

## ORIGINAL ARTICLE

# Being heard – Supporting person-centred communication in paediatric care using augmentative and alternative communication as universal design: A position paper

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## Abstract

Person-centred care, with its central focus on the patient in partnership with health-care practitioners, is considered to be the contemporary gold standard of care. This type of care implies effective communication from and by both the patient and the healthcare practitioner. This is often problematic in the case of the paediatric population, because of the many communicative challenges that may arise due to the child's developmental level, illness and distress, linguistic competency and disabilities. The principle of universal design put forth in conventions and legislation means that the design of products and services should be usable by all people, to the greatest extent possible. Augmentative and alternative communication encompasses strategies, for example pictures and apps, that are typically used with people with communication disability. In this position paper, we argue for the universal use of augmentative and alternative communication to support person-centred communication and care for children, regardless of age or potential disability. Clinical examples are shared from three different paediatric care settings where pictorial supports were applied universally. Interviews were conducted with children and adolescents (with and without disabilities), parents and healthcare practitioners, and the principles of universal design were used as a framework to demonstrate how person-centred communication is supported in paediatric care.

## KEYWORDS

augmentative and alternative communication, communication, communication development, human rights, paediatric care, person-centred care, pictorial support, universal design

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## 1 | INTRODUCTION

In today's healthcare, there is an increasing tendency to work in a person-centred manner, in other words to foreground the perspective of the patient, rather than that of the professional (Britten et al., 2020; Leplege et al., 2007; Öhlén et al., 2017). A core concern in person-centred care is to initiate a partnership between the patient and the healthcare practitioner where the emphasis is on elicitation of the patient's own story (Britten et al., 2020; Fors et al., 2020). Language and communication are therefore central (Öhlén et al., 2016). Regarding the healthcare of children, this perspective requires that children should have the ability to understand healthcare practitioners (i.e. have the receptive language skills) and to express themselves (i.e. have the expressive language skills). This may be problematic for many children, especially when they are ill and distressed, as they may have a communicative vulnerability due to either their age (not being able to participate in verbal interaction yet), severity of illness, lack of proficiency in the majority language and/or understanding of the culture within healthcare (Blackstone & Pressman, 2016).

Communicative vulnerability also includes communicative disorders, either of a temporary nature (e.g. patients receiving medical interventions that may influence their ability to speak) or as part of a permanent condition (e.g. autism, intellectual disability or cerebral palsy) (Costello et al., 2015). Combinations of these underlying factors are common and often not known beforehand by healthcare practitioners (Blackstone, 2015; Blackstone & Pressman, 2016). In this paper, we therefore argue for the development of person-centred communication strategies in paediatric care, according to the principles of universal design, by applying augmentative and alternative communication (AAC) means and strategies, mainly pictorial support and easy-to-read texts. Using three examples from paediatric care where universally designed augmentative support was implemented, we suggest how person-centred communication and care for children and adolescents (with and without communication challenges) in healthcare settings can be supported.

In the next section, the results and excerpts from interviews with children, parents and healthcare practitioners at the different clinics are discussed based on the principles of universal design as a framework. The processes and theories that are relevant for person-centred paediatric care are also outlined.

## 2 | BACKGROUND

### 2.1 | Person-centred communication and person-centred care

Exercising the human right to influence one's own health and quality of life could be challenging for children with paediatric health conditions (Rodgers et al., 2019). Thus, the way in which adults communicate with the child becomes critical, even if the child's condition does not involve a particular communication impairment per se.

Even if the idea of recognising children as persons is undisputed, history provides a long list of examples where children's perspectives have not been taken into consideration. In the case of paediatric healthcare, separating children from their family was seen as routine practice, while standardly asking children about their pain is seen as a comparatively recent practice (Twycross et al., 2015).

In this paper, we position communication in paediatric care as a person-centred approach to care. First, it should be noted that in this field it is common to use the terms 'family-centred care' (Almasri et al., 2018; Hill et al., 2018; Rea et al., 2018) and 'child-centred care' (Coyne et al., 2016, 2018), and that both these conceptualisations sometimes refer to a person-centred approach (though not necessarily so). Previous discussions about the concepts of 'centredness' have highlighted a child-centred approach and suggest that person-centredness lacks an explanation of how to manage maturity and autonomy in children (Coyne et al., 2018). Child-centred care stresses a thinking as well as a practice that focuses on the child. According to Coyne et al. (2018), there is an asymmetric power relationship between children and adults, and it is necessary to give the child a voice. Since a person-centred approach highlights all human capacities and rights, both autonomy and maturity can easily be included in person-centredness. In this paper, we argue that person-centredness is also applicable to and relevant for paediatric care.

Given that person-centred care has been clearly emphasised in adult care, there is a risk of uncritically transferring notions about adults onto children. Therefore, we selected person-centred ethics related to childhood development and maturity (Nilsson et al., 2015) and included the scope of transition to young adulthood. A broad tradition exists in philosophy as to what constitutes a person and personhood. We selected the philosophy held by Paul Ricœur (1994), who in turn had been influenced by a broad range of philosophical traditions (Kristensson Ugglå, 1994). Ricœur (1994) puts the notion of personhood in the context of an ethical intention: 'aiming at the good life, with and for others, in just institutions'. Following this, the child as a person lives in mutual relations with self and others – these are intrapersonal ('the good life'), dialogical ('with and for others') and institutional ('just institutions') relationships. From developmental psychology, we know that the parent or guardian is extremely important for the child, and that institutional and societal prerequisites not only put boundaries in place for children's development of the self, but also open up new possibilities. At the core lies the assumption that any person, including a child, is someone with a biography and someone who is both capable and vulnerable (Ricœur, 2011). From this follows the importance in child healthcare to ask, for example, who the child is; to provide different means of supporting the child's self-reflection; to have dialogues with the child's parents and other healthcare practitioners; and to enforce and sustain communicative justice for children (Carter & Ford, 2013).

