nature, or “release the disease” from your body. Others may promise to strengthen the “weak” part of the body. Very commonly, they claim that something “helps” a physical function. These are all unscientific and fuzzy expressions that should make you suspicious. When a real medicine is approved to enter the market after years of research, this medicine has a very specific indication, for example – for the treatment of diabetes. Medicines are not approved for “balancing your body chemistry” or similar vague expressions.

5. Beware of conspiracy theories

Conspiracy theories are spread very often by alternative medicine healers. They claim that the medical profession, pharmaceutical companies, and government have joined forces to cover up any treatment the alternative healers are trying to sell. It is not logical that a large number of people from the medical, pharmaceutical, or government community would oppose therapies that could one day help themselves or their neighbors. No one has ever proved such a conspiracy theory.

6. Beware of therapies that have secret ingredients and effects

Alternative medicine healers often state that the ingredient of their medicinal product or the way in which their procedure is performed is a secret. Of course, quacks want to keep their methods a secret so that others cannot prove that they are not working. In standard medicine, however, there is no such thing. When your physician prescribes a medicine, the medicine’s package insert contains a piece of paper clearly listing the ingredients of the medicine, possible side effects, and instructions for taking the medicine. True scientists want to share what they have learned as part of the medical science process because then that knowledge benefits all mankind. Therefore, beware of therapies that have secret ingredients and effects known only to the provider.

7. Be aware that there is a placebo effect, which cannot cure conditions and is short-lived

The word “placebo” comes from the Latin word “*placere*”, which means “I will please” or “I will do good”. In the strict sense, it is a false product/therapy, which does not contain medicinal substances with a pharmacological or actual effect. The placebo effect describes a situation where a person is convinced that the medicine or treatment they receive has a beneficial effect even though the product, for example, contains only sugar and the injection contains only saline.

Because of suggestions, beliefs, expectations, and distractions, patients who have been given useless treatments often experience relief. Some of the placebo effects can be actual changes in a person's physical condition, while others are changes that patients can experience, although there were no changes in their actual disease. Placebo never leads to a cure and can only have a short-term effect.

8. Natural therapies with herbal "medicines" are not necessarily effective and safe

Many people think plants provide a natural way to heal the disease and are always "safe." True, many plants have hundreds or even thousands of chemicals that have not been fully studied. Some may prove useful, but others may be poisonous. However, not everything called "herbal medicine" is really a cure. For a true medicinal product to be marketed, the quality, efficacy, and safety of each medicinal product must be established. Therefore, there are laws on medicines and strict regulations on how medicines are tested and studied with scientific methods. Sadly, many of the alleged "herbal remedies" have not been tested in that rigorous way at all but are merely advertised with unfounded claims of health effects.

9. Be careful if someone invites you to "think for yourself" instead of trusting official medicine

If someone asks you to "think for yourself" instead of believing what healthcare professionals and official medicine say, be very careful! Also, if they say that some therapy will work for you even though it has not been proven to work in others, do not believe it. Don't let them manipulate you emotionally. If you do not feel that your physician is helping you enough, do not rush to unusual alternative treatments. Discuss your feelings and concerns with your physician, and if you are still unhappy with your care, it may be time to see another physician for a second opinion. The quacks are counting on your desperation to buy their products.

10. Critically review the "evidence" offered by alternative medicine

Read carefully advertisements and claims related to some magical solutions to health problems. If this "evidence" consists of testimonies from satisfied users, pamphlets, self-published books, or articles from popular media, you should avoid such products. The alternative healers often mention research, such as in "research has proven…", but do not specify which research is involved, i.e., there is no reference to specific research that one could look up and check. If they have research results for their products, those results should be published in scientific literature, in real scientific journals, where that research will undergo a verification process called a scientific review. If there are references mentioned, look for those scientific studies in the literature on the Internet and then check with your physician about the authenticity of these studies.

Evidence-based medicine

Prof. Livia Puljak, MD, PhD

Most important messages:

- Evidence-based medicine involves using the best available evidence, the experience of healthcare professionals, and patients' decision-making preferences to achieve the best patient outcomes.
- For the use of evidence-based medicine, first, we start by asking a clearly formulated question, then we look for research evidence in the literature, the quality of this evidence is assessed, a decision is taken in collaboration with the patient, and then the impact of this decision is assessed to see if the desired outcome has been reached.
- There are many published studies in some areas of medicine, few in others.
- When there is more research on a topic, these studies do not have to have the same or similar result – sometimes, their results can vary significantly.
- Systematic reviews are studies that summarize medical evidence on a given topic. They help the reader understand all the evidence that exists on a particular subject in scientific literature, draw conclusions for medical practice and future research, and assess the quality and reliability of existing evidence.
- Cochrane systematic reviews are considered the gold standard in scientific evidence synthesis; Cochrane, the international non-profit organisation, prepares those reviews.
- Each Cochrane systematic review contains a summary written in lay, i.e., plain language.

Evidence-based medicine (EBM) includes using the best available evidence, the experience of healthcare professionals, and patient decision-making preferences to achieve the best patient outcomes. Only when these three are taken together – the evidence from the research, the experience of the clinician and the wishes of the patient – can the best outcomes in medicine be expected. Relying on research evidence implies that health decisions are made based on the latest, solid, reliable scientific evidence. What kind of evidence are we looking for? Right now, the best evidence. It is not the perfect evidence from research. It is the best evidence that exists right now. However, it should not be old or outdated evidence; we need to find modern, up-to-date evidence.

In practice, adopting the best medical decision-making information starts with asking the right questions and using the best research evidence to answer those questions. Sometimes, when a patient has a very rare or unusual condition, very little high-quality information can be found. To do the best for the patient then, a healthcare worker may need to rely on a good understanding of medical science and work out what is best, based on that knowledge. Sometimes, it is necessary to rely on the experience of older and wiser colleagues. However, multiple studies have been conducted in many areas of medicine, which may or may not have the same result. Sometimes, there are hundreds of clinical studies involving hundreds or even thousands of patients, all of which have similar results. In these situations, counseling a patient about the advantages and disadvantages of a type of treatment is relatively easy. On the other hand, sometimes the results of different studies are contradictory, or available studies have not looked at the same type of patients (5).

Practical steps in the use of evidence-based medicine

The evidence-based steps in the use of medicine are as follows:

1. Definition of the medical question: a physician or other expert seeks information to find the correct diagnosis,
2. Searching for the best evidence: a physician or other expert seeks evidence from research that answers the medical question posed
3. Evidence quality assessment: it is not enough to find evidence from research; but it is important to assess both their quality and our confidence in research results; not all research has been carried out and written well. Rigorous research methods are used to assess the quality and certainty of the evidence, looking at the way the research was conducted and possible biases affecting the study results.
4. Treatment, i.e., decision-making based on evidence: based on the first three steps, the patient and the healthcare professional together make an informed decision on the treatment
5. Process assessment: the expert and patient assess whether the desired outcome has been reached and adjust treatment decisions accordingly if necessary (6).

Involving patients in decision-making processes is important in building new guidelines on treatment principles. This includes reading, understanding, and acting based on health information, working with experts to assess and select the right treatment options; and providing feedback on results. Patients can play an active role at all levels of the process (6).

Assessment of different types of research evidence

Not all scientific evidence is the same. There are different types of research, and they do not all have the same value and validity. Some types of research have a higher risk of bias or a potential for erroneous results due to how they are conducted. It is, therefore important to know the different levels of evidence and their relative ranking (6).

The levels of evidence (or evidence hierarchy) is a system used to rank different types of medical research based on their quality, reliability, and possibility of bias. Studies from laboratories, experimental animals, and models are the least useful for making conclusions about human health. The highest level of scientific evidence is considered to be systematic literature reviews, studies that summarize the results of all research findings on a given topic (7).

Systematic literature reviews

A systematic review is a type of study that summarizes the results of research studies. The studies being summarized may be published in the scientific literature or not – unpublished studies may also be analyzed if someone makes their results available. Systematic reviews are studies conducted because there are many results from various research studies in many areas of medicine, and not all these studies necessarily have the same result. When searching scientific literature databases, one faces the problem of too much literature, and sometimes those studies draw a different conclusion. In such situations, if multiple studies on the same subject have different results, we ask ourselves which study we should trust (8).

A systematic literature review begins with a narrow medical question, such as “whether high doses of vitamin C are useful for treating the common cold.” After that, researchers write a research protocol detailing which types of research will be sought in the literature, how literature will be searched, how data from the research will be extracted, how the quality and certainty of the included studies will be assessed, how data will be analyzed and presented (8).

It is recommended to publish a systematic review protocol online in the protocol registries in order to make research methods publicly available and transparent. Once the protocol has been completed, researchers are taking steps to develop a systematic review. In order to carry out a sound systematic review, it is important that at least two persons are involved at all stages of such a literature review in order to avoid the possibility of accidental errors and bias (8).

When literature search, data extraction, data analysis, and evaluation of the quality and certainty of the included studies are completed, conclusions for medical practice and future research are drawn. These conclusions are made on the basis of an analysis of all research findings available and have a much higher value as evidence than any individual study included in a systematic review. The conclusions of the systematic review are based on a much larger number of participants than any individual study included in the review. The conclusions for medical practice provide an answer to the medical question raised. Conclusions for future research are also made because by examining existing literature, researchers get the impression of what new research is needed and what deficiencies of existing research are worth correcting in future research (8).

Systematic reviews should be periodically updated by searching the literature again and verifying whether new studies on the topic have been published since the date of the last search. Otherwise, the information contained therein becomes obsolete. Imagine searching scientific literature today to find all the research that answers a question. A few years from now, new studies may have been published in the literature in the meantime, that may change earlier conclusions. Periodically updating the literature searches and the inclusion of new evidence are therefore recommended to make sure that systematic reviews include current and up-to-date evidence (8).

Cochrane

Cochrane is an international nonprofit organization founded in 1993 in the United Kingdom. It produces Cochrane systematic reviews, which are considered a gold standard when it comes to systematic literature reviews (9).

Cochrane's vision is a world of better health for all, where health and care decisions are based on high-quality evidence. Cochrane is an independent, diverse, global organization that collaborates in creating reliable evidence syntheses, makes them accessible to everyone, and advocates for their use. Cochrane's work is internationally recognized as a benchmark for quality information on healthcare effectiveness (9).

Cochrane's systematic reviews can be found on the Cochrane Library website. That page has a search engine that allows you to access the available Cochrane reviews using free text words, or the page can be searched by topic. In July 2023, the Cochrane Library contained more than 9,000 Cochrane systematic reviews in various fields of medicine (10).

Plain language summaries of Cochrane systematic reviews in the Cochrane Library

Scientific articles usually contain an abstract (or a summary), a short text summarizing the most important messages of that scientific article. To clarify the main messages of research findings to people without medical education, Cochrane has decided to publish a plain-language summary (PLS) of each Cochrane systematic review. The PLSs of Cochrane systematic reviews are translated into multiple world languages so that patients can read them in their original language (11).

Examples of topics addressed in Cochrane's systematic reviews

Parents and carers of children with developmental disabilities can find many systematic reviews in the Cochrane Library that can be useful and interesting to them.

For example, a systematic review titled "**Music therapy for autistic people**" was published in 2022 and included 26 studies with a total of 1,165 participants. By analyzing all of these studies, the authors obtained evidence that music therapy is probably associated with a higher probability of global improvement for autistic people, probably helps them improve overall autism severity and quality of life, and probably does not increase side effects immediately after the intervention. The certainty of evidence was assessed as moderate for these four outcomes, meaning that the researchers are moderately confident in those research findings. No clear evidence of difference was found for social interaction, non-verbal communication, and verbal communication measured immediately after intervention. For these outcomes, the certainty of evidence was assessed as low or very low, meaning that the actual result may be substantially different from those results. Compared to earlier versions of this systematic review, the new studies included in the 2022 update helped to increase the certainty and applicability of the results of the literature review, as the inclusion of more studies increased the number of participants in the review, extended age groups, longer intervention periods were examined, and subsequent assessments were included, and mainly using validated tools measuring generalized behavior (i.e., behavior outside the context of therapy). The authors conclude that this new evidence is important for people with autism and their families, as well as for policy-makers, service providers, and clinicians, in order to help decide the types and quantities of interventions to be provided and in resource planning. The authors conclude that more research is needed to confirm the results obtained and to examine whether the effects of music therapy are permanent (12).

Cochrane systematic review "**Overall prognosis of preschool autism spectrum disorder diagnoses**" was published in 2023. The authors of the review wanted to examine whether a preschool child diagnosed with autism spectrum disorders before the age of six remained diagnosed at the re-examination a year or more later. They also examined whether any factors related to the particular child, the way the child was diagnosed with autism, or the research methods used in the studies, were associated with a lower or higher probability of the child continuing to meet the diagnostic criteria for autism spectrum disorder over time. Factors relating to a particular child included the age of the child at initial and subsequent diagnostic assessment, their IQ result, their ability to perform daily life tasks for the child of their age (the result of adaptive behavior), and their assessment of the ability to communicate with those around them (the linguistic result). Factors related to how children were diagnosed included the type of tools or criteria used to diagnose, the length of time between diagnostic assessments, and whether a multidisciplinary team made the diagnosis. Factors related to research methods included the year the study was published and the reliability of the evidence. A total of 49 studies from the scientific literature met the inclusion criteria, and 42 of them (11,740 children) had data that could be used. The largest study included 8,564 children, and the smallest study included 11 children. These studies were carried out in 13 countries, of which 16 were conducted in the United States. The average age of children was three years at first diagnosis and six years after follow-up. The mean length of follow-up was 2.86 years. An analysis of all the studies involved showed that 9 out of 10 (90%) preschool children diagnosed with autistic spectrum disorder maintained their diagnosis a year or more later. For one of the 10 children who no longer met the diagnostic criteria for autism diagnosis at follow-up, it was not possible to assess whether the diagnosis had changed because they became more mature over time or because they received an intervention or if the original diagnosis was incorrect (13).

Cochrane systematic review titled "**Beginning reading interventions for children and adolescents with intellectual disability**" was published in 2019. It included 7 studies involving 352 children and adolescents with intellectual disabilities. The results of the literature review showed that beginning reading interventions were moderately effective in improving phonological awareness, word reading, decoding skills, oral reading fluid and language skills in children and adolescents with intellectual disabilities. The quality of evidence was low and moderate in the five outcomes analyzed by the authors. None of the studies described the adverse effects of the interventions studied (14).

Cochrane's systematic review of "**Methylphenidate for children and adolescents with attention deficit hyperactivity disorder (ADHD)**" was published in 2023. The authors of this systematic review found 212 studies in the literature involving a total of 16,302 children or adolescents with ADHD. Most of the studies compared methylphenidate with placebo. Most of the studies included a small number of children - about 70 children, average age of 10 years (ages ranged from 3 to 18 years). Most of the studies were short, with an average duration of about one month; the shortest study lasted only one day and a maximum duration of 425 days. Most of the research was done in the United States. By analyzing all studies, a systematic literature review showed that, compared to placebo or no treatment, methylphenidate could improve ADHD symptoms (evidence based on 21 studies involving 1728 children), could not affect serious adverse effects (26 studies, 3,673 subjects), could cause less serious adverse effects (35 studies, 5,342 subjects), could improve general behavior (7 studies, 792 subjects) and could not affect quality of life (4 studies, 608 subjects). The authors of the systematic review state that their confidence in the review results is limited for several reasons. It was often possible for the participants to know what therapies they were taking, which could have affected the results. The reporting of results was not complete in many studies, and for some outcomes, the results varied between studies. The studies were small and used different scales to measure symptoms. Most studies lasted only a short period, making it impossible to assess the long-term effects of methylphenidate. Around 41% of the studies were funded or partially funded by the pharmaceutical industry (15).

Cochrane systematic review "**Parent-mediated interventions for promoting communication and language development in young children with Down syndrome**" was published in 2018. Only 3 studies on the subject were found in the literature, involving a total of only 45 children between 29 months and six years of age. Two of the three studies found no differences in children's language abilities after parents performed the interventions for which they were trained. However, the same two studies revealed that children in the intervention group used several words specifically targeted after the intervention; this result was not maintained after 12 months. The study that gave parents the highest amount of intervention described the improvement of overall measures of overall language proficiency for children in the intervention group. One study found no changes in parental stress levels immediately or up to 12 months after intervention in either group. All three studies noted changes in how parents spoke and communicated with their children immediately after the intervention, and most of the strategies were maintained by the intervention group 12 months later. One study reported an increase in the socializing skills of children who received the intervention. No study showed language weakening in any group after intervention. The authors conclude that new research on this topic is needed (16).

Literature

1. Complementary and Alternative Medicine. Link: https://www.cancer.gov/about- cancer/treatment/cam.
2. Global Complementary and Alternative Medicine Market [2023] | New Report Anticipates Industry to Surpass USD 435020.27 Million in Revenue by 2030. Link: https://www.marketwatch.com/press-release/global-complementary-and-alternative-medicine-market-2023-new-report-anticipates-industry-to-surpass-usd-43502027-million-in-revenue-by-2030-2023-04-24.
3. The Unbearable Cost of Drug Development: Deloitte Report Shows 15% Jump in R&D to $2.3 Billion. Link: https://www.genengnews.com/gen-edge/the-unbearable-cost-of-drug-development-deloitte-report-shows-15-jump-in-rd-to-2-3-billion/.
4. Vandana P, Simkin DR, Hendren RL, Arnold LE. Autism Spectrum Disorder and Complementary-Integrative Medicine. Child Adolesc Psychiatr Clin N Am. 2023;32(2):469-94.
5. What is Evidence-Based Medicine? Link: https://s4be.cochrane.org/start-here/what-is-evidence-based-medicine/.
6. Evidence-based medicine. Link: https://toolbox.eupati.eu/resources/evidence-based-medicine/.
7. Levels of medicine. Link: https://openmd.com/guide/levels-of-evidence.
8. Khan KS, Kunz R, Kleijnen J, Antes G. Five steps to conducting a systematic review. J R Soc Med. 2003;96(3):118-21.
9. About us. Cochrane. Link: https://www.cochrane.org/hr/about-us.
10. The Cochrane Library. Link: http://www.cochranelibrary.com/.
11. Plain language summary format. Link: https://www.cochrane.no/how-write-plain-language-summary.
12. Geretsegger M, Fusar-Poli L, Elefant C, Mossler KA, Vitale G, Gold C. Music therapy for autistic people. Cochrane Database Syst Rev. 2022;5(5):CD004381.
13. Brignell A, Harwood RC, May T, Woolfenden S, Montgomery A, Iorio A, et al. Overall prognosis of preschool autism spectrum disorder diagnoses. Cochrane Database of Systematic Reviews. 2022(9).
14. Reichow B, Lemons CJ, Maggin DM, Hill DR. Beginning reading interventions for children and adolescents with intellectual disability. Cochrane Database Syst Rev. 2019;12(12):CD011359.
15. Storebo OJ, Storm MRO, Pereira Ribeiro J, Skoog M, Groth C, Callesen HE, et al. Methylphenidate for children and adolescents with attention deficit hyperactivity disorder (ADHD). Cochrane Database Syst Rev. 2023;3(3):CD009885.
16. O'Toole C, Lee AS, Gibbon FE, van Bysterveldt AK, Hart NJ. Parent-mediated interventions for promoting communication and language development in young children with Down syndrome. Cochrane Database Syst Rev. 2018;10(10):CD012089.

Characteristics of developmental difficulties/disabilities

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Most important messages:

- Common psychological problems associated with disability include emotional, social and adjustment problems.
- Children with developmental disabilities or chronic diseases are more likely to have low mood and depression than their peers.
- Children with developmental disabilities often have difficulties with self-esteem and socialization
- Adults (parents, family, educational staff) can help children with developmental disabilities to progress and adapt positively to their disability.
- Parents of children with developmental disabilities should also take care of their health, because of the possibility of burning out while taking care of the child's needs.

Introduction

Disability includes any condition that makes it difficult for a person to perform certain activities or have fair access in a given society. It can be cognitive, developmental, intellectual, mental, physical, sensory, or a combination of these. A disability may be present from birth or may be acquired during a person's lifetime and, by nature, may be easily visible or invisible. Developmental disabilities include a group of conditions that occur as a result of impairments in physical/somatic health, learning, language or behavior. These conditions begin during the developmental period, can affect daily functioning, and usually last throughout a person's life (1).

The United Nations Convention on the Rights of Persons with Disabilities defines disability as "long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may impede [a person's] full and effective participation in society, on an equal basis with the others" (2).

Here are some recent facts about developmental disabilities:

- There are almost 240 million children living with a disability in the world, or 1 in 10 children has some kind of disability. Psychosocial difficulties affect the majority of these children, regardless of age (3).
- Children with disabilities are more likely to be exposed to certain violations of child protection rights, including various forms of violence (4).
- Children with disabilities are 25% less likely to attend kindergarten, 49% more likely to never attend school, 47% more likely to be out of primary school, 33% more likely not to attend secondary school (4).
- Children with disabilities experience higher rates of multidimensional poverty, compared to children without disabilities. For children aged 2 to 4 years, 38% of those with more than one functional disability, experience three to five deprivations, compared to only 12% of children without functional disabilities (4).
- Children with disabilities are 42% more likely to be underweight, and 34% more likely to be developmentally delayed (4).
- Children with disabilities face poorer health outcomes, may have delayed development, face a higher risk of contracting infectious diseases, and are less likely to benefit from life-saving measures (5).

- Data suggest that institutionalization of children with disabilities continues in many countries and regions across high- and low-income countries (6).
- Globally, it is estimated that every third child in institutions is a child with developmental difficulties (7).

The psychological characteristics of developmental disabilities in children can vary depending on the specific disability and individual experiences. In general, common psychological problems and characteristics associated with disabilities include:

1. **Emotional challenges -** individuals with disabilities may experience a range of negative emotions, such as frustration, sadness, anger, and anxiety. These emotions can arise from various factors such as mobility limitations, communication difficulties, or social stigma. The most common challenges in the emotional sphere are:

- Depression and depressed mood - people with developmental difficulties/disabilities may be at greater risk of developing depression later in life due to challenges they face, such as limited mobility, chronic pain, communication difficulties, or social isolation. Dealing with daily obstacles and social barriers can contribute to feelings of hopelessness and sadness. The most typical symptoms include difficulty in sleeping and eating, lack of energy, lack of interest in activities they previously enjoyed, problems in concentration, pessimism, hopelessness, sadness, irritability, and even suicidal thoughts. Moreover, preschool depression is characterized by motor problems in gross motor skills and coordination. Depression can be like a vicious cycle; as symptoms can progress, the individual can experience additional stress and sadness, which can push them deeper into the depression.
- Anxiety - anxiety disorders, such as generalized anxiety disorder or social anxiety disorder, may be present in people with disabilities. Uncertainty about the future, fear of judgment, or concern about their ability to navigate the physical or social environment can contribute to increased levels of anxiety.
- Low self - esteem-people with developmental difficulties/disabilities can struggle with low self-esteem, often due to negative social attitudes, discrimination, or feelings of being different or less capable. This can affect their overall sense of self-esteem. Lower self-esteem in children is a known factor in the development of depression in children and adolescents. High self-esteem is a protective factor against mental health problems, drug abuse, high levels of anxiety, criminal behavior, and antisocial tendencies and behavior (9, 10).
- Elevated stress levels - life with a disability often involves managing additional stressors, such as coping with various medical interventions, adapting aids, or facing accessibility challenges. Effective coping strategies and support systems are critical for managing stress and maintaining mental well-being.

2. **Social challenges**-developmental difficulties/disabilities can affect an individual's social interactions and relationships with other people. Some children may have difficulty making friends, maintaining relationships, or participating in social activities because of physical or communication barriers. As a result, feelings of isolation and loneliness can arise.
3. **Adjustment difficulties**-adjusting to life with a disability can be a significant psychological challenge. It can include accepting physical limitations, redefining

personal goals, and adjusting to a new way of living. The adjustment process can vary in duration and intensity, depending on the individual and their support network.

Despite the challenges, many individuals with developmental disabilities show remarkable resilience and strength. They learn to adapt, develop coping strategies, and find ways to navigate their environment.

Coping with emotional challenges

Coping with depressive and anxious moods

Children often feel down, moody, or have negative thoughts. These feelings are a part of the development and a part of learning to manage emotions. But childhood depression is more than just feeling sad, strong, or weak. Depression in children is a mental health problem that affects children's thinking, mood, and behavior.

Children with disabilities or chronic conditions are more likely to experience low mood and depression than their peers. This happens for many reasons. For example, children with disabilities or chronic conditions often have pain, feel different from their peers, feel that their condition interferes with everyday life, experience violence, have difficulty mastering schoolwork, and experience difficult medical procedures.

Here are some specific ways parents can help their child deal with those feelings:

- help your child to think not only about its own health but also outside of it: what is that child is successful in, in which fields does he achieve success, what is important to the child, what are the child’s interests, in which activities does the child feel happy?
- encourage socialization both with children who have similar experiences and with children without disabilities. Support your child's friendships and activities and help them find ways to make and maintain new relationships. For example, you can invite friends or organize various fun activities.
- develop a plan to help your child keep up with schoolwork and friends while the child is away for necessary treatments.
- encourage your child to tell trusted friends about his disability or condition. This can strengthen their friendships and help them feel more supported.
- help your child discover what calms the child or helps the child cope with negative emotions. For example, the child may want to be hugged or cuddled with a favorite toy.
- help your child learn how to manage his emotions.
- let your child know it's okay to be angry or frustrated, and encourage the child to be kind to himself when he feels that way.
- help your child learn what the child feels by building an emotional vocabulary from an early age. For example, "You have a big smile on your face, you must be happy to see me." Or "You're crying... you must be sad because you can't play with your friends" (11, 12).

Coping with low self-esteem

Because children with developmental disabilities face a wide range of challenges, from emotional, to behavioral, and educational, developing confidence in one's own abilities, also known as self-esteem, is not as simple as it might be for a child without a disability. However, essential to any well-being is developing positive self-esteem.

A study by Alesi, Rappo, and Pepi (2014) found that the relationship between depressive symptoms and school achievement could be attributed to variables such as lower self-esteem among students, including lower perceived academic competence and intelligence. The study further demonstrated the importance of addressing self-esteem in order to prevent depression in students, as well as to support students already suffering from depression (8).

Here are some specific ways parents can help foster self-esteem:

- accepting the child's limits – this is essential for your child's confidence. Although parents can deal with conflicting emotions surrounding their child's special needs, it is important for children to know that they are accepted and loved just as they are. This includes accepting their unique limits and abilities, if we want the child to try and push their limits.
- focusing on positive traits – children gain self-confidence when they do something good and get recognition for it from their loved ones. Help your child focus on what he is really good at and encourage him to use those skills as much as possible. Everyone has things they cannot do and things they can do. Not all students will excel in their academic skills. Poor academic performance can have a demoralizing effect on a child. However, if a parent pays attention to and celebrates the child's positive qualities, such as putting effort into learning, regularly writing homework, etc., this will encourage both parents and children that they have other reasons to be confident and happy, even if school success is not the strongest point. Helping children discover and celebrate their unique strengths will set them up for confidence and success.
- adjusting the pace of learning – children with developmental difficulties/disabilities can be extra sensitive to their slower pace of learning and feel discouraged when their efforts do not result in immediate success. When learning something new, everyone has to make an effort to master the tasks. As a parent, you can break down difficult tasks into smaller tasks. Then celebrate the achievement of each step, no matter how small.
- rights, but also responsibilities for children – having their own responsibilities allows children to feel capable and confident. Children need to be given opportunity to accomplish simple tasks. The best tasks that contribute to the child's self-esteem are self-care activities, where it is very important to teach children to be independent in dressing and undressing, taking off their shoes, preparing their bag, etc. Children should also be given feedback about how successful and independent they are, in as much as possible. Also, it is important to include children in all house chorses, such as putting away dishes, helping with meal preparation, etc., which contributes to their positive self-image. Completing simple chores provides an opportunity for pride to grow. Give your child realistic responsibilities according to his or her abilities. Even if your child doesn't want to do the work, having the responsibility and knowing that others depend on him or her to complete the task builds self-esteem and a sense of connection and accomplishment.
- children don't like to think they are different – it lowers their self-esteem and arouses negative emotions. This doubt will also affect how they interact with their peers. Talk to your child and try to understand why the child feels offended, and encourage dialogue. Through this process, the child feels heard and, most importantly, it shows that you genuinely care about his well-being.
- it is only natural that everyone has strengths and weaknesses – make children feel positive by teaching them not to give up. Set small daily goals, and by completing them daily, they will build and rebuild their confidence.

- you are preparing your child for a better future – maybe that means having a job and a family and going beyond just getting good grades in school. So, the main focus should be on helping your child become independent. Therefore, help your child succeed in life, not just be a good student (13, 14).

Coping with social difficulties

Children with developmental disabilities often face social challenges.
Here are some specific ways parents can help a child cope with social difficulties:
- encourage children to have social communication;
- provide time and place to play with other children;
- attend social events and activities that are specially designed for children with disabilities. This can help your child meet other children who face similar challenges;
- join groups to learn social skills, or a specific program, or therapy. These types of programs can provide your child with structured opportunities to practice and improve social skills;
- encourage eye contact and communication through games and activities;
- help the child understand and follow social rules and norms;
- and you, as a parent, be a good role model by communicating positively with the child;
- encourage your child to watch television shows or movies featuring characters with disabilities;
- make sure they have opportunities to interact with adults who have positive social skills;
- teach them social skills explicitly through books, games, and other activities;
- teach the child body language, and at the same time, you yourself model the correct body language;
- point out when other people use good body language;
- role play different social situations with your child so he can practice using correct body language;
- some specific things you can teach your child about body language include: making eye contact, smiling, maintaining an open posture, and using appropriate gestures. By helping your child understand and use body language effectively, you can improve their social skills immensely (15).

Many children with developmental disabilities struggle with understanding social cues or holding conversations. And conversation is a key social skill. So, you need to help your child practice his conversation skills. Here are some tips:
- make sure to get the child's attention before you start talking;
- get down to his level and make eye contact;
- use simple language and short sentences;
- ask open-ended questions that require more than a yes or no answer;
- give the child time to respond. Allow pauses in the conversation;
- repeat what the child says to show you are listening;
- encourage the child to ask questions too;
- be patient and positive. Avoid correcting the child or getting frustrated if the conversation does not go smoothly. Just because your child has a specific way of doing things doesn't make them incapable. Children do certain things differently and that is absolutely fine.

Do not be upset and do not look down on your child. Accept the new normal, stay positive and fair;
- adjust the expectations you set. Having a disability does not mean being a failure in life. You also need to be mentally and emotionally strong for the sake of your child;
- try to find common interests to talk about. This can make the conversation more enjoyable for both of you;
- make sure the conversation is balanced. Alternate talking and listening;
- end the conversation on a positive note by saying something like, "I enjoyed talking to you!"

Coping with adjustment difficulties

When a child is adjusting to a developmental disability, it is essential that parents provide love, support, and understanding. Here are some ways parents can help in this process:
- open and honest communication - create a safe space where your child feels comfortable discussing their feelings, concerns and questions about their difficulties. Encourage children to express themselves openly and address any misconceptions or fears they have;
- educate yourself and your child - learn about the specific disability your child has and its potential impact on their daily life. Share this information with your child in an age-appropriate way, helping him understand his abilities and limitations;
- encourage self-advocacy - teach your child to advocate for himself by expressing his/her needs and seeking appropriate support. Encourage children to communicate their requests to teachers, peers and other relevant individuals, encouraging independence and self-confidence;
- promote a positive self-image - help your child develop a positive self-image by focusing on his strengths, talents, and abilities. Encourage children to engage in activities they enjoy and excel at, increasing their confidence and sense of achievement;
- foster a supportive environment – create an inclusive and supportive environment both at home and in the community. Encourage family members, friends, and teachers to understand and accept your child's needs. Help them build accepting and inclusive peer relationships;
- seek appropriate resources and therapies - explore and take advantage of available resources, therapies, and support groups that can help your child's development and help them overcome challenges. Occupational therapy, speech and language therapy, physical therapy, psychotherapy, and counseling services may be helpful depending on the nature of their disability;
- encourage independence and autonomy - encourage your child to be independent and develop life skills relevant to his abilities. Provide children with opportunities to make choices, solve problems and engage in age-appropriate responsibilities, encouraging their sense of autonomy;
- emphasize endurance and perseverance - teach your child the importance of resilience and perseverance when faced with challenges. Help children understand that failures are a natural part of life and that they have the strength to overcome obstacles and achieve their goals;

- raise awareness of the importance of communication - some children with disabilities will be able to talk to you, others not. But they communicate, even though they don't speak. Communicatoin is wider term than simply speech; even people that do not talk can communicate. For example, when a newborn child comes into a family, the child communicates without speaking. A parent learns to recognize what their child likes or dislikes by the way they smile, laugh or cry. The same thing happens with children with developmental difficulties/disabilities who cannot speak. They tell you what they like by smiling or laughing and what they don't like by crying or an upset face. Assisted communication or alternative and augmentative communication, includes symbol, assistive devices, strategies and techniques used by individuals with the aim to enhance their communication. It is aimed for individuals with complex communication problems;
- stimulate the child's development - children are stimulated by everything in their environment: by sounds, by interactions, by your smile. So, if your child with a developmental difficulty/disability is around you, you should make sure you spend time talking to them, explaining in simple language what you are doing, smiling with them, telling them about their surroundings, making noises, and allowing them to react to them. Everything you do, as you move around the house and do household chores, include your child in it. Move your child into the room in which you are working. Tell them what you do: I'm washing the dishes; I'm putting the dishes in the water. Always tell them exactly what you are doing. You can also stimulate them by directly playing with them, by making small toys in the home, putting rocks in a bottle and shaking them, or waving different coloured ribbons in front of their eyes. There are many things you can do with just the things you have in and around the home. All this will stimulate them;
- play various games with the child - children with disabilities enjoy playing with them, just like any other child. They enjoy while you read to them, while you show them pictures, while you tickle them, while you hug them. They answer you with laughter and smiles. They will tell or show you if they don't like a certain game. They will stop laughing, rejoicing. Try something else. You will find something because you know them best. If you do not have much time to play with your child, other family members in your home may also play with your child with a disability. Siblings are often very careful with their siblings with disabilities. They stimulate them because they talk to them a lot and play with them. Their relationship is not burdened by whether the sibling has a disability. They are played with just like anyone else;
- maybe your child has a disability, but he also needs discipline in his life. This means they need to understand and respect the rules their parents/guardians set. You may need to adapt a few of them to help them in their learning process;
- limit the amount of time your child spends in front of the screen. Along with the negative impact on the rest and sleep, the use of screens negatively affects complete development, communication, emotional development, posture and attention. A child who does not sleep sufficiently will have problems with daily functioning. Try to set a bedtime routine, and by introducing it gradually, get your child to follow it. Remember that children need a healthy amount of sleep to rest and reset, so they should go to sleep early;

- connect with support networks-seek out support networks, both online and offline, where you and your child can connect with other families and individuals who have similar experiences. Sharing experiences and insights can provide a sense of belonging and practical advice;
- professional guidance - consult with health professionals, therapists and counselors who specialize in working with children with disabilities. They can provide valuable guidance, strategies, and interventions tailored to your child's specific needs.

Remember, each child's experience with a disability is unique, and it is important to adjust your support to their individual requirements. By fostering a nurturing environment and promoting their strengths, parents can help their children thrive and adjust positively to their disability.

Finally, find time for yourself. Don't forget to take care of yourself. It will not do anyone any good if you burn out while taking care of your child's needs. You need to be emotionally and mentally fit to create a healthy life. Your child depends on you. You won't help your child much if you're exhausted and stressed. So take time for yourself. Do something fun to help you relax. You should also eat healthy and sleep well. Talking and sharing your daily struggles will help you realize that you are not alone. Other parents facing the same struggles will encourage and support you. Plus, you might learn some new ways to help your child thrive.

Literature

1. Francis, Leslie; Silvers, Anita (October 1, 2016)."Perspectives on the Meaning of "Disability"". AMA Journal of Ethics. 18(10): 1025-1033doi:10.1001/journalofethics.2016.18.10.pfor2-1610.ISSN2376-6980.PMID27780027
2. Resolution / adopted by the General Assembly, A/RES/61/106. UN General Assembly, Convention on the Rights of Persons with Disabilities. 24 January 2007. (Accessed May, 20 2023)
3. United Nations Children's Fund, 'Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities', New York, 2022,https://data.unicef.org/resources/children-with-disabilitiesreport-2021
4. Jones, Lisa, et al., 'Prevalence and Risk of Violence Against Children with Disabilities: A systematic review and meta-analysis of observational studies', The Lancet, vol. 380, no. 9845, 2012, pp 899–907, doi: 10.1016/S0140-6736(12)60692-8
5. United Nations Children's Fund and Leonard Cheshire Disability and Inclusive Development Centre, 'Disability Prevention Efforts and Disability Rights: Finding common ground on immunization efforts', UNICEF, New York, 2020.
6. Petrowski, Nicole, Claudia Cappa, and Peter Gross, 'Estimating the Number of Children in Formal Alternative Care: Challenges and Results', Child Abuse & Neglect, vol. 70, 2017, pp. 388–398. doi:10.1016/j.chiabu.2016.11.026; p. 395
7. Committee on the Rights of the Child, 'United Nations Global Study on Children Deprived of Liberty', Office of the United Nations High Commissioner, Geneva, 2019, <www.ohchr.org/en/treaty-bodies/crc/unitednations-global -study-children-deprived-liberty>, accessed 23 June 2022; chapter 7, p. 191
8. Alesi M, Rappo G, Pepi A (2014) Depression, Anxiety at School and Self-Esteem in Children with Learning Disabilities. Psychology Abnormal Child 3:125.
9. Lindsay, G., Dockrell, J., & Palikara, O. (2010). Self-Esteem of Adolescents with Specific Language Impairment as They Move from Compulsory Education. International Journal Of Language & Communication Disorders, 45(5), 561-571.
10. LaBarbera, R. (2008). Perceived Social Support and Self-Esteem in Adolescents with Learning Disabilities at a Private School. Learning Disabilities -- A Contemporary Journal, 6(1), 33-44.
11. Morris, AS, Criss, MM, Silk, JS, & Houltberg, BJ (2017). The impact of parenting on emotion regulation during childhood and adolescence. Child Development Perspectives, 11(4), 233-238. doi: 10.1111/cdep.12238.
12. Hurrell, KE, Houwing, FL, & Hudson, JL (2016). Parental meta-emotion philosophy and emotion coaching in families of children and adolescents with an anxiety disorder. Journal of Abnormal Child Psychology, 45(3),

569-582. doi: 10.1007/s10802-016-0180-6.
13. Brummelman, E., Crocker, J., & Bushman, BJ (2016). The praise paradox: When and why praise backfires in children with low self-esteem. Child Development Perspectives, 10(2), 111-115.https://doi.org/10.1111/cdep.12171.
14. Leijten, P., Gardner, F., Melendez-Torres, GJ, van Aar, J., Hutchings, J., Schulz, S., Knerr, W., & Overbeek, G. (2019). Meta-analyses: Key parenting program components for disruptive child behavior. Journal of the American Academy of Child & Adolescent Psychiatry, 58(2), 180-190.https://doi.org/10.1016/j.jaac.2018.07.900.
15. Kellie S. Bennett & David A. Hay(2007) The Role of Family in the Development of Social Skills in Children with Physical Disabilities, International Journal of Disability, Development and Education, 54:4, 381-397, DOI:10.1080/10349120701654555

Characteristics of intellectual disabilities

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Most important messages:

- Intellectual disability refers to a certain state of functioning that begins before the age of 18, and which is marked by significant limitations in both intellectual functioning and adaptation.
- The more severe the degree of intellectual disability, the earlier the signs can be noticed.
- Impulse control is a common problem for people with intellectual disabilities, as is low self-esteem.
- Intellectual disability is not a condition that can be solved quickly, it is a lifelong challenge.
- Caring for a child with intellectual disabilities is often exhausting for parents.
- Many people with intellectual disabilities can live a quality and fulfilling life, full of love and care.

Introduction

The term intellectual disability (ID) can be used to refer to a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development (1).

ID refers to a particular state of functioning that begins prior to age 18, characterized by significant limitations in both intellectual functioning and adaptive behavior. The definition of ID has been revised a number of times during the past few decades as people's understanding of the disorder has changed and in response to various social, political, and professional forces. The most widely accepted definition of ID is that of the American Association for Intellectual and Developmental Disabilities: "ID is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18" (2).

Levels of ID vary greatly in children. Children might have difficulty letting others know their wants and needs and caring for themselves. ID could cause a child to learn and develop more slowly than other children of the same age. It could take longer for a child with ID to learn to speak, walk, dress, or eat without help, and they could have trouble learning in school, outside of scool and have many other problems.

ID can be caused by a problem that starts any time before a child turns 18 years old, even before the birth. It can be caused by injury, disease, or a problem in the brain. For many children, the cause of their ID is not known. Some of the most commonly known causes of ID, like Down syndrome, fetal alcohol syndrome, fragile X syndrome, genetic conditions, birth defects, and infections, happen before birth. Others happen while a child is being born or soon after birth. Still, other causes of ID do not occur until a child is older; these might include serious head injury, stroke, or certain infections. These different causes mean each person's disability is unique. There is no single set of shared traits or features.

Usually, the more severe the degree of ID, the earlier the signs can be noticed. However, it might still be hard to tell how young children will be affected later in life.

There are many signs of ID. For example, children with ID may:

- sit up, crawl, or walk later than other children

- learn to talk later, or have trouble speaking
- find it hard to remember things
- have trouble understanding social rules
- have trouble seeing the results of their actions
- have trouble solving problems (3).

ID and behavioral problems

Behavioral challenges among young individuals with ID are prominent and have raised significant concerns among mental health professionals. Individuals with ID often exhibit behavioral issues such as stereotypes, aggression, and violence, which can result in self-harm, harm to others, or property destruction (4, 5). Moreover, the social environment in which children with ID live and interact also influences their behavioral problems. However, due to a lack of awareness and knowledge, atypical behaviors in individuals with ID may be mistakenly perceived as signs of mental illness. Nonetheless, studies have indicated that these behavioral problems among individuals with ID increase the likelihood of developing mental illness (6-8). Evaluating behavioral issues in individuals with ID poses considerable challenges due to cognitive and communication deficits. Direct observation or reports from teachers and caregivers are the only means to assess behavioral problems in individuals with ID (9). Consequently, various tools have been developed to gather accurate information from parents and teachers.

Impulse control is a prevalent issue among individuals with ID, as they often struggle with linking actions to their consequences. This difficulty in establishing cause-and-effect relationships results in challenges with regulating impulsive behaviors. Consequently, this lack of impulse control leads to various unfavorable outcomes. Another related issue is the presence of low frustration tolerance. When an impulse is restrained, it necessitates the capacity to endure a certain level of frustration, which is known as frustration tolerance. Frustration tolerance is a crucial skill in personal development, enabling individuals to cope with minor everyday frustrations comfortably. Enhancing frustration tolerance plays a vital role in mitigating the negative consequences associated with impulsive behavior (10).

Self-control is the ability that enables us to manage our behaviour, emotions and thoughts. It includes regulation of stress, delaying pleasure, motivating ourselves and achieving personal goals. Parents often inquire about self-regulation, which we explain in two differen contexts, precisely because parents often do not undertand how frustrations, or excesive excitement, that cannot be control, happens in completely different conditions and environments. The first context of self-regulation is related to frustrations and other negative feelings. The second context is self-regulation with positive experiences, and excessive happiness in that moment. In both situations, a child experiences high levels of excitement, that enables us an insight into their ability for self-regulation.

Low self-esteem is a prevalent challenge experienced by individuals with ID. Self-esteem typically develops as children acquire problem-solving skills, which in turn contribute to building self-confidence. However, individuals with limited intellectual functioning encounter difficulties in problem-solving tasks. Effective problem-solving requires sustained attention and persistence in the face of challenges, abilities that are often constrained in individuals with limited intellectual functioning. As a result, low self-esteem may develop. It's worth noting that psychiatric disorders such as depression can sometimes coexist with intellectual disabilities and contribute to low self-esteem. Nevertheless, it is important to recognize that many individuals with ID lead fulfilling lives and exhibit positive well-being, not displaying problematic behaviors.

Dealing with ID difficulties

ID is not a condition that can be resolved quickly; it is a lifelong challenge. However, as a parent, you have the opportunity to support and prepare your children throughout their lives, equipping them with the necessary skills and knowledge to lead independent and flourishing lives. This process takes time, and it is important to approach it with a long-term perspective, ensuring that your children have the tools they need to navigate the world and thrive autonomously.

So, here are some tips:

- start treatment early: early intervention helps to maximize the child’s potential as early experiences play a critical role in brain development. It is also strengthened by stable relationships with caring and responsive adults, safe and supportive environments and appropriate nutrition.
- learn about ID: enhancing your knowledge about your child's ID is crucial for both your own empowerment and your ability to support your child effectively. By gaining a comprehensive understanding of the spectrum of your child's ID, you become equipped with the insights necessary to anticipate their needs and make informed decisions about their upbringing and future. The more knowledge you possess, the better equipped you are to provide the appropriate guidance and support required for your child's overall well-being and development.
- be patient, be hopeful: your child, like every child, has a whole lifetime to learn/grow.
- promote self-reliance in your child by actively fostering their independence: for instance, assist your child in acquiring essential daily care abilities, including dressing, self-feeding, using the restroom, and personal hygiene. To facilitate the teaching of life skills, consider the following tips: initiate the teaching of a new skill when you observe that your child demonstrates readiness. Support your child in comprehending the purpose of the activity and the sequential steps involved, as this significantly facilitates the learning process of the skill. By ensuring your child understands the underlying reasons and the sequential order of the task, you enhance their ability to acquire the skill more effectively. Teach a skill one step at a time by breaking them down. For example, taking a shower: take off your clothes, turn on the shower, adjust the water temperature, scrub body with soap and rinse, dry body with towel, dress your self-up. It is useful to use visual schedule, an illustrated calendar for daily activities and tasks. In a visual schedule, for each step there is a picture. Printed pictures can be glued, for example, to the bathroom mirror and then a parent announces the next step of the activity with each new picture.
- establish routines to make it easier for your child to learn daily living skills and become more independent.
- use pictures (visual schedule) of activities in a sequential order as and when they would appear each day. It is a great way to promote independence and help your child learn routines. These pictures include step-by-step description of daily activities that a child is expected to engage in.
- provide direct and immediate feedback to form a connection between cause and effect.

- find out what skills your child is learning at school, and find ways for your child to apply those skills at home. For example, if the teacher is going over a lesson about money, take your child to the supermarket with you. Help him count out the money to pay for your groceries. Help him count the change.
- meet with the school and develop an Individualized Education Program to address your child's needs. Keep in touch with your child's teachers. Offer support. Find out how you can support your child's school learning at home.
- explore your child's learning styles. The first key to success is to understand how he learns so you can meet that child's needs. If the child is a visual learner, provide bright colors and information that is memorable for them to recall. Use contrasting colors that trigger brain neurons to activate and become more interesting for them to remember. If he is an auditory learner, use music, sounds, and words to express the material when teaching. If he is a kinesthetic or tactile learner, use the sense of touch and physical movement to provide excitement and entertainment to engage the brain to remember better. Once you can identify your child's learning style(s), it will be easier to help him grasp material on grade level better.
- find opportunities in your community for social activities, such as scouts, recreation center activities, sports etc. These will help your child build social skills and have fun.
- talk to other parents whose children have an intellectual disability. Parents can share practical advice and emotional support.
- forget about what others say. Stigma may contribute to poor psychological health by increasing psychological distress and reducing quality of life. Do not let the stigma keep you or your child down. Ensure that your child is able to fully integrate with their communities. Support your child, listen to them, be affectionate, and empower them.
- repeat, repeat, repeat. Once you know their learning style, the second key is to provide constant, daily, repetitive practice of a given skill. Repetition is so important in brain development. However, for children with developmental disorders, the ability to retain information is a challenge. What new information your child learned one day may have been forgotten the next day.
- practice makes progress, not perfection. A typical person has to repeat a skill over and over and over before he has mastered it. Your child with an ID is no different. They need supportive environments with patience and guidance, and constant practice to learn how to be successful. The parent's ability to understand how their child learns and the child having the time to practice a skill over and over will make it much easier to master. Your child wants to be successful, regardless of his disability. He can be successful in every aspect of life. However, they need to know someone is walking alongside them while they do the hard work in their life.
- like any other child, children with ID develop and learn at different rates and ways. What is important is for you to continue to be patient and be affectionately supportive, as well as work hard to help your child hone his adaptive capabilities so that he may reach his full potential in life. With your help and that of those around you, your child can live a happy and fulfilling life (11).

Taking care of a child with ID can take a lot out of any parent. It is important not to neglect your own needs, get sufficient rest; eat well; take time for yourself; and reach out to others for support. Get family members or friends to fill in for you while you enjoy some time away.

Literature

1. Department of Health (United Kingdom) (2001). Valuing people: A new strategy for learning disability for the 21st century: A white paper. Retrieved from http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf.
2. American Association on Mental Retardation. (2002). Mental Retardation: Definition, Classification, and Systems of Supports, 10th Edition. Washington, DC: American Association on Mental Retardation.
3. https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html
4. Lowe K, Allen D, Jones E, Brophy S, Moore K, James W. Challenging behaviours: prevalence and topographies. J Intellect Disabil Res. 2007 Aug;51(Pt 8):625-36. doi: 10.1111/j.1365-2788.2006.00948.x. PMID: 17598876.
5. Smith K R, Matson J L. Behavior problems: differences among intellectually disabled adults with co-morbid autism spectrum disorders and epilepsy. Res Dev Disabil. 2010;31(05):1062–1069. [PubMed] [Google Scholar]
6. Lakhan R. Effect of play and exposure on development of children with intellectual disabilities through community-based rehabilitation. Indian Journal of Physical Medicine and Rehabilitation. 2009;20(01):13–18. [Google Scholar]
7. Grey I M, Hastings R P. Evidence-based practices in intellectual disability and behaviour disorders. Curr Opin Psychiatry. 2005;18(05):469–475. [PubMed] [Google Scholar]
8. Rojahn J, Matson J L, Naglieri J A, Mayville E. Relationships between psychiatric conditions and behavior problems among adults with mental retardation. Am J Ment Retard. 2004;109(01):21–33. [PubMed] [Google Scholar]
9. Kerr M P. Behavioral assessment in mentally retarded and developmentally disabled patients with epilepsyEpilepsy & behavior: E&B 2002;3(6S1):14–17 [PubMed]
10. Hartley SL, Maclean WE. Coping Strategies of Adults with Mild Intellectual Disability for Stressful Social Interactions. J Ment Health Res Intellect Disabil. 2008 Apr;1(2):109-127. doi: 10.1080/19315860801988426. PMID: 20234803; PMCID: PMC2838717.
11. Thompson S. Parenting children with intellectual disability: Children with intellectual disabilities, Independently published (2023)

Characteristics of cognitive disabilities

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Most important messages:

- Difficulties in cognitive abilities, which are typical for Attention deficit Hyperactivity Disorder (ADHD) and learning disabilities, can have a significant negative impact on a child's progress in school.
- Common signs are learning difficulties, reading and writing, math skills, attention and time management.
- Children who suffer from learning disabilities can often feel frustrated because they cannot master the school materials despite making considerable efforts.
- Every fifth child has learning and attention problems, such as dyslexia and ADHD.
- Some children with learning disabilities may exhibit disruptive behavior at school as a defense mechanism.
- It is important to understand that these children are just as intelligent as their peers and can achieve a lot, but they are too often mistaken for being lazy or not intelligent enough.

Cognitive skill disabilities, which are found in attention deficit hyperactivity disorder (ADHD) and learning disabilities, can significantly affect your child's ability to thrive in school. It is crucial to comprehend the nature of cognitive skills, recognize the indications of cognitive skill deficiencies, and grasp their implications for your child.

One of the easiest ways of understanding what cognitive skills are is to refer to Bloom's classification as follows:

- knowledge: remembering information
- comprehension: understanding what has been communicated
- application: using general concepts to solve problems
- analysis: breaking down information into parts to see relationships between ideas
- synthesis: making something new by organizing information into new relationships or patterns
- evaluation: deciding which methods should be used to solve problems (1).

When a child uses these cognitive skills to understand and learn, this is called cognitive processing. These cognitive skills encompass various thought processes such as perception, reasoning, memory, and judgment.

Occasionally, children may encounter difficulties with certain subjects or skills in school. However, if a child consistently faces challenges with a specific set of skills despite putting in considerable effort, it could indicate the presence of a learning disorder. A learning disorder signifies that a child experiences difficulty in one or more areas of learning, regardless of their overall intelligence or level of motivation.

Common signs that a person may have learning disabilities include the following:

- problems reading and/or writing
- problems with math
- poor memory
- problems paying attention
- trouble following directions
- clumsiness

- trouble telling time
- problems staying organized (2).

Parents should also be attentive to the following common indicators of learning disorders in their child:

- difficulty comprehending and following instructions
- trouble retaining information that has just been communicated to them
- inability to attain proficiency in reading, spelling, writing, and/or math skills, resulting in academic setbacks
- challenges in distinguishing between right and left; struggling to recognize words or exhibiting a tendency to reverse letters, words, or numbers (for example, switching 29 with 92, "t" for "d," or "on" for "no")
- lack of coordination in activities such as walking, sports, or tasks that involve fine motor skills like holding a pencil or tying shoelaces
- frequent loss or misplacement of homework, schoolbooks, or other essential items
- difficulty grasping the concept of time, leading to confusion with terms like "yesterday, today, tomorrow" (3).

Various learning disorders include the following examples:

- dyslexia, which involves challenges in reading.
- dyscalculia, which entails difficulties with math.
- dysgraphia, which relates to struggles with writing.

People with dyslexia usually have trouble connecting letters and sounds and spelling and recognizing words (4). People with dyslexia often show other signs of the condition. These may include:

- having a hard time understanding what others are saying
- difficulty organizing written and spoken language
- delay in being able to speak
- difficulty expressing thoughts or feelings
- Difficulty learning new words (vocabulary), either while reading or hearing
- trouble learning foreign languages
- difficulty learning songs and rhymes
- slow rate of reading, both silently and out loud
- giving up on longer reading tasks
- difficulty understanding questions and following directions
- poor spelling
- problems remembering numbers in the sequence (such as telephone numbers and addresses)
- trouble telling left from right (5, 6).

A child who has trouble writing or has very poor handwriting and does not outgrow it may have dysgraphia. This disorder may cause a child to be tense and twist awkwardly when holding a pen or pencil. Other signs of this condition may include a strong dislike of writing and/or drawing grammar problems, trouble in writing ideas, a short interest in writing, trouble writing thoughts in a logical sequence, leaving words unfinished or omitting them when writing sentences (7).

Children who experience learning disorders may often feel frustrated by their inability to master a subject despite putting in substantial effort. Consequently, they may exhibit behaviors such as acting out, displaying helplessness, or withdrawing from academic activities. Additionally, learning disorders can coexist with emotional or behavioral disorders like ADHD or anxiety. The combination of these challenges can significantly impede a child's success in school. It is vital to accurately diagnose each disorder to ensure that the child receives appropriate assistance tailored to their specific needs.

Parents frequently experience concerns when their child encounters learning difficulties in school. While various factors can contribute to such challenges, a prevalent cause is a specific learning disorder. Children with learning differences may possess normal intelligence, yet the presence of a specific learning disorder can raise questions about their overall cognitive abilities among teachers and parents. These children often exert great effort to follow instructions, concentrate, and demonstrate good behavior at home and school. However, despite their diligent efforts, they struggle to master academic tasks and consequently fall behind. One in five children in the U.S. have learning and attention issues such as dyslexia and ADHD (8).

Learning disorders are believed to stem from challenges within the nervous system that impact the ability to receive, process, or communicate information effectively. There is a possibility of these disorders having a familial pattern as well. In some cases, children with learning disorders may also exhibit hyperactive behavior, characterized by an inability to remain seated, easy distractibility, and a short attention span.

