Factsheet

Transitional care for young people with intellectual disabilities and co-occurring health conditions: the perspective of parents/carers

April 2026

Samra Hussain, Femke Vennik, AnneLoes van Staa & Jane Sattoe | Rotterdam University of Applied Sciences

Introduction

The transition from pediatric to adult care represents an important phase in the lives of young people with intellectual disabilities (ID) and co-occurring physical and/or mental health conditions. There are indications that parents/carers in the Netherlands feel lost during this period, but a systematic exploration of their experiences is lacking. Understanding these experiences is essential for improving the transition to adult care and developing solutions that align with the needs of this population. Within the STEP UP (Dutch: STAP OP) research project, the experiences of parents/carers with this transition were therefore explored. This factsheet summarizes the key findings.

Methods

Survey

Between April and October 2025, a nationwide online survey was conducted among parents/carers of children with ID and co-occurring physical and/or mental health conditions. A total of 52 parents/carers completed the survey either fully or partially.

The survey was based on the validated On Your Own Feet Transition Experiences Scale (OYOF-TES) for parents. It included questions about parents' and carers' expectations and perceived barriers regarding the transition, as well as their experiences with the involvement and practices of healthcare professionals.

Parents/carers were asked to focus on one specific transition from pediatric to adult care when completing the survey, for example, within hospital care, rehabilitation services, or mental health care.

Interviews

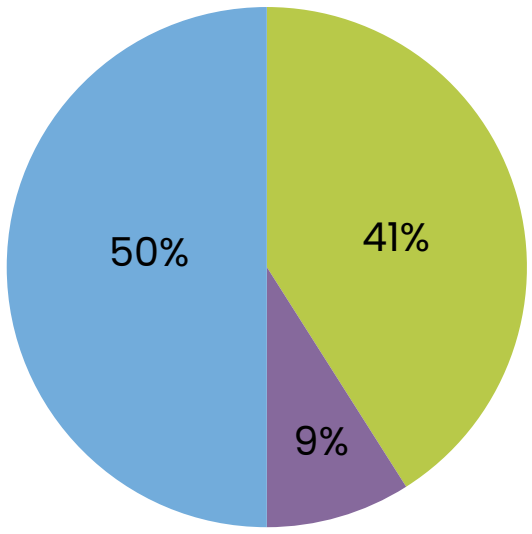
In addition to the survey, semi-structured interviews were conducted with parents. Seven interviews were conducted individually, while three parents participated in a group interview. The group interview provided an opportunity to further explore similarities and differences in parents' experiences.

Five interviews were conducted in the spring of 2025; the remaining interviews took place in the fall and winter of that year.

During the interviews, parents were asked about their experiences with the transition to adult care, what went well, and what could be improved.

Background characteristics

Characteristics of the children



Survey:

My child has an ID and additional:

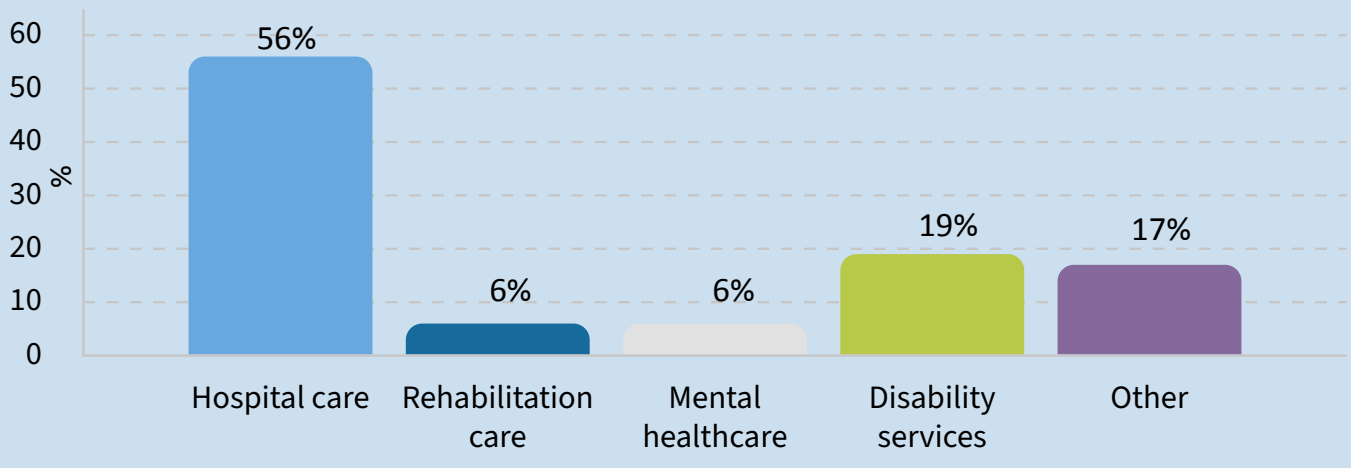
- physical and mental health conditions
- physical health conditions
- mental health conditions (including behavioral conditions)