A person-centred approach differs from patient-centred care where it is the patient who is put at the centre. Here, communication is understood socially, and it is interactively shaped from a constructionist perspective (Jarvis, 2006; Schütz, 1972). This perspective differs fundamentally from the linear view of communication as the

transfer of information from a sender to a receiver, which clearly is discarded in the field of communication research but tends to prevail in practice-related documents. We claim that a constructionist perspective supports a view of the child being heard and approached in an attempt to understand her/his view, preferences, fears, wishes, troubles and so forth – all in striving to create a partnership. Through guided participation (Rogoff, 2003), children communicate and learn in close cooperation with others and with the environment (Tomasello, 2013) when they are seen as active and capable (Rogoff, 2003; Vygotsky et al., 1978).

This understanding of person-centred paediatric care is based on three key elements: generating a co-created partnership; eliciting the child's story; and safeguarding the partnership through documenting the child's story, preferences and care plan (Britten et al., 2017, 2020; Ekman et al., 2011; Fors et al., 2020). The research-based evidence for a person-centred paediatric approach is sparse, and proxy reports by parents (Almasri et al., 2018; Hill et al., 2018) seem to be more common than reports from children themselves. The applicability of self-reports by children, however, is reported to be high (Allen et al., 2018; Almasri et al., 2018). The person-centred paediatric approach is typically offered through multiple formats (Allen et al., 2018) and reported to be embedded in key settings where the child is cared for. Parents have also reported on the impact of the environment (Hill et al., 2018). 'Patient- and family-centred care' can enable adolescents and young adults (aged 16 to 25 years old) to engage emotionally and socially with their healthcare practitioners, thereby empowering the young adult and their families in the care process (Allen et al., 2018). Still, to provide guidance for paediatric care, the actual communicative practices in these care approaches often need to be more detailed and explicated. This motivated us to adopt a practical approach, supported by AAC means and strategies, on how to facilitate person-centred communication in paediatric care. Such approach can be used both with and by children – and open up new possibilities.

## 2.2 | Children's development, decision-making and autonomy

In general, children are considered to constitute a vulnerable group, specifically if they are in need of healthcare (Nilsson et al., 2020). The United Nation's Convention on the Rights of the Child (CRC) provides the ethical framework for children's healthcare. It also focuses on equality in communication between healthcare practitioners and children (United Nations, 1989). To co-create this partnership, the child needs knowledge to comprehend the topic(s) as well as the skills to make any decision. If this knowledge is lacking, some decisions should not be taken by the child alone. Even if healthcare practitioners strive to obtain the child's perspective, this is not necessarily always the best for the individual child. Children sometimes lack autonomy and then they require assistance, such as that a parent or healthcare practitioner should take the decision – from the child's perspective (Nilsson et al., 2015). The decision should always

be in line with the ethical approach about what is in the child's best interest, which explains why ethics and philosophy of the person is stated as 'the good life' (Ricoeur, 1994).

The level of autonomy is dependent on the child's cognitive development, and this must be considered in decision-making. Younger children can make decisions concerning concrete issues that are close to their everyday life (Huus et al., 2015), while older children should be at liberty to make decisions about treatments with long-term consequences (Nilsson et al., 2015). Shared decision-making is a sensitive process that should be handled with care (Shier, 2001). It is known from previous research that there is often a discrepancy between the perspective and experience of the child and their parents regarding the child's health status (Oltean & Ferro, 2019; Poulain et al., 2020). According to Uzark et al. (2012), and parents sometimes have difficulty interpreting their child's emotional status in a valid way, while Zhou et al. (2008) report disparity between children's views of their own pain and their parents' proxy assessment of such pain. For example, a study that mapped children with diabetes type 1 showed that parents' proxy reports had more negative affect, more pain, and more fear than what the children themselves reported (Hanberger et al., 2021).

The discrepancy between the adults' observations and the child's own view clearly necessitates healthcare practitioners to take the child's perspective into account whenever possible. Although there is currently a tendency in decision-making to let the child's story be central in the decision, parents and healthcare practitioners should always consider the child's level of autonomy. It seems that the best interest of the child is served when decisions are made somewhere between the two ends of the continuum, that is, neither solely from an adult's view of the child's needs, nor solely from the perspectives of the children themselves. Instead, the desired solution is to use a person-centred paediatric care perspective to combine the child's experience with the expertise of parents and healthcare practitioners (Nilsson et al., 2015).

Furthermore, a recently published EU standard prescribes minimum requirements for patient involvement in healthcare, including a person-centred approach in paediatric care (SIS, 2020). Healthcare professionals have to listen to the child's story in order to create a care plan that focuses on the child's needs (Fors et al., 2020).

## 2.3 | Language and health literacy challenges in a multilingual society

Decision-making and communication involving the child is hampered not only by the child's immaturity, but also by language difficulties that are common in today's multilingual society. When children have a different cultural background or language to the healthcare practitioner, or when they have limited language skills, they may not have the required (health) vocabulary to express themselves (Blackstone, 2015).