Mental health experts recognize that early intervention can mitigate some long-term repercussions of learning disorders. However, if these disorders are not identified and addressed promptly, they can have a compounding effect over time. Despite their earnest efforts to learn, the child experiences increasing frustration and may develop emotional difficulties, including diminished self-esteem, due to repeated failures. Some children with learning disorders may exhibit disruptive behavior in school as a defense mechanism. It's important to understand that these children are as smart as their peers and can achieve at high levels but too often are misunderstood as lazy or unintelligent. In the absence of adequate academic or emotional support, individuals with learning and attention issues are at a significantly higher risk than their peers of grade retention, suspension, and dropout. Furthermore, these individuals often face challenges in the workplace and have a higher likelihood of involvement with the criminal justice system. However, it is possible to prevent this downward spiral with appropriate interventions and support.

Initially, it is crucial to understand a child's learning difficulties comprehensively and anticipate their impact on various aspects such as communication, self-help skills, discipline, play, and independence. Expert evaluation becomes essential to assess the multiple factors influencing the child. Mental health professionals can facilitate this evaluation process, collaborating with school professionals and others to conduct comprehensive educational testing and determine the presence of a learning disorder. This involves engaging with the child and their family, evaluating their situation, reviewing educational testing results, and consulting with the school. Based on the findings, experts will provide recommendations regarding appropriate school placement, the need for specialized support like special educational services or speech-language therapy, and guidance for parents in fostering their child's optimal learning potential.

In some cases, individual or family psychotherapy may be suggested, and medication could be prescribed to address symptoms of hyperactivity or distractibility. Parents must carefully consider finding the right balance of support for their child's educational goals, aiming to strengthen the child's self-confidence, which is crucial for healthy development. Additionally, it is important to provide parents and other family members with a deeper understanding of coping strategies for living with a child who has learning disorders.

Understanding behaviors

Parenting children with learning disabilities, ADHD, and related disorders can frequently be perplexing. A significant source of confusion and difficulty for parents lies in the substantial disparity between their children's abilities and limitations. These children often exhibit high intelligence, possess extensive knowledge, and demonstrate excellent reasoning skills, yet struggle with reading and writing. Both educators and family members may urge them to exert more effort, and despite their sincere endeavors, they are often labeled as lazy. Consequently, they tend to exert many more of their peers' effort.

Parents often encounter additional confusion when trying to differentiate between a child's inability and unwillingness to perform certain tasks. It can be particularly frustrating for parents to feel a lack of control over the actions of a young child or to grapple with whether to push an adolescent or lower their expectations. Within this state of uncertainty, parents tend to question themselves, asking, "What is wrong with me?" instead of considering their child's challenges. Shifting the focus to understanding their child's difficulties can be a therapeutic approach for both parents and children.

In some instances, children's apparent behavioral issues may stem from their challenges in accomplishing certain tasks. Children often withdraw or act out when confronted with overly demanding tasks. It can be beneficial for parents to recognize that when children strongly dislike something, it can serve as a valuable diagnostic tool, indicating areas of difficulty or impossibility for them. For instance, if a child enjoys dance, art, and music but dislikes drama, it could be indicative of a speech/language problem. Similarly, a child's aversion to math or reading typically highlights areas of struggle. Conversely, children's preferences and interests often provide insight into their strengths and abilities.

While receiving a diagnosis can provide some assistance, the daily task of addressing these issues is no small feat. The planning process is often complicated by the conflicting perspectives of teachers, physicians, psychologists, and social workers. Not only may they disagree on the diagnosis itself, but they may also have differing opinions on the most effective treatments or programs for a child. This can be highly frustrating and anxiety-inducing for parents who must gather all the information and make decisions, even if they may be uncertain or prone to making mistakes. Furthermore, parents must constantly be used to potential problems at home and in other settings, such as recognizing when their children are tired, frustrated, or on the verge of an outburst. They must rely on their intuition to gauge how long their child can endure a social gathering, sit in a restaurant, or interact pleasantly with visitors. While all parents face these challenges to some extent, it is notably more demanding when raising children with these particular needs.

Parents raising children with cognitive difficulties are continuously engaged in the complex task of interpreting what strategies are effective, identifying sources of frustration for their child, and determining what brings them joy. They find themselves constantly analyzing and meticulously reflecting upon daily activities and engaging in problem-solving efforts. This process involves recognizing and nurturing the child's strengths, understanding their interests, identifying areas of difficulty, and devising plans to manage their behavior and support their overall development. It requires careful thought, analysis, and thoughtful decision-making on the part of the parents.

Dealing with cognitive difficulties

Parents can play a crucial role in supporting children with learning difficulties. Here are some ways parents can help:

- seek professional assessment: if you suspect your child has a learning difficulty, consult with professionals such as pediatricians, psychologists, or educational specialists who can provide a diagnosis and recommend appropriate interventions.
- foster open communication: maintain open and supportive communication with your child. Encourage them to express their feelings, frustrations, and concerns about their learning difficulties. Validate their emotions and let them know you are there to support them.
- educate yourself: learn about your child's specific learning difficulty and understand its impact on their learning process. Research reputable sources, attend workshops, or join support groups to gain knowledge and strategies to help your child.
- collaborate with teachers and school staff: establish a strong partnership with your child's teachers and school staff. Share information about your child's learning difficulties, discuss their needs, and work together to create an Individualized Education Program or a tailored learning plan.
- provide a structured and supportive environment: create a structured routine at home to help your child develop good study habits. Establish a quiet and organized study area, minimize distractions, and provide necessary tools such as a comfortable desk, appropriate lighting, and educational resources.
- address difficulties with time and space: Space and time are organizing systems involved in every task, every performance and every aspect of life. Many children with learning disabilities are very disorganized – unable to keep their rooms anything but a complete mess, unable to accomplish even the simplest task in a timely fashion, unable to follow instructions, likely to lose belongings frequently, and appearing lost in time and space. Problems with sequencing explain why they have trouble remembering the days of the week, seasons, the alphabet, counting, and the order of tasks and instructions. These problems are why they have trouble beginning projects, sustaining them, and finishing them. Poor organization affects not only home life and relationships with friends, who will take only a certain amount of forgetting and being late, but also academic life. Poor organization means forgetting to bring home the homework or not having the time management skills to meet deadlines. It affects being able to establish priorities - what is most important to study, what is less so. Often, this disorganized behavior looks oppositional and hostile, when actually it stems from the very nature of the learning disability. Parents and teachers of children with learning disabilities can help them by providing clear structuring of time and space. Visual aids can help children with structuring space. For example, shelves can be used instead of drawers so children can see where things belong and how to put them back. The use of other visual cues, such as lists or labels, can augment efforts to help children organize tasks and belongings. Parents can also assist their children by engaging them in planning activities. Examples include planning celebrations, planning a garden, organizing what needs to be done to collect food for the homeless dogs, or any other kind of planning that involves developing lists, going shopping, checking off the lists, and then charting the tasks still to be done (which can

then, in turn, be checked off). All of these projects are useful, engaging, and have the hidden agenda of working on organization skills.

- utilize multisensory learning techniques: many children with learning difficulties benefit from multisensory learning approaches. Incorporate visual, auditory, and kinesthetic elements into their learning activities. For example, use manipulatives, visual aids, audio recordings, or physical movements to reinforce concepts.
- provide additional support: explore tutoring or educational therapy options to supplement your child's learning. These professionals can provide specialized instruction tailored to your child's needs.
- encourage strengths and interests: focus on your child's strengths and interests to boost their confidence and motivation. Encourage activities they excel in, whether it's art, sports, music, or other hobbies. Celebrate their achievements and emphasize their unique talents.
- foster a positive mindset: Help your child develop a growth mindset by emphasizing the importance of effort, perseverance, and learning from mistakes. Encourage them to see challenges as opportunities for growth and celebrate their progress along the way.
- keep things in perspective. A learning disability isn't insurmountable. Remind yourself that everyone faces obstacles. It's up to you as a parent to teach your child *how* to deal with those obstacles without becoming discouraged or overwhelmed. Don't let the tests, school bureaucracy, and endless paperwork distract you from what's really important – giving your child plenty of emotional and moral support.
- remember that your influence outweighs all others. Your child will follow your lead. If you approach learning challenges with optimism, hard work, and a sense of humor, your child is likely to embrace your perspective or at least see the challenges as a speed bump, rather than a roadblock. Focus your energy on learning what works for your child and implementing it the best you can
- develop social and emotional skills. Learning differences combined with the challenges of growing up can make your child sad, angry, or withdrawn. Help your child by providing love and support while acknowledging that learning is hard because their brain learns in a different way. Try to find clubs, teams, and other activities that focus on friendship and fun. These activities should also build confidence. And remember, competition isn't just about winning (9).

Remember, each child is unique, and strategies that work for one may not work for another. It's important to adapt and tailor your approach to your child's individual needs. Additionally, seek ongoing support from professionals, support groups, and other parents who are going through similar experiences.

Literature

1. Bloom, B. S.; Engelhart, M. D.; Furst, E. J.; Hill, W. H.; Krathwohl, D. R. *(1956*). Taxonomy of educational objectives: The classification of educational goals. Vol. Handbook I: Cognitive domain. New York: David McKay Company
2. Learning Disabilities Association of America. (n.d.). Symptoms of learning disabilities. Retrieved July 15, 2023, from https://ldaamerica.org/
3. American Psychiatric Association. Diagnostic and statistical manual of mental health disorders: DSM-5 (5th ed). Washington, DC: American Psychiatric Publishing, 2013

4. Ahmad W, Arun P, Nazli N, Ratnam V, Mehta S, Raina D. Understanding of Behavioral Problems Among Young Persons with Intellectual Disability: A Self-Report. J Neurosci Rural Pract. 2022 Feb 9;13(2):295-300. doi: 10.1055/s-0042-1743213. PMID: 35694082; PMCID: PMC9187377.
5. Grey I M, Hastings R P. Evidence-based practices in intellectual disability and behaviour disorders. Curr Opin Psychiatry. 2005;18(05):469–475.
6. Fragel-Madeira, L. et al. (2015). Dyslexia: A Review about a Disorder That Still Needs New Approaches and a Creative Education. Creative Education, 6, 1178-1192. http://dx.doi.org/10.4236/ce.2015.611116
7. Berninger VW, May MO. Evidence-based diagnosis and treatment for specific learning disabilities involving impairments in written and/or oral language. J Learn Disabil. 2011;44:167-83.
8. Shaywitz S., Shaywitz B., Dyslexia (Specific Reading Disability), Pediatr Rev (2003) 24 (5): 147–153 https://doi.org/10.1542/pir.24-5-147
9. Medalia A., Revheim N. Dealing with cognitive dysfunction, The New York State Office of Mental Health Family Liaison Bureau, 2023

Characteristics of children with neurological disorders

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Most important messages:

- Neurological disorders in children are a broad category of health conditions that affect the central and peripheral nervous system, i.e. all the nerves that connect the organs to the brain and spinal cord.
- Neurological disorders in children manifest in different ways and have different symptoms and causes.
- Cerebral palsy is the most common cause of motor difficulties in childhood and is a permanent condition.
- Caring for a child with a neurological disorder can be both rewarding and challenging.
- Parents should build a support network, connect with other parents and be well informed about their child's condition.
- Parents should celebrate their child's achievements and focus on the child abilities instead of limitations.
- Positive behavior encourages self-confidence and development.

Introduction

The nervous system begins to develop while the child is still in the womb and continues during childhood and into adolescence. Neurological disorders in children are a broad category of medical conditions that affect the central nervous system (brain and spinal cord) and the peripheral nervous system,that is, all the nerves that connect the organs to the brain and spinal cord. Neurological disorders are characterized by dysfunctions in any segment of the nervous system. These disorders can affect anyone in any age group, but children are especially vulnerable due to their developing brains (1). Neurological disorders in children manifest in different ways that result in significant obstacles in the body's overall functioning, such as impairments of physical, memory, motor, speech, emotional and cognitive functions. It leads to difficulties in movement, speech, ability to think or overall mental health.

Childhood neurological disorders have a variety of causes and understanding these causes is essential for diagnosis, treatment and support. They can be congenital, meaning they are present at birth, or they can develop (acquired) later in childhood due to genetic factors, environmental influences (neurotoxins, hypoxia), infections, injuries, or other unknown causes.

Several common causes have been identified:

- **genetic factors** - mutations or genetic abnormalities can significantly affect a child's development. Inherited genetic conditions, such as Down syndrome, fragile X gene and Rett syndrome, are associated with neurological damage. During early development, spontaneous genetic mutations leading to neurological disorders can occur (1);
- **prenatal factors** - many neurological disorders occur during pregnancy due to a variety of prenatal factors, including (1):
  - maternal infections (eg rubella, cytomegalovirus or Zika virus during pregnancy);
  - exposure to toxins: harmful substances during pregnancy (eg, alcohol, tobacco, certain medications or narcotics/drugs);

- birth complications: complications during the perinatal period and delivery, such as lack of oxygen (asphyxia), premature birth, low birth weight or trauma during delivery.

- **postnatal factors** - neurological disorders can also be acquired or develop after birth, due to various factors (1):

- infections: postnatal infections, such as meningitis or encephalitis;
- traumatic brain injuries: severe head injuries from falls, accidents or physical abuse;
- environmental factors: exposure to harmful toxins such as lead or certain pesticides;
- metabolic disorders: the body cannot properly break down or process certain substances;
- unknown causes: the exact cause of a neurological disorder may remain unknown.

Some of the most common neurological disorders in childhood are:

- **cerebral palsy** (CP) - a group of disorders affecting movement, muscle tone, and motor skills, often caused by brain damage during or shortly after birth
- **epilepsy**-a condition characterized by recurrent seizures, which are caused by abnormal electrical activity in the brain
- **autism spectrum disorders**-developmental disorders affecting communication, social interaction, and behavior
- **attention deficit hyperactivity disorder (ADHD)** - a condition characterized by difficulties in maintaining attention, hyperactivity and impulsive behavior
- **intellectual disability** - a condition characterized by limitations in intellectual functioning and adaptive behavior
- **developmental delay** - a condition when the child does not reach developmental milestones at the expected age
- **Tourette syndrome** - a neurological disorder characterized by repetitive, involuntary movements and vocalizations called tics
- **Rett syndrome**-a rare genetic disorder that predominantly affects girls (leading to severe cognitive and physical impairments: developmental delay, loss of mobility or hand function, with characteristic hand movements)
- **muscular dystrophy -** a group of genetic disorders that cause progressive muscle weakness and loss of muscle mass
- **migraines** - recurrent severe headaches that can affect a child's daily life (1, 2).

Percentage-wise, the most common pediatric neurological disorders included seizures/epilepsy (37.7 %), CP (37.7 %), and central nervous system infections with complications (6.2 %) (2). Some of these neurological disorders can be mild and do not significantly affect the daily life and activities of children and parents/guardians, while others can be severe and have a significant impact on the daily life and development of the child. Functional neurological disorders (FNDs) are multinetwork brain disorders that encompass a wide range of neurological symptoms (2). They leave significant psychosocial, educational and financial burdens on children and their families and a significant burden on the health care system (3).

How do you know if your child has a neurological disorder?

Neurological disorders are characterized by abnormal functioning of the nervous system, which manifests itself in different ways. By recognizing the warning signs and seeking timely intervention, parents, caregivers, and health professionals can make a significant difference in a child's life and inclusion. Those are as follows:

1. **Delayed developmental milestones**

As they grow, children reach different developmental milestones, such as rolling over, crawling, walking, talking, and socializing with others. Although the time frame for reaching these milestones can vary, monitoring a child's progress is essential to meet age-appropriate expectations. Delayed developmental milestones can be a red flag for neurological disorders, indicating that the brain is not developing or functioning properly.

Some warning signs include:

- inability to make eye contact or respond to hearing his name;
- difficulty sitting or crawling by eight months;
- cannot walk independently until 18 months;
- loss of language or social skills that the child previously had;
- inability to pronounce at least 15 words at the age of two (4).

2. **Regression in skills**

A worrisome warning sign of a neurological disorder is the regression of previously acquired skills. Regression refers to the loss or decline of abilities that a child once learned (4). This loss can occur in a variety of developmental areas, including speech, motor skills, social interaction, or cognitive abilities. Regression can manifest differently depending on the child and the specific skills that are affected.

- speech regression-a child who previously had a vocabulary of words and could communicate effectively may suddenly begin to lose words or have difficulty expressing themselves, forming sentences, forgetting words, or understanding and following orders
- regression of motor skills-a child who previously achieved age-appropriate motor milestones, such as crawling, walking, or fine motor skills (eg, holding objects or writing), may show regression in their motor skills
- social and emotional regression-children with neurological disorders may also lose previously developed social interactions, such as making eye contact, responding to their name, or engaging in reciprocal play. Emotional regression may manifest as increased irritability, difficulty managing emotions, or regression to earlier developmental stages (e.g., tantrums) (5).

3. Seizures and epilepsy

Seizures can manifest in different ways, and the symptoms experienced during the episode depend on the brain area that is affected (6). Common types of seizures in children include:

- generalized – affect both sides of the brain and can cause loss of consciousness, convulsions, muscle rigidity, or subtle changes in behavior;
- focal - occur in a specific region of the brain and can result in localized symptoms, such as repetitive movements, altered sensations, or changes in emotions or thought patterns;
- absence - these attacks are brief episodes of staring and decreased responsiveness that are often misinterpreted as daydreaming. The child may seem temporarily disconnected from the environment during this event;
- epilepsy - it is diagnosed when a child experiences recurrent seizures. However, not all seizures indicate epilepsy, as an episode can occur due to various factors such as febrile fever or head trauma. However, if the child has experienced multiple episodes, the healthcare professional should order tests to diagnose epilepsy.

4. Atypical movements or behaviors

These atypical movements or behaviors can manifest in a variety of ways and provide valuable clues for early detection and intervention.

- atypical movements-tics, tremors, jerky movements;
- atypical behaviors-repetitive behaviors, obsessive-compulsive behavior, impulsivity or hyperactivity;
- association with neurological disorders-atypical movements or behaviors may indicate underlying neurological conditions as Tourette syndrome etc. (6).

5. Constant headaches

While occasional headaches are common and often benign, persistent or recurring headaches during a child's daily activities should be evaluated by a healthcare professional (7). Here are signs to look out for:

- types of headaches-there are different types of headaches that children can experience, including tension headaches or migraines or cluster headaches;
- duration and frequency-persistent headaches in children usually occur frequently or last for a long period of time as daily, several times a week, or last for hours or days;
- accompanying symptoms-along with persistent headaches, children may have other symptoms that provide valuable diagnostic information, such as nausea or vomiting, sensitivity to light or sound, aura or prodromal symptoms (visual disturbances, e.g., seeing flashing lights or zigzag lines).

6. Sensory processing issues

Sensory integration is the process during which sensory information from our senses of sight, hearing, touch, taste, smell, movement, etc., reaches our brain through nerves, is processed to make sense of it, and then we can respond with an action. Not all stimuli are equally important. For example, if we are walking in a park, we fall, and injure our leg during the fall. In this example, while we were walking, our nerves were sending numerous sensory inputs to the brain about various things we saw, heard, or felt. However, the information that our movement was suddenly interrupted was more important than the others and required a quick response. When the brain receives information about the sudden stop, loss of balance, and recognizes the potential danger of injury, it sends a message to the arms to extend forward immediately. So, receiving information from our senses, interpreting it, and preparing a response – that is sensory integration.

Children with sensory integration difficulties may have problems in one or more sensory areas. Sensitivity in a particular sensory area may be decreased (hyporeactivity) or heightened (hyperreactivity). Additionally, there is a distinction between a sensory seeker and a sensory avoider.

A sensory seeker is a person who actively seeks out sensory experiences because they need more sensory input to feel satisfied or regulated. These individuals may enjoy activities that provide strong sensations, such as swinging, spinning, loud noises, or rough play. They tend to crave stimulation from their environment and may be more energetic or adventurous.

On the other hand, a sensory avoider is a person who is overly sensitive to sensory input and tends to avoid or withdraw from it. They may become overwhelmed by sensations that others find normal, such as loud sounds, bright lights, certain textures, or physical contact. Sensory avoiders often react by withdrawing, becoming anxious, or even having meltdowns when confronted with sensory stimuli they find too intense.

Both types reflect different ways people process sensory information, and understanding these preferences can help tailor environments and activities to better support individuals' needs.

When a child has sensory processing difficulties, it can affect their ability to effectively process and integrate sensory stimuli, leading to atypical responses. Children with sensory processing difficulties may experience challenges in one or more sensory areas:

- tactile sensitivity. Some children will have heightened sensitivity and avoid touch and certain textures, while others may respond weakly or not at all to certain stimuli. If sensitivity is heightened, it leads to discomfort or avoidance of specific textures, fabrics, or sensations.
- auditory sensitivity-hypersensitivity to sound (everyday, common sounds are perceived as too intense or disturbing);
- visual sensitivity-sensitivity to light, glare, or specific visual patterns or stimuli;
- proprioceptive sensitivity – the proprioceptive system provides information about joint and body movements, the range, strength, duration, direction of movements, the position of the body or body parts in space, and muscle tone. Children with sensory integration difficulties in this system may have heightened proprioceptive sensitivity, causing them to tire easily, lack strength, have low endurance in physical activities, frequently seek support while moving, and appear clumsy or stiff at first glance.

  On the other hand, a child with insufficient proprioceptive sensitivity is constantly in motion, jumping, "never staying still," not respecting personal space, and often engaging in physical contact with others, pushing, or throwing themselves onto others, though not aggressively. They may seem clumsy—struggling with tasks like threading beads, buttoning, building with blocks, writing, chewing on clothes or other objects (more than their peers), and while running or walking, they might watch their feet.
- vestibular sensitivity – the vestibular system is a sensory system that creates a sense of balance and spatial orientation in order to coordinate movement with balance. Children who have difficulties with the vestibular system may have either heightened vestibular sensitivity or insufficient sensitivity.
- problems in coordination, balance or body awareness.

Sensory processing problems can be associated with neurological disorders (e.g., ADHD, autism). Children may exhibit over- or under-reactivity, difficulties in motor coordination, and emotional and behavioral effects.

7. Communication difficulties

Communication encompasses various aspects, including speech, language and social interaction (8). Delay in speech and language development is a significant indication of communication difficulties. Children may show the following signs:

- start speaking later than expected, have a limited vocabulary or difficulty forming words and sentences;
- difficulty acquiring new words or using a wider range of vocabulary to express them;
- difficulties in articulating sounds and pronouncing words correctly;
- difficulty using appropriate grammar and sentence structure, resulting in simplistic or incorrect speech patterns.

Communication difficulties include receptive language (understanding spoken language) and expressive language (expressing thoughts and ideas). Signs may include:

- difficulties in understanding and implementing spoken instructions or responding appropriately;
- limited use of language, reduced ability to express their needs, thoughts or feelings through language;
- difficulties in maintaining a conversation, in exchanging listener-speaker roles, and in understanding social cues during interactions.

Some children with communication difficulties struggle with non-verbal communication skills, such as:

- difficulty making and maintaining eye contact during social interactions;
- showing reduced use of gestures, such as pointing, waving, or nodding, to communicate or express themselves;
- difficulty conveying or interpreting facial expressions, which affects their ability to understand and respond to emotions.

The challenges and management of most of these conditions where children's intellectual and cognitive abilities are affected are described in appropriate sections of this document.

Here we will focus on CP, as one of the most common neurological diseases that in childhood is a cause of disability, i.e."long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, can hinder their full and successful participation in society, on an equal basis with others" (9).

Literature

1. https://longevity.technology/lifestyle/how-to-identify-neurological-disorders-in-children
2. Treatment Approaches for Functional Neurological Disorders in Children, Areti Vassilopoulos, Shekeeb Mohammad,Leon Dure, Kasia Kozlowska,Aaron D. Phobian,Curr Treat Options Neurol.2022; 24(2): 77–97. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8958484/
3. Stephen CD, Fung V, Lungu CI, Espay AJ. Assessment of emergency department and inpatient use and costs in adult and pediatric functional neurological disorders. JAMA Neurol. 2021;78(1):88–101. doi: 10.1001/jamaneurol.2020.3753.
4. https://www.neurocenternj.com/blog/warning-signs-your-child-may-have-a-neurological-disorder/
5. https://www.unitypoint.org/news-and-articles/signs-of-child-regression-what-to-do—unitypoint-health
6. https://www.hopkinsmedicine.org/health/conditions-and-diseases/epilepsy/seizures-and-epilepsy-in-children
7. https://www.health.harvard.edu/blog/8-things-to-watch-for-when-your-child-has-a-headache-2017051611761
8. https://www.cincinnatichildrens.org/health/c/communication
9. UN Convention on the Rights of Persons with Disabilities;United Nations Organization,2007. https://nsiom.org.mk/konvencija.

Characteristics of children with cerebral palsy

Introduction

Cerebral palsy (CP) is the most common cause of motor disabilities in childhood. It encompasses a group of neurological disorders that affect motor skills (movement and posture, muscle coordination, muscle tone) and developmental skills, and in many cases, vision, hearing, and other senses. CP can appear before or during childbirth or in the first two years of life caused by abnormal brain development or brain damage during pregnancy or shortly after birth that affects a person's ability to control their muscles (1).

Signs and symptoms appear during infancy or preschool. In general, CP causes impaired movement associated with exaggerated reflexes, limp or stiffness of the limbs and body, unusual posture, involuntary movements, unsteady gait, or some combination of these. People with CP can have trouble swallowing and often have eye muscle imbalances, where the eyes do not focus on the same object, or they may have a reduced range of motion at various joints due to muscle stiffness.

CP is a lifelong disorder. Therapy and other treatments help many people with CP live independent lives. Although there is no specific cure, treatments with symptomatic drugs, surgical interventions, and rehabilitation can significantly reduce symptoms and help improve body functions. Advances in technology, such as robotic devices that assist with locomotion, are changing the lives of people with CP. Promising research and treatment breakthroughs offer hope for people with CP and provide more opportunities for children and adults to reach their full potential (3).

Representation of CP

CP is the most common motor disability in childhood. Recent population-based studies from around the world report prevalence estimates ranging from 1 to nearly 4 per 1,000 live births. The prevalence of CP is higher in premature or low birth weight children (3).

Types of CP

CP is classified in two ways (3):
- according to which parts of the body are most affected and
- according to which movement disorder is most pronounced.

As a result of damage to different areas of the brain, there are four types of movement disorders in people with CP (3):

- spastic CP–about 75% of people with CP have spastic form. It is characterized by stiff, tight muscles that contract uncontrollably. Movements, including walking and talking, appear choppy, interrupted due to muscle spasticity (stiffness);
- dyskinetic CP-this type of CP causes irregular movements of the limbs, face and tongue. Movements can be smooth and slow or fast and unpredictable. The face may appear to curl or contort. Movements are more difficult when the person is active. People with dyskinetic CP often have trouble swallowing saliva, so they may drool;
- ataxic CP–this type of CP causes problems with depth perception, coordination and balance (difficulty standing, or the inability to move without swaying or falling). Children with this type of CP often walk with their feet spread apart (they seem to shake when they move);
- mixed types–damage to more than one brain area can cause several symptoms at once. A person with mixed CP has a combination of symptoms of spastic, dyskinetic and ataxic CP.

Areas of the body affected by CP:
- all four limbs (quadriplegia);
- legs only (diplegia);
- limbs on one side of the body (hemiplegia).

Reasons for CP

The cause of CP and its effect on function vary widely. Some people with CP can move; others need help. Some people have intellectual disabilities, but others do not. Epilepsy, blindness or deafness may also be present as accompanying conditions (4).

At the heart of CP is abnormal brain development or damage to the developing brain. This usually happens before the child is born–in intrauterine development, but may occur at birth or in early childhood. In many cases, the cause is unknown.

Many factors can lead to problems with brain development. Some include:

- gene mutations that result in genetic disorders or differences in brain development;
- maternal infections affecting fetal development;
- stroke, disruption of blood supply to the developing brain;
- bleeding in the brain while the fetus is in the womb or as a newborn;
- infections in infancy that cause inflammation in or around the brain;
- traumatic injuries to the newborn's head (e.g., the result of an accident, fall, or physical abuse);
- lack of oxygen to the brain associated with a difficult perinatal period or childbirth (although birth asphyxia is a much less common cause than previously thought).

Risk factors

A number of factors are associated with an increased risk of CP:

- **Mother's health**-certain infections or toxic exposures during pregnancy can significantly increase the child's risk of CP:
- cytomegalovirus–this common virus causes flu-like symptoms and can lead to birth defects if the mother has her first active infection during pregnancy;
- rubella–this viral infection can be prevented with a vaccine;
- herpes–an infection that can be transmitted from the mother to the child during pregnancy, affecting the womb and placenta;
- syphilis–sexually transmitted bacterial infection;
- toxoplasmosis–infection caused by a parasite found in contaminated food, soil and feces of infected cats, dogs;
- Zika virus infection–this infection is spread through a mosquito bite and can affect the developing brain of the fetus;
- intrauterine infections–include infections of the placenta or fetal membranes;
- exposure to toxins (e.g., exposure to methylmercury);
- other conditions–that affect the mother and slightly increase the risk of CP include thyroid problems, preeclampsia, or epilepsy/seizures (4).
- **Disease of infants** –Diseases in a newborn child that can significantly increase the risk of CP include:
- bacterial meningitis–bacterial infection causes inflammation in the membranes surrounding the brain and spinal cord;
- viral encephalitis–a viral infection that similarly causes inflammation of brain tissue and the membranes surrounding the brain and spinal cord;

- severe or untreated jaundice–Jaundice appears as yellowing of the skin. The condition occurs when certain byproducts of "used" blood cells/erythrocytes are not filtered out of the bloodstream;
- bleeding in the brain–this condition is usually caused by a stroke of the child in the womb or in early childhood (4).

• **Pregnancy and birth factors** –although the potential contribution of each is limited, additional pregnancy or birth factors associated with an increased risk of CP include:

- low birth weight–children weighing less than 2.5 kg are at greater risk of developing CP. This risk increases with decreasing birth weight;
- multiple children–the risk of CP increases with the number of children who share the uterus. The risk may also be related to the likelihood of preterm birth and low birth weight. If one or more of the children die, the risk of CP in the survivors increases;
- premature birth–children born prematurely are at greater risk of CP. The earlier the child is born, the higher the risk of CP;
- complications during childbirth–problems during the perinatal period and delivery can increase the risk of CP (4).

Prevention

Most cases of CP cannot be prevented, but you can reduce the risks. If you are pregnant or planning to become pregnant, start a family, you can take these steps to stay healthy and minimize pregnancy complications:

- make sure you get adequate and continuing prenatal care–regular visits to your physician during pregnancy are a good way to reduce health risks for you and your unborn child. It can help prevent premature birth, low birth weight and infections;
- make sure you are vaccinated–vaccination against diseases such as rubella, preferably before you become pregnant, can prevent an infection that can cause brain damage to the fetus;
- take care of yourself–the healthier you manage your pregnancy, the less likely you are to develop an infection that results in CP;
- avoid alcohol, tobacco, uncontrolled intake of various medications and illegal drugs. They are associated with the risk of CP.
- take your child to your physician for regular check-ups;
- rarely, CP can be caused by brain damage that occurs in childhood. Practice good general safety;
- prevent head injuries to your child by providing a car seat, bicycle helmet, bed rails and proper supervision.

Signs/Symptoms of CP

Signs and symptoms of CP can appear at birth or in the first years of life. They vary from person to person, and symptoms range from mild to severe. CP can affect the whole body, or be limited to one or two limbs, or one side of the body. Some people with CP have disabilities that make it difficult to speak, walk, or perform everyday tasks. Generally, signs and symptoms include problems with movement and coordination, speech and eating, developmental and other problems.

Symptoms vary depending on the type of CP. They include:

- **Movement and coordination**

- stiff muscles and exaggerated reflexes (spasticity), the most common movement disorder;
- variations in muscle tone, too stiff (hypertonia) or too loose (hypotonia); infants with hypotonia cannot control their heads, and their limbs may be very flexible;
- stiff muscles with normal reflexes (rigidity);
- lack of balance and muscle coordination (ataxia);
- tremors or jerky involuntary movements;
- slow bending movements;
- favoring one side of the body, such as only reaching with one arm or dragging a leg while crawling; children with hemiplegic CP can crawl using only one leg and one arm; older children may limp when walking;
- difficulty walking, such as walking on tiptoes, stooping, scissoring with crossed knees, wide walking, or asymmetrical walking;
- difficulty with fine motor skills, such as buttoning clothes or picking up utensils (2).

- **Speech and eating**

- delay in speech development;
- difficulty speaking;
- difficulty sucking, chewing or eating,
- excessive drooling or trouble swallowing.

- **Development**

- delay in achieving motor skills, such as sitting or crawling;
- learning difficulties;
- intellectual disability.
- delayed growth, resulting in lower than expected growth.

- **Other problems**

- seizures (epilepsy);
- hearing difficulties;
- vision problems and abnormal eye movements;
- abnormal sensations of touch or pain;
- bladder and bowel problems, including constipation and urinary incontinence;
- mental health problems such as emotional disturbances and behavioral problems.

The brain disorder that causes CP does not change over time, so symptoms usually do not worsen with age. However, as the child gets older, some symptoms may become more or less obvious. Both muscle shortening and stiffness can worsen if not treated appropriately (2).

Diagnosis and tests

Diagnosing CP at an early age is important for the well-being of children and their families and can take several steps (4):

- **Development monitoring** - Developmental monitoring means tracking a child's growth and development over time. At each office visit, the physician monitors the child's development, asking if the parents have any concerns about their child's development, taking or updating the child's developmental history, and watching the child during the check-up for any movement problems. and posture. It is especially important to monitor the development of children at higher risk for developmental problems due to preterm birth or low birth weight. The parent should share information about the milestones their child has reached, as well as any delays. If any concerns about the child's development arise during monitoring, then a developmental screening test should be done as soon as possible.

- **Developmental screening -** During the developmental screening, a short test is given to see if the child has specific developmental delays, such as motor function or movement. Some developmental screening tests are in the form of interviews or questionnaires filled out by parents; others are tests given to the child by the physician. It is recommended that all children be screened for developmental delays during regular visits (at 9, 18, and 24 or 30 months of age). When a child is 9 months old, many aspects of movement can be easily observed. However, mild movement delays that were not detected at the 9-month screening may be more readily apparent by the time the child is 18 months old. By the time a child reaches 30 months, most of the movement delays can be noticed. The developmental screening test it can also be given whenever the child's parents, physician, or others involved in the child's care have concerns about the child's development. If the results of the screening test are cause for concern, then the physician will refer to:
- **Developmental and medical evaluations and early intervention** - Specialists may suggest brain imaging tests, such as X-ray computed tomography (CT scan) or magnetic resonance imaging (MRI), which show the location and severity of brain damage. An electroencephalogram (EEG), genetic testing, or metabolic testing, or a combination of these, may also be done.

CP is generally diagnosed during the first or second year after the birth.

Management and treatment

There is currently no cure for CP, but treatments are available to help people with the condition be as active and independent as possible (5). Treatment is multifaceted because there are many variations from one child to another. In order to achieve the best results, it is necessary to consult and engage a multidisciplinary team of experts. The goal of CP treatments is to improve movement, speech and quality of life (5).

Treatment goals for CP

Treatment depends on the type of CP your child has and the severity of the condition. Pediatricians, along with other specialists, create a plan with treatment goals individualized to the child's needs (5, 6, 7, 10). Although these can vary depending on the severity of the condition, the general goals of a treatment plan usually include ways to:

- coping with the medical condition;
- pain management and control;
- assistance with behavior and social interactions;
- promoting independence/reliance:

- assistance with eating, bathing and dressing;
- optimizing mobility;
- help in education and learning.

It is crucial to start therapy as early as possible. Skilled therapists can help children learn to walk, communicate and take care of themselves. They can also help you learn how to provide therapeutic opportunities for your child at home.

Treatment plans are different for everyone and may include:

- **therapy:** physical, occupational and speech therapies improve the way a child moves, plays and interacts with the world;
- physical therapy is one of the most important forms of treatment for children with CP. Most physician's recommend physical therapy for all children with CP, regardless of how mild or severe the disorder, helping children maintain balance, posture, crawling, climbing, walking, and strengthening muscles (6, 8);
- occupational therapy helps children improve function in performing daily activities (at home, at school or in the community, and later in life, at work).
- speech and language therapy aims to help children better understand language and to communicate more effectively. This can be done through sign language, signs and the use of augmentative communication devices.
- **medicines**:
- gamma-aminobutyric acid (GABA) derivatives: muscle relaxants such as baclofen can help with stiffness and spasms (8, 9);
- anticonvulsants;
- botulinum toxin (Botox) injections temporarily loosen muscles to improve range of motion and stiffness (8, 12);
- laxatives to soften the stool;
- psychoactive drugs (to improve sleep).
- **Surgery** – a physician may recommend a surgical procedure to improve children's mobility with CP. There are many types of surgery; these include procedures on the feet, ankles, legs, hips, wrists, arms, shoulders or spine. Each child's circumstances are unique, and their medical team will tailor a treatment plan to their needs. Surgeons can lengthen tendons and muscles or correct problems in the spine. Certain patients may benefit from a procedure called selective dorsal rhizotomy, in which surgeons reduce muscle spasticity in the legs by cutting overactive nerves in the spine (11-14).

Innovations in the treatment of CP

Researchers continue to work on better solutions to manage and even cure CP. These are some of the current areas of research into treating this condition (15):

- **early diagnosis-**researchers are closer to being able to identify infants who will develop CP. Early diagnosis allows for interventions that can significantly limit disability.
- **systemic hypothermia-**important early intervention includes cooling the infant's brain to slow or even reverse the brain damage that causes CP;
- **constraint-induced therapy-**is a promising new therapy that involves limiting the child's stronger limb. This forces the weaker limb to develop more force;

- **functional electrical stimulation-**delivers electrical currents to stimulate muscles in hopes of restoring some movement;
- **botox-**botulinum toxin injections can help control spastic muscles.

Prognosis

Prognosis varies widely and depends on the severity of the condition. Many children with CP get better with therapy and other treatments. People with mild CP live full, independent lives. If symptoms are more severe, the child may need round-the-clock care to help with eating, bathing, dressing and using the bathroom. Most children with CP learn to walk, either independently or with a walker or crutches. CP is not a progressive disease. Although symptoms may affect your child differently as they grow and develop, they should not worsen over time unless another medical condition is causing health problems.

Complications

Muscle weakness, muscle stiffness, and coordination problems can contribute to numerous complications in either childhood or adulthood, including:

- contracture–shortening of muscle tissue due to severe muscle tightness that may result in stiffness/spasticity. Contracture can inhibit the growth of bones, cause their bending, joint deformities, complete or partial dislocation of the joint. It can include hip dislocation, curvature of the spine (scoliosis) and other orthopedic deformities;
- malnutrition–swallowing or feeding problems can make it difficult for a child with CP, especially an infant, to get enough nutrition. This can stunt growth and weaken bones. Some children or adults need a feeding tube to get enough nutrition;
- mental health problems–people with CP can have mental health conditions, such as depression. Social isolation and the challenges of coping with a disability can contribute to depression. Behavioral problems may also occur;
- heart and lung diseases–people with CP can develop heart and lung disease (breathing disorders). Swallowing problems can result in respiratory problems, such as aspiration pneumonia;
- osteoarthritis–pressure on joints or abnormal joint alignment due to muscle spasticity can lead to the early onset of this painful degenerative bone disease;
- osteoporosis–fractures due to low bone density can result from several factors, such as lack of mobility, inadequate nutrition, and the use of certain medications (eg, antiepileptic drugs).
- other complications–include sleep disorders, chronic pain, skin breakdown, intestinal problems, and oral health problems (2).

How to help your child with CP?

Children with CP have special needs. Although your child's physicians and therapists handle much of their treatment, there are many ways you can lend a hand and make your child's life easier.

CP affects each person differently, so no two families have the same experience when it comes to caring for their child. Whether your little one has mild or severe CP, there are a number of ways you can help them do their best.

From birth, your child is exposed to and cared for by a large number of health professionals, from pediatricians and specialists in other fields to therapists and other professionals. But it is also wise for you to be informed about your child's health.

Many physicians prefer that parents be as involved as possible in the care of children with CP. That way, you'll most effectively help make health decisions, learn which treatments and therapies work, and see when treatment is successful or unsuccessful. When physicians see you as a key part of the team, you are more likely to feel satisfied with your child's care.

It is important to note that each neurological disorder can have a unique set of symptoms, causes, and treatment approaches. Early diagnosis and intervention are key to managing these conditions and supporting children in their development and well-being.

Support for parents or guardians of children with neurological disorders

Support for parents or caregivers of a child with a neurological disorder is critical as they navigate the challenges and complexities of caring for their child's unique needs.

Caring for a child with a neurological disorder can be both rewarding and challenging. As a parent or guardian, it is essential that you take care of yourself while providing the best possible support for your child.

Here are some resources and ways of support that may be helpful:

- **seek professional support -** connect with health professionals experienced in treating children with neurological disorders. Neurologists, pediatricians, therapists, and special educators can provide valuable information, guidance and treatment options for your child;
- join support groups - look for support groups or online communities of parents and caregivers of children with similar neurological conditions. These groups can offer emotional support, practical advice and a sense of belonging with people who understand what you are going through;
- **educate yourself**–learn as much as possible about your child's specific neurological disorder. Understanding the condition, its symptoms, treatment options and prognosis can empower you to make informed decisions and advocate for your child's needs;
- **therapies and interventions**-explore different therapies and interventions that may benefit your child, such as physical therapy, occupational therapy, speech or behavioral therapy. These therapies can improve your child's quality of life and development;
- **care for rest**–caring for a child with a neurological disorder can be challenging. Look for care services that will allow you to take a break knowing that your child is in safe and capable hands;
- **government assistance**–inquire about government assistance programs that may provide financial support or additional resources for children with disabilities;
- **parent training programs**–some organizations offer parent training programs to provide parents with skills and strategies to effectively manage their child's condition;

- **online forums and communities**–participate in online forums and communities dedicated to parents of children with neurological disorders. These platforms can offer advice, emotional support and a sense of community;
- **self care**–it's important to take care of yourself. Don't hesitate to ask friends, family or professionals for support if you feel overwhelmed or stressed. Caring for a child with a disability can be physically and emotionally draining. Make sure you prioritize self-care, get enough rest, eat well, and engage in activities that bring you joy and relaxation;
- **build a strong support network**–reach out to family, friends and neighbors for help and understanding. Having a trusted support network can make a significant difference in managing the challenges that come with caring for a child with a neurological disorder;
- **advocacy groups**–connect with advocacy organizations that focus on your child's specific neurological disorder. These groups can offer resources, advocacy advice, and updates on research and treatment advances;
- **use therapy services**–depending on your child's needs, consider occupational therapy, speech therapy, physical therapy, or other therapeutic interventions. These services can help your child improve their skills and independence;
- **counseling or therapy**–consider seeking individual or family counseling to address the emotional challenges that come with caring for a child with a neurological disorder;
- **be organized**–keep all relevant medical and educational reports in one place, including test results, treatment plans and school evaluations. It will make it easier to track your child's progress and communicate effectively with healthcare providers and educators.
- **plan for the future** –it is essential to plan for your child's future, keeping legal and financial issues in mind;
- **advocate for your child**–be a strong advocate for your child's rights and needs. Work closely with your child's school to ensure they receive appropriate educational support and accommodations.
- **the consultation with a lawyer** with expertise in disability planning can be useful. Remember that every child's situation is unique and finding the right support system can take time;
- **contact healthcare professionals**, community organizations and other parents who have gone through similar experiences;
- **stay positive** –celebrate your child's achievements, no matter how small. A positive outlook can create a nurturing environment that promotes growth and development;
- **set up play dates with other children** (e.g., if your child has CP, tell others about how CP affects your child; mention interests they share);
- **enroll your child in a community program**, such as art, music and sports. Also, consider joining a support group or social group for parents of children with disabilities (16)
- **communication, cooperation and seeking external support** can improve the functioning of the family when the child has a disability. When a child is diagnosed with a condition that causes a disability (eg, CP), their entire family is affected. Parents must consider how their responsibilities as guardians will develop (or siblings have a sibling with a disability).
- **extended family members -** they need to think about what they want their role to be in the life of a child with a disability. For example, CP is lifelong, so family involvement in

the life of an individual with CP will likely extend beyond that person's childhood. Families that communicate, cooperate, and also take time to care for themselves are likely to thrive and be a positive resource for a child with CP (17).

Remember, you are not alone on this journey, and there are numerous resources available to support you. Your child's healthcare providers can guide you to the appropriate services and support organizations. In addition, many national and international organizations offer information, helplines, and online resources for parents and caregivers of children with neurological disorders.

Literature

1. https://www.healthline.com/health/cerebral-palsy
2. https://www.mayoclinic.org/diseases-conditions/cerebral-palsy
3. https://my.clevelandclinic.org/health/diseases/8717-cerebral- palsy
4. https://www.cdc.gov/ncbddd/cp/diagnosis.html
5. https://www.nhs.uk/conditions/cerebral-palsy/treatment/
6. https://www.cerebralpalsyguidance.com/cerebral-palsy/treatment/
7. https://www-cerebralpalsyguidance-com.cerebral-palsy/treatment/
8. National Institutes of Health. (n.d.). What Are Common Treatments for Cerebral Palsy? Retrieved from:https://www.nichd.nih.gov/health/topics/cerebral-palsy/conditioninfo/treatments
9. Intrathecal Baclofen TherapyCleveland Clinic Information Center. 15 June 2001.
10. Cerebral Palsy Treatment & Management: Approach Considerations, Management of Abnormal Movements, Neurosurgery and Orthopedic Surgery. (2019, November 10). Diseases & Conditions - Medscape ReferenceRetrieved from:https://emedicine.medscape.com/article/1179555-treatment
11. Cerebral Palsy: 4 Treatments to Try Before Surgery. (n.d.). Johns Hopkins Medicine, Based in Baltimore, Maryland. Retrieved from:https://www.hopkinsmedicine.org/health/conditions-and-diseases/cerebral-palsy/cerebral-palsy-4-treatments-to-try-before-surgery
12. Cerebral Palsy Medication: Neuromuscular Blockers, Botulinum Toxins, Muscle Relaxants, Benzodiazepines, Anticholinergic Agents, Dopamine Prodrugs, Anticonvulsant Agents, Alpha2 Adrenergic Agonist Agents. (2019, November 10). Diseases & Conditions - Medscape Reference. Retrieved from:https://emedicine.medscape.com/article/1179555-medication
13. Surgery for Cerebral Palsy in Children. (n.d.). Patient Care at NYU Langone Health. Retrieved from:https://nyulangone.org/conditions/cerebral-palsy-in-children/treatments/surgery-for-cerebral-palsy-in-children
14. On the treatment fo cerebral palsy. (1962, April 1). American Academy of Pediatrics. Retrieved from:https://pediatrics.aappublications.org/content/29/4/605
15. National Institutes of Health. (2021, September 29). Cerebral Palsy: Hope Through Research. Retrieved from:https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Cerebral-Palsy-Hope-Through-Research#3104_24
16. https://childrenhealth.org/en/parents/cp-checklist-younger.html
17. https://www.everydayhealth.com/cerebral-palsy/how-keeping-functioning-as-family-when-child-cerebral-palsy/

Characteristics of physical disabilities in children

Danijela Zorchec, psychologist, educational assistant

Most important messages:

- Physical disability can be defined as a permanent impairment of mobility, sight, - speech and hearing caused by any medical condition.
- Physical disability can be temporary or permanent, and the reasons can be different.
- All physical health problems also have a psychological dimension.
- The rate of psychological difficulties among deaf and blind children has increased.
- During the COVID-19 pandemic, children with pre-existing mental and physical disabilities were at the greatest risk of having their difficulties worsen.

A physical disability can be defined as a permanent mobility, visual, speech, and hearing impairment from any health condition, whether congenital or acquired, meaning such difficulties may be present from birth or may develop at any point during a person's lifetime. A physical disability is anything that limits the physical function of the child's body and can include challenges with large motor skills like walking or fine motor skills like holding objects and using scissors (1).

Signs that may suggest a physical disability in a child are:

- The child is not able to raise both arms fully without any difficulties
- The child is not able to grasp objects without any difficulty, does not reach for toys
- The child has an absence of any part of the limb
- The child has a difficulty in walking
- Has deformity in neck, hand, finger, waist, legs
- Has difficulty in sitting, standing, walking
- Has difficulty lifting, holding, keeping things on the floor
- Has difficulty in moving or using any part of the body
- Lacks bodily coordination
- Epileptic behavior/have tremors
- Joint pains
- Has trouble releasing objects voluntarily
- Reaches only with one hand, even when feeding himself
- Doesn't put hands out to catch himself if falling (2).

Different types of physical disabilities

Physical disability indicates any physical limitations or disabilities that inhibit the physical function of one or more limbs of a certain person. It can be temporary or permanent. The causes of this kind of disease are various. Any person can acquire it through accident, injury, illness post-surgery effects and heredity. Some examples of physical disability are:

- Acquired brain injury – injury due to damage that happens to the brain after birth. Can be caused by a blow to the head, stroke, infection, disease or a lack of oxygen.

- Spinal cord injury – disability due to too much pressure applied and/or if the blood or oxygen supply to the spinal cord is cut. It leads to loss of function, such as mobility or feeling.
- Spina bifida – incomplete formation of the spine and spinal cord in utero. It can cause the spinal cord and nerves to be exposed on the surface on the back of a child, instead of being inside a canal of bone surrounded by muscle.
- Cerebral palsy – disability due to an injury to the developing brain before or during birth, caused by a reduced blood supply and lack of oxygen to the brain.
- Cystic fibrosis – inherited genetic condition, which affects the body's respiratory, digestive and reproductive systems.
- Muscular dystrophy – a group of genetic disorders that lead to progressive and irreversible weakness and loss of muscle mass.
- Dwarfism – short stature which can be caused by over 300 genetic or medical conditions. It is generally defined as an adult height of 4 feet 10 inches or less, with the average height of someone with dwarfism being 4 feet.
- Amputation – indicates removal of part of all of a body part that is enclosed by skin. Causes can be an accident, animal attacks, surgery or warfare.
- Visual impairment – limitation of one or more functions of the eye or visual system. Person's eyesight cannot be corrected to a „normal" level.
- Hearing impairment – impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance (3)

In the following section, some of those conditions will be described in more detail.

Visual impairment

Visual impairments include low vision and blindness and refer to any degree of impairment to a person's ability to see that affects his or her daily life. Blindness technically refers to a total absence of vision, although the term is often used to refer to severe visual impairments that result in a need to primarily use nonvisual sensory information. Low vision refers to visual impairments that are less severe than blindness but still impact a person's ability to complete daily activities to some degree. People with low vision may need to use tools and techniques to enhance their ability to use their limited vision, or they may need to use nonvisual means to complete tasks.

Etiology and prevalence of visual impairment

Gilbert et al., 1999 (according to Sapp, 2010) reference that the rate of visual impairments in children in wealthy nations is approximately 1–2 per 1000 children, with only approximately 1 in 10 000 having a severe visual impairment or total blindness. In developing countries, the rates of severe visual impairments are estimated to be ten times higher than in wealthier nations, occurring at a rate of one in 1000 children (4)

The most prevalent types of visual impairments vary depending on age and geographic location. For children in developing countries, the most prevalent forms of visual impairments are vitamin A deficiency, corneal scarring, trachoma (an eye infection), inherited conditions, and onchocerciasis (river blindness caused by a parasitic worm that lives in contaminated waterways). Except for inherited conditions, all of these causes of visual impairments are preventable through proper nutrition, hygiene, and medical care. Unfortunately, many children in developing countries do not have access to these basic needs that would prevent their visual impairments.

In wealthier nations where basic nutrition, sanitation, and healthcare are more readily available, different causes result in most childhood visual impairments. In the US, the most common causes of visual impairments in children are cortical vision impairment, optic nerve hypoplasia, retinopathy of prematurity, albinism, and abnormalities in the eye structures. Some of these causes of visual impairment are often associated with the presence of additional disabilities (e.g., cortical visual impairment), and the rates of these etiologies have increased as medical care allows children with more severe disabilities and children born with extremely low birth weights to survive (4)

Signs of visual impairment in children are:

- Eyes that don't move together when following an object or a face
- Crossed eyes, eyes that turn out or in, eyes that flutter from side to side or up and down, or eyes that do not seem to focus
- Eyes that bulge, dance, or bounce in rapid rhythmic movements
- Pupils that are unequal in size or that appear white instead of black
- Repeated shutting or covering of one eye
- Unusual degree of clumsiness, such as frequent bumping into things or knocking things over
- Frequent squinting, blinking, eye-rubbing, or face crunching, especially when there's no bright light present
- Sitting too close to the TV or holding toys and books too close to the face
- Avoiding tasks and activities that require good vision (5).

The impact of vision impairment on children

Vision impairment changes how a child understands and functions in the world. Impaired vision can affect a child's cognitive, emotional, neurological, and physical development by possibly limiting the range of experiences and the kinds of information a child is exposed to.

Nearly two-thirds of children with vision impairment also have one or more other developmental disabilities, such as intellectual impairment, cerebral palsy, hearing loss, or epilepsy. Children with more severe vision impairment are more likely to have additional disabilities than children with milder vision impairment (6).

Early intervention for children with vision impairment

Early intervention is the best way to support your child's development. Early intervention includes therapies, education, and other supports that will help your child reach their full potential. Early intervention should also include helping you learn how to bond with your child and interact with them in ways that support their development. Children learn the most from the people who care for them and with whom they spend most of their time, so everyday bonding, play, and communication with you can help your child a lot.

There are several specialists who are trained to work specifically with children who have severe vision loss. These might include orthoptists, physiotherapists, orientation and mobility specialists, occupational therapists, counsellors and special education teachers.

It's good to see yourself as working in partnership with your child's professionals. Combining your deep knowledge of your child with the professionals' expertise makes you more likely to get the best outcomes for your child (7).

Hearing impairment

For those who can hear, auditory connection to the world is usually taken for granted. Hearing is a complex physiologic process, and when lost or diminished, it can affect health, independence, well-being, quality of life, daily function, and everyday communication. The loss of hearing - gradual or acute, mild or severe, present since birth or acquired in older age - can significantly affect one's communication abilities, quality of life, social participation, and health. In the United States, an estimated 30 million individuals (12.7 percent of Americans ages 12 years or older) have hearing loss. Globally, hearing loss has been identified as the fifth leading cause of years lived with disability (8).

Etiology of hearing impairment

Clinically, hearing impairment is classified into two major categories: conductive loss and sensorineural loss. Both types of hearing impairment can be congenital or acquired. Congenital hearing loss is typically identified at birth via hearing screening or from the family history. It may have a genetic or non-genetic origin. Most forms of congenital hearing loss are not syndromic and are associated with autosomal recessive transmission. Additional causes of congenital hearing loss that are not hereditary include maternal infection, kernicterus, trauma during birth, and medication toxicity. Although there is a genetic component, acquired hearing loss is usually related to environmental factors. Noise exposure, ototoxic medications, and aging are the leading causes for acquired sensorineural loss. Other forms of acquired sensorineural loss include autoimmune disorders, sudden sensorineural hearing loss, head trauma, etc. The main causes of acquired conductive hearing loss include otosclerosis, otitis media, obstruction of the ear canal, tympanic membrane perforation, cholesteatoma, or tympanosclerosis.

Treatment of hearing impairment

Depending on the type and severity of hearing impairment, three treatment options are available: hearing aids, middle ear implants, and cochlear implants. These devices all use a microphone to pick up acoustic signals. However, they use different signal processing techniques and, most importantly, have totally different output signals (9).

