

Communication and safety challenges with ASD/ID patients and coping strategies

***dr. Viktorija Piščalkienė
dr. Lijana Navickienė
Kauno kolegija Higher Education Institution
Kaunas, Lithuania***

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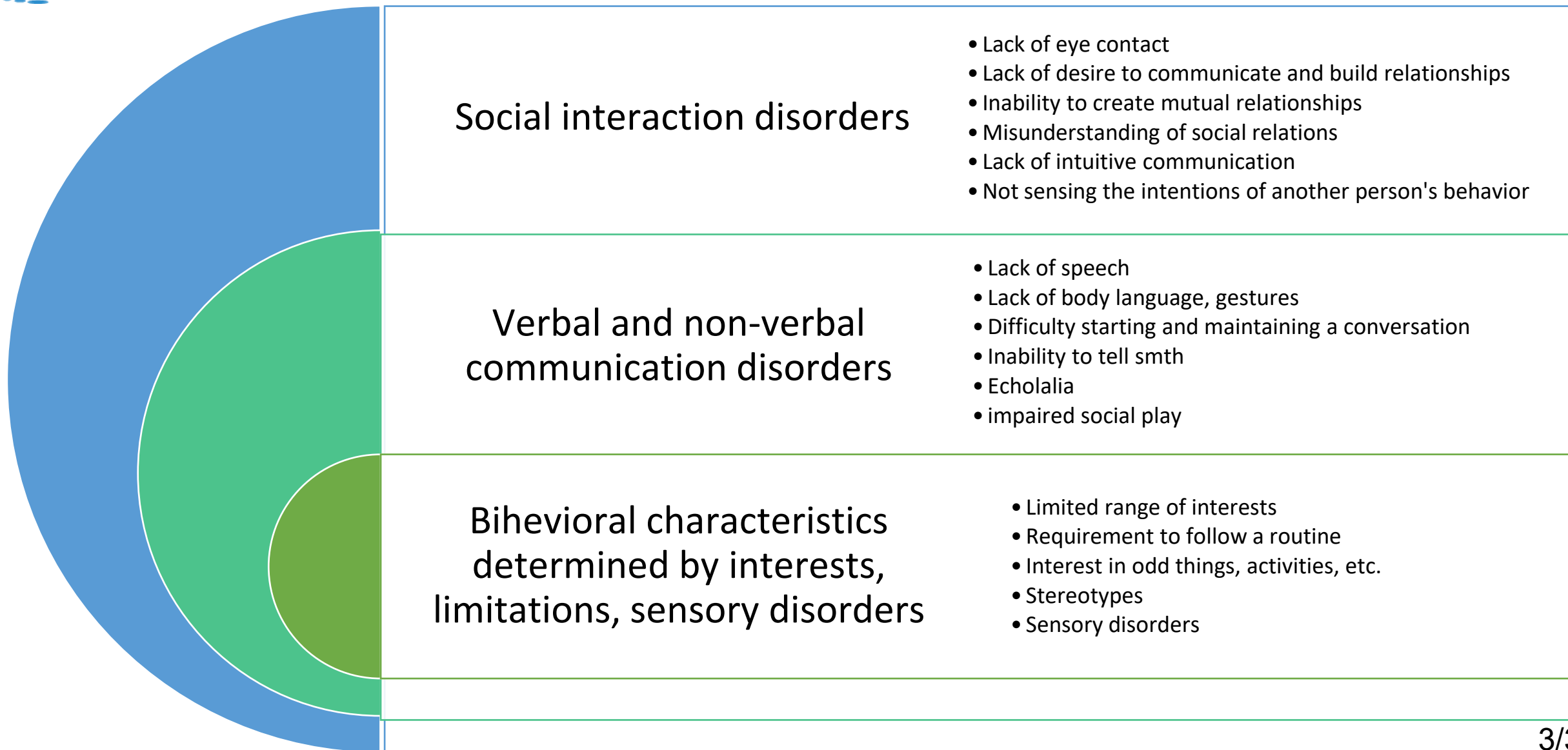
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Healthcare for ASD/ID people

- People with disabilities face significant disparities in health and health care.
- Studies show that autistic adults experience greater unmet health care needs, greater emergency room use, less use of recommended preventive care services, lower satisfaction with health care, lower health care self-efficacy, and a greater number of barriers to health care than nonautistic adults.
- Many ASD/ID characteristics can directly impact health care.
- Effective physician-patient communication correlates with improved patient health outcomes, even in general populations.