Sweden and South Africa, the countries represented in our research group are illustrative examples. Sweden has a large influx

of migrants and refugees who speak a variety of different languages, while South Africa has a multi-cultural society who speak 11 official languages and 44 additional living languages – including those of a large portion of African migrants (Benjamin et al., 2016). A number of studies show that language barriers could pose a risk to patient safety (Deumert, 2010; van Rosse et al., 2016) and that they often lead to stress among healthcare practitioners (Blackstone & Pressman, 2016; Kalengayi et al., 2015). It is also common among migrants to have limited health literacy skills (besides the fact that functional health literacy can be decreased for anyone suffering from severe illness), which in turn affects their interaction with the healthcare system and their understanding of health-related communication (Hunter-Adams & Rother, 2017; Wångdahl, 2017).

## 2.4 | Communication disability and the right to augmentative and alternative communication

Children with cognitive and/or communication disabilities constitute one more group that poses a challenge regarding person-centred paediatric care. It is vital to consider this group due to their potential frequent need of healthcare, as well as their increased need of personalised communication. The latter was demonstrated in a study by Thunberg et al. (2015) who asked parents of children with different types of communication disabilities to suggest how their children's healthcare could be improved. Four categories emerged in this interview study: a need for tailored care; the importance of communication and understanding between the child and practitioners; perceived safety due to interaction and environment; and finally, the importance of skills and knowledge of AAC and special needs (Thunberg et al., 2015). AAC provides strategies and tools to support understanding and expression when spoken or written language and communication is not effective. It may also include the use of manual signing, synthetic speech (on speech-generating devices) as well as the use of different types of graphic resources such as pictorial schedules, communication boards/displays and communication apps (Bornman & Tönsing, 2019).

The United Nations' Convention on the Rights of Persons with Disabilities (CRPD) is intended to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (United Nations, 2006). The Convention is based on eight general principles, including individual autonomy (i.e. the freedom to make one's own choices), full and effective participation and inclusion in society, and accessibility. Three articles are pertinent to our research: Article 7 specifically focuses on children with disabilities and their right to express themselves and have assistance according to age and disability. Article 21 highlights the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, including AAC. Article 25 notes that healthcare practitioners are required to provide equivalent quality of care to persons

with disabilities as to others and to take all appropriate measures to ensure their access to healthcare and healthcare communication.

## 2.5 | Principles of universal design

The notion of 'universal design' is strongly proposed throughout the CRPD, meaning that the design of products, environments, programmes and services should be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design (United Nations, 2006). In 1997, a working group of architects, product designers, engineers and environmental design researchers formulated the seven principles of universal design (North Carolina State University, 2020). The intention of these principles (displayed and further specified in Table 1) was to guide the design of environments, products and communications. In the discussion of person-centred paediatric communication that follows below, the principles of universal design are used as a framework.

## 2.6 | *KomHIT* – communication support in healthcare programme

The *KomHIT* (in English: *Come here*) web resource was developed to support the communication rights of patients in healthcare situations, especially for communication-vulnerable patients (i.e. those who experience speech and language challenges, also as a consequence of illness, with a main focus on children and on the use of AAC means and strategies). In *KomHIT*, communication and communication support materials are designed and used according to the principles of universal design (UN General Assembly, 2007). It is believed that, should healthcare practitioners know how to augment communication with patients who are communication vulnerable, communication will be facilitated, and the quality of healthcare will be enhanced for all patients. Therefore, *KomHIT* aims to promote the generalised use of AAC means and strategies to all patients as a routine element of healthcare, mainly in the form of pictorial support and simple, easy-to-read texts. The *KomHIT* programme provides both information and education, and easily available communication tools and materials. Supportive pictorial communication material can be created, stored, and searched using an open access web resource ([www.bildstod.se](http://www.bildstod.se)), and the captions to each of the pictures can also be translated into languages commonly spoken in the Swedish care context, such as English, Arabic and Somali.

Another web resource shares information about communication rights in healthcare (<https://www.vgregion.se/ov/dart/fardigt-material/vard/>) and offers educational resources, mainly in the form of illustrative video examples and video-recorded lectures. The videos demonstrate how AAC, mainly in the form of pictorial support, can be used with communication-vulnerable patients (e.g. those patients who do not understand the language used in the healthcare system or those who have a communicative disability), as well as for patients with no communication challenges (Figure 1).

TABLE 1 The seven principles of universal design: Clarification and guidelines (University of North Carolina)