Hearing impaired and children with autism

There is little information about children with both sensorineural hearing loss and autistic symptoms. Since each of these disorders has a profound effect on the development of language and communication, their joint effects are likely to be cumulative and devastating. Early identification of both disorders is essential to provide appropriate habilitation at the language learning age, when intervention is most effective.

Deaf children acquire language laboriously unless they belong to the small minority who have signing deaf parents. Autism, in addition to deafness, makes the acquisition of language even more challenging since all preschool children with autism, including those who have healthy or reasonably healthy intellectual skills, have a communication disorder. Sign language (i.e., language by eye) has been recommended for hearing in children with autism. Unfortunately, not all autistic children do well with signs because their pragmatic deficits interfere with the communicative use of gestures.

Attributing abnormal behaviors of deaf children to hearing loss and missing the diagnosis of hearing loss when autistic symptoms are prominent are serious clinical errors that highlight the difficulty clinicians often encounter when differentiating hearing loss from autism, especially in children with mental deficiency and other disabilities.

It is easy to overlook autistic features in such children who have been admitted to hospital frequently and are so obviously disabled. We stress, however, that a pessimistic attitude during infancy is not warranted for children with ear and branchial-arch malformations, many of whom are hearing-impaired, in as much as many are neither mentally deficient nor autistic and have a much better long-term outlook than one might have assumed in infancy (10).

Psychological aspects of physical health

The need to integrate support for mental and physical health is not limited to those people meeting formal diagnostic criteria. All physical health problems have a psychological dimension, particularly when they involve learning to live with a long-term condition, which may require a profound process of internal adaptation and can be accompanied by significant functional impairment, economic disenfranchisement, and social isolation. From a patient perspective, a meaningful definition of integrated care must also include the provision of integrated psychological support to help people adapt and manage their health effectively. Failure to do so can be associated with poor outcomes and faster disease progression. It is also important to consider the psychological aspects of health as opposed to illness. The case for integrated approaches applies to prevention and health promotion as much as to treatment and care. There is a great need for much greater inclusion of a mental health and well-being perspective within public health programs targeting risk factors for heart disease, lung disease, stroke, cancer, and other preventable conditions. Similarly, integrating mental and physical health is particularly important in relation to the perinatal period. Although not an illness, this is a time when mental and physical health are very closely connected and during which psychological needs are not always well addressed (11).

Mental health implications of COVID-19 on children with disabilities

The everyday lives of individuals across the globe have been severely affected by COVID-19. Amidst this, it became important to keep children with physical and mental disability not only physically safe but also look after their psychological and emotional well-being. In particular, social distancing and its effects were extremely novel and difficult to understand for children, especially those experiencing developmental and intellectual delays. This affected their well-being and placed them at a higher risk for clinically significant mental health issues.

In 2020, UNICEF (according to Patel, 2020) reported that the entire education system shifted online with schools being suspended nationwide in 189 countries since April 2020. While online classes were proving to be favorable for most students, little was talked about its psychological impact on children with disabilities. Children with pre-existing mental and physical disability were at utmost risk. Most online platforms were not compatible with assistive technology for teaching children with visual impairments or hard-of-hearing children. Challenges of online learning coupled with a lack of recreational activities that can be done at home can prove to be frustrating for children with such physical disabilities.

Apart from online classes, it is important to mention that wearing masks greatly hindered children's communication development. This includes young children who, during normal development, do not yet verbalize but absorb nonverbal communication and facial expressions, as well as children with communication difficulties who rely on lip-reading, studying nonverbal communication, and similar cues. The same example can be applied in the healthcare system to other conditions when communicating with healthcare workers who are wearing masks, as the masks complicate communication for both children and adults with communication challenges.

Furthermore, developing social skills and social interaction has been one of the hardest issues for children with autism. Social distancing and having no access to outdoor activities deteriorated their development. Conducting international research on mental health consequences on children with physical and mental disability is of utmost importance to seek long-term solutions to combat this issue (12).

Mental health in relation to vision impairment

The rate of mental health difficulties is increased in deaf children and adolescents compared with the general population, according to most studies. Many factors have been associated with the risk of developing mental health problems among deaf adolescents: factors related to deafness or hearing loss, including cause, degree, age of onset, and additional complexities, and psychological and interpersonal factors (13).

A sizable body of literature suggests that people with vision impairment are at increased risk for specific mental health problems. In particular, a number of studies have demonstrated a link between vision impairment and depression. Nearly one-third of individuals with visual impairments and disabling eye diseases experience mild depressive symptoms.

Additionally, data from community samples indicates that people with low vision and/or blindness are 1.6–2.8 - times more likely to develop depression compared to those without vision impairment, even after controlling for demographic variables (Demmin & Silverstein, 2020). Concern about having to live with vision loss in the future, and/or having to cope with knowledge that one has a progressive condition can contribute to anxiety, even in the absence of reduced visual abilities. Studies reported that anxiety levels among adolescents with congenital blindness were elevated relative to their sighted peers (14) and that children with myopia (nearsightedness) experienced significantly higher levels of depression and anxiety than their peers without vision impairment (15).

Mental health in relation to hearing impairment

According to Bysveen Lier, about 1 in 1000 children and adolescents are deaf or hard of hearing. It has been hypothesized that they have a higher burden of mental health problems. The studies done so far indicate that the prevalence of mental health problems is 2-3 times higher than among their hearing peers, ranging from 20 to 50%. Four factors seem to impact significantly on mental health in this group: communicative problems, additional disability, low IQ, and abuse/physical discipline. Several other factors, such as having only one parent and no siblings and the low educational level of the parents, are assumed to represent risks. Some studies show that gender and choice of school may also be important factors (16).

Hearing-impaired children and adolescents basically suffer from the same psychiatric illnesses as other children, but it seems that some diagnoses/symptoms are more frequent than in the hearing population: affective symptoms, peer problems/social problems, behavioral problems, and autism/pervasive developmental disorders. Significant differences have not been demonstrated with regard to substance use, ADHD, psychotic episodes, and rule-breaking behavior.

Depressive symptoms in these children and adolescents possibly result from the experience of having a handicap, being bullied at school, lack of important communication abilities and opportunities to express and discuss their concerns and feelings, being physically disciplined, etc., compared to their hearing peers.

Bysveen Lier also indicates that the prevalence of psychosocial problems is three times higher in the population of deaf and hard of hearing. Behavioral problems also seem to be twice as big as in the deaf and hearing-impaired population. The lack of communication skills and ability to understand other children's reactions and feelings will likely cause peer and behavioral problems. Autism is also raised amongst these children, i.e., the prevalence is 2-4%, compared to 1,1% in the rest of the population. In many of the deaf and hard-of-hearing children and adolescents, a lack of skills in 'Theory of mind' has been demonstrated, causing them to have both behavioral and peer problems. Theory of mind is the ability to recognize and understand mental states in themselves and others, such as beliefs, wishes, intentions, desires, and knowledge (16).

Experiences of families and siblings of children with physical disabilities

Several studies point out that siblings of children with disabilities are more anxious and more withdrawn or depressed than siblings of non-disabled children. Other studies report that siblings of children with disabilities express more aggressive behavior and experience more difficulties in social and peer relationships. Sources of stress in the sibling relationship include problems associated with meeting needs, providing direct services, and developing an identity. The parents' attitude toward the child with a disability is an important factor in sibling adaptation. The way in which parents cope with raising a child with a disability in part determines the sibling adaptation. Furthermore, several studies suggest that parents who demonstrate acceptance of the child with a disability and convey positive attitudes are often adopted by siblings and are therefore of importance in sibling adaptation (17).

Parents are typically the key members of a family, and the role of parents in the rehabilitation of children with physical disabilities is increasingly being recognized. Regular and active participation by parents during all phases of treatment of children with physical disabilities is a vital part of the overall management. However, providing a high level of care that a child with long-term functional limitations requires may affect the psychological health of the parents. Psychological problems such as depression may limit the role of parents in the management of the child's illness. Emotional distress in a parent may contribute to emotional and psychiatric distress in the child and may affect the family's ability to cope with the illness; thus, the illness may have a greater impact on the family. Therefore, early identification of parents who are at risk of poor mental health is important because interventions are likely to be more successful if they target modifiable determinants of parenting burdens and address specific parental needs.

In one study, it was found that 44% of parents of children with physical disabilities had poor mental health. Thus, it was suggested that greater physical disability in the child does not necessarily lead to worse parental mental health. This study suggests that parents of children with physical disability were at risk for psychiatric disorders. In dealing with the mental health needs of parents having children with physical disabilities, clinicians should take care to evaluate the particular reactions of each parent and provide adequate intervention in cases where negative effects are evident or persist over time. Referral of these parents for treatment may prevent the development of more severe symptoms, which may interfere with effective parenting (18).

Parenting a child with visual impairments

There are a number of ways that you can help your child with visual impairments:

- **provide direct, hands-on experience with real objects and materials**

Children with visual impairment will need to have direct experience in order to understand the world around them. They do not have the benefit of learning through visual observation, and this lack of incidental learning means that they will learn best by touching and doing things. For example, if you give the child a glass of milk by handing her the cup, she won't know where it came from. She needs to be shown that the milk is kept in the refrigerator, the cups are on the shelf in the cabinet, the milk is poured into the cup, and the cup is placed on the table. When she is finished with the milk, she needs to take the cup to the sink and rinse it to place in the dishwasher or wash it by hand. While each step takes time, going through each part of the process will help her understand what it means to "have a glass of milk". If the cup appears magically in her hand and is taken away from her when she finishes it, she will be missing many foundational concepts about how the world works.

- **engage the child in multisensory experiences that are meaningful**

It is important to offer the child items made of various materials, such as wooden and metal spoons or measuring cups, wire whisks, pieces of fabric, and hard, soft, squishy, and bumpy items. While most toys are made of plastic, a child can learn a great deal from experimenting with items commonly found in the kitchen or around the house. Household activities, such as cooking, offer lots of opportunities to learn about wet/dry, hot/cold, big/little, heavy/light. Helping with the dishes, watering plants, and running the vacuum cleaner are great ways to learn about important activities of daily life. Pouring water or dried beans, digging in the sand or dried rice or noodles, can all help the child to develop important motor skills, as well as sensory awareness and tactile discrimination.

find out what environmental adaptations can help your child

The vision professionals who work with your child will make suggestions that are specific to your child's vision on how to help him or her move and function as independently as possible. This may include increasing contrast (such as placing a yellow cup on a black or dark solid-colored placemat).

- **read aloud to your child**

It is important to read aloud to your child each day, preferably with books that are accessible in braille or large print. Talking about the story is a great way to promote your child's language development.

- **organize the space in your house so that the child can learn to locate things independently.**

It is important to keep things in predictable locations, so that the child can find them more easily. Clothing, toys, books, kitchen and bath items can all be stored in the same place each time, for example. Perhaps the bottom shelf in the living room should be designated as your child's shelf so that she knows she can find her toys and books there. You can mark the shelf with her name in braille or large print, as well as a tactile symbol, to help her to locate it more easily.

- **teach your child responsibility, just as you would your other children**

Your child should be expected to do the same chores and put away her own belongings, just as your other children are taught to do. As mentioned above, keeping the living space organized will help her be more independent in putting things away. You can teach her to make her bed, put her dishes in the sink, put her laundry in the hamper, and put trash in the bin, just as you would any other child (19).

Parenting a child with hearing impairments

Parents coping with their children's hearing impairment face unique challenges with unwavering determination. Their unwavering support, adaptability, and advocacy create a nurturing environment where their children can thrive, fostering communication, empowerment, and endless possibilities. Through their resilience, parents empower their children with hearing impairment to embrace their unique identities and reach their full potential, reminding the world that the power of love and acceptance knows no bounds.

There are a number of ways that you can help your child with hearing impairments:

- **in the home**

Houses today are not designed with the needs of hard-of-hearing people in mind. Therefore, we need to rearrange our homes to make them more user-friendly for hard-of-hearing people. The aspects we need to put into practice are light, distance and noise.

a) Light - almost all hard-of-hearing people lipread; to do that, they need adequate light. Parents can do that by adjusting the light to fall on everyone's faces but not in their eyes. This affects the light coming from the windows, too. Parents mustn't arrange the living room furniture so that a chair or a sofa is in front of the window because anyone sitting there would be backlit by the outside light, making it hard to lipread.
b) Distance - unlike people with normal hearing, hard-of-hearing people need to be close go the speaker in order to hear him.
c) Noise - A common enemy of understanding speech in background noise. Turn off the TV, or radio as that interferes with the child's ability to hear speech. If traffic or other outside noise is a problem, shut windows or doors on that side of the house (20).

- **empower their success**

Offering love and encouragement shows your child that you accept them for who they are. Paying attention and spending time together can help your child feel relaxed and confident. Make sure to offer reassurance whenever needed. Giving them responsibilities at home, such as weekly chores, puts them on equal footing with their siblings and peers. It is important to raise your child, as much as possible, as you would if they had normal hearing.

Helping them develop healthy coping skills ensures they can handle both success and failure later in life. Finding the balance between protecting them and giving them the freedom to participate in activities without you may be hard, but preparing them for the real world is important. This can help them become strong, independent, self-reliant adults.

- **understanding what goes into their hearing treatment is also important**

Allowing your child to pick out the desired hearing aid color and any fun accessories, such as a charm, can help them engage with the process (21).

- **social support**

Connect with other parents of children with hearing impairments through support groups, online communities, or local organizations. Sharing experiences and advice can provide emotional support, practical tips, and a sense of belonging. Social support networks can be a rich source of information, knowledge, and resources. Parents can exchange information about the latest technologies, therapies, and educational resources available for children with hearing impairments (22).

- **celebrate uniqueness**

Embrace and celebrate your child's uniqueness. Focus on their individual strengths, talents, and interests. Encourage them to pursue activities they enjoy and provide opportunities for self-expression. By fostering a positive self-image, you empower your child to strive for their personal best.

Literature

1. Zziwa S., Babikako H., Kwesiga D., Kobusingye O., Bentley J.A., Oporia F., Nuwematsiko R., Bachani A., Atuyambe L.M., Paichadze N. Prevalence and factors associated with utilization of rehabilitation services among people with physical disabilities in Kampala, Uganda. A descriptive cross-sectional study. BMC Public Health. 2019. 19:1742
2. Jayne M. Identification and assessment. A Handbook for Parents of Children with Disabilities. 2020 August.
3. Wanjohi A. Types of Physical Handicaps, Causes, Characteristics and Interventions. Kenya Project Organization.
4. Sapp W. Visual Impairment. International Encyclopedia of Education, Third Edition. 2009 January 1;880–885.
5. Nandini N., Haseen T. Visual Impairment, including blindness. Special Education. Krishna Publication House.
6. Kaminer RK, McMahon E. *Blindness and visual impairment.* Pediatrics in Review 1995;16:77-8.
7. de Verdier K, Ulla E, Löfgren S, Fernell E. Children with blindness – major causes, developmental outcomes and implications for habilitation and educational support: a two-decade, Swedish population-based study. Acta Ophthalmology. 2018 May;96(3):295–300.
8. National Academies of Sciences, Engineering and Medicine, Blazer DG, Domnitz S, Liverman C.T. Hearing Health Care for Adults: Priorities for Improving Access and Affordability Committee on Accessible and Affordable Hearing Health Care for Adults. National Academies Press (US) [Internet]. 2016 Sep 6;1–308. Available from: www.national-academies.org.
9. Zeng FG, Djalilian H. Hearing impairment. 2009 Jul 29;325–348. Available from: https://faculty.sites.uci.edu/hesplab/files/2015/08/2010-Zeng-Djalilian-Oxenford.pdf
10. Jure R. Hearing-impaired children. Developmental Medicine & Child Neurology. 1992 January;33(12):1062-1072. Available from: https://www.researchgate.net/publication/21378135
11. Naylor C, Das P, Ross S, Honeyman M, Thompson J, Gilburt H. Bringing together physical and mental health. A new frontier for integrated care. Journal of the Royal Society of Medicine. 2016;109(10):364–366.
12. Patel K. Mental health implications of COVID-19 on children with disabilities. Asian Journal of Psychiatry. 2020 December;54:102273.
13. van Gent T, Sleeboom-van Raaij I. Mental Health Problems of Deaf Children and Adolescents: An Overview. Diversity in Deaf Education [Internet]. 2016 Jul 26;381–416. Available from: https://academic.oup.com/book/5127/chapter/147735354

14. Demmin DL, Silverstein SM. Visual Impairment and Mental Health: Unmet Needs and Treatment Options. Clinical Ophthalmology [Internet]. 2020 Dec 3;14:4229–4251. Available from: http://doi.org/10.2147/OPTH.S258783
15. Li D, Fai Chan V, Virgili G, Piyasena P, Negash H, Whitestone N, et al. Impact of Vision Impairment and Ocular Morbidity and Their Treatment on Depression and Anxiety in Children, a Systematic Review. Ophthalmology [Internet]. 2022 Oct;129(10):1152–70. Available from: http://creativecommons.org/licenses/by/4.0/
16. Bysveen Lier F. Mental health in deaf and hearing-impaired children and adolescents. Master thesis. 2013
17. Pit-Ten Cate IM. Experiences of siblings of children with physical disabilities: an empirical investigation. Disability Rehabilitation [Internet]. 2000 Jun 15;22(9):399–408. Available from: www.tandf.co.uk}journals
18. Hung JW, Wu YH, Chiang YC, Wu WC, Yeh CH. Mental Health of Parents Having Children with Physical Disabilities. Chang Gung Medical Journal. 2010 Feb;33(1):82–91.
19. Cushman C. 10 Tips for Parents of Children with Visual Impairments – Paths to Literacy. Available from: https://www.pathstoliteracy.org/10-tips-parents-children-visual-impairments/
20. Bauman NG. Successful Hearing Loss Coping Strategies. Learn About Hearing Series. 1998;
21. Tips for Raising a Child with Hearing Loss. Heuser Hearing Institute. 2021. Available from: https://thehearinginstitute.org/tips-for-raising-a-child-with-hearing-loss/
22. Indiana ML, Sagone E, Fichera SLO. Are coping strategies with well-being in deaf and blind parents related? European Journal of Investigation in Health, Psychology and Education. 2021 Dec 1;11(4):1422–1439.

Sexual and reproductive health among persons with disabilities

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Most important messages:

- Parents should start conversations about body changes, boundaries and consent early, using age-appropriate language and terms. The key is continuous and open dialogue.
- Children should be taught about the right to personal space and bodily autonomy, so that they understand that their body belongs to them and that they have the right to say no.
- Accurate, comprehensive sexuality education tailored to the child's mental level should be offered, including information on relationships, consent, sexual health and safety.
- The child should be prepared for physical and emotional changes during puberty. We should discuss menstruation, hygiene, and any special challenges you may face with your new condition.
- Parents should create role-play scenarios that will help children understand the information and use it when needed.
- Parents should ensure that the child has access to health professionals who are familiar with the sexual and reproductive needs of persons with developmental disabilities.
- Adults should be aware of the increased sensitivity to abuse that children with developmental disabilities may face.

Introduction

Sexuality is an important part of human nature. According to the definition of the World Health Organization (WHO), "A central aspect of being human throughout life includes sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction." It is experienced and expressed through thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships... Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors" (1).

As a multidimensional process, sexuality is closely related to basic human needs to be liked and accepted, to show and receive affection, to feel valued and attractive, and to share thoughts and emotions. Sexual function is related to anatomical and physiological characteristics, personality and emotions, as well as ethical, spiritual, moral and cultural beliefs. In general, sexuality is a very complex personal and social phenomenon (2).

Like all other people, people with disabilities have sexual thoughts, feelings and activities. The sexual and reproductive health (SRH) of people with disabilities is neglected by both the community and those working on SRH issues, placing these people among the most marginalized groups when it comes to SRH services (3).

Due to increased vulnerability, persons with disabilities have the same or even greater demands on SRH services. Among other things, they are exposed to a greater risk of sexual abuse, sexually transmitted infections and unwanted pregnancies, and in some situations, even without their consent, they can be subjected to procedures such as forced abortion and sterilization.

Also, people with disabilities often face barriers in informing and accessing services for their own reproductive health.

Reproductive health

According to the WHO, reproductive health is a state of complete physical, mental and social well-being, and not just the absence of disease or physical and mental weakness in all spheres related to the reproductive system, its functions and processes (1, 3). Essential for reproductive health are the care of the health of the sexual reproductive organs, hormonal status, sexuality, pregnancy and family planning. Of course, reproductive health cannot be separated from mental health.

Sexuality

Sexuality should be considered in a context that is broader than genital sex and includes:

- socialization of the gender role;
- physical maturation and representation of the body;
- social relations and
- future social aspirations (4).

Children and adolescents with developmental disabilities, like all children, are sexual persons and can express desires and hopes for marriage, procreation and a normal sex life as adults. However, the presence of a disability can affect the development of sexual identity, confidence, desire, function and the ability to find a partner.

Sexual arousal can be initiated by a visual, auditory, olfactory or thought stimulus, supporting the claim that the brain is the main sex organ in humans.

Physical arousal and sexual function can be impaired in the presence of some neurological conditions, even when sexual feelings and needs are not affected. When genital arousal or contact is limited, sexuality can often be expressed through intimate conversations and touches with a partner or through choice of clothing, hairstyle, and fashion accessories. Creativity and inducing psychogenic arousal can increase intimacy and pleasure.

The biological sex drive is often reflected in the desire for self-stimulation. Masturbation is a developmentally appropriate activity, ie. a completely normal part of development. Children begin to discover their bodies in this way between the ages of two and six. While adults see masturbation as sexual behavior, children simply experience pleasure. It is important to note that difference.

Masturbation among persons with disabilities

Masturbation is a normal behavior through which some adolescents with developmental disabilities learn about their own sexual functioning. It can be an appropriate outlet for sexual feelings and urges, and adolescents who engage in it should not be shamed or reprimanded when it occurs in an appropriate context and in a private setting.

The subject of masturbation can be an uncomfortable one for parents and teachers to deal with, but it is a normal part of growing up. As long as masturbation is occasional and does not interfere with the ability to do other things, there is no need for alarm.

Unlike young people and children without disabilities who understand that masturbation is a private behavior, children with disabilities will likely need to be taught directly the negative social consequences of touching their private parts in public. For some younger children or children with high support needs, simply 'interrupting and redirecting' or providing a behavioral substitute, such as playing with a particular object, may be sufficient. However, for older children who can understand the negative social and legal consequences of public masturbation, direct guidance is essential.

You, as a parent, can try to make this behavior acceptable:

- create a safe space and time when masturbation is acceptable; by setting clear boundaries about when and where the behavior is appropriate, your child will learn that it is okay to explore, but with limits.
- you use visual aids such as pictures, signs, and symbols to mark a particular room as a private space. Sometimes a visual schedule that defines "private time" can prevent masturbation at other, inappropriate times of the day.
- refrain from belittling your child or his body; whether you approve of masturbation or not, you don't want your child to learn that his genitals are bad or wrong. If your personal beliefs do not support touching, it is important to convey this in a way that does not make the child feel embarrassed. Sexual shame carries over into adulthood and can have a huge impact on self-esteem and relationships in the future.
- provide alternatives. Parents/families should know that it is not easy to replace these behaviors with others that would be more acceptable; nothing makes your child feel as good as masturbating. However, try to think of sensory activities that will provide other forms of pleasure. This can be things like gently stroking their back, using a scalp massager, or feet massaging. You can also involve him/her in highly stimulating activities that don't necessarily provide sensory pleasure, but bring him/her pleasure in other ways (e.g., watching his/her favorite movie or cooking favorite meal together).
- encourage exercise to reduce arousal. Options may include going for walks, running on the treadmill, or riding a bicycle during times of the day when the child is usually trying to masturbate. This will keep the child engaged in an alternative activity and may reduce the intrinsic desire to touch.

Having a disability does not prevent an individual's sexual maturity, nor does it remove their sexual desires, feelings and needs. As with any individual, having the appropriate knowledge, support and boundaries will help these individuals engage in such activities in a healthy, safe and happy way. This support should come from appropriate sexuality training. The training will increase knowledge and confidence in discussing the topic, as well as the development of appropriate policies to respond to questions about sexuality and masturbation. Unfortunately, the situation is often not like this, and so many individuals must find their way through the development and dangers that come with a lack of information.

The sexual self-image of persons with disabilities can be altered by societal attitudes and, even more tragically, be further influenced by sexual abuse or harassment. Social and psychosocial barriers can be a greater obstacle to an adolescent's sexual development than limitations due to the disability itself. Early social experiences play a key role in the psychosexual development of children and adolescents. Promoting independence by mastering appropriate skills as greetings, eye contact, body language, providing personal space, self-advocacy skills, and telephone and computer skills create a strong foundation for developing more complex social skills.

The sexual and reproductive rights of persons with disabilities

People with disabilities have the same human rights as people without disabilities. Sexual and reproductive health and rights encompass both freedoms:

- the freedom, without pressure, to make decisions about whether and when to reproduce
- rights, such as the right to access the full range of basic SRH services.

No group has ever been so severely restricted or negatively treated in terms of their reproductive rights as women with disabilities (5, 6). The UN Committee on the Rights of Persons with Disabilities has clearly identified that discrimination against women and girls with disabilities in the area of sexual and reproductive rights, including gender-based violence, is a clear violation of several provisions of the UN Convention on the Rights of Persons with Disabilities (7).

A few examples of violations of the reproductive rights of persons with disabilities:

- **Imposed and/or forced sterilization-**women with disabilities are particularly exposed to this risk, performed under the auspices of legitimate medical care or with the consent of others on their behalf. Forced sterilization refers to a procedure that results in sterilization in the absence of the free and informed consent of the person undergoing the procedure, including cases in which the sterilization is authorized by a third party. It is considered to be such a case if the procedure is carried out in circumstances other than when there is a serious threat to life. Forced sterilization occurs when financial or other incentives, misinformation, misrepresentation, undue influence, pressure, and/or intimidation tactics are used to force an individual to undergo the procedure (8, 9).
- **Imposed/forced contraception.** Women with disabilities, like all women, have the right to safe and effective contraception. However, widespread discriminatory attitudes and stereotypes about the reproductive capacity of women with disabilities make it difficult to obtain accurate information about contraceptive options. Although the contraceptive needs of women with disabilities do not differ substantially from those of the general population, the patterns of contraceptive use among women with disabilities and women without disabilities differ greatly (10). Women with disabilities (especially women with intellectual disabilities) are more likely to be sterilized and prescribed long-acting injectable contraceptives than to be prescribed oral contraception.
- **Denial of motherhood, parentage and parental rights.** Women with disabilities are discouraged or denied the opportunity to give birth and raise children. They were and continue to be perceived as asexual, dependent care recipients and generally incapable of caring for children, rather than caregivers. On the contrary, women with intellectual disabilities in particular can be considered too sexual, which creates a fear of reproducing children with disabilities. As a result of such perceptions, they are denied the right to reproductive autonomy and self-determination. Recent data shows that a parent with a disability (usually a mother) is ten times more likely than other parents to have custody of a child removed, with the child being removed by authorities based on the parent's disability rather than any evidence for his neglect (12, 13).

According to a study conducted in North Macedonia, women with disabilities experienced sexual harassment, following, commenting and touching in public places (14).

Development of the sex organs of the fetus during pregnancy

In the period of early organogenesis during pregnancy, from the 3rd week after conception, the formation of blood vessels begins, while blood cells are created only in the second month of pregnancy. On the 21st day, the primitive heart connects with the blood vessels and the primitive cardiovascular system is formed, which is the first functional system in the fetus. From the 4th to the 7th week of gestation, all other organs and systems are formed, while the sex organs are created later. The difference between the male and female fetuses can be observed in the 9th week and, finally, in the 12th week of pregnancy (15). During the period of organogenesis, taking medicines that are not prescribed by a physician can cause damage to certain developing organs/systems.

Congenital anomalies of the female genital organs

Congenital anomalies of the female sex organs can be the result of genetic malformations or the harmful effect of some external factor during the formation of the fetus (such as chemical substances, high temperature, and various radiations). Anomalies of the external sex organs (clitoris, vagina, hymen) are usually solved surgically in hospital facilities:

- *absence or underdeveloped female genital organ* - it is the duty of the health professionals to explain to the parents that this defect of the female genital organ is often accompanied by defects of other organs; therefore, it is necessary to do additional examinations. It is the duty of parents and professionals to talk to the girl about the consequences of her future sex life, and to explain the possibility of surgical treatment, and the duration of the intervention, which can enable uninterrupted sexual relations.
- *deformation of the hymen* - this defect occurs due to non-opening of the hymen, so during menarche/first menstruation, the flow of menstrual blood is absent. It is accompanied by premenstrual pains in the girl, as well as swelling around the vagina due to accumulated blood. Parents should take the child to the physician immediately because there is a risk of blood return, vaginal enlargement and tumor-like swelling. Parents should be explained that if timely intervention is not done to open the hymen, there is a risk of permanent damage to the internal sex organs, which can cause sterility or impossibility of conception.
- *deformations of the uterus* - in the case of an underdeveloped or deformed uterus, parents, together with professionals, should explain to these girls that they will never get menstruation and that surgical intervention that would enable successful pregnancy is not possible. In such situations, malformations of other organs are also possible, so additional investigations must be done.
- *ovarian defects* - deffects in the gonads or ovaries, may mean their complete absence or only remnants of them, which is usually a congenital condition. It is the duty of the parents of these children to do a genetic test, which will show what deformations there are in the sex genes. The most striking condition of ovarian deformities is found in Turner's syndrome, a rare disease, the basis of which ispartial or complete absence of one of the X-chromosomes.It should be explained to the parents that in these children, due to the lack of estrogen hormones, there is a danger of progressive osteoporosis, a bone disease that leads to weak and brittle bones. Even with a simple fall or exposure to slightly greater force (such as bending, sitting, coughing, sneezing or twisting) there is

a risk of breaking a bone. Also, in these girls, strabismus is often detected, as well as below-average intelligence and the absence of sexual characteristics. Also, parents must know that in girls who have remnants of the ovaries, consultation with a gynecologist is necessary, who may recommend their surgical removal due to the risk of malignancy.

It is very important to emphasize that hormones are not given to induce menstruation, but they are necessary to prevent osteoporosis and other complications due to estrogen deficiency.

Puberty

Puberty is a specific period in the child's development characterized by gradual maturation of secondary sex characteristics, accelerated growth and emotional instability. The pattern of sexual maturation in children and adolescents with disabilities may differ from that of other children, in terms of precocious or delayed puberty.

Premature puberty is defined as the development of pubertal changes at an age lower than the accepted lower age limits for the onset of puberty - before age 8 in girls and age 9 in boys. It can be an additional challenge for children with disabilities who can often be socially immature; to affect the already changed image of their own body and self-esteem, to increase the complexity of activities related to self-care and maintaining personal hygiene, as well as to increase the risk of sexual victimization (16, 17).

Premature puberty in children with disabilities:

- adolescents affected by neurodevelopmental disabilities are 20 times more at risk of precocious puberty compared to the general population, while some girls with autism spectrum disorders may have a slight delay in menarche (first menstruation);
- in adolescents with cerebral palsy, puberty tends to start earlier and end later than in children with typical development.

Factors that can affect the pace and time of sexual maturation are:

- chronic malnutrition in childhood - it is well known that adolescents whose disability impairs their nutrition or is associated with some chronic inflammation may have delayed puberty (18). Diet and nutritional status influence pubertal development and are responsible for almost 25% of the changes during puberty. Severe malnutrition is associated with impaired bodily functions.
- the cumulative stress - in this fragile population, cumulative stress is often present, which can cause changes in metabolic and physiological processes.
- the use of medicines (eg, long-term anticonvulsant therapy) may further affect the levels of various sex hormones that are reflected in pubertal development.
- also, puberty development is affected by various brain malformations related to pituitary dysfunction. However, the role of genetic factors and fetal programming should not be excluded (19).

Although not always recognized, delayed puberty is not entirely benign and may be associated with an increased risk of metabolic and cardiovascular disorders, changes in bone mineralization, and fracture risk later in life. This has been observed especially in patients with disabilities in whom early cardiovascular and metabolic damage is already present due to multisystem dysregulation (16).

Puberty in female children is a process of biological changes and physical development that are a prerequisite for sexual reproduction; that is, the possibility of becoming pregnant becomes a reality. At puberty, there is a period of rapid skeletal growth and development of secondary sexual characteristics, such as breast growth and the appearance of body hair, and finally, the onset of the first menstruation (menarche). In our climate, menarche usually occurs between 12 and 13 years of age, and it is considered that the first menstruation should occur no later than 17 years of age. When talking to girls about their first period, parents should be careful in preparing what the bleeding should be; that is, there are three important features of the menstrual cycle–duration, strength and regularity. On average, the bleeding lasts 3 to 5 days, the strength, that is, the loss of blood, is 20 to 100 ml, and the measure of the strength of the bleeding is the number of pads used per day. The parent should explain to their girl that it is expected and possible that the cycle will be irregular in the first two years in order to avoid the psychological stress due to the irregularity, but of course, the frequency of receipt and the length of the bleeding should be recorded. A more serious condition is when the bleeding does not stop and is very profuse. If it is profuse and lasts longer than 2 weeks, the parents must take the girl to a physician because very serious health complications can occur.

Menstrual cycle

The menstrual cycle is the result of periodically repeating changes that occur in the ovaries and endometrium (the inner lining of the uterus that is shed with each period) from menarche (first menstruation), to menopause (last menstrual bleeding). The normal duration of menstrual bleeding is from 3 to 7 days. Any bleeding beyond 7 days is not considered normal. A normal menstrual cycle is considered an approximately equal period of time from the first day of bleeding to the last day before the new bleeding. This cycle lasts 28 days, plus or minus 3 days.

In the absence of menstruation, we distinguish two categories:

- absence of menstrual bleeding up to 16.5 years, followed by absence of secondary sex characteristics and
- absence of menstruation until the age of 18, although secondary sex characteristics are normally developed.

The absence of menstruation is usually the result of disorders in the development of the ovaries or uterus, so the prognosis and prospects for treatment are very small. Parents should know the cause of this condition, as well as the outcome of therapy, which is not always successful. A complete scan of the entire reproductive tract, genetic testing, hormonal status, and especially a check of adrenal and thyroid gland function is mandatory.

Pain associated with menstruation or dysmenorrhea

Dysmenorrhea, or painful menstruation, is one of the most common menstrual disorders. It is manifested in the first few days of the monthly cycle (immediately before and during the menstrual cycle) as strong pain in the lower abdomen followed by cramps, sweating, rapid heartbeat, nausea, dizziness, diarrhea, and vomiting.

During the cycle, one in three women have difficulties in carrying out daily activities. It is also estimated that over 50% of women suffered from dysmenorrhea during the reproductive period, 80% of them experienced this problem in the first two to three years after menarche (15). Treatment consists of education and support and the use of nonsteroidal anti-inflammatory drugs that will relieve pain, thereby reducing anxiety and uncertainty.

Premenstrual syndrome

Premenstrual syndrome or PMS is a group of symptoms in the body and in the psyche, which occur in the second half of the menstrual cycle. The most common symptoms are:

- somatic: abdominal distension, feeling of increased body weight, fluid retention, pain and discomfort in the chest, hot flashes, headache, pain in the lumbar region of the spine,
- psychological: irritability, aggression, tension, anxiety, depression, lethargy, difficulty sleeping, change in appetite, change in sex drive, tearfulness, reduced concentration and coordination.

These symptoms are alleviated and even disappear with the use of certain medications.

Premenstrual and menstrual cramps affect the lives of many women, so it is important to accurately determine the causes that lead to dysmenorrhea in order to establish appropriate therapy. If your girl suffers from pain before or during their period, talk to her and help her find appropriate medical support models for this delicate health condition.

Characteristics of the menstrual cycle in adolescent girls with disabilities

During the first two years after menarche, menstrual cycles are associated with abnormal uterine bleeding. Irregular menstrual cycles can be caused by thyroid diseases, high prolactin levels (due to mood-stabilizing drugs), polycystic ovary syndrome, and coagulopathies that are resistant to treatment or that cause anemia.

Girls and women with disabilities face greater challenges during the menstrual cycle, both hygienically and with dignity. They face double stigma both because of social norms related to gender and menstruation and because they have a disability. Menstruation is a source of shame for girls and women with disabilities, with consequences such as social isolation and even forced sterilization. Health workers are often consulted about issues about menstruation, bleeding, maintaining hygiene, treatment of painful periods, PMS, as well as about contraception in this category of children.

Hygiene needs of adolescent girls with disabilities during menstrual periods

Meeting these needs is critical to ensuring their comfort, dignity, and well-being. Different disabilities can present unique challenges, so a personalized approach is essential. Here are some tips to help meet the hygiene needs of girls with disabilities during their periods:

- *communication and education*- Depending on the girl's cognitive and communication abilities, the parent (at best, the mother) should offer age-appropriate information about menstruation. In doing so, use visual aids, social stories, or simplified language to explain the changes occurring in the girl's body and menstrual hygiene practices.
- *selection of menstrual products*: Take into account the girl's physical abilities and sensory sensitivity when choosing menstrual products. Options such as menstrual cups, reusable cloth pads, or adaptive underwear may be more comfortable and practical for some girls with disabilities.
- *establishing a routine* - create a predictable menstrual care routine that includes regular checks for the need to change menstrual products. Use visual schedules or reminders as needed to help achieve routine and consistency.
- *auxiliary hygiene* - depending on the girl's level of independence, she may need help changing and disposing of menstrual products.

- *bathroom availability* - make sure the bathroom is accessible, safe and equipped with the necessary materials such as soap, water, wastebasket.
- *discreet wear* -provide a discreet option to wear menstrual products to help the girl have privacy and dignity, especially at school or in public places.
- *dealing with unexpected menstrual bleeding* - be prepared for potential unexpected and unpleasant situations during menstruation. Have spare clothes, tissues and a plan to handle the situation calmly and compassionately.
- *physical comfort* - brace yourself for any physical discomfort a girl may experience during menstruation. Use heating pads, hot baths, or pain relievers (under medical direction) to relieve menstrual cramps if needed.
- *consent and privacy* - respect the girl's right to privacy and seek her consent before providing assistance or discussing her menstrual needs with others.
- *inclusion and support in the school* - work with educators and school staff to create an inclusive environment for girls with disabilities during their period. Ensure they have access to appropriate facilities and support during school hours.
- *supporting emotional needs* - menstruation can be emotionally challenging for any girl, and it can be especially challenging for girls with disabilities.

Remember that the needs and preferences of each girl with a disability are unique, so it's essential to tailor advice based on individual abilities and circumstances. Being considerate, compassionate, and understanding can greatly contribute to the well-being and comfort of girls with disabilities during their menstrual periods.

Adolescent girls who successfully manage and are independent in toileting can be trained to use hygiene products. In some cases, we have to decide on the suppression of menstruation with the medicines that are responsible for delaying the menstrual cycle - the continuous taking of contraceptives, placement of an intrauterine device (spiral), etc. In doing so, it is important to discuss with the patient and the parent before making a decision according to the clinical findings - anemia, continuous bleeding, and high risk of unwanted pregnancy.

It is important to explain that menstrual suppression does not change the risk of abuse and sexually transmitted diseases. Of course, in the case of resistance to the use of oral contraceptives, a spiral insertion is resorted to using anesthesia.

Care before becoming pregnant

Care for persons with disabilities before pregnancy is defined as:

- care in order to identify health risks;
- implementing a plan to optimize the health of the mother and the fetus, as well as to prevent unwanted pregnancy;
- plan for continuous monitoring of pregnancy until delivery;
- counseling to stop using alcohol and smoking;
- control of body weight and nutritional status;
- continued use of folic acid;
- in consultation with their therapist, to stop or reduce the doses of drugs such as immunosuppressants, anticoagulants, medicines with a potentially harmful effect on the fetus.

Pregnancy, labor pains, and childbirth

It is estimated that approximately 12% of women in their reproductive years, aged 15 to 44, have some kind of disability that affects their daily activities and quality of life (20, 21). Most often, women with disabilities have a lower level of education, are less likely to be married, are more likely to receive health insurance, and are more likely to be users of services.

Childbirth for women with disabilities should be tailored to the specific needs of the mother/child dyad (4). Like other women, these women are often anxious and worried about labor and the act of giving birth itself, but due to the presence of a disability, additional challenges and concerns arise.

Women with disabilities, in many cases, reported that the decision on the type of delivery was made arbitrarily without being consulted or without considering the possibility of a natural/vaginal delivery. Many women worry that they will be forced to have a caesarean section just because they have a disability.

Although there are circumstances in which cesarean delivery is warranted for the safety and well-being of the woman and her newborn, these decisions should be based on sound obstetrical indications, not just the presence of a disability.

An additional concern for many women with disabilities is anesthesia during labor and delivery. Most of them can be safely given the same anesthesia as other women, although the risks should be considered. Consultation with an anesthesiologist during the prenatal period and formulation of an anesthesia plan is recommended (22).

Achieving successful communication is of crucial importance. Clear and specific speech, writing, speaking/lip reading, using hearing aids or hiring an interpreter, and sign language are examples of strategies to promote successful communication. Communication with a mother with a disability requires patience, empathy, and understanding. The approach may vary depending on the mother's specific needs and abilities.

Here are some general tips to help you communicate effectively:

- be respectful and patient - treat the mother with respect and be patient when communicating. Allow her enough time to process the information and respond;
- use clear and simple language - keep your speech clear and avoid using jargon or complex terms. Use short sentences and repeat important information if necessary;
- be a good listener-pay attention to what the mother is saying and listen actively. This will help you better understand her needs and feelings;
- use visual aids if necessary - depending on specific needs, visual aids such as pictures or written instructions can help with communication;
- use non-verbal cues-non-verbal cues, such as facial expressions, gestures and body language, can improve communication and make it easier for the mother to understand your message;
- show empathy and understanding - try to put yourself in her shoes and understand her perspective. Be compassionate and supportive;
- allow time for response - give her enough time to process information and respond. Avoid rushing or finishing her sentences;
- ask for clarification - if you're not sure about something she said or meant, politely ask for clarification. It is better to ask for clarification rather than make assumptions;
- respect her choices - recognize her autonomy and respect her decisions as much as possible;

- adapt to her communication style-observe how she prefers to communicate and adjust your approach accordingly. Some people can use sign language, communication devices etc;
- avoid speaking loudly-unless she is hearing impaired and asks you to speak louder, avoid raising your voice unnecessarily;
- engage in joint activities - participate in activities she enjoys, this can provide you with a more relaxed atmosphere for communication;
- be supportive and offer help-offer help when appropriate, but also not to be too intrusive;
- be open to learning - if there are specific challenges or unique communication needs, be open to learning new techniques or approaches to improve communication.

Remember, communication is a two-way process and it is essential to be patient and understanding as you create a supportive and inclusive environment for the disabled mother.

Prolonged recovery may result from the experience of childbirth, care of the newborn, and risks associated with the woman's specific disability. These women need a longer time to recover from a caesarean or spontaneous delivery,

The hospital room should be adapted to allow better access to the newborn. Advice, encouragement and help for the breastfeeding procedure, as well as a way to more comfortably place the child at the breast, is needed. Women should be encouraged to resume therapy discontinued during pregnancy soon after delivery to prevent symptoms and prevent worsening of disability and subsequent discontinuation of breastfeeding.

Contraception–temporary prevention of pregnancy

There are several ways to prevent unwanted pregnancy, such as:

- measurement of basal temperature, which is biphasic – below 37ºC until ovulation and above 37ºC after ovulation; a drop in basal temperature occurs before getting the menstrual cycle. The certainty of not getting pregnant is highest after 3 days from the beginning of the phase with an elevated temperature.
- the Ogino-Knauss method – an old method that today's women have an app for on their phones; the annual menstrual calendar is analyzed, after which the shortest and longest menstrual cycle is detected. Days 1-7 of a woman's menstrual cycle are considered infertile. Days 8-19 are considered fertile/unsafe for unprotected intercourse. The period after the 20th day until the end of the cycle is considered infertile. The Ogino-Knaus method has great advantages over other contraceptive procedures because it is a natural, physiological process, there are no disturbances in the body of a woman or a man, neither physically nor mentally. However, this method is risky in case of irregular cycles and unwanted pregnancy may occur.
- spermicidal creams, suppositories, foams;
- barrier techniques such as diaphragm, cervical cap, male condom, female condom;
- oral or injectable steroid contraceptives;
- spiral;
- sterilization in both men and women;
- abortion with medication or curettage.

The correct use of contraceptive pills guarantees a high percentage of protection, but it is always emphasized that the pills should be taken at a certain time of the day, and if the time gap between two pills is longer than 36 hours, the contraceptive effect stops. If the patient has not taken a tablet for more than 2 days, we advise her to stop the therapy. Then there are two possibilities–bleeding occurs, which largely indicates the fact that the person is not pregnant, and it is advised to start a new pack of pills after 5 days of bleeding. If bleeding does not occur after stopping the tablets, a possible pregnancy should be considered, so further use of the tablets is not allowed until the pregnancy is confirmed.

Use of contraceptives in adolescence

When making a decision when the earliest sexually active girls can start using oral contraception, we always start from one rule - a minimum of three regular menstrual cycles are required with ovulation achieved in order to avoid the possibility of physiological damage, i.e., to be sure that the use of contraceptive substances will not cause permanent impairment of further reproductive function.

Abortion as a method of contraception

Abortion can be performed if:

- continuation of the pregnancy endangers the patient's life;
- as a necessary act to prevent the escalation of the physical or mental health of the pregnant woman;
- the gestational age is not more than 24 weeks, and the termination of the pregnancy is a less risky act for her than the continuation of the pregnancy, which includes the risk of leading to damage to the physical and mental health of the patient, or to the existing child/children;
- if there is a verified risk that the newborn will have serious congenital anomalies that are usually detected early with prenatal tests as early as the 10th week of gestation.

Of course, abortion should not be a choice for contraception since, to a large extent, the patients face the consequences of the procedure. In any case, the gynecologist is obliged to inform the patient about the procedure and the possible risks to her physical and mental health and prescribe mandatory therapy and controls after the intervention.

Imposed or forced contraception

Women with disabilities, like all other women, have the right to safe and effective contraception. Although the contraceptive needs of women with disabilities do not differ substantially from those of the general population, the patterns of contraceptive use among women with disabilities and women without disabilities differ greatly.

In women with intellectual disabilities, injectable contraceptives that have a prolonged effect are often resorted to rather than prevention with oral contraception. Women with disabilities are also less likely to be involved in choosing and making decisions about the type of contraception they should use.

It is of great importance to advise on the correct use of the pills. It is essential to give correct, accurate information when prescribing contraceptives, such as noting that the effectiveness of the pills is reduced if they are taken together with anticonvulsants, with some antibiotics and tranquilizers, as well as with some anti-inflammatories medicines.

Prevention of cervical cancer

Women with disabilities need the same primary and preventive reproductive health care as women without disabilities, namely:

- Primary prevention of cervical cancer includes:
  - vaccination for human papillomavirus (HPV) and
  - sexual health education.
- Secondary prevention is achieved by:
  - screening methods, such as a Pap test, an HPV test, or a combination of the two.

Refusal of Pap tests in women with disabilities may be justified by physicians because of the low risk of sexual activity and, thus, exposure to HPV. However, HPV can be found in children before any sexual activity.

Cervical cancer screening guidelines recommend:

- for female patients aged 21 to 29, a Pap smear test every 3 years;
- for female patients aged 30 to 65, Pap smear test every 3 years;
- high-risk HPV self-testing every 5 years or an HPV test combined with a Pap smear test every 5 years (23).

An initial appointment with a physician reserved to better get to know and understand the patient's special needs should be considered.

As recommended by the American College of Obstetricians and Gynecologists (ACAG) and the American Academy of Pediatrics (AAP), a pelvic exam is not necessary before age 21 or to start hormone therapy. If the adolescent is not sexually active, a pelvic exam is rarely indicated. When pelvic examinations are indicated, women with disabilities should be informed about the procedures and the instruments used, and the approach should be respectful of their privacy. Adolescent girls should be allowed to have a trusted carer present during the examination (17, 24).

Rape, incest and domestic violence

Children with disabilities are, above all, vulnerable because they are children. They may be victimized by adults on whom they rely or who exercise significant control over the child's well-being, safety, and access to external resources. Children are also used to accepting the authority of adults, and in the case of young children, this is reflected in their acceptance that adults have the right to touch them.

The dynamics of child sexual abuse create significant barriers to disclosing this violence. One study found that about 75% of sexually abused children wait more than a month to tell someone about the abuse, and nearly 50% wait more than 5 years to disclose it. Some even remain forever undiscovered (25). This study did not include children with disabilities, but it can easily be expected that these numbers are similar or even higher in this vulnerable and understudied population.

The risk of sexual violence is also increased due to physical and intellectual disabilities. Mobility and communication barriers contribute to aspects of this population's vulnerability, making it difficult for victims to access support, escape dangerous situations, or disclose their abuse. Each type of disability appears to contribute to a higher risk of violence, but intellectual disabilities, communication disorders, and behavioural disorders contribute to even greater levels of risk. Children with disabilities are 3 times more likely to be victims of sexual abuse, and the rates reported for children with intellectual and/or mental health disabilities are even higher (26).

While the previously mentioned statistics show a high rate of victims of sexual violence, there are significant gaps in knowledge about the scope of the problem. Much of the research that exists is decades old, and definitions of disability vary from study to study. Children with disabilities are also often and systematically denied sex education.

Our culture too often wrongly views people with disabilities as asexual and incapable of participating in healthy and fulfilling relationships. Without access to the sexuality education that most children without disabilities receive, many children with disabilities face additional challenges distinguishing between appropriate and inappropriate behavior and, consequently, are unable to label certain behaviors as abuse. It is this lack of awareness and other barriers, such as feelings of shame, self-blame and fear, that lead to even lower disclosure rates.

Supporting parents, carers and teachers to advocate for the safety of our children is of the utmost importance. Positive conversations around sexuality and consent can help create a safe space where children can talk about sex and come forward if they have been abused. Arming parents and caregivers with tools to prevent abuse and identify the signs and symptoms of sexual violence will only help support victims in their journey to healing.

Of utmost importance in the fight against sexual abuse of children is the promotion of sexual health education and accessibility to services, as well as the creation of safe environments that will enable victims to disclose abuse. To be effective, these prevention strategies must be carefully adapted for people with disabilities.

What is the physician's duty to the victim of sexual violence:

- to repair the injuries in a timely and appropriate manner;
- to perform appropriate tests for the prevention and treatment of infections and pregnancy;
- careful and exhaustive data collection, documented medical history,
- detailed examination of the patient and specification of observed injuries;
- taking samples from the victim's clothing;
- taking a vaginal, rectal, oral, pharyngeal and semen sample;
- taking pubic hair;
- nail and nail polish sampling;
- taking saliva for secretory substances;
- handing over the samples to appropriate forensic institutions;
- emotional support;
- conversation with the victim about the possible consequences of injuries, sexually transmitted diseases, pregnancy;
- mandatory organization of professional help in the shortest possible time.

Sexually transmitted diseases

Sexually transmitted infections are infections acquired during sexual contact. Bacteria, viruses and parasites that cause disease can be transmitted from one person to another through blood, semen, vaginal or other secretions from the human body. Sometimes, these infections can be transmitted asexually, in other ways, such as from mother to fetus during pregnancy or childbirth, through blood transfusions or using a used needle. Sexually transmitted diseases do not always manifest symptoms; these people can feel completely healthy and not even know that they are infected until complications arise or their sexual partner shows symptoms.

Which symptoms and signs should prompt a parent to seek medical help:

- rash or ulcers in the mouth and genitals;
- pain and burning during urination;
- unusual discharge from the genitals;
- unusual and smelly vaginal discharge;
- painful sexual relations;
- enlarged and tender lymph glands;
- pain in the lower abdomen;
- fever;
- redness of the neck, palms and feet.

Symptoms may appear after a few days of sexual contact, but depending on the organism and the cause of the infection, they may appear after several years. The most common sexually transmitted disease is HPV infection. Its best prevention is the HPV vaccine for girls and boys aged 11 to 12 years, no later than 26 years.

Sexual education for persons with disabilities

Sexual education is a process based on studying the cognitive, emotional, physical and social aspects of sexuality, creating respectable social and sexual relationships.

Having a physical or cognitive disability does not change sexuality and the desire to express it. According to the WHO, "sexuality is part of basic needs and a characteristic that should not be separated from other aspects of human life" (3). Therefore, sex education among this population should be adapted to their disability.

There are several factors that can limit their possibility of sexual activity:

- sexual education for children, young people and adults with special needs is usually limited or does not exist at all within the family.
- the access to information in the schools of those persons is limited because they are mostly rejected from the environment, finish primary education, and a very small percentage continue education at a higher level where they could receive adequate education specific to sexual health.
- many of them cannot read or write, so sex education programs should be adapted to the level they can accept as people with a lower educational level.

Effects on the development of sexuality of persons with disabilities have:

- sex education has positive effects, including an increase in sexual activity and familiarity with the human body, a reduction in risk-taking, and a reduction in the frequency of unprotected sex.
- information materials, and information in the media, should also be accessible and adapted to these persons.
- it is necessary to equally involve and engage the entire socio-economic establishment for the care of persons with disabilities.
- sexual education should implement in its programs the ways of prevention of premature and unwanted pregnancy, sexual health and sexually transmitted diseases and

contraception. Programs that promote abstinence as the only model for delaying sexual activity have proven unacceptable and unsuccessful.
- young people through the digital world receive information about their body, sexuality, in a way that ensures their anonymity, so they should be offered digitally compatible information and educational programs through this type of communication.
- parents and family are primary source of information, giving the person the opportunity to get an idea of the values of creating a family, responsibility and care for children.

The role of the parent in the sexual education of children

Every parent wants to give their child the support and knowledge they need to become a responsible, healthy and happy adult. Children need to know that you love them and accept them for who they are. Teaching your child about sexual health and sexuality is part of your role as a parent. Many things about sexuality you have already shown them and learned from birth and early development. They learn from:

- the way others physically touch them;
- the way their bodies react and feel about other people;
- what according to your family and your beliefs is right or wrong to do and say;
- the words family members use or don't use for body parts;
- observing the relationships around them;
- observing gender roles.

They also collect a lot of information outside the family, whenever they watch TV, movies, listen to music and talk to friends. That is why it is necessary for them to receive straight and accurate information from adults. Sometimes parents feel unsure or uncomfortable talking about sexual health and sexuality because:

- they are not comfortable talking about the sex organs and their function;
- sexual health was not discussed when those parents were children;
- they are not sure if talking about sexuality will give their child the right to experiment in that area;
- they are not sure what, how much and at what age their child should know.

It's okay to feel uncomfortable talking about sexual health. You will gain more confidence the more you discuss these topics. You may feel a little awkward saying them out loud. You can practice them when you are alone until you feel more comfortable. Other topics, words related to sexuality are not words you probably use every day.

You could also:

- learn more about the topic you want to discuss so that you feel confident in your knowledge. There are many resources that can offer you relevant information;
- ask your spouse/partner or your friends to help you practice talking about the topic;
- start with short conversations. For many children, giving information in frequent mini-conversations works better than one long conversation. If you don't feel like you have to tell your child everything in one conversation, it will probably help reduce your anxiety;
- keep trying. Children can also be shy about speaking at first. Over time, they will begin to feel more relaxed and less embarrassed;

- the conversation should be a dialogue; two-way conversations can help your child be more willing to ask you questions. You can ask children about their thoughts on a topic or if they are curious about certain things;
- answer their questions honestly–tell your child what he wants to know using words he can understand;
- provide accurate information–studies show that young people tend to get most of their information (or misinformation) about sexual health from friends;
- share your beliefs, concerns, values - your child needs to know what is important to you;
- help your child make good decisions and stick to them;
- visual strategies are key - people with developmental disabilities are almost always visual learners. When possible, use images, videos, photographs, role-playing or other concrete techniques;
- repeat and reinforce concepts over time–one-off "sex conversations" are rarely functional for anyone (disabled or not). People with disabilities usually benefit from hearing/seeing/discussing concepts in different environments and contexts over time. Think of sex education as a "process" rather than a "session." Then, look for opportunities to repeat and reinforce the information during relevant situations that make sense to your child (teachable moments);
- use simple, unsophisticated language that makes sense to your son or daughter: Sexuality is a difficult subject for many people. When the topic is uncomfortable, it's common to unconsciously speak faster (because the sooner we're done, the better!), to use big words (because we may find it difficult to say the slang), or to introduce complex analogies that are confusing and abstract. Try to use language that makes sense to your son or daughter and slow down a bit. Give them time to process what you teach;
- learn facts and boundaries: facts are facts. Body parts have names and words have definitions. People with disabilities tend to struggle more with social rules and boundaries than words and definitions. Learn facts and boundaries to improve understanding and social appropriateness.

