FACTSHEET

Transitional care for young people with intellectual disabilities and co-occurring conditions:

challenges and opportunities according to healthcare professionals

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Introduction

The transition to adulthood represents a crucial stage for young individuals with intellectual disabilities (ID) and co-occurring physical and/or mental health challenges. This period is marked by significant changes across various aspects of life, including healthcare. Typically, around the age of 18, the transition from pediatric to adult medical care occurs. During this shift, ensuring continuity and quality of care is essential, especially for those with complex healthcare needs. Yet, in practice, achieving this often proves challenging. Within the STAP OP research project, we assess the current state of transitional care for this diverse group of young individuals—spanning from mild to severe ID, often accompanied by physical and mental health problems—and develop recommendations for improvement.

Objective

This factsheet presents healthcare professionals' perspectives on transitional care for young people with ID and co-occurring physical and/or mental health problems. We focus on three aspects: what constitutes good transitional care, which challenges are encountered, and which factors hinder or facilitate the transition process.

Methods

Interviews
Between October 2024 and January 2025, twelve semi-structured interviews were conducted with healthcare professionals working in pediatric and/or adult care and involved in transitional care. The interviews explored experiences, challenges, and success factors in transitional care practices.

Interview participants N=12

- Social worker 1
- Internist 1
- Nurse practitioner 1
- Physiotherapist 1
- (Pediatric) neurologist 1
- Psychiatrist 1
- General pediatrician 2
- Pediatric rehabilitation physician 1
- Physician Assistant (PA) 1
- Intellectual disability (ID) physician 2

Survey
In addition, a national survey was conducted among healthcare professionals. A total of 233 respondents (partially) completed the questionnaire. The survey included both closed and open-ended questions, designed to identify key components of transitional care, perceived challenges, the involvement of young people and their parents, and organizational characteristics.

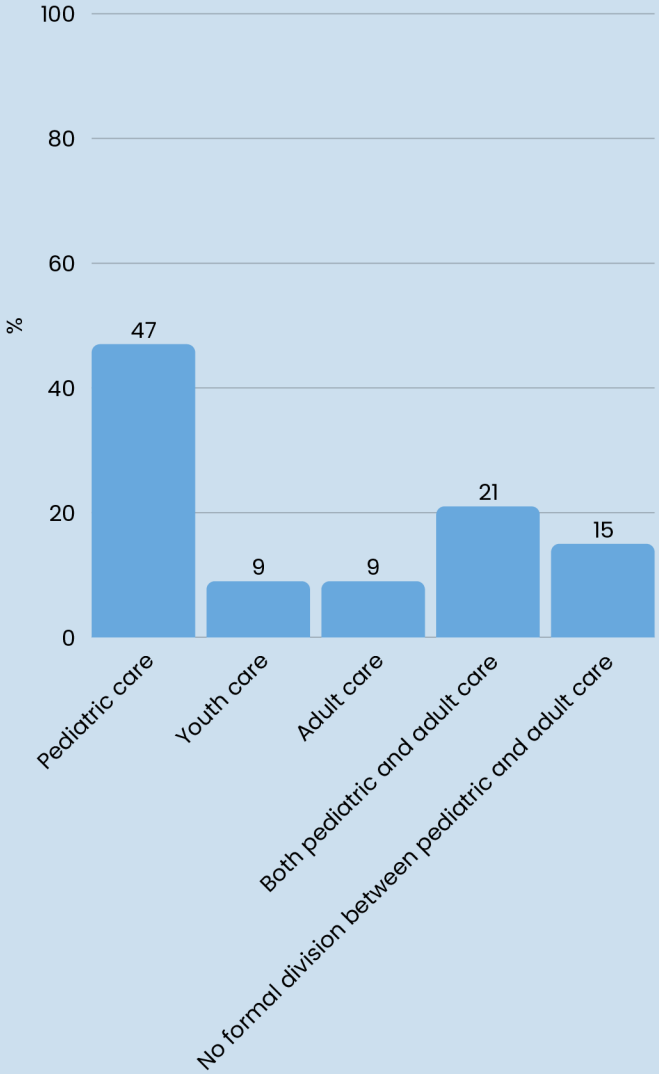
Survey participants
The professional backgrounds of the survey respondents were highly diverse. The following disciplines were most frequently represented:

- (Specialized/general) pediatrician 20%
- ID physician 10%
- Nurse Practitioner/PA 10%
- (Specialized) nurse 8%
- Pediatric rehabilitation physician 6%

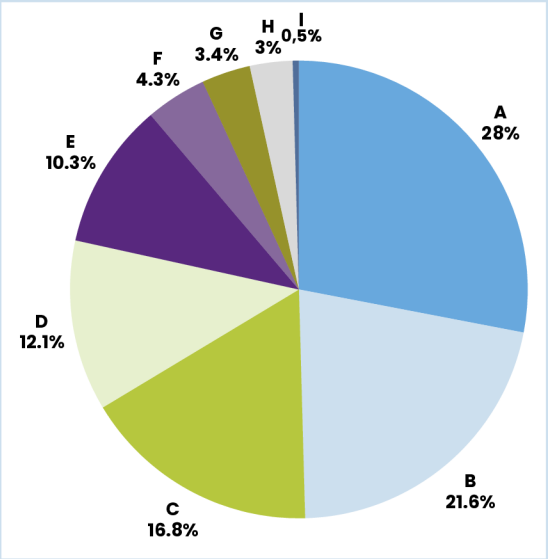
N=220

The following overviews indicate the sectors, organizations, and target groups the survey respondents are involved in.