n=44

Interviews:
The children represented in the interviews showed a similar distribution of physical and mental health conditions as those represented in the survey.

Which transition was the focus of this survey?

When completing the survey, I focused on the transition from pediatric to adult care within:



n=52

Interviews:
During the interviews, parents/carers primarily discussed the transition within hospital care. Other transitions, such as those involving rehabilitation services, mental health care, and services for individuals with intellectual disabilities, were also discussed, but less frequently.

Time since the transition

How long ago did the transition to adult care take place?

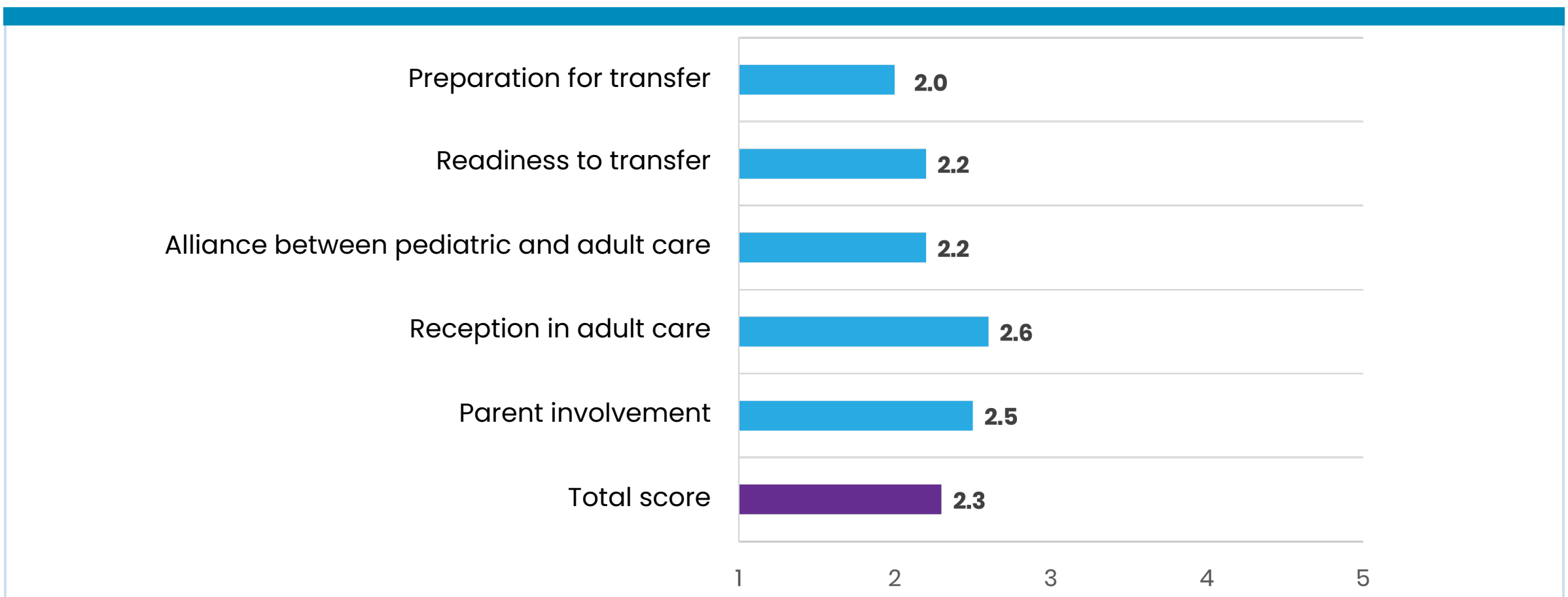
	Survey (n=47)	Interviews (n=10)
0-3 years	74%	70%
3-5 years	9%	10%
More than 5 years	17%	20%

For both the **survey** and the **interviews**, most parents/carers had experienced the transition to adult care within the past three years.