Research tells us that children and teenagers who have regular conversations with their parents/guardians about sex and relationships are less likely to take risks with their sexual health and more likely to be healthy and safe. So it's never too early and never too late to start talking to your child about sex and relationships. As soon as children start learning to talk, you can teach them the names of their body parts. When they are starting to socialize with other children, you can teach them to respect other people and talk about their feelings. These things lay the foundation for healthy sexuality and healthy relationships later on.

How do you keep the conversation age-appropriate?

It's all about what details you include. For example, if a 5-year-old child asks, "What is birth?" you can answer: "When the child comes out of the mother's body." As the child grows, you can add more details to this sentence.

When your child comes to you with a question about sex and relationships, take a moment to appreciate the good work you've done to get you to this point. If he feels comfortable asking you these questions, it means your child trusts and respects you. Here are some tips for answering those questions:

- don't jump to conclusions about why they're asking what they're asking. You can say, "Can you tell me what you already know about it?" or "What have you heard about that?"
- keep your answers short and simple and explain new words your child may not have heard before;
- after you reply, leave the conversation open. You can say, "What other questions do you have about things like this?" or "What is going on in your life/at school that makes you think more about these things?"
- check their understanding. After answering a question, you can ask, "Does that answer your question?" or "What do you think about that?"
- if you don't know the answer to the question, you can look it up alone or together with him. You can say, "I'm glad you asked me that question. I'm not sure how to explain it/what the answer is. Let's take a look at it!"

Remember, it's okay if you feel a little uncomfortable or if you or your child feel embarrassed. Try to overcome your shame. It will be worth it for both of you and the more you practice answering difficult questions, the easier it becomes.

Parents who take the time and effort to teach their children with disabilities about sexuality show incredible love, understanding and commitment. Their willingness to engage in these important conversations shows that they prioritize their child's overall well-being and development. By providing age-appropriate guidance, parents can encourage their children to make informed decisions and navigate their emotions and relationships in a safe and supportive way. By understanding the unique needs and challenges that children with special needs may face, these parents create an environment of trust, respect and open communication. They play a key role in fostering a positive self-image and promoting healthy attitudes towards sexuality, ensuring their children grow up with confidence and a strong sense of self-worth. Additionally, parents who engage in these conversations help break down societal stigmas surrounding individuals with disabilities and contribute to creating a more inclusive and compassionate society. Their efforts not only benefit their own child, but also serve as an example to others, fostering empathy and understanding towards all individuals, regardless of their abilities.

In essence, parents who teach their children about sexuality are true advocates, champions and guardians, providing a strong foundation for their child's emotional and social development, which will positively impact their lives into adulthood.

Literature

1. Sexual and Reproductive Health and Research: Defining sexual health [website]. Geneva: World Health Organization, 2022. (http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/).
2. Holland-Hall C, Quint HE (2017).Sexuality and Disability in Adolescents. Section of Adolescent Medicine. Nationwide Children's Hospital, The Ohio State University College of Medicine: Pediatr Clin N Am 64, 2017; 435–449(https://pubmed.ncbi.nlm.nih.gov/28292457/).
3. World Health Organization & United Nations Population Fund. (2009). Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note. World Health Organization (https://apps.who.int/iris/handle/10665/44207).
4. Riddle I, Romelczyk S, Sparling E. (2011). Effective Communication for Health Care Providers: A Guide to Caring for People with Disabilities. Newark, DE. Center for Disabilities Studies, University of Delaware (https://www.cds.udel.edu/wp-content/uploads/2017/02/effective-communication.pdf).
5. Rashida M. (2012). Report of the Special Rapporteur on violence against women, its causes and consequences; UN General Assembly; UN Doc. A/67/227.(https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session23/A_HRC_23_49_English.pdf).

6. In Frohmader C and Meekosha H. (2012) 'Recognition, respect and rights: Women with disabilities in a globalized world.' In Disability and Social Theory, Edited by Dan Goodley, Bill Hughes and Lennard Davis, London: Palgrave Macmillan.(https://link.springer.com/chapter/10.1057/9781137023001_17).
7. The Committee on the Rights of Persons with Disabilities (CRPD), 2022 [website]. United Nations Human Rights Treaty Bodies, UN Human Rights High Commissioner (https://www.ohchr.org/en/treaty-bodies/crpdWWDA).
8. Human Rights Watch (HRW), Open Society Foundations and the International Disability Alliance (IDA). (2011). Sterilization of Women and Girls with Disabilities: A Briefing Paper.http://www.wwda.org.au/Sterilization_Disability_Briefing_Paper_October2011.pdf
9. International Federation of Gynecology and Obstetrics. (2011). Female Contraceptive Sterilization. (http://www.wwda.org.au/FIGOGuidelines2011.pdf).
10. Haynes R., Boulet S., Fox M., Carroll D., Courtney-Long E. (2017). Contraceptive use at last intercourse among reproductive-aged women with disabilities: an analysis of population-based data from seven states. Contraception 2017: 97: 538-545 (https://pubmed.ncbi.nlm.nih.gov/29253580/).
11. Frohmader C. (2013) OpCit., Dowse L. (2004) Moving Forward and Gaining Ground: The Sterilization of women and girls with disabilities in Australia, for Women with Disabilities Australia (WWDA)(https://wwda.org.au/wp-content/uploads/2013/12/Moving_Forward_Gaining_Ground.pdf)
12. Women with Disabilities Australia (WWDA) [website]. Parenting Issues for Women with Disabilities in Australia - A Policy Paper (May 2009) (www.wwda.org.au/motherhd2006.htm).
13. Ziegler S. Gender and Disability Study. GIZ and Handicap International, Munich, 2012. (https://www.giz.de/de/downloads/07_Study%20on%20the%20intersection%20of%20Gender%20and%20Disability.pdf)
14. Coalition Sexual and Health Rights of Marginalized Communities, Skopje 2019.Research on the scope of gender-based violence against women and girls in the public space in the municipality of Tetovo[Research on the scope of gender-based violence against women and girls in the public space in the municipality of Tetovo][website] (in Macedonian) (http://coalition.org.mk/wp-content/uploads/2019/08/Rodovo-zasnovano-nasilstvo-MK_13_WEB.pdf.).
15. Shaw R., Soutter W., Stanton S. Gynaecology, Second edition, Churchill Livingstone (1992)
16. Calcaterra V, Cena H, De Silvestri A, Di Mitri M and Pelizzo G. (2019).Disorders of Puberty in Severely Neurologically Impaired Children: Is Delayed Puberty an Underestimated Problem? Front Pediatr 2019; 7:462.(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6867996/).
17. Quint EH, O'Brien RF. (2016). Committee on Adolescence, North American Society for Pediatric and Adolescent Gynecology.Menstrual Management for Adolescents With Disabilities. Pediatrics 2016;137(4):e20160295, 2016.(https://publications.aap.org/pediatrics/article/138/1/e20160295/52591/Menstrual-Management-for-Adolescents-With?autologincheck=redirected).
18. Holland-Hall C, Quint HE. (2017).Sexuality and Disability in Adolescents. Section of Adolescent Medicine, Nationwide Children's Hospital, The Ohio State University College of Medicine : Pediatr Clin N Am 64 (2017) 435–449, 2017.(https://pubmed.ncbi.nlm.nih.gov/28292457/).
19. American College of Obstetricians and Gynecologists' Committee on Adolescent Health Care in collaboration with committee member Joanna H. Stacey. (2016).Committee Opinion No. 668: Menstrual Manipulation for Adolescents With Physical and Developmental Disabilities.Obstet Gynecol 2016 Aug;128(2)(https://pubmed.ncbi.nlm.nih.gov/27454732/).
20. Centers for Disease Control and Prevention. Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016. MMWR: Morb Mortal Wkly Rep 2018;67(32):882–887. [PMC free article] [PubMed] [Google Scholar]
21. Statistics Canada. Disability in Canada: initial findings from the Canadian Survey on Disability. Ottawa, ON: Statistics Canada; 2016. Available from:https://www150.statcan.gc.ca/n1/en/pub/89-654-x/89-654-x2013002-eng.pdf?st=Ig7aO92L[Google Scholar]
22. Smeltzer SC. (2007).Pregnancy in Women With Physical Disabilities.J Obstet Gynecol Neonatal Nurs 2007 Jan-Feb;36(1):88-96(https://pubmed.ncbi.nlm.nih.gov/17238953/).
23. Baruch L, Bilitzky-Kopit A, Rosen K, and Limor Adler L. (2022).Cervical Cancer Screening Among Patients with Physical Disabilities. Journal of Women's Health 2022 31:8, 1173-1178, 2022(https://pubmed.ncbi.nlm.nih.gov/35072543/).

24. Public Health Agency of Canada, Center for Communicable Diseases and Infection Control. Ottawa, Canada. (2013). Questions and answers: sexual health education for youth with disabilities (https://www.canada.ca/en/public-health/services/infectious-diseases/sexual-health-sexually-transmitted-infections/reports-publications/questions-answers-youth.html#i).
25. Smith et al, "Delay in Disclosure of Childhood Rape: Results from a National Survey," 2000.
26. Lund, Emily M., and Vaughn-Jensen, J. "Victimization of Children with Disabilities," The Lancet, Volume 380 (Issue 9845), 867-869, 2012.

Associated diseases (comorbidities) in children with developmental disabilities

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Most important messages:
- Associated diseases in children with developmental disorders are common, but sometimes remain unregistered.
- The most common are neurological diseases (epilepsy), sleep disorders and gastrointestinal problems (reflux).
- Regularly check the child's eyesight and hearing, and if necessary, a neurological and psychiatric examination.
- If the child has allergies, he may be sensitive to gluten. Consult your physician about introducing a special diet.
- If the child has sleep problems, sleep apnea, insomnia, try to find the cause with the physician and start treatment.
- Create a sleep routine according to the individual needs of your child.

In children and adolescents with developmental disorders, the presence of associated diseases, the so-called comorbidities, is much more common than in other children. Associated diseases can be psychological/mental and physical. They represent a significant diagnostic problem, especially in children who do not speak (non-verbal children). Due to the inability to express and explain physical problems, they may manifest with sleep disorders, increased sensitivity and irritability (1). Therefore, if such behaviour occurs in children, the physician should consider the possibility of physical diseases, e.g. migraines or headaches, as a cause of behavioural changes. For example, banging heads in children with autistic spectrum disorder (ASD) may indicate headaches or migraines. Aggression and self-harm are common in non-verbal children when they suffer pain, for example, due to an ear infection. Food rejection can be associated with food allergies or dental problems, etc. The lack of clear guidance and tools for screening for these ASD-related organic diseases is a significant constraint for the timely detection and treatment of comorbidities. The same was observed for children with Down syndrome, cerebral palsy, and other developmental disabilities.

1. Most common associated diseases in children with autism spectrum disorder

Neurological diseases

Among the commonly associated diseases in children with ASD are various neurological diseases, the most common of which is epilepsy. The frequency of epilepsy in children with ASD varies according to intellectual limitations, age, gender, and the cause of epilepsy, but on average, around 14% of children with ASD also have epilepsy. It is much more common in girls than in boys (2).

Timely diagnosis and treatment of epilepsy are of great importance, as it not only keeps epilepsy under control but significantly improve ASD symptoms, cognitive function and behaviour. Other neurological complications include cerebral palsy, migraines and headaches. Peripheral nervous system defects leading to impaired hearing or vision are also more common in children with ASD.

In recent years, evidence has indicated that chronic inflammation of the central nervous system, i.e. neuroinflammation, plays a significant and perhaps crucial role in the development of ASD in children. Inflammation of the nervous system can result from an injury, infection or disease and is thought to lead to changes in brain function. This theory is supported by the fact that the autopsy of ASD patients has shown that these patients typically have reactive nerve cells (microglia and astrocytes), which are formed in response to chemical substances released as a result of inflammatory processes. Under the influence of these substances, nerve cells change their size and shape, and thus their interconnections, resulting in an increased number of immature compounds between them (synapses) and thus cognitive and behavioural impairment typical of patients with ASD (3).

Inflammation of the foetal nervous system may occur during pregnancy if the mother has a viral or bacterial infection or autoimmune/rheumatic disease. However, this does not mean that any inflammation in the mother's body will result in ASD in the offspring, as the occurrence of inflammation of the nervous system in the child is influenced by the period of pregnancy in which the inflammation occurred, as well as by the strength of the mother's immune response. Pathogenic bacteria in the mother's body stimulate the secretion of substances that increase inflammation (cytokines) and pass through the placenta. This passage can result in inflammation in the foetal brain, resulting in damage to the brain's white matter and causing neurodevelopmental disorders. Evidence for this theory was found in the blood, brain, and fluid surrounding the nervous system of patients with ASD (3). Mothers with long-term inflammation, such as joint disease called rheumatoid arthritis or inflammatory bowel disease called ulcerative colitis, are also more likely to have a child with ASD than mothers without these diseases.

In addition to ASD, inflammation of the nervous system is common in other neurodegenerative diseases, such as Alzheimer's disease and similar dementia or Parkinson's disease.

Interestingly, inflammation of the nervous system is closely related to disturbances in the composition of bacteria in the gut, which will be discussed further in this chapter. Omega-3 fatty acid supplementation reduces inflammation and improves the composition of intestinal bacteria, so it has been postulated that perhaps it could alleviate ASD symptoms (4). Sunflower oil, rich in omega-6 fatty acids, is most commonly consumed in our homes, and it may intensify inflammation. Therefore, taking omega-3 fatty acids in food could counterbalance the high intake of omega-6 fatty acids. It is particularly important that pregnant women take omega-3 supplements so that the foetus develops properly, and in particular, the foetus's brain and eyes (retina) are sensitive to omega-3 deficiency. The chance of a child getting ASD decreases by as much as 40% if the mother takes omega-3 fatty acid supplements in the second half of pregnancy and reduces the dietary omega-6 intake. Therefore, a useful advice would be to replace sunflower oil with olive oil. The best source of omega-3 fatty acids is fish oil, which is also a good source of vitamins A and D.

However, if the child already has ASD, the studies are inconsistent as to whether the addition of omega-3 fatty acids may lead to a significant improvement in the symptoms of ASD. While some researchers describe a noticeable improvement in symptoms of hyperactivity, lethargy and recurrent/stereotypical behaviour after 6 weeks of taking 1.3 g of fish oil daily, others found no significant improvement even with higher doses and longer duration of the study. Overall, the best results were achieved in stereotypical and social behaviour, followed by language development, while the lowest effects were recorded in reducing reactive aggression (3). However, there is a lack of high-quality research on children with ASD taking omega-3 fatty acids in order to draw reliable conclusions.

Sleep disorders

Almost 50% of children with ASD have sleep disorders and, according to some studies, up to 80% of children and adolescents. These disruptions negatively affect the quality of life and increase stress in children with ASD and their families. Children and adolescents with ASD and sleep disorders have significantly fewer social contacts, poorer memory and speech, more pronounced repetitive behaviour and worse cognitive functions than children with ASD but no sleep disorders (5). The most common sleep disorders are difficulty falling asleep (30-45 minutes before bedtime), awakening during the night (on average 2-3 hours of waking during the night) and poor sleep quality. This leads to fatigue, bad mood, reduced attention, and difficulty learning. Sleep is known to be necessary for the normal development of many complex physiological processes in the body, including the normal development of the brain and cognitive functions. Another important consequence of low-quality sleep can be increased aggression, anxiety, hyperactivity and sensitivity to all changes in the environment.

Precise guidelines for testing neurological and other physical diseases would significantly improve the timely diagnosis and treatment of children with ASD. These studies should be conducted in an environment that is comfortable for children with ASD, and, of course, appropriate therapy should be introduced if necessary. Pediatricians should pay special attention to children who have any neurological disorder without ASD diagnosis, as neurological disease may occur before signs of autism. It is similar to peripheral nervous system damage manifested as visual or hearing impairment, which should also draw the attention of both physicians and parents/carers to an increased risk of ASD. In these children, social contacts, relationships with other children and adults in the surrounding area should be monitored regularly and reacted in a timely manner, with early parental involvement, as evidence confirms that this significantly improves the results of therapy and the symptoms of ASD are less pronounced (6).

In sleep disorders, the first step is to diagnose. In this case, the parent/caregiver plays a key role. The parent should detail the history of sleep disorders and keep a log of the child's sleep, night awakening and sleep length to determine whether there is a sleep disorder.

Sleep disorders can be treated with medicines (pharmacological approach) and other therapies (non-pharmacological approach). A non-pharmacological approach implies sleep hygiene and the establishment of a daily routine (7). Going to bed should always be at the same time, the environment should be calm, and the child should not be allowed any activity that would impede sleep. The bedroom should be quiet, dark and cold. Hours before bedtime, sleep-impairing food and beverages, such as digestible food, coffee and caffeinated beverages (e.g., Coca-Cola), should be avoided. A warm bath before bedtime may seem relaxing, but it should be noted that some children have the opposite effect. Lullabies and quiet music can also help to tranquilize. Physical activity is recommended, but at least 3-4 hours before bedtime, ideally 4-6 hours before bedtime. Of course, children's diversity and individual needs should be taken into account, and their bedtime routines should be shaped accordingly. If this routine does not yield results, medicines should be considered in consultation with a physician. Studies have shown that melatonin supplementation is effective in improving sleep length and quality, but cessation of supplementation brings sleep disorder back to baseline. Melatonin has no effect on some children.

Melatonin is generally well tolerated; its side effects are headache, dizziness, stomach problems, and tiredness, which usually can be addressed by reducing melatonin dose. Long-term supplementation with melatonin has shown no adverse reactions or the need to increase the dose over time, and melatonin can generally be considered a safe supplement (8).

Gastrointestinal disorders

Children with ASD often have problems with the stomach and intenstines, including diarrhoea, constipation, acid reflux in the oesophagus ("heartburn"), stomach ache, and hernia (9). Stomach problems are estimated to be about three times more common in children with developmental disabilities than in children with typical development. Girls are particularly prone to these problems. Sleep disorders are common in children who also have digestive problems, indicating the association of these disorders. The causes of gastrointestinal disease may range from intestinal bacterial disorders, irritable bowel syndrome ("nervous bowel"), and inflammatory bowel diseases, such as ulcerative colitis and Crohn's disease.

Inflammatory bowel diseases are autoimmune diseases, and the characteristic symptoms are abdominal pain, diarrhoea, blood in the stool, weight loss; untreated can lead to complications requiring surgical treatment. The causes of these diseases are not clear, but according to some theories, there is a genetic basis that is the same for inflammatory bowel diseases and ASD. What has been confirmed so far is that people with ASD are 1.66 times more likely to develop inflammatory bowel disease than people without ASD, so this supports the theory that there is a common genetic basis for these diseases (10). In addition to genetics, intestinal microorganism composition disorders (intestinal microflora) may contribute to the development of as symptoms and inflammatory bowel disease.

Recent research has increasingly shown that the development of autism in children is closely linked to the microorganisms in their gut, the so-called intestinal microbiota. The association between the brain and the intestine is two-way: bacteria that live in the gut produce substances that act in blood on the brain and can cause depression and anxiety but also increase the desire to socialize. On the other hand, the brain sends signals that control the bowel movement. A comparison of the intestinal microbiota in children with AS and their peers without AS shows significant differences in intestinal flora. Children with AS have an increased amount of bacteria in the gut that produce inflammatory substances/cytokines, which also leads to digestive disorders. Supplementation with a probiotic containing *Lactobacillus acidophilus* in just 3 months improved stomach problems (stomach pain, diarrhoea and constipation) and affected the severity of autism, improving speech and language, socialisation and cognitive functions. Best results are achieved when probiotic supplementation is combined with a restrictive diet that excludes casein and gluten, i.e. milk and milk products and wheat-based products (11). In addition to probiotics, the role of prebiotics in establishing healthy intestinal microflora should not be neglected. Supplementation with prebiotics reduces stomach pain and discomfort, but some prebiotics have been shown to reduce the secretion of stress hormone – cortisol, and it was concluded that prebiotics may have a positive effect on ASD signs and symptoms (12). In addition, intestinal microbiota transplants have been carried out in children with ASD in recent years. Although the results obtained show some improvement in ASD symptoms, the number of studies is still small, and there are no long-term results of monitoring children undergoing intestinal microflora transplantation, so reliable conclusions on the effectiveness of this method cannot yet be drawn. It is also encouraging that in previous studies, children have not had significant adverse effects of this intervention, although the US Food and Drug Administration (FDA) warns of the possibility that donors' malignant cells, ulcerative colitis or Crohn's disease, or resistance to all known antibiotics from donor to recipient, may also be transmitted by intestinal microflora transplantation.

Candidiasis

Many physicians, psychologists, and special education teachers dealing with ASD propose that one of the possible causes of ASD is the overgrowth (excessive multiplication) of *Candida*, a form of yeast. This is one of the most controversial issues regarding the ASD. So far, there is insufficient evidence to draw reliable conclusions. Recent studies show the presence of *Candida* in the intestines of children with ASD twice as often as in healthy children. According to some studies, as many as 80% of children with ASD have *Candida* overgrowth, as opposed to 19-28% of children who do not have ASD but also have this yeast. Despite these data, studies are not entirely reliable as the presence of *Candida* is, in most cases, confirmed by a microscopic examination of the stool rather than by a culture, that is a much more reliable method. It is also clear that an excess of *Candida* causes stomach problems, which are common in children with ASD, but it is questionable whether *Candida* is the cause or just the result of a disturbed intestinal microbiota. It should be noted that many children with ASD do not have *Candida* overgrowth, and therefore no fungal infection needs to be treated.

Back in the 1980s, it was found that some children with ASD had Candida in their intestines, most often as a result of taking antibiotics, but no association with the development of autism has been established since then. However, *Candida albicans* has been shown to secrete toxins into the bloodstream that affect the immune system and brain, causing inflammation of the nervous tissue, thereby contributing to autistic behavior. Furthermore, *Candida* can cross the blood-brain barrier and colonize the brain, causing structural damage to the white matter of the brain (13).

Treatment with *Candida* involves diet. A sugary diet is very suitable for the development of *Candida*, so it is advisable to omit sugar from the diet. On the other hand, a protein-rich diet is very unfavourable for *Candida*. In addition to nutrition, the use of probiotics is very useful in this respect. Dietary supplements/probiotics containing bacteria of the genus *Lactobacillus* were associated with a significant reduction in *Candida* in faeces and/or urine in children of different ages taking probiotics for 2-12 months. In addition to *Candida*-reducing probiotics based on *Lactobacillus acidophilus*, *Lactobacillus reuteri*, *Lactobacillus rhamnosus*, studies have also been conducted on probiotics containing *Saccharomyces boulardii* which have also been shown to reduce *Candida* growth, binding and biofilm formation, but these results are limited by a small number of studies.

Among medicines used to treat fungal infections (called antifungals), nistatin and fluconazole are the most commonly used. Despite its frequent use in children with ASD, there are no studies showing the effect of nistatin on ASD itself. Likewise, the safety of its long-term use, e.g., years of nistatin intake, is unclear. The best results in *Candida* elimination were achieved by combining antifungal and probiotics. However, it has not been confirmed that treatment with *Candida* leads to a significant improvement in ASD symptoms and one of the main reasons is the small number of children who participated in the studies and the results are unreliable (13).

Autoimmune diseases and allergies

Allergies, in particular atopic dermatitis/eczema, asthma, and allergic rhinitis, as well as food allergies, are common in children with ASD (14).

Immune regulation disorders and inflammatory processes are typical characteristics of both allergic and neurodevelopmental disorders, indicating common pathophysiology. The development of these disorders may be influenced by many factors, such as maternal depression and anxiety, diabetes in pregnancy, maternal allergic status, nutrition, exposure to environmental contaminants, microbiome dysabiosis and early sleep disorders (15). But it cannot be said that any of these factors is a direct cause of autism.

It is assumed that pain and discomfort caused by allergic reactions may cause or aggravate recurrent and/or stereotypical behaviour typical of ASD. This is particularly true of poorly verbal children, who cannot express their problems in another way. Recognising and treating allergies can, therefore, greatly help reduce the symptoms of asthma.

Children with allergies are very likely to be hypersensitive to gluten (although this does not necessarily mean that they have celiac disease, but rather non-hypotensive) and have shown positive results in gluten-free nutrition. The development of allergies in early childhood has also been shown to increase the likelihood of developing ASD, and of all allergies, food allergies have the greatest impact (15). On the other hand, asthma is significantly more associated with attention deficit (ADHD) than with ASD (16).

Concerning associated asthma and allergies, eczema in children with ASD may be associated with more severe symptoms of autism (17). For eczema, ASD-related symptomatology, which includes increased sensing (tactile) sensitivity and decreased or excessive reactivity to touch, may aggravate skin problems caused by eczema. This link between eczema and ASD may be due to the common embryonic origin of skin tissues and nerves in early development, i.e., as early as the first trimester of pregnancy (17).

Among autoimmune diseases in children with ASD, inflammation of the nervous tissue and inflammatory bowel diseases have already been mentioned, but type I diabetes also occurs with inflammation of the nervous tissue. It should be noted that the level of antibodies against the nerve cells is directly related to the severity of the symptoms of ASD. In addition, parents with an autoimmune disease (celiac disease, diabetes, rheumatoid arthritis, psoriasis or hypothyroidism) have been shown to be significantly more likely to have a child with ASD (18).

2. Most common associated diseases in children with Down syndrome

Down syndrome (DS) is the most common neurodevelopmental disorder at birth and is genetically conditioned. It affects 1 in 700-800 children. Children with DS can have a number of associated diseases, which seriously impair their quality of life, ranging from congenital heart defects, digestive tract disorders, celiac disease, blood disease, and thyroid disease, to emotional diseases, behavioural disorders and ASD.

Many of these diseases can be missed because they do not give clearly pronounced symptoms, so children and adolescents with DS should undergo detailed and regular annual examinations.

Sleep disorders

Sleep disorders are extremely common in children with DS, among which the frequency of apnoea (sleep respiratory arrest) is particularly worrying. This disease not only impairs sleep quality but can be caused by serious health problems such as pulmonary hypertension or heart disease. Parents/educators are often unaware that the child has this problem and should pay attention to whether the child snores and stops breathing during sleep and inform the pediatrician if they notice a problem (19).

Insomnia is common among other sleep disorders in children with DS. It is reflected in difficulties falling asleep, awakening during the night, or early morning awakening. On the other hand, some children with DS are overly sleepy during the day, making them tired, nervous, and even affecting behavior that resembles hyperactivity and attention deficit disorder (20).

The causes of sleep disorders may be associated with DS, may be due to another organic disease, and may be the same as in children with typical development (puberty, emotional problems, staying late at night, etc.). Sleep problems can be caused by heart or lung disease, thyroid disease, obesity, epilepsy, and muscle or bone pain, and the cause must be treated to improve sleep quality. Medicines used in children with DS, especially medicines for anxiety, depression, and other psychiatric conditions, often cause sleep problems. In that case, the psychiatrist should change the medication or dosage to minimize the effect on sleep.

Therefore, the parent or caregiver should pay attention to the child's sleeping problems, and if such problems are noticed, find the cause and discuss the treatment options with a physician. Sleep disorders not only disrupt the quality of life of the child and parents/carers but can also indicate serious associated diseases requiring treatment, so sleep disorders should be taken very seriously.

Thyroid diseases

In children with DS, thyroid disease is the most common endocrine problem, namely hypothyroidism and/or Hashimoto's disease. Hypothyroidism or hypothyroidism is a decrease in thyroid function with insufficient hormone excretion. It can be congenital and appear as early as after birth or acquired during life. Hashimoto's disease is an autoimmune disease where the body produces antibodies that attack the thyroid gland, and it starts secreting less hormones over time. Hypothyroidism, or decreased thyroid function, should be suspected if the child has high blood cholesterol, is obese, or is sluggish and sleepy. Mood swings are also common (21). Diagnosis is relatively simple: hormones and antibodies from the blood are analysed, and therapy, in agreement with the endocrinologist, solves hypothyroidism. However, subclinical hypothyroidism with no clearly expressed symptoms is very common in children with DS. In order to detect the disease in a timely manner, it is recommended that blood tests of thyroid hormone are performed once a year in patients with DS. (TSH and free T4) and anti-Thyroid peroxidase (anti-TPO) antibodies to rule out hypothyroidism (22).

Heart and lung diseases

Diseases of the heart and blood vessels are the leading cause of morbidity and death in DS patients. Congenital heart disease is very common in children with DS, and it is estimated that about half of children with DS have congenital heart failure. These diseases can be detected already during pregnancy by ultrasound examination in the second trimester, around 18-22 weeks. Therefore, each pregnant woman should undergo an ultrasound examination in the second or third trimester. If changes suggestive of DS and heart disease are observed, childbirth should be planned to reduce the possibility of complications. Some of the disorders can be surgically resolved in the first weeks after childbirth. If this is not possible, congenital heart problems should be monitored regularly throughout life, including electrocardiogram (ECG), cardiac ultrasound, occasional Holter wearing (ECG records the electrical activity of the heart continuously over 24 hours or longer), and cardiac load test (ergometry) (23).

Pulmonary hypertension is an increased blood pressure in the lungs that leads to the narrowing of the blood vessels and reduced blood flow to the lungs, and is often associated with heart disease, although it can also occur in children with DS who do not have heart problems. Pulmonary hypertension usually occurs in the first year of life. In most children, therapy produces good and lasting results. About 30% of children have long-term or recurrent diseases in life, but this is usually the case in children with other lung disease. Since the disease is asymptomatic in many children, diagnosis is not easy. There are no reliable blood tests showing pulmonary hypertension or diagnostic guides, but the disease is often detected in children with cardiovascular disease, cardiac ultrasound, and other diagnostic methods for testing cardiac disease (24).

In children with pulmonary hypertension, regular ECG and heart ultrasound monitoring is required, and the results should be interpreted according to cardiac anatomy and previous therapy. Even if the cause of pulmonary hypertension is clear, e.g., the diagnosis of congenital heart disease must exclude other possible causes such as apnoea (25). Cardiac catheterisation may be recommended for diagnosis, and a more detailed study of pulmonary hypertension, but the risks of this invasive intervention should also be considered. Treatment of pulmonary hypertension is supervised by a cardiologist and a pulmonologist.

Gastrointestinal diseases

In children and adolescents with DS, there is a spectrum of gastrointestinal diseases that can be congenital or occur during life. These diseases can be mechanical or functional. In particular, gastroesophageal reflux disease (GERD) which is manifested by restoring gastric contents to the oesophagus should be noted. GERD affects many children with DS and often remains undiagnosed and untreated. If untreated, GERD may cause a number of serious complications. Symptoms include heartburn, burping and vomiting. Treatment is aimed at reducing symptoms, restoring damaged mucous membranes and preventing complications. The treatment involves spending 24 hours a day in an elevated position at an angle of 60^{o}, even while sleeping. This position is often sufficient to reduce the symptoms of reflux disease. If this does not achieve satisfactory results, medicinal products for the reduction of gastric acid are given. In cases where medicines cannot help, reflux is surgically managed, which is one of the most common surgeries in children with DS (26). However, the decision on the surgical procedure should be taken carefully with a thorough risk-benefit assessment. A parent should pay attention to whether a child has reflux so that the child can be diagnosed and treated as soon as possible.

3. Most common associated diseases in children with cerebral palsy

Children with cerebral palsy (CP) have many associated diseases, both physical and mental, which can be divided into several groups.

Neurological diseases

Neurological complications in children with CP often result in epilepsy. The frequency of epilepsy depends on many factors, e.g., it is much more common in children with quadriplegia than in paraplegia, then it is particularly common in children with CP who also have mental retardation and other factors that affect the onset of epilepsy. Treatment of epilepsy in children with CP is the same as in children without CP. The prognosis also depends on many factors, but the general opinion in the literature is that antiepileptics are abolished if the child has not had epileptic seizures in the last two years. Seizures are most likely to come back after stopping treatment in children with spastic hemiparesis or seizure of one-half of the body (27).

Of the other neurological problems, due to the possible complications of CP affecting the vision and hearing of the child, parents are advised to regularly monitor the vision and hearing of the child in ophthalmologists and otorhinolaryngologists who have experience in working with children with developmental disabilities, so that the problem can be detected in time and start therapy.

Sleep disorders occur primarily because the CP child is limited in movement, making it difficult or impossible for him to change his position during sleep, which greatly disrupts sleep. Associated epilepsy, anti-epileptic medicinal products, and gastroesophageal reflux also contribute to poor sleep quality. A thorough examination, including medical history, therapy, and polysomnography, may help detect and treat sleep problems and determine optimal therapy.

Gastrointestinal diseases

For children with CP, as well as for their parents and caregivers, digestive problems are among the biggest problems affecting the quality of life of the entire family.

The most common problem with as many as 90% of CP children is swallowing. Signs of this disorder are increased saliva secretion (the child is “drooling”), cough, asphyxiation, wet breathing, asphyxiation, and changes in appetite. An experienced physician or nutritionist may notice these problems by observing the child during meals. If there is a suspicion of difficulty in swallowing, a video-fluoroscopy is performed to monitor all stages of chewing and swallowing food. The best results are achieved if the problem is in the oral cavity, i.e., where chewing is inadequate and swallowing is normal.

As many as 75% of children with CP have reflux (GERD). The causes are multiple: damage to the central nervous system, most of the time spent lying down, taking mainly liquid food, and others. Slow gastric emptying in CP leads to food retention in the stomach and triggers reflux-related problems. Therefore, children with CP are very often vomiting and inflammation of the oesophagus, as well as erosion of dental enamel, which creates additional dental problems. Treatment is similar to that of children with reflux who do not have CP – correction and placement so that they spend part of the day sitting down, especially after meals, then incorporating solid food if possible and eventually medicines to reduce gastric acid. If medicinal products do not visibly improve, gastroscopy and/or colonoscopy is recommended to rule out intestinal obstruction (28).

Significant digestive problems in children with CP include constipation. Causes lie in poor bowel movement, and the consequences may include stomach pains, bloating, nervousness, poor appetite, and growth retardation. In extreme cases, the wall of the intestine may break, which can be life-threatening and require urgent treatment at the hospital. A clinical examination with detailed information on the child, a diet with enough fiber and fluid, and eventually, medicines given to clean the intestines is necessary to start appropriate treatment.

Respiratory diseases

In children and young people with CP, respiratory disease is the most common reason for treatment in hospitals and premature mortality. The functioning of the respiratory tract itself may be impaired by the weakness of the muscles involved in breathing. Furthermore, the problems mentioned above with chewing and swallowing, as well as reflux disease, can significantly contribute to lung complications due to the entry of saliva, food, liquid, or stomach contents into the lungs. Muscle weakness, increased tone and poor movement coordination due to CP also contribute to respiratory problems. To reduce the possibility of inhaling (aspirating) food or drink into the lungs, very careful feeding, proper food selection and feeding are required in an upright position where the neck and head are supported in an upright position. The bigger challenge is to prevent the aspiration of saliva. Above all, there is a need to reduce over-secretion, for which exercises and different medical approaches exist. Medicines can effectively reduce the production of saliva, but they can also go to the other extreme, where saliva becomes excessively dense, especially in the morning. Botox injections and surgical treatment of salivary glands are also available (29). Reflux should also be treated to prevent lung diseases.

In addition to gastrointestinal causes, muscle weakness and motor damage to the airways may lead to asphyxiation. Enlargement of the tonsils, tongue cramps, muscular weakness of the trachea can also cause obstruction of breathing. Symptoms include loud and difficulty breathing, apnoea, and enlargement of the neck. Some of these causes can be removed by surgery.

Urinary tract diseases

Children with CP have an increased risk of urinary tract problems, including incontinence, frequent urination, difficulty urinating, and urinary infections. Spasms of skeletal muscles may be associated with muscle spasms in the bladder wall (detrusor muscle), which allow the bladder to fill with urine when relaxed. However, when collected, it reduces the bladder capacity. Recognising this problem is very important for treating children with CP, primarily to protect the kidney from disease. However, for children who do not have pronounced problems, this problem is not easy to spot, and regular checks with urologists are recommended.

A routine urine examination in children with CP showed a high frequency of urinary infections. These infections are painful and unpleasant; if untreated, they lead to complications. To avoid this, it is desirable to periodically analyse the urine of children with CP and treat any infections detected (30).

In order to achieve continence, i.e., to manage urination, a mature urinary tract and autonomous nervous system are needed. For a child to go to the toilet on his own, she needs certain intellectual and communication skills and developed fine motor skills. If a child has these qualifications, he or she should be provided with suitable equipment – a raised toilet seat, dresser, handrails, and adapted clothes so that the child can take them off and put them on comfortably.

Conclusion

Children and adolescents with developmental disabilities are much more susceptible to associated diseases (comorbidities) than children with developmental disabilities. The most common comorbidities are neurological diseases, sleep disorders, and respiratory and gastrointestinal diseases. Many children with AS have inflammation of the nervous system and immune dysfunction, so allergies are also very common in these people. These organic diseases must be recognised and treated, which greatly increases the success of treating the underlying disease. To this end, it would be best to set up emergency medical units/services trained to work with children with developmental disabilities and to identify symptoms, so that children receive appropriate therapy and a better quality of life, as well as their families. This would greatly benefit the health systems themselves as timely and appropriate treatment would reduce complications and save significant resources to treat the resulting complications.

Literature

1. Pan P-Y, Bölte S, Kaur P, Jamil S, Jonsson U. Neurological disorders in autism: A systematic review and meta-analysis. Autism. 2021;25(3):812-30.
2. Strasser L, Downes M, Kung J, Cross JH, De Haan M. Prevalence and risk factors for autism spectrum disorder in epilepsy: a systematic review and meta-analysis. Developmental Medicine & Child Neurology. 2018;60(1):19-29.
3. Veselinović A, Petrović S, Žikić V, Subotić M, Jakovljević V, Jeremić N, et al. Neuroinflammation in autism and supplementation based on omega-3 polyunsaturated fatty acids: A narrative review. Medicina. 2021;57(9):893.
4. Madore C, Leyrolle Q, Lacabanne C, Benmamar-Badel A, Joffre C, Nadjar A, et al. Neuroinflammation in autism: plausible role of maternal inflammation, dietary omega 3, and microbiota. Neural plasticity. 2016;2016.
5. Ji Q, Li S-J, Zhao J-B, Xiong Y, Du X-H, Wang C-X, et al. Genetic and neural mechanisms of sleep disorders in children with autism spectrum disorder: a review. Frontiers in Psychiatry. 2023;14.
6. Green J, Pickles A, Pasco G, Bedford R, Wan MW, Elsabbagh M, et al. Randomised trial of a parent-mediated intervention for infants at high risk for autism: Longitudinal outcomes to age 3 years. Journal of Child Psychology and Psychiatry. 2017;58(12):1330-40.
7. Karthikeyan R, Cardinali DP, Shakunthala V, Spence DW, Brown GM, Pandi-Perumal SR. Understanding the role of sleep and its disturbances in Autism spectrum disorder. International Journal of Neuroscience. 2020;130(10):1033-46.
8. Rzepka-Migut B, Paprocka J. Efficacy and safety of melatonin treatment in children with Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder—a review of the literature. Brain sciences. 2020;10(4):219.
9. Mouridsen SE, Isager T, Rich B. Diseases of the gastrointestinal tract in individuals diagnosed as children with atypical autism: a Danish register study based on hospital diagnoses. Autism. 2013;17(1):55-63.
10. Kim JY, Choi MJ, Ha S, Hwang J, Koyanagi A, Dragioti E, et al. Association between autism spectrum disorder and inflammatory bowel disease: A systematic review and meta-analysis. Autism Research. 2022;15(2):340-52.
11. Leader G, Abberton C, Cunningham S, Gilmartin K, Grudzien M, Higgins E, et al. Gastrointestinal symptoms in autism spectrum disorder: a systematic review. Nutrients. 2022;14(7):1471.
12. Grimaldi R, Gibson GR, Vulevic J, Giallourou N, Castro-Mejía JL, Hansen LH, et al. A prebiotic intervention study in children with autism spectrum disorders (ASDs). Microbiome. 2018;6(1):1-13.

13. Herman A, Herman AP. Could Candida Overgrowth Be Involved in the Pathophysiology of Autism? Journal of Clinical Medicine. 2022;11(2):442.
14. Muskens JB, Velders FP, Staal WG. Medical comorbidities in children and adolescents with autism spectrum disorders and attention deficit hyperactivity disorders: a systematic review. European child & adolescent psychiatry. 2017;26(9):1093-103.
15. Chua RXY, Tay MJY, Ooi DSQ, Siah KTH, Tham EH, Shek LP-C, et al. Understanding the link between allergy and neurodevelopmental disorders: a current review of factors and mechanisms. Frontiers in neurology. 2021;11:603571.
16. Kaas TH, Vinding RK, Stokholm J, Bønnelykke K, Bisgaard H, Chawes BL. Association between childhood asthma and attention deficit hyperactivity or autism spectrum disorders: a systematic review with meta-analysis. Clinical & Experimental Allergy. 2021;51(2):228-52.
17. Jameson C, Boulton K, Silove N, Guastella A. Eczema and related atopic diseases are associated with increased symptom severity in children with autism spectrum disorder. Translational Psychiatry. 2022;12(1):415.
18. Wu S, Ding Y, Wu F, Li R, Xie G, Hou J, et al. Family history of autoimmune diseases is associated with an increased risk of autism in children: a systematic review and meta-analysis. Neuroscience & Biobehavioral Reviews. 2015;55:322-32.
19. Hoffmire CA, Magyar CI, Connolly HV, Fernandez ID, van Wijngaarden E. High prevalence of sleep disorders and associated comorbidities in a community sample of children with Down syndrome. Journal of Clinical Sleep Medicine. 2014;10(4):411-9.
20. Stores G, Stores R. Sleep disorders and their clinical significance in children with Down syndrome. Developmental Medicine & Child Neurology. 2013;55(2):126-30.
21. Capone GT, Chicoine B, Bulova P, Stephens M, Hart S, Crissman B, et al. Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. American Journal of Medical Genetics Part A. 2018;176(1):116-33.
22. Al-Issa SD, Al-Kahtani KF, Khader HJ, Al-Jurayyan RN, AM N. Thyroid dysfunction in patients with Down Syndrome: Beyond hypothyroidism. 2023.
23. Dimopoulos K, Constantine A, Clift P, Condliffe R, Moledina S, Jansen K, et al. Cardiovascular complications of Down syndrome: scoping review and expert consensus. Circulation. 2023;147(5):425-41.
24. Bush DS, Ivy DD. Pulmonary hypertension in the population with Down syndrome. Cardiology and Therapy. 2022:1-15.
25. De Lausnay M, Ides K, Wojciechowski M, Boudewyns A, Verhulst S, Van Hoorenbeeck K. Pulmonary complications in children with Down syndrome: A scoping review. Paediatric Respiratory Reviews. 2021;40:65-72.
26. Ram G, Chinen J. Infections and immunodeficiency in Down syndrome. Clinical & Experimental Immunology. 2011;164(1):9-16.
27. Delgado MR, Riela AR, Mills J, Pitt A, Browne R. Discontinuation of antiepileptic drug treatment after two seizure-free years in children with cerebral palsy. Pediatrics. 1996;97(2):192-7.
28. Trivić I, Hojsak I. Evaluation and treatment of malnutrition and associated gastrointestinal complications in children with cerebral palsy. Pediatric Gastroenterology, Hepatology & Nutrition. 2019;22(2):122-31.
29. Marpole R, Blackmore AM, Gibson N, Cooper MS, Langdon K, Wilson AC. Evaluation and management of respiratory illness in children with cerebral palsy. Frontiers in pediatrics. 2020;8:333.
30. Uwaezuoke SN, Aronu AE. Routine Screening and Treatment of Urinary Tract Infection May Be Justified in Children and Adolescents with Cerebral Palsy: A Systematic Review. Iranian Journal of Pediatrics. 2020;30(4).

Characteristics of sensory processing issues in children with developmental difficulties

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Most important messages:

- Sensory difficulties can manifest as hypersensitivity (excessive sensitivity/reaction) or hyposensitivity (insufficient sensitivity/reaction) to stimuli. Common senses affected include touch, sound, sight, taste and smell.
- Parents should notice which situations or environments cause their child to overreact or underreact.
- Parents can create safe sensory spaces (low lighting, a quiet corner or soft furniture) at home where their child can retreat when they are overwhelmed by stimuli.
- Consistent routines can provide a sense of security and predictability, reducing anxiety associated with sensory stimuli.
- New activities or changes in the routine should be introduced gradually, giving the child time to adapt.
- Adults should allow the child additional time to process information and respond.
- Professional therapists can provide sensory integration therapy and suggest tailored strategies to help a child cope with sensory difficulties.

Sensory processing relates to the way one detects, regulates, interprets, and responds to sensory stimuli. Sensory processing includes physiological and behavioral components: The physiological aspect of the process relates to structural changes or the functioning of the nervous system. The behavioral aspect relates to the individual's capacity to regulate reactions to stimuli adaptively to the environmental requirements. Typical sensory processing enables adaptive and organized reactions to environmental demands, while atypical patterns of sensory processing may negatively influence the functioning of the individual in everyday life. It is estimated that 15% of the typical population experiences different levels of atypical sensory processing patterns (1).

Dunn's 1997 model of sensory processing (according to Ben-Avi et al., 2012) comprises two axes of sensory processing: the neurological threshold of the individual (high or low) and his/her behavioral response. For each of the neurological thresholds, the behavioral response strategy can be:

- *active:* an active behavioral response is expressed by actions that aim to cope with the neurological threshold
- *passive:* a passive behavioral response is characterized by a lack of effort to reduce or increase the stimulation, even if the stimulus does not match the neurological threshold.

The interactions between the threshold and behavioral response form four manifestations:

1) sensation avoiding - which represents low neurological thresholds and an active response strategy
2) sensory seekers - high neurological thresholds and an active response strategy. These persons will try to meet their neurological threshold and actively seek high-intensity stimuli in order to actively increase the strength of the response.
3) sensory sensitivity - low neurological threshold and a passive behavioral response. These individuals will not act actively to stop or reduce the level of sensory threshold while experiencing discomfort.

4) low registration - passive response and high neurological threshold. These persons will respond to sensory stimuli either slowly or not at all.

The sensory processing patterns are likely to impact the individual's psychological functioning. Children's ability to regulate sensation - the process of noticing, organizing, and integrating information from the environment and their body and then processing and responding appropriately - greatly contributes to self-regulation (1).

Definition of Sensory Processing Disorder

Sensory Processing Disorder (SPD) is a condition affecting at least one in twenty children who experience sensations in taste, touch, sound, sight, smell, movement, and body awareness in a vastly different manner from how other children their age do. What may be typical activities for most children are a daily struggle that may result in social, emotional, or academic problems. A person with SPD finds it difficult to process and act upon information received through the senses, which creates challenges in performing countless everyday tasks (2).

Common symptoms for the different types of sensory difficulties in children

1. *Auditory difficulties*
   - The infant or child may not respond to sounds or may have delayed speech or language comprehension.
   - Poor listening skills
   - Needing extended time to process information
   - Have low academic performance
   - Have behavioral problems
   - Difficulty with reading, spelling and vocabulary (3).

2. *Visual difficulties*
   - Eyes that don't move together when following an object or a face
   - Crossed eyes, eyes that turn out or in, eyes that flutter from side to side or up and down, or eyes that do not seem to focus
   - Eyes that bulge, dance, or bounce in rapid rhythmic movements
   - Pupils that are unequal in size or that appear white instead of black
   - Repeated shutting or covering of one eye
   - An unusual degree of clumsiness, such as frequent bumping into things or knocking things over
   - Frequent squinting, blinking, eye-rubbing, or face crunching, especially when there's no bright light present
   - Sitting too close to the TV or holding toys and books too close to the face
   - Avoiding tasks and activities that require good vision (4).

3. *Tactile difficulties*
   - Avoidance of certain clothing or shoes, even though they seem to fit fine and are made out of fabrics that are usually comfortable
   - Avoidance of contact with other children

- Objecting to having their hair cut or combed, or having their teeth brushed
- Dislike of activities involving tactile materials (finger painting or playing with "squishy" art supplies such as modeling dough or clay)
- They appear to be "picky eaters" because certain food textures are hard to tolerate
- flinching or turning away when the wind blows against their face
- Aversion to being approached from behind. May rub skin or scratch area being touched (5).

4. *Olfactory difficulties*
   - Difficulties with eating
   - Fails to notice extreme odors or seeks out strong odors
   - Behaviors around people wearing perfume or aftershave
   - Difficulties in keeping up hygiene routines
   - Loss of appetite.

5. *Gustatory difficulties*
   - Refusal to eat certain food
   - PICA: Ingestion of non-edible substances
   - Holding food in mouth, not swallowing it
   - Licks or tries to eat things e.g., soil, grass, materials, metals.

6. *Vestibular and balance difficulties*
   - Dizziness and visual acuity problems, especially with head movements such as when turning to look at something
   - Imbalance
   - Difficulty navigating in the dark
   - Frequent falls
   - Motion sickness or sensitivity
   - Developmental and reflex delays, that are sometimes revealed by slower achievements of milestones such as riding a bicycle, swimming, and stairs climbing.
   - Abnormal movement patterns
   - Ear pressure (6).

7. *Proprioception difficulties*
   - Balance issues, such as having trouble standing on one foot or frequent falls while walking or sitting
   - Uncoordinated movement, such as not being able to walk in a straight line
   - Clumsiness, such as dropping or bumping into things
   - Poor postural control, such as slouching or having to place extra weight on a table for balance while sitting
   - Trouble recognizing their own strength, such as pressing on a pen too hard when writing or not being able to gauge the force needed to pick something up
   - Avoiding certain movements or activities, such as climbing stairs or walking on uneven surfaces, because of a fear of falling
   - Hypo sensitiveness to touch (7).

8. *Interoception difficulties*

- Difficulty with recognizing when hungry, full or thirsty
- Trouble with potty training, incontinence, or constipation
- Trouble identifying when sleepy
- Trouble identifying emotions in self/others
- Inability to recognize building signs of distress and independently using coping strategies during times of distress
- Difficulty reporting illness or symptoms such as headaches, nausea, fever, etc (8).

Sensory difficulties and autism

Sensory processing difficulties strongly correlate with levels of autistic traits in the general population, suggesting the potential contribution of sensory atypicality to social difficulties in Autism Spectrum Disorder (ASD). Moreover, recent findings from prospective studies support the idea that sensory difficulties might even precede difficulties in social functioning and that the two of them might be more closely related than considered initially. It was found that children at familial risk of developing ASD showed higher levels of sensory-seeking behaviors at 18 months and these were predictive of the later social difficulties measured by Autism Diagnosis Observation Schedule, 2nd edition (ADOS-2) at 36 months. Sensory issues might indeed be central to autistic symptomatology and even precede and predict the emergence of social difficulties and repetitive behaviors in the developmental cascade. The first signs of sensory aberrance can encompass lower sensorimotor abilities, enhanced visual search, and attention to detail. They appear before the emergence of evident behavioral signs of autism and predict future diagnosis. Both behavioral and neurophysiological findings suggest that children with ASD show difficulties in suppressing targets surrounding visually-attended area, which explains why enhanced visual search is often reported in this population (9).

Children with autism demonstrate a variety of challenging behaviors that may impact the family; however, sensory-related behaviors are one area in which parents frequently report seeking treatment. It is estimated that over 80 percent of individuals with autism demonstrate behaviors that may be related to poor sensory modulation, such as self-stimulation (excessive rocking or spinning), and the most common example reported by parents is that a child is playing with a car in a way that it is only speening the wheels. Furthermore, such children can have avoiding behaviors (such as placing hands over ears in response to typical levels of auditory input), sensory seeking (twirling, chewing, et cetera) and ‘tuning out’ behaviors (such as not responding to their name or other environmental cues) (10).

Sensory difficulties of children with autism inside the home

Children with autism love routines and greater challenges arise once a child has adopted a routine, which then changes unexpectedly. New, unplanned situations are unpredictable and, as such, bring new, unexpected sensory experiences.

Morning and bedtime routines were perceived to be challenging, partly because of the child’s sensory issues. Time constraints always pressure the family to leave on time for work and school. Meltdowns are mostly at this time due to the multitude of stimulations that take place during the morning routine, as well as the time demands that usually accompany these routines. Families often found mealtimes, specifically dinner, difficult because of the child’s sensory issues.

Children with sensory sensitivities often refuse to eat specific types of food due to sensitivity to food textures.

Sensory difficulties of children with autism outside the home

Outside the home, families describe experiencing difficulty taking family vacations and going to community events. Plane rides, sightseeing, long car rides, and crowds presented challenges. Children with autism had trouble managing the stimuli associated with traveling to and from a vacation destination.

Sensory difficulties of children with autism and impact on siblings

The sensory processing difficulties of the child with autism affect not only the child and the parents, but also the siblings. A child with autism often monopolizes the attention of one or both parents, forcing the siblings to receive less attention from their parents and be more independent in their activities. Caregivers often feel guilty when they are unable to spend as much time with their other children as they do with a child with autism.

Parents of children with autism are constantly vigilant about the environment to evaluate the sensory impact of it on their child with autism. Inside the home, there are fewer unexpected sensory stimuli and greater predictability, decreasing the hyper-vigilance that the parents experience. Parents can control the home environment, which relieves some of the focus needed on the child. Outside the home, caregivers feel that they need to be on guard to prevent problems in the community constantly. Parents constantly evaluate the environment to gauge their child's reaction (11).

Strategies developed to improve participation for families of children with sensory difficulties and autism

- Use visual supports for sensory input: Visual aids can be used to demonstrate different sensory input options and allow the child to choose which ones they prefer. For example, a visual chart with pictures of different textures or sensory activities can help the child communicate their preferences.
- Implement a sensory toolkit: Create a portable sensory toolkit that includes items and tools your child finds calming or stimulating. This could include fidget toys, noise-canceling headphones, stress balls, textured objects, or visual aids. The toolkit can be taken along to various environments to help manage sensory challenges.
- Offer deep pressure activities: Deep pressure can be calming for children with sensory difficulties. Activities such as deep hugs, using weighted blankets or vests, or engaging in compression activities (e.g., squeezing a stress ball) can provide the desired sensory input.
- Create a sensory-friendly bedtime routine: Establish a soothing bedtime routine that incorporates sensory-friendly elements. This can include dimming lights, playing soft music or white noise, using aromatherapy with calming scents, or incorporating calming sensory activities before bed, such as gentle massage or deep pressure exercises.
- Environmental adaptations: Make modifications to the child's environment to minimize sensory triggers. This could involve using noise-canceling headphones, providing a

designated quiet area, using curtains or blinds to control lighting, or reducing clutter and visual distractions.

- Planned exposure of the child to necessary sensory information: Work with an occupational therapist to first conduct a sensory integration assessment, based on which you will plan the child's exposure to the necessary sensory information. Such exposure consists of various activities and games that will provide the child with the specific information they need for better sensory integration. Address sleep issues.
- Practice self-care: Taking care of yourself as a parent is crucial. Managing the challenges of parenting a child with autism and sensory difficulties can be demanding. Make time for self-care activities that help you relax and recharge, such as exercise, hobbies, or seeking support from friends and family (12, 13).

What can parents do for sensory difficulties?