Principle	Clarification	Guidelines
Principle 1: Equitable Use	The design is useful and marketable to persons with diverse abilities.	1a. Provide the same means of use for all persons: identical whenever possible; equivalent when not. 1b. Avoid segregating or stigmatising any persons. 1c. Ensure that provisions for privacy, security, and safety are equally available to all persons. 1d. Make the design appealing to all persons.
Principle 2: Flexibility in Use	The design accommodates a wide range of individual preferences and abilities.	2a. Provide choice in methods of use. 2b. Accommodate right- or left-handed access and use. 2c. Facilitate the person's accuracy and precision. 2d. Provide adaptability to the person's own pace.
Principle 3: Simple and Intuitive Use	The design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.	3a. Eliminate unnecessary complexity. 3b. Be consistent with the person's expectations and intuition. 3c. Accommodate a wide range of literacy and language skills. 3d. Arrange information consistent with its importance. 3e. Provide effective prompting and feedback during and after task completion.
Principle 4: Perceptible Information	The design effectively communicates necessary information to the individual, regardless of ambient conditions or the individual's sensory abilities.	4a. Use different means (pictorial, verbal, tactile) for redundant presentation of essential information. 4b. Provide adequate contrast between essential information and its surroundings. 4c. Maximise 'legibility' of essential information. 4d. Differentiate elements in ways that can be described (i.e. make it easy to give instructions or directions). 4e. Provide compatibility with a variety of techniques or devices used by individuals with sensory limitations.
Principle 5: Tolerance for Error	The design minimises hazards and the adverse consequences of accidental or unintended actions.	5a. Arrange elements to minimise hazards and errors: most-used elements, most accessible; hazardous elements eliminated, isolated, or shielded. 5b. Provide warnings of hazards and errors. 5c. Provide fail-safe features. 5d. Discourage unconscious action in tasks that require vigilance.
Principle 6: Low Physical Effort <sup>a</sup>	The design can be used efficiently and comfortably, and causes a minimum of fatigue.	6a. Allow person to maintain a neutral body position. 6b. Use reasonable operating forces. 6c. Minimise repetitive actions. 6d. Minimise sustained physical effort.
Principle 7: Size and Space for Approach and Use <sup>a</sup>	Appropriate size and space are provided for approach, reach, manipulation and use, regardless of individual's body size, posture, or mobility.	7a. Provide a clear line of sight to important elements for any seated or standing person. 7b. Make reach to all components comfortable for any seated or standing person. 7c. Accommodate variations in hand and grip size. 7d. Provide adequate space for the use of assistive devices or personal assistance.

<sup>a</sup>Principles 6 and 7 mainly deal with physical access which is not the focus of this paper.

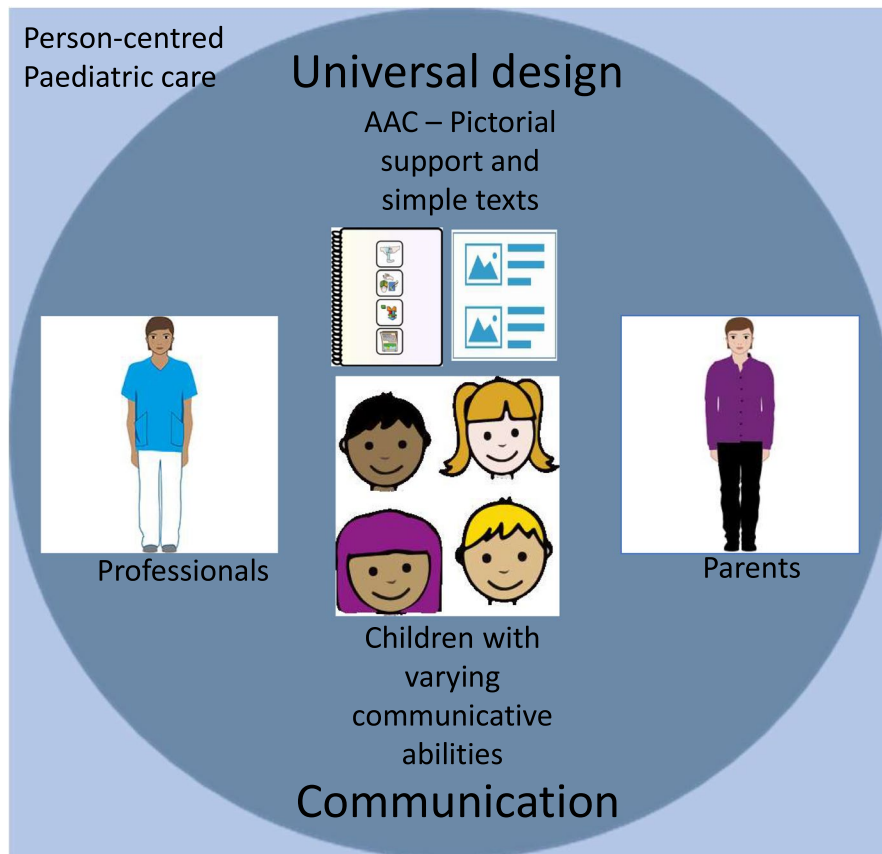
### 3 | CASE EXAMPLES

Three case examples from Swedish paediatric practices are presented to demonstrate and discuss the use of a communication strategy based on universal design principles and applying AAC means and strategies. All three clinics participated in a project that implemented the *KomHIT* programme and had been approved by the ethical review board at Gothenburg University. Interview data were collected and analysed as part of the project by students doing a Master's degree in either nursing (Vaanta Benjaminsson, 2016; Vaanta Benjaminsson & Nilsson, 2017) or in speech-language pathology (Beijer, 2016; Lindbladh & Schönberg, 2019). Results and

excerpts from their interviews done with children, parents and healthcare practitioners at the clinics are included in the discussion section of the paper.

#### 3.1 | Clinical settings and participants in the case examples

All three case examples come from clinics that accommodated children and adolescents (0–18 years of age). One clinic was part of a regional University Hospital, and the second was part of a county hospital, while the third clinic was attached to a small local hospital.



