

# BEHIND THE CLOSED DOORS: CHILDREN'S DREAMS IN INSTITUTIONAL CARE



# ACKNOWLEDGEMENTS

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*\*All the names of the children in this document have been changed to protect identity*



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OF DENMARK**  
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# EXECUTIVE SUMMARY



Ukraine is amongst the countries with the highest number of children raised in residential institutions rather than in families in the world. Children raised in these institutions - orphanages, medical institutions, psychiatric facilities, boarding schools, children's homes - face profound impacts on their physical and mental health, exposure to high risk of violence and abuse, and are often left poorly prepared for life outside these institutions. The war has dramatically increased the risks they face.

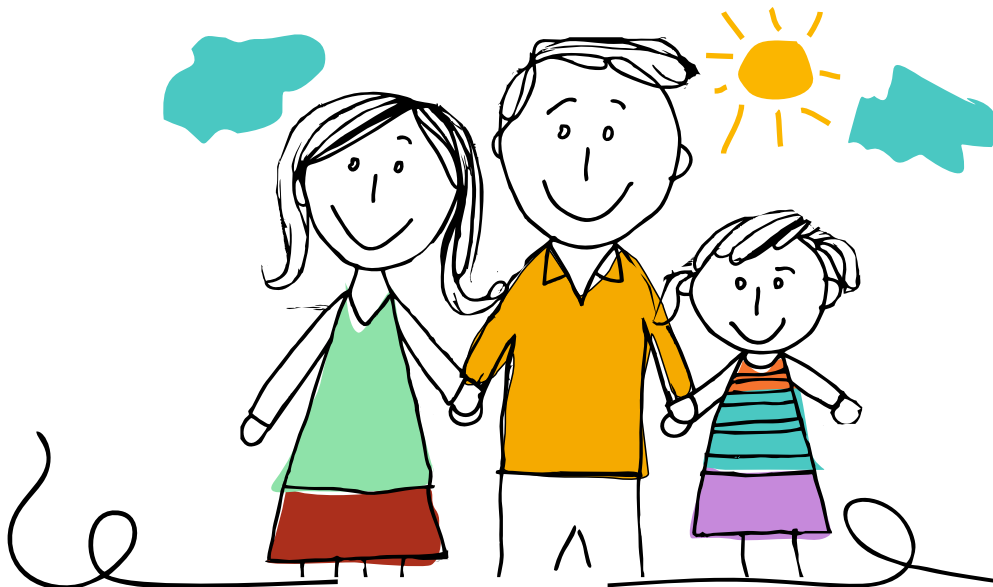
This research is unique in Ukraine. The voices of children in institutions are rarely heard. Even when children in institutions are consulted, children with disabilities are often excluded. This report is based on specialised research with 100 children with disabilities living in institutions in Ukraine, many of which have communication challenges or high support needs (HSN), and seek to raise their voices at a time when the government of Ukraine has recommitted to a process of reforming the system of institutional care in the country.

Despite the limitations in verbal communication among many of the children and young people who participated in the research, through their interactions with researchers, all were able to provide information regarding their likes and dislikes, hopes, fears, wishes, frustrations and dreams. The children displayed a wide range of personalities and preferences, belying the uniform treatment they experience and that is characteristic of institutional care.

Notwithstanding these individual differences, there were strong commonalities in their experiences and desires, including:

- **The importance of family:** Many children expressed a strong desire for family connections, reflecting a deep understanding and need for familial relationships.

- 67% expressed or indicated their wishes to have a family who will love and understand them
- 90% demonstrated their desire for a stable, permanent adult in their life.
- **Social interaction and independence:** All children enjoyed social interactions when approached properly, showing a high demand for trusted adult relationships.
  - 89% of the children and young adults expressed their desire to do things independently and showed their desire to move more freely, without restrictions.
- **Desire to learn and achieve:** Nearly all children responded positively to learning opportunities, showing joy and increased motivation when their achievements were recognised.
  - 88% of the children and young people expressed their desire and ability to learn more by participating in new activities, exploring new environments, and trying to figure out previously unknown games and puzzles.
- In one institution where there had been significant individualised intervention with the children and young people over the previous few months, this percentage rose to 98%.
- **Creativity:** Many children displayed a strong interest in creative activities, such as art and music. Children could concentrate for longer periods when doing such activities, which also helped reduce challenging behaviours.



*"When children are engaged in creative activities such as drawing or music, they concentrate longer, which helps to reduce behavioral challenges"*

- **Frustration at confinement:** Some children confined to lying in bed or sitting in their wheelchairs had become very passive or expressed their upset through crying, self-harming or aggression. These behaviours and emotions changed dramatically when they were allowed to move on the floor and interact with the researchers, with toys and activities, or with other children.
- **Internally Displaced Children** appeared to be significantly more likely to experience high levels of anxiety in unfamiliar situations or when meeting new people. These children would routinely 'freeze' when the researchers entered the room and required a great deal of time and careful approach before they began to relax.

The findings in this research highlight the neglect inherent in placing children in institutions, the prioritisation of the needs of the institutions over the needs of the children themselves, as well as the clear lack of an effective system or mechanism for institutional personnel or government inspectors to gather children's opinions or feedback. Far from listening to these children and acting upon their views, a prevailing "medical model" of disability in Ukraine – in which disability is viewed as the result of one or more physical defects – often leads to the assumption amongst staff of institutions that these children cannot communicate or that they lack significant thoughts. Similarly, the children are commonly perceived as "uneducable" and therefore rarely included in any formal education.

This creates a self-reinforcing cycle as the belief that children cannot communicate or learn leads to a lack of engagement: this lack of meaningful communication with the children leads to developmental delays and attachment issues, which in turn reinforces the initial belief.

Children's individual personalities are thereby suppressed, leading to passivity or misinterpreted actions such as self-harming or aggressive behaviour. It appears obvious that care for children with disabilities, deprived of a family environment, must become child-focused and humane.

## **LOOKING AHEAD**

The voices of children who participated in this research should be heard by Ukrainian authorities and society and inform and influence the government's planned reforms to its child protection system, including as part of its accession process to the European Union.

As the government of Ukraine moves ahead with the implementation of these plans, it should **take into account the opinions and interests of children with disabilities and high support needs during the planning and implementation of the Strategy for ensuring the right of every child in Ukraine to grow up in a family environment.**

# METHODOLOGY AND CHILDREN AND YOUNG PERSONS INVOLVED

Researchers carried out a series of one-to-one specialised sessions with 100 children and young people with disabilities, including children with high support needs (HSN) and limited verbal communication, in 5 institutions in different regions of Ukraine. The research was carried out during a period December 2023 – March 2024 inclusive.

The data were analysed both qualitatively – to represent diverse, nuanced experience – and quantitatively – where consistent patterns emerged from the qualitative data.

The methodology included the standard ethical considerations for involving children – and particularly children with disabilities – in research while ensuring their truly meaningful participation<sup>1</sup>.

## AGE AND GENDER OF CHILDREN

The children and young people were aged between 6 and 34 years, with the majority (74%) aged between 11 and 17 years. 61% were male and 39% were female<sup>2</sup>.

## INTERNALLY DISPLACED PERSONS (IDPS)

39% of the children and young people have been internally displaced due to the war – having been evacuated from Eastern Ukraine. It is likely they had experienced extreme distress due to bombardment and/or the sudden move from one institution to another.

## TYPE OF DISABILITY

Of the 100 children and young people:

- 88% are persons with intellectual disabilities
- 78% are persons with physical disabilities

## PRINCIPLES UNDERPINNING THE METHODOLOGY

**Do no harm.** The research methodology was informed by a risk analysis to ensure that the process itself was a positive experience for the children involved. The risk analysis has informed the methodological approach, which prioritises, above all else, the safeguarding and meaningful participation of children and young people.

**Meaningful inclusion and participation** informed the sampling, the choice of methodological approach, the selection of partners, and the selection of team to design and implement the research

**Youth and disability leadership.** The research team included young people with lived experience of institutionalisation, as well as persons with disabilities and their family members.

**Action research.** All research processes have an impact. This research was designed as action research, in which all impact of the research process is intentional and seeks to avoid any unintentional negative consequences.



- 70% have both intellectual and physical disabilities
- Three children were found not to have disabilities and apparently had been placed in the institution due to behavioural and other issues.
- 14% are persons with health conditions resulting in HSN
- 83% have high support needs (HSN).

## LEVEL OF INDEPENDENCE AND MOBILITY

The children and young people had varied levels of independence and mobility, which has a significant impact on a person's control over their own life – and their access to their basic human rights.

- 42% were able to walk and perform physical tasks with only minimal support
- 29% had limited mobility – they were able to do some physical tasks with support
- 29% had extremely limited mobility. They spent a great deal of time in bed and occasionally used wheelchairs or strollers.

## LEVEL OF COMMUNICATION

The children and young people also had varied levels of communication skills.

- 16% had a fairly well-developed ability to communicate verbally – they were able to answer quite complex questions and express themselves
- 20% had minimal verbal ability – they could say a few words
- 66% were completely non-verbal – they did not use verbal communication at all.

*29% of children and young people had severely limited mobility, spending much time in bed and occasionally using a wheelchair or stroller.*





# BACKGROUND

Institutional care settings are distinguished by large numbers of children being looked after by a relatively small number of staff who are frequently unable to provide children with the consistent care and attention they require. Institutional care has lasting effects on children's physical and psychological development, with particularly severe consequences for younger children who are admitted to these facilities.

In 2022, Ukraine had one of the highest rates of child institutionalization in the world, with approximately 100,000 children living or studying in over 700 institutions across the country, and 15,000 of whom had disabilities. While some of the children attended institutions to receive educational services, over half of the children resided in institutions around the clock for various reasons<sup>3</sup>. Children in institutional care in Ukraine were at significant risk of abuse and exploitation, especially those with disabilities and with high support needs<sup>4</sup>.

Ukrainian child protection system faces new threats and additional risks as the war escalates in February 2022. Some institutions were evacuated en masse, either to safer regions of Ukraine away from the front lines, or across borders to other countries, which is typically a deeply traumatic experience. In the East and South of Ukraine, a number of institutions along with children residing there, came under temporary occupation. Furthermore, due to the increased rates of parental mortality, disappearance, participation in hostilities, and family separation, more children are in danger of being institutionalized.

In October 2022, the UN Committee on the Rights of the Child and the UN Committee on the Rights of Persons with Disabilities published a joint urgent call to action for evacuated Ukrainian children with high support needs, who face a disproportional risk of death as a result of the particular neglect associated with institutionalization. The Committees called upon the government of Ukraine to promptly conduct individual support needs assessments for children, prioritising family reunification and the provision of temporary foster family care for all children currently residing in institutions<sup>5</sup>.

In the early months of the conflict, some 39,000 children were returned home from institutions, yet *"26,000 children were not being monitored or supported after having ostensibly been returned from institutions to their families or guardians."*<sup>6</sup> During 2022, thousands of children gradually returned to institutions, and according to official figures from the government, as of the beginning of 2024, an estimated 29,766 children are permanently residing in institutional care facilities, including roughly 4,500 children with disabilities<sup>7</sup>.



## **MOMENTUM FOR REFORM**

Driven by the current momentum of the European Union accession process<sup>8</sup>, as well as the personal commitment of key government figures and the First Lady of Ukraine, there is renewed impetus to reform Ukraine's child protection system, efforts that had not yielded significant results for children with disabilities in institutional care.

The Cabinet of Ministers of Ukraine has established the Coordination Center for Family Upbringing and Child Care Development to coordinate different agencies involved in child protection reform. The government of Ukraine has developed a draft Strategy for Ensuring the Right of Every Child in Ukraine to Grow up in a Family Environment for 2024-2028<sup>9</sup>. This is also complemented by the "Plan for the Ukraine Facility", which includes measures for the deinstitutionalization of children, required for the implementation of the EU's economic support package for the country's recovery, development and integration into the EU<sup>10</sup>.