Children experiencing visual issues

1. Create a calm and controlled environment: Set up a quiet, well-lit space where your child can relax and engage in activities. Consider using a play tent or installing blackout curtains in their bedroom to control light levels and provide a soothing atmosphere.
2. Use sunglasses outdoors: Encourage your child to wear sunglasses on bright sunny days to protect their eyes from excessive sunlight and glare. This can help reduce discomfort and sensitivity to light.
3. Modify home lighting: Instead of using harsh strip lights, consider diffusing the lighting in your home. You can choose spotlights or use alternative lighting fixtures that provide a softer and more gentle illumination. This can help alleviate any discomfort caused by bright or flickering lights.
4. Choose clothing colors wisely: Avoid dressing your child in white and yellow tones, as these colors can be overly bright and cause visual strain. Dress your child in softer, muted tones that are easier on the eyes.
5. Use colored filters for reading: If your child struggles with reading, you can cover book pages with yellow film or use colored overlays. This can help reduce visual stress and improve their reading experience.

Children experiencing auditory issues

1. Gain your child's attention before speaking: Before communicating with your child, make sure they are focused on you. This can be done by making eye contact, using gentle touch, or calling their name. Ensuring their attention will help them better understand and respond to what you're saying.
2. Allow processing time: Children with visual issues may need extra time to process information. Reduce the amount of verbal communication and give your child sufficient time to process what they've heard before expecting a response. This can help them better understand and participate in conversations.
3. Use headphones in noisy places: To minimize the impact of loud sounds in noisy environments, provide your child with headphones. This can help reduce auditory overload and provide a more comfortable experience in crowded or loud settings.

4. Assess the environment for sound levels: Take note of the sound levels in your child's surroundings. Check for sources of excessive noise such as a loud television, blaring music, people talking loudly, hand dryers in public toilets, or barking dogs. Reducing exposure to high noise levels can help alleviate sensory discomfort.
5. Introduce new places gradually: When introducing your child to new places, start during quiet times and gradually increase the duration of their visits. This gradual exposure can help them acclimate to new environments and reduce sensory overwhelm.

Children experiencing tactile issues

1. Establish a special communication signal: Check with your child to find a non-verbal way to express love or reassurance. For example, a firm squeeze on the shoulder can serve as your unique way of saying "I love you" or providing comfort.
2. Give warning before touching: Sensory sensitivities can make unexpected touch uncomfortable for some children. To respect their boundaries, give them a verbal warning before initiating physical contact. This allows them to mentally prepare and reduces any potential discomfort.
3. Address sleep problems: If your child experiences sleep difficulties, consider making adjustments to their sleep environment. Adding a few more blankets can provide extra weight, which can provide deep pressure and a calming effect on their body. Also, adjusting the room temperature to be cooler may also promote better sleep.
4. Engage in "heavy work" activities: For children who are under-sensitive to touch, engaging in activities that involve "heavy work" can help with calming them. Encourage them to participate in tasks such as vacuuming, riding a bike, pushing a shopping trolley, carrying groceries, or climbing on playground equipment. These provide deep pressure and sensory input, promoting a sense of calm and regulation.
5. Choose comfortable clothing in various colors: Choosing the same comfortable outfit in different colors allows for both comfort and individual style. Consider buying the next size up to ensure a comfortable fit that accommodates their sensory needs.
6. Minimize irritation from clothing: Cut out labels from clothes to reduce discomfort caused by scratching or irritation. Additionally, turning socks inside out or purchasing "seamless socks" can help minimize irritation from labels and seams, providing a more comfortable wearing experience.

Children experiencing olfactory issues

1. Consider and control the environment: Pay attention to the sensory aspects of your child's environment. Consider factors such as lighting, noise levels, temperature, and overall sensory stimulation. Making adjustments to create a more soothing and comfortable environment can help reduce sensory overload and promote well-being.
2. Avoid strongly perfumed products: Strong fragrances can be overwhelming and trigger sensory discomfort for some children. Avoid using strongly perfumed personal care products, such as perfumes or lotions, as well as cleaning products with strong scents. Go for milder or fragrance-free alternatives to minimize sensory triggers.
3. Incorporate sensory sessions with preferred smells: Engage in sensory activities that involve preferred smells. This can include using scented playdough, essential oils, or

scented candles during sensory sessions. These activities can provide a calming and enjoyable sensory experience for your child.

4. Build tolerance to uncomfortable smells: If your child is sensitive to certain smells, gradually expose them to those smells in a controlled manner to help build tolerance. Start with low-intensity exposure and gradually increase their exposure over time. This can help desensitize their sensory response and reduce discomfort.

Children experiencing gustation or taste issues

1. Establish a consistent mealtime routine: Create a regular routine for meals and snacks to provide structure and predictability for your child. Minimize excessive snacking or "grazing" between meals to encourage a healthy appetite during designated mealtimes.
2. Use a divided plate: Utilize a plate with sections to separate different consistencies of food. This can help your child visually and tactilely distinguish between different food items and textures, making it easier for them to navigate their meal.
3. Implement a "sensory diet": Incorporate a daily routine of sensory experiences, including opportunities to play with food, which can help your child explore different textures, tastes, and smells in a controlled and supportive environment. Engaging their senses through play can gradually expand their comfort and familiarity with a variety of foods.
4. Gradual desensitization: Introduce new foods through a process of gradual desensitization. First, offer a very small amount of new food (e.g., 1/16 of a teaspoon) several times during the meal. This approach allows your child to gradually get used to the taste, texture, and sensory aspects of the food without overwhelming them. Over time, you can gradually increase the amount of food offered. What's important is to offer choices. New tastes and textures can always be available on the table, but it’s also important never to force the child to try them. When the child feels confident about a certain food, they will try it. Feeding is complex because it often involves the tactile system, and anything that the child is uncomfortable touching with their fingers, they won’t put in their mouth. That’s why it’s good to allow the child to touch the food with their fingers at first, even smear it around, without the expectation that they will eat what’s offered right away.

Children experiencing balance and vestibular issues

Hypersensitive strategies require predictable, slow and rhythmical movements. It is important to have the hypersensitive individuals initiate and be in charge of these activities whenever possible:

- gentle swinging
- rocking back and forth
- walking
- slow twirling.

Hyposensitive strategies require fast and unpredictable movements:

- bouncing (eyes are trained to re-focus with the head)
- jumping
- running
- hopscotch.

Children experiencing proprioception issues

1. Engage in floor exercises and equipment exercises: Encourage your child to participate in floor exercises such as squats and standing on one leg. These activities can help improve balance, coordination, and body awareness. Additionally, using equipment like a wobble board can further enhance their balance and stability.
2. Practice fine motor exercises: Engage your child in activities that promote fine motor skills, such as using small objects, manipulating buttons or zippers, or practicing handwriting or drawing. These exercises can help develop their dexterity and coordination.
3. Use weights for body orientation: Consider incorporating weighted objects or wearables to provide additional sensory input and improve body orientation. Weighted vests, blankets, or wrist/ankle weights can provide deep pressure and proprioceptive feedback, which can help promote a sense of grounding and body awareness.
4. Utilize visual supports for orientation: Provide visual supports to assist your child with orientation. This can include using visual cues or landmarks in their environment to help them navigate and orient themselves. For example, using pictures or signs to indicate different areas or creating a visual schedule to guide them through daily activities. For example, children with difficulties in the proprioceptive system have a poorer understanding of their own body, i.e., the boundaries of their body. These children often push against things, lean on furniture or walls, rest their elbows on tables, or frequently kick things, as these actions help them get feedback on where their body is in space.
5. Play catch or engage in continuous movement: Encourage your child to play catch or engage in activities that involve continuously moving a ball or object from one body part to another. This can help improve hand-eye coordination, tracking skills, and overall motor coordination.

Children experiencing kinesthetics issues

These strategies include activities that integrate many parts of the body and therefore help the systems mature.

1. Swinging: Engage in swinging activities, such as on a playground swing or a sensory swing. Swinging helps promote coordination, balance, and vestibular system development.
2. Wheelbarrow: Encourage your child to participate in wheelbarrow walking, where they walk on their hands while a partner supports their legs. This activity strengthens the upper body, core muscles, and improves coordination.
3. Rolling: Practice rolling movements, such as forward rolls or log rolls. Rolling activities help with body awareness, spatial orientation, and coordination.
4. Walking: Regular walking, especially on different surfaces or terrains, supports overall body strength, endurance, and balance.
5. Bike Riding: Riding a bike is an excellent activity for integrating multiple body parts. It enhances leg strength, coordination, and balance while also providing a cardiovascular workout.
6. Jump rope: Jumping rope improves coordination, timing, and cardiovascular fitness. It engages the whole body and strengthens leg muscles.

7. Crawling: Encourage crawling on hands and knees, which promotes cross-body coordination, upper-body strength, and motor planning.
8. Scooters: Riding scooters helps develop balance, coordination, and leg strength. It engages multiple muscle groups and supports overall motor skills.
9. Crab walking: Practice crab walking, where the child walks on their hands and feet with their belly facing upwards. This activity strengthens the upper body and core muscles.
10. Swimming: Swimming involves the whole body and is an excellent activity for overall muscle development, coordination, and cardiovascular fitness.
11. Obstacle courses: Set up obstacle courses that include a variety of movements such as crawling, jumping, climbing, balancing, and running. Obstacle courses provide opportunities to integrate different body parts and develop various skills.

Children experiencing interoception issues

1. Self-Awareness and Reflection: Encourage individuals to develop self-awareness by reflecting on their internal sensations regularly. This can involve checking in with themselves throughout the day, identifying and labeling their bodily cues, and understanding how those cues relate to their emotional and physical states.
2. External Cues and Reminders: Use external cues and reminders to prompt individuals to attend to their internal sensations. This can include setting alarms or reminders on the phone or using visual cues like sticky notes to remind them to eat, drink water, take breaks, or engage in self-care activities.
3. Daily Routine and Predictability: Establishing a consistent daily routine can help individuals anticipate and manage their internal sensations. Regular meal times, sleep schedules, and self-care activities can create a sense of predictability and help individuals meet their interoceptive needs.
4. Sensory Strategies: Engage in sensory strategies that can provide external input and support interoceptive awareness. Deep-pressure activities like weighted blankets, sensory fidgets, or tactile stimulation can help individuals connect with their bodies and regulate their internal sensations.
5. Mindfulness and Relaxation Techniques: Practice mindfulness and relaxation techniques to improve interoceptive awareness and manage associated stress or discomfort. Deep breathing exercises, meditation, progressive muscle relaxation, or guided imagery can help individuals tune into their bodily sensations and promote relaxation.
6. Communication and Support: Encourage individuals to communicate their interoceptive needs to trusted individuals in their lives. This can involve expressing their needs for breaks, meals, or emotional support. Having a supportive network can provide understanding and assistance in managing interoceptive challenges.

Art therapy and sensory difficulties

Art therapy can include art and pre-art activities that allow for therapeutic physical activity and sensory stimulation while also providing opportunities to explore nonverbally topics and concerns of personal significance. Through artwork, these broad areas of concern can be addressed simultaneously. The kinesthetic activities recommended by occupational therapy for the sensory child are consistent with those often used with children striving for psychological integration. Tactile experiences of art and pre-art activities with clay, or finger painting with tempera or acrylic paints, help dissociative children to integrate experience through the opportunity to "touch, create and form objects".

They stress the value of the fusion experiences inherent in working with clay or similar materials. Impulsive behaviors of children diagnosed with ADD or ADHD point to the need to facilitate relaxation and offer opportunities for centering. Smitheman-Brown and Church (according by Kearns Diane, 2004) found that offering art therapy group members a centering, mandala-based art activity at the beginning of group sessions facilitated focus and improved performance in the group session. As part of a comprehensive program of treatment, such strategies might help these students more readily attend to tasks and achieve their potential. For a young student whose is sensory challenges manifest as behavioral and attentional problems, offering a centering art activity as the initial experience of the school day may provide a similar effect. Henley, 1998 (according to Kearns Diane, 2004) describes a number of successful art therapy activities for children with ADHD. Henley cited Jackson's discovery that exciting guided imagery exercises, implemented as a drawing, attained the same kind of paradoxical effect seen with stimulant medication. Despite their stimulating content, such exercises helped impulsive children be calmer and more focused. It appears that projects that inspire excitement and novelty can enhance focus in children with ADHD. Although such novelty and excitement may be helpful in curbing the impulsivity of the child with ADHD, routine and regimen are also critical to the containment of impulsive behavior, particularly during the time between activities. In the educational setting, emphasis, even for the young student, is on product rather than process. Completion of classroom assignments can provide a great challenge to the child whose sensory difficulties manifest as attentional symptoms. Focusing an art therapy session on the experience of the art or pre-art activity could minimize the pressure to produce an end product comparable to those of same-age peers. This would allow the student to avoid feelings of being overwhelmed or intimidated and potentially experience positive behavioral effects as a result of the art activity (14).

Literature

1. Ben-Avi N, Almagor M, Engel-Yeger B. Sensory Processing Difficulties and Interpersonal Relationships in Adults: An Exploratory Study. Psychology 2012 [Internet]. [cited 2023 Jul 8];3(1):70–77. Available from: http://dx.doi.org/10.4236/psych.2012.31012
2. Miller L.J. Sensational Children: Hope and Help for Children with Sensory Processing Disorder. Penguin Publishing Group. 2014 May 6.
3. Yalçinkaya F, Keith R. Understanding auditory processing disorders. Turk J Pediatr. 2008 Mar-Apr;50(2):101-5. PMID: 18664071.
4. American Optometric Association. (n.d.). Preschool vision: 2 to 5 years of age. St. Louis, MO: Author. Online at: http://www.aoa.org/patients-and-public/good-vision-throughout-life/childrens-vision/preschool-vision-2-to-5-years-of-age?sso=y
5. Chu S. Tactile Defensiveness - Information for Parents and Professionals. Dyspraxia Foundation. 2013. Available from: https://dyspraxiafoundation.org.uk/wp-content/uploads/2013/10/Tactile_Defensiveness.pdf

6. Gaye W., Rine R.M. Pediatric Vestibular Disorders – Recognition, Evaluation and Treatment. Vestibular Disorders Association. Available from: https://vestibular.org/sites/default/files/page_files/Pediatric%20Vestibular%20Disorders_1.pdf
7. Kaviraja K. Proprioception Impairment and Treatment Approaches in Pediatrics. Intechopen. 2021 March 9. Available from: http://dx.doi.org/10.5772/intechopen.96382
8. Children and Family Health, Devon. Interoception Advice Sheet for Children with Sensory Difficulties. Available from: https://childrenandfamilyhealthdevon.nhs.uk/wp-content/uploads/2020/06/handout-sensory-differences-interoception-may-2020.docx
9. Kojovic N, Hadid L Ben, Franchini M, Schaer M. Sensory processing issues and their association with social difficulties in children with autism spectrum disorders. J Clin Med. 2019 Sep 20;8(10):1–16.
10. Schaaf RC, Toth-Cohen S, Johnson SL, Outten G, Benevides TW. The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. Autism. 2011 Mar 23;15(3):373–389.
11. Daly G, Jackson J, Lynch H. Family life and autistic children with sensory processing differences: A qualitative evidence synthesis of occupational participation. Front Psychol. 2022 Oct 20;13:940478. doi: 10.3389/fpsyg.2022.940478. PMID: 36389552; PMCID: PMC9651035.
12. National Autistic Society, Visual supports, Link: https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/visual-supports
13. Gerhardt, P, Cohen, M. (2014) Visual supports for people with autism: a guide for parents and professionals. Woodbine House
14. Kearns Diane. Art therapy with a child experiencing sensory integration difficulties Art Ther (Alex). 2004;21(2):95–101.

Pain and pain measurement in children with developmental disabilities

Prof. Livia Puljak, MD, PhD

Most important messages:

- Pain is always a subjective feeling and represents what a person says it is; there is no objective way of measuring or verifying someone's pain.
- Procedures from regular care that may not be perceived as painful (e.g., personal hygiene and physiotherapy procedures) may be painful in certain children with physical impairments.
- All care requiring physical contact can be painful, and particular attention should be paid to small children and children with high dependence on others.
- Many children with intellectual disabilities can self-assess their pain
- For children unable to express their pain on their own, it is important to observe the child's behavior and detect pain-related behaviors, such as crying, behavioral changes, and emotional changes.
- Pain interferes with sleep in children and young people with intellectual and developmental disabilities.

Definition of pain

As defined by the *International Association for the Study of Pain* (IASP), pain is an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage (17). Pain is always a subjective feeling and represents what a person says it is; there is no objective way of measuring or verifying someone's pain.

Frequency and risk factors for care-related pain in children with physical impairment

Children with developmental disabilities may have various physical impairments. These disturbances may be permanent or transient and may be due to various causes. A common factor among children with physical impairments is that they have significant limitations in activities and participation and have greater needs for care and rehabilitation. Children's daily lives are often organized around medical and other interventions coordinated by a multidisciplinary team (physicians, nurses, physiotherapists, occupational therapists, carers, etc.). Despite the professional and caring relationship of these experts, some procedures are described as painful in children with, for example, cerebral palsy. Personal care (washing, dressing, hygiene) and physiotherapy (stretching and starting) (18) may be painful in these children.

The study of pain in children with physical impairments has been carried out more frequently in recent years, but most studies have looked at long-term (chronic) pain or pain caused by physical therapy, while other types of pain have rarely been considered. For example, little is known about acute pain caused by treatments and interventions in care, including routine personal care carried out in rehabilitation centers. Furthermore, most of the studies were conducted in children with cerebral palsy, which is the most common cause of physical disability (18).

Painful experiences reduce quality of life, limit participation in social and educational activities, relate to behavioral problems and depression and have a negative impact on the wider family circle. The intensity and frequency of pain in cerebral palsy vary according to the age of the child (a higher frequency and intensity of pain has been reported in adolescents than in fewer children), gender (a higher frequency in girls than in boys), and the severity of motor damage (a higher frequency in severity than in lesser stages of disease). However, pain can also be very common in children with other types of physical disability requiring care and rehabilitation. The presence of motor and cognitive difficulties, limited communication skills, chronic pain and frequent care interventions expose such children to a high risk of pain caused by different care procedures (18).

A study in children with various physical impairments showed that 3.6% of interventions used during care could be painful and that personal care (oral care, transmission, bandaging) was most often painful. Children with neurological disorders have also been shown to be at the highest risk of pain caused by care. These results demonstrate the need to assess pain caused by all types of care and therapeutic actions involving direct physical contact with children with physical impairment (18).

The literature also described procedures to relieve pain in children with physical impairments as insufficient or inappropriate. Research shows that only 27% of procedures use procedures to prevent pain. This result is likely to underestimate the pain caused by various procedures (18). In summary, all care requiring physical contact can be painful, and particular attention should be paid to small children and children with a high level of dependence on others (18).

Measurement of pain in children with intellectual disabilities

Children with intellectual disabilities today survive in higher numbers and live longer. However, they may have more pain than children with typical development because of their long-term (chronic) physical problems, complex medical disorders, and more frequent injuries and medical procedures (19). A study on the daily pain profile of children with developmental disabilities showed that up to 35% of children with intellectual disabilities living in the community are in pain every week, and the average duration of their pain every week was 9 to 10 hours (20). There are tools to assess pain in children with intellectual disabilities, but they are not always used in practice. So, it is believed that this group of children suffers from pain that could be better controlled with our current knowledge. The key to encouraging better treatment is better judgment, which allows better detection and monitoring of pain and reduces the likelihood of neglect of pain (19).

Early research into the pain of people with intellectual disabilities is scarce. Earlier studies focused mainly on the description of individual cases, which often represented abnormal reactions to pain. Reynell conducted the first study in 1965 to examine the consistency of treatment of pain in children with cerebral palsy. He showed that these children experience pain under the same circumstances where most children are expected to experience pain, that their response to pain is visible, and that they do not differ due to the level of damage (21).

By 1995, a series of studies were published that focused on the development of pain assessment tools for children and/or adults with intellectual disabilities. These studies have shown that standardised tools can be used. Discussions with parents have shown that pain-related behavior may vary depending on the level of intellectual disabilities in children. Among patients with mild or moderate intellectual disabilities, 57% were able to provide information about pain in words. Furthermore, 45% of parents of children with severe intellectual disabilities stated that their child showed some combination of indirect behaviors when suffering pain. The most frequent signs of pain described were crying and behavioural changes or emotional changes (19).

Self-assessment of pain is often referred to as a gold standard of pain assessment. Since it plays a central role in the literature for others, and since healthcare professionals often prefer to use self-assessment as the first line of pain assessment, it is important to consider it as an opportunity to assess pain in people with intellectual disabilities (19).

Since the 1990s, much has been done to create pain assessment tools for children with intellectual disabilities. Such a tool is, for example, the face, leg, activity, cry and comfort ladder (Face, Legs, Activity, Cry and Consolability scale, FLACC scale) to evaluate pain in children from 2 months to 7 years of age or people unable to express their pain verbally. This assessment scale is used to observe the behaviour of a person. A scale called Child's Facial Coding System measures facial activity and assesses whether facial movements are expressions that could indicate pain. There are other scales, i.e. measuring tools for the assessment of pain in children with intellectual disabilities (19).

However, assessments of pain intensity, through self-assessment, and assessments of pain-related behaviour are only the beginning of the pain assessment when approaching a child. It is also necessary to look at other aspects of the child's behavior. For example, self-injury can be a sign that pain is present, and it can also help to locate pain. Changes in functioning may also indicate the presence of pain. For example, studies showed that children showed significantly more abilities in days when they felt no pain than in days when they had pain, and pain affected all areas of functioning, including their communication, daily life, social and motor skills (19).

New research suggests that children with intellectual disabilities use different coping strategies when they have pain, with different results. Thus, an assessment of how a child deals with pain can help guide the child to use his or her most effective strategy or to try new strategies if those he or she has previously used have not helped him or her. While there are some indications that children with intellectual disabilities can describe how to deal with pain when it does not hurt them, the description of a parent can be the most valid way to understand a child's strategies and skills to deal with pain. As our knowledge of pain assessment increases in children with intellectual disabilities, it is important that we include in the pain therapy of those children all available scientific evidence-based procedures. The particular vulnerability of this group calls for particular attention to be paid to the assessment of their pain in order to better alleviate their pain (19).

Pain interferes with sleep in children and young people with intellectual and developmental disabilities

Long-term pain (chronic pain) and sleep problems are common for children with intellectual and developmental disabilities. The examination of parents and carers of children with intellectual disabilities showed that children suffering from pain had much more sleep problems and more night awakening. In particular, parasomnia [sleepwalking, night terrors, nightmares, talking in the sleep (sometimes vulgar words) and aggressive movements during sleep, night cramps in the legs] and breathing disorders during sleep were common. The pattern of sleep problems varied depending on whether the child was taking painkillers. Children with pain also had significantly shorter typical sleep periods. The presence of sleep problems did not differ depending on the functional level or whether children were taking sleeping remedies. However, parents of children taking sleeping remedies noted that both sleep resistance and sleep duration were more problematic for them. These data show that pain disturbs sleep in children with intellectual disabilities even when treated with medicines (pharmacological treatment). The results of the study suggest that pain should be considered during the evaluation and treatment of sleep problems in children with intellectual disabilities (22).

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Literature

1. IASP Announces Revised Definition of Pain. International Association for the Study of Pain. Link: https://www.iasp-pain.org/publications/iasp-news/iasp-announces-revised-definition-of-pain/.
2. Dubois A, Hall C, Courtois-Communier E, Brasseur A, Cacioppo M, Brochard S. Incidence and risk factors for care-related pain in children with physical disabilities. Eur J Phys Rehabil Med. 2023;59(3):414-24.
3. Breau LM, Burkitt C. Assessing pain in children with intellectual disabilities. Pain Res Manag. 2009;14(2):116-20.
4. Breau LM, Camfield CS, McGrath PJ, Finley GA. The incidence of pain in children with severe cognitive impairments. Arch Pediatr Adolesc Med. 2003;157(12):1219-26.
5. Reynell JK. Post-operative disturbances observed in children with cerebral palsy. Dev Med Child Neurol. 1965;7(4):360-76.
6. Breau LM, Camfield CS. Pain disrupts sleep in children and youth with intellectual and developmental disabilities. Res Dev Disabil. 2011;32(6):2829-40.

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Treatment of pain in children with developmental disabilities

Prof. Marta Čivljak, MD, PhD, psychiatrist

Most important messages:

- Pain in children with developmental disabilities is more often unrecognised or inappropriately treated due to difficulties in verbal and non-verbal communication.
- The first step in managing pain is assessing pain.
- The difficulty in distinguishing pain from other symptoms can be overcome by observing pain-related behaviour and using a pain assessment tool.
- People with developmental disabilities and their parents or carers should be involved in the pain assessment and treatment plan.
- Persons with developmental disabilities should be offered the same standard of care as all others.
- Multiple (multimodal) approaches including treatment with medicines (pharmacotherapy) and methods for treatment of non-medicated pain, are most useful in treating pain.
- The use of medicines requires adherence to the principles for the treatment of pain in children and an individual approach, as people with developmental disabilities tend to develop adverse effects (side effects) on medicines.
- Particular care should be taken to break down the medicine in the body used in people with developmental disabilities due to interactions with other medicines they are taking, but also due to other problems.
- It is desirable to encourage the use of pain treatment methods without medicines that raise the pain threshold, increase pain tolerance and change the way and thus the quality of life.
- There is limited evidence of effective practices to treat the pain of people with developmental disabilities and there is no clinical guidance on the safe and effective treatment of these people.

Pain and injuries in early life, if inadequately treated, can lead to long-term adverse effects (1). When assessing pain in paediatrics, it is important to look at physiological, behavioural, psychological and developmental factors. Therefore, a holistic approach including:

- consideration of the child's age and level of development,
- considering how a child communicates and reacts with his environment,
- consideration of any specific circumstances (such as diagnosis, disease stage, terminal illness)
- assessment of family/caregiver dynamics (2).

Pain is a subjective feeling and there is no objective way to assess one's pain. Many children with developmental disabilities experience more pain than their peers who do not have developmental disabilities because they are more likely to experience injury (3). Furthermore, children with developmental disabilities also have other health problems (comorbidities) which make them more likely to undergo different diagnostic procedures which are often painful in themselves (4).

It is useful in such situations to create visual representations of specific procedures (e.g., blood drawing, blood pressure measurement, spirometry, etc.) so that the child, especially one who communicates using the Picture Exchange Communication System (PECS) or another visual medium, can have an idea of what to expect. When something is predictable, it is easier to handle.

The pain experience is a negative experience for all children, and the presence of pain in children with developmental disabilities greatly affects their ability to function adaptively. Proper assessment and treatment of pain are key to achieving good quality of life related to child health and are the basis for the best day-to-day and long-term functioning of children (1, 2).

Assessment of pain and treatment of pain in young children, especially in children with developmental disabilities, is often a major challenge due to existing barriers in verbal and non-verbal communication (5). Despite many challenges, more research is needed in this area to develop specific guidelines and protocols for the assessment and treatment of pain among these people (6).

As pain is a subjective experience, it can be expressed in atypical or unknown ways in persons with significant cognitive and communication difficulties (5). The International Association for the Study of Pain points out that "*inability to communicate verbally does not negate the possibility that an individual experiences pain and needs appropriate pain management*." However, in practice, pain generally remains unrecognised and undertreated in people with developmental disabilities (7-9). Therefore, an assessment of pain is a necessary prerequisite for proper treatment.

Assessment of pain

The aim of the pain assessment is to recognise the presence of pain and monitor response to pain therapy administered.

The initial assessment of the child's pain shall include a conversation with the child and the parent/guardian adapted to the patient's age and clinical context. Self-reporting or self-assessment of pain is considered a gold standard for the assessment of pain, which is why the patient should self-pronounce the existence and intensity of pain whenever possible (10). However, more evidence is needed to make self-reporting/self-assessment of pain the recommended first step in accessing children to assess pain, even in the case of children with only mild intellectual disabilities (11).

What if a person cannot say for himself that he is suffering pain or cannot describe it? Then how do we evaluate their pain?

Answer: We look at pain-related behaviours. This is considered a valid approach in the assessment of pain in those who cannot report it themselves (7).

Therefore, it is important to observe and recognise such behaviours as these patients may have atypical painful facial expressions or changes in activity that often do not differ from other symptoms or signs. For example, specific behaviours can include a smile or laughter in a child with pain, stiffness or incompatibility, the appearance of a "freezing phenomenon" described as a sudden interruption of the patient's facial activity and movement, etc. (2). In addition, children with autistic spectrum disorders may recover more slowly from harmful stimuli than other paediatric patients, while people with down syndrome usually show delayed expression of pain and also have difficulty accurately describing where symptoms are felt (2).

Specific pain-related behaviours were investigated in studies conducted on children following surgical procedures or in studies conducted on parents/caregivers aimed at examining their perception of pain in their children (11). Table 1 describes certain behaviours associated with pain.

Table 1: pain-related behaviours; from Valkenburg and associates (11)

Category	Examples
Vocalization	She cries, she whines, she groans, she breathes, she breathes abruptly
Facial expression	Because of his face, he frowns, he has a swollen forehead, squints, wide-eyed eyes, squeezes his teeth, gnashes his teeth, has a disturbed look
Comfort	It is not possible to comfort a child and make him feel comfortable
Interaction	Withdrawn, seek comfort
Sleeping	A disturbed sleep, either he's sleeping too much or he's not sleeping.
Movement	It has increased movements of arms and legs, restless and swirling, easily twitching, retracting to the touch, twisting or turning
Tonus	He's got stiff limbs, he's squeezing his fists, he's twisting his back, he's resisting the movement.
Physiological changes	Increased heart rate (tachycardia), sweating, shivering, discolouration, paleness, breath retention, tears
Atypical features	Blunt face, laughter, breath retention, self-injury

In addition to observation, existing tools for the detection and assessment of pain in people with cognitive impairment should be used during the pain assessment (7, 8). Such tools can help healthcare workers and parents identify the child's specific pain-related behaviour. The use of existing tools provides useful information, but these tools also have limitations (7). So far, none of the existing tools can be specifically singled out or recommended as better or more effective than others (7). Some of these tools are described in detail in the previous chapter.

Multimodal approach in pain management

Pain is most often due to the effects of several factors, making multiple (multimodal) approaches including pharmacotherapy (treatment with medicinal products) and non-pharmacological methods of pain treatment (non-medicinal techniques) the most useful in treating pain (8). Parents and caregivers should be adequately trained to recognise and assess pain, but also actively involved in the treatment programme (8).

Treatment of pain with medicines

When treating pain, a clear treatment plan should be documented- All persons involved in patient care should be informed about that treatment plan. Treatment of pain with medicines in people with developmental disabilities depends on the symptoms present, but is based on the same principles as those applied to people without these disabilities (8).

The World Health Organization (WHO) has not issued specific guidelines for the treatment of pain in children with developmental disabilities, but sets out certain principles in its guidelines for the treatment of pain for each child:

- the analgesic or painkiller must be of adequate strength and duration of action,

- the analgesic should be administered the right way (oral, intravenous, suppository — rectal, subcutaneous, intramuscular),
- analgesic should be administered at the right intervals
- the analgesic should be administered at the right individual dose, based on the age and weight of the child (12).

Also, according to the WHO principles, the treatment of pain in children should be guided by a “two-stage approach”. This two-step approach involves selecting a category of analgesics depending on the severity of the pain the child is suffering. If the child is judged to be in mild pain, we consider paracetamol and ibuprofen as a first-choice analgesic. If, however, the child is judged to be in moderate to severe pain, opioid administration should be considered. Morphine is the first medicine chosen in the second step, although other potent opioids should be considered and used as an alternative in case of an adverse reaction to morphine (12).

The correct timing of administration means administration at intervals sufficient to achieve effective analgesic concentration and not administration as needed. Therefore, the analgesic is administered at the recommended intervals (12).

The route of administration should be individualised and the simplest, most effective and painless route of administration should be chosen. The medicine should be administered by mouth as tablets, drops or syrups whenever possible as this route is the simplest and least painful. If oral administration is not possible, the next best option is to administer the medicine to a vein (intravenously). Sometimes it is necessary to adjust the dose of the medicine as strictly as possible if it is given into a vein. Rectal route of administration (use of suppositories) is acceptable in smaller children and is very uncomfortable in the elderly. Administration of the medicine under the skin and into the muscle (subcutaneous and intramuscular routes) is painful and should be avoided unless they are the only possible route of administration (12).

The existence of long-term (chronic) pain or the performance of certain diagnostic procedures and surgical procedures requires the administration of painkillers (analgesia). There are a number of studies showing that children with intellectual disabilities receive lower doses of analgesia during surgery and are less monitored in terms of post-operative pain assessment (8). The authors describe how paediatric anaesthesiologists are concerned about analgesia during surgery because they consider children with intellectual disabilities to be more sensitive to the depressive effect of opioids on the central nervous system and respiration (11). On the other hand, a study conducted in the Netherlands showed that anaesthesiologists have different approaches in caring for children with intellectual disabilities and that most think that children with intellectual disabilities are not more sensitive to pain or require more analgesia (13).

In the medical literature we also find data that people with developmental disabilities are at higher risk of developing adverse effects (side effects) associated with medicinal products. This is mainly attributed to immature Regulation of autonomic reactions, low nutritional status, impaired renal and hepatic function and concomitant use of multiple medicinal products that may increase the risk of drug-induced adverse reactions. In addition, some types of disability are associated with anatomical and physiological changes, such as scoliosis and other musculoskeletal deformities. These changes can significantly contribute to difficulty breathing (hypoventilation) and airway obstruction (obstruction) (8).

Therefore, when medicines are used in people with developmental disabilities, their particular characteristics should be considered. Variations in drug degradation in patients with

metabolic disorders and syndromes that may consequently have interactions (interaction) with other medicinal products and different drug metabolism and excretion (7) should be considered.
In conclusion, despite previous studies, evidence of effective pain treatment practices in people with developmental disabilities is limited and there is no clinical guidance on safe and effective different treatments for patients in this population.

Treatment of pain without medicines

Non-pharmacological methods (without medicines) for pain treatment may be used alone or in combination with medicines and include socio-cultural, physical, behavioural and cognitive methods (8). The aim of these methods is to increase the level of endorphins in the body that some call our own endogenous morphine. Endorphins are natural chemical compounds that our body produces under certain circumstances, which are in the opioid neuropeptide class because they resemble opiates as they relieve pain, lower temperature and lift mood (9).

Social interventions

Social interventions include changing or changing the environment, availability of well-known caregivers, distraction (distraction), humour, leisure activities, etc. Such techniques enable the promotion of comfort and relaxation and the engagement of persons with intellectual disabilities themselves. Changing the environment is one of the techniques that can consequently lead to pain reduction, but the availability of well-known caregivers is also important because lack of continuity and change could cause anxiety and concern, and thus even more intense pain. Distraction or discouragement works by distracting attention from pain and by listening to music, watching television, or reading a book. The use of oil or aromatherapy has also been shown to help relieve pain by stimulating relaxation (8, 9).

Spiritual intervention

Spirituality and spiritual care allow persons with intellectual disabilities to express themselves through a medium that provides pleasure, comfort, peace and tranquillity. Music, art, dance, humour, religious practices, and prayer can be used to solve spiritual needs and spiritual dimensions of pain (8, 9).

Psychological interventions

Emotions and thoughts can greatly influence the transmission of pain signals. Psychological ways of alleviating pain are aimed at increasing self-control, behavioural change and cognitive changes, not directly eliminating pain. Therefore, psychological interventions are recommended to increase pain control and reduce stress levels, and may also be useful for reducing pain in people with intellectual disabilities. These interventions include massage, distraction of attention, work, music, leisure activities, biofeedback therapy, breathing exercises, progressive muscle relaxation, visualisation, guided images and relaxation, and cognitive behavioural therapy (8, 9).

Cognitive behavioural therapy is often used to treat long-term (chronic) pain, as there is increasing evidence that belief in pain and pain-related fear actually more incapacitate a person than the pain itself. A person who believes that "his/her pain will not harm him" will experience fewer negative experiences than one who believes that "his/her pain will drive him crazy." The most frequently described cognitive techniques in the literature were psychoeducation and interventions directed directly at thoughts and beliefs. Most of the research that examines these techniques is about positive outcomes. However, more research is needed in this area (8.9).

Physical therapy

The main goal of physical therapy is to reduce pain and possibly make it easier for people with developmental disabilities to cope with pain. Physical therapy may include muscle strengthening, body training (postural training), seating training, splints, exercises and various rehabilitation programmes (8, 9).

Use of simple tools such as ice or heat application, hot tub, massage, acupuncture, vibration, transcutaneous electrical nerve stimulation (TENS) and regulation of environmental factors (lighting and ventilation) can be useful for pain relief (8, 9).

Warmth reduces pain by vasodilatation (widening of blood vessels). Similarly, cold treatment increases the pain threshold and reduces its intensity, swelling, and inflammation. Placing in a certain position can be important in the treatment of pain (e.g. gastroesophageal reflux, certain physical defects, etc.) and as well as moving can prevent pain from occurring or reduce intensity, increase blood flow and prevent muscle contractions and cramps. TENS works by sending a lot of painless messages to the same place in the spinal cord where the pain message is received, thereby reducing the possibility of sending messages about the pain that is received and processed in the brain, as the amount of information that nerve pathways can process is limited at the same time (8, 9).

Massage is thought to be effective for relaxation, but scientific evidence for its efficacy as a support therapy in clinical practice is extremely limited (8, 9).

Literature

1. Siden H, Oberlander TF. Pain Management for Children with a Developmental Disability in a Primary Care Setting. In: Walco, G.A., Goldschneider, K.R., Berde, C.B. (eds) Pain in Children. Humana Press. https://doi.org/10.1007/978-1-59745-476-6_4. 2008.
2. Webb TL, Sanders JE. Pediatric Pain. In: Pain Management Guide. https://www.emra.org/books/pain-management/pediatric-pain.
3. Sinclair SA, Xiang H. Injuries among US children with different types of disabilities. Am J Public Health. 2008;98(8):1510-6.
4. van Schrojenstein Lantman-de Valk HM, Walsh PN. Managing health problems in people with intellectual disabilities. BMJ. 2008;337:a2507.
5. International Association for the Study of Pain (IASP). Pain in Individuals with an Intellectual Disability: Scope of the Problem and Assessment Challenges. 2021. Link: https://www.iasp-pain.org/resources/fact-sheets/pain-in-individuals-with-an-intellectual-disability-scope-of-the-problem-and-assessment-challenges/.
6. Lotan M, Icht M. Diagnosing Pain in Individuals with Intellectual and Developmental Disabilities: Current State and Novel Technological Solutions. Diagnostics (Basel). 2023;13(3).
7. Hauer J, Houtrow AJ, Section On H, Palliative Medicine COCWD. Pain Assessment and Treatment in Children With Significant Impairment of the Central Nervous System. Pediatrics. 2017;139(6).
8. El-Tallawy SN, Ahmed RS, Nagiub MS. Pain Management in the Most Vulnerable Intellectual Disability: A Review. Pain Ther. 2023;12(4):939-61.
9. Doody O, Bailey ME. Interventions in pain management for persons with an intellectual disability. J Intellect Disabil. 2019;23(1):132-44.
10. Birnie KA, Hundert AS, Lalloo C, Nguyen C, Stinson JN. Recommendations for selection of self-report pain intensity measures in children and adolescents: a systematic review and quality assessment of measurement properties. Pain. 2019;160(1):5-18.
11. Valkenburg AJ, van Dijk M, de Klein A, van den Anker JN, Tibboel D. Pain management in intellectually disabled children: Assessment, treatment, and translational research. Dev Disabil Res Rev. 2010;16(3):248-57.

12. World Health Organization. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020. Available at: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020.
13. Valkenburg AJ, van der Kreeft SM, de Leeuw TG, Stolker RJ, Tibboel D, van Dijk M. Pain management in intellectually disabled children: a survey of perceptions and current practices among Dutch anesthesiologists. Paediatr Anaesth. 2012;22(7):682-9.

Management of challenging behaviors

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Most important messages:
- Adults should recognize situations or environments that encourage challenging behavior in children. Most often, these are patterns in a certain time, place or during certain activities.
- Behavior often has a purpose, such as seeking attention, avoiding tasks, or expressing frustration. Understanding the function can help address basic needs.
- Parents should establish constant daily routines in order to provide the child with predictability and security. Using visual schedules can help a child understand what to expect.
- Desirable behavior is reinforced with praise, rewards or other positive things.
- Parents should validate their child's feelings and experiences, let the child know that it is okay to feel upset and that they are there to help the child.
- Adults should react to challenging behavior calmly and consistently, avoiding to react with anger or frustration.
- Children should learn to use techniques such as deep breathing, counting or a quiet period to help them calm down in moments of heightened emotion.
- The school and parents should cooperate and advocate together for positive support for behavior in the classroom.

Definition of challenging behaviors

Just like us, children behave differently at different times. Feeling upset, sad, cross, frustrated, and many other emotions are normal and healthy parts of their life. Many children go through phases of testing boundaries, and they are likely to behave in ways that are harder to manage when they are tired, ill or stressed. It is usual for younger children to have tantrums sometimes, while older children may sometimes shout, storm out or lash out (1).

Challenging behavior is defined by Emerson, 2001 (according to Leader & Mannion, 2016) as "culturally abnormal behavior(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit or delay access to and frequent use of ordinary community facilities" (2).

Causes of challenging behavior

The way your child behaves is a communication about how they're feeling. Younger children rely heavily on communicating through their behavior because their language skills, as well as their understanding of themselves and the world around them, are still developing. When your child is acting out, it can be useful to think about the image of an iceberg. We only see the tip of an iceberg because the majority of the ice is floating underwater. Similarly, when your child behaves in certain ways, there will be a range of emotions under the surface that you can't see - and your child is unlikely to be aware of these or able to talk about them without help.

Underneath their challenging behavior, a child may be feeling:

- angry	- invisible	- anxious
- jealous	- guilty	- insecure
- bored	- ashamed	- sad
- overwhelmed	- unloved	- frustrated
- ignored	- worried	- uncertain

Experiences your child might be going through that can trigger some of these hidden feelings and lead to challenging behavior include:

• changes like moving into a new class, moving to secondary school or having a new adult or sibling in their life
• changes within the family, such as parents separating or a family member becoming ill
• changes in routine, or a lack of consistent routine
• not having clear and consistent boundaries, rules and limits
• being bullied, either inside the home, at school, online or elsewhere
• difficulties in relationships, including with friends, siblings and one or both parents
• comparing themselves to siblings, peers or others
• finding it difficult to communicate and express themselves
• copying behaviors learned from others
• getting stuck in cycles of behavior they cannot break on their own
• being expected to do tasks that are beyond their age and development
• not having basic needs met – such as feeling safe and loved, attention from and quality time with parents or carers, and having fun and playing
• experiencing or witnessing abuse such as domestic violence (3).

Impacts of challenging behaviors

Seriously challenging behaviors may significantly impair the health and/or quality of life of the person themselves, those who care for them and those who live or work with them. Self-injurious behaviors can result in damage to the person's health through secondary infections, malformation of the sites of repeated injury through the development of calcified hematomas, loss of sight or hearing, additional neurological impairments and even death. Similarly, serious aggression may result in significant injury to others as well as to the person themselves as a result of the defensive or restraining action of others.

However, the consequences of challenging behaviors go far beyond their immediate physical impact. Indeed, the combined responses of the public, carers, care staff and service agencies to people who show challenging behaviors may prove significantly more detrimental to their quality of life than the immediate physical consequences of the challenging behaviors themselves. These social responses may include the following:

- *abuse* - it is, perhaps, not surprising that the difficulties involved in caring for people with challenging behaviors and, in particular, the management of episodes of challenging behavior, may, at times, lead to inappropriate reactions from carers and care staff. Some of these reactions include physical abuse. When caring for individuals with challenging behaviors, it is essential for caregivers and care staff to receive proper training and support to handle such situations effectively and responsibly. The goal should always be to provide a safe and nurturing environment for the individuals in their care. In conclusion, the management of challenging behaviors requires a compassionate and patient approach, with a focus on prevention, proper training, and a supportive work environment. By valuing and respecting the dignity of the individuals in their care, caregivers and care staff can provide the best possible support and avoid inappropriate reactions, including physical abuse.
- *social exclusion, deprivation and systematic neglect* - challenging behaviors are a major cause of stress experienced by parents and have been associated, among other

factors, with families' decisions to seek an out-of-home residential placement for their son or daughter. Children and adults with challenging behaviors are significantly more likely to be excluded from community-based services and to be admitted, re-admitted to or retained in more remote and more institutional settings. Once admitted to institutional care they commonly spend much of their time in materially deprived surroundings, disengaged from their world and avoided by staff. Within community-based settings, challenging behaviors may serve to limit the development of social relationships, reduce opportunities to participate in community-based activities and employment, and prevent access to health and social services. Finally, people who show challenging behaviors are unlikely to receive effective support for their challenging behaviors (3).

Autism spectrum disorder and challenging behaviors

One of the most common co-occurring problems with autism spectrum disorder (ASD) is challenging behaviors.

In one study focusing on the relationship between challenging behavior and the severity of symptoms of ASD it was found that 94.3% of the total sample group of 176 children aged between 2 and 17 years exhibited some form of challenging behavior. Matson et al. (2008) reported that 63% exhibited an externalizing form of challenging behavior, and 83% exhibited an internalizing challenging behavior. The three most commonly observed behaviors in those children were: repeated and unusual vocalizations (60.2%); repeated, and unusual body movements (54%); and aggression towards others (50%). Further analysis of a possible relationship between the severity of ASD and the severity of challenging behaviors indicated that stereotypic or repetitive behaviors, self-injurious behavior, and aggressive or destructive behavior were more likely to be displayed by an individual with a more severe form of ASD. Most importantly, deficits in social interaction were found to significantly predicthallenging behavior (4).

Children with ASD have problems in three main areas of their development:

- social interaction and understanding
- all aspects of communication-verbal and non-verbal
- flexibility of thinking and behavior, including problems with imagination.

These particular difficulties increase their vulnerability to developing behavior that presents a significant challenge to carers and teachers.

Difficulties in social interaction - relating to others

For many years, the classic and the most common image of autism was of a child who showed no interest in (or actually avoided) contact and interaction with others. As understanding of autism has increased, a broader and more varied picture of social difficulties has been recognized. Some children do seem to be indifferent to other people, may seem to 'live in a world of their own' and may be distressed by efforts to interact with them. Another group of children appears to make no active effort to initiate interaction, but they may respond if others take the initiative. The third group of children, which appear to be active, represents children who may be very interested in social contact with others but who tend to break the 'unwritten rules' for how to go about this. They may talk at others rather than with them, can appear rather intrusive and may be inappropriately familiar or too formal and rather stilted.

These different difficulties can create all kinds of problems. Table 1 shows different types of problems such difficulties can cause. It is relatively easy to imagine how these behaviors could be seen as challenging in themselves or else how they could easily create a situation where challenging behavior is the result (5).

Table 1. Difficulties in social interaction - relating to others in children with autism

An underlying difficulty in …	Creates a problem with…
Enjoying contact with people	• being frightened or stressed by contact with other people • reducing the motivation to communicate • restricting opportunities to learn form, and about, other people • not being bothered about pleasing other people
Understanding other people’s feelings	• causing offence without being aware • forming and keeping friendships or other close relationships • knowing how to react to other people’s feelings • appearing egocentric or insensitive
Understanding other people’s reactions	• making sense of unspoken messages about how to behave in certain situations • understanding other people’s intentions • being able to get the message behind people’s words
Making sense of the rules in social situations	• knowing how and when to join in • appearing too familiar or pushy • coming over as to formal or standoffish • going too far without realizing

Difficulties in communication

All children with autism have some degree of difficulty in understanding the communication of others. Quite a large minority of children may never develop speech or get past the stage of echoing words and phrases that they have heard others using. Even when speech and language seem to develop along typical lines a youngster is likely to have subtle but significant difficulties in using language in social situations and for social purposes. The communication problems experienced by children with autism contribute directly to many of the challenging behaviors they can present. In Table 2, some of the underlying difficulties in communication and the problems those can create for the child are presented (5).

Table 2. Difficulties in communication in children with autism

An underlying difficulty in …	Creates a problem with …
Expressing needs	• Letting someone know what he wants • asking for help • explaining that he is worried or in pain • explaining that he does not understand
Using language in social situations	• letting people know that he has got something to tell them • keeping a conversation going • making sure that the other person gets a turn in the conversation
Understanding other people's language and communication	• understanding what other people want him to do • making sense of why they want him to do those things • interpreting what others are saying with their bodies, faces and tone of voice
Taking thing literally	• how to tell if someone really means what they are saying or if it is just a turn of phrase • how to avoid looking silly

Difficulties in flexibility of thinking and behavior

Children who are very young or at a relatively early developmental level may become hooked on very specific physical sensations. They may be fascinated by looking at things from a particular angle or watching things that spin. Lights may fascinate them or they may be tuned in to other senses - particular textures, smells or sounds holding their attention. Sometimes a child creates the sensations by their own repetitive movements, such as spinning, flapping or tapping. The patterns of play that emerge at a later stage may be quite restricted. A child may only focus on one very specific feature of a toy or concentrate on making collections or arrangements of objects. If imaginative play does develop, this may be quite repetitive or inflexible - repeatedly acting out scenes from the same video or insisting that a game be always played in exactly the same way, for example. In older and more able children, these difficulties may take the form of intense interests or obsessions. Sometimes the focus of interest may seem rather peculiar - such as street lights, circuit diagrams or vacuum cleaners. Alternatively, it may be the strength of the fascination, and its domination of the child's life, that is unusual.

Difficulties in flexibility are also apparent from the routines, rituals and resistance to change that are frequently a feature of autism. These have been very neatly summed up as a 'need for sameness'. Children may create rituals and routines for themselves - insisting that things are arranged, done or even said in a certain way. It is also common for them to latch on to the way things have been done (by a parent or teacher) and then insist that this is the way they should always be done in the future. Always wanting to go on the same route, to the same shops is an example that will be familiar to many parents, and resistance to unfamiliar foods is especially common.

Difficulties in flexibility are very closely linked to challenging behavior. The repetitive behaviors, rituals and restricted interests may be challenging in themselves. Also, problems can arise when the environment (and the people who are such a vital part of that environment) is unable to accommodate the youngster's 'need for sameness'. Therefore, it is important to expose children to changing routines. The following table illustrates some of these difficulties (5).

Table 3. Difficulties in flexibility of thinking and behavior

An underlying difficulty in …	Creates a problem with …
Needing „sameness"and routine	• dealing with unexpected and unavoidable changes to routines • making transitions from one activity to another • handling any sort of uncertainty about what is happening next or what will happen in the future • dealing with anxiety if the need for sameness cannot be met
Having repetitive patterns of play, rituals and obsessions	• restricting opportunities for developing and learning other, more productive or appropriate skills • isolating your child from interaction with other people • including into, and restricting the lives of other people in your child's environment
Imagination	• anticipating what might be going to happen in the future • predicting the consequences of actions • recognizing danger

Common challenging behaviors in children with autism

- *Disruption* - occurs when an individual exhibits inappropriate behavior that interferes with the function and flow of his surroundings. Examples include banging, kicking or throwing objects, knocking things over, tearing things, yelling, crying, or swearing.
- *Elopement* - refers to running away and not returning to the place where a person started. In autism, elopement is often used to describe behaviors in which a person leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away.
- *Incontinence* - is the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper. Sometimes, there is an underlying physical concern that might need treatment or incomplete toilet training that may need additional teaching. For some individuals, it may be a sign that there is difficulty recognizing body signals before it is too late. Sometimes an individual learns to use 'peeing his pants' or urinating on the floor as a means of gaining attention or escaping an undesirable task or situation.

- *Non-compliance* - is used to describe when an individual does not or refuses to follow the directions, rules or wishes of someone else. Non-compliance can be passive, such as not following a direction, or active, such as whining/crying, becoming aggressive or self-injurious.
- *Obsessions, compulsions, and rituals* - often strong, irresistible urges that can result in difficulty with a person's ability to cooperate, to manage change or to be flexible and adjust. The compulsion involved in obsessions and rituals can often lead to additional challenging behaviors if they are interrupted or forbidden.
- *Physical aggression* - is an act of force that may cause harm to another person, and might include hitting, biting, grabbing, hair pulling, slapping, kicking, pinching, scratching, pulling, pushing, head butting, or throwing things.
- *Property destruction* - includes behavior in which belongings or property are harmed, ruined or destroyed and might include breaking, throwing, scratching, tearing, defacing, etc. belongings (his or those belonging to others).
- *Self-injury* - is the attempt or act of causing harm to a person's own body severe enough to cause damage. Self-injury can present in a wide range of behaviors, including head banging, hand-to-head banging, body slamming, hitting or punching oneself, eyeball pressing, biting oneself, wound picking, and hair pulling.
- *Tantrum or meltdown* - describes an emotional outburst that might involve crying, screaming, yelling and stubborn or defiant behavior. The person might lose control of his physical state, and may have difficulty calming down even if the desired outcome has been achieved (6).

What are temper tantrums?

Temper tantrums are a common behavior problem in preschool children who may express their anger by lying on the floor, kicking, screaming, and occasionally holding their breath. Tantrums are natural, especially in children who are not yet able to use words to express their frustrations. Tantrums typically occur at age 2 to 3 when children are forming a sense of self. The toddler is old enough to have a sense of "me" and "my wants" but is too young to know how to satisfy the wants. Tantrums are the result of high energy and low ability to use words to get needs or wants met.

There can be many causes of tantrums. Some of the causes are indicators of family problems: inconsistent discipline, criticizing too much, parents being too protective or neglectful, children not having enough love and attention from their mother and father, problems with the marriage, interference with play, emotional problems for either parent, meeting a stranger, rivalry with brothers or sisters, having problems with speech, and illness. Other common causes of temper tantrums include being hungry or tired (7).

Parent-child relationship is proven to affect interpersonal skills and adaptive development among young children. Healthy, positive, close, warm, supportive and accepting child-parent relationship should be strengthened so as to limit abrupt behavior in young children. Parents need to practice positive interaction skills and develop disciplinary skills to correct the child's behavior. Use the acronym C.A.L.M. to recollect the ways to avoid frequent tantrums and teach primary caregivers these skills:

- *communicate well.* Parent should be role model for young children. They should use excellent communication skills and shunning away negative behavior like arguing and yelling. Adults can provide illustrations of feeling words like "angry," "sad," "tired," or "hungry." Offering facial depictions of feelings (such as a gloomy face, annoyed face, and happy face) allows toddlers to first-rate the image that best describes their feelings. Teach older children to prompt emotions verbally.
- *attend to the child's needs*. Give the child a positive response by giving adequate time. Examples of positive responses include reading to the child, playing games, and including the child in routine activities like cooking and cleaning. Caregivers also can avoid frustration by childproofing the home and offering age-appropriate playing material that distract the child away from exploring dangerous or undesirable objects. Parental expectations of behavior should be age-appropriate.
- *limit child's exposure to violent television viewing, which forecasts adolescent and adult aggression*. Let the child share their feelings and listen. Allow the child to regulate decisions by offering choices that are acceptable to the caregiver. Avoid saying "no," too often. Never allow the child's safety at risk while doing what he wants.
- *make naptimes and mealtimes a daily routine as far as possible.* If the toddler is away from home or misses their usual mealtimes, have simple, healthy food such as dried fruit or crackers available (8).

What can parents do about tantrums?