Main autism characteristics



Communication and interaction

- ASD/ID individuals have atypical communication. There is great heterogeneity between patients in regards to communication strengths, challenges, and styles. An individual patient's ability to communicate may vary greatly between modes of communication (e.g. spoken vs. written language).
- There may be large differences in receptive vs. expressive communication. For example, someone may understand spoken language, but not be able to speak, or may speak fluently, but not be able to process auditory information accurately.
- There may also be large variations in communication in an individual patient from one time to the next, depending on the environment, medical illness, or other stressors.

Communication barriers

- ASD/ID people have impairments in social interaction, verbal and non-verbal communication. Repetitive and stereotyped behaviors are characteristic to these people (Botha et al., 2022). These people have difficulties in interpreting both spoken and body language, which makes communication difficult.
- Communication barriers are the most common challenge faced by healthcare professionals when working with ASD or ID patients. These barriers are related to the lack of social interaction skills, limited verbal communication, difficulty understanding nonverbal cues, problems with language comprehension, behavioral and sensory issues.

Limited social interaction

- Patients with ASD/ID may have limited social skills, making it difficult for them to interact with healthcare providers or other patients. They may take instructions very literally, do not understand things like sarcasm or irony. They do not understand humor and metaphors at all, have limited and sometimes unusual aspirations, can speak with an unnatural intonation.

Difficulties with verbal communication

- Many individuals with ASD/ID may struggle with verbal communication, making it difficult for them to express their needs or understand medical instructions.

Verbal communication - problems with language comprehension

Literal language

- It is common for ASD people take language very literally.
- These people usually do not understand things like sarcasm or irony. They do not understand humor and metaphors at all, have limited and sometimes unusual aspirations, can speak with an unnatural intonation.

"They asked him, on a level of one to ten, where is your pain. First time he said, 'How do you weigh your pain? ... I don't weigh my pain'".

Verbal communication - problems with language comprehension

Precise language

- It is also common for ASD/ID individuals to require very precise language. This often becomes a concern when healthcare providers offer relatively vague information or ask patients broad, open-ended questions.

'How do you feel?' Too vague. 'Can you describe your symptoms?' I can somewhat answer this, but not fully. It's a starting point, not end point. Specific questions related to symptoms are good: 'Does your side hurt?' 'Are you keeping food down?'

Verbal communication - problems with language comprehension

Difficulties in understanding abstract concepts, medical terminology

- Individuals with ASD or ID may have difficulty understanding abstract concepts such as time or cause and effect. For example, it may be difficult for them to understand the other person's point of view and feel what he wants to say. If a person with ASD knows the information in theory, it may still be difficult for them to imagine what it might be because of differences in the social imagination.
- These people may also have limited health literacy skills and medical terminology understanding. which can make it difficult for them to understand medical information and instructions provided by healthcare professionals.

Verbal communication barriers- challenges for healthcare providers

Limited verbal communication skills of ASD/ID patients can make it difficult for healthcare professionals to gather information about their symptoms or medical history, to explain complex medical information to them.

Atypical non-verbal communication

- ASD/ID patients may have difficulty understanding or expressing nonverbal cues such as facial expressions, body language or tone of voice, which can lead to misunderstandings during communication.
- Patients may inadvertently seem rude because of their atypical body language or facial expressions (potentially in addition to use of very direct language).
- ASD/ID people often avoid eye contact, make repetitive motions, also called "stimming". Examples include hand flapping, rocking, or pacing. Stimming may be an effective coping mechanism, especially during times of stress such as medical visits.

Sensory issues

- People with ASD or ID may have sensory processing issues. This may take the form of increased or decreased sensitivity to sounds, lights, smells, touch, or taste.
- Atypical sensory processing can affect their ability to process auditory, visual, or tactile information. They may have great difficulty filtering out background noise, processing information in over-stimulating environments, or processing more than one sensation at a time.
- They may be hypersensitive to certain stimuli, such as bright lights or loud noises, which can make it difficult to communicate in a healthcare setting.
- Issues related to hypersensitivity or hyposensitivity to sensory input can affect the patient's ability to tolerate physical exams or medical procedures.

Other factors that may interfere with effective ASD/ID people communication

- Patients with ASD/ID may have a **limited attention span**, making it difficult to stay focused during medical appointments. Healthcare providers should break down information into smaller, more manageable chunks and use clear and concise language.
- Many ASD/ID people **have difficulty processing information quickly or communicating in real time**. Patients may not be able to process language or information quickly enough to respond to questions or make healthcare decisions.