Results

Assessment of the transition process

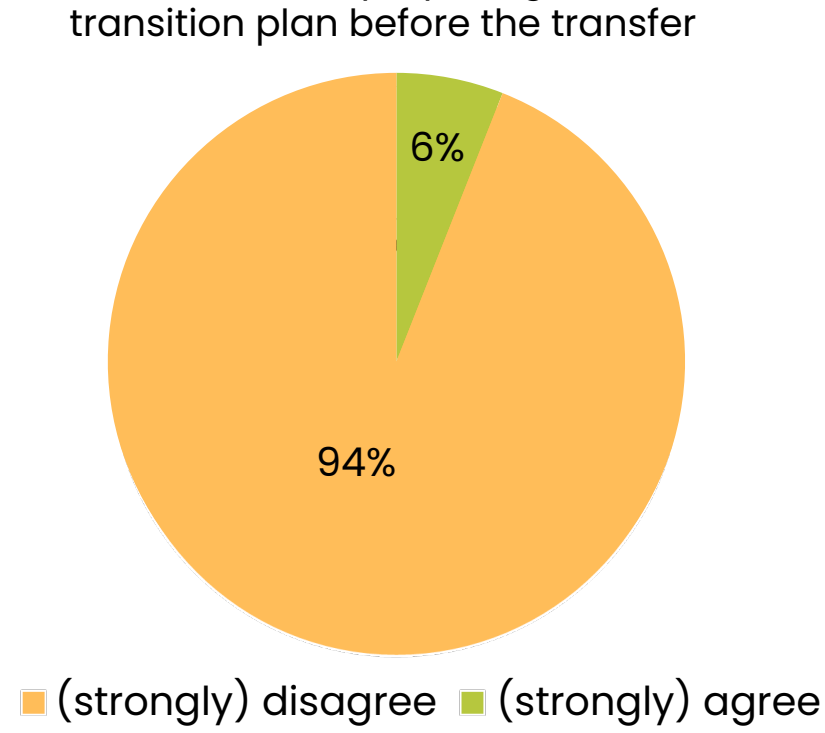
In the survey, parents/carers rated different aspects of the transition to adult care on a scale from 1 (strongly disagree) to 5 (strongly agree). The figure below shows the mean total and subscale scores of the OYOF-TES for each aspect. Higher scores indicate more positive experiences with the transition. The low scores indicate that there is considerable room for improvement.



Preperation for transfer

During preparation for transfer, it is important that the young person and parents/carers know what to expect. Key elements include jointly developing a transition plan to support the young person during the transition, meeting the new care team in a timely manner, and receiving sufficient information about the transition.

- **Transition plan**: the survey showed that 94% of respondents indicated that no written transition plan had been developed together with the young person and their parents/carers.
- **Meeting the new care team**: 31% of parents/carers had met the adult care team before the transition; for 66%, this meeting had not taken place.
- **Information**: 77% of respondents reported that they had received insufficient information, compared with 16% who felt they had received sufficient information.



Results

Which interventions were implemented (multiple answers possible)

n=34

Individual transition plan (e.g. Skills for Growing Up or Ready Steady Go)	6%
Written or digital information materials	6%
Information session for young people and parents/carers	6%
Healthcare checklist: transition from 18- to 18+	6%
Transition coordinator	9%

Statement:
"When I think back to the period when my child left pediatric care, I feel that we had to figure out many things ourselves and received little support in finding appropriate care"