There are a number of ways to handle a tantrum. Strategies include the following:

- Remain calm and do not argue with the child. Before you manage the child, you must manage your own behavior. Spanking or yelling at the child will make the tantrum worse.
- Think before you act. Count to 10 and then think about the source of the child's frustration, this child's characteristic temperamental response to stress (hyperactivity, distractibility, moodiness), and the predictable steps in the escalation of the temper tantrum.
- Try to intervene before the child is out of control. Get down at the child's eye level and say, "You are starting to get revved up, slow down." Now you have several choices of intervention. You can positively distract the child by getting the child focused on something else that is an acceptable activity. For example, you might remove the unsafe item and replace with an age-appropriate toy.
- You can place the child in time away. Time away is a quiet place where the child goes to calm down, think about what he or she needs to do, and, with your help, make a plan to change the behavior.
- You can ignore the tantrum if it is being thrown to get your attention. Once the child calms down, give the attention that is desired.
- Hold the child who is out of control and is going to hurt himself or herself or someone else. Let the child know that you will let him or her go as soon as he or she calms down. Reassure the child that everything will be all right, and help the child calm down. Parents may need to hug their child who is crying and say they will always love him or

her no matter what, but the behavior has to change. This reassurance can be comforting for a child who may be afraid because he or she lost control.

- If the child has escalated the tantrum to the point where you are not able to intervene in the ways described above, then you may need to direct the child to time-out. If you are in a public place, carry your child outside or to the car. Tell the child that you will go home unless he or she calms down. In school, warn the child up to three times that it is necessary to calm down and give a reminder of the rule. If the child refuses to comply, place him or her in time-out for no more than 1 minute each year of age.
- Talk with the child after the child has calmed down. When the child stops crying, talk about the frustration the child has experienced. Try to help solve the problem if possible. For the future, teach the child new skills to help avoid temper tantrums, such as how to ask appropriately for help and how to signal a parent or teacher that he or she knows they need to go to "time away" to "stop, think, and make a plan." Teach the child how to try a more successful way of interacting with a peer or sibling, how to express his or her feelings with words and recognize the feelings of others without hitting and screaming.

Never, under any circumstances, give in to a tantrum. That response will only increase the number and frequency of the tantrums. Explain to the child that there are better ways to get what he or she wants. Do not reward the child for calming down after a tantrum. Some children will learn that a temper tantrum is a good way to get a treat later. Never let the temper tantrum interfere with your otherwise positive relationship with the child. Teach the child that anger is a feeling we all have and then teach her how to constructively express anger (9).

What are meltdowns?

Meltdowns are an involuntary physical and emotional reaction to a situation from which there is no perceived escape. The person is typically unaware of what is happening, so there is no intention to hurt others. Autism-related meltdowns result from peaking stressors and overload of the nervous system, causing an explosive behavioral release. Stressors sometimes simultaneously preceding a meltdown may include:

- sensory, emotional or information overload
- numerous or overly difficult tasks or performance demands
- unexpected life and/or environmental changes or having to deal with the unfamiliar
- intense frustration due to an inability to regulate the expected outcomes
- typical adult life stressors such as work demands, family, money and health issues.

The person experiencing the meltdown may not be mindful of overload-producing stressors but may nonetheless feel driven to escape the stress-producing situation. If that is impossible, a meltdown may ensue. Once a meltdown is in progress, control will usually not be regained until the episode has run its course.

Meltdowns may occur for anyone when there is no escape, such as during natural disasters. But those with autism often have lower stress thresholds and are thus at higher risk (10). When persons with autism can feel themselves becoming overloaded, and a meltdown is building up, they might express their discomfort in non-verbal ways. This might look like:

- pacing the room
- rocking back or forth

- asking repetitive questions for reassurance
- asking to leave
- finger flicking
- bolting away from the situation (11).

Management of meltdowns

S.C.A.R.E.D. or Safe, Calm, Affirmation, Routine, Empathy, and Develop is an intervention strategy for de-escalation of meltdowns as quickly as possible. In Table 4 S.C.A.R.E.D. is presented in short version (12).

Table 4. S.C.A.R.E.D calming techniques for children and adults with autism

S-Safe: The initial focus should be to provide an environment that is safe and secure.	**Do** remove unwanted stimulation or guide the individual to a less stimulating environment. **Do** remove social pressure from the situation. **Don't** try to restrain the individual. **Don't** leave him/her alone.
C-Calm: Remain calm. There is no need for you to be out of control.	**Don't** try to „process" what has happened or is happening. **Do** talk in a strong, calm and reassuring voice.
A-Affirmation: Provide validation of affect and acknowledge that the individual is doing the best he/she can to resolve the situation.	**Don't** ask unnecessary questions or challenge responses. **Do** refer to the individual by name and acknowledge his/her fear.
R-Routine: The individual's comfort zone is far more likely to be in his/her repetition of routines.	**Don't** attempt to interfere with harmless routines like repetitive statements or walking in figure eights. **Do** reflect his/her behavior and perception, encourage his/her routine, provide environmental support for his/her routines.
E-Empathy: Understand from the autistic individual's perspective.	**Don't** lecture about the effect his/her behavior is having on others. Don't humiliate or shame. **Do** acknowledge his/her fear and show that you are there to support him/her.
D-Develop an intervention strategy: An intervention plan reduces the frequency, duration, intensity and negative outcomes of meltdowns.	**Don't** rely on a generic strategy. **Don't** develop a strategy without thorough consultation with the individual and his/her family. **Do** work with the individual to develop concrete behavioral strategies for assisting during a meltdown.

What is the difference between tantrums and autism meltdowns?

The key difference between tantrums and meltdowns is that a tantrum is a choice, aimed at reaching a goal and can be stopped. Meltdown is an involuntary response to a stimulus.

In both meltdowns and tantrums, the caregiver should pay attention to what might have caused it and why the child might be reacting the way they are. Tantrums are most often caused by frustration from a child not being able or allowed to do something. Tantrums are not usually a result of sensory overload, and they can be worsened by tiredness or hunger. When it comes to autism meltdowns, various environmental factors can affect different people. Remember that the trigger may not seem like a big deal to a neurotypical person or even to another autistic person, so it's important not to dismiss an autistic person if they say they are uncomfortable.

A sensory meltdown can occur at any point across an individual's lifetime. However, autism meltdowns can feel worse for children because they are less likely to understand what is happening or be able to remove themselves from a situation. Adults with autism may have learned masking techniques to disguise meltdowns.

However, an adult is much less likely to have a tantrum than a child. Most children progress beyond tantrums as a way of communicating when they are very young, as they become more capable of voicing their displeasure and have more agency.

If an individual is experiencing an autism meltdown, their reaction or future reactions cannot be shaped by rewards. Providing them with incentives, rewards, or punishment cannot stop them from having an autism meltdown; it won't influence their brain's ability to process an overload of information. Unlike autism meltdowns, tantrums can be, and often are, shaped by rewards. If a child is rewarded for good behavior or is disciplined for bad behavior, the incentive can stop a current tantrum or prevent future ones.

Although busy, public environments can trigger sensory meltdowns, they do not always require an audience, and the individual is not trying to get a reaction out of someone else. Autism meltdowns can even happen when the individual is alone, as they can be triggered by unexpected changes in plans or feeling overly stressed. However, tantrums require an audience and can be stopped by other people's actions. When a child is having a temper tantrum, they can usually be calmed down by a parent removing them from the situation, ignoring them, giving them what they want, or providing incentives to calm down.

One of the most important differences between autism meltdowns and tantrums is that autism meltdowns should not be considered 'naughty behavior'. An autistic person cannot help experiencing intense sensory overload, and their reactions are due to a lack of control. Even if a sensory meltdown is explosive and aggressive, scolding the individual for this behavior in the moment can make the situation worse. It might make them feel embarrassed, fearful or resentful. A meltdown is a vulnerable time for an autistic person, particularly autistic children, so it's important that they feel safe and can trust whoever may be caring for them. Tantrums, however, occur when a child loses their temper or something is happening that doesn't go their way. They want to draw attention and know which behaviors will do that. When typical tantrum behaviors like screaming and crying stop working, they may resort to other naughty behavior to elicit more extreme reactions, like drawing on the walls, throwing things or hurting others.

Two types of reaction are typical of autism meltdowns - an explosive reaction or a withdrawal. Explosive reactions may involve screaming, shouting, aggressive behavior or crying. On the other hand, less explosive reactions may include refusing to communicate or interact, withdrawing themselves or shutting down. Withdrawal behaviors can be discreet and sometimes go unnoticed, so it's critical to be aware of this reaction. When it comes to tantrums, children usually react in an explosive way that can appear similar to an explosive autism meltdown. However, unlike sensory meltdowns, tantrums are not typically characterized by withdrawal behaviors.

Sometimes, individuals may physically harm themselves while having an autism meltdown. The sufferer is completely overwhelmed; they can lose control and harm themselves or others without being able to register what they're doing. For example, they may fall to the floor, hit themselves (a form of harmful stimming) or throw things around the room. However, a child having a tantrum is unlikely to harm themselves physically. Although they may lash out and hit things, and may injure themselves by accident, more often than not, they will purposely react with a lack of real force (11).

Challenging behaviors and parental stress

Challenging behaviors are a known predictor of high parenting stress in families of children with autism spectrum disorders. Raising a child with autism has been linked to higher levels of parenting stress, psychological distress, and mental health problems in parents. More specifically, the presence of challenging behaviors such as hitting, property destruction and self-injury may predict higher levels of parenting stress (13). The duties of a parent towards a child with disabilities become even more demanding when the child manifests challenging behaviors or behavioral problems. Problems in the behavior of a child diagnosed with autism can have an effect on the parents' mental health, and also influence their style of parenting. Parents with autistic children are consistently reported to experience great parental stress, and are known to have higher levels of stress than parents of typically developing children and children with other disabilities such as Down syndrome. The functionality of a parent may also be affected and may lead to depression and deprived well-being (14).

What can parents do for challenging behaviors?

- Think of ways to help the child, young person or adult to stay happy and calm:
  What makes a good day for them? Can you make their favorite activities available? How can you help them to communicate with you or understand you/what is happening?
  - Teach simple communication, e.g. a sign for „finished“
  - Talk to the child in a way they respond well
  - Rewards: Can be spoken praise e.g. „well done“, „that's great“, a thumbs up sign etc.
  - Setting boundaries is important so that the child knows what behavior is expected of them. Use a variety of communication methods to help them understand what to do e.g. pictures, signs and speech
  - Routine and structure: Make a visual plan of the day for the child to follow so they know what will happen next. Be consistent with routines during key moments of the day (e.g., routines related to preschool, feeding, sleeping), but not during free time. In a child's free time, it is important to engage in different activities.
- What can you do when behavior becomes challenging? Recognize the early warning signs of the behavior and think about how to respond when you see those. Knowing what helps

them maintain their baseline or keep them calm/content means you can offer those things they like.

- Divert or distract
- Use body gestures/signs
- If safe, not responding to or „ignoring“ the behavior
- Withdraw from the situation
- Stay as calm as possible.

• What can you do if the behavior is happening or about to happen?
    - Use body gestures/signs but never point your finger
    - If safe, try not responding to, or ignoring the behavior – but not ignoring the child
    - Give personal space
    - Listen, don't bombard the child with questions
    - Observe and be prepared to respond if required.
• What can you do after the behavior? Be careful as there is a risk of the behavior escalating again. Your family member will need time to return to their usual behavior and may need extra space or time to calm down. It is a time to keep an eye on them but not be too intrusive.
    - Give them time and space
    - They may need to rest or to sleep
    - Something to eat or drink
    - A calm activity like TV
    - Go for a walk or sit in the fresh air if you can
    - Talk to someone and reflect
    - Check everyone is okay (15).

Literature

1. Nicholls G, Bailey T, Grindle CF, Hastings RP. Challenging behaviour and its risk factors in children and young people in a special school setting: A four wave longitudinal study. J Appl Res Intellect Disabil. 2023 Mar;36(2):366-373. doi: 10.1111/jar.13066. Epub 2022 Dec 23. PMID: 36564858; PMCID: PMC10108066
2. Leader G, Mannion A. Challenging Behaviors. Handbook of Assessment and Diagnosis Of Autism Spectrum Disorder. 2016. pg. 209–232.
3. Emerson Eric, Einfeld Stewart L. Challenging Behaviour - Google Books. Cambridge University Press. 2011. pg. 10–12. Available from: https://books.google.mk/books?hl=en&lr=&id=orgMzQdy2PIC&oi=fnd&pg=PR7&dq=management+of+challenging+behaviour&ots=bt9s4vMs-2&sig=1bj8OZ3IQKqr-yucaUt6gTkx6Ac&redir_esc=y#v=onepage&q=management%20of%20challenging%20behaviour&f=false
4. Carr M.E. Self-management of Challenging Behaviours Associated with Autism Spectrum Disorder: A Meta-Analysis. Australian Psychological Society [Internet]. 2016 Apr;1–18. Available from: https://www.researchgate.net/publication/303841113
5. Whitaker Philip, Joy Helen, Edwards David, Harley Jane. Challenging Behaviour and Autism: Making Sense - Making Progress; a Guide to preventing and managing challenging behaviour for parents and children - Google Books. National Autistic Society. 2001 [cited 2023 Jul 25]. pg. 5–10. Available from: https://books.google.mk/books?hl=en&lr=&id=1TCuhWVMOroC&oi=fnd&pg=PA3&dq=challenging+behaviour+and+autism&ots=-gWPTDqXM0&sig=1X8CMrdST5U851_X00exdhbpCVg&redir_esc=y#v=onepage&q&f=false
6. Challenging_behaviors_tool_kit. Autism Speaks. 2012;1–71.
7. Fetsch R, Jacobson B. Children's Anger and Tantrums. Colorado State University Extension [Internet]. 2013; Available from: www.ext.colostate.edu
8. Findings E, Chaudhary P, Kaur Randhawa R, Choudhary P, Scholar N, Professor A. A review of Detailed Assessment, Management and Parent Education Regarding Temper Tantrum Behavior in Younger Children.

International Journal of Creative Research Thoughts (IJCRT) [Internet]. 2021 May;9(5):2320–2882. Available from: www.ijcrt.org
9. Harrington R.G. Temper Tantrums: Guidelines for Parents. University of Kansas [Internet]. 2013;1–3. Available from: http://www.nasponline.org/resources/behavior/tantrums_ho.aspx
10. Bedrossian L. Understand autism meltdowns and share strategies to minimize, manage occurrences. Disability compliance in higher education, Volume 20, issue 7, 2015;
11. Autism awareness center, Seven Differences Between Tantrums vs Autism Meltdowns [Internet]. Available from: https://www.experia.co.uk/blog/7-differences-between-tantrums-and-autism-meltdowns/
12. Mazefsky C., Lipsky D., Richards W. Managing Meltdowns: Using the S.C.A.R.E.D Calming Technique with Children and Adults with Autism. Journal of Autism Developmental Disorders. 2010 Jul;40(7):916–7.
13. Argumedes M, Lanovaz MJ, Larivée S. Challenging Behaviors and Parenting Stress 1 Brief Report: Impact of Challenging Behavior on Parenting Stress in Mothers and Fathers of Children with Autism Spectrum Disorders. Journal of Autism Developmental Disorders. 2018 Jul;48(7):2585–2589.
14. Rahman PA, Jermadi H. Parental Stress and Parenting Styles in Managing Autistic Children with Behavior Problems. Malaysian Journal of Medicine and Health Sciences. 2021;17(SUPP3):2636–9346.
15. Challenging behaviors foundation, Johnson Laura. Quick Read Challenging Behavior Guide. 2020.

Emotional regulation in children with developmental difficulties

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Most important messages:

- Adults should recognize emotional triggers, specific situations, environments or events that cause strong emotional reactions in the child, such as anxiety, anger or sadness.
- It should be understood that the child's difficulties can affect his emotional regulation.
- Parents should create a safe, quiet space at home where the child can retreat when feeling anxious.
- Daily routines provide children with a sense of security and predictability.
- Adults should encourage open communication, where the child can talk about his/her feelings and confirm his/her emotions without judgment.
- Adults should show the child how to deal with stress, frustration or sadness in a constructive way.
- Adults should praise and reward the child for the appropriate expression of his emotions and effective management of feelings.

What is emotional regulation?

Emotional regulation is “the ability to respond to the ongoing demands of experience with the range of emotions in a manner that is socially tolerable and sufficiently flexible to permit spontaneous reactions as well as the ability to delay spontaneous reactions as needed” (1). In simpler terms, self-regulation skills enable us to monitor and determine what emotions we experience, act upon, and display. No matter our age, this can be difficult for even the healthiest of people - and for children with special needs, it may seem impossible.

Emotional regulation refers to the process of managing and controlling our emotions effectively. It empowers individuals to consciously choose their emotional responses and actions, rather than being overwhelmed or dictated by their emotions. This skill allows us to handle different emotional stimuli we encounter daily in three possible ways:

1. initiating actions triggered by emotions (not the most ideal approach)
2. inhibiting actions triggered by emotions (also not the most ideal approach)
3. modulating responses triggered by emotions (the best choice) (2).

By employing emotional regulation, we can prioritize which emotions are significant and respond to them in a manner that is beneficial rather than harmful.

The significance of emotional regulation lies in its ability to provide individuals with a sense of control over their emotions. It enables them to make conscious decisions on how to respond to various emotional situations, contributing to their overall well-being. Children facing challenges such as anxiety disorders, learning disabilities, ADHD, or other special needs might find it a bit more challenging to develop this skill. These individuals may be more prone to experiencing negative emotions and struggling with their self-esteem. Children with disabilities can face unique challenges in emotional regulation due to the impact of their disability on various aspects of their development. It's important to note that disabilities are diverse, and each child's experience will be different.

Promising research indicates that teaching emotional regulation skills to children can yield positive results. In one study, children who received such training experienced 46% fewer disciplinary referrals at school in just four months (3). Properly managing emotional reactions can significantly improve a child's life in a meaningful way (4). Moreover, emotion regulation strategies can be taught, and learning these skills can enhance a child's well-being, foster positive emotions, and enable them to respond thoughtfully rather than overreacting to emotional triggers.

How to foster emotional regulation with children

Emotional regulation skills help people handle and express their emotions. They should be taught within the family, and there are many age-appropriate options that you can do with your little one to walk them through processing their feelings:

- **Show and tell** - don't just tell your child how to self-regulate, show them with your own behavior! Children often model what they see at home. When you display positive coping strategies, they see a practical example to follow.
- **Take five** - ask a child to delay his or her response instead of reacting immediately. Studies show that taking a break and completing a distraction task can lessen the severity of the response (5).
- **Top the charts** - when children don't have an adequate emotional vocabulary, it is difficult for them to articulate their needs and struggles. Creating a feelings chart is one effective way to help them decipher, explain, and regulate their emotions. You may even want to equip family members with this tool, empowering them to help your child have conversations about feelings. It takes a village!
- **Cause and effect** - clarifying consequences, especially for children with special needs, eliminates the guesswork for them. Whether it's chores and rewards or tantrums and losing their Nintendo privileges, create clear consequences so they can understand the impact of their choices and behavior. Talk these scenarios through with them.
- **Breathwork** -this brings them to the present moment and brings them to their body. Additionally, breathwork can benefit both mental and physical health (6).
- **Diet and nutrition** - children with developmental difficulties tend to be picky eaters and have more food allergies than others. In consultation with your pediatrician, you should set a specific diet and healthy nutrition for their allergies.
- **Improving immune function and removing pathogens** - stress can actually take a toll on the immune system, and the microbiome of children with special needs can also need some help. In consultation with your pediatrician, you can set use of some supplements, specific foods or probiotics for improving their microbiome.

Emotional Regulation Disorder

Poor emotional regulation can cause problems in reactions and judgment, friendships, work, school, and stress management. **In emotional dysregulation, negative emotions can run disorganized and dramatic responses are common.**

However, a more intense condition can be known as an **emotional regulation disorder.** Individuals with this disorder can present exaggerated, impulsive emotional reactions. These may look like fits of anger, accusing, crying, hysterics, accusations, emotional instability, insecurity, and feeling worthless.

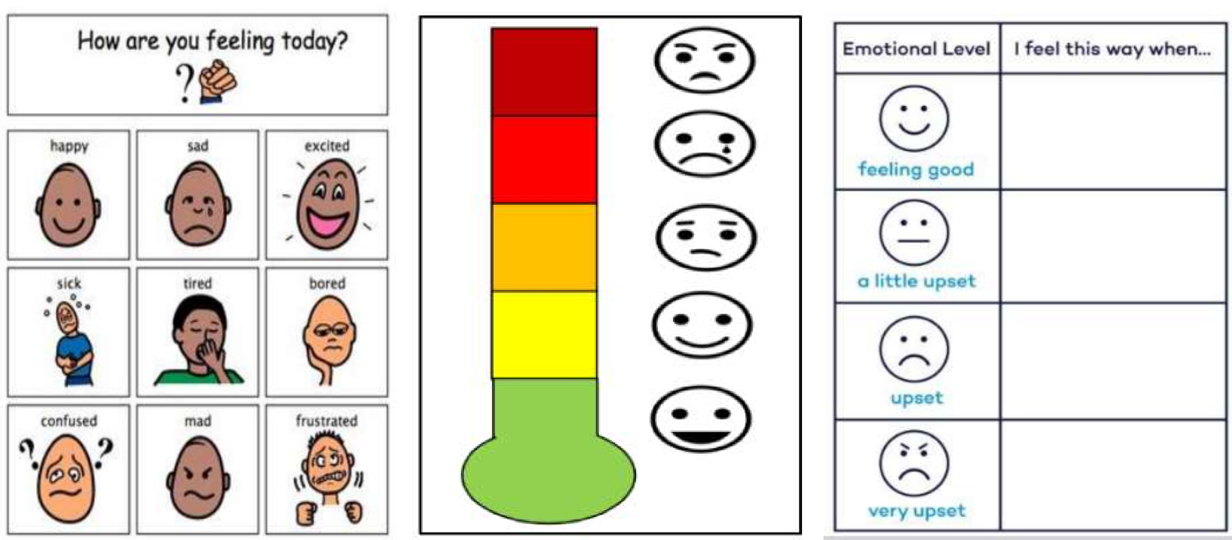
Parenting a child to proper emotional regulation

For many children with autism and/or learning difficulties, effective emotional regulation must be taught directly to them. Here are some strategies to help your child develop emotional regulation, or self-regulation:

1. provide your child with consistency and stability - this helps your child to know that even when they are feeling big emotions that are overwhelming, you are there to help them.
2. help your child to understand big emotions. Explain a feeling by using words that they can understand - use pictures, books or videos to help you explain:
    a. be responsive and talk about emotions with your child. Label their emotions as they naturally happen throughout the day, so that they become aware of their different emotional states. For example, “You are mad because your toy is broken”. “You’re smiling, I think you must be happy.”
    b. label emotions in natural contexts. When you’re reading a book, watching a video or visiting friends you can point out emotions to them – “Look, Ana is smiling. She’s happy.” Keep your language simple and at your child’s level of understanding.
3. if your child struggles with a strong feeling, encourage them to name the feeling and what caused it. However, if your child has become very upset or dysregulated, that is not the time to label the feeling. Wait until this time has passed and address it at a time when your child is calmer and more able to listen. Remember, it is okay to feel any feeling, such as anger, and everyone feels angry at times. Acknowledging your child’s feelings will be very important to help them to regulate: “I know you are angry because you can’t go to the park”, helps your child to recognize the emotion, and also gives the message that you recognize the emotion, and can validate their feelings. This can then lead to problem-solving when they are able to think more calmly - what can they do when they feel angry that is more appropriate than hitting or throwing things for example? Teaching your child alternative strategies to manage their emotions can be very useful in supporting them to develop greater levels of emotional regulation. The message is: “It’s ok to feel angry, but it’s not okay to hurt myself or others, or to break things. It is ok to talk about it or take a break.”
4. for older children, you can try and teach your child coping strategies. For example, they may take 5 deep breaths, count to 20 in their head, or walk away and spend time alone. Practice scenarios in your home where they can practice using the coping strategies, and they can get used to using it for future reference. Strategies could also include asking adults for help, “Say it, don’t do it”, for example saying “I am mad” instead of throwing the toy, relaxing and trying again later and asking for a hug.
5. praise your child when they show self-regulation and manage a tricky situation. For example “You were so good at waiting your turn”, “I like the way you shared with your brother when he asked”. This is really important, and particularly if your child manages to respond appropriately to a tricky situation that they can struggle with, such as waiting their turn or sharing. Remember to give more attention to behaviors you would like to see increase-this can be a helpful way of bringing your child’s attention to the behavior, and gives them the message that they can get your attention for appropriate behaviors.

6. model self-regulation for your child. Children learn from watching us, and how we respond to situations. Show your child how you respond to a frustrating task. For example, you could say: “Wow this is really hard to do, and I’m feeling frustrated. I’m going to take a break and come back to it when I feel calmer”. Show that you are breathing calmly, and thinking about a situation before acting. This is easier said than done, and we all get frustrated sometimes, but try to remember that your child is learning from your response to difficult situations too.
7. when appropriate, using a social story that incorporates how your child feels and appropriate ways to react to a situation may be useful. This can be useful if there is a particular situation that brings up feelings for your child that they find difficult to manage, such as losing a game, or waiting for their turn. In the social story, explain the feeling, but give some solutions also about how to best respond to the feeling.
8. for older children, using a visual system such as an emotional thermometer, or a 5-point scale may be useful (Picture 1). This is a visual system that can help organize your child’s thinking when they are working through difficult moments. When you first introduce this system, talk through the chart, and allow them to create their own labels for each level. They can then come up with different situations that make them feel at specific levels. Or, ask them about how they would feel in a certain scenario. You can refer to the chart when you sense your child is becoming dysregulated, and use it to effectively help them remember to use coping strategies when they feel themselves becoming upset or dysregulated (7-9).

Figure 1. Visual systems for learning emotional self-regulation



Emotional regulation strategies in childhood development

There are many strategies of how you can emotionally regulate in childhood development. Here are the major strategies for improving a child’s regulation processes, though it should be noted that not all are equally helpful or positive:

Dialectical Behavior Therapy (DBT) is a psychotherapy technique used to help individuals improve their distress tolerance, control negative thoughts, understand and moderate their emotions, improve quality of life, and set goals for the future. DBT involves both individual therapy and group work. The emotion regulation skills taught include:

- Being aware of both positive and negative emotions, and how to identify them.
- The ability to name and label emotions.
- Self-awareness about one's current feelings.
- Knowing and using desirable reactions in everyday life.
- Improved ability to manage stress and use positive coping techniques.

DBT is often not implemented until a child is 10 or older (10).

Cognitive Behavioral Therapy (CBT or cognitive therapy) may help children with anxiety worry less and increase their emotional awareness. However, this and other studies express concern that it does not affect regulation of other emotions like anger or sadness (11).

Situation selection refers to the strategy of keeping the child away from situations that will be harmful or negatively impact their emotional experience. This is about helping a child learn to choose what situations they place themselves in, considering their own reactions in advance (9).

Situation modification is the term used for the attempt to change the emotional tone of a situation, whether through physical distancing, humor, changing the subject, or another method.

Exercise can be effective in decreasing perceived stress and emotional distress in just two months, according to one study (12).

Attentional deployment can take many forms of redirecting attention either toward or away from an emotionally-charged situation. This may look like:

- *Distraction*-while this isn't a long-term option for helping your child's emotional regulation, short-term distraction may temporarily help with emotion dysregulation.
- Other methods include worry, rumination, and thought suppression, all of which are "maladaptive," or have negative results over time (13).

Cognitive change is a way of changing how the child processes the situation so as to alter its meaning in their mind. This can be done through:

- *Reappraisal*, in which an individual reinterprets a situation or event to give it a new emotional meaning. In most cases, this is considered a positive strategy. For example, something that a child previously thought was "the end of the world" is now just a bad day at school.
- *Distancing*, referring to a child's ability to remove oneself from the situation and see things objectively, can be quite helpful. In fact, it's been shown to decrease negative reactions, heart rate, and blood pressure when used as a strategy.
- Good-natured *positive humor* can help with emotional regulation, but negative humor does not have the same results (15).

Literature

1. Cole PM, Michel MK, Teti LO. The development of emotion regulation and dysregulation: a clinical perspective. Monogr Soc Res Child Dev. 1994;59(2-3):73-100. PMID: 7984169
2. Davidson, R. J. (1998). Affective style and affective disorders: Perspectives from affective neuroscience. Cognition & Emotion, 12(3), 307-330.
3. Wyman PA, Cross W, Hendricks Brown C, Yu Q, Tu X, Eberly S. Intervention to strengthen emotional self-regulation in children with emerging mental health problems: proximal impact on school behavior. J Abnorm

Child Psychol. 2010 Jul;38(5):707-20. doi: 10.1007/s10802-010-9398-x. PMID: 20180009; PMCID: PMC2880630.

4. Graziano PA, Reavis RD, Keane SP, Calkins SD. The Role of Emotion Regulation and Children's Early Academic Success. J Sch Psychol. 2007 Feb 1;45(1):3-19. doi: 10.1016/j.jsp.2006.09.002. PMID: 21179384; PMCID: PMC3004175.
5. Wang, C. S., Sivanathan, N., Narayanan, J., Ganegoda, D. B., Bauer, M., Bodenhausen, G. V., & Murnighan, K. (2011). Retribution and emotional regulation: The effects of time delay in angry economic interactions. *Organizational Behavior and Human Decision Processes, 116*(1), 46–54. https://doi.org/10.1016/j.obhdp.2011.05.007
6. Ma X, Yue ZQ, Gong ZQ, Zhang H, Duan NY, Shi YT, Wei GX, Li YF. The Effect of Diaphragmatic Breathing on Attention, Negative Affect and Stress in Healthy Adults. Front Psychol. 2017 Jun 6;8:874. doi: 10.3389/fpsyg.2017.00874. PMID: 28626434; PMCID: PMC5455070.
7. Wyman PA, Cross W, Hendricks Brown C, Yu Q, Tu X, Eberly S. Intervention to strengthen emotional self-regulation in children with emerging mental health problems: proximal impact on school behavior. J Abnorm Child Psychol. 2010 Jul;38(5):707-20. doi: 10.1007/s10802-010-9398-x. PMID: 20180009; PMCID: PMC2880630.
8. Dadomo H, Grecucci A, Giardini I, Ugolini E, Carmelita A, Panzeri M. Schema Therapy for Emotional Dysregulation: Theoretical Implication and Clinical Applications. Front Psychol. 2016 Dec 22;7:1987. doi: 10.3389/fpsyg.2016.01987. PMID: 28066304; PMCID: PMC5177643.
9. Gross, J. J. (1998). The emerging field of emotion regulation: An integrative review. *Review of General Psychology, 2*(3), 271–299. https://doi.org/10.1037/1089-2680.2.3.271
10. Valentine, S. E., Bankoff, S. M., Poulin, R. M., Reidler, E. B., & Pantalone, D. W. (2015). The use of dialectical behavior therapy skills training as stand-alone treatment: A systematic review of the treatment outcome literature. Journal of clinical psychology, 71(1), 1-20.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/25042066
11. Suveg C, Sood E, Comer JS, Kendall PC. Changes in emotion regulation following cognitive-behavioral therapy for anxious youth. J Clin Child Adolesc Psychol. 2009 May;38(3):390-401. doi: 10.1080/15374410902851721. PMID: 19437299
12. Oaten M, Cheng K. Longitudinal gains in self-regulation from regular physical exercise. Br J Health Psychol. 2006 Nov;11(Pt 4):717-33. doi: 10.1348/135910706X96481. PMID: 17032494.
13. Nolen-Hoeksema, S., & Morrow, J. (1993). Effects of rumination and distraction on naturally occurring depressed mood. *Cognition and Emotion, 7*(6), 561–570. https://doi.org/10.1080/02699939308409206
14. Gross, J. J., & John, O. P. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. *Journal of Personality and Social Psychology, 85*(2), 348–362. https://doi.org/10.1037/0022-3514.85.2.348
15. Samson AC, Gross JJ. Humour as emotion regulation: the differential consequences of negative versus positive humour. Cogn Emot. 2012;26(2):375-84. doi: 10.1080/02699931.2011.585069. Epub 2011 Jul 15. PMID: 21756218.

Bullying management and children with disabilities

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Most important messages:

- Adults should be attentive and notice unexpected changes in the child's behavior, such as withdrawal, anxiety, depression, anger or physical injuries.
- Adults should encourage the child to talk about his day and listen to him without judgment, using open-ended questions to help the child express his/her feelings and experiences related to peer violence.
- Adults should reassure the child that if he/she is being bullied, it is not his/her fault.
- Parents can use different roles in the game to help the child practice assertive responses.
- Children should be provided with positive reinforcement and praise for their strengths and achievements.
- Parents should seek the help of a mental health professional who can provide the child with strategies for dealing with the emotional impact of peer violence.
- Parents should cooperate with the educational staff at school if violence occurs during classes.

Olweus in 1999 (according to Piskin M.) has described bullying with reference to three criteria:

1) it is aggressive behavior or intentional harm doing,
2) it is performed repeatedly and over time,
3) it takes place within the context of an interpersonal relationship characterized by an imbalance of power (1).

Importantly, bullying is distinct from interpersonal conflicts or “rough play”. While disagreement, teasing and conflict are part of growing up, bullying is an extreme form of peer conflict or teasing and can be harmful, both physically and psychologically.

Bullying does not only occur between children who bully and those who are bullied, but is considered a group phenomenon in which other children participate. Bystanders can assist the bully, or try to help the victim, or they can withdraw and try not to get involved. Bullying incidents usually involve several bystanders, and in most cases these bystanders do not try to stop the bullying, which may be interpreted by the bully as a reinforcement to continue the bullying. However, it has also been shown that when bystanders intervene and try to stop the bullying, they are effective in a majority of the cases (2).

Bullying can take different forms as:

- Physical bullying: hitting, slapping or pushing someone
- Verbal bullying: name calling, gossiping or threatening someone
- Non-verbal abuse: hand signs or text messages
- Emotional abuse: threatening, intimidating or humiliating someone
- Exclusion: ignoring or isolating someone
- Undermining, constant criticism or spreading rumors
- Controlling or manipulating someone
- Making silent, hoax or abusive calls.

- Racial, sexual, transphobic or homophobic bullying
- Bullying someone because they have a disability (3).

Signs of child bullying

Many parents are concerned that their child might be a victim of child bullying. Some of the signs that a child is being bullied include:

- Comes home with torn, damaged, or missing pieces of clothing, books etc.
- Has unexplained cuts, bruises, and scratches
- Has few, if any friends, with whom he or she spends time
- Seems afraid of going to school, walking to and from school, riding the school bus, or taking part in organized activities with peers (such as clubs)
- Takes a long, "illogical" route when walking to or from school
- Has lost interest in school work or suddenly begins to do poorly in school
- Appears sad, moody, teary, or depressed when he or she comes home
- Complains frequently of headaches, stomachaches, or other physical ailments
- Has trouble sleeping or has frequent bad dreams
- Experiences a loss of appetite or
- Appears anxious and suffers from low self-esteem (4).

Who's at risk?

Any child can be bullied for any reason. If a child is seen as different in some way, or seen as an easy target, they can be more at risk. This might be because of their race or ethnic background, gender or sexual orientation. Or it could be because they appear anxious or have low self-esteem, lack assertiveness and are shy or introverted. Popular or successful children are also bullied, sometimes because others are jealous of them. Sometimes, a child's family circumstances or home life can be a reason for someone bullying them. Disabled children can experience bullying because they seem to be easy target and less able to defend themselves (3).

What do we know about bullies?

Children who engage in bullying behaviors seem to have a need to feel powerful and in control. They appear to derive satisfaction from inflicting injury and suffering on others, seem to have little empathy for their victims, and often defend their actions by saying that their victims provoked them in some way. Studies indicate that bullies often come from homes where physical punishment is used, where the children are taught to strike back physically as a way to handle problems, and where parental involvement and warmth are frequently lacking. Children who regularly display bullying behaviors are generally defiant or oppositional toward adults, antisocial, and apt to break school rules. A significant number of young people who bully others have been bullied themselves. Researchers suggest that children who bully are self-focused, highly competitive, exhibitionistic, and aggressive. Others propose that children who bully lack empathy and tend to be manipulative and self-seeking in their interpersonal relationships (5).

Children who bully can be grouped by their level of involvement as:

a) Ringleaders - organizing a group of bullies and initiating the bullying

b) Followers - who join in the bullying once it is started and
c) Reinforcers - who do not actively join in, but reinforce more passively by watching and laughing or encouraging the bullying (6).

Why do children bully?

It's important to keep in mind that children don't bully because they are "bad children." Children engage in all kinds of behavior that isn't a reflection of who they are as a person. They're still figuring things out. They can be nice children who have made some mistakes. There are many reasons why an otherwise well-behaved child might be unkind to other children. Here are a few:

- The child wants to fit in with a group of friends who are picking on one classmate.
- They are getting bullied at home or at school, and are trying to regain a sense of power by acting aggressively toward others.
- They are looking for attention from teachers, parents, or classmates, and haven't been successful getting it other ways.
- They are, by nature, more assertive and impulsive than their peers.
- They have a tendency to perceive the behavior of other children as hostile, even when it is not.
- They do not fully grasp how their behavior is making the victim feel. This is particularly true of younger children (7).

Consequences of bullying

The consequences can be grouped into three broad categories:

- educational consequences during childhood and adolescence,
- health consequences during childhood and adolescence,
- all consequences during adulthood.

Educational consequences during childhood and adolescence

Children who are frequently bullied are more likely to feel like an outsider at school, while indirect bullying specifically has been shown to have a negative effect on socialization and feelings of acceptance among children in schools. Accordingly, a child's sense of belonging at school increases as bullying decreases. In addition, being bullied can affect continued engagement in education. Compared with those who are not bullied, children who are frequently bullied are nearly twice as likely to regularly skip school and are more likely to want to leave school after finishing secondary education. Children who are bullied score lower in tests than those who are not (8).

Health consequences during childhood and adolescence

Being a victim or an active bully is associated with an increased risk of mental and physical health problems. Children who are bullied suffer more often from health complaints such as sleeping problems, headache, stomach ache, bedwetting and depression, and have more often suicidal thoughts. Active bullying is found to be associated with higher levels of depression, and emotional and behavioral disorders. The stress caused by bullying could lead to a higher number of health complaints, but children with health problems such as depression or anxiety may also be more vulnerable to being bullied by other children (2).

Consequences in adulthood

Childhood bullying can lead to three main negative outcomes in adulthood for victims, bullies and bully–victims: psychopathology, suicidality and criminality. A strong dose-response relationship exists between the frequency of peer victimization in childhood and adolescence and the risk of adulthood adversities. For example, frequently bullied adolescents are twice as likely to develop depression in early adulthood compared with non-victimized peers, and this is seen in both men and women. The impact of childhood bully victimization on adulthood mental health outcomes is staggering. Approximately 29% of the adulthood depression burden could be attributed to victimization by peers in adolescence, and bully victimization by peers is thought to have a greater impact on adult mental health than maltreatment by adults, including sexual and physical abuse. Finally, these consequences reach beyond the realm of health, as childhood bullying victimization is associated with a lack of social relationships, economic hardship, and poor perceived quality of life at age 50 (6).

Bullying and children at risk

Over the past two decades, education for students with disabilities has gone through many changes. Historically, students with disabilities were educated separately from their age peers in either special schools or different classes. The concept of separate schools and classrooms continues to be challenged on its efficacy for students with disabilities. As the emphasis on including students with disabilities into general education classrooms has increased, educators have been primarily focused on their academic success. Much less emphasis has been placed on social integration. While it remains important to evaluate academic progress, it is also important for students with disabilities to succeed socially. As students with disabilities are increasingly being taught with their non-disabled peers, they are subject to a different range of childhood experiences and may be at an increased risk for bullying. Unfortunately, these experiences are not always positive, and they can have an enormous impact on children (9).

Children with physical, developmental, intellectual, emotional, and sensory disabilities are at an increased risk of being bullied. Children with special health needs, such as epilepsy or food allergies, also may be at higher risk of being bullied. Bullying can include making fun of the children because of their allergies or exposing them to the things they are allergic to (10). While both children with and without disabilities face significant negative emotional, educational and physical results from bullying, children with disabilities are both uniquely vulnerable and disproportionately impacted by the bullying phenomena (11).

The experience or anticipation of being bullied can shape a young person's sense of self and social relationships and can have a corrosive and damaging impact on their self-esteem, mental health, social skills and progress at school. These effects can be particularly felt by disabled children and young people who are often socially excluded in any case. For many disabled children and young people, bullying can be an insidious and relentless pressure that can dominate their lives, leaving them feeling depressed and withdrawn. This is particularly true if the bullying is not dealt with promptly and is allowed to continue. For many disabled children and young people, the bullying continues over many years and blights lives into adulthood. Disabled children and young people are often frightened that they will be bullied and this makes them scared to go places and try new things, which ultimately prevents them from feeling safe, enjoying and achieving (8, 12).

What parents can do about bullying

- Talk to your child about bullying. Explain what bullying is and that it is wrong. Let your child know that you will be there to help him or her – and always follow through. Be supportive of the child and encourage him or her to describe who was involved and how and where the bullying happened. Be sure to tell the child that it is not his or her fault and that nobody deserves to be bullied or harassed. Do not encourage the child to fight back. This may make the problem worse.
- Help your child learn how to react to bullying, as-"Speak up when bullying happens", "Try not to cry or lash out in front of the bully", "Walkaway", "Tell a trusted adult".
- Ask the child specific questions about his or her friendships. Be aware of signs of bullying, even if the child doesn't call it that. Children with disabilities do not always realize they are being bullied. They may, for example, believe that they have a new friend, although this "friend" is making fun of them.
- Talk with the child's teacher immediately to see if the problem can be solved
- Put your concerns in writing and contact the principal if the bullying or harassment is severe or the teacher doesn't fix the problem. Explain what happened in detail and ask for a prompt response. Keep a written record of all conversations and communications with the school.
- Be persistent. Talk regularly with the child and with school staff to see whether the behavior has stopped.
- Help your child develop new friendships. Try to connect your child to other children who are positive influence and have things in common with your child.
- Work with other parents. It takes a group effort to stop bullying. Work with other parents to respond to bullying if it is happening in your neighborhood after school hours.
- Contact the parents of the child who is bullying. Getting parents involved is the right approach only for persistent acts of intimidation and when you feel the parents will be receptive to working in a cooperative manner with you. Call or e-mail them in a non-confrontational way, making it clear that your goal is to resolve the matter together. But in most cases, teachers or counselors are the best ones to contact first.
- Role-play "what if" scenarios. Role-playing is a terrific way to build confidence and empower your child to deal with challenges. You can role-play the bully while your child practices different responses until they feel confident handling troublesome situations. As you role-play, teach your child to speak in a strong, firm voice (3, 8, 13, 14).

Literature

1. Piflkin M. School Bullying: Definition, Types, Related Factors, and Strategies to Prevent Bullying Problems.
2. Fekkes M, Pijpers FIM, Verloove-Vanhorick SP. Bullying: who does what, when and where? Involvement of children, teachers and parents in bullying behavior.; Available from: https://academic.oup.com/her/article/20/1/81/632611
3. U.S. Department of Health and Human Services, Stop bullying, Link: https://www.stopbullying.gov/
4. Olweus, D. Bullying at School. What we know and what we can do. NY: Blackwell. 1993.
5. Banks, Ron. Educational Resources Information Center Digest. 1997. Bullying in Schools. Available from: https://www.vtaide.com/png/ERIC/Bullying-in-Schools.htm

6. Lodge J. Children who bully at school. Child Family Community Australia paper. Australian Institute of Family Studies. 2014.
7. Child Mind Institute, My Child is a Bully. Signs of Bullying. What Makes a Bully. 2023 Available from: https://childmind.org/article/what-to-do-if-your-child-is-bullying/
8. Armitage R. Bullying in children: impact on child health. BMJ Paediatrics Open 2021;5:e000939. doi:10.1136/bmjpo-2020-000939
9. Carter BB, Spencer VG. The Fear Factor: Bullying and Students with Disabilities. International Journal of Special Education. 2006;(1).
10. Lieberman, J., Weiss, C., Furlong, J., Sicherer, M., & Sicherer, S. (2010). Bullying among pediatric patients with food allergy, Annals of Allergy, Asthma & Immunology, 105, 282-286.
11. Young Jonathan, Ne'eman Ari, Gelser Sara. Bullying and Students with Disabilities A Briefing Paper from the National Council on Disability. National Council on Disability. 2012;
12. National Children's Bureau. Bullying and disability. 2007 Aug 1; Available from: https://anti-bullyingalliance.org.uk/sites/default/files/uploads/attachments/bullying-and-disability.pdf
13. Center for Safe Schools. What Every Parent Should Know About Bullying. Highmark Foundation. Available from: https://www.octorara.k12.pa.us/cms/lib/PA50000610/Centricity/Domain/63/BPParentGuide2013.pdf
14. Education Law Center (2002). What can you do if your child with a disability is being harassed by other students? (Fact sheet). Retrieved August 10, 2005, from www.elc-pa.org.

Physical activity of children with developmental disabilities

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Most important messages:

- Movement enables children to gain their first experiences of the environment.
- The development of basic motor skills is an aspect that is of key importance in early childhood because it is the basis for the development of intellectual and emotional abilities.
- Sports and exercises for children with autism not only develop physical performance, but also improve social integration and communication skills, and reduce the possibility of inappropriate behavior.
- The recommendation of the World Health Organization is that children aged 5-15 should spend at least 60 minutes a day in moderate to intense physical activity.
- For the development of a child's physical fitness, a regular program of physical activities combining components of aerobics, strength, flexibility and capability exercises, ball games and neuromuscular training is recommended.

Early childhood is one of the critical periods for the physical and intellectual development of a child. As 70% of neuronal connections in the brain form during preschool age, these connections form the basis of the child's later abilities and traits. The brain is designed to learn and solve problems, initially simple and later complex. The earliest challenges the brain needs to solve are related to movement. Children solve problems spontaneously, intuitively and in an unstructured way. Later, through better-organized movement, children acquire various motor skills, abilities and sensory experiences, thus gaining a new understanding of themselves and their surroundings. Children move into social interactions and group dynamics, thus gaining a sense of autonomy and independence. A physically stimulating and diverse environment undoubtedly has a significant impact on children's mental functions, as well as on the development of their potential abilities (1).

Early development of motor functions

Motor development is linked to intellectual development, which implies the connection between the child's ability to move, handle objects and carry out motor activities; and the child's cognitive abilities, which include attention, perception, language, memory, logical thinking, etc. Movement and handling of objects gives children an opportunity to explore the environment, acquire sensory information and build mental performances; and vice versa, cognitive information affects the modeling and perfection of motor movements (2).

Furthermore, motor development is linked to spoken-language development in childhood. In particular, the start of specific, rough childhood motor skills (such as sitting and walking) shows that experience in new positions and motion styles can predict receptive and expressive language at specific time points; also, rough and fine motor skills help stimulate linguistic development from infancy to early childhood (2).

Basic motor skills are divided into rough and fine motor skills. Rough motor includes large muscle groups (such as sitting, crawling, walking, jumping or running alone), while fine motor includes activation of smaller muscle groups (such as grabbing, manipulating objects or drawing) (3).

Indicators of slow development of gross motor skills are related to difficulties in walking, jumping, skipping and performing elementary movements to the extremities; then throwing, catching, general clumsiness and coordination of movements and reduced ability to maintain balance (3, 4).

When it comes to fine motor skills, this refers to: visual motor, visual motor integration, manual skill and pencil-holding and writing ability (graphomotor skills). Less functional differences can be made between these different terms, which are the focus of research when examining the development of specific skills (5).

The following is an overview of early indicators (milestones) of proper motoric development in different development periods of children (6).

Gross and fine motor skills from birth to 10

- 1-3 months: A child lifts shoulders and head from the floor, arms are half open, limb movements are symmetrical, legs are connected when held under the armpit. A child is looking at a moving object left-right.
- 4 months: A child is in control of head movements, likes to move his hands, sucks his thumb. He grabs objects with his whole fist, plays with his hands, looks at them, puts a pacifier or rattle in his mouth.
- 5-6 months: Sits with a light support, holds the head steadily, leans on feet with fingertips on the floor. Grabs the entire palm and outstretched thumb, gradually adapts the grip to the size and shape of the object, grabs the desired toy with both hands, transfers the toy from hand to hand.
- 7-9 months: Gets into a sitting position, sits on his own, stands by his back, starts crawling. Bangs and shakes an object, hits one another, can hold two objects, throws everything on the floor. Catches small objects with a thumb and forefinger (like tweezers; tweezing grip).
- 10-12 months: walking with support, descending with support to retrieve the object, moving objects back and forth. Catches small objects by opposing the thumb and index finger (tweezing grip), inserts buttons into the vessel, and mimics drawing with pen on paper.
- 13-14 months: stands alone and can take 10 steps. Picks up and puts small objects in a bottle, can put two cubes on top of each other.
- 15 months: walking solo and rarely falling.
19-22 months: runs, gets down the stairs, opens the door, kicks the ball. Turns the pages of the book, throws objects without a specific direction, enjoys throwing and catching games, colors on paper.
- 2 years: walks peacefully, runs.
- 3 years: can walk on toes and heels, standing shortly on one leg, runs evenly and fast. Imprecisely cuts paper with scissors, draws a circle when shown, uses markers and wooden crayons, builds an accordion of paper, builds a tower of nine to ten cubes.
- 4 years: marches to the rhythm of music, descends down the stairs one foot in front of the other, drives a tricycle, skips an obstacle 20 cm wide. Tries to draw a person - head and limbs, crosses the square, transcribes a few printed letters, bends the paper obliquely.
- 5 years: jumps on one leg, can stand on toes, runs in a changing direction. Draws a house, tree, human figure – recognizable drawing, cross triangle, distinguishes difficult from easy.
- 6 years: rides a bike (sleds, skates, roller skates), jumps the rope with both legs together, hangs for 10 seconds holding on to the bar, plays badminton, jumps from a height of 40 cm. Catches the little ball with both hands from 3 meters away. Makes a paper ball with one hand, hits the target

with the ball, winds the thread, touches each finger with a thumb, makes a paper fan, uses a pencil cutter.
- 7 years: increasing muscle strength and movement coordination; can ride a bicycle independently, skipping a rope. Likes to draw and can precisely copy a large number of two-dimensional shapes.
- 9 years: better coordination of small muscles, more graceful movements. Develops various skills, swims, prefers active and challenging games - sports and tries to be better at sports. Knows how to use simple tools like a hammer and a screwdriver. Can play all kinds of musical instruments.
- 10 years old: gets speed and coordination, runs into the sprint, skips the ball fast, can hit the ball with a bat with good coordination. A child is skillfully balancing by walking on a narrow beam. A depth/perspective appears on the drawings.

If the causes of slowing motor development cannot be easily determined, it is important to detect them as early as possible so that the child can start rehabilitation or elimination on time.

Motor development and stimulation in children with developmental disabilities

P arents tend to notice when a child does not reach the expected motor milestones of development relative to other children. Parental concerns about the child's development are the starting point for the assessment (7).

Children with developmental disabilities may have different types of developmental disabilities, such as: visual disturbances, hearing disturbances, physical disturbances and motor function disturbances, difficulties in intellectual functioning, difficulties in speech-language development, socio-emotional-behavioral nature, specific learning difficulties, etc. Some examples of developmental disorders may include autism, attention deficit and hyperactivity disorder, cerebral palsy, Down syndrome, specific language disorder, etc.

One of the frequent companions of these disorders is impairment of motor functions (movement function), and most of these children are psychomotor retarded since birth, which significantly impairs their quality of life. Difficulties may arise in controlling movement, balance, coordination and development of fine motor skills.

In children with autism spectrum disorder (ASD), exercise levels may be significantly lower compared to their normally developing peers (8, 9). The limited level of physical activity in persons with ASD can be attributed to their impairment in motor, social communication, senses (sensors) and other behavioral domains (9). The inability to perform complex motor activities can lead to the tendency to simple and sedentary activities such as watching television or using a computer (10). In addition, the social and communication difficulties of children with ASD can significantly impair their ability to engage in group sports and establish relationships with peers. Sensory modulation problems in children with autism may affect their ability to play and avoid activities with intense sensory stimulation (10). Similarly, behavioural problems or preferences such as very limited interests, adherence to inflexible schedules and preferences for highly predictable, structured activities may limit the choices of children's activities with ASD (10, 11).

For the development of the physical fitness of a child with ASD, a regular exercise programme combining aerobic components, strength, flexibility and agility exercises, ball games and neuromuscular training is recommended to achieve maximum results in fitness and physical composition (12). Children with autism aged 6 to 8 years should develop cardiovascular and muscle endurance. For these children, there are various sports activities such as running, cycling, balance (rotating and walking on the line), water games, swimming, walking, stationary, two - or three-wheeled bicycles, running, dancing, and using trampolines (13). Sport and exercise in children with autism not only develop physical performance, but also improve social integration and communication skills and reduce the ability to exhibit inappropriate behaviour (14).

On the other hand, children with attention and hyperactivity disorder (ADHD) as the main characteristic show problems with increased activity, carelessness and impulsivity, which significantly affects their behaviour and executive functions (15). Moderate-intensity aerobic exercises that can improve the executive functions of these children, their behavioural control, work memory and cognitive flexibility are recommended (16).

Cerebral palsy (CP) is caused by brain injuries and leads to a motor delay in childhood. Children with CP may experience visual, hearing, speech and possibly intellectual impairment; then feeding difficulties, slow motor development with tone and movement disorders (7). A holistic approach to the assessment of a CP child is essential to ensure that restrictions are addressed comprehensively. Furthermore, intellectual assessments are extremely important for any rehabilitation programme (17). The aquatic exercise programme is effective in the functional rehabilitation of children with spastic CP (18).

Although they differ in expression and degree of difficulty, children with intellectual disabilities share common characteristics such as early motor, cognitive and behavioural impairments, comorbidities, social adjustment problems, etc. Physical activity may be beneficial for children with intellectual disabilities, due to a positive impact on motor, social, behavioural and cognitive functions (9). Cognitive disorders of children are considered an obstacle to physical activity, indicating the need for the child's day structure and thorough preparation of activities, as well as cognitive support to motivate the child (19). One example of intellectual disabilities is Down's syndrome. Overweight and obesity are common side effects in people with Down syndrome, so light physical activities such as walking can be useful in achieving health benefits. If possible, resistance training can also improve muscle strength in the upper and lower limbs. In addition, stimulation of the mouth and face may increase the problems of this part of the body common in these people, such as difficulty swallowing (20).

In general, children with developmental disabilities can benefit from structured therapeutic programs such as physical therapy, occupational therapy, or game therapy to support their motor development. These programs are individually adapted to the child and are aimed at strengthening muscles, improving balance, coordination of movements and motor control.

Motor stimulation at a very early age is important in order to develop a complete motor profile and appropriate skills and increase their effectiveness. Areas of motor skills development needed to participate in everyday life include body awareness, motor planning, mutual motor integration, balance skills and fine motor control (21). The World Health Organization (WHO) recommends that children aged 5-15 should spend at least 60 minutes a day in moderate to intensive physical activity (22). Early treatment involving work on: rough motor, fine motor, movement coordination, strengthening of body musculature, etc. is important.

Through regular physical activity, free and organized play, children learn spatial (i.e., front/back, right/left, up/down, in/outside, big/small, etc.), time (before/after, quick/slow, sequential/alternating, etc.), quantitative (full/small, whole/part, etc.) and qualitative elements (hard/easy, hard/soft, rough/smooth, etc.) of specific movement patterns. These elements are fundamental to the combination of movement patterns that encourage the development of motor coordination. In children aged three to five, the process of motor learning is aimed at adopting a broad repertoire of basic motor skills, enabling the expression of coordinated and conditioned motor skills (23).

All movement system activities, including crawling, walking, running, jumping, throwing, catching, pushing, kicking, swinging, climbing, etc. contribute to the development of general motor skills. All perceptual motor activities, including assembly, disassembly, tearing, cutting, insertion, stacking, stringing, rolling, painting, etc. contribute to the development of fine motor, upper limb coordination, and vision motor coordination.