Despite concerns over specific aspects of the government's approach to deinstitutionalization, such as its approach to establishing "family-type" homes for children<sup>11</sup> and small group homes for children<sup>12</sup>, the overall efforts to overhaul reform of the child protection system are welcome and long needed.

## **STRUCTURAL CHALLENGES TO COMPREHENSIVE REFORM**

The Ministry of Social Policy is the primary agency in Ukraine responsible for family and children affairs, however, their capabilities are not sufficient for inter-ministerial coordination in such a complex remit as reforming the institutional care system. Children's institutions in Ukraine are under the jurisdiction of three ministries: the Ministry of Education and Science, the Ministry of Social Policy and the Ministry of Health. The absence of adequate coordination between these and other agencies might pose substantial challenges in setting integrated national policy, budgeting, planning, and implementation for deinstitutionalization reform.

Reform processes are further complicated by the recently undertaken decentralization of state responsibilities. *Hromadas* – local/municipal authorities – have a great degree of independence but have low capacity, limited resources and do not always prioritise children in institutions, nor do they recognize that there are better possibilities for children.

The war has triggered greater challenges for Ukraine's child protection system, resulting in huge institutional evacuations, personnel relocation and staff outflow, and reduced budgets as the military effort is prioritized.

In addition to these policy, resource and coordination issues, Ukrainian legislation requires significant improvement since it perceives the child only as an object of protection and still envisages institutional care for children<sup>13</sup>. According to Ukrainian legislation, children who cannot live with their family due to "difficult life circumstances"<sup>14</sup> may have their upbringing "carried out by relatives or foster families, centers for social and psychological rehabilitation of children, shelters for children, *other institutions for children*."<sup>15</sup>

There are fewer safeguards against institutionalization for children with disabilities in Ukraine. The Family Code of Ukraine allows parents to leave a child in a maternity hospital or other healthcare facility if the child “has significant physical and (or) mental health conditions”<sup>16</sup>.

In Ukraine, it is common for people with disabilities to remain in institutional care facilities long after they reach the age of 18. Current legislation provides for institutionalization of persons with disabilities throughout their lives, including children’s homes - specialized boarding schools, and residential homes for the elderly and disabled persons. The regulations for each of these institutions do not include provisions for finding a family for a child, involvement in community life, or the prospect of choice.

### **LACK OF MECHANISMS TO LISTEN TO CHILDREN**

In Ukraine, there is no consistent and unified practice for capturing children’s perspectives, nor is there a mechanism in place to guarantee that their views are properly integrated, interpreted and applied to legislative, administrative, and judicial procedures and decisions. The legislation notes the importance of taking the child’s opinion into consideration and provides for minimal procedural standards when an official decision is being made regarding a child.

However, officials and adults often do not comprehend children speaking on critical matters, and children are frequently not consulted when making national-level decisions or adopting laws concerning children. Laws are not being translated into a child-friendly language, active youth is generally supported by civil society only to boldly voice their ideas, youth or children councils are frequently constituted explicitly.

State servants and personnel in institutional care facilities have typically not received training or had access to methods that might help them understand how to communicate effectively with children.

These structural flaws and systemic weaknesses in the broader child protection system as well as in institutions more specifically are much more evident in the case of children with disabilities, including those who are non-verbal or have limited verbal ability.

#### **RIGHT TO A FAMILY LIFE, AND INTERNATIONAL GUIDELINES ON INSTITUTIONS**

Ukraine has ratified the UN Convention on the Rights of the Child, requiring it to ensure that a “child shall not be separated from his or her parents against their will, except where the competent authorities, in accordance with a judicial decision, determine in accordance with applicable law and procedures that such separation is necessary in the best interests of the child.”

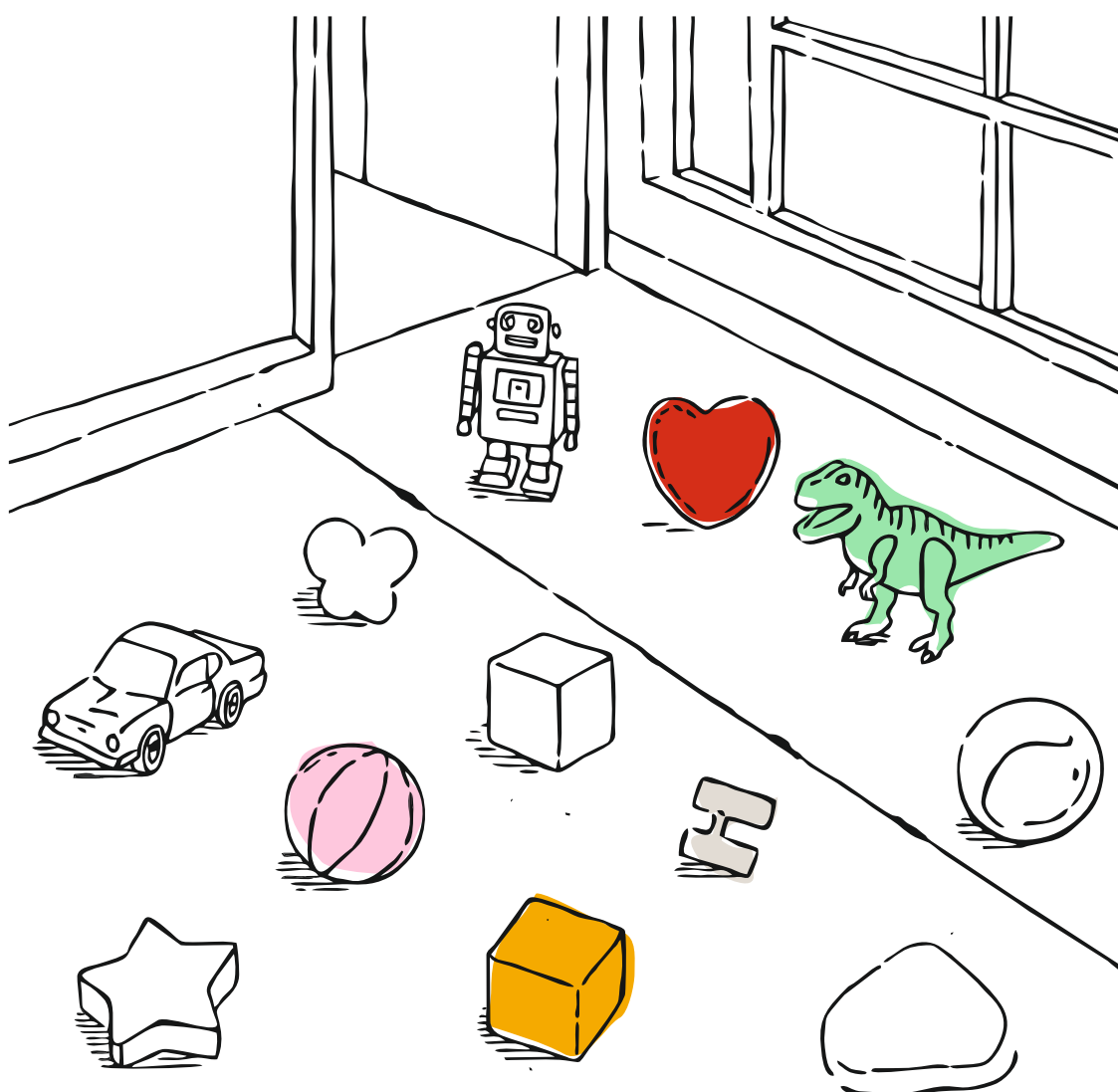
This priority given to family care is also contained in the Guidelines for the Alternative Care of Children adopted by the UN General Assembly in 2010, which emphasize that “the child protection system should aim to prevent the separation of children from their families and create opportunities for reunification”. These guidelines say that residential care should be “limited to

cases where such a setting is specifically appropriate, necessary and constructive for the individual child concerned and in his/her best interests.”

Both Ukraine and the European Union have also ratified the Convention on the Rights of Persons with Disabilities, which states that “under no circumstances may a child be separated from his or her parents on the grounds of disability of either the child or one or both parents.”

The Committee on the Rights of Persons with Disabilities, the expert body which monitors implementation of the Convention, issued Guidelines to state parties which state unequivocally that institutionalization is “a form of violence against persons with disabilities” and that “large or small group homes are especially dangerous for children.”

The Guidelines also state that “there is no justification to perpetuate institutionalization. States parties should not use lack of support and services in the community, poverty or stigmas to justify the ongoing maintenance of institutions, or delays to their closure. Inclusive planning, research, pilot projects or the need for law reform should not be used to delay reform or to limit immediate action to support community inclusion.”



# KEY FINDINGS

## PERSONALITY, HOPES AND DREAMS

Despite the limitations in verbal communication among many of the children and young people, through the interactions between them and the researchers, 100% of the participants were able to provide information regarding their likes and dislikes, hopes, fears, wishes, frustrations and dreams. These have been summarised according to patterns that emerged when analysing the data.

### Desire to be more independent and have fewer restrictions

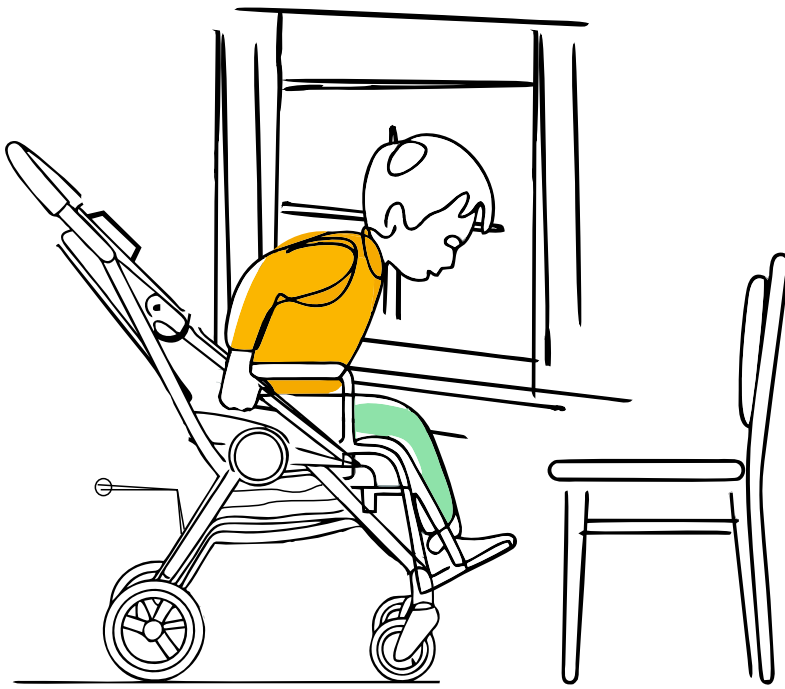
***89% of the children and young adults expressed their desire to do things independently and showed their desire to move more freely, without restrictions.***

Notably, there was one institution in the study where there had been significant individualised intervention with the children over the previous few months – in this particular institution this percentage rose to 98%.

*Researchers noticed that Andriiko, an 11-year-old boy with HSN, was tied to a wheelchair around the waist. His caregiver explained that because his muscles are very weak, he cannot keep himself in a sitting position. Researchers carefully removed Andriiko from the wheelchair, transferred him to the hoist and placed him in a sitting position, resting on a soft chair. He was very glad that he was no longer in the chair and began playing with the toys and researchers. Andriiko makes eye contact and often smiles happily when spoken to. When researchers asked if he liked being in the game room with researchers, Andriiko understood the question and answered “yes” clearly.*

Previous research demonstrates that physical restraints are used quite commonly in institutions for children with disabilities in Ukraine.<sup>17</sup> Sometimes these restraints are due to a lack of appropriate equipment, such as seating and wheelchairs designed for the individual. In other cases, the child may wish to move around, but there are too few personnel to provide supervision – and it is considered unsafe. In other cases, children are restrained due to self-harming or aggression towards other people. This is an example of the impact of institutional culture – where the needs of the institution take precedence over the needs and rights of the people living there. In Andriiko’s case, it was clear that these physical restraints and lack of the right assistive devices meant he could not engage in activities that he enjoyed and that stimulated him.