20% (strongly) disagree **2%** neutral **78%** (strongly) agree

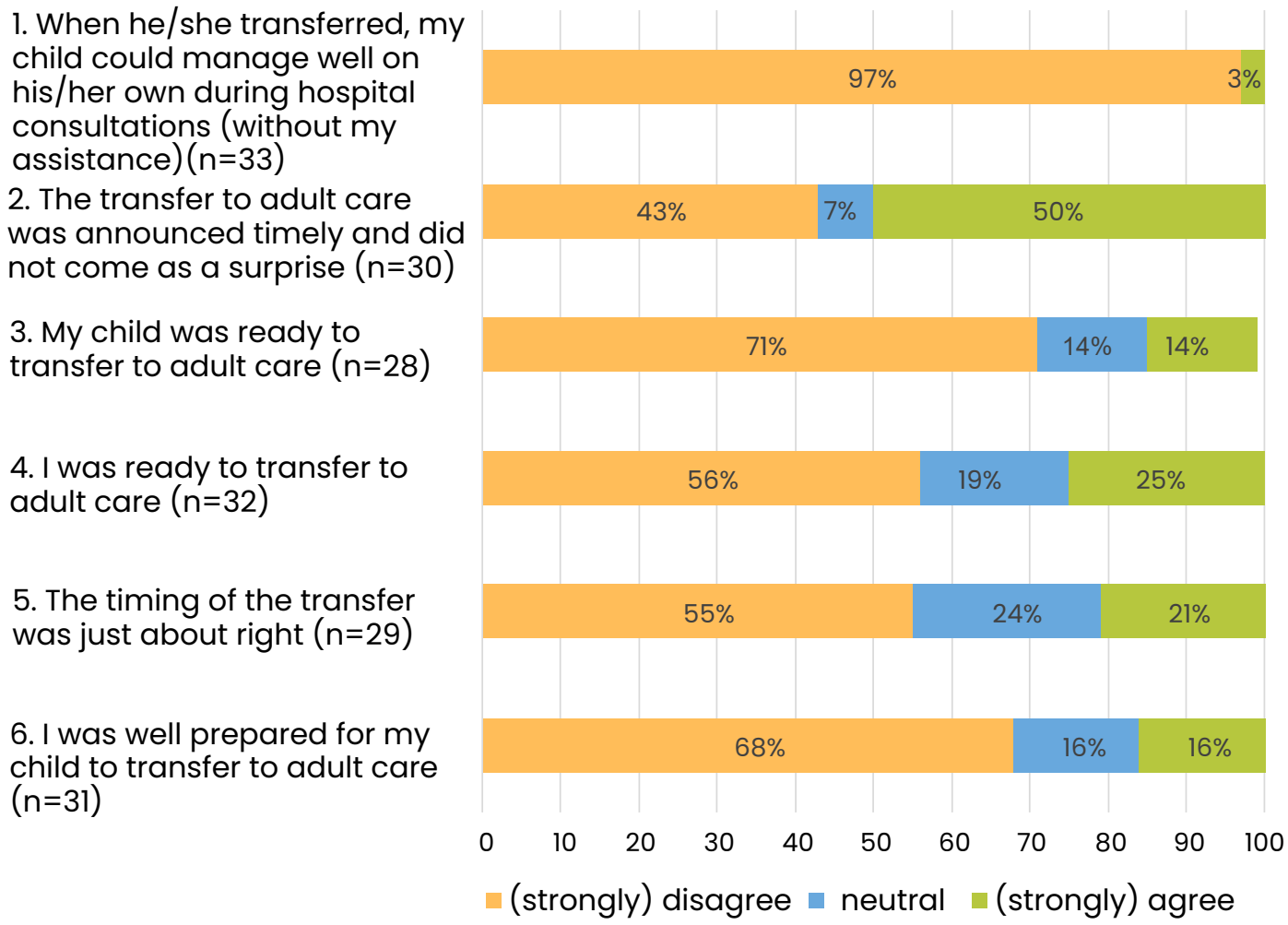
The interviews showed that parents/carers had different experiences with the information provided during the transition to adult care. Some felt sufficiently informed, while others felt insufficiently informed. These differences were related to:

- **Fragmented information provision:** information and support came from different sources, depending on the care setting and specific information needs, such as healthcare professionals, social workers, and organizations such as MEE or Per Saldo.
- **Need for active guidance:** parents/carers want more than just information or an overview of what needs to be arranged. They expressed a need for someone who thinks along with them, walks alongside them throughout the process, and, where necessary, checks whether agreed steps are actually being taken.

"***Having someone who keeps an eye on things, listens, and walks alongside you when needed.*** *Everything worked out in the end, but a little support would have been helpful. So that you don't have to reinvent the wheel every time.*" (parent L)

Readiness to transfer

Readiness for transfer to adult care refers to the extent to which young people or their parents/carers feel prepared and ready to make the transition to adult healthcare. According to most parents/carers, this readiness was insufficient. Most parents/carers felt that neither they nor their child were ready for the transition, perceived the timing of the transfer as suboptimal, and felt insufficiently prepared for the transfer. Opinions differed regarding whether the transition had been announced in a timely manner.