**FIGURE 1** Augmentative and alternative communication (AAC) using pictorial support and simple texts as universal design supporting person-centred communication in paediatric care

The regional clinic was a clinic specialising in child and adolescent psychiatry (from here on referred to as 'the child psychiatry clinic'). It served a high incidence of children with special needs with regard to communication – most often developmental language or neuropsychiatric disorders (most commonly autism spectrum disorder), along with psychiatric disorders (see Table 2). The other two clinics were paediatric clinics for children and adolescents with a variety of paediatric conditions (of which the majority did not have special needs regarding communication or cognition). These clinics will be referred to as 'the county hospital' and 'the local paediatric clinic', respectively. Table 2 provides more detailed information about the clinics, participants, focused healthcare procedures and the procedures for collection and analysis of the interview data used in this article.

### 3.2 | Implementation of the *KomHIT* communication-in-healthcare programme

Experience and research suggest that, to successfully implement *KomHIT* as well as other interventions or approaches, the responsibility should be clear (Rycroft-Malone et al., 2013; Thunberg et al., 2019). The *KomHIT* programme therefore recommends the appointment of one or two communication mentors to be responsible for the implementation process and the development of pictorial resources to support communication. The mentors at the clinics all took part in a 6-hour on-site course. Besides attending presentations on communication rights, communication disabilities, supportive strategies for communication and a suggested implementation process, the main

goal was to teach participants how to design and produce pictorial material using the free web tool [www.bildstod.se](http://www.bildstod.se).

The training started with mentors informing the participants about the overall purpose and methods used in the *KomHIT* intervention, and discussions and video clips from the web resource were used. Thereafter, each clinic discussed their specific need and how to proceed with the pictorial supports. The mentors then developed the pictorial resources, also in consultation with experts from DART (Centre for Augmentative and Alternative Communication and Assistive Technology), which acted as the project leader of the *KomHIT* project. Once the pictorial material was completed, it was presented to all healthcare practitioners during a meeting so as to provide opportunities for practice during role play. The practitioners were also informed about evaluation activities and collection of data. The communication materials that were developed at the three clinics are listed in Table 2. Examples of these materials are displayed in Figures 2–4.

## 4 | DISCUSSION


The principles of universal design were used to discuss this position statement on communication and person-centred paediatric care to the results and excerpts from three case examples where AAC methods and strategies were applied. Numbers 6 and 7 of the seven principles of universal design were not included in this discussion, since they only relate to physical aspects or effort (size and space for approach and use, see Table 1) and thus did not fall within the focus of this study.




TABLE 2 Overview of clinical examples. Information about clinics, procedure, type of pictorial support, interview participants, type of interview and description of analysis

Clinic	Procedure	Pictorial support	Interview participants	Semi-structured interviews	Analytical framework and brief outline of analysis
Child and adolescent specialist psychiatric clinic, regional hospital	New visit, Follow-up of medical treatment, Information about OCD treatment	<ul style="list-style-type: none"> <li>• Invitation letter with pictorial support.</li> <li>• Communication boards (for waiting room and for medical treatment).</li> <li>• Schedule book with pictorial support for visit.</li> <li>• Information leaflet about OCD treatment.</li> </ul>	4 parents (all mothers) of 3 girls and 1 boy; 9–17 years old with OCD, depression, anxiety, bipolar disease) 6 professionals (doctor, 2 nurses, social worker, 2 psychologists)	Individual telephone interviews 2 dyadic interviews and 2 individual interviews in private room at the clinic	Content analysis (Graneheim & Lundman, 2004) All transcriptions were read several times to identify meaning units. These were condensed to identify the core meaning. The codes were then grouped to categories and subcategories.
Paediatric medical and day surgery ward, county hospital	Nitrous oxide during needle-related examinations and treatments	<ul style="list-style-type: none"> <li>• Information leaflet with pictorial support sent home.</li> <li>• Schedule book with pictorial support for visit.</li> </ul>	17 children (9 boys, 8 girls) 7–13 years old	Individual interviews 0.5–2 hours after treatment in private room at the hospital	Qualitative content analysis (Elo & Kyngäs, 2008). Meaning units were selected to form condensed meaning units. These were grouped into codes and then subcategories that were abstracted into categories.
Paediatric medical and day surgery ward, local clinic	Needle procedure and/or day surgery (due to assessment or intervention for stomach (2); ear (1) or genital problems (1)	<ul style="list-style-type: none"> <li>• Invitation letter with pictorial support and simple text,</li> <li>• Schedule book with pictures (for one child with ASD).</li> </ul>	6 parents (4 families) 4 children (1 girl, 3 boys) 6–11 years old (2 with ASD, 2 with neurotypical development)	Individual interviews in the families' homes Interview in the home supported with pictures (Talking Mats) and in two cases with a parent present	Thematic analysis (Braun & Clarke, 2006) All transcriptions were read several times and relevant text was marked and coded. The codes were then sorted according to content, to form themes and subthemes.


Abbreviations: ASD, Autism spectrum disorder; OCD, Obsessive compulsive disorder; TD, typical development.

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**FIGURE 2** Examples of AAC material that were used in the child psychiatry clinic: To the left, the first page of an invitation letter for drug monitoring that was sent home to the child. To the right, a communication board that was placed in the clinic's waiting room

#### 4.1 | Principle 1: Equitable use

The first principle of universal design states that the design should be useful and marketable to people with diverse abilities, and that segregation and stigmatisation should be avoided (Table 1). As such, 'Equitable Use' may be regarded as basic and overarching while the principles that follow constitute the specifications and descriptions of aspects that need to be considered to enable equitable use. All three clinics sent out texted material as well as AAC material to all children – not only to those children with an identified disability or language problem, as is typically done in practice and research when AAC is used within healthcare (Hemsley & Balandin, 2014; Blackstone & Pressman, 2016). Furthermore, the material was meant to be used by the children as well as by their parents. The healthcare practitioners believed that the provision of information with pictures and simple texts, compared to the text-only materials offered before, would probably make parents more likely to share it with the child when talking about the proposed healthcare visit. The practitioners felt that this was important seeing that the child was the patient and hence had the right to knowledge.