Behavioral and safety challenges

Individuals with ASD/ID can exhibit a wide range of behavioral characteristics, including:

- **Restricted and repetitive behaviors and interests:** many individuals with ASD/ID engage in repetitive behaviors, such as hand flapping or lining up objects. These behaviors can interfere with daily activities and social interactions.
 - **Difficulty with change and transitions:** People with ASD/ID may have difficulty adjusting to changes in routine or unexpected events, leading to anxiety and behavior problems.
 - **Challenging behaviors:** Individuals with ASD/ID may engage in challenging behaviors, such as aggression, self-injury, or property destruction, due to difficulties with communication, sensory sensitivities, or frustration.
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- Patients with ASD/ID may become anxious or stressed in unfamiliar or overwhelming environments, such as hospitals or clinics.
 - Hospitalization of a child with ASD/ID can provoke behavioral changes such as aggression, tantrums, hitting, kicking, biting, scratching and even throwing furniture. For health professionals, these behavioral changes can create safety concerns, make communication more challenging and complicate the delivery of health services.
 - Healthcare providers should try to create a calm and predictable environment, use a consistent approach to communication, and provide reassurance and support.



Children with ASD/ID are more likely to suffer injuries

TYPES OF INJURIES:



**open
wounds**



**head
injuries**



**upper limb
injuries**



**bone
fractures**



other
*poisoning, car
accidents, cycling
injuries, choking*

What is important for coping with ASD/ID patients communication and safety challenges?

- To ensure the quality of ASD/ID people care and the safety of patients child and health professionals, professionals need to be aware of the special nature of this patient group, which requires careful assessment, interdisciplinary collaboration, family involvement and knowledge of the ASD/ID individual specific needs.
- Being aware of how to deal with such a patient can lead to less stress, better quality care and a safer stay in the healthcare facility for the patient, the family or caregivers, and the healthcare professionals.

Health professionals should be aware of ASD/ID characteristics



An individual may have various developmental and communication disabilities, anxiety, agitation, aversion of touching, he/she is more likely to play alone, may not respond to his/her own name, may lack empathy, may be characterized by repetitive behaviors and unusual reactions to the way things sound, smell, taste, look, or feel.

Individual's inability to communicate, to be provoked by other stimuli may lead to outbursts of anger or aggression, increasing the risk of injury to the child or others.

Strategies to address ASD/ID patients communication and safety challenges (1)

- **Using clear and concise language:** simple, specific and direct language to communicate information; providing explanations that are tailored to the patient's level; avoiding figurative language, idioms, or sarcasm; avoiding broad questions; being mindful of the nonverbal cues.
- **Using visual aids:** visual aids such as pictures, written instructions, social stories or gesture cues can be helpful in enhancing communication, explaining safety procedures and reducing anxiety.
- **Allowing processing time:** individuals with ASD/ID may need extra time to process and respond to information, so it is important to give them extra time to process and respond.
- **Speaking in a calm and neutral tone:** avoiding using a tone of voice that may be perceived as confrontational, as this may increase anxiety and interfere with communication.

Strategies to address ASD/ID patients communication and safety challenges (2)

- **Ensuring safe environment, being mindful of sensory sensitivities:** providing a safe environment that is free from hazards and potential triggers for challenging behaviors; being aware of the individual's sensory sensitivities and making adjustments as needed. For example, turning down bright lights or lowering the volume of sounds can make communication easier; turning off mobile phones or their sound; avoiding unnecessarily touching the patient; encouraging patient or supporters to bring objects to reduce or increase sensory stimuli (headphones to block noise, sunglasses or hats to block light, or sensory toys such as stress balls, gum, spinning tops, or soft fabric).
- **Showing empathy and understanding:** showing empathy and understanding can help build a positive rapport with the individual and make them feel more comfortable communicating with the healthcare professional. Healthcare providers should be patient, supportive, and non-judgmental; not forcing patient to make eye contact.