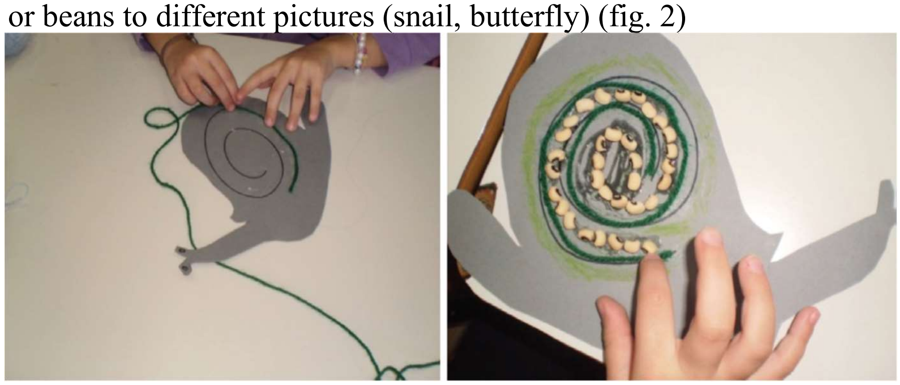
The following programmes will have an impact on the development of coordination:

- To develop general motor skills;
- For toning and gaining autonomy;
- To develop mobility skills;
- To develop jumping and jumping skills;
- For the development of throwing and catching skills;
- For the development of running skills;
- To develop balance;
- For the development of vision-motor coordination;
- For the development of manipulative capacity;
- For the development of graphomotor;
- Relaxation (24).

A fine motor programme in a survey of preschool and early school children (25) had a positive impact on the children participating in it, including the following activities:

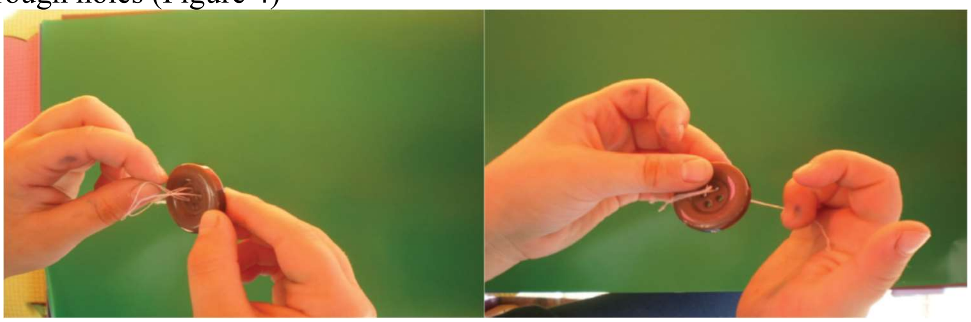
• snapping newspaper leaves into pieces with fingers
• use of images from magazines to merge already drawn identical images (Figure 1)

• gluing wool or beans to different pictures (snail, butterfly) (fig. 2)

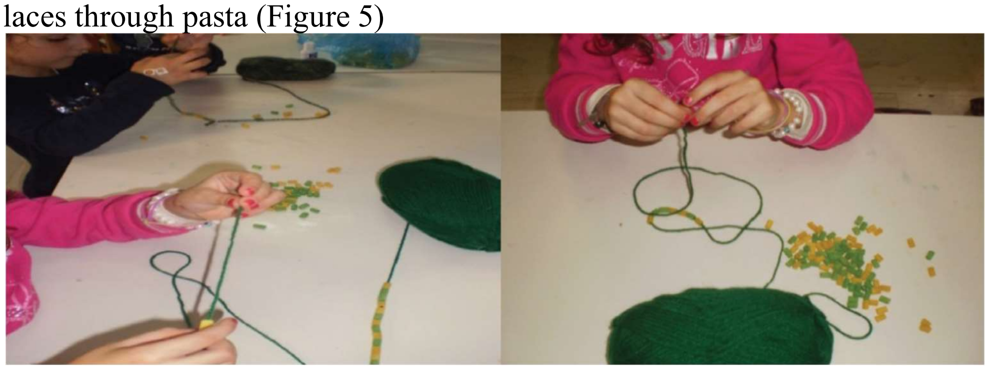


• cutting the pages of magazines into pieces using scissors (Figure 3)

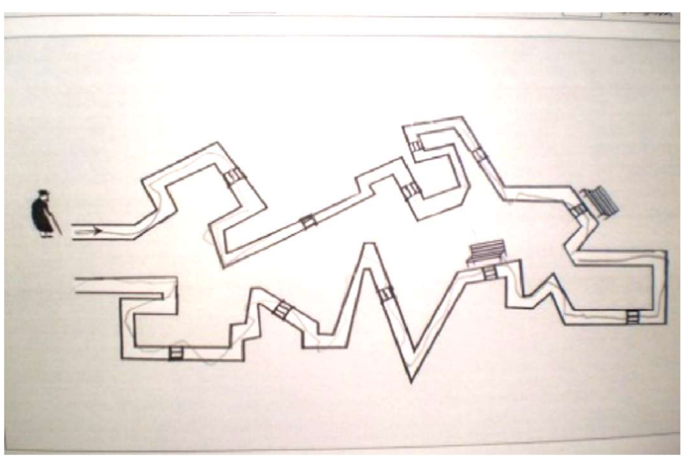
• copying different drawings shown (e.g. houses, clouds, flowers, trees, fish, etc.)
• thread through holes (Figure 4)



• drawing laces through pasta (Figure 5)



• Graphomotoric development exercises that included writing from left to right of paper, etc. (Figure 6)



• Making small paper balls and sticking them over a circle or two overlapping lines.

Recommendations for physical activity of parents themselves

Caring for a child with developmental disabilities can be complex and sometimes exhausting for parents, resulting in increased stress, which can harm their physical and mental well-being. Therefore, self-care and maintaining the optimal health of parents of children with developmental disabilities is of great importance for the welfare of the child.

Many studies have shown that mothers usually have more responsibilities in the day - to - day activities of childcare and household chores, and that as primary caregivers, they were physically less active than fathers. Mothers also often experienced selfish self-isolation and exercise. They had a tendency to see themselves as a central figure in the health and well-being of the family and felt that taking time to care for themselves was detrimental to the family (26).

Researchers examined various dilemmas and compromises for women when trying to balance family life with physical activity and showed that motherhood is a double-edged sword because there are social pressures to be perfect Supermoms, which can make mothers wonder if it is acceptable to put oneself first (26).

However, parental/maternal involvement in physical activity is associated with reduced stress. Physical activity is associated with improved thinking ability, reduced depression and anxiety, better sleep, weight control and ability to manage daily activities. Some of the guidelines to facilitate the exercise of physical activity by parents are that it should be an activity that is easily feasible and accessible (such as walking), that it should be carried out in a society or group (with other parents/friends, near the house or after work), with music that helps motivate them to participate in the activity (27).

Conclusion

Parental support and engagement, the structure and dynamics of the functioning of the family, and cooperation with experts play an important role in promoting the physical activity of children with developmental disabilities. The family situation is seen as the key to motivation, and the contribution of an expert team to improve the active way of life is necessary. Stakeholders should cooperate among themselves, among different paediatric healthcare units, as well as outdoors with other organisations. An example of parental support suggested in previous studies is parental education on the well-being of physical activity and the importance of giving the child an opportunity to be active (28).

Literature

1. Čoh M. Motor and intellectual development in children: a review. Facta Universitatis, Series: Physical Education and Sport. 2021:515-23.
2. Gonzalez SL, Alvarez V, Nelson EL. Do gross and fine motor skills differentially contribute to language outcomes? A systematic review. Frontiers in psychology. 2019;10:2670.
3. Clark JE, Metcalfe JS. The mountain of motor development: A metaphor. Motor development: Research and reviews. 2002;2(163-190):183-202.
4. Webster EK, Martin CK, Staiano AE. Fundamental motor skills, screen-time, and physical activity in preschoolers. Journal of sport and health science. 2019;8(2):114-21.
5. Strooband KF, de Rosnay M, Okely AD, Veldman SL. Systematic review and meta-analyses: Motor skill interventions to improve fine motor development in children aged birth to 6 years. Journal of Developmental & Behavioral Pediatrics. 2020;41(4):319-31.
6. Mitić M. Deca sa smetnjama u razvoju, potreba i podrška. Beograd: Republički zavod za socijalnu zaštitu. 2011.

7. Brown KA, Parikh S, Patel DR. Understanding basic concepts of developmental diagnosis in children. Translational pediatrics. 2020;9(Suppl 1):S9.
8. MacDonald M, Esposito P, Ulrich D. The physical activity patterns of children with autism. BMC research notes. 2011;4(1):1-5.
9. Srinivasan SM, Pescatello LS, Bhat AN. Current perspectives on physical activity and exercise recommendations for children and adolescents with autism spectrum disorders. Physical therapy. 2014;94(6):875-89.
10. Reynolds S, Bendixen RM, Lawrence T, Lane SJ. A pilot study examining activity participation, sensory responsiveness, and competence in children with high functioning autism spectrum disorder. Journal of autism and developmental disorders. 2011;41:1496-506.
11. Borremans E, Rintala P, McCubbin JA. Physical fitness and physical activity in adolescents with Asperger syndrome: A comparative study. Adapted Physical Activity Quarterly. 2010;27(4):308-20.
12. Bricout V-A, Pace M, Dumortier L, Miganeh S, Mahistre Y, Guinot M. Motor capacities in boys with high functioning autism: Which evaluations to choose? Journal of Clinical Medicine. 2019;8(10):1521.
13. Moor J. Playing, Laughing and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers Second Edition: Jessica Kingsley Publishers; 2008.
14. Yanardağ M, Yılmaz İ, Özgen A, Aras Ö. Approaches to the Teaching Exercise and Sports for the Children with Autism. International Journal of Early Childhood Special Education. 2010;2(3):214-30.
15. American Psychiatric Association D, Association AP. Diagnostic and statistical manual of mental disorders: DSM-5: American psychiatric association Washington, DC; 2013.
16. Zhidong C, Shujie L, Aiguo C, Anmin L, Jian Y, Xia X, et al. Expert consensus on the dose-effect relationship of physical exercise delaying cognitive decline in the elderly. 上海体育学院学报. 2021;45(1):51-65, 77.
17. Dalvand H, Dehghan L, Hadian MR, Feizy A, Hosseini SA. Relationship between gross motor and intellectual function in children with cerebral palsy: a cross-sectional study. Archives of physical medicine and rehabilitation. 2012;93(3):480-4.
18. Akinola BI, Gbiri CA, Odebiyi DO. Effect of a 10-week aquatic exercise training program on gross motor function in children with spastic cerebral palsy. Global pediatric health. 2019;6:2333794X19857378.
19. Boman C, Bernhardsson S. Exploring needs, barriers, and facilitators for promoting physical activity for children with intellectual developmental disorders: A qualitative focus group study. Journal of Intellectual Disabilities. 2023;27(1):5-23.
20. Ruiz-González L, Lucena-Antón D, Salazar A, Martín-Valero R, Moral-Munoz J. Physical therapy in Down syndrome: systematic review and meta-analysis. Journal of Intellectual Disability Research. 2019;63(8):1041-67.
21. Kurtz EA. Understanding motor skills in children with dyspraxia, ADHD, autism, and other learning disabilities: A guide to improving coordination: Jessica Kingsley Publishers; 2007.
22. Bull FC, Al-Ansari SS, Biddle S, Borodulin K, Buman MP, Cardon G, et al. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. British journal of sports medicine. 2020;54(24):1451-62.
23. Colella D, Morano M. Gross motor development and physical activity in kindergarten age children. International Journal of Pediatric Obesity. 2011;6(sup2):33-6.
24. Nikolić S, Ilić-Stošović D, Ilić S. Razvojna procena i tretman dece predškolskog uzrasta: Resursni centar „Znanje “, Beograd.; 2015.
25. Spanaki IE, Venetsanou F, Evaggelinou C, Skordilis EK. Graphomotor skills of Greek kindergarten and elementary school children: Effect of a fine motor intervention program. Comprehensive Psychology. 2014;3:01.9. IT. 3.2.
26. Lewis B, Ridge D. Mothers reframing physical activity: family oriented politicism, transgression and contested expertise in Australia. Social Science & Medicine. 2005;60(10):2295-306.
27. Johnson NL, Bekhet AK, Sawdy R, Zint E, Wang J, Pena S, et al. Parent physical activity: A systematic review of the literature and recommendations for parents of children with autism spectrum disorder. Journal of Physical Activity and Health. 2022;19(2):132-47.
28. McGarty AM, Westrop SC, Melville CA. Exploring parents' experiences of promoting physical activity for their child with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities. 2021;34(1):140-8.

Nutrition for children with developmental disabilities

Research prof. Danijela Ristić-Medić, MD, PhD

Most important messages:

Cerebral paralysis

- Children with cerebral palsy have a higher risk of malnutrition, so keep a diary of the child's diet.
- Children with cerebral palsy should drink enough fluids, take small bites and chew carefully.
- In order for the child to master the swallowing technique, use the help of a physiotherapist, it is necessary for the parents to master the technique of positioning the child, touch stimulation techniques in the area of the lips and in the mouth as well as fascilitation techniques and use the various aids available to facilitate the feeding process.

Down's syndrome

- Children with Down syndrome have frequent constipation, so keep the child adequately hydrated and encourage the intake of foods rich in fiber.
- Children with Down's syndrome have a higher risk of obesity, so keep obesity under control, monitor calorie intake, adjust the diet and make sure that the child has daily light physical activity.
- The high frequency of celiac disease and lactose intolerance in children with Down syndrome requires a special approach to nutrition under the supervision of a physician.

Autism spectrum

- There is no universal "best diet" for children with autism spectrum disorders. The recommendation is a dietary approach that promotes and has health benefits, a varied diet with the availability of all food groups.
- Most children insist only on a certain type of food, the way it is prepared and presented, specific rules during meals, as well as certain cutlery.
- Eating a large amount of food in a short period of time can be common in children on the autism spectrum.
- Gluten-free diet shows primarily individual positive changes in behavior, performance and social interactions in children on the autism spectrum.
- The analysis of the diet of children with autism showed a small amount of vitamin C, vitamins B1, B2, B6, B9 and B12 and vitamin A in their diet.

Based on the available studies, dietary problems in children with developmental disabilities were found to be significantly more common than in children with typical development. The causes of problems with the diet of children with developmental disabilities are the result of a combination of different factors and arise from the clinical picture itself (Table 1).

Table 1 Basic nutritional issues for selected developmental disabilities in children [1,2]

Developmental disabilities	Nutritional diagnosis	Aetiology/signs and symptoms
Down syndrome	Inadequate oral intake	Difficulty swallowing Weak breast-feeding
	Altered function of digestive organs	Obstipation Hypotonia Low activity level Insufficient fibre intake Celiac disease
	Overweight/obesity	Estimated excessive energy input Reduced energy needs related to hypotonia
Cerebral palsy	Excessive energy input Overweight	Low level of mobility and activity Reduced energy consumption Antispasmodic medicinal products
	Inadequate oral intake Insufficient body weight (Underlying global nutrition assessment)	Lack of coordination for self-feeding Oral motor dysfunction/dysphagia Hypertonia, dystonia
	Altered function of digestive organs	Obstipation Gastroiesophageal reflux disease Delayed gastric emptying Undesirable effects of medicinal products
Spina bifida	Difficulty swallowing	Common respiratory infections

		Cough/choking on oral food intake
	Altered function of digestive organs	Low fluid and fibre intake Irritable bowel syndrome
	Overweight/obesity Inadvertent weight gain	Limited mobility Reduced energy needs due to low growth
Autism spectrum disorders	Inadequate oral intake	Sensory hypo - and hyperreactivity Limited interests Conduct rigidity
	Insufficient body weight	Motor problems
	Altered function of digestive organs	Opstipation

In the literature, the term "food problems" has multiple meanings and is used most often to describe behaviour in the diet and when feeding such as:

- dietary selectivity,
- rejection of food,
- aggressive behaviour and tantrums (fits of rage) during feeding,
- lack of appetite,
- problems with chewing and swallowing,
- presence of symptoms of spike disorders (eating inedible substances, non-food items),
- vomiting,
- as well as repetitive (repeating) and ritual patterns of meal behaviour (3, 4).

Children need adequate nutrients and calories to maintain good health as well as to maintain proper growth and development (Table 2) (5.6). Nutrition can present a significant challenge and effort for children with developmental disabilities. The feeding process depends on psychomotor development, i.e. oral motor capacity (7). Problems with feeding any child can be stressful for both the child and the parents. Helping a child cope with eating problems can be a long and slow journey, difficult for parents. Parents' efforts lead to better child health and dietary flexibility.

Which affects the feeding process:

- The taste and smell of food and what it feels like in your child (sensory questions).

- Parents' experiences with food also affect nutrition. When all of these work well, feeding progresses well. If there are problems with one of these, this can affect the feeding process.
- Following the same time, place, and routine helps your child to know what will happen during meals and what you want from him/her during meals.
- It is essential that parents take notes:
- What does a child eat?
- How much does he eat?
- What does he refuse to eat?
- How does a child behave during a meal?

When should a parent be concerned?

- If a child loses weight,
- If the child weighs more than the child's age recommendations,
- If a child eats uniform food,
- If eating behavior causes stress.

Table 2 Energy needs of children with developmental disabilities [5,6]

Diagnosis Clinical condition	Age	Calorific input required
Down syndrome	Boys: 5-12 years Girls: 5-12 years of age	16.1 kcal/cm height 14.3 kcal/cm height
Prader-Willi syndrome	Children and adolescents	10-11 kcal/cm height for weight maintenance 8.5-11 kcal/cm height for gradual weight loss
Spina bifida	Children > 8 years min active or approximately 50% of the recommended intake for post-childhood age	9-11 kcal/cm height for weight maintenance 7 kcal/cm height for weight loss
Cerebral palsy	Children: 5-11 years	13.9 kcal/cm height with mild to moderate physical activity 11.1 kcal/cm height for serious physical limitation
Ataxic cerebral palsy	Adolescents	Up to 6,000 Cal/day

Obesity-overweight

Children with developmental disabilities have a 59% higher risk of obesity than children with typical development (8). Obesity occurs when your child's caloric intake is greater than the energy needs over a long period of time without adequate energy consumption. In this case, excess calories are stored in the body in the form of energy reserves (glycogen, fat) and consumed in case of increased physical needs or if the body is starving. A child will not be obese if there is a balance between food intake and energy consumption.

How do you assess whether your child is obese?

Based on an assessment of the timetable and development of subcutaneous fat.

- Body mass index (BMI) > P85 - children at risk of developing obesity!
- Body mass index (BMI) > P97 - premature children!

Obesity calculation formula:

$$BMI = \frac{TM(kg)}{TV(m)^2}$$

The body mass index (BMI) shall be calculated when the body weight of the child expressed in kilograms is divided by the body height of the child expressed in square metres.

Children with developmental disabilities should be systematically monitored for weight (8.9). Physicians-nutritionists or dieticians prescribe a therapeutic diet for weight loss.

Example: Most children with Prader-Willi syndrome need care and attention throughout the day, especially due to uncontrolled appetite. Without proper support and food plan, children often overeat and gain weight and quickly become obese. A person with Prader-Willi syndrome will need high-quality nutrient-rich foods, food supplements and calorie restriction to balance calorie intake with calories burned (10).

Malnutrition

Children with developmental disabilities in middle-developed countries have two to three times the risk of malnutrition compared to their peers with typical development (11). Malnutrition is defined as an “imbalance” between nutrient requirements and inputs resulting in cumulative energy, protein or micronutrient deficits that may adversely affect growth, development and other relevant outcomes. Anthropometric status is an indicator of malnutrition, of which weight and height are the most commonly used diagnostic tools for malnutrition of children with developmental disabilities. Special growth graphs have been developed for children with Down syndrome and cerebral palsy (12).

How to boost your child's balance of food intake and consumption?

It is very difficult for a child to “sit all day” and consume unnecessary amounts of food. It is known that today, fruit is represented in minimal quantities, children do not eat vegetables, fish is completely unknown, for wholemeal bread - parents often say “My children will not eat it”, etc. Accordingly, parents need guidance on child nutrition.

In most cases, children with developmental disabilities do not consume sufficient amounts of calcium, potassium, magnesium, fibre, vitamin E, and D.

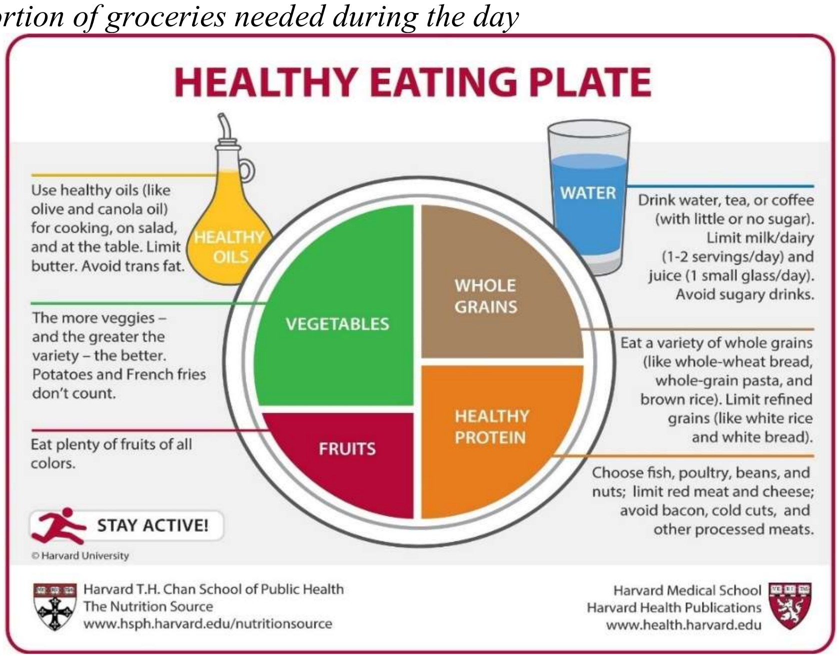
List of foods in which the concentration of these nutrients is highest:
Calcium – dairy products with a lower fat content, *chia* seeds, sardines, almonds, dried figs, oranges, white beans, spinach, kale, broccoli.
Potassium – legumes, potatoes, bacat, avocados, prunes, tomatoes and yogurt.
Magnesium – whole grain products, nuts, pumpkin seeds, spinach and beans.
Fibres:
1. whole grains (barley, quinoa, oat flakes and popcorn)
2. pulses (beans, lentils, soya beans, peas)
3. fruit (apples, avocados, green bananas and berries)
4. vegetables (broccoli, carrots, asparagus, sprouts)
5. nuts and seeds (almonds, walnuts, sunflowers and linseed)

Vitamin E – vegetable oils (corn, sunflower, soya, as well as wheat germ oil), cold pressed oils, sprouts (wheat, maize), walnuts (nuts, almonds, peanuts), sunflower seeds, olives, oatmeal, eggs, green vegetables (spinach, broccoli).
Vitamin D – salmon, tuna, mackerel, yolk, mushrooms (7, 13, 14).

Recommendation for proper selection of foods for children with developmental disabilities

To create a clear picture of the necessary basic diet, make a list of allowed and unauthorized foods with an expert to help you navigate. In recent years, access has been simplified and the meal is determined by “my plate” (Figure 1). (15) So a shallow plate, usually for lunch or dinner, is divided into four parts. Proteins (fish, chicken, pulses, nuts) are placed in the first, carbohydrates (whole grains) and in the remaining two raw vegetable salads and/or cooked vegetables and fruits.

Figure 1. Proportion of groceries needed during the day



Basic principles of proper diet for children:
Adequate or optimal diet: contains sufficient quantity and optimal ratio of proteins, carbohydrates, fats, vitamins, minerals and water according to the needs of the child
Balanced or balanced diet: appropriate combination of different food groups, balanced ratio of solid and liquid food
Moderate diet: control of the size of the portion
Variety of meals: foodstuffs of different colours on a plate
Full diet: ensures a feeling of fullness and satisfaction after meals (16.17).

Combination of groceries

It is desirable not to mix more different types of protein in the same meal as this makes digestion more difficult. It is desirable not to mix several different types of carbohydrates in the same meal as combining them in one meal results in an increase in the calorific value of the meal.

Proteins - meat, fish, eggs, milk and milk products

When it comes to meat, it is best to use young and lean meat prepared by cooking, marinating, melting or baking in your own juice. Fish is an excellent choice of protein and is easily digested. Prepare it by baking or boiling. Eggs are an important source of nutrients and should be present in your child's diet. In the absence of lactose intolerance, it is desirable to use products with as little milkfat as possible (young cheese, partly or wholly skimmed milk, yogurt, kephir, sour milk). Legumes in the diet provide proteins of plant origin and in combination with cereals, a complete intake of amino acids is achieved.

Carbohydrates - bread, pasta, potatoes, rice

The types of cereals used in the diet will also depend on whether your child has celiac disease. When cereal products are used, whole grains are certainly a healthier choice. The best way to prepare a potato is to cook it or cook it in an oven with as little fat as possible. The use of whole rice and other whole grains increases the uptake of beneficial plant fibres.

Vegetables

When buying vegetables, choose seasonal, preferably domestic. Prepare as much fresh raw salad as possible. If vegetables need heat treatment, this should be done by cooking, steaming, or baking with as little fat as possible.

Fruit

It's best for a child to eat fresh fruit, but a good choice is dried or frozen fruit. When using dried fruit or nuts, take into account the amount the child eats because of the high-calorie value. Fruit is desirable only in the form of morning or afternoon snacks.

Intake of confectionery and sweet drinks

Children naturally like candy, and it's up to parents to choose and limit the amount. Due to the potential risk of diabetes and excessive weight, it is important to avoid adding sugar to your child's diet in any form. The consumption of sugar, especially during pregnancy and childhood, and the consumption of carbonated beverages in pregnant women may negatively affect the cognitive functions of the child, while the consumption of fruit in children may lead to an improvement in cognitive functions (18). It is recommended to reduce the consumption of sugar or added sugar to below 25 g per day (approximately 6 teaspoons per day) and to limit the consumption of sweetened beverages to less than one serving per week (200-355 ml per week). Based on the available data and related uncertainties, the intake of added and free sugars should be as low as possible in the context of a nutritionally appropriate diet. Reducing the intake of added and free sugars to a similar extent would reduce the intake of total sugars (19).

Acquisition of eating habits

When a child is born, it can distinguish between sweet and sour and in the first three months prefers sweet and frowns on sour and bitter. That's one of the reasons she likes the taste of her mother's milk. The child's sense of taste will develop over time, and about the fifth month it can also distinguish between salty foods. As more and more buds appear in the language, reactions to certain foods will change over time. Until the first year of life, the child needs to be fed slowly, so that he has more time to explore different flavors, learn to enjoy food, and decide which foods he prefers, but also gradually accept the food he refused. All of this takes time, smaller children start eating junk food on average after more than ten servings. No salt, sugar, artificial sweeteners and flavour enhancers are added to children under one year of age. If a parent does not become accustomed to healthy and natural tastes from infancy, it will be difficult to win the battle with additives and flavour enhancers found in sweets, savoury snacks, and fast food (20).

In recent years, the number of diets and recommendations available via the Internet, newspapers or other media has increased sharply. There are also mobile applications through which it is possible to consult “online”, discuss with other groups of members, order delivery “to the door”, but the most important thing is that parents of children with developmental disabilities consult experts.

Food allergy and intolerance

The occurrence of unwanted reactions to food, both intolerance and allergies, is constantly increasing in children, especially in children with developmental disabilities (21). At one time, children were significantly less allergic to food, usually to one, possibly two, food ingredients, and today allergies to three or more food ingredients are very common in children. According to the Ordinance on the labelling, labelling and advertising of foodstuffs, the largest potential allergens must be identified on the packaging: cereals containing gluten, and goods made from these cereals, crustaceans and crustacean products, eggs and fish products, peanut products, soya and soya products, milk and milk products (including lactose), nuts and their products, celery and celery products, sesame seeds and sesame products.

Adverse reactions to food may be mediated by immunological and non-immunological mechanisms. Food allergies are immune-mediated (immunoglobulin E (IgE) mediated; IgE non-mediated; mixed or pooled (IgE mediated and IgE non-mediated reactions)), while food intolerances are caused by non-immune mechanisms including toxic, pharmacological, genetic and metabolic reactions. Food intolerances are much more common than food allergies, and the most common triggers are low molecular weight chemicals and biologically active food components. Symptoms of food allergy and food intolerance are often similar and include gastrointestinal symptoms (abdominal pain, cramps, diarrhoea, constipation and bloating) of skin (rashes and eczema) and respiratory problems. Symptoms of allergy are intense and can occur within half an hour of food consumption, but up to a few hours later. Food intolerance gives less symptoms, which are mainly limited to digestive problems.

The most common examples of food intolerance are carbohydrate intolerance (lactose and fructose), pharmacologically active food components (histamine and tyramine) and food additives (sulphite, sodium glutamate). In all cases of unwanted reactions to food prevention is important, i.e. avoiding certain foods or ingredients that cause unwanted reactions. In case of lactose intolerance, the therapy consists of adding the missing enzymes, while the only treatment of gluten enteropathy is the ejection of gluten peptides from the diet (22).

Dietary specificities of children with Down syndrome

1. **Children with Down syndrome often face digestive problems, which can lead to imprisonment**

Recommendations:

Keep the child hydrated - If the child does not inject enough fluid, his colon will withdraw all water from the food during digestion, making it difficult to expel the stool due to reduced muscle tone.

Encourage the consumption of fiber - children with Down syndrome often face digestive problems, which can lead to constipation (obstipation). To combat constipation (obstipation), a kid with Down syndrome needs to eat fiber-rich food, such as apples, berries, avocados, lentils, bananas, quinoa, oats, popcorn, and sweet potatoes.

2. **Children with Down syndrome are at higher risk of obesity and are often overweight.**

Recommendations:

Keep your obesity on alert – even if your child eats the same amount and type of food, doing the same activity at the same intensity as his healthy peers, they will burn 15% less calories than their peers. Decreased thyroid function is often diagnosed, which may contribute to obesity. Due to slower basal metabolism, your child uses less energy when resting or sleeping. **Ensuring a diverse and balanced diet is essential for proper growth and development.** Feed your child nutrient-rich food and limit fast food without nutritional value. Children with Down syndrome should be breast-fed for as long as possible to create a better immune system, but also to prevent obesity.

Keep track of how many sweet drinks your child drinks. Carbonated beverages, sports drinks, chocolate milk, and fruit juices have too much sugar that makes it easier to thicken. It's important to know how much sugar your child drinks. Sugar-sweetened beverages are the largest source of added sugar in children's nutrition.

Decreased calorie intake and increased physical activity. The restriction of calorie intake to children under 18 years of age is inevitably performed under medical supervision.
Almost all evidence for effective weight management interventions for young people with Down syndrome includes components that focus on healthy nutrition and physical activity. Specific dietary recommendations vary widely in research, so no approach has proved to be better than the other.

The common components of successful dietary interventions in children with Down syndrome are:

- making specific recommendations for the number of portions from each food group;
- promotion of low-energy-density food (e.g. fruit, vegetables and lean meat)
- limiting high energy density foods (e.g. sweet and roasted foods);
- avoidance of complete dietary restrictions;
- allowing children to eat their favorite food moderately;
- monitoring of food intake and diet using simple pictorial images (7).

3. **Children with Down syndrome have a high incidence of celiac disease.**

Recommendations:

Gluten avoidance - If your child has been diagnosed with gluten enteropathy, all wheat, barley and rye products are excluded from use, and at the beginning of a gluten-free diet it is often recommended to exclude oats. This gluten-free diet can be diverse and satisfying if your child's diet includes fruits, vegetables, eggs, millet, quinoa, rice, buckwheat, chickpeas, beans, pulses, fish and chicken. Celiac disease is treated by completely eliminating gluten from the diet. The products that can be used are maize, rice, buckwheat, millet, quinoa and amaranth. In case of anaemia and malnutrition, it is recommended to take additional vitamins and minerals at the advice of the physician.

4. **Children with Down syndrome are more susceptible to lactose intolerance (milk sugar).**

Milk and all lactose-containing milk products should be removed from the diet of the child and lactose-free products should be administered moderately and are now available. Some medicines, meat products and confectionery may contain lactose. It is recommended to consume yoghurt with probiotics (good bacteria) that digest lactose while also supporting the whole digestion. If dairy products are completely eliminated, in order to compensate for the lack of calcium from milk and dairy products, account should be taken of its intake and other foods in which it is abundant should be included in the diet: white beans, sardines, dried figs, green leafy vegetables (chard, spinach, cabbage, kale), apricots, oranges, broccoli, almonds, sesame and tofu cheese (9.23).

Nutritional specificities of children with cerebral palsy

The establishment of an adequate and varied diet for children with cerebral palsy is quite complicated, with a number of doubts, and its implementation in practice can be particularly demanding for parents. The various associated diseases these children often suffer from, including difficulty swallowing, chewing, problems with the digestive organs and various allergies, but also with mobility and reduced motor functions make daily eating difficult. Attention and patience as a parent are needed. There are steps that parents can take to facilitate the feeding process. Given that each child is a story for himself and that each case of cerebral palsy is special, it is recommended that parents always consult their physician on drawing up an individual diet plan for their child (5, 24, 25)

1. **In addition to a diverse and nutritionally adequate diet, it is extremely important that the child ingests enough fluid to avoid dehydration.**

Recommendations:

Often, children with cerebral palsy have difficulty eating and drinking liquids because they have difficulty swallowing. Some children with cerebral palsy tend to stick out their tongue and have difficulty keeping their mouths shut. These kids feed on soft food. Parents often have to use physiotherapists to master swallowing techniques. By exercising, the child can gradually learn to use a spoon.

2. Keep a diary of the child's diet with cerebral palsy

Recommendations:

Often during the day, a child eats something along the way that can affect his appetite during his regular meals. It is only when it is put on paper that you see how often forgotten bites actually happen. Keeping a diet diary (example - Table 3) has proven to be very effective in the long term, so it is important that the parent persists. This detailed overview of your child's diet can be a great help to your physician in understanding the diet patterns that your child has adopted. They will have insight into the variety of food the child eats, as well as the changes that need to be made.

Table 3 Diary (example - one day, 5-year-old child)

Meal time (beginning-end)	**Place of meals (house, restaurant the street, vehicle)**	**Type of meal** (breakfast, lunch, dinner, snack)	**Meal society** (only, family, collective)	**Type of food preparation method** (cooked, roasted, fried, dystano, fried, fresh)	**Details meals** (amount of spoon, cups, pinch..)	**Mood** (neutral, good luck, reluctantly, angrily, aggressive, boring, tired, rejecting food)	**Food (eaten, not eaten)**
8.00-8.30	house	breakfast	only	Oatmeal Milk Banana	½ cups 150 ml Medium	reluctantly	Meal eaten
11.00-11.20	vehicle	snack	only	Apple	Medium	neutral	Eaten half a meal
14.00-15.00	house	lunch	family	Broccoli soup Roast chicken Cabbage salad	1 plate 120 g 1 cup	furiously rejects	Not eaten Add a potato that

							loves
17.00-17.30	street	snack	only	Tangerines	2 small	neutral	Eaten meal
19.30-20.30	house	dinner	only	Bread slices Poached egg Butter Tomatoes Yogurt	60 g 1 egg 1 spread ½ 200 ml	tired	Eaten half a meal
		between meals		Chocolate Pudding	50 g 1 cup	good luck.	

3. Children with cerebral palsy are at higher risk of malnutrition

Recommendations:

Children with cerebral palsy often have malnutrition problems due to pain and problems that can occur during feeding. In addition to losing muscle weight and weight, malnutrition is also characterized by symptoms such as a persistent feeling of cold, pale and dry skin, as well as lower immunity and frequent illnesses and colds. If you suspect that your child is not inputting enough vitamins and minerals at any time, be sure to contact your physician to avoid serious consequences.

4. Children with cerebral palsy have long meals

Recommendations:

The reasons may range from physical and health problems that prevent a child from eating, to child indifference, and to eating as an obligation. So, each meal of a child should be an important event for parents. It would also be good to try to plan each meal at the same time during the day. Choose a colorful plastic dish that your child will like, which is safe and reduces the possibility of injury in case of an accident. By establishing such a rhythm, the child will have a healthy habit of eating at the same time each day. Learning about food through smell and touch can also have positive results and bring the child into a mood to eat. Involve the child in making meals with you, of course nothing complicated, adapted to the child's abilities, with simple tasks for the child such as adding certain ingredients.

5. What vitamins and minerals are most commonly needed by children with cerebral palsy?

Recommendations:

No supplements should be given to the child unless prescribed by the physician. What is most commonly recommended for children with cerebral palsy as supplements are calcium, vitamin D, phosphorus and magnesium (24.25). Calcium is a mineral that helps the development and functioning of bones and teeth. As for vitamin D, it is extremely important for the immunity and absorption of calcium from food, and the best natural sources of this vitamin are in the sun when the skin is not covered with clothing. It is best, if the feeding process is adequate, to inject these nutrients with food. Phosphorus is found in milk products, but also in seeds, meat, fish, eggs and nuts. Magnesium is a mineral that plays a major role in energy production, is essential for protein synthesis, transmits nerve impulses, but is often not enough in the human body, especially in people with cerebral palsy, so sometimes it is necessary to take it further with the consent of a physician.

Key questions to be asked to parents to assess feeding/swallowing problems in children with cerebral palsy:

1. How long does it take to feed your child?
   Reply: more than 30 minutes, regularly
2. Is meal time stressful for a child or parents?
   Answer: Yes, if one or the other, or both.
3. Does your child gain adequate weight?
   Response: lack of weight gain over 2-3 months in a toddler, not just weight loss
4. Are there any signs of respiratory problems?
   Response: increased congestion at mealtime "cramped" voice, respiratory disease

If the answers are in the upper form, your child has a feeding disorder.

What are the challenges with nutrition, and why do they occur in children with autism?

Based on available studies, 60-80% of children with autistic spectrum disorders have nutritional problems (2, 3). How can a parent recognize that his child with autistic spectrum disorder has a nutritional problem?

If a child notices that a certain type of food is rejected, he has a limited repertoire of foods that he accepts to eat, he often eats only one food in a meal (e.g. selective consumption of only certain foods, such as those rich in carbohydrates) (26).

The key diagnostic symptoms of autism are thought to be: repetitive (repeated) and stereotypical behaviour, tendency to routines and rituals, limited interests, as well as resistance to change and new ones, greatly affect dietary selectivity, most children insist only on a certain type of food, a particular way of preparing and presenting it, special rules during meals, as well as certain cutlery (27).

In 70-90% of children with autistic spectrum disorder, there are specific patterns of sensory processing of information in the form of hyper or hyposenitivity that also significantly contribute to increasing dietary selectivity and food aversion of a particular texture, colour, appearance, taste, smell and temperature. In addition, children with autistic spectrum disorder are more likely to experience food neophobia than children with typical development, namely child resistance and refusal to take new and unknown foods (4).

Children with autistic spectrum disorders have further difficulties in consuming food due to problems in the field of cognitive ability, primarily in the functioning of the (executive) functions responsible for planning, controlling and carrying out the target activities, as well as problems in motor functioning in the field of fine motor (26, 28).

In short, the dietary problems of children with autism spectrum disorder are (29, 30):

- Limited range of texture, colour, taste, smell or temperature of food
- Food presentation rituals
- They eat or put non-food products in their mouths (SO-called PIZZA)

- Compulsive eating (consumption of large amounts of food over a short period of time, with no feeling of control and no compensation)
- Packing large amounts of food in the mouth
- Voluntary vomiting, cramps and rumination (vomiting and reswallowing)
- Refusal to feed or failure to improve texture, associated with a limited range of sensitivity to the texture of food when accepting a novel food.

These behaviours in the diet of children with autistic spectrum disorders can lead to health and other developmental problems because consumption of only certain foods can result in malnutrition and slow development of the child, as well as lack of vitamins and minerals needed by the body.

Dietary approach in children with autism spectrum disorder

There is no "best diet" for children with autism spectrum disorder (31). The recommendation is a dietary approach that promotes and has health benefits:

- Limits the intake of simple sugars, salts, saturated fats, trans fats and cholesterol.
- It has a moderate fat intake, mainly from healthy vegetable oils (olive, flax, pumpkin).
- It includes sufficient whole grains, fruits, vegetables and a good source of calcium (dairy products, fortified food or food supplements).
- Restricts confectionery, juices, desserts, processed meat and savoury snacks (e.g. chips).
- It contains low-fat proteins mainly from plant sources and a limited amount of animal proteins (i.e. meat).
- Most children with autistic spectrum disorders, who refuse to eat a variety of foods, are fed a multivitamin/mineral supplement recommended by their physician. The additive should only provide 100% of the recommended dietary intake that is suitable for the individual (32).
- Gluten-free diet therapy in children with autistic spectrum disorder shows individual positive changes in their behaviour, appearance and social interactions (22).
- In people with autism spectrum disorders, gluten-free/caseless and ketogenic diets, camel milk, turmeric, probiotics and fermented foods can potentially play a role in alleviating the symptoms of autism, while consumption of sugars, additives, pesticides, inorganic processed foods and digestible starch can exacerbate symptoms. This requires new research to make general evidence-based recommendations (33, 34).
- There is currently insufficient evidence for a relationship between diet and childhood autism symptoms (35).

Nutritional requirements of children with autism spectrum disorders

- Physiological needs are the same as for other children for basic macronutrients and micronutrients
- An analysis of the diet of children with autism showed a low prevalence of vitamin C; vitamin B1, B2, B6, B9 and B12 and vitamin A in their diet (36).
- Rare cases of serious dietary deficiencies such as rickets (vitamin D), scurvy (vitamin C) and visual impairment (vitamin A) with serious aversion to food have been reported.
- Lower levels of ferritin and vitamin D have been observed in some children.
- Children who continuously receive food supplements (vit A, B6, B12, C, E, D, calcium,

iron) often intake more than the recommended daily needs for these vitamins and minerals. The application of supplements must be conditional on the absence of a particular vitamin or mineral (32).
- During the visit to the physician, the pediatrician should check the diary and take supplements.

Medical conditions that may affect the feeding of children with autistic spectrum disorders

- The child reacts to abdominal pain. If your child does not want to eat, it may be his way of avoiding stomach problems. Discomfort caused by nausea or pain may cause a child to reject food that he or she ate before these symptoms.
- Constipation can also cause stomach cramps and cause food rejection.
- Problems such as acid reflux or stomach problems caused by medicines a child takes every day can cause stomach pains and make him not eat.
- An allergy to certain foods. If you notice that food your child regularly eats causes stomach problems, rashes, itching, or other symptoms, it may be an allergy to food.
- Dental problems
- Swallowing problems

Your child's pediatrician in the above-mentioned medical conditions decides on the need for specialist consultations such as allergy or gastroenterologist.

DRINKING (putting items other than food in the mouth) may be associated with

- Lack of iron
- Late stage of development (children exploring objects with their mouths)
- Obsessive behavior and anxiety

Drug interactions. Some stimulants used in autism may reduce your appetite. This can reduce the amount of food a child eats, which can affect growth. Other medicines may increase your appetite or affect the absorption of certain vitamins and minerals. If your child is taking medicines, ask your physician about possible side effects.

Additional reasons for feeding problems in children with autistic spectrum disorders:

- Persistence of feeding difficulties due to developmental retardation
- Obsessions related to food presentation, texture, colour or taste
- Anxiety about changes or things that are new
- Possible sensory differences in the perception of taste, texture and smell and related food avoidance
- Learned patterns of behavior.

What can a parent do at home to help in situations with eating problems?

Frequently asked questions by parents:

1. Why does my kid like processed food/carbs, but he refuses to eat fruit and vegetables?
   Carbohydrates are often mild (e.g. they do not have strong colours, tastes, smells). Crunchy products stimulate the child's senses. In contrast, fruit and vegetables have stronger colors, flavors, and fragrances. Your child's reaction to these sensory factors can help you understand his or her preference for certain foods.

2. How can I prevent my child from evicting certain foods from his diet and encourage him to eat a variety of foods?
   It is important to offer food that the child already loves, as well as food that the child still does not love. The good rule is to offer only three groceries at once. Include one or two items that your child already loves and one that your child does not yet accept. If your child does not tolerate new food on his plate, place the new food next to him or her on a special plate to make the child accustomed to the new food. Introduce new food in small snacks in a fun or familiar way to increase your child's likelihood of eating it.

3. My kid hates a custom chair for kids, but he won't come to the table and sit down and eat with the rest of the family. He prefers to walk and eat. How can I convince him to sit down and eat with us?
   There are a number of reasons why children with autism may have difficulty sitting at a table during meals. Some children are hyperactive and find it difficult to sit still even for a short time. The presence and smell of certain foods can be unbearable for a child. Your child may avoid sitting at the table with family members because in such social situations he becomes anxious. Depending on which of these factors is present, several methods may be helpful. Engaging in motor activities (jumping, running) before and after normal meal routines may seem reassuring and help prepare your child for meals. When a child approaches the table to pick up something he wants to eat, commend him for reaching the table and slowly encourage him to spend more time at the table, even if he is just standing there. In the end, you should feel comfortable enough to sit down for a while.

4. We started with new ideas for feeding about three weeks ago, but we only notice small changes in the child's diet. Shouldn't it be better by now?
   Starting and solving feeding problems through small, subtle, consistent changes will most likely result in long-term, permanent changes in your child's eating habits. It is common for children to improve, but they also occasionally return to old eating habits. Any small success is significant (36).

Recommendations for parents according to the feeding Guide (Autism Speaks Autism Treatment Network, ATN)

- *Do not allow snacks, food or drink to be available to your child during the day.*

Why? This reduces appetite, the willingness to try new foods during main meals, increases the number of total calories ingested during the day. Set a time period on the day he can nibble. If your family nibbles or eats so much during the day, so will your child. Family members should also be careful not to eat snacks between meals. The child is recommended to have five or six meals during the day without taking any additional food, especially snacks.

- *Position of the child during feeding*

Place the child in a high chair, at a table that suits the child, so that he can sit upright, without leaning, rocking, or kicking. A girdle or other supports may be used to support the foot. This physical stability stimulates good feeding behavior and reduces disturbing behavior by allowing the child to feel safe.

- *Limit meal time*

Limit the meal time to 30 minutes and the meal time to 15 minutes. Then move all the food and direct the child to other activities.

- *Reduce disturbing factors (distractions)*

Because of distractions like television, pills, telephones, a child cannot focus on food. You only feed a child when it's awake and careful.

- *Involve your child in the feeding process*

Allow your child to help you choose and make meals even if they do not taste the final product. Your child's involvement allows him to explore and play with different foods, without expecting to have to eat them. Food represents a multisensory experience; therefore, it is important to give the child the opportunity to explore, crumble, crush, and smear different food textures, and not to prevent them from doing so. Everything that reaches the mouth must first go through our hands, especially for children with challenges in the tactile system.

- *Practice a pleasant and healthy diet*

Children learn by watching. During family meals, parents and other children can be examples of good feeding behavior for a child. Feeding is a social event, and we particularly emphasize that during mealtimes, other family members should eat at the same time. Meals should always be eaten in a high chair or at the table, without exception. Make the mealtime fun, and don't focus too much on the child eating. Avoid constant shouting, persuasion, and begging. By bringing wholesome food for the whole family, you show your child how to choose wholesome food.

- *Reward your child's positive behavior*

Commend your child when he approaches you or tries new groceries. Instant rewards, such as blowing balloons or stickers, can be useful in stimulating a new way of feeding. Remember that rewarding good behavior during meals will increase the likelihood of this happening again.

- *Ignore the child's negative behavior*

When possible, ignore a child when he spits, throws, or refuses food. Remember, you don't want to encourage such behavior by paying attention to them. Proper management of such behaviour when difficult may require professional advice (36).

Medical evaluation of feeding problems for children with developmental disabilities

- History and physical examination, lab tests.
- Allergy testing for determining nutritional allergies
- Nutritional consultancy with a dietician or nutritionist to evaluate calorie intake and intake adequacy (deficit or surplus).
- The child should receive speech and/or work therapy (assessment and intervention) for oral motor dysfunction or sensor limitation.
- Common - bite reflex, tongue thrust, lip pull, sensory, nasal regurgitation
- Appropriate food/liquid, dishes, location, equipment, technique/support (therapist)
- Changing the texture of food, liquids, thickeners.

Brief general recommendations:

- Children should be offered routine meals and snacks.
- The meal time should be calm and free of disturbance to the household.

- Adults should sit with their children and eat the same food.
- Children with motor skills should feed themselves.
- At each meal, the caregiver should provide food that is eaten by the family, but at least one food known to be accepted by the child. That way the kid has something he'll probably eat.
- A child should be asked to eat. Begging and threats shouldn't happen. Once the child is finished, he should be allowed to leave the table.

There is no food and drink until the planned snack or meal to make the child hungry for a meal.

- If a family culture is without a meal schedule, it is unlikely that a child will follow a different schedule.
- Children who do not see their families eating vegetables are unlikely to eat them.
- Families may need help in determining meal times and meal patterns.
- Specialised feeding problems such as mouth shrinkage, rumination, severe spades and intense aversions require the support of experts experienced in behavioural (psychologists) or oral motor therapy (speech or work therapy).

The usual traps for parents, carers or carers are:

- The expectations of the amount of food to be eaten are too high.
- Concerns about food compromise or dehydration lead to relaxation and allowing the child to eat empty calories (candy and juices)
- If the child's behaviours (e.g. food rejection, agitation) have always had an effect on getting the food they want or on being able to stop eating and get up from the table, the child intensifies these troubled behaviours in the collective. Caregivers should be advised of this in case of a newly administered child (5.37-40).

Literature

1. Ptomey LT, Wittenbrook w position of the Academy of nutrition and Dietetics: nutrition services for individuals with Intellectual and developmental disabilities and special health care news. J acad nutr diet. 2015; 5:593-608.
2. Marí-Bauset S, Zazpe I, Mari-Sanchis A, Lopis-González A, Morales-Suárez-Varela M. food selectivity in Autism spectrum Disorders: a Systematic review. J child Neurol. 2014 29:1554-61.
3. Adamovic M, Birgermajer D, Sretenovic I, Stoseljevic M. eating problems in primary school age children with Autism spectrum disorder. Belgrade, October, 29-30th, 2021 Proceedings 269-276 file:///C:/Users/USER/Downloads/bitstream_4341.pdf
4. Vissocker RE, Latzer Y, carpenter O, Rabenbach A, Gal E. eating problems and patterns Among Toddlers and young boys with and without Autism spectrum Disorders. Research in Autism spectrum Disorders 2019; 59: 1-9.
5. Bell KL, Samson-Fang L. Nutritional management of children with cerebral palsy: a practical Guide. EUR J Clin nutr 2013; 67 (Suppl 2): S13-S16
6. IOM DRI: the essential Guide to the utrient requirements. Washington, DC: National academies Press 2006.
7. Klein A, Uyehara M, Cunningham A, Olomi M, cash K, Kirk CM. Itional care for children with Feeding difficulties and disabilities: A scoping review. PLOS Global public Health. 2023 Mar 17; 3:e0001130.
8. Bandits L, Danielson M, Esposito LE, Foley JT, Fox MH, Frey GC, et al. Obbesity in children with developmental and/or physical disabilities. Disabil Health J 2015; 8 (3): 309-16.
9. Ptomey LT, Oreskovic NM, Hendrix I, Nichols D, Agiovlasitis S. weight Management recommendations for youth with Down syndrome: expert recommendations. Front Pediatr 2023; 10:1064108.
10. Miller JL, Tan M. dietary Management for adolescents with Prader-Willi Syndrome. Adolesc Health Med ther 2020; 11:113-118.

11. Bouma S. Diagnosing Pediatric Malnutrition. Nutr clinic impact 2017; 32:52-67.
12. Health resources and services Administration, maternal and child Health Bureau. The CDC growth charts for children with Special Health care news. https://www.medicalhomeportal.org/link/5550 (15August 2023, date last accessed).
13. YASUDA H, Tsutsui T. assessment of infantile mineral imbalances in Autism spectrum Disorders (ASDs). INT J Environ RES public Health 2013; 10 (11): 6027-43.
14. Villagomez A, Ramtekkar U. Iron, magnesium, Vitamin D, and Zinc Deficiencies in children proposing with symptoms of attention deficit/hyperactivity disorder. Children (Basel). 2014; 1 (3): 261-79.
15. https://www.hsph.harvard.edu/nutritionsource/healthy-eating-plate/
16. https://www.hsph.harvard.edu/nutritionsource/kids-healthy-eating-plate/
17. Faizan in, Rouster AS. Nutrition and hydration requirements in children and adults. [Updated 2022 AUG 29]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan -. Available from: https://www.ncbi.nlm.nih.gov/books/NBK562207/
18. Cohen JFW, Rifas-Shiman SL, young J, Oken E. associations of Prenatal and child sugar take with child cognition. Am J Prev Med 2018; 54:727-735.
19. Huang Y, Chen Z, Chen B, Li J, Yuan X, Li Jet al. Dietary sugar Consumption and Health: umbrella review. BMJ 2023; 381:e071609.
20. De Cosmi V, Scaglioni S, Agostoni C. early taste experiences and later food choices. Futures 2017, 9:107.
21. Xu G, Snetselaar LG, Jing J, Liu B, Strathearn L, Bao W. Association of food allergy and other Allergic conditions with Autism spectrum disorder in children. PIT Netw open 2018; 1(2):e180279.
22. Sumathi T, Manivasagam T, Thenmozhi, AJ. The roll of gluten in Autism. In: Essa, M., Qoronfleh, M. (EDS) personalized food intervention and therapy for Autism spectrum disorder Management. Advances in neurobiology, Springer, Cham 2020 vol 24 https://doi.org/10.1007/978-3-030-30402-7_14
23. Roccatello G, COCCHI G, Dimastromatteo RT, Cavallo A, pearl GB, Selicati M, Forchielli ML. Eating and lifestyle habits in Youth with Down Syndrome attending a care program: an exploratory lesson for future improvements. Frontiers in nutrition 2021; 8 641112.
24. Rebelo F, Mansur IR, Miglioli TC, Meio MDB, Junior SCG. Dietary and nutrition interventions in children with cerebral palsy: A systematic literature review. PLOS one. 2022; 17:e0271993
25. Cohen Kadosh K, Muhardi L, Parikh P, basso M, Jan Mohamed HJ, Prawitasari T, et al. Nutritional support of Neurodevelopment and cognitive function in infants and young children-an Update and Novel Insights. Utrients 2021; 13:199.
26. Gal E, Gal-Mishael R, Vissoker RE, Hedley D, bury SM, carpenter O. eating challenges in children with Autism spectrum disorder: Development and Validation of the “aut-eat” Questionnaire (AEQ). J Autism Dev Disord 2022; 52:811-822.
27. Leader G, Tuohy E, Chen JL, Mannion A, Gilroy SP. Feeding problems, Gastrointestinal symptoms, challenge behavior and sensory issues in children and adolescents with Autism spectrum disorder. J Autism Dev Disord 2020; 50:1401-1410.
28. Nadon G, Feldman DE, Dunn W, Gisel E. Association of sensory processing and eating problems in children with Autism spectrum Disorders. Autism RES treat 2011; 2011:541926.
29. Malhi P, Saini S, Bharti B, Attri S, Sankhyan N. Sensory processing function and Mealtime behavior problems in children with Autism. Indian Pediatr 2021 SEP 15; 58:842-845.
30. Sathe N, Andrews JC, McPheeters ML, Warren ZE. Nutritional and dietary events for Autism spectrum disorder: A Systematic review. Pediatrics 2017; 139(6):e20170346.
31. Li YJ, Li YM, Xiang DX. Supplement intervention associated with Nutritional deficiencies in Autism spectrum Disorders: a systematic review. EUR J nutr 2018; 57:2571-2582.
32. Hammers H, Sanlier N. current Nutritional Approaches in Managing Autism spectrum disorder: A review. Neurosci nutra. 2019 22:145-155.
33. Yu Y, Huang J, Chen X, Fu J, Wang X, Pu L, Gu C, Cai C. efficacy and Safety of diet technologies in children with Autism spectrum disorder: A systematic literature review and meta-analysis. Front Neurol. 2022; 13:844117.
34. van der Wurff I, Oenema A, de Ruijter D, Vingerhoets C, van Amelsauort T, RUTTTEN B, et al. A scoping literature review of the relation between nutrition and ASD symptoms in children. Utrients. 2022 Mar 26; 14 (7): 1389.