*11-year-old Danylo enjoys walking on his own. He gets very upset when his caregivers require him to sit in a stroller for walks. Danylo demonstrated his abilities for the researchers by independently walking to the bedside and getting on and off a chair using minimal support. He was extremely proud to show off his achievement.*



*"Danylo is very proud of the fact that he was able to walk to the bed and sit on a chair on his own"*

*Danylo's case, again, shows how the needs of the institution take precedence. When taken out for walks, he wishes to walk, but is made to sit in a stroller – this is likely to be either because he would slow the group down, or because there would be too few personnel to supervise him and keep him safe. This restriction is a source of extreme frustration for *Danylo*. It should also be noted that to develop more mobility, children need regular opportunities to practice and build up their skills.*

*Karyna, a 12-year-old girl, shows frustration when she is faced with the limitations of living in an institution. She is often frustrated when she is required to follow rules that she does not understand and will do things that are forbidden to show how much she values her freedom. Karyna is creative – she loves having her nails painted and cuts paper to fit her nails when nail polish is not available.*

*16-year-old Milana has physical disabilities and HSN. When first meeting the researchers, she was shy but began to open up by showing her notebook with her personal thoughts and drawings. Milana loves to draw and read. Milana can speak and shared with researchers that she likes taking walks and even enjoyed a trip to the dentist. Milana shared that she would love to visit the sea in all types of weather and shared her drawings of the sea.*

These two examples show teenage girls expressing their creativity. In Karyna's case, we see the beginnings of an interest in personal appearance – and a desire to express her individuality through personal care.

In Milana's case, we see a desire to connect with the world outside the institution and to connect with nature. She clearly has imagination and creative abilities and enjoys expressing her individuality through art.

These glimpses provide examples of the impact of institutional culture – and the restrictions this brings – on the children's lives. However, they also provide insights into the children's individual personalities, their likes, dislikes and wishes. Consistently, a strong pattern emerged regarding children's and young people's desire to learn and achieve.



## Desire to learn more, achieve more and have those achievements recognized

**88% of the children and young people expressed their desire and ability to learn more.** They demonstrated their enjoyment of learning by participating in new activities, exploring new environments, and trying to figure out previously unknown games and puzzles.

In the institution where there has been significant individualised intervention over the previous few months, this percentage rose to 98%.

*9-year-old Mark's carer spoke enthusiastically about his recent achievements. He recently learned to pronounce some sounds and continues to actively develop his phonetics. He is now able to communicate things he wants. When the researchers entered his room, he happily demonstrated his new skill of lying on his stomach while holding his head high.*

*14-year-old Serhii likes to learn new things. He tried to draw with various felt-tip pens and made various lines that looked like insects in motion. He chose bright colours and worked with a smile on his face. He worked hard on his drawing, continuing to return to it until completion.*

*12-year-old Ivan was interested in many toys and activities: an umbrella, a large ball, many small toys, and blocks which he carefully and joyfully packed into the box. He especially liked the drum and cymbals. Ivan played this drum and cymbals with a wide smile, making loud sounds from the two instruments at the same time. When Ivan collected all the blocks in a box, he poured them out again and began to assemble them again.*

*During the activities, when he was praised and supported, he blossomed into an even bigger smile. He gladly accepted help, understanding the questions asked of him. Ivan even managed to independently involve other adults nearby in his activities.*

*Until recently, 9-year-old Zahar could not hold anything in his hands as they were constantly clenched into fists. One of the caregivers took time every day to knead the child's hands, engage with him, and use sensory toys. Now, Zahar can hold a ball, swing a bat, and press the buttons on a toy. He is now able to crawl and eat independently with the help of a spoon. He enjoys spending time out of his wheelchair and playing with new toys and games.*

*When the researchers first arrived and sat down next to 19-year-old Stepan and said hello, he did not react. Ten minutes passed like that. After some time, Stepan took the toy the researcher placed near him in his hands. He brought it very close to his eyes, examining it carefully. He realized that it makes sounds after shaking it several times. However, he quickly lost interest in it and returned to intense shaking. One of the caregivers reported that Stepan adores music, so the researcher turned on the music on their phone. Stepan turned his attention to the phone. He simply watched intently, showing his interest. It was clear from the way Stepan's face changed that he liked it. He seemed to relax, stopped shaking, and spent 15 minutes listening.*

*18-year-old Ihor loves to learn and was excited to show how he could write. He almost always writes the same letter, which looks like a capital A, and he can “read” familiar words. It is very important to Ihor that he gets the answers right.*

Mykola, Ivan, Serhii, Zahar, Stepan and Ihor all live in the institution where an intensive interaction programme had been running for 3 months by the time the researchers arrived. They have become accustomed to being supported to learn new things and to take pride in their achievements. This has also demonstrated that children and young people who were considered ‘uneducable’ have very significant potential for learning and cognitive development.

In the other institutions, children’s positive engagement in learning new things did not always appear immediately. Some engagement was needed to build trust and help children manage challenging behaviours. However, after several sessions, nearly all the children and young people were engaging and learning new things.

*Liza, a 16-year-old girl with HSN, began by observing from a distance, continuously playing with her feet and removing her socks. Liza does not like wearing socks. When she saw the bright toys in the researcher’s hands she reached for them. She immediately threw the toy away and continued to do the same with all the other toys the researcher was holding. She reached for the ball again and threw it away again. Then, she began to do various manipulations with the ball herself, she liked it so much. She showed the researchers she liked the game by clapping her knees together, the researchers joined her in clapping their knees. This made Liza laugh.*

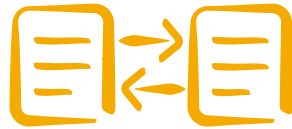
Liza is an example of how much children enjoy learning and stimulation. She also expressed joy when the researchers mimicked her clapping her knees. This suggests she was enjoying their approval, but also the fact that the researchers understood what her knee-clapping meant. She has enjoyed the connection, communication and mutual understanding.

*11-year-old Mykola is an inquisitive child. He likes learning new things through his individual learning style. His way of learning includes throwing objects, putting objects into his mouth, listening to different sounds, and spinning objects. Mykola is intrigued by other children and often asks to be included in their play.*

This behaviour in an 11-year-old child might be understood as challenging behaviour rather than learning. However, Mykola’s case demonstrates the fact that he is in the early stages of learning and communication. Throwing objects and using the mouth to feel and sense objects are normal stages of development for infants. It is likely that, due to his institutionalisation, Mykola missed these stages of development, hence his current behaviour.

*Oleh, a 17-year-old boy with HSN, gestured with his hand to unlock a phone. He easily started going to YouTube and Google looking for photos. At first, he was happy to find any photos on the internet, but the researcher noticed he paid special attention to animals. With the help of the researcher, they looked for more photos. When asked which photos he liked the most he said that he liked dogs and cats, he showed through his appearance that he thought they were beautiful. When asked if he would like to have a puppy, he nodded his head to say yes.*





Most children and young people with HSN in institutions in Ukraine are described as 'palliative'. There is a belief that they are going to die young – and often their level of awareness and understanding and their cognitive ability are considerably underestimated. As a result, interaction and communication with children with HSN is often limited to the provision of food, administering medication, bathing and changing nappies. Due to this lack of stimulation, children with HSN are often listless and may have a vacant expression on their faces – or they self-stimulate or self-harm. Yet this research showed that many children and young people with HSN – like Oleh – have quite sophisticated skills and levels of understanding.

*When researchers first met Mykhailo, a 13-year-old boy with HSN who was recently placed into the institution when his parents were deprived of their parental rights, he happily greeted them by stretching out his arms to be carried. Institution staff explained that this is how he was transported when he lived with his family. The researcher could not carry Mykhailo and instead helped him walk with support. He went directly to the windows in the corridor to see what was going on outside, he smiled and demonstrated that he could stand on his own for one minute. He was very proud to show his ability to stand. The researchers could see the excitement in his eyes while walking with assistance. Mykhailo likes books and when he sees something he finds interesting he points to show it to others. When Mykhailo saw an image of a ball he decided to play ball with the researcher. He enjoyed the game and laughed while playing. Mykhailo did not want to return to bed when the time was up.*

*Nazar, an 11-year-old boy with HSN, was running from window to window in the playroom when researchers first met him. The staff explained that Nazar loves to be outside. When he is inside, nothing can distract him from the window. He spent most of the session examining the windows, however, when he became tired, he approached the teacher and sat hugging her for some time before returning to the windows. When researchers took Nazar outside, he ran and smiled. He helped the other children on the carousel and showed the researchers with his facial expressions that he was proud of this.*

Mykhailo and Nazar's stories both demonstrate a desire to learn more and become more independent. They both desire to spend time outside. They enjoy achieving new things and interacting with other people. Nazar demonstrated how much enjoyment he gains from being useful and helping other people.

There appeared to be a marked difference among the children who were IDPs and had been evacuated to the institutions in early 2022. The researchers found that many of the IDP children 'froze' when meeting new people or did not react or acknowledge the presence of others. Researchers explained:



*“When researchers said hello, he did not react. He did not react to his name. I put the rattle toy next to him and joined him in shaking it. Ten minutes passed like that. After some time, Stepan took the toy in his hands”.*

*“We also noticed that he reacts warily to strangers and often stands against the wall for long periods of time”.*

*“The researcher sat down next to him and later gently touched him, as if asking for permission, he "froze" even more. Then he started rocking very intensely from side to side, moving his head and whole body”.*

*“When we first met, he came in with a downcast look and immediately sat down. He seemed to be focused on himself, in his thoughts, and had a distant expression on his face. After some time, he started to look at us and answer in short words”.*

*“She is quiet and seems unsure at first, rarely makes eye contact, and answers questions briefly”.*

*“When the researchers and children started to get to know each other, she watched the guests, pretending that she was not interested in us”.*

*“He heard unfamiliar voices and froze in a sitting position in bed, he listened to what was happening. We approached and explained that we came to meet and play together. Later, a shy smile appeared during the conversation, he held out his hand for greeting.”*

*“He was sitting calmly with his arms folded on his chest and looking intently ahead. I said hello but he seemed frozen, followed only with his eyes, did not show activity.”*

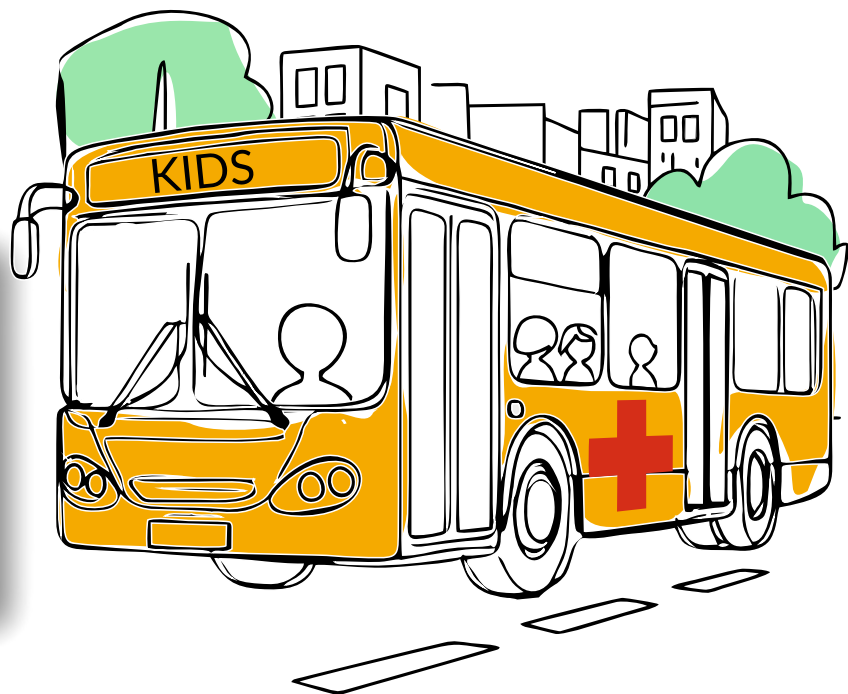
*“He greets all new people with a "checking" look, looks stern and in the eyes of the question - why have they come. When all the children get to know each other, I watch how his curiosity and desire to approach also ignite.”*



Reluctance to engage and fear or wariness of strangers was noted also in children who were not IDPs but was more pronounced among a greater percentage of the children who were IDPs.