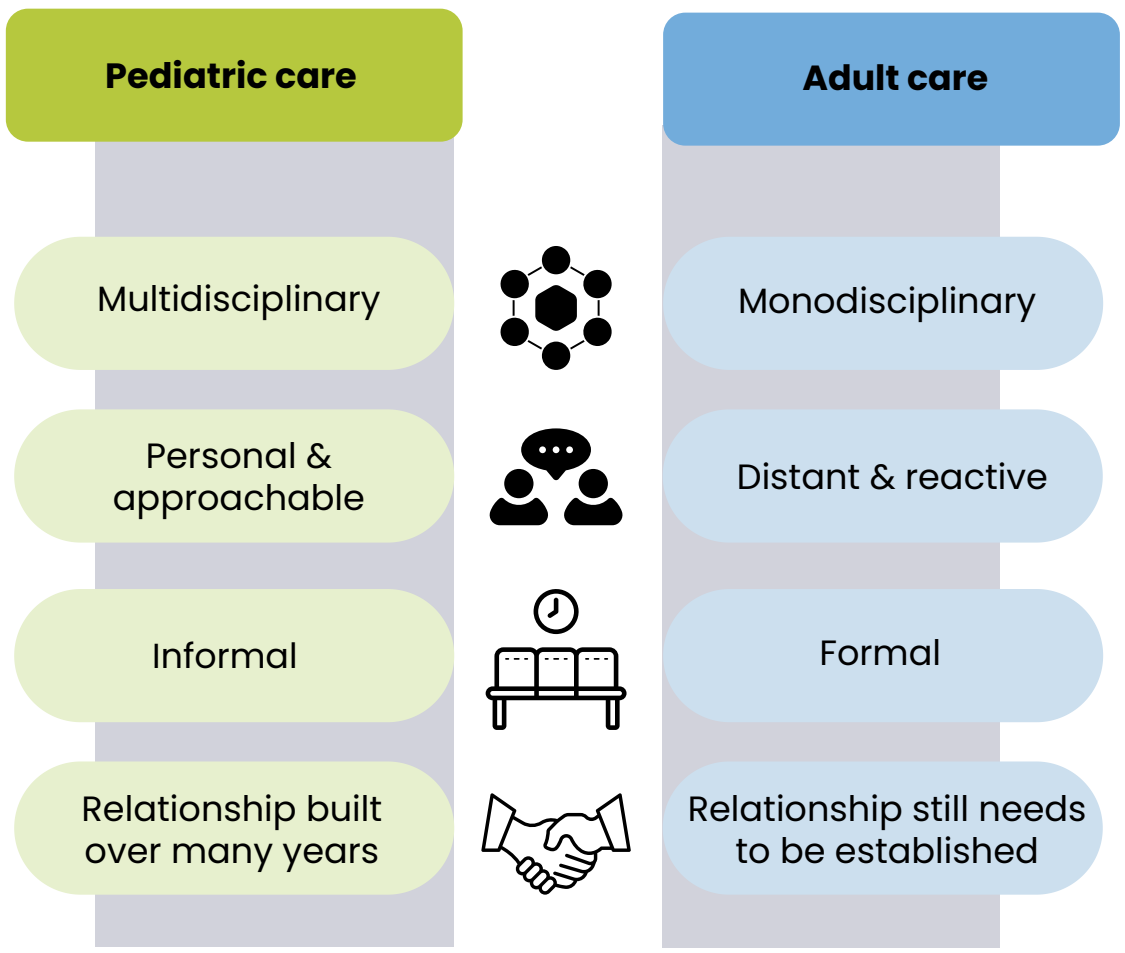
Results

- The transition to adult care often takes place at a time when **young people and their parents/carers feel insufficiently prepared**. This highlights the importance of adequate support throughout the transition process.
- In pediatric care, parents/carers **have become familiar with established ways of working and have built trusting relationships with healthcare professionals**. They experience uncertainty about how adult care is organized and about rebuilding these relationships.

"It is well organized now. Just let us stay here. What on earth is my Miffy fan supposed to do in an adult hospital?" (parent K)

Alliance between pediatric and adult care

Alliance between pediatric and adult care refers to how well care is aligned when a young person transitions to adult care. This includes topics such as consistency in treatment recommendations and ways of working, collaboration between healthcare professionals, and clarity about what is expected of the young person and what they can expect from adult care. It also includes the extent to which care in the new setting feels familiar and recognizable.