This becomes even more so that it is aimed at those who are actually patients and who should have that information.

(Practitioner, child psychiatry clinic)

The practitioners at the child psychiatry clinic also believed that the provision of communication material with pictures, which

could be taken home and used there, could make parents more active and children more involved, even after the visit to the clinic. It is important for everyone to talk and discuss the visit, as this constitutes a basic element in person-centred care processes, namely creating one's personal story (Britten et al., 2020; Fors et al., 2020). Person-centred paediatric care invites the child into the process of decision-making and negotiating of care, and researchers argue that universal access to pictorial support and possibly other supportive tools may be necessary to involve children in person-centred care (Carter & Ford, 2013; Nilsson et al., 2020). In one of the clinical examples, a parent shared how her son was given the option to point to pictures to choose the order in which the medical procedure would be conducted. Being part of the decision-making about his care procedures and treatment gave him control during the care, something the healthcare practitioners also expressed as being important. The parent emphasised that it was the child's care and that he/she should therefore be empowered to make decisions.

So, then he was in full control, he was in control over his visit. And the children should have that, it is still their visit.

(Parent, child psychiatry clinic)

Principle 1 emphasises equitable use, and although the pictorial material was intended and perceived as a way to increase young children's participation, the pictures were regarded as beneficial for most paediatric patients and their parents. This perception was clearly



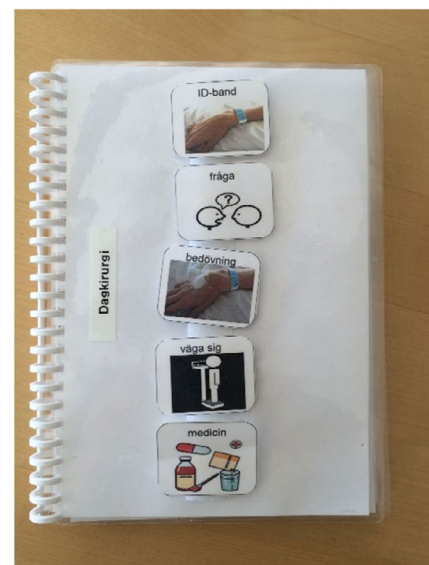
	You will be informed about what will happen		The nitrous oxide is sedative and analgesic. You will inhale nitrous oxide for three minutes to get the full effect of the medication, then you will inhale nitrous oxide as long as necessary
	You will get topical anesthetic		The joint injection is given and afterwards you will get a patch
	The staff will ask you if you have pain, and how you feel		You will breathe oxygen to perk up
	You can choose a topic that you like to talk about or listen to music		You will get juice or water ice afterwards
	You will get medicine so that it will not hurt		You will answer questions about your perceptions of having nitrous oxide
	Now you are allowed to go to the playroom or the teenage room		The staff will ask you if it hurt, and how you felt
	You can go to the toilet and pee		If you received joint injection in the knee or foot, you can borrow crutches or a wheelchair for 24 hours
	The staff or yourself removes the patch with topical anesthetic		You need to take it easy for the rest of the day
	Mom or Dad can go with you		Now it's finished, goodbye!
	You will be on a gurney		

FIGURE 3 Example of AAC material that was used in Example 2 in the county hospital: An invitation letter that was sent home with information about nitrous sedation

FIGURE 4 Examples of AAC material that were used in the local paediatric clinic: To the left, the first page of information that was sent to the child to inform them about day surgery. To the right, the first page of a pictorial schedule book that was given to the child upon arrival at the clinic. The pictures are removed one by one as the activities are completed. The practitioners or parent can also rearrange pictures to explain potential changes. The pictures that are 'ticked off' (completed) are placed at the back to be used for communication about what the child has achieved

operation

	Sätta pvk
	Få patient kläder
	Vänta på operation
	Kissa innan operation
	Åka säng till operation



observed in some situations, such as during the first visit or when new information was presented. One parent at the local paediatric clinic thought that the use of pictorial support also benefited her.

So, this was very, that [pictorial support] was good for me too (LAUGHING) as a parent [...] and being able to see how everything looked and knowing where we were going and so, it was really good.

(Parent, local paediatric clinic)

One parent of a child with behavioural challenges on the autism spectrum stated that the pictorial support helped in decreasing her own concerns about her child's treatment.

... I was terribly nervous, so sickly nervous. [...] Then when I got the pictorial support it was lowered a lot, because then I could explain to him and stake out like that day for him and, and for myself.

(Parent, local paediatric clinic)

Older children at the clinics also felt positive towards the pictorial support.

Now, my daughter is fourteen, so she is a little bit older, but I don't think it made any difference, if she was, like, five or eight or ten or fourteen, she really liked it, still, you know. She can connect with it.

(Parent, child psychiatry clinic)

## 4.2 | Principle 2: Flexibility in use

Principle 2 of universal design reads that the design should be flexible and accommodate a wide range of individual preferences and abilities (Table 1). In the interviews, it was mentioned that the children were sometimes shy or insecure when they encountered new people in new settings. They had difficulty in using their speech then and thus needed other means to express themselves.