There is no doubt that the children evacuated from the occupied territories had experienced additional trauma, likely due to experiencing air raid sirens and bombardment, as well as displacement. Research carried out with Ukrainian refugee families across Europe found that children with intellectual disabilities had experienced much greater anxiety than children without disabilities and had taken longer to recover and adapt to their new environment.<sup>18</sup> Unplanned moves from one institution to another can be extremely distressing for all children, but particularly for children with intellectual disabilities. It is likely, therefore, that in addition to the effects of institutionalisation, IDP children were suffering compound trauma associated with war and the unplanned move, and were still suffering these effects more than two years following evacuation. This trauma appeared to affect how safe they felt interacting with other people, which in turn affected how they presented in terms of their desire to learn and achieve. Additional time, patience and care were required on the part of the researchers to gain the children's trust.

*"A research among Ukrainian refugee families in Europe showed that children with intellectual disabilities experienced much more anxiety than children without disabilities"*



### **Ability to concentrate**

Children who have not developed a healthy attachment usually have shorter attention spans. This is crucial to child development because children with short attention spans often have greater difficulty in learning – and need to be supported to develop their abilities to concentrate on one thing.

This research showed that, with some exceptions, there was a stark contrast between the children in the institution who had been receiving intensive interaction for several months (and who had, therefore, begun to develop attachments) and those who had not received such interventions. The former group demonstrated considerable ability to concentrate for quite long periods of time.

However, the latter group were less able to concentrate initially, but some began to build their skills rapidly:

17-year-old Oleh can concentrate on different activities such as blocks and puzzles for about five minutes at a time. When he saw another child drawing, he became interested and wanted to try. He was able to concentrate for more time on this activity, drawing grass and big sweeping lines. At subsequent meetings Oleh was less restrained and smiled more. He likes bright colours and enjoys watercolour painting with his fingers or paints.

11-year-old Artem paid attention to each toy for several minutes, then immediately threw it away. His attention constantly switched to something else, and he moved around the room. The boy did not like most of the toys - they were constructors and puzzles, mosaics, and other educational items. Artem liked the two big balls that were lying along the wall. He ran up to them and tried to leave, but it was inconvenient for him because they were too big, so he accepted my offer to jump on one of them, which had two handles. He liked this fun more and a smile appeared on his face, but this activity also lasted for only a couple of minutes. He enjoyed listening to music but again moved on after five minutes.

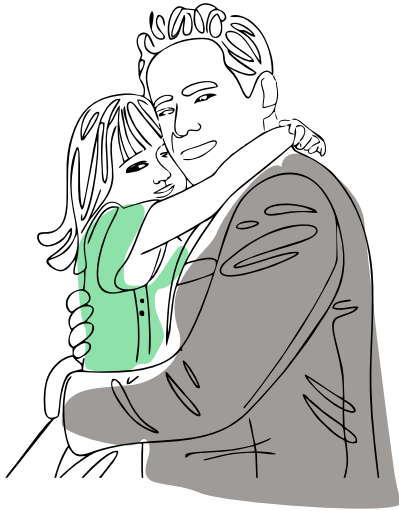
Trying out different activities to find the ones that children enjoyed most also helped in building concentration span.

7-year-old Vitalii moves all the time and rarely stands still. He quickly took toys, put them on the sofa, then on the floor, then transferred them to other places. Vitalii chose toys spontaneously, they were soft toys, then a large plastic constructor, kalimba, wooden constructor, later small and large balls. He does not focus on anything specific, he chooses an object, twists it in his hands, periodically takes it to his mouth, studies a little and loses curiosity. Vitalii enjoyed swinging and was able to stay in this activity for over ten minutes.

15-year-old Dasha was happy to meet the researchers and excitedly began to hug them as soon as they entered the playroom. Researchers noticed that Dasha is quite small and thin for her age but is not limited in her motor activities. When the researchers sat with her at the table, she began to grab all the toys, examining one and quickly switching to the next. She focused only for short periods of time and clapped her hands with joy while playing. Between sorting toys, she stopped many times to pat the researcher on the head. Dasha became upset when it was time to leave the researchers, clearly telling them to sit and trying to block the exit. Dasha enjoyed the attention she received throughout the session and was upset when it ended.



Dasha's story showed how much she enjoyed learning, stimulation and human interaction. Her desire to connect with other people is noteworthy in another way. Whilst human relationships are vital to all of us, indiscriminate affection is a classic sign of a lack of attachment and is common among children and young adults raised in institutions. It is particularly concerning in a 15-year-old girl, as this makes her vulnerable to sexual exploitation or abuse.



*" Indiscriminate attachment is a classic sign of attachment disorder and is common among children and young people in residential care."*

Among the group of children and young people from the institutions where there had been no previous intensive interaction prior to this research, there were some exceptions – children and young people who could concentrate for a considerable period of time.

*30-year-old Sofika painted her dreams for about 30 minutes - a whole field of green round flowers turned out. Sofika chose red, and then blue and made such circles on the field. All the time while painting, Sofika asked about the work of the researchers, whether they liked it. Sofika has been living in an institution for a very long time. Sofika explained that on holidays they were taken to a pizzeria and for walks in the park. She is also very happy when various specialists, volunteers and benefactors come and always tries to communicate with them.*

*16-year-old Hanna is a young girl with HSN and has been in the institution her entire life. Hanna does not like loud noises and covers her head with both hands when the world is too loud. When she entered the playroom, she chose the furthest corner of the room and did not like the noise of the other children. Hanna prefers to play independently and can play with toys for long periods of time, she especially likes soft objects. When the researchers tried to engage her in a game, she smiled but chose to play the game on her own. Hanna enjoyed playing near the researchers, away from the other children but did not play with the researchers.*

However, for some children, the ability to concentrate was masked by behavioural issues that likely relate to a lack of attachment and the effects of institutionalisation.

*14-year-old Iryna has intellectual disabilities and HSN. Iryna loves attention and was excited to meet the researchers. At first, Iryna had difficulty concentrating on any activity, constantly looking at the adults for attention or becoming distracted by other children in the room. When adults were not engaging with her, she hit her head with her fist and once put a pencil deep in her mouth in order to attract the attention of the adults. Iryna's caregivers report she often hits and bites herself to get their attention but is gentle and enjoys being close to adults when they are available to her. When the researchers took Iryna to a quiet area she was able to concentrate, building with lego and playing with musical instruments. As she relaxed, she began to enjoy the activities and did not self-harm.*

Iryna's self-harming, which might be interpreted as a behavioural disorder, reduces when she receives positive attention. She gets lonely, bored and distressed when adults are not available to her - which is most of the time. If Iryna was provided consistent one-to-one intensive interaction for a period of weeks, it is likely that her self-harming would reduce and she would be able to concentrate and learn more.



## Cognitive ability – learning new things and solving problems

As can be seen from the stories above, many of the children and young people demonstrated cognitive abilities far beyond what was expected of them by institution personnel. The children's abilities were masked for several reasons: because many have limited mobility and limited or no verbal communication, this was often interpreted as the children having extremely limited understanding – and no desire or ability to communicate. This, in turn, leads to the belief that children cannot learn. However, as the following demonstrates, when engaged through intensive interaction, many of the children learned new things quickly – and were delighted at this learning.

*12-year-old Maksym, seeing the puzzle on the table, sat down at it himself and began to enthusiastically assemble the pictures. Maksym quickly put together six types of four-picture puzzles. Researchers were delighted with how quickly and correctly Maksym completed the puzzles, so when he returned to the table, researchers showed him their admiration for his results. Maksym was very pleased, he looked for the gaze of every adult to see approval and share his joy.*

*16-year-old Nastia looked at the different types of toys around her and chose something she hadn't seen before - a kalimba musical instrument. Researchers showed her how to finger the strings and where the notes are. She carefully tried to press the strings with two fingers and do it at different tempos, following the instructions and staying very interested in the task for 30 minutes.*

*11-year-old Roma became interested in a box of lego. He worked with the blocks in an interesting way: before changing their position, he brought them to his mouth, licked them and bit them. Then he tried to hold three pieces - two in his hands and one in his mouth. He tried to take a new part, passing one part to an adult, thus demonstrating the need for help. When he lost interest in an activity, he rocked back and forth. During meetings with Roma, we learned that he can skillfully connect the parts of a large lego to each other, assemble a pyramid according to size.*

The following excerpt shows how taking time and approaching a young person with HSN in the right way can transform the way the person interacts and learns.

*17-year-old Kyrylo cannot move on his own and cannot do anything without support. When the researchers first met Kyrylo, he was sitting very quietly in his cradle by his bed, he was putting his fingers deep into his mouth, first one hand then the other. The researchers sat down next to Kyrylo and cautiously greeted him. He turned, but his expression did not change. They gently touched his hand, which he was holding on his stomach, and pulled it as if suggesting the direction of movement, and he began to react, moving slightly in the chair and vocalizing something. The researcher understood that he was not against physical contact.*



Later, the researchers explained to Kyrylo that they were going to the rehabilitation room to play, commenting on everything on the way and greeting everyone around. Kyrylo raised his face to everyone, and it seemed that he wanted to say hello. First, the researcher showed him the whole box of toys that make noise, then lifted each toy in turn and very slowly made sounds, he looked around intently, looked at the toys, at the box and seemed not to lose his attention. The researcher studied Kyrylo's answers. He took his hands from his mouth and exhaled loudly as they softly rattled the tambourines, so they asked permission with a touch and put the bracelet with the tambourines on his arm. Kyrylo didn't move for a few minutes, the researchers tapped on his hand and suddenly he moved his hand several times and looked at the tambourines and moved his hand again. He straightened up in his chair, began to turn his head from side to side. And it became clear that he understood that he himself had made the tambourines sound.

Under Ukrainian legislation, all children have the right to formal education. This is a recently established right and, in the past, this was not the case: some children with intellectual disabilities were considered 'uneducable'. Although the right now exists in theory, it takes time for this to translate into practice and, at present, children with HSN in institutions are rarely included in formal education. And for some who are included in education, there are questions as to whether educators have the right methods or sufficient resources to encourage their learning.

However, this research demonstrates that, despite having been excluded from the education system, all the children and young people involved in the study have the potential to learn more – and all but one expressed the desire to learn more and gained great pleasure out of learning and achieving new things.



*«The study shows that although all of the children and young people who participated were excluded from education, they have the potential to learn. All but one of them expressed a desire to learn and enjoyed learning.»*

According to personnel in the institution, 16-year-old Bohdan is detached from the world, does not interact with others, shows no interest in classes, and has not responded to teaching. Bohdan has been in the institution since childhood. Bohdan's arms and legs are underdeveloped, and he is sedentary. When researchers first met him, they noticed he was sitting silently, staring, and did not react to actions or movements. The researcher began rolling a small ball, and Bohdan did not respond. Then, the researcher pressed a button and the ball lit up in different colours. Bohdan looked over and covered the ball with his hand. He played this game of covering the ball with the researcher for ten minutes and even tried to press the button to light the ball.