35. Wartanian, C. overview of Nutritional therapy for Autism spectrum disorder. In: Essa, M., Qoronfleh, M. (EDS) personalized food intervention and therapy for Autism spectrum disorder Management. Advances in neurobiology, 2020 vol 24. Springer, Cham, https://doi.org/10.1007/978-3-030-30402-7_17.
36. http://imh.org.rs/data/13%20Vodic-za-hranjenje.pdf
37. Molina-López J, Leiva-García B, PLANELLS E, PLANELLS P. food selectivity, Nutritional inadequacies, and Mealtime behavioral problems in children with Autism spectrum disorder compared to neurotypical children. INT J eat Disord. 2021; 54:2155-2166.
38. All V, Mullan B. individual differences in Executive function predict distinct eating behaviours. Appetite. 2014; 80:123-30.
39. Chistol LT, Bandini LG, mouth A, Phillips S, Cermak SA, Curtin C. Sensory sensitivity and food selectivity in children with Autism spectrum disorder. J Autism Dev Disord. 2018; 48:583-591.
40. Esteban-Figuerola P; canals J; Fernández-Cao. C; Aria Val V. Differences in food Consumption and nutrition take between children with Autism spectrum Disorders and typically developing children: A meta-analysis. Autism 2019; 23:1079-1095.

Abuse of children with developmental disabilities

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Most important messages:

- Child abuse can be physical, sexual, emotional (psychological), neglect and exposure to family or intimate partner violence.
- The causes of child abuse may vary and are usually a combination of several factors: individual (parents and children), relational and social.
- Children with developmental disabilities are at greater risk of abuse than children without disabilities.
- Most often children with developmental disabilities are abused by their family members because of stress, frustration, and health problems they have as parents of children with developmental disabilities.
- Children with developmental disabilities are often abused and/or neglected in the care institutions.
- There are clear signs of abuse and neglect that parents should recognize.
- It is important that parents of children with developmental disabilities care for their own health because it is the only way they can benefit their child.
- It is important that parents of children with developmental disabilities be networked and open to help.

Child abuse involves behavior that deviates from the rules of conduct and endangers physical or emotional harm. So far, four forms of child abuse have been most frequently discussed: physical abuse, sexual abuse, emotional abuse (psychological abuse) and neglect (1, 2).

However, the literature has recently mentioned the fifth form of child abuse: exposure to domestic or intimate partner violence (1, 3, 4).

Physical abuse is defined as the use of intentional acts and physical forces that inflict bodily harm. Specific forms are shaking (cherry), dropping, kicking, biting and applying burns (e.g. oiling or cigarettes) (1, 2).

Sexual abuse includes contact and contactless sexual acts carried out by any adult or child in a position of power over the victim in order to seek or obtain physical or mental sexual satisfaction (1, 2).

Emotional or psychological abuse is inflicted by a parent or guardian and includes hostile interactions (such as disparagement, humiliation, embarrassment, child ridicule and child rejection), emotional unavailability (ignoring the child), developmentally inappropriate interactions, disregard for the child's individuality and isolation of the child from society or non-integration of the child into society (1, 2).

Neglect represents a failure to meet the child's basic physical, emotional, educational and health needs, i.e. failure of the parent or guardian to meet the child's needs as appropriate to the child's development level and as recognized in the child's cultural context. When a child is not provided with food, clothing, adequate housing, and protection from possible injuries, we speak of physical neglect. Emotional neglect involves the absence of tenderness, love, or other forms of emotional support. Educational neglect includes the absence of care for the child's enrolment in school and attendance or organization of home-schooling where possible. Health neglect is the absence of care to ensure adequate preventive care for the child, such as vaccination, as well as treatment in case of physical or mental health problems (1, 2).

Exposure to domestic violence involves the exposure of a family member to physical attacks, threats or damage to property by another adult or teenager who normally lives in a household. This type of violence also extends to witnessing other forms of behaviour: sexual, financial or verbal compulsion or isolation from family and/or friends (1, 3).

Causes of abuse

The causes of child abuse may vary and are usually a combination of several factors: individual, relational and social (5).

The results of a pooled analysis of the results 68 studies show that the most common factors related to child abuse are parental addiction diseases, childhood abuse history and violence by an intimate partner. Social support was the most significant protective factor at all levels and for all types of abuse other than child sexual abuse, but the definition differed greatly between studies. Physical abuse had the most risk factors unique to this species and then neglect, and the violence of an intimate partner was a frequent risk factor for all types of child abuse. Less research has been found on emotional abuse, sexual abuse and protective factors (6).

The risk of abuse and/or neglect is more common in children under the age of four and in children with developmental disabilities (5). Studies show that children with developmental disabilities are at greater risk of abuse than children without disabilities (7-10). In their research, Sullivan and Knutson conclude that children with developmental disabilities are 3.4 times more likely to be abused than peers without developmental disabilities (10).

The results of the literature analysis done by Jones and associates estimate that 26.7% of children with developmental disabilities were exposed to some form of violence, 20.4% to physical violence and 13.7% to sexual violence. Furthermore, the results show that children with developmental disabilities are more than three times more likely to experience any form of violence compared to their untroubled peers (11).

A recent analysis of several studies shows that despite all public health activities children with developmental disabilities are still exposed to all kinds of violence, especially children living in families with poor means (12).

There are studies examining how so-called ecosystems affect the abuse of children with developmental disabilities, which are: socio-demographic characteristics (age, gender, education), micro-systems (parent-child relationship and domestic violence), exosystems (parental stress, parents' social support and housing) and macro-systems (culturally defined parental practices). Furthermore, research shows that children with developmental disabilities and their families often face social risk factors, such as isolation, discrimination and lack of support, which may increase their risk of becoming victims of abuse (13). In this text, we will describe the risk factors for abuse in two categories: risk factors related to family characteristics and parenting and risk factors related to the specificities of a child with developmental disabilities (13).

Risk factors related to family characteristics and parenthood

Research shows that caring for a child with developmental disabilities requires extra effort and can increase family stress. The causes of stress are related to: additional financial costs, lack of time, anxiety arising from frequent unforeseeable situations, the physical and emotional health of parents or carers as well as their concerns about the future (14). Whittingham and associates published the results of a study summarising data collected from focus groups where parents of children with cerebral palsy were discussed (15).

The challenges faced by these parents are divided into the following groups:

- Pressure due to lack of time - arising from the need to take the child for examination, therapy, hospitalization etc.
- Additional parental tasks - related to the child's health. Parents of children with developmental disabilities must invest time to help the child at home, carry out therapy, administer medication, organise equipment, provide mobility assistance, prepare special meals. In addition, they are parents and advocates of their children.
- Parenting under the lump of the public - parents of children with visible difficulties feel almost constantly under the control of the public and become increasingly difficult when the child's actions attract the attention of the public.
- Managing the child's behaviour - parents of children with developmental disabilities have a difficult task of discerning which child's behaviours are the result of his physical and mental limitations, which are rebellious and require assertive parental intervention.
- Parenting without standards - parents of children with developmental disabilities state that they are in doubt about setting realistic goals for their child and realistic expectations (15).

Furthermore, there is evidence that parents caring for children with developmental disabilities have lower health (physical and mental) than parents of children without disabilities: more common are back pain, headache, migraines, stomach problems, etc. These parents are also more likely to be anxious, angry, frustrated, or depressed, suffering from sleep disorders, guilt, and Dr (14).

A high level of stress and concern for self-health may impair the ability of parents to provide adequate care to their children and may thus also be the cause of abuse (14). Therefore, parents of children with developmental disabilities should be made aware of the importance of caring for personal physical and mental health.

Parents of children with developmental disabilities often isolate themselves socially, perhaps not realizing that their children are more at risk of being abused than other children. They are also not prepared to recognise risky situations and protect children in such situations. Linking parents of children with developmental disabilities to enable social interactions (e.g. support groups, associations, etc.) can help them better protect their children and make them feel better themselves (14).

The family function is also "under trial." It includes communication, cohesion, flexibility, realisation of the related role in the family and confrontation processes within the family. Families with children with developmental disabilities, especially those with children with intellectual disabilities, are more burdened, less functioning, less satisfied with their marriage, and less harmonious (16). All of this results in tension and conflicts between couples, lack of closeness between parents and other children and possible negative effects on the quality of life in the family of children with developmental disabilities (17).

However, these negative experiences do not apply to all parents of children with developmental disabilities. In some families, it is children with developmental disabilities that can be a source of positive changes such as stronger cohesion within the family, improved intimacy among family members and a review of health and life values (17). It is therefore of paramount importance to foster positive family relations and to build support networks to enable better family functioning.

Low-income families often have lower housing conditions, which may make it difficult to care for a child with developmental disabilities. Such housing conditions, as well as financial uncertainty, can be a source of frustration and stress, which are known risk factors for abuse. Furthermore, such families often live in less developed areas of the city with an unsafe neighbourhood and thus a weaker social network, which is often an additional source of stress (13).

Risk factors related to the specificities of a child with developmental disabilities

Many risk factors for abuse may be linked to the characteristics and specificities of the child itself with developmental disabilities. For example, due to developmental difficulties, a child may feel isolated or infirm (13).

Children with behavioural problems, such as attention/hyperactivity disorder (ADHD) or other behavioural problems, are more likely to experience physical abuse because parents may become frustrated with the child's hard-to-bear behaviour and will react strongly (18).

Children who are less able to do things on their own rely more on adult care and help. These children are more likely to be sexually abused or neglected by adults (18).

Abusers can take advantage of children who have problems with speech, hearing, or who have limited ability to protect themselves, do not understand well social situations, or what abuse is. These children are more likely to experience sexual abuse (18).

Abuse of children with developmental disabilities in institutions

Although children with developmental disabilities are most often subjected to abuse by family members, abuse of these children is also possible in institutions by other persons who take care of them.

Safe and stable relationships between parents and children and between parents and other adults are an important prerequisite for protecting children from abuse.

Parents may prevent child abuse if they recognise signs of possible abuse such as sudden behavioural changes or unusual behaviour, cuts and bruises, fractures (not related to a disease), burns, complaints from the child about painful genitals. They may also prevent neglect if they recognise signs of neglect such as persistent hunger or thirst (not for health reasons), dirty hair or skin, chronic diaper rash (not for health reasons).

There are verified websites on the internet that have evidence-based advice. One such site is that of the US Centres for Disease Control and Prevention (CDC) (18). Important CDC advice on the problem of child abuse with developmental disabilities are:

- Find out what your child does when he's not home.
- Meet the people who take care of your child.
- Leave your child alone with someone you know and who can take care of your child in a place where your child will be safe from harm and danger.
- At school, everyone must treat your child with dignity.
- Your child should not be punished by abuse, restraint, or solitude.

- Take steps to make sure that your home is a safe place for your child so that he or she does not get hurt.
- Talk to your child about conduct and situations that are safe and unsafe.
- Remind your child of the safe adults he can contact.
- Role-playing and practicing how to find a safe adult can help young children learn where to go.

If you think your child has been abused or neglected:

- Talk to your child's physician about this
- Take the child to a hospital or physician's office for examination
- Call the police.
- Call an association that brings together parents of children with developmental disabilities.

Take care of your health:

- Being a parent is the hardest job. As a parent, you can easily overload yourself, especially if you have a disabled child or other special health needs.
- Have realistic expectations about what your child can and cannot do.
- If you are frustrated, give yourself time to calm down and focus again!
- Ask the people you trust to help you.
- Try to think positively.
- Take some time for yourself.
- Talk to a health care professional like your physician or therapist if you do not know how to deal with your child's behavior.
- There are many resources that help parents to be the best parents and provide a safe and caring world for their children (18).

In conclusion, addressing abuse in children with developmental disabilities is a matter of paramount importance, requiring multiple approaches. These vulnerable children deserve a safe and stimulating environment where they can thrive and be protected from any type of damage. Addressing abuse in children with developmental disabilities requires a comprehensive and compassionate approach, including awareness raising, prevention, support services, empowerment, cooperation, reporting mechanisms, legal protection and research. By working together, we can create a safer and more stimulating environment for these children, enabling them to realise their full potential and lead full lives without abuse and injury.

Literature

1. Mehta D, Kelly AB, Laurence KR, Haslam D, Williams KE, Walsh K, et al. Child Maltreatment and long-term physical and mental Health Outcomes: an Exploration of Biopsychosocial Determinants and implications for Prevention. Child Psychiatry Hum Dev. 2023; 54 (2): 421-35.
2. MSD Manual of Diagnostics and therapy. Child abuse. Link: http://www.msd-prirucnici.placebo.hr/msd-prirucnik/pedijatrija/zlostavljanje-djece.
3. Gardner MJ, Thomas HJ, Erskine HE. The Association between Five forms of child Maltreatment and Depressive and anxiety Disorders: A systematic review and meta-analysis. Child abuse Negl. 2019; 96:104082.
4. Ford-Gilboe M, Wathen CN, Varcoe C, MacMillan HL, Scott-Storey K, Mantler T, et al. Development of a brief measure of intimate partner violence experiences: the Composite abuse scale (revised) - short form (CASR-SF). BMJ open. 2016; 6(12):e012824.

5. Centers for disease control and Prevention. Violence Prevention. Risk and Protective factors. Link: https://www.cdc.gov/violenceprevention/childabuseandneglect/riskprotectivefactors.html.
6. Younas F, Gutman LM. Parental risk and Protective factors in child Maltreatment: A systematic review of the existence. Violence abuse trauma, 2022:15248380221134634.
7. Lightfoot E, Hill K, LaLiberte T. privilege of children with disabilities in the child Welfare system and out of home placement: an exposure of administrative records. Children and Youth services review. 2011,; 33 (11): 2069-75.
8. Corr C, Santos RM. Abuse and young children with Disabilities: A review of the literature. Journal of early intervention. 2017; 39 (1): 3-17.
9. Putnam-Hornstein E, Needell B. predictors of child Protective Service Contact between birth and age Five: an exit of California's 2002 birth Cohort. Children and Youth services review. 2011; 33 (8): 1337-44.
10. Sullivan PM, Knutson JF. Maltreatment and disabilities: a population-based epidemiological study. Child abuse & neglect. 2000; 24 (10): 1257-73.
11. Jones L, Bellis MA, wood S, Hughes K, McCoy E, Eckley L, et al. Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. Lancet. 2012; 380 (9845): 899-907.
12. Fang Z, Cerna-Turoff I, Zhang C, Lu M, Lachman JM, Barlow J. Global Estimates of violence against children with disabilities: an updated Systematic review and meta-analysis. The Lancet child & adolescent Health. 2022; 6 (5): 313-23.
13. Elicit A, Murphy S, Skovgaard C, Lausten M. physical violence against children with disabilities: A Danish National birth Cohort prospective study. European Journal of Psychotraumatology. 2023; 14 (1): 2173764.
14. Murphy ON, Christian B, Caplin DA, young PC. The Health of caregivers for children with disabilities: caregiver perspectives. Child care Health Dev. 2007; 33 (2): 180-7.
15. Whittingham K, wee D, Sanders M, Boyd R. responding to the challenges of parenting a child with cerebral palsy: a focus Group. Disability and residence. 2011; 33 (17-18): 1557-67.
16. Al-Krenawi A, Graham JR, Al Gharaibeh F. the impact of Intellectual disability, caregiver Burden, family functioning, marital quality, and sense of Coherence. Disability & Society. 2011; 26 (2): 139-50.
17. Kim J, Kim H, Park S, Yoo J, Gelegjamts D. Mediating effects of family functioning on the relationship between care Burden and family quality of life of caregivers of children with Intellectual disabilities in Mongolia. J Appl rees Intellect Disabil. 2021; 34 (2): 507-15.
18. Centers for disease control and Prevention. Safety and children with Disabilities. Childhood Maltreatment Among children with Disabilities. Link: https://www.cdc.gov/ncbddd/disabilityandsafety/abuse.html.

Stress management in families of children with developmental difficulties

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Most important messages:

- Every parent of a child with developmental disabilities should take care of their own health, and seek support from family, experts and other parents.
- Parents should focus on the positive side, maintain a healthy perspective and encourage family unity.
- Parents should share responsibilities and find time for rest and breaks.
- Parents should educate themselves about their child's condition and effective coping strategies.
- Knowledge can reduce anxiety and encourage informed decision-making.
- Parents should celebrate small victories, which boosts the child's moral and self-confidence.
- Parents should set realistic expectations, be flexible in their plans and understand that it is normal to have ups and downs.
- Parents should focus on what they can control, not what they can't.

Introduction

Raising children brings parents joy and satisfaction. However, parents generally face a plethora of challenges after the birth of a child. Consequently, raising children induces stress and demands that the parents make numerous changes in their lifestyles and accept responsibilities. Parents may experience parental stress while raising children, especially if children have developmental difficulties (DD) (1).

Parenting stress was conceptualized as the stress caused by characteristics associated with both children and parents (e.g., parental personality and pathology, attachment patterns, adaptability, children’s demandingness, mood, or any present disease), which determine the pressure parents feel in their parental role (2). Parent-related stress represents the level of dysfunction in the parent–child system related to the parent’s functioning in particular. Parent-related stress includes components of personality and pathology, such as the parent’s subjective feelings of emotional availability to the child, parenting confidence, and investment in parenting. Stressors related to situational factors also contribute to parent-related stress in this framework, such as spousal or partner relationships, perceptions of social isolation, parental health, and feelings of restriction in the parenting role (3).

The financial and psychological burden experienced by family members of children with DD inevitably increases over time. When such issues remain unresolved, the tensions and conflicts within the family can become chronic and severe, even leading to the breakdown of the family. Family conflicts have been reported by 57.8% of families of children with DD, along with the finding that families experience conflict over the burden of care for children with DD or lack of understanding between the family members. As parents raising children with DD require more physical, psychological, and economic resources than parents of children without DD, they experience higher levels of parental stress than parents raising children without DD (1).

Studies report that parents of children with DD have greater difficulties in regulating their emotions, which in turn will negatively affect their behaviors towards their children, as well as their children’s behaviors and well-being. Furthermore, co-parenting and dyadic coping processes have been identified as key factors in successful adaptation for couples facing challenges such as parenting a child with a disability. Co-parenting refers to the ways in which couples collaborate to overcome difficulties and solve problems. Similarly, dyadic coping strategies, such as stress communication and supportive dyadic coping, are essential for effective coping. Parents who possess strong emotion regulation skills are more likely to engage in positive dyadic coping and to utilize less hostile communication, which in turn, promotes better cooperation and enhances relationship satisfaction. This collaboration can be undermined by stress itself, perpetuating conflict and leaving children in a vulnerable situation. Lack of co-parenting behaviors leads to interparental conflict, which usually links to negative outcomes such as lower levels of relationship satisfaction and poorer marital quality, while dyadic coping is strongly related with greater relationship satisfaction, and its enhancement promotes parents' supportive co-parenting (2).

Impact on the family members

Parental stress can have a negative effect on the physical and psychological health of the parents.

Physical health outcomes of parents with children with DD

Family caregivers tend to report poor physical health at a higher rate than non-caregivers, and have shown to experience physical strain from caregiving more often. Further, family caregivers have frequently reported chronic fatigue and poor sleep as a result of stress associated with caregiving responsibilities. Chronic stress related to daily, long-term challenges has been linked to increased risk of heart disease, cancer, gastrointestinal disorders, high blood pressure, overweight/obesity, asthma, and reduced immune functioning. Health problems associated with stress may be exacerbated by family caregivers' low prioritization of their health and well-being (4).

Mental and emotional health outcomes of parents with children with DD

Although many family caregivers report that caring for a child with DD has had a positive impact on their lives, caregivers also report negative mental/emotional health outcomes due to chronic stress. Specifically, caregivers of children with DD have shown to report persistent feelings of anxiety, depression, guilt, and overall psychological distress at a higher rate than non-caregivers. Family caregivers also experience higher levels of stress, depression, and anxiety when the children they care for exhibit challenging behaviors (e.g., aggression, defiance, hyperactivity). All these outcomes can affect the individuals' behavior, cognition, and emotions and, particularly on the individuals' quality of life. They not only affect the daily functioning of individuals, such as changes in weight and sleep patterns, depressed mood, and loss of interest or enjoyment; they can also lead to suicidal ideation and may have a negative impact on raising children (1). Child disability diagnosis, severity, and age, along with the age of the caregiver, have been shown to impact negative psychological outcomes for caregivers of children with DD. Overall, caregivers have identified the need for improved mental and emotional support, and report concerns that their worsening psychological well-being might interfere with the ability to meet the long-term needs of their children (5).

Effect on marriage in parents with children with DD

When parents first learn that their child has DD, their emotional responses vary and have a profound effect on their relationships. Some studies report that divorce rates in parents of children with DD have been reported higher than those who do not have children with DD. The vulnerability to divorce can be explained by the high level of parenting demands and stress of having a child with DD and the subsequent decrease in receptiveness to the needs of one's spouse during these times. Marital distress is affected by the characteristics of the child. When comparing fathers to mothers, the fathers' satisfaction with the marriage was unrelated to the child's skills or behaviors, whereas the mother's marital satisfaction was moderately correlated with the child's behavior. Parents who openly discussed topics related to their children, other feelings and concerns, and their preparedness for the responsibility of children were identified as helpful to maintaining their marriages. Support factors outside the immediate family system, such as external social support through respite care, have been shown to be a significant predictor of marital quality for both husbands and wives (6).

Impact on siblings of children with DD

Siblings of children with DD experience a combination of emotional, relational, familial, and societal peculiarities that can produce tension affecting the sibling and their family. Each child's personality and temperament play an important role in his response toward a sibling, including one with a disability.

Each child's reaction to having a sibling with DD will vary depending on his or her age and developmental level. The responses and feelings of the child toward the sibling with DD are not likely to be static, but rather tend to change over time, as the child adapts to having a brother or sister with DD and copes with day-to-day realities.

Siblings have their own needs themselves. Their sister or brother with DD will get a larger share of attention. While having a sibling with DD presents challenges, it also comes with opportunities.

Children who grow up with sibling with DD may have more of a chance to develop many good qualities, including:

- Patience
- Kindness and supportiveness
- Acceptance of differences
- Compassion and helpfulness
- Empathy for others and insight into coping with challenges
- Dependability and loyalty that may come from standing up for their brother or sister
- Ability to advocate.

Siblings also can grow up feeling the negative effects of having a sibling with DD and may act out to get parents' attention. The impact on family dynamics can go much deeper par ticularly with siblings of children with DD, who may:

- Feel alone or jealous about extra attention for their sibling and interpret it as rejection
- Wish they had medical problems to get more attention
- Worry they might „catch" what their sibling has
- Be overly helpful or non-compliant for attention
- Try to ease parent's burdens by not making demands or feeling guilty if they do

- Feel guilty for their own good health or have negative thoughts about their siblings with special needs
- Feel embarrassed or resent having to involve their sibling with neighborhood friends
- Resent having to care for a sibling or worry about their sibling's future.

Depression, a serious mood disorder in which the patient feels sad or worthless, can affect siblings of a child with DD. Depressive symptoms may be linked to other emotional difficulties, such as the child being resentful or embarrassed by her challenged sibling. The depressed child may also be scared about her/his sibling, feel guilty about being „normal", or be angry about a lack of attention from her/his parents. Red flags for depression include withdrawal, frequent crying, hopelessness, appetite changes, loss of interest, sudden or gradual marked behavior changes, and talking about self-mutilation.

Furthermore, the sibling of a challenged child may feel extra pressure on him/him, either to take care of his sibling or to do the activities that his sibling cannot. Even if the parents are not putting pressure on the child, he/she may feel as though they are. The child may also feel lost or ignored, thinking that all of the attention is being directed at the challenged sibling. Parents should be aware of signs that the child needs help or more one-on-one time. If the child strives for perfection and has poor concentration or self-esteem, parents may consider those signals and act accordingly. Siblings may feel obligated to compensate for the child with the disability, to make up for that child's limitations. They may be acting as a surrogate parent, assuming more responsibility than would be usual in the care of a sibling (7).

Considering the attention given to the child with DD, siblings may neglect their own issues. In some cases, siblings experience parentification where they are expected to have many responsibilities for themselves and their sibling to assist overburdened parents. These siblings develop duties similar to those of parents, leading to them overlooking their own need to act like children. Although this sense of responsibility exhibited by these siblings may be seen as positive to parents, it may actually be a precursor to emotional distress (8).

Effect on grandparents with children with DD

Just as parents and siblings of children with DD must adapt to unexpected roles and changes in family roles, grandparents may find themselves in an unfamiliar and challenging position. The inherent assumption for many grandparents, particularly grandmothers, is that they serve as educational experts for their children, offering advice and information regarding parenting, from toilet training to discipline. As young adults become parents, they often come to value their own mothers more, and their mothers may reciprocate by acknowledging their adult children's status as a parent. Grandparents typically look forward to the time of their lives in which their knowledge is respected and valued while the demands on their time are limited. When a child has a DD, these expectations are largely put aside, and the primary role of being a grandparent changes to being a supportive figure for their adult child in his or her time of need. However, grandparents may struggle with double grief: they may grieve for the loss of the grandchild that they anticipated, and may experience a deep sadness for their own adult child.

Common reactions of grandparents when they find out their grandchild has DD can include:

- Distress,
- Sadness,
- Depression,

- Anxiety,
- Shock,
- Denial,
- Disillusionment, and
- Uncertainty.

After the grandparents have accepted their grandchild's diagnoses, they often respond by becoming more involved and fulfilling a number of supportive functions in the family. In particular, they provide instrumental support, such as grocery shopping and childsitting, as well as emotional support, household responsibilities, or economic and medical support for areas related to school, spiritual, or recreational activities. Findler, 2004 (according to Cauda-Laufer, 2017) found grandparents interpreted the change in their lives as an opportunity for personal growth from the experience of helping to raise a grandchild, watching him or her grow and develop, and the accompanying sense of love, vitality, and joy.

In conclusion, raising a child with DD affects the parents individually, and affects the relationships of parents and the roles and responsibilities of siblings and grandparents. For all family members, the expectations and roles frequently change when a child with DD is born. Many families experience grief, sadness, and negative effects of raising a child with DD. However, researchers have discovered many positive effects, such as a stronger sense of family cohesion, increased compassion, and an overall sense of personal growth (9).

Educational problems in children with DD

Which educational problems will arise depends, first of all, on the type of DD, its severity, gender, age, additional characteristics of the child and the willingness of the family to alleviate them.

Based on the characteristics of temperament, children can be classified into three groups:

1) The easy-to-educate group – Some characteristics of the children in this category are good breeding, neat hygiene habits and a very pronounced curiosity.
2) The difficult-to-educate group – parents describe children from this group like children that often cry, they don't have proper hygiene habits, they eat and sleep disorderly, they react violently to any attempt to impose the will of peers or adults, and some react by withdrawing from unfamiliar situations.
3) The group of "uninterested children", consist of children that show general passivity, withdrawal from unfamiliar situations, negativism and weak reactions to any stimulus.

Even a child without DD can be difficult to raise. However, in children with DD, the frequency of occurrence of educational difficulties and their symptoms is higher are more complex and often last for a very long time, sometimes throughout life.

The inclusion of a child with DD in the education system is still a difficult problem to solve.

The key educational problem related to the education of a child with DD is the *motivation* for education. Parents of all categories of children with DD are focused on the expectation that medical help will solve, or at least alleviate the child's (and their) problem and direct all of their energy towards finding medical help. It is not uncommon for a family to sell off property and go with the child "to the end of the world" because they heard that someone there solved the problem they were having. With that valuable time lost, the child lags behind in education, which significantly hinders his development. Loose relationships with peers become even looser. In a particularly difficult situation are children with physical deficiency or sensory difficulty. Around the age of twelve, they develop a strong sense of self-awareness, dominated by the awareness of the consequences of developmental difficulties in adulthood.

From a theoretical point of view, Olport's suggestion about teleological integrity could have the greatest practical help in solving this problem. For both the child and the parents, the source of the loss of motivation comes from their belief that the effort worth investing in the education of the child in their situation does not make sense. People with severe DD, even with the highest level of education, find it difficult to find work. And when they find it, it's a job well below their educational opportunities, which additionally reinforces the feeling of the futility of the previous effort, and represents an example for others with DD "that it is not worth trying". Increasing the number of available occupations for people with DD, and increase of the sense of the meaning of effort at an early age represents one of the possible solutions to this problem.

The fear of the future, both for the child and for the parents, represents both mental and educational problem. It makes motivation for every activity difficult, both for the development of the child and for the functioning of the family. Parents most often ask the question: "What will happen to the child when we die?" This question is obsessively repeated and is a powerful source of mental tension. Fears, disintegration, purposeful motivations, disappointed expectations and similar problems are strongly associated with the child's educational difficulties. The absence of spontaneity in the family at an early age and during later development makes it difficult for the child's development within the limits of what is possible, and thus mental health problems and educational problems of the child, they become an untangleable knot. If nothing is done, they become more and more complex and difficult to solve (10).

Predictors of stress levels in parents with children with DD

Child factors

Numerous characteristics of children with DD have been found to affect the levels of stress that their parent’s experience.

- The *severity of the child’s impairment* is a strong predictor of parental stress. According to many studies the more severe the intellectual disability of the child, the more negative effects on the parents’ stress levels.
- While several child factors can contribute to the increased level of stress experienced by parents of children with DD, *severity of the child’s behavioral problems* is one of the strongest predictors of parental stress. Children with difficulties are at great risk of having a variety of behavioral disorders including self-stimulation, self-injury, and aggressive behavior. Children with DD demonstrate behavior problems at a rate four times higher than children without DD. Parents whose children with DD experience behavioral problems have additional challenges and demands placed on them. These children may need more individual attention and effective behavioral intervention plans.
- The *age of a child* with DD has also been found to predict parental stress levels. A family may experience greater stress when their child with DD enters school and parents become more aware of the achievement differences between their child and same-age classmates. When the child enters school, more time and effort is needed on the part of the parent to help the child be successful. Additionally, as children get older,

parents may not have access to information on how to cope with older children with DD.

- Although there is less evidence in this area, the <u>*gender of the child*</u> with DD may also play a role in the level of stress a parent experiences. In one study conducted by Frey, Greenberg, and Fewell (1989) (according to Dervishaliaj E., 2013) it was found that the child's gender predicted both the mothers' and fathers' parenting stress with parents of boys experiencing higher stress levels. They also found that fathers were more affected by the child's gender than mothers. Fathers may find it more difficult to adjust their expectations of their sons due to the emphasis on shared recreational activities between father and son rather than caregiver and child. Fathers of children with severe DD may have fewer opportunities for recreation with their child (11).

Parents of children with DD are aware of and sensitive to the reactions of neighbors, friends, and strangers, and adverse reactions may affect the stress experienced by these families.

Parent factors

- Parent gender: A number of studies have shown that there are different levels of stress depending on the gender of the parent of the child with difficulties. The mother of a child with DD is often the primary caregiver and is acutely aware of her child's DD. Therefore, many studies showed that mothers of children with DD may experience higher levels of stress than fathers. Also, there is a difference between mothers and fathers in the coping strategies they use. While fathers tend to suppress their feelings, or to avoid them by working until late or staying away from home, mothers tend to vent their feelings. Mothers tend to experience a wider range of feelings (from grief, sadness, anger and crying) and talk more about their emotional distress with others. Mothers are found to be more stigmatized by their child's disorder (11).

Supporting stress reduction for family caregivers

Given the well-documented physical and psychological health risks associated with caregiving stress, it is critical to support caregivers in reducing stress and improving overall well-being. Social support refers to individuals' subjective evaluation that they will be able to receive the desired support and help at the time of need from the surrounding social networks, including their spouse, relatives, friends, coworkers, or community (1). The following strategies have been shown to reduce negative outcomes among family caregivers of children with difficulties.

Stress-reduction activities

Several strategies can be used by parents of children with DD to reduce stress and improve their health and well-being, specifically:

- Healthy eating
- Maintenance of a restful sleep cycle
- Meditation
- Regular exercise
  - Taking a walk with the child on a nice day
  - Practicing yoga or stretching during nap and bedtime
  - Getting outside for some fresh air or gardening

In addition, coping skill building, mindfulness, and cognitive behaviorally based therapy (CBT) have been found to be effective as a means to reduce stress in family caregivers.

Respite care

Another strategy caregivers can use to reduce stress involves respite care, defined as "planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult. As a parent of a child with DD, allow yourself to take short breaks while trained professionals or volunteers care for your child. This can help reduce stress and prevent burnout (4).

Support groups

Interventions aimed to promote greater social support can help reduce stress in caregivers of children with difficulties. Effective interventions include parents or caregivers engaging with other parents or caregivers through an in-person or social media-based support group.

Parent Training

Given that caregivers often report that their child's behavioral problems impact their stress levels, interventions that teach caregivers how to manage problematic behavior at home and in the community have also been found to be beneficial to caregivers (5). Some training techniques can be:

- *setting realistic expectations:* set realistic expectations for your child's development and progress can reduce feelings of frustration and stress.
- *time management:* parents often face additional responsibilities when caring for a child with DD. Learning time management skills can help you balance caregiving tasks with other family and personal obligations, reducing feelings of overwhelm.
- *education about the DD*: learning about the specific disability and its characteristics can empower you as a parent and provide a better understanding of your child's needs and behaviors.
- *stress management techniques:* parents can benefit from learning stress management techniques like deep breathing, mindfulness, and finding time for self-care. Managing your stress better can positively impact your interactions with your children.
- *communication strategies:* communication can be a challenge for some children with DD. Using visual aids, sign language, or augmentative and alternative communication (AAC) devices, can enhance your parent-child relationship and reduce frustration.

Psychological interventions

Researchers have established various interventions in an effort to help parents reduce stress associated with raising a child with a disability and become more effective in their parenting skills. Researchers have found positive psychology is effective in helping individuals with depression. Because parents of children with DD are at risk for depression, researchers have utilized various positive psychology intervention programs to help parents reduce their depressive symptoms and increase their psychological well-being (9).

Mindfulness-based stress reduction may be a wide disseminated and often cited example of heedfulness coaching that has been shown to cut back stress, depression, and anxiety. Mindfulness-based stress reduction teaches people to look at things and thoughts during a nonjudgmental manner while not reacting to them unthinkingly and helps folks develop an additional automatic consciousness of experiences, and will represent a good instrument for the reduction of stress (12). Research has shown that mindfulness-based stress reduction is an effective program for reducing stress in parents of children with special needs. In addition, parents who have participated in a mindfulness-based program have demonstrated significant reductions in anxiety and stress and improvements in empathic concern, which can foster positive parent-child relations. Mindfulness-based interventions are comprised of activities to increase the persons' ability to be attentive to the present moment, and often include meditation practices as well as activities that promote self-awareness. Evidence has shown that practicing mindfulness results in better emotional self-regulation during periods of acute stress increases cognitive flexibility. Therefore, the caregiver who practices mindfulness may be more present and aware of their reactions in the moment and may respond without negative emotional or perceptual influences. Potential benefits may also extend to the child. Parents who participated in mindfulness-based programs noted reduced behavior problems and increased social skills in their children. When the parent practices self-compassion, they may approach stressful moments with more presence and ease, which may provide the child with a more positive model for responding to challenging situations (13).

Journal writing

Another effective stress management technique is journal writing. This can be a great way for parents of children with DD to get in touch with their feelings and confront their worries. However, it can sometimes be hard to find the energy or inspiration to keep up with a journal. Setting aside ten minutes every other night or after an important appointment or milestone is a great way to make time. It is important to set a realistic goal for journaling and not dwell on missed opportunities (14).

Taking a "time out"

Parents need to be mindful of giving themselves a "time out" when they feel like they're about to lose their temper. It is a healthy way to deal with stress in the moment and models good coping skills for their children as well. Parents can effectively do this by finding a quiet place for a few minutes, practice deep breathing, close their eyes and tune out the chaos long enough to regain composure.

Do not judge yourself too harshly

You are undoubtedly doing your best under difficult conditions. Being a parent of a child with DD is tough, really tough. It is important to set realistic expectations and small achievable goals. It is better to overachieve and set the bar higher next time than to underachieve and feel demoralized. Spending time with other parents of children with DD may help with this. While their situation is different and nobody can ever completely understand what you are going through, it is good to share mutual experiences and feelings.

Conclusion

Parents of children with DD are an incredible source of inspiration and love. They possess a unique strength that shines brightly in the face of challenges. Their unwavering dedication, compassion, and resilience are truly remarkable, making them true superheroes in the lives of their children. These parents demonstrate boundless patience, always taking the time to understand their child's individual needs and providing unwavering support to help them thrive. Their unconditional love knows no bounds, and they consistently go above and beyond to ensure their children receive the care, attention, and opportunities they deserve. In the face of adversity, they become advocates and fierce protectors, fighting tirelessly for their child's rights and inclusion in all aspects of life. Their determination and advocacy help break down barriers and foster a more inclusive and understanding society for children with DD.

Despite the challenges, these parents find joy and celebrate every milestone, no matter how big or small. They create a loving and nurturing environment, where their children can flourish and feel safe. Their ability to see the unique beauty in their child's abilities and personality is truly heartwarming.

The bond between parents and children with DD is a testament to the power of unconditional love and the resilience of the human spirit. These parents teach us the true meaning of patience, compassion, and selflessness, inspiring us to appreciate life's blessings and embrace diversity. In every step of their journey, these parents show us the strength and beauty that can emerge from adversity. Their unwavering commitment to their children's well-being and happiness serves as a beacon of hope and a reminder of the power of love to overcome any obstacle. They are truly heroes in the eyes of their children and the world around them.

Literature

1. Park GA, Lee ON. The Moderating Effect of Social Support on Parental Stress and Depression in Mothers of Children with DD. Occupational Therapy International. 2022;1-8. Available from: https://doi.org/10.1155/2022/5162954
2. Priego-Ojeda M, Rusu PP. Emotion regulation, parental stress and family functioning: Families of children with DD vs normative families. Research in Developmental DD [Internet]. 2023 August;139:104548. Available from: https://doi.org/10.1016/j.ridd.2023.104548
3. Woodman AC, Mawdsley HP, Hauser-Cram P. Parenting Stress and Child Behavior Problems within Families of Children with Developmental DD: Transactional Relations across 15 Years. Research in Developmental DD. 2015 January;36C:264-276. Available from: doi: 10.1016/j.ridd.2014.10.011
4. Auerbach, E., Perry, H., & Chafouleas, S.M. (2019, November). Stress: Family caregivers of children with disabilities. Storrs, CT: UConn Collaboratory on School and Child Health. Available from: http://csch.uconn.edu/.
5. CSCH Brief by Emily Auerbach A, Perry H, Chafouleas SM. Stress: Family Caregivers of Children with DD. Why Focus on Family Caregivers? How do Family Caregivers Experience Stress? Collaboratory on School & Child Health. 2019; Available from: http://www.caregiving.org/pdf/research/Report_Caregivers_of_Children_11-12-09.pdf.
6. Hartley SL, Barker ET, Seltzer MM, Floyd FJ, Greenberg JS, Orsmond GI, Bolt D. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology.* 2010;24:440–457.
7. Bozymowski JA, Mccullough MD, Milonas CC, Genest TJ, Farley EV. Tool Kit for Siblings of Children with Special Needs. Board of Education-Macomb Intermediate School District. 2011 May. Available from: www.misd.net
8. Milevsky A. Siblings of Children with DD. Siblings Issues in Therapy. Palgrave Macmillan London. 2016.
9. Cauda-Laufer N. Raising a Child with a Disability: Coping Mechanisms and Support Needs. PCOM Psychology Dissertations. 2017. Available from: http://digitalcommons.pcom.edu/psychology_dissertations/432
10. Mitić Marija. Deca sa Smetnjama u Razvoju Potrebe i Podrška. Beograd; 2011.
11. Dervishaliaj E. Parental Stress in Families of Children with DD: A Literature Review. Journal of Educational and Social Research. 2013 Oct 1;

12. Nirmalafousta A, Rymalamathen. Promoting Mental Health by Stress Management to Parents of Disabled Children. International Journal of Innovative Research in Technology. 2022 February;8(9);628-632; ISSN: 2349-6002
13. Shaffer EJ, Lape JE, Salls J. Decreasing Stress for Parents of Special Needs Children through a Web-Based Mindfulness Program: A Pilot Study. The Internet Journal of Allied Health Sciences and Practice. [Internet]. 2020 January 1;18(4):16. Available from: https://nsuworks.nova.edu/ijahsp
14. Ford, B. Q., Lam, P., John, O. P., & Mauss, I. B. (2018). The psychological health benefits of accepting negative emotions and thoughts: Laboratory, diary, and longitudinal evidence. Journal of Personality and Social Psychology, 115(6), 1075-1092.

Interventions to support parents of children with developmental disabilities

Prof. Livia Puljak, MD, PhD

Most important messages:

- There are various interventions designed to support parents of children with developmental disabilities.
- These interventions can be divided into four groups: family system programs, educational programs, interactive programs and positive behavior support.
- Programs focused on parental characteristics such as stress, depression and coping can have significant effects on reducing the psychological stress of parents of children with developmental disabilities.
- The effectiveness of programs designed to teach parents to apply approaches that improve the skills (eg, developmental, language, social, play) of their children with developmental disabilities has been documented.
- Interactive programs are designed to strengthen positive social interactions between parents and young children with developmental disabilities.
- For parents of young children with developmental difficulties, their child's behavior is often a challenge, whish leads to a negative parent-child relationship and creates a lot of stress for the parents. For this purpose, programs have been developed, whose goal is to support positive behavior.

Interventions designed to support parents of children with developmental disabilities can be divided into four overlapping areas: family system programs, educational programs, interactive programs and support for positive behavior.

Family system programs

Family system programs tend to focus on parental traits, such as stress, depression, or confrontation, based on the assumption that changes in these traits will affect the quality of parenting. Singer and colleagues (2007) conducted meta-analysis examining the primary and secondary effects of parental and stress management interventions for parents of children with developmental disabilities (1). Among the 17 studies analysed, the authors found three types of intervention: behavioural parental education (i.e. teaching parents behavioural skills); interventions in coping skills, based on principles of cognitive behavioural therapy; and a combination of those two. They found that interventions in all three groups had significant effects on the reduction of mental stress in mothers and fathers of children with developmental disabilities (1).

In a study involving 70 families of children with autism spectrum disorders, Tonga and associates (2006) provided training to parents to manage behaviour in the group and individual approaches. They found a significant positive impact of education on parents (2).

Feldman and Werner (2002) provided behavioural management training with follow-up over a period of 3 to 6 months for parents of children with developmental delays and revealed significantly lower levels of depression for parents who participated in therapy (3).

Singer and colleagues (2007) note that interventions that take place over a longer period of time and have multiple components (e.g. those related to parents' well-being and parental skills) have led to a greater reduction in parental stress than those of a shorter period (1).

In a study of 59 parents of children with autism, parents received six individual sessions in the troubleshooting educational programme, adapted to problem-solving therapy (Feinberg and colleagues, 2014). Each session focused on working on a problem recognized by the mother using steps of problem-solving therapy (target setting, discussion, solution assessment, solution selection and action planning). The results of the study showed that intervention reduced the symptoms of parental depression, but not their level of stress (4).

A newer trend is the application of awareness training (*mindfulness*) for parents of children with developmental disabilities, with the aim of reducing stress and potentially increasing self-efficacy. Benn and associates (2012) conducted studies to investigate the effects of awareness-based stress mitigation techniques and to detect significant positive effects on stress reduction and related variables (e.g., personal growth) (5). The effects of these techniques were seen in the competence of carers (5) and in a small number of behavioural problems reported by teachers (Neece, 2014) (6).

Educational programmes

Extensive literature documents the effectiveness of programmes designed to teach parents in applying a skills-promoting approach (e.g. development, language, social, toys) for their children with developmental disabilities (7, 8). Roberts and Kaiser (2011), for example, found strong positive effects on the receptive and pronounced language skills of young children with intellectual disabilities in a pooled analysis of 18 studies on language education programmes carried out by parents using a control group (9). This result indicates that children receiving treatment from parents and speech therapists have made comparable progress, which in turn indicates that, when properly educated, parents can be effective language developers for children with developmental disabilities (9).

Programmes instructing parents to promote reading skills of their young children with developmental disabilities also documented positive effects. Two studies (10, 11) showed the effectiveness of parents' dialogue (common) reading approaches in improving reading skills of young children with linguistic backlog. In these approaches, parents read a book to their child, follow the child's understanding through questions, give the child the opportunity to respond, repeat, and work out what the child is saying, invoke illustrations to enhance meaning, praise, and encourage the child, and focus on making reading fun.

Especially for children with autism spectrum disorders, interventions involving parents have produced positive results. Many comprehensive treatment programmes are designed for children with autism spectrum disorders and almost all involve parental involvement (12). These comprehensive programmes consist of a set of practices addressing the different development needs of the child and generally take place over a longer period of time (e.g. 1-2 years or more). Some programs start under the supervision of experts in institutions, and parents also carry them out at home. The Early Start Denver Model (ESDM) is the best and best-verified example of this approach. Dawson and colleagues (2010) conducted an experimental evaluation of ESDM and showed significant effects of this approach on children's cognitive developmental and adaptive behaviour (13).

In the ImPACT study (14), which teaches parents of children with autism spectrum disorder how to promote their children's socio-communication skills during daily routines and activities, Stadnick and colleagues (2015) found that parents can faithfully intervene and the programme produced positive results in children (15).

Other studies have shown positive effects of early intensive behavioural therapy by parents. For example, in a pooled analysis of 13 studies, Strauss and colleagues (2013) found that early intensive behavioural interventions by parents were more effective than those carried out by therapists only (16). In short, parental involvement appears to be an essential element of early interventions for children with autism spectrum disorders and may in some cases produce stronger positive results than such interventions where parents are not directly involved. The emphasis is on how professionals should provide all the necessary information to parents and make an effort to explain everything, from the initial diagnosis to the interventions, so that parents can implement them at home and communicate with other professionals. Since children with disabilities are often involved in therapies at multiple locations, the transfer of information is crucial to ensure that everyone is working towards the same goals, which will lead to better and faster results.

Interactive programs

Interactive programmes are designed to promote positive social interactions between carers and young children with developmental disabilities. They are based on research showing that some young children with developmental disabilities have difficulty in interacting positively with their parents and others (17), and sometimes parents can communicate with their children in ways that discourage social interaction (e.g. they can overdirect the child) (18, 19). These interventions teach parents how to set up play situations that stimulate interaction and how to react in a particularly encouraging way. Mahoney and colleagues (2006) (20) applied a *responsive parenting* approach (approach) that led to an increase in social interactions among children with developmental disabilities (21, 22). For many young children with autism spectrum disorders, joint attention - a specific form of parent-child interaction that is the basis for later communication development - is limited or does not develop. Several researchers developed interventions designed to promote joint attention of small children with autism spectrum disorders with their parents who showed positive effects (23, 24).

Support for positive behaviour

For parents of young children with developmental disabilities, the behaviour of their child is often challenging, leads to a negative parent-child relationship and creates great stress for parents (25). Different approaches have been developed to promote parental practices related to behavioural management. One such approach - intervention and support for *positive behavior (*PBIS) - is a multi-component program that includes strategies to prevent problematic behaviour and increase the level of intervention in behaviour (26). Durand and associates (2013) examined the effects of PBIS on parents and their children with developmental disabilities and serious behavioural challenges (27). They found significant progress in challenging behavior, as well as a reduction in parental pessimism. The effects of the PBIS model were stronger when matched with a complementary optimism training programme aimed at helping parents identify and change their parenting-related thinking patterns (27).

The Positive Parenting Program (Triple P) was originally designed for children of school age with behavioural disorders and was used with parents of small children with behavioural and mental health impairments (28). The adaptation of this program, called Stepping stones, was used with the parents of young children with developmental disabilities. Individual studies (29) and a pooled analysis of a number of studies (30) that examined the Stepping stones programme revealed strong effects on reducing challenging behaviour and improving broader aspects of parenting (e.g. style, adjustment, parental relationship). Similarly, the *Incredible Years Programme* was originally designed for parents of children of school age with behavioural disorders (31), but adapted and applied to parents of young children with developmental disabilities. McIntyre (2008) showed that the *Incredible Years Programme* reduced negative parent-child relationships and child behavioral problems (32).

In another study targeting parents of children with autism, researchers included 16 families with children aged 3-6 years with autism diagnosis and disruptive behaviours described by parents (33). This study assessed the RUPP (*Research Units on Pediatric Psycho-pharmacology*) structured 11-session program designed to teach parents of children with autism and serious behavioral problems the skills needed to reduce their children's disruptive behaviour. In one group, parents reported a decrease in their children's disruptive behaviour and improvements in their adjustment (33).

Literature

1. Singer GH, Ethridge BL, Aldana SI. Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: a meta-analysis. Ment Retard Dev Disabil Res Rev. 2007;13(4):357-69.
2. Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, Rinehart N. Effects on Parental Mental Health of an Education and Skills Training Program for Parents of Young Children With Autism: A Randomized Controlled Trial. Journal of the American Academy of Child & Adolescent Psychiatry. 2006;45(5):561-9.
3. Feldman MA, Werner SE. Collateral effects of behavioral parent training on families of children with developmental disabilities and behavior disorders. Behavioral Interventions. 2002;17(2):75-83.
4. Feinberg E, Augustyn M, Fitzgerald E, Sandler J, Ferreira-Cesar Suarez Z, Chen N, et al. Improving Maternal Mental Health After a Child's Diagnosis of Autism Spectrum Disorder: Results From a Randomized Clinical Trial. JAMA Pediatrics. 2014;168(1):40-6.
5. Benn R, Akiva T, Arel S, Roeser RW. Mindfulness training effects for parents and educators of children with special needs. Dev Psychol. 2012;48(5):1476-87.
6. Neece CL. Mindfulness-Based Stress Reduction for Parents of Young Children with Developmental Delays: Implications for Parental Mental Health and Child Behavior Problems. Journal of Applied Research in Intellectual Disabilities. 2014;27(2):174-86.
7. Girolametto L, Weitzman E, Clements-Baartman J. Vocabulary intervention for children with Down syndrome: Parent training using focused stimulation. Infant-Toddler Intervention: The Transdisciplinary Journal. 1998;8(2):109-25.
8. Green J, Charman T, McConachie H, Aldred C, Slonims V, Howlin P, et al. Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. The Lancet. 2010;375(9732):2152-60.
9. Roberts Megan Y, Kaiser Ann P. The Effectiveness of Parent-Implemented Language Interventions: A Meta-Analysis. American Journal of Speech-Language Pathology. 2011;20(3):180-99.
10. Crain-Thoreson C, Dale PS. Enhancing Linguistic Performance:Parents and Teachers as Book Reading Partners for Children with Language Delays. Topics in Early Childhood Special Education. 1999;19(1):28-39.
11. Dale PS, Crain-Thoreson C, Notari-Syverson A, Cole K. Parent-Child Book Reading as an Intervention Technique for Young Children with Language Delays. Topics in Early Childhood Special Education. 1996;16(2):213-35.

12. Odom SL, Boyd BA, Hall LJ, Hume KA, Volkmar FR, Paul R, et al. Comprehensive treatment models for children and youth with autism spectrum disorders. In F.R. Volkmar, R. Paul, S.J. Rogers, and K.A. Pelphrey (Eds.), Handbook of Autism and Pervasive Developmental Disorders (4th ed., pp. 770-787). Hoboken, NJ: John Wiley & Sons. 2014.
13. Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, et al. Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. Pediatrics. 2010;125(1):e17-e23.
14. Ingersoll B, Wainer A. Initial Efficacy of Project ImPACT: A Parent-Mediated Social Communication Intervention for Young Children with ASD. Journal of Autism and Developmental Disorders. 2013;43(12):2943-52.
15. Stadnick NA, Stahmer A, Brookman-Frazee L. Preliminary Effectiveness of Project ImPACT: A Parent-Mediated Intervention for Children with Autism Spectrum Disorder Delivered in a Community Program. J Autism Dev Disord. 2015;45(7):2092-104.
16. Strauss K, Mancini F, Fava L. Parent inclusion in early intensive behavior interventions for young children with ASD: A synthesis of meta-analyses from 2009 to 2011. Research in Developmental Disabilities. 2013;34(9):2967-85.
17. Adamson LB, Bakeman R, Deckner DF, Nelson PB. Rating Parent–Child Interactions: Joint Engagement, Communication Dynamics, and Shared Topics in Autism, Down Syndrome, and Typical Development. Journal of Autism and Developmental Disorders. 2012;42(12):2622-35.
18. Cress CJ, Moskal L, Hoffmann A. Parent Directiveness in Free Play With Young Children With Physical Impairments. Communication Disorders Quarterly. 2008;29(2):99-108.
19. Lussier BJ, Crimmins DB, Alberti D. Effect of Three Adult Interaction Styles on Infant Engagement. Journal of Early Intervention. 1994;18(1):12-24.
20. Mahoney G, Perales F, Wiggers B, Herman B. Responsive teaching: early intervention for children with Down syndrome and other disabilities. Downs Syndr Res Pract. 2006;11(1):18-28.
21. Karaaslan O, Mahoney G. Effectiveness of responsive teaching with children with Down syndrome. Intellect Dev Disabil. 2013;51(6):458-69.
22. Karaaslan O, Diken IH, Mahoney G. A randomized control study of responsive teaching with young turkish children and their mothers. Topics in Early Childhood Special Education. 2013;33(1):18-27.
23. Kasari C, Gulsrud AC, Wong C, Kwon S, Locke J. Randomized Controlled Caregiver Mediated Joint Engagement Intervention for Toddlers with Autism. Journal of Autism and Developmental Disorders. 2010;40(9):1045-56.
24. Schertz HH, Odom SL, Baggett KM, Sideris JH. Effects of Joint Attention Mediated Learning for toddlers with autism spectrum disorders: An initial randomized controlled study. Early Childhood Research Quarterly. 2013;28(2):249-58.
25. Hastings RP. Parental stress and behaviour problems of children with developmental disability. Journal of Intellectual & Developmental Disability. 2002;27(3):149-60.
26. Dunlap G, Fox L. Positive behavior support and early intervention. In W. Sailor, G. Dunlap, G. Sugai, and R. Horner (Eds.), Handbook of Positive Behavior Support (pp. 49-71). New York: Springer. 2009.
27. Durand VM, Hieneman M, Clarke S, Wang M, Rinaldi ML. Positive family intervention for severe challenging behavior I: A multisite randomized clinical trial. Journal of Positive Behavior Interventions. 2013;15(3):133-43.
28. Sanders M, Calam R, Durand M, Liversidge T, Carmont SA. Does self-directed and web-based support for parents enhance the effects of viewing a reality television series based on the triple P--Positive Parenting programme? Journal of Child Psychology and Psychiatry. 2008;49(9):924-32.
29. Sofronoff K, Jahnel D, Sanders M. Stepping Stones Triple P seminars for parents of a child with a disability: A randomized controlled trial. Research in Developmental Disabilities. 2011;32(6):2253-62.
30. Tellegen CL, Sanders MR. Stepping Stones Triple P-Positive Parenting Program for children with disability: A systematic review and meta-analysis. Research in Developmental Disabilities. 2013;34(5):1556-71.
31. Webster-Stratton C. Randomized trial of two parent-training programs for families with conduct-disordered children. Journal of Consulting and Clinical Psychology. 1984;52(4):666-78.
32. McIntyre LL. Parent training for young children with developmental disabilities: randomized controlled trial. Am J Ment Retard. 2008;113(5):356-68.

33. Bearss K, Johnson C, Handen B, Smith T, Scahill L. A Pilot Study of Parent Training in Young Children with Autism Spectrum Disorders and Disruptive Behavior. Journal of Autism and Developmental Disorders. 2013;43(4):829-40.

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Table of contents