... it is not always that the children feel, like, safe with new people, or so, or want to express or to talk to, even if they can. And then it is very positive that you can - because he got pictures and could choose what he wanted to do first, and then it was good enough for him to point to the pictures.

(Parent, local paediatric clinic)

It was also clear that the children and their families used the pictorial material for other purposes than what had been anticipated by the healthcare practitioners. For example, some children said that they used the pictorial support to tell their family what would happen at the hospital. Meeting the patient's preferences and abilities is also at the core of person-centred care (Fors et al., 2020). It is interesting to note

that in order to realise this, the first step actually implies a preparedness to meet a broad range of preferences and abilities with regard to communication. As such, universal design may facilitate this.

## 4.3 | Principle 3: Simple and intuitive use

Principle 3 refers to a design being easy to understand, regardless of the person's experience, knowledge, language skills or current concentration level (Table 1). Children, parents and healthcare practitioners all described the invitation letters with pictures and step-by-step easy-to-read texts as clear and easy to follow (Beijer, 2016; Lindbladh & Schönberg, 2019; Vaanta-Benjaminsson & Nilsson, 2017).

... when you do not have complete control yourself as a parent, it also becomes more difficult to guide your child and make it feel safe. [...]. We can support in a completely different way if we know what, what they should do or the different steps ...

(Parent, local paediatric clinic)

Several children were of the opinion that the pictorial support was effective as it showed what was going to happen and increased their understanding of the course of events (Beijer, 2016; Lindbladh & Schönberg, 2019; Vaanta-Benjaminsson & Nilsson, 2017). One parent at the local paediatric clinic suggested that the child had more control about what would happen during the day of the operation than he himself had. Parents also experienced that pictorial support provided opportunities for conversation and questions from the child (Beijer, 2016; Lindbladh & Schönberg, 2019). Pictures were considered easier to talk about than just written information.

It's more of something you can share with your child. Otherwise, when you only get a texted paper with like a date included, it will not be so much that you talk about it, but this is actually more to talk about, I think.'

(Parent, local paediatric clinic)

In this sense, the structure and pictures seemed to facilitate communication and person-centred paediatric care by establishing a basis for common understanding and providing tools for negotiation, all in alignment with recent theories of communication management (Rogoff, 2003; Tomasello, 2013).

A parent who did not speak Swedish as a first language benefited greatly from the pictures as well as from the fact that important words were marked in bold and that the text had been structured in a grid format (Beijer, 2016). This report of the visual structure supporting the understanding of a parent speaking a different language from the healthcare practitioner is both promising and important in view of the large number of patients in today's healthcare who are facing language challenges (Blackstone & Pressman, 2016; Hussey, 2012; Pascoe et al., 2018). The problems experienced by the patients inevitably lead to stress in healthcare practitioners (Kalengayi et al.,

2015). The reported benefit is also confirmed by research indicating that the use of pictorial support may facilitate understanding and the building of partnerships with parents who speak other languages than healthcare practitioners (Thunberg et al., 2019). This is important since both clinical practice and research with regard to person-centred care have been criticised for not having previously focused on patients with a communication vulnerability, such as patients speaking other languages than the language typically used in the healthcare context (Coyne et al., 2018).

Principle 3, 'Simple and Intuitive Use', also states that design should be consistent with expectations, which are important for building trust and partnership in person-centred care (Table 1). Some children stated that it was important for them that the communication was not deceptive and that the pictorial support was consistent with what subsequently happened.

Well, it was like I imagined it would be.

(Child, county hospital)

In this way, the children felt that they were in control of the situation, which made them feel stronger.

First I didn't want to see the picture with the needle but then you did not see the needle so much and then it looked like when you take a sample of blood in the arm, but a very big arm ... I felt that, I can do that.

(Child, county hospital)

The practitioners generally were of the opinion that younger children and children with disabilities benefited most from the pictorial support. According to the practitioners, they received many positive comments about the invitation letter from parents of children with different disabilities. They mentioned attention deficit hyperactivity disorder (ADHD) and autism spectrum disorders as conditions that benefited most from the invitation letter with pictorial support. One nurse shared how she had met patients who would have been challenging to examine without pictorial support, as they would not have been able to understand spoken communication – due to their disability or their not being able to understand the majority language spoken by the practitioners. This finding was very positive – as communication-vulnerable patients also have a legal right to receive information and participate in their own care. The latter has not often been focused on in research into person-centred care (Forsgren, 2017).

Principle 3 furthermore stipulates that design should provide effective prompting and feedback during and after task completion (Table 1). This aligns to 'the story' and 'the documentation', which are key concepts of person-centred care for children (Britten et al., 2017; Ekman et al., 2011; Fors et al., 2020). The interviews clearly showed that this was the case, and that healthcare practitioners, parents and children experienced that the children's participation increased – both before, during and after the hospital visit. Some children found that the pictorial support made it easier for them to talk about

the hospital visit when they were at home (Vaanta Benjaminsson & Nilsson, 2017). One child suggested that it facilitated conversations with practitioners during the hospital visit (Beijer, 2016). Furthermore, a number of children were of the opinion that it was good to be able to mark off or remove pictures of completed steps at the hospital by using the pictorial support resources.

Yes, he communicated in the meantime as well and said that yes now it comes here and now we have done this, now we have to mark it. Or now we will do, now we will do this, because he has a memory as well, so he has memorised the pictures...