Angelina is a 12-year-old girl with HSN and a hearing impairment. Although she uses a hearing aid, she is not able to hear well. When researchers met her, Angelina looked at them and smiled and allowed gentle touch. It was clear to the researchers that she understood their requests – she smiled for the camera, gestured to watch the video of herself, built using lego, and tried to imitate movements. Angelina's caregivers use gestures to communicate with her. However, she was never given the opportunity to learn sign language and has had a hearing impairment since birth. Researchers witnessed Angelina communicate effectively with her caregivers and suspect she may not have an intellectual disability at all but is deprived of the education she needs – and to which she has a right.

14-year-old Mykyta has HSN and a visual impairment. Mykyta uses his hands to interact with the world. He loves to touch and pull objects within his reach, and he especially loves toys that make sounds. According to his caregivers, he does not have an interest in playing with other children. However, the researchers observed that when he is close to other children, he touches them, grabs them, and pulls them to himself. His caregivers report that he must stay fixed in his wheelchair because he is very hyperactive.

Clearly, there is an urgent need to provide individualised formal education to all children and young people with disabilities in institutions – including those with HSN.

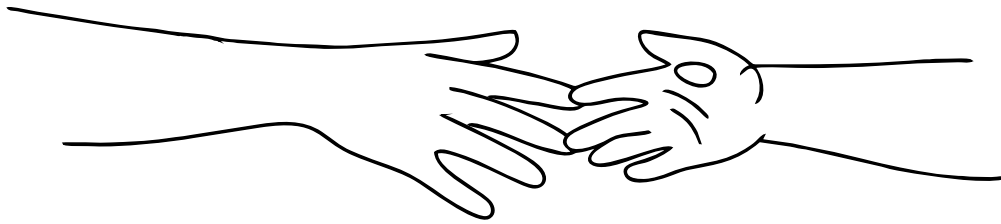
### Enjoyment of social touch

Children with disabilities and HSN in institutions rarely experience a positive social touch. Often the only physical contact they experience is during mealtimes and personal care. Because there are too few personnel, these interactions are often hurried – and not always gentle. Movements and physical contact may be sudden and unexpected. For children unused to sensory stimulation, this can be stressful.

In addition, as demonstrated earlier, children who have not formed healthy attachments may have difficulties in developing normal, healthy relationships, understanding boundaries with strangers and understanding appropriate and inappropriate physical contact. Helping children and young people learn to enjoy and engage with appropriate social touch is an important stage of development.



**57% of the participants enjoy social touch**, but for many, this was only possible after getting to know someone and giving their consent. 11% of children and young people do not like being touched – even after getting to know someone. 21% of children and young people enjoyed physical contact and, worryingly, would initiate touch with individuals they did not know. This is also known as ‘indiscriminate affection’ and is a common trait in children who have not formed a healthy attachment.



*"57% of children and youth enjoy social touch, but many of them are ready for it only after getting to know each other and getting consent"*

*When researchers first met 11-year-old Polina she did not react in any way to their greetings. One person gently touched her hand, and she began squirming slightly in her chair with an expression of curiosity and displeasure on her face. While getting to know Polina, researchers found that although she did not enjoy physical touch, she enjoyed playing with the play dough – showing delight on her face at the sensory stimulation as she squeezed the dough between her toes. Gradually, when she established a relationship with one researcher, Polina began to trust her. Slowly she began to like being held in her arms and she relaxed, smiling. Eventually, she used her feet to stroke the caregiver's hair and made sounds of pleasure.*

*17-year-old Vlad is very friendly, but when he meets new people, he seems to freeze and become shy when he receives attention. Vlad begins to turn away, covering his face with his hands, but at the same time smiling. His smile allowed researchers to see that he desired attention and communication. Soon, he began to communicate with the adults.*

Sometimes, such behaviours might indicate that children do not want to engage in physical contact. However, patient efforts to build trust can help the children feel safe to engage in and enjoy social touch, which is essential to healthy development.

Of equal – or perhaps even greater – concern are the situations where children are overly physical with complete strangers:

*When researchers first met 12-year-old Maksym he was walking with a group on the street near the institution. He literally "bounced" on them with hugs and called them 'mum'. He not only wanted to hug, but also to kiss and it was quite difficult for them to pull away.*

*When the researchers first met 16-year-old Nastia, she immediately responded to the greeting, smiling, and extending her hand. She said her name and tried to hug the researchers.*

*13-year-old Tymur came to researchers in the playroom with great joy, immediately began to hug the researchers. From the very beginning of the interaction, Tymur was very excited. He actively walked around the room, interested in everything and not knowing what to choose, then returned to the researchers again and began to hug.*

*When researchers first arrived to meet 18-year-old Ihor, he was very energetically walking along the corridor of the institution and talking very loudly, although there was no one around. When the researchers called Ihor's name, he turned very quickly and rushed to them, hugged them and said hello.*

The indiscriminate affection demonstrated by Maksym, Nastia, Tymur and Ihor may initially seem like positive behaviour – and can be heartwarming and enjoyable for people who meet them. However, these behaviours demonstrate that the children have not developed attachments and are therefore indicative that other attachment-related challenges and developmental delays are likely to be present. However, they are also concerning from the perspective of safeguarding.

Children and young people who display indiscriminate affection are at a higher risk of sexual abuse or sexual exploitation because they do not understand safe boundaries in relationships and the danger that can be posed by strangers.

This is particularly concerning where a high number of volunteers visit the institutions, with insufficient – or no – background checks or supervision.

### **Desire to communicate likes, dislikes and opinions – and to be understood**

#### **All participants expressed their desire to communicate and be understood.**

61% of children and young people were nervous at first, in new and unfamiliar situations. They demonstrated high levels of stress or anxiety when they did not understand what was going on around them or when things were not explained to them in a way they could understand. Moreover, 12% of children and young people displayed extremely high levels of stress and anxiety when meeting new people, being touched without permission, or moving to an unknown area.

Again, children who have not developed healthy attachments are less able to cope with new situations and more prone to stress and anxiety. But this does not mean they cannot communicate or do not wish to communicate.

After some time, all participants began to open up and communicate, once they felt safe and understood. This took longer for some children and young people than for others, particularly for IDP children.

At first, it seemed that Matvii refused to communicate, turned his face away, swayed, vocalized intensively with displeasure. But later the researchers saw so many of his smiles and heard his laugh. It turned out that Matvii really liked when his legs and feet were touched, smeared with cream and simply gently massaged, and when smeared with paint, he could make his own prints with paint on paper and look around. He really likes to lie under the transparent silvery crispy film, which shimmers in the sunlight, just shimmers and crunches, he can hold it tightly with his hands. And he also loves when the wind blows in his face, from the so-called "parachute" Matvii laughs. Through intensive interaction, many of the children and young people who had limited or no verbal communication were able to express strong opinions on what they liked and disliked, how they liked to spend their time and how they liked to be engaged.

Although 16-year-old David is non-verbal, he has strong likes and dislikes and can communicate his needs with his face and emotions. Stretching out his hand, he shows what he wants, and he turns away to show he does not like something. It makes him happy when the adults around him understand his communication. David loves seeing dogs and smiles and laughs when he has the opportunity to interact with a dog.

13-year-old Alisa has HSN and only has the ability to move her head and neck. She is fed with a bottle, is extremely small for her age, and spends her days lying in bed. When researchers entered her room, she began to react with chaotic head movements to say hello. The researcher complimented Alisa, and she responded with a smile. They asked her if she would like to listen to music and she smiled and made a long musical sound. She never took her eyes off the researchers and engaged with them throughout the entire visit. When Alisa does not like something, she turns her head and shows with her eyes that it is not what she wants. The personnel in the institution told researchers that Alisa screams loudly when she is hungry.

In some instances, the child's particular disability may affect the way they behave and interact. It is important that the adults in the child's life learn to understand the child's behaviour as a form of communication – and to interpret what that means. In this way, the adults can find ways to respond to the child's communication that makes them feel safe and understood. For example, a child with a visual impairment or hearing impairment may respond differently and require adults to adapt their communication.

Yehor, a 9-year-old boy with HSN and visual impairment, froze when researchers first entered his room, listening to what was going on around him. Researchers explained that they came to meet him and play together, and he reached out his hand with a smile. Yehor clearly told researchers which games he liked and did not like by saying "I don't want to" or "yes" when offered options. Yehor initiated a walk outside of his room by reaching out his hand to the researcher and showing them around the institution. When it was time for the researchers to leave, Yehor did not want to end the walk or return to his room.

Because Yehor has a visual impairment, for him to feel safe in new situations, it is important for people to approach him gently and to explain with a kind voice what is happening.

Sometimes, children express their dislikes through challenging behaviours:

*13-year-old Lev has strong opinions, and he desires that those around him understand his wants and needs. According to his caregivers, Lev's behaviour changes depending on how he is treated. With some caregivers, Lev can show aggression towards other children, yet with others, he does not touch the other children and concentrates on activities he enjoys. Lev is able to concentrate and focus on activities he enjoys for 20 minutes or more.*

However, these behaviours are often misunderstood by the carers. They are viewed as negative behaviours that require correcting – or even punishing – rather than being understood as attempts to communicate. Of course, this type of communication is not ideal, but an intensive approach – based on mirroring – can be used to help children and young people gradually learn more positive ways to communicate their feelings, wishes and opinions.

*When researchers first met Olya, a 19-year-old with HSN, her caregiver warned that she could be aggressive and hurt others. The researcher sat opposite Olya and began to repeat her movements. After some time, she began to notice and watch the researcher, smiling. At one point she grabbed the researcher's hair and began to pull hard, not letting go. Olya's signals were confusing: at times she smiled, gave high-fives with a pen, allowed herself to be touched, displayed pleasure in communication, and yet at another moment she unexpectedly tried to hurt others.*

*After spending time with Olya, researchers began to understand that she was simply probing the boundaries and checking their reaction to her actions and had no intention of harming anyone. Based on the actions of her caregiver, the researchers can conclude that the girl is often subject to total control, and therefore does not understand how to react to new people and does not understand boundaries.*

*During the entire time with the researchers, the caregiver tried more than once to control Olya's behaviour so that she would not harm researchers or hurt them. The researchers stopped these attempts, telling the caregiver their thoughts about why exactly the girl behaves the way she does and why it is not surprising and how best to respond to her certain actions. What is important is the fact that the carer was very surprised that without her commands and control, Olya stopped doing aggressive actions in her opinion (in fact, there was definitely no aggression), she was amazed at how easy it was to establish contact with the girl and calm her down.*

*As researchers spent time mirroring her movements and communication, her outbursts stopped. She began to react to their actions and stopped shaking. When researchers played music, she started dancing with them, smiling happily. When they showed Olya speech therapy gestures and sounds she happily repeated everything for them correctly, making an effort to get everything right.*

The situations of Yaroslav and Kira were similar.

*Caregivers told researchers that 9-year-old Yaroslav often shows aggression to other children and adults and to himself. Yaroslav often gets upset during transitions – when music is turned off, changing rooms, or ending a lesson.*

Researchers found that Yaroslav adores attention and may hurt himself or others to attract the attention of an adult. In addition, they learned that Yaroslav has various sensory needs. Yaroslav likes loud sounds very much; he can even put a drum to his ear and knock on it very loudly. He enjoys having music playing and likes to dance and move his body. While working with researchers who understood his communication style, he never showed aggression and was able to participate in activities.