Strategies to address ASD/ID patients communication and safety challenges (3)

- **Collaborating with caregivers:** collaborating with caregivers can provide insight into the individual's communication needs and preferences, and help ensure that communication is effective and appropriate.
- **Using the individual's preferred mode of communication:** some individuals with ASD/ID may prefer alternative forms of communication, such as written communication, sign language (ex. PECS - picture exchange communication system) or assistive technology (VOCA - voice output communication aids; speech-to-text, eg. Dragon Naturally Speaking; word-completion programs, electronic or paper organizers, or visual or electronic reminders and alarms to help with prompting or sequencing.).
- **Working in a team:** working in a team with other healthcare professionals, including behavioral therapists or security personnel, to manage safety concerns and ensure the safety of everyone involved.

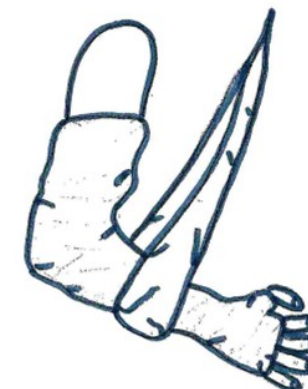
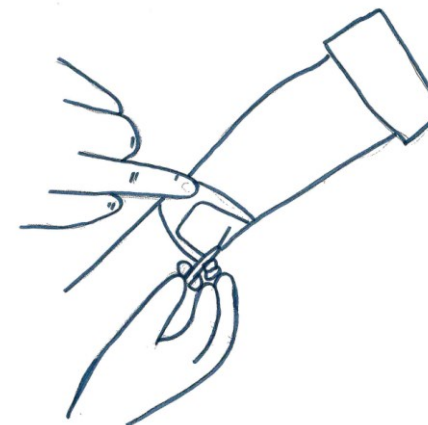
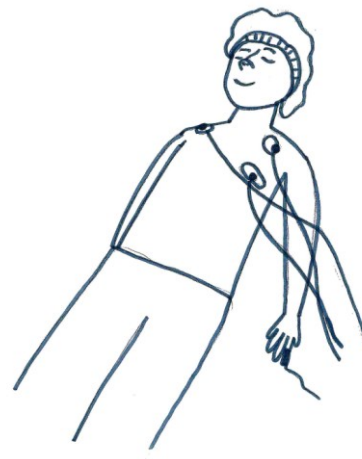
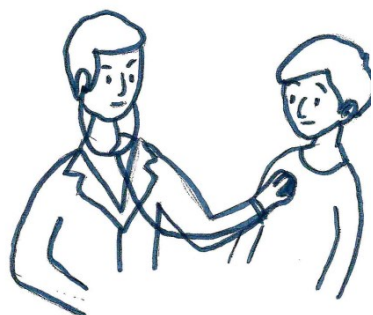
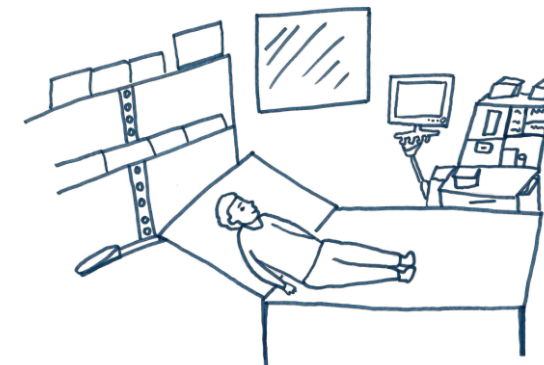
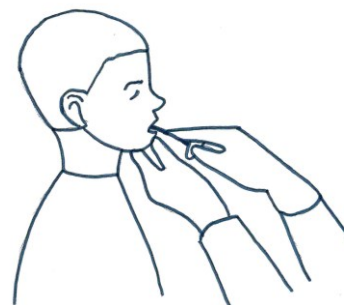
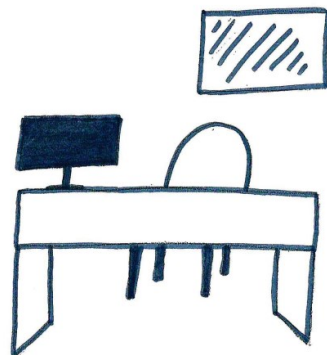
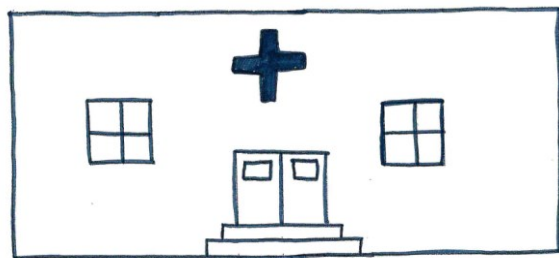


α-STEP

ADVANCING SOCIAL INCLUSION THROUGH
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European Cooperation in
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Project "Inclusive healthcare for children with autism spectrum disorders". Original drawings by the project promoters, project manager Viktorija Piscalkiene, members Silva Kostylioviene, Rita Juchneviciene, Vaida Valyte, Jolanta Uloziene, Evelina Lamsodiene, student Betarice Turkeviciute, Kaunas College, 2023 (Lithuania, Kaunas).