(Parent, local paediatric clinic)

In the example above, it is interesting to note the recurring use of the word 'we', which indicates that the child and/or parent perceived the communication and the carrying out of the care procedures as a mutual project. This corresponds with a person-centred communication approach for children (Britten et al., 2017; Nilsson et al., 2015) that builds on a constructionist view of communication as described and referred to earlier (Jarvis, 2006; Schütz, 1972).

#### 4.4 | Principle 4: Perceptible information

The principle of 'Perceptible Information' upholds that the design should communicate necessary information effectively (see Table 1), regardless of ambient conditions or the person's sensory abilities. Thus it has a bearing on 'the story' and 'the documentation' of person-centred care components (Britten et al., 2017). The principle also suggests that design should use different modes for redundant information. This was clearly seen in the three examples. The practitioners at the child psychiatry clinic held the opinion that the pictorial support was beneficial for both parents and children in supporting memory, and they alluded to the fact that memory is enhanced if more senses are used. The children at the county hospital reported that the visual and easy-to-read text enabled them and their parents to review and discuss what would happen, and the needle-related procedure was de-dramatised (Vaanta Benjaminsson & Nilsson, 2017). The children felt that they understood what was going to happen during the needle-related procedure and as such they were less anxious.

Like, it's good to have both pictures and text because it's like you understand it better...That's how they explained it and such. Yes, I thought it was good that we received [some] because then you felt a little bit more [thinking] um, prepared.

(Child, county hospital)

Both children and parents at the local paediatric clinic thought that the combination of pictures and easy-to-read text was beneficial. One parent pointed out that supporting text is important, as a

picture without text can have several meanings. Some parents said that pictorial support made their children feel more secure than when only spoken communication was used. One parent said that the pictures in the invitation letter lightened the mood and made something that was difficult – to visit a hospital – a little more fun. The friendly impression given by the invitation letter with pictures was also considered to have the potential to influence the child's perception of the healthcare practitioners positively and consequently it made the hospital visit less frightening.

You know, she's thinking: "Oh, these people are going to be friendly when I get there, because I got this really nice, friendly form at the beginning", you know, "and it's got pictures." So then, when you go there, and everyone is friendly, then you start relaxing, I think.

(Parent, child psychiatry clinic)

This quote from the parent of a child who visited the child psychiatric clinic supports the fact that the adding of pictorial support apparently facilitated partnership building, even before the physical meeting occurred. This is central to person-centred care (Britten et al., 2017). The parent's remark also acknowledges the importance of an ordinary illustrated smiley face in the building of relationships within person-centred care.

#### 4.5 | Principle 5: Tolerance for error

Principle 5 of universal design states that hazards and the adverse consequences of accidental and unintended actions should be minimised (Table 1). Provision of fail-safe features regarding design is emphasised as important. In the three clinical examples, both practitioners and parents who were interviewed talked about the life situation of parents who (having many other things to think about) sometimes tend to read written information a little carelessly. Both parents and practitioners were of the opinion that the provision of pictorial support that is more readily understood, reduces the risk of mistakes. For example, the practitioners reported that in the past there were often misunderstandings about whether to eat or not before a test, or when to take medicine, which they hoped could be avoided in the future by adding pictorial support. Some children at the county hospital admitted that the pictures and text had drawn their attention to the fact that they could be in pain, but also that they would be asked about this. It turned out that if the healthcare professional forgot to ask the children to self-report their pain experience, the children themselves asked for it.

The practitioners ask if it is painful and how it feels now, yes. It was good.

(Child, county hospital)

This example illustrates how the documentation enhanced with pictures supported partnership building and the child's active participation in the healthcare procedure.

## 5 | CONCLUSION

In this position paper, we advocate the use of universally designed communication containing pictorial support and supplemented by easy-to-read texts to support person-centred paediatric communication and care processes. This is demonstrated by case examples relating to five principles of universal design. The pictorial resources support a partnership between the child, parents and professionals by eliciting the child's story and documenting it throughout the healthcare procedure: before, during and after the healthcare visit. This was recognised both for children and adolescents with and without disabilities and also in families who did not share the healthcare practitioner's language. The sending home of pictorial support materials prior to a healthcare visit may facilitate understanding of what is going to happen – both for the children and their parents. It enables them to become more positive and prepared for what is expected to happen, and it also builds a partnership with the healthcare practitioners. The access to material with pictorial support during the healthcare procedure seems to create a common ground for understanding, communication and negotiating of care. All of these are central processes in person-centred paediatric care and they involve the practitioners, the parent and the child. AAC as applied to paediatric healthcare can meet the requirements of the principles of universal design in being equitable, flexible, simple and intuitive, perceptible, as well as tolerant of error.

Migration and digitalisation have emerged as two strong contemporary global trends in the quest for more sustainable communication within paediatric care in line with the increasing focus on meeting the communicative rights of children as set out in conventions and other legislation. Digitalisation in itself also provides more options of universally designed communication combining text, pictures, speech and videos. However, these possibilities also call for reflection, new knowledge and research. Based on our experiences and studies in this field, there is an exploding interest in the use of more pictorial resources, apps and other digital solutions within healthcare. Unfortunately, there still are very few published studies on the effects of these, certainly not in considering communication vulnerability or universal design. In the clinical examples referred to in this paper, we demonstrated how universally designed communication supported person-centred care processes. As part of our ongoing research, we are investigating the effect of applying these ideas in designing and evaluating a digital app to assess and manage the symptoms of children and adolescents within a wide range of long-term paediatric conditions.

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#### DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.



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