When researchers first met Kira, a 16-year-old girl with intellectual disabilities, behavioural disorders, and HSN, she was excited but anxious. Kira made sharp movements, loud sounds, and waved her arms. She bit her hands and researchers noticed she had several scratches and bruises. When music was turned on, Kira showed signs of enjoyment and was able to calm down and focus on various activities for 5-7 minutes at a time. She worked on a puzzle and drew a picture but continued to be easily distracted by others in the room. When her nurse stroked her hair, she made sounds of pleasure.

Often, when children are non-verbal, carers in institutions interpret this as a complete lack of understanding, awareness and ability to communicate.

18-year-old Denis is non-verbal and spends his days in bed. His caregivers report that he rarely leaves his bed, does not communicate, and does not move. When the researchers asked Denis if he would like to go into another room, he smiled. After some time, he enjoyed sitting in comfortable chairs and began playing by throwing toys and shaking maracas. He began initiating hand-holding with the researchers and put his face close when someone spoke to him.

In other cases, children actively reject communication – and this is wrongly interpreted by carers as the child not wanting to or not needing to communicate:

When researchers first met 15-year-old Vadym who has physical and intellectual developmental disabilities and high support needs, he had a blanket over his head and was lying on the floor. When researchers tried to remove the blanket, Vadym held tightly, protesting. However, when they started talking with another child, Vadym threw back the blanket on his own. They asked him to join them, and he got up and followed the researchers. He then initiated a change of route and led them to a large bright rehabilitation room. At first, he did not participate in any activities offered by adults instead moving around the perimeter of the room.



In some cases, the fact that children refuse to communicate is mistakenly interpreted by caregivers as an unwillingness or lack of need for communication



*After some time, he began to play with the toys, distinguishing them by size and volume and he showed great interest in toys with sound. This activity only held his attention for a short time, researchers noted that he quickly gets tired of any activity. After several meetings with Vadym, he began to accept more touches and hugs, allowed himself to be rolled on the fitness ball, and even allowed himself to be held in the arms of the researchers, he even fell asleep on them.*

Many of the children's stories demonstrate that they very much want to communicate, but that communication must be at their pace and according to their likes and dislikes. In an institution, carers do not have sufficient time to respond to individual communication styles and needs. It is possible to support children without verbal skills to communicate and express their opinions, but this requires a careful approach and takes time. In many instances, the researchers found that institution personnel believed that because the children did not communicate verbally, they were unable to communicate at all. As a result, personnel rarely attempted to communicate with the children. This further compounds the children's isolation and lack of stimulation, creating an ever-descending spiral of developmental delays and challenging behaviours.

It is also evident that many of the children and young people demonstrated a range of behaviours and responses that suggest they have not formed healthy attachments. Given the evidence of how crucial attachment is to all aspects of healthy child development – including brain development – this is a serious concern and is likely to exacerbate the children's intellectual disabilities.

## **CHALLENGING BEHAVIOURS AND SELF-HARMING**

Children who have not developed healthy attachments are more likely to experience high levels of stress, frustration and anxiety and have difficulties in regulating their emotions. In children in institutions, this is sometimes expressed through challenging behaviours or self-harming.

*11-year-old Vova, smiling, threw slippers at the nurses, attracting attention and expecting a reaction. Several times researchers saw Vova grab the caregiver's hair and pull it to him when she was talking to other children. After spending time with Vova, the researchers saw in him a desire to play together, however, he is wary of strangers and often stands against the wall for long periods of time.*

*18-year-old Yura suddenly ran from the researchers when they first met. He was moving very fast, and the researchers were not able to catch up with him. He grabbed everything that came his way and threw everything off the surfaces. The faster the researchers and caregivers ran, the faster he ran away. The caregivers told the researchers that Yura often eats non-edible food, preferring long threads, laces and plastic pieces, which can make him sick. Once, he tore his clothes into long ribbons across his shirt, practically cutting it in half, it was impossible to distract him, he was very nervous when the ribbons were taken from him and he was not allowed to eat them.*

Often the response to such behaviours is to try to exert control: self-harming behaviours are controlled through physical restraints or the use of sedative medication; aggression towards others and destruction of property are often met with punishment, isolation, restriction of enjoyable activities and, at times, physical or medical restraint.

However, it is likely that these behaviours derive primarily from the lack of a healthy attachment to a family member or other trusted adult, as well as from boredom and loneliness. Therefore, the standard punitive, isolating and controlling responses are likely only to further exacerbate the behaviours rather than correct them. A different approach is required – as demonstrated by the Intensive Interaction approaches the researchers used.

## **FAMILY, RELATIONSHIPS AND ENVIRONMENT**

### **Family**

When the research methodology was designed, it was assumed that the children and young people would not be able to share information about their families or to share their opinions about family life. However, the children and young people surprised us:

- 7% of the children and young people reported spending some time with family when they visited the institution.
- 67% expressed or indicated their wishes to have a family who will love and understand them
- 90% demonstrated their desire for a stable, permanent adult in their life.

*When Matvii, a 7-year-old boy with HSN, was asked to draw his dream he nodded and began to draw. Semicircles and other lines began to appear. Researchers asked him directly what he was drawing, and he made it clear through his gestures that it was several people. Matvii cannot speak, but he tries to explain what he would like to say with gestures and movements. When the researcher asked if it was a family, Matvii nodded 'yes'. According to his caregivers, Matvii has relatives, however, they rarely visit him, and his parents are deprived of parental rights.*

*Caregivers told researchers that 18-year-old Gleb jumps on his father with all his strength and hugs him tightly on rare visits. They never see such a strong emotional reaction of joy in Gleb's other life situations.*

*Veronika, a 23-year-old young adult with physical and intellectual disabilities, misses her parents very much and expressed hope to find the love of a significant adult who will remain in her life. Veronika often calls the employees and visitors of the institution "mum." She understands that these individuals are not her mother, but she misses her parents very much. Veronika loves to be independent and helps in the institution by cooking and taking care of younger children. Veronika told the researchers that her mother is good and comes to visit every weekend with gifts. But in fact, no one from her family has visited for many years.*

Another young adult, 34-year-old Oleksii, told researchers that his mother often comes to visit him. It was important for him to tell this and he told it quite confidently, emphasizing its importance. However, the caregiver informed the researchers that, unfortunately, no one had come to visit Oleksii for many years.

When 13-year-old Damir was given the opportunity to explore a playroom, he was drawn to the bright soft toys. He was interested in touching them and holding them close. Damir put the toys to bed, cuddled them and placed them in various situations, acting out a story of family. Sometimes, Damir demonstrated one toy going away from the group for a time. He hugged the toy when it returned.

These stories demonstrate children's and young people's powerful desire for a family, that does not seem to diminish with age. It is also clear that children with limited communication skills also understood the meaning of family and shared the same wish for a family of their own.

Sibling relationships are also crucially important. Unfortunately, the institutional system often separates siblings if one of the siblings has a disability.

Children with limited communication skills also realize the importance of family and have the same desire to create their own family.



17-year-old Viktoriia has physical disabilities and uses a wheelchair. She needs adult support but strives to be independent. Viktoriia's caregivers told researchers that she has a biological mother and sisters that she does not ever see. Viktoriia told researchers that she loves reading fairy tales, watching TV, and taking walks outside in the fresh air. She dreams of having a family of her own and meeting her little sister who lives in another institution.

In Kristina's case, the siblings were not separated, and this relationship is important to her:



*14-year-old Kristina has intellectual disabilities and HSN. Although timid during the first meeting with researchers, she slowly began to gain confidence and explore new toys and activities. Kristina played with one object for 10 -20 minutes at a time and then chose a new activity. She liked when researchers gave her tasks and was happy to be able to complete them. Her sister lives at the institution and Kristina enjoys spending time with her.*

It is also significant that relationships with family – and contact with family – could have a significant impact on behaviour. One boy in the institution did not have disabilities but was institutionalised due to behavioural issues. Yet it became apparent to the researchers that much of his challenging behaviour related to the loss of family:

*Yevhen, a 14-year-old boy, told the researchers that he did not like the institution. Yevhen does not have intellectual developmental disorders and his degree of need for support is doubtful. When researchers began to learn about Yevhen's education, it became obvious that the boy knew how to read and write and knows the basics of addition and subtraction. He communicates with understanding, asks questions, constructs answers and conclusions, had no physical developmental limitations, yet was in an institution for children who need a high level of support.*

*Three years ago, Yevhen was taken from his parents who were later deprived of parental rights. At first, he was placed in a special boarding school. After some time, the administration of the boarding school initiated the expulsion of the child from their institution, claiming that Yevhen had suicidal tendencies and needed constant round-the-clock supervision, which they could not provide. The child was transferred to an orphanage-boarding house of the II-I V profile of the social protection system. The employees of the institution where the boy is currently staying claim that, despite Yevhen's depression, no suicidal attempts have been recorded.*

*Despite the fact that Yevhen can study, he has not been examined by an inclusive resource center, does not attend a general educational institution, and is not provided with educational services even in the form of individual education. The inclusive resource center near the institution refused the administration of the institution to examine the children and provide them with correctional services, believing that since the institution is regional, they should not serve its pupils. Also, secondary educational institutions near the institution cannot enroll children from the institutions and cannot determine appropriate educational programs for them.*

*Educators and caregivers from the institution are trying to ensure the educational process for the boy on their own, although this is not their function. However, he does not like to study here, he does it reluctantly, out of spite. The researchers get the impression that Yevhen simply has no motivation to study, as it is situational, uninteresting, and without a hint of competitiveness.*

*Yevhen has pleasant memories of his family, the best is of a trip the whole family took to the sea (according to the boy, it was three or four years before he was removed from family care). He reports that he loves his brothers and sisters very much. According to Yevhen, he and his sister and brother were taken away from their parents, while the*

*younger sisters remained in the family. Yevhen does not know where his brother and sister were placed, he does not know anything about them, none of the adults ensured the boy's communication with them. When talking about his relatives, the boy was very sad, even depressed, but he wanted to talk about it, even though it hurt him.*

*Yevhen is the oldest in his group, and himself admits that he is sometimes too strict with other children, and he can order them with the consent of adults. The caregiver told researchers about Yevhen's performance with one of the pupils, who moves around in a wheelchair, on one of the holidays. They were dressed in Renaissance style, very beautiful and performed a beautiful slow dance to soft music. Yevhen was very careful and caring with his partner, protected her, moved with the girl to the music with great pleasure.*

*Although he has beloved caregivers and friends, he lacks opportunities to do what he wants, eat what he chooses, and leave the institution. He shared that he loves hot dogs and dreams of going to the zoo again and visiting the sea. Yevhen misses his sisters and brother and does not know where they are.*

In some cases, while children enjoy contact with their family, visits can also lead to distress. This can sometimes be used as a reason by personnel in institutions to discourage visits.

*11-year-old Ruslan gets very excited when his mother comes to visit. She often brings him a small snack and he will later refuse to eat the institution food, hoping for his mother's return.*

The authors and researchers were surprised by the number of children and young people who told us about their desire for family, how vital those family relationships are to their happiness and well-being – and how that desire continues into adulthood.

## **Relationships with trusted adults and friendships**

Many of the children and young people demonstrated a desire for attention and affection from the caregivers. When this is not forthcoming, some express their frustration through challenging or self-harming behaviours.

*15-year-old Pavlo becomes very upset when adults are distracted by other children or stop paying attention to him. He sometimes screams and injures himself in order to get the attention he craves.*

Friendships were also important to a significant number of the participants.

- 43% of participants indicated that they have friends with whom they enjoy spending time playing and talking
- worryingly, 5% of children report not having friends.

Friendships are vital to all of us – but particularly to children who grow up separated from family.

Many of the children and young people indicated their wide and varied interests and hobbies that they liked to engage in – alone or with others.