Before the visit

It is recommended to **obtain individualized information** from patients, supporters or caregivers about the following:

- Patient's ability to understand spoken language.
- Patient's ability to speak.
- Patient's ability to read and write.
- Patient's use of alternative and augmentative communication (AAC). AAC may include picture-based systems (e.g. picture boards), text-based systems (e.g. text-to-speech programs), sign language, or other signs or behaviors. They may be stand-alone devices, programs on computers, tablets, smartphones, or informal systems (e.g., picture cards, notes on a piece of paper).
- Patient's preferred mode of communication.
- Patient's ability to use the telephone for between-visit communications (and more effective alternatives if telephone communication is not effective).
- Degree to which communication normally varies based on environmental factors or stress.

Tips for effective interaction with ASD/ID children (1)

Visit to hospitals should be planned in advance (*unless it is an urgent health problem*):

- Parents should be given time to become familiar with the healthcare facilities that will be providing treatment and care for their child. It is recommended that parents call the health facility and talk to medical staff about how children with ASD/ID are cared for, how they work with parents, and whether they involve parents in the care of their child.
- If it is a planned visit, parents can prepare the child for the visit to a health facility and for procedures that are scheduled by creating stories, using cards, pictures or photos.

Tips for effective interaction with ASD/ID children (2)

Involving the family in the care and treatment of the child:

- The family knows the child with ASD/ID communication patterns and daily routine best.
- The child has to follow various instructions in a hospital. This may provoke the child to change behavior, become angry or aggressive.
- Parents can prepare a detailed plan in advance to meet the child's health needs, which should include the medication the child is on, a brief description of the ways to communicate with the child, a list of all the sensory and nutritional problems, irritants and the methods used to calm the child.
- Parents can explain and prepare the child for the examination, treatment and nursing procedures in a way that is understood by the child, using pre-prepared charts, photographs and history taking. It is recommended that parents do not leave the child alone and participate in all the procedures whenever possible.

Tips for effective interaction with ASD/ID children (3)

Have the best method for communicating with with ASD/ID child:

- It is important for health professionals to know the most appropriate methods of communicating information.
- Parents should inform health professionals about best methods of communicating with the child.
- It is recommended that when the child with ASD/ID is admitted to a health care facility, health professionals obtain all information from the child's parents.
- It is ideal if the parents have a pre-filled information sheet on all the communication and health features of a child with ASD/ID. However, if the parents do not have such written information, it should be done by health professionals. The easiest and quickest way to do this is to have an information sheet ready to use, including best methods of communicating with the child, signs of increasing anxiety, stimuli provoking anger and aggression, methods to calm the child down, sensitivity to smells, sounds, touch, possible stereotypical routine movements.
- Most children with ASD/ID respond best to short, concise instructions. It is important to avoid the word "no" when dealing with these children. The use of visual tools such as photo/picture schedules, communication boards, labeling of objects on wards and in departments is recommended.
- It is recommended to explain to the child the benefits of drinking medication, injections, taking temperature etc. and to include these procedures in the daily routine, creating stories, using cards/pictures.

Template for Admission Assessment Tool for the Child with ASD/ID

1. What causes your child to have increased anxiety? Please list common triggers.
2. What is the best method to communicate with your child?
 - a. Verbal, Picture, Sign Language, Other _____
 - b. Are there any special communication tools (ex: spell board) that we can obtain during your child's stay?
3. How should staff members approach your child?
4. Is your child particularly sensitive to touch, sound, smell, sight, or taste?
5. Does your child have any obsessive/restrictive behaviors?
6. How does your child demonstrate if he or she is in pain?
7. What are your child's early signs of increasing frustration and anxiety?
8. What are your best methods to comfort and de-escalate your child?
9. What are your child's strengths?
10. What is your child's home routine? We welcome you to bring in clothes, belongings, and food from home to make your child more comfortable. Please feel free to stay.