Collaboration between healthcare professionals
Organizational differences between pediatric and adult care make good coordination particularly important. Currently, this coordination is often insufficient:

- **Lack of contact:** 45% of respondents indicated that no contact had taken place between pediatric and adult care professionals regarding their child's care.
- **Insufficient collaboration:** 59% indicated that there had not been adequate collaboration between pediatric and adult care.
- **Impact on parents/carers:** they often have to provide important information themselves and arrange appointments and follow-up.

"We were sitting in the waiting room at the hospital. And I said to my daughter: 'It's so different here, wow. I don't see any toys at all. You only see adults.' So, we talked about that together as well. We said to the doctor: 'Well, this place is a bit boring." (parent K)

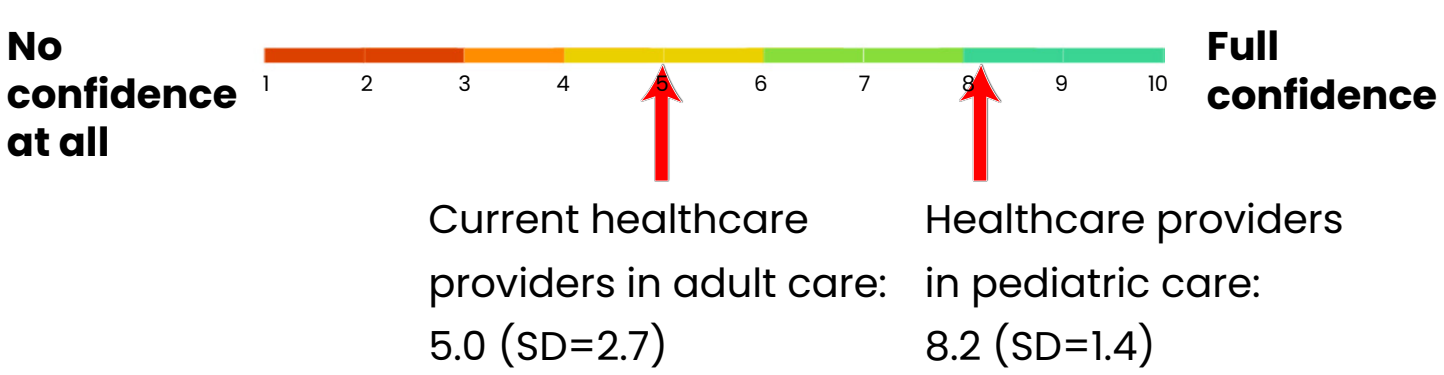
Results

Reception in adult care

Reception in adult care refers to how young people and their parents/carers experience their current care. This includes, among other things, trust in healthcare professionals, satisfaction with the care provided, the extent to which healthcare professionals are well informed about the young person and their condition, and whether they feel well supported within adult care.

- Only 25% of respondents felt that the new care team was well informed.
- A formal handover between pediatric and adult care is often absent when the care situation is stable.
- Having the same healthcare professional after age 18 helps preserve knowledge of the young person's medical history.