*Hanna, a 24-year-old young adult with HSN, was happy to tell the researchers about her life, her likes and dislikes. Hanna cannot walk, but she is able to do various activities in a wheelchair. Hanna has a best friend and enjoys spending time with other adults and children. She loves learning poetry and singing. Researchers noticed that it was difficult for her to discuss some topics, unrelated to cognitive disorders, but rather to her lack of experience or "sensory hunger." Hanna speaks confidently and is able to answer questions, but she has difficulty discussing some topics. Unfortunately, researchers learned that due to the refusal of the inclusive resource center to examine the children of the institution, Hanna does not receive any educational services.*

*According to her caregivers, 12-year-old Alina strives for independence and is always very friendly with everyone, she always wants to spend time together with others. During the first introductions to the researchers, she happily smiled and wanted to kiss their cheek.*

*15-year-old Mykyta got great pleasure from walking in the forest area together with friends and guests. He was so happy when everyone gathered, and he looked for those who were lagging behind, paying attention to everyone. Mykyta smiled sincerely at everyone, waved his hands, and loudly uttered happy sounds. When asked if Mykyta is always in a good mood, his caregivers expressed he gets upset in bad weather.*

### Spending time alone and personal space

- 23% of participants demonstrated to researchers that they would like to have time alone
- 26% indicated that they do not like to be alone
- 30% of children and young people communicated that they like to have personal space and possessions.

*On first meeting with 11-year-old Demian researchers saw that he did not move around and seemed to prefer to sit alone. In future meetings, Demian felt comfortable next to an adult while putting together puzzles and building with toys. He calmly accepted the help of the adult. Later, during a walk, he looked for an adult to go with him to a specific far corner of the institution grounds which he is very interested in.*

*Researchers noticed that 15-year-old Oleksandr prefers to have a familiar adult with him most of the time. He also hopes to have his own personal space with his favourite toys because sometimes he likes to hide and play alone.*



*Oleksandr, like 30% of children and young people, likes to have personal space and things, because he sometimes likes to play alone*

For some children, engaging with an adult was required in order for them to enjoy engaging in play and learning activities.

*14-year-old Yeva has HSN and spends most of her day lying in her bed. When researchers entered her room and said hello, she greeted them by smiling and making sounds. Yeva cannot speak words but is able to make sounds and use facial expressions to communicate. She showed researchers that she enjoys drawing, putting together puzzles, playing with stuffed toys, and building with blocks. Yeva was able to concentrate on individual activities for 20 minutes.*

*17-year-old Sofia has physical and intellectual disabilities and HSN. Sofia's caregivers report she has poor concentration and quickly switches from one activity to another. However, when working with researchers, Sofia spent a long time drawing, building with lego, listening to music, and dancing. She showed which activities she enjoyed by smiling. Her caregivers told researchers that Sofia craves attention from adults and will scream and hit herself to attract attention.*

It should be noted that, in addition to desiring time and interaction with other people, it is normal for children and young people to want some time alone, some privacy and access to their own personal things – particularly as they get older. This can be difficult to achieve in an institution.

*When in a group, 12-year-old Karyna is usually on her own, prefers independent play, does not come into contact with any of the children, and rarely comes into contact with adults. During walks on the street, she generally distances herself from the group. After spending time with Karyna, she noticed that the researchers were rolling small balls on the floor. She was interested in it. The girl finally paid attention to the researchers and started rolling balls toward them and catching balls from them.*

Whilst Karyna seems to enjoy being alone, this may be because it is what she is accustomed to; when provided careful opportunities to engage in social interaction, she did so and began to enjoy it.

*In the playroom, 12-year-old Ostap constantly peeked in the direction of other boys, watched what they were doing and got up to sit next to them. His attention was drawn to a musical mat that another boy was playing with.*

*Caregivers explained that it is difficult for 26-year-old Serhii to be in a group of children and young people. He constantly wants to leave the group, and sometimes even runs away. Serhii prefers to be with adults and offers them his help in anything. According to the employees of the institution, Serhii does not like to be in a group of peers, as it is difficult for him to adapt to a large number of people with different, unpredictable behaviour. In a group, he feels in constant tension as he is distracted and disturbed by noise. Serhii himself told the researchers that he has two friends with whom he likes to spend time.*

These stories demonstrate how different each child and young person is – with individual desires to engage and communicate with some people and not with others, and in particular circumstances.

It is significant that the responses of the children to our research questions expressed the same diversity of opinions, likes and dislikes, wishes, hopes and desires as found in research with children who have grown up in the care system in other countries. This will be explored in more detail in the conclusions.

# CONCLUSIONS AND RECOMMENDATIONS

## GENERAL CONCLUSIONS

Interpreting the rich data from the interactions between the researchers and 100 children with disabilities who participated in the research – many of whom have high support needs (HSN) and limited verbal communication – has produced striking results, which are summarised here.

### **The children have a great deal to say**

Firstly, the results clearly demonstrate that the children can communicate and have a great deal to say. Most children, once given the opportunity, voiced opinions or indicated preferences on a wide range of issues that affect their daily lives, their health and their happiness. And many children and young people were also able to communicate about their hopes and dreams.

### **The medical model of disability creates barriers to communication and understanding**

The fact that these children's voices are not usually heard highlights the impact of the medical model of disability. Most personnel in the institutions expressed a belief that the children cannot communicate or do not have anything of significance to say – beyond indicating their basic needs for food and personal care. Moreover, personnel lack the skills to overcome barriers to communication for two reasons. Firstly, because they have insufficient time to interact individually with children. Secondly, they have not received the training and access to methods that would help them understand how to communicate effectively with children who are non-verbal, have limited verbal ability or challenging behaviours.

### **The children and young people have diverse personalities and opinions**

It was striking to see how different all the children and young people are – in their personalities and opinions. Some children were boisterous, sociable and full of energy. Others were quiet and more reserved – they needed more time and support to begin to open up to the researchers. Some were indiscriminately affectionate. Others found it extremely stressful to be approached by or have physical contact with strangers – displaying high levels of anxiety through their behaviour.

The children and young people had many different likes and dislikes. Some loved music; others art. Some enjoyed time interacting with trusted adults or friends; others had a desire for personal space and time alone.

Despite the diversity of opinions and personalities, some strong patterns were evident, where many of the children were in agreement – these are summarised below.



## **THE IMPACT OF INSTITUTIONALISATION WAS EVIDENT IN MANY WAYS**

The wonderful individual personalities of the children were hidden.

Due to the 'block treatment' inherent in how institutions operate, children had learned long ago that there was no point in expressing individual needs or wishes because nobody would respond. Consequently, children either lay passively in their beds or chairs – which was interpreted by personnel as their needs having been satisfied; or they engaged in stereotypical behaviours (rocking, hand-flapping, self-harming, aggression) – interpreted by personnel as 'naughtiness' that required discipline, or as a consequence of their disability or 'health condition'.

The researchers only discovered how diverse, responsive and opinionated the children were by engaging over a period of several days – finding out how the children liked to communicate and letting the children lead the communication.


All the children and young people demonstrated developmental delays and behaviours that are a common consequence of not having formed an attachment.

The inability of the system to respond to individual needs means there were many issues related to a lack of attachment – from severe delays across all spheres of development (physical, cognitive, emotional, social), to challenging behaviours, to indiscriminate affection, to fear of physical contact. Again, these effects of institutionalisation were largely misinterpreted by personnel – and decision-makers – as a consequence of children's disabilities or health conditions. This, in turn, resulted in an underestimation of the children's potential for learning, development, communication and independence.

### **Many children and young people were at the early stages of communication**

Because many children and young adults had very limited verbal communication for their chronological age, this is interpreted by the system as being due to low IQ, or profound intellectual disability. However, due to having spent their entire lives in institutions, many of the children and young people have never had the opportunity to develop an attachment and, in turn, to pass through the stages of development that provide the fundamental building blocks of communication. Many personnel were surprised to see how well the child interacted with the researchers after a period of time – and how much the child communicated. This labelling of children as having a profound intellectual disability may, in many cases, result in a considerable underestimation of the children's potential to learn, grow and develop.

This results in a self-reinforcing cycle: if we do not believe the children can communicate or have the potential to learn, we do not communicate with them or provide them with opportunities to learn. This results in a lower likelihood that we will engage them in communication and encourage the building blocks of child development. This, in turn, reinforces the belief that children cannot communicate or learn. And so, the cycle continues.



The State as a parent does not know how to communicate with children with limited communication in its care.

When very young children are in the early stages of developing communication – even before they have any verbal communication – their parents understand exactly what they need and what they are trying to tell us. And parents continuously communicate with their children, encouraging the formation of attachment and early learning across all developmental domains. This is also the case with children with disabilities who grow up in families. Even if others cannot understand what they are trying to say, the parents usually understand – and make great efforts to encourage their children’s communication and development.

When children are removed from families and placed in institutions, the State has taken on the role of parent. Yet the nature of the institutionalised system and the prevailing medical model of disability means that the adults entrusted by the state to parent the children do not engage in meaningful communication with them.

The researchers noted that many personnel understood some of the children’s communication when it related to their basic needs (i.e. when they are hungry or require assistance with personal care). However, the personnel were rarely able to respond to that communication: if a child was hungry but it was not mealtime, they would simply have to wait.

Moreover, the personnel rarely attempted to communicate with the children beyond basic care. In the institutions, there is little time for kind words or singing to the child, and few opportunities to ask them how they would like to be treated or give them choices in what to eat, when to eat, what to play and learn and with whom. The few minutes of engagement with children during mealtimes and personal care is often silent, with hurried, rough physical movements, and may not even involve eye contact. This discourages the development of attachment and early learning.

Moreover, it was clear that there was no mechanism for the institution managers – or even the government inspectors to ascertain the children’s opinions about anything. When monitoring visits of the institutions are undertaken, the monitors focus on observing the situation in the institution, consulting documents and discussion with senior personnel.



## **PATTERNS AMONG THE FINDINGS**

### **The importance of family**

The entire research team was struck by how many of the children communicated about family. Some missed their own family – were happy when family visited and upset when they left; others communicated their desire to be part of a family. Perhaps this should not be surprising, since this is a fundamental, powerful driving force for most children who are separated from families and live in institutions. However, we were taken by surprise by the strength of feeling and the sophistication of the children's and young people's understanding of what family means and how much they are missing.

### **Relationships**

Some children and young people, according to personnel, did not like social interaction. Yet the researchers found that all children and young people did enjoy interacting with others, so long as this was approached in a way that addressed children's fears and anxieties.

A very high percentage of children expressed a wish for more social interaction – with friends and, particularly, with trusted adults. In the absence of family, adults in their lives who love them, guide them and support them are exceptionally important to the children and young people.

### **Desire to learn and achieve – and to have their achievements recognised and appreciated**

Almost 100% of the children and young people responded positively to opportunities to learn new things. As their achievements were encouraged and praised, this energised the children and young people, who then wanted to learn and achieve even more. They expressed great joy during these learning activities.

### **Creativity – joy in art and music**

Most of the children and young people were very creative when provided the opportunity. Some enjoyed music – others enjoyed engaging in art. And the children were often able to concentrate for much longer on creative activities than other activities. In addition, engaging in art or music often reduced challenging behaviours.

### **Distress and frustration at being confined – in bed, in wheelchairs, inside the building, inside the grounds**



Many of the children expressed frustration or distress at being confined. They expressed great enjoyment in being able to move freely, but often felt their freedom of movement was limited. For some children, that meant they were confined to lying in bed or sitting in their wheelchairs with no occupation. This would result in children becoming very passive – staring into space – or becoming upset and expressing themselves through crying, self-harming or aggression. These behaviours and emotions changed dramatically when they were allowed to move on the floor and interact with the researchers, with toys and activities, or with other children.