Tips for effective interaction with ASD/ID children

(4)

Minimize change, maintain routine:

- When the child arrives on the ward, he/she should be helped to become familiar with the ward. It is recommended to give the family time to settle in, not to allow too many staff on the ward and, if necessary, to put a 'Do not disturb' sign on the door.
- If the child smells certain familiar smells, allow the parent to use essential oils to replicate the smell.
- Encourage the child's family to bring the child's favorite objects to the hospital for various activities, such as toys, books or other items that calm the child.
- If the child has a particular food preference or sensitivity to smells, the family should bring in food from home if possible to reduce the change in routine. Keeping to a routine of meals, daily activities and playtime can reduce the child's anxiety and agitation.

Tips for effective interaction with ASD/ID children (5)

Ensure safe environment and reduce the factors that affect sensorimotor behavior:

- Minimize the length of a visit to a health facility for a child with ASD/ID e.g. in a primary care facility, a child with ASD/ID is referred to the appropriate specialist as quickly as possible.
- Provide alternative seating options (mat, large ball or mattress on the floor).
- It is important that a family member or other person a child knows well is present all the time, 24 hours a day.
- Health professionals should work with the family to identify which stimuli particularly excite the child: touch, sound, smell, sight, taste or food.
- In a healthcare facility, it is recommended to reduce light and noise levels in and around the ward. If it is not possible to reduce the noise in the healthcare facility, it is recommended for the child with ASD/ID to wear headphones to reduce the sound. Staff are advised to turn off mobile phones or their sound, if possible, before entering the child's ward.
- If a child with ASD/ID has frequent escapes or leaves the house unsupervised (sometimes called 'running away' or 'wandering'), it is recommended to stick a 'STOP' sign on the inside of the ward door to remind the child, who is used to reacting to visual signals, to stay in their room.

Tips for effective interaction with ASD/ID children (6)

Permanent health professionals caring for ASD/ID child:

- Aggression is provoked by new, constantly changing staff.
- Although it can be complicated, it is important to look for opportunities to minimize staff changes.
- The abundance of strangers can trigger or provoke unwanted behavior or aggression in a child with ASD/ID, so it is important to avoid showing these children to medical students. If necessary, no more than two students should be allowed to see the child.

Specific features of medicine use:

- The FLACC* or face pain scale** is recommended to assess pain in a child with ASD/ID.
- Parents' views on the child's pain assessment should not be ignored, as parents are the most aware of the child's pain symptoms.
- Health professionals should also ask the family what non-medication methods the parents have used at home to relieve the child's pain.

*<https://www1.health.gov.au/internet/publications/publishing.nsf/Content/triageqrg~triageqrg-pain~triageqrg-FLACC>

**<https://www.iasp-pain.org/resources/faces-pain-scale-revised/>

A task (1)

Hospital emergency department. A 17-year-old girl Ema arrives accompanied by her mother. According to her mother, Ema has a severe intellectual disability and autism. For several days Ema's behavior has changed: she covers her ears with her hands more often than usual, screams loudly, and episodes of auto aggression often begin (hitting her head with her hands). The mother suspects that Ema has a headache or something else because after giving her painkillers, the girl calms down for a while. Ema's communication is very limited: she doesn't answer questions, has difficulty focusing her gaze, reluctantly makes eye contact, and doesn't always follow orders. According to her mother, Ema is particularly sensitive to environmental stimuli: stronger, unusual sounds, doesn't like to be touched, is annoyed by bright lights, and doesn't like sudden changes in body position. Often, overstimulation of stimuli can lead to spontaneous behavior: loud screaming, running, and self-harm. To calm down, she simply sits down where she was standing, covers her ears with her hands, closes her eyes, and swings her torso.

A task (2)

The sequence of actions for personal health care professionals (*number from first to last according to the order of services*):

- ☐ temperature measurement;
- ☐ visual examination of the patient;
- ☐ conversation with the accompanying person;
- ☐ blood pressure measurement;
- ☐ patient registration;
- ☐ reduction of environmental stimuli (choosing a secluded place, dimming the lights, etc.);
- ☐ taking blood from a vein;
- ☐ anamnesis collection;
- ☐ ear examination;
- ☐ visual procedure card "temperature measurement";
- ☐ visual procedure card "blood sampling from a vein";
- ☐ visual procedure card "ear examination";
- ☐ visual procedure card "blood pressure measurement".

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Thank you for your attention!

viktorija.piscalkiene@go.kauko.lt
lijana.navickiene@go.kauko.lt