Average confidence in healthcare professionals



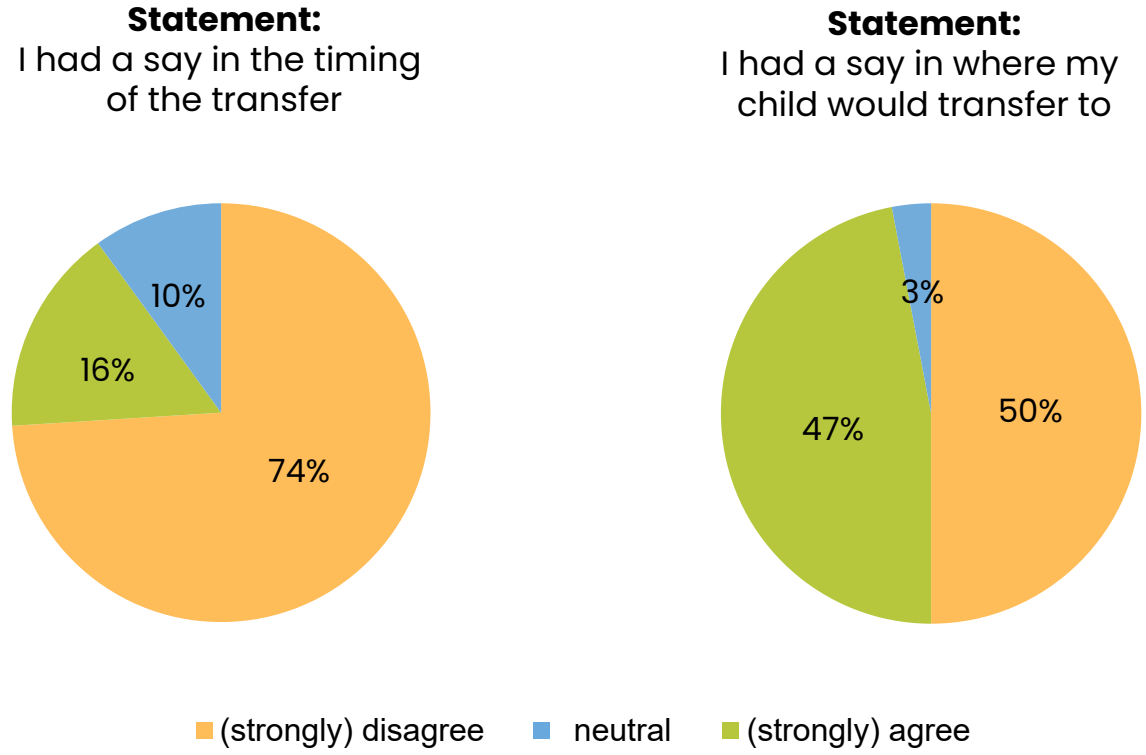
The interviews showed that lower confidence in adult care was associated with:

- **Limited knowledge and experience among healthcare professionals** in caring for young people with ID and complex health conditions.
- **Having to build a new trusting relationship**, as the new healthcare professionals do not yet know the young person.
- **Uncertainty about finding appropriate follow-up care**, particularly for young people with complex medical needs.

Parent involvement

Parent involvement refers to the extent to which parents/carers are involved in important decisions about their child's transition to adult care. This includes decisions about the timing of the transition and where their child will be transferred for adult care.

The **survey** showed that many parents/carers were not involved in decisions about the transition.



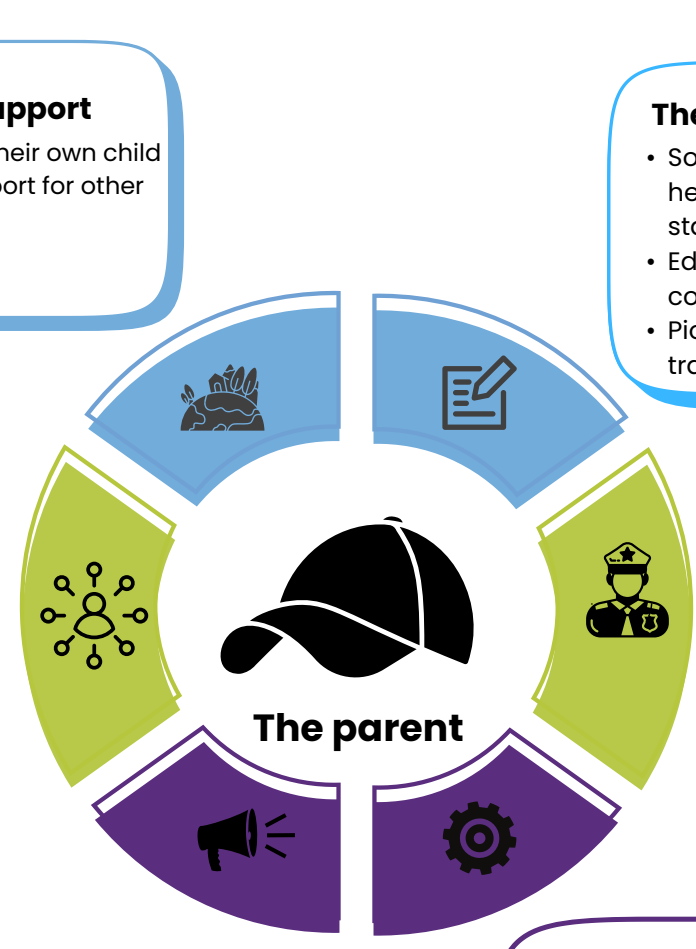
Results

The many hats parents wear

The way the transition to adult care is currently organized requires parents/carers to take on many different roles at the same time. The figure on the right illustrates the many "hats" that parents/carers often wear during this transition.