Other children expressed a desire to get out of the building – or to go for walks outside the institution. One young woman has a strong desire to go to the sea: she dreams about this and continuously paints pictures of the sea.

### **Short attention span and ability to concentrate**

Many of the children demonstrated a short attention span or ability to concentrate. Again, this may be interpreted as being the result of an intellectual disability. However, it became clear that abilities to concentrate improved after several sessions with each child. If children are not used to being engaged in communication and learning activities, they need practice to extend the amount of time they can stay concentrated. There is a risk that their cognitive ability – and their potential to learn, grow and develop – are considerably underestimated.

### **Gender-specific issues**

There was no significant gender-based difference in the findings, with one exception: girls were much more likely than boys to be able to concentrate on activities and to have a longer attention span. And boys were more likely to have challenging behaviours.

There could be a range of reasons for this. For example, autism is much more common in boys than girls – and can be linked to behavioural challenges. It may also be that the personnel (who are predominantly female) may find older teenage boys with challenging behaviours more difficult to manage – and may therefore give them even less attention than the girls receive. Whatever the reason, the finding is significant and should be taken into account by the authorities when planning the DI process and improvements to care.

### **Age-specific issues**

There were some significant correlations related to age. Although most children craved individual attention from adults, this was more pronounced among younger children. Strong friendships with other children were more common among teenagers.

Older teenagers and young adults were more likely to be interested in their personal appearance and expressing their individuality. And, significantly, some of the young adults expressed a wish to have special relationships – like any other young people.

This issue is important as there is a tendency to assume that adults with intellectual disabilities are 'child-like' and, therefore, do not have a sexuality or desires for intimate relationships. There are two serious potential consequences. Firstly, the institutional system denies them their right to fall in love, have relationships, get married and have children.

Secondly, treating adults as if they are children poses potential safeguarding risks. In many of the institutions for children with disabilities in Ukraine, there is a mixture of unrelated children and adults sharing bedrooms and regularly left unsupervised. There is even a mixture of genders in the same bedrooms. Ukraine is not the only country where this happens. It is a common occurrence in large institutions across Central and Eastern Europe and it is of great concern.

### **Issues specific to internally displaced children and young people (IDPs)**

We analysed any specific correlations for internally displaced children and young people. We only found one significant correlation – but it is important. IDP children and young people appeared to be significantly more likely to experience high levels of anxiety in strange situations or meeting strange people. The researchers consistently described the behaviour of many of these children as 'freezing' when the researchers came into the room, and requiring a great deal of time and careful approach before they began to relax.

These children and young people have experienced compound traumas, due to institutional abuse and neglect, as well as experiences of bombardment, evacuation and displacement. It should be noted that other research found that children with disabilities who fled the war with their families experienced higher levels of anxiety than children without disabilities.

However, it is also well-known that children with disabilities and HSN who are moved suddenly from institutions to other placements often find this experience highly traumatic. It is of great concern that, more than two years after evacuation, internally displaced children and young people are still displaying unusually high levels of anxiety. This has significance for any future evacuation of children with disabilities from institutions.



## **THE GOVERNMENT OF UKRAINE AND REGIONAL AUTHORITIES SHOULD:**

### **1. Take into account the opinions and interests of children with disabilities and high support needs while planning and implementing the Strategy for ensuring the right of every child in Ukraine to grow up in a family environment**

- Define and implement a structure for alternative care and parenting of children that considers children`s potential and their natural need in learning, communication, and personal development, independent of their health conditions or disability.
- Ukraine, as a state party to the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, should adhere to the UN Committees' Guidelines and prioritize family-based care for children with disabilities.
- Rather than investing in institutional care facilities, fund the provision of intensive individual care, support, and training of specialists.

### **2. Introduce mechanisms to listen, understand and communicate with children to ensure that all decisions made about children are based on individual wishes and best interests.**

- Provide legislative and practical procedures for communication with children on key matters, taking their opinions into account and reporting to children and youth, and recognizing children as subjects of rights and members of society.
- Make it obligatory for all individuals responsible for monitoring institutions to consult children and listen to their feedback.
- Train all monitoring personnel of the national and regional authorised services, as well as others involved in children`s care, such as institution personnel, social workers, teachers, and medical personnel, on how to communicate with children with disabilities and limited verbal communication.

### **3. Urgently assess all institutions for children with disabilities and high support needs to:**

- Identify those at the highest risk of preventable mortality or other forms of harm.
- Engage and train dedicated teams of Care and Psychosocial Support Workers (CPSWs) to carry out Intensive Interaction activities with children at the highest risk of harm.
- Facilitate that each institution`s CPSW team focuses on building attachment and helping children passing through the early developmental stages they have missed.
- Use this programme as a basis to begin preparing children for life outside the institutions.

### **4. Prioritise children with disabilities and high support needs in the deinstitutionalization process.** Ensure best practices are followed, including:

- Recognizing children's potential to develop and learn – and to contribute to society.

- Believing in families' potential and ability to care for children with disabilities if provided the needed support.
- Undertaking thorough assessments of families with children with disabilities in order to facilitate reunification or, at least, to restore family connections.
- Developing high-quality foster family care for children with disabilities who are unable to return home to their biological or extended families.
- Providing community support services to biological, extended, adoptive and foster families of children with disabilities.

***5. Ensure that emergency plans for evacuation of children with high support needs from institutions consider the unique risks involved***

- Provide mental health and psychosocial support (MHPSS) to help people with high support needs during and after evacuations in adjusting to their new environments. Where government capacity does not exist, coordinate with competent national or international organisations to provide this service.
- Ensure that government staff or non-governmental organisations providing MHPSS during and after evacuation are trained in appropriate methods to support people with high support needs who have lived in institutions.
- If people with high support needs have been evacuated to other institutions, ensure that they are prioritised while planning and implementing deinstitutionalization.

## **RECOMMENDATIONS FOR THE INTERNATIONAL COMMUNITY AND DONORS**

***1. Prioritise funding the deinstitutionalization process, including enhancements to care and support*** for children with disabilities who require a high level of support

- Prioritise financing for family support, alternative family care and supported independent living.
- Ensure funded programmes are inclusive of children with disabilities and inquire about how the perspectives of children with disabilities and high-support needs have been incorporated in planning of programmes.
- Ensure that funds are not used to create new institutions, whether large or small, or to maintain existing institutions' buildings.

***2. Provide funding for Ukrainian civil society organisations that work with*** children and young people, who have been formerly institutionalized, to take the lead in the deinstitutionalization process.

- Support these organisations, including with funding opportunities, to become more inclusive of children and young people with disabilities.

# REFERENCES

<sup>1</sup> Full details of the methodological approach are available upon request

<sup>2</sup> Reliable gender statistics on children with disabilities in institutions is absent, however, in general, the number of boys living in institutions are a little bigger than that of girls

<sup>3</sup> Such as difficult life circumstances in the family, disability or health conditions, obtaining specialized education and others

<sup>4</sup> In 2015, Disability Rights International documented children in institutions in Ukraine “left in physical restraints or kept in beds and cribs where their arms and legs atrophy from disuse. Separated from society and without the protection of family and friends, children are subject to beatings, rape, and other forms of routine violence”

<https://bettercarenetwork.org/sites/default/files/No%20Way%20Home%20-%20The%20Exploitation%20and%20Abuse%20of%20Children%20in%20Ukraine%27s%20Orphanages.pdf>

Cases of physical restraints applied to children in institutions are also observed during the child rights monitoring, which is carried out within the mandate of the Commissioner of the Parliament for Human Rights (for example, the material of 2023

[https://www.ombudsman.gov.ua/news\\_details/zvyazani-diti-vidsutnist-ukrittia-ta-antisanitariya-rezultati-monitoringovo-vizitu-do-dityachogo-budinku-internatu-u-m-dnipro](https://www.ombudsman.gov.ua/news_details/zvyazani-diti-vidsutnist-ukrittia-ta-antisanitariya-rezultati-monitoringovo-vizitu-do-dityachogo-budinku-internatu-u-m-dnipro))

<sup>5</sup> UN CRC and UN CRPD joint call

<https://www.ohchr.org/sites/default/files/documents/hrbodies/crc/statements/2022-10-07/CRC-CRPD-statement-Ukraine-children.docx>

<sup>6</sup> “We Must Provide a Family, Not Rebuild Orphanages”: The Consequences of Russia’s Invasion of Ukraine for Children in Ukrainian Residential Institutions, Human Rights Watch, 2023, P.8

[https://www.hrw.org/sites/default/files/media\\_2023/03/crd\\_ukraine0323web.pdf](https://www.hrw.org/sites/default/files/media_2023/03/crd_ukraine0323web.pdf)

<sup>7</sup> The total number of children in institutional care facilities is 93,088, including 15,646 children with disabilities (most children do not live in institutions all the time but return home every day or on weekends and/or holidays).

<sup>8</sup> An association agreement in 2014 between the EU and Ukraine set standards and reforms for Ukraine to move towards membership of the EU, and created a framework for bringing social policy, including child protection, in line with EU standards. In its recent conclusion on Ukraine's application for EU membership, the European Commission stated that the high number of children in institutions in Ukraine is “of serious concern and needs to be addressed immediately.”

<sup>9</sup> Draft on the Ministry of Social Policy of Ukraine website <https://www.msp.gov.ua/projects/892/>

<sup>10</sup> Ukraine Plan 2024 – 2027, p.125-126 <https://www.ukrainefacility.me.gov.ua/wp-content/uploads/2024/03/ukraine-facility-plan.pdf>

<sup>11</sup> Ibid p.137 For criticism of the plan see Ukraine Recovery: Statement by the Global Coalition on Deinstitutionalization and Ukrainian Disability Rights Organisations, December 2023

<https://validity.ngo/2023/12/15/ukraine-recovery-statement-by-the-global-coalition-on-deinstitutionalization-and-ukrainian-disability-rights-organisations/>

<sup>12</sup> UCRN position regarding existing and development of small group homes in Ukraine,

<https://childrights.org.ua/news/pozycziya-umpd-buduvaty-novi-sporudy-dlya-mbd-pogana-ideya/>

<sup>13</sup> Other Ukrainian legislation does clearly prioritise family-based care, but even here accepts that “a child may be placed in an institution ... if for some reason it is not possible to place him or her in a family.” Law of Ukraine “On Ensuring Organizational and Legal Conditions for Social Protection of



<sup>14</sup> According to the National Social Service of Ukraine, in response to a request for public information, as of January 1, 2024, "the total number of children registered as suffering from difficult life circumstances amounted to 52,891 children. In connection with disability - 60 children, for suffering from domestic violence - 14,589 children, and for other reasons - 38,242 children"

<sup>15</sup> Paragraph 4 of Article 231 of the Law of Ukraine "On Childhood Protection". Emphasis added. See also Article 24 of the same law.

<sup>16</sup> Back in 2011, the UN Committee on the Rights of the Child recommended that Ukraine remove the relevant provision of Article 143 of the Family Code of Ukraine, but it is still in force. Family Code of Ukraine, <https://zakon.rada.gov.ua/laws/show/2947-14#Text>

<sup>17</sup> Mathews, E. (2015). No way home: The exploitation and abuse of children in Ukraine's orphanages: Disability Rights International. No Way Home: The Exploitation and Abuse of Children in Ukraine's Orphanages | Disability Rights International. <https://www.driadvocacy.org/reports/no-way-home-exploitation-and-abuse-children-ukraines-orphanages>

<sup>18</sup> Mulheir et al (2023). Bridging the Gaps. Four studies of the situation of Ukrainian children with disabilities and their families since the war began. An extended summary. European Disability Forum. <https://www.edf-feph.org/publications/bridging-the-gaps-four-studies-on-ukrainian-children-with-disabilities/>

**BEHIND THE CLOSED DOORS:  
CHILDREN'S DREAMS IN  
INSTITUTIONAL CARE**