Depending on the young person's care needs, some roles may be more demanding than others.

The skills and (financial) resources of parents/carers also influence which roles become the most demanding.



1

Pillar of support

- Caregiver for their own child
- Source of support for other parents

2

The living manual

- Source of information for healthcare professionals, support staff, and family members
- Educator about their child's condition
- Pioneer in navigating the transition to adult care

3

The legal guardian

- Curator
- Budget manager
- Legal representative
- Financial manager

4

The care coordinator (without formal authority)

- Coordinating and aligning care with healthcare professionals
- Project manager, case manager, and liaison for the young person
- Constantly informing, organizing, and following up
- Maintaining the overall overview because no one else has the complete picture

5

The advocate

- Speaking up when needed
- Fighting for their child's interests
- Feeling compelled to be assertive
- Thinking outside the box

6

The networker

- Finding the right healthcare professionals and building lasting relationships with them
- Maintaining the image of being a "competent parent" in interactions with professionals
- Learning from other parents
- Alerting others to problems and abuses

Taking on many different (and sometimes demanding) roles at the same time places a substantial mental and emotional burden on parents/carers. The experiences of parents/carers show that, during this phase, they primarily need three types of support: (1) active guidance and practical support, (2) clear and timely information about the transition process, and (3) recognition of their expertise and a trusting partnership with healthcare professionals.

A. Active guidance and practical support

- A healthcare professional taking the lead
- Healthcare professionals who think along with families
- A central point of contact
- Continuity in appointments
- Warm handover
- Being guided step by step

B. Clear information about the process

- Knowing what to expect
- Step-by-step overview
- Timely information
- Practical information about arrangements and procedures

C. Recognition and trust

- Relational continuity
- Recognizing parents/carers as experts on their child
- Taking the time to get to know the child

Conclusions

Many parents/carers of young people with ID and co-occurring physical and/or mental health conditions report that they are left to figure out and coordinate much of the transition to adult healthcare on their own. Support from healthcare professionals may be available, but not always. Information is fragmented, handovers are often incomplete, and collaboration between pediatric and adult healthcare services is often insufficient. As a result, parents/carers often have to take on multiple roles at once, which adds to the burden during a period they already experience as challenging and life-changing. For many parents/carers, the transition feels like they have to reinvent the wheel. Based on these challenges, the recommendations below aim to improve and structurally strengthen the transition to adult healthcare.

Recommendations

Micro

- **Parents/carers:** start preparing for the transition early and make use of available support from relevant organizations and peer support networks.
- **Healthcare professionals:** prepare for the transition in a timely manner by developing a transition plan, providing clear information, and facilitating an introduction to the new healthcare team. Ensure active coordination with involved healthcare professionals, recognize the expertise of parents/carers, and actively involve them in decision-making.

Meso

- Appoint a **transition coordinator** to guide the transition process and maintain oversight.
- Increase the use of (effective) **interventions and tools** that support the transition, and apply them in a more targeted manner.
- Provide **training and guidance** for healthcare professionals on transition care.
- Embed transition care in **policy** to ensure clear and consistent implementation.

Macro

- Ensure **appropriate funding** and the necessary conditions for transition coordination.
- **Organize and provide the active support** requested by parents/carers.
- **Simplify administrative processes.**
- **Involve parents/carers and young people** (where possible) in the evaluation of transition care.

Research limitations

- Participation in the survey and interviews was voluntary. This may have resulted in self-selection bias, as parents/carers with more significant experiences may have been more likely to participate.
- The number of participating parents/carers was limited, and young people themselves could not be interviewed or surveyed.
- The respondents were primarily parents/carers of young people with more complex healthcare needs.
- Despite the instruction to describe one specific healthcare transition, some parents/carers appeared to reflect on multiple transitions in their open-ended survey responses.

Acknowledgements

We would like to thank:

- All parents/carers who participated in the survey and interviews;
- The Academic Board and Patient Parent Board for reflecting on the research findings;
- ZonMw for funding this study.

Questions about this factsheet?
Email: stap-op@hr.nl