Sector of employment of survey respondents (N=204)



Institution of employment of survey respondents (N=232)



A – University medical center
B – Care institution for people with ID
C – General hospital
D – Rehabilitation center
E – Other
F – Mental health care institution
G – Specialized orthopedagogical treatment center for young people with mild ID and severe behavioral problems
H – (Small-scale) residential facility for people with ID
I – Pediatric home care organization

Target groups with whom survey respondents work on a daily basis (N=204)	**Percentage (100%)**
Young people with ID and co-occurring somatic *and* mental problems	47%
Young people with ID and co-occurring somatic problems	32%
Young people with ID and co-occurring mental problems (including behavioral problems)	13%
Other	8%

Interview results

What constitutes good transitional care?
According to healthcare professionals, good transitional care consists of the following elements:

🧱 Structure: establishing a solid foundation

- Timely start of the transitional process and good expectation management
- Flexible age of transition
- A treatment plan addressing all life domains and the young person's future aspirations
- Family-oriented approach and clear information provision
- Availability of coordinator or named worker (<18 + >18 years)
- Required expertise in-house (e.g. general practitioner, IDP)
- Good logistics and possibility of aftercare (incl. check whether transition has been successful)
- Supporting guidelines (no protocol!) for each condition
- Smooth reimbursement

🤝 Process: making the transition together

- Seamless transfer through warm handover and comprehensive information sharing
- Effective collaboration within the available network of healthcare professionals
- Multidisciplinary consultation and shared decision-making about follow-up care
- Involvement and active participation of the young person and their family

🎯 Outcome: good care, a good transition

- The young person receives the best care through continuity and achieving care goals.
- The young person and parents feel satisfied and confident in adult care.
- The young person transitions smoothly into adult care, without health loss or trauma.
- The young person feels welcome, taken seriously, and safe in the new setting.
- The young person and parents know where to go and who to contact.
- The young person adheres to medical treatments.
- The young person experiences the highest possible level of well-being.

What challenges are experienced in current transitional care in the Netherlands?
According to healthcare professionals, the three main challenges are:

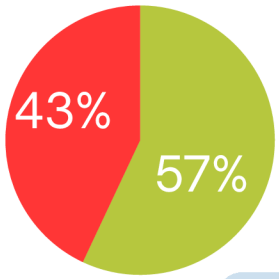
1

Problems with transfer: limited availability of professionals

57% of respondents indicate they **always or often** know who to refer a young person to;

43% only know this **sometimes, rarely, or never.**

Especially in case of more complex care needs, it proves to be difficult to organize appropriate follow-up care.



N=142

Specialized adult care is often insufficiently equipped to handle the complex care needs of young people with ID and co-occurring physical and/or mental challenges.

As a result, continuity of care depends on contingent factors, such as the availability of professionals with **personal affinity** for this population and a **strong network**.

The ID physician could be a stable, connecting link in the handover process, but due to a **shortage of ID physicians, restrictive financing structures, and limited availability (only during office hours)**, the deployment of this professional group is not always feasible.

Pediatrician:
"With these kinds of children they just say out loud, and I think they are right, 'I cannot offer this.' If the child has a thyroid problem, you can refer them to an internist-endocrinologist. That specialist can handle that part, but not the rest of the care."

2

Continuity issues: implementation depends on people, time and lack of reimbursement and policy

At both **institutional and departmental levels, policies on transitional care are often lacking.** Moreover, there is **no structural financing or reimbursement** in place. As a result, transitional care is easily perceived as an "extra" that disappears in times of time pressure or staff shortages. Implementation then depends on the personal commitment of healthcare professionals, which makes the continuity of transitional care fragile.

Person-dependent implementation

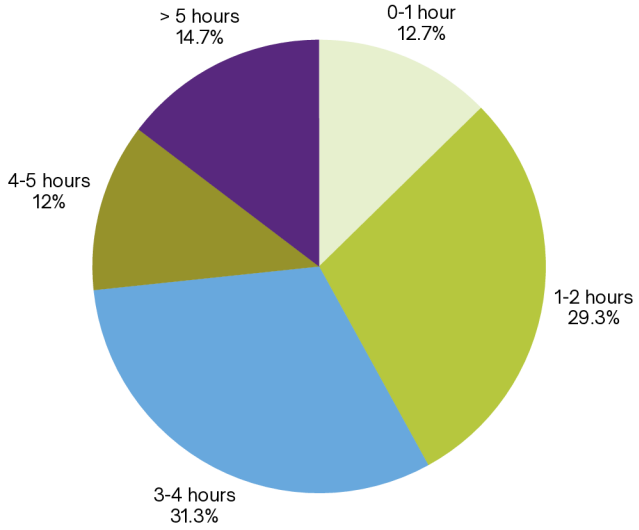
Physician assistant:
"In recent years, we experienced that things came to a standstill. That happened because the previous transition coordinator left."

Time-dependent implementation

Pediatrician:
"Due to the shortage of nurses, hospitals often think: 'the basic care must continue.' As a result, the extras—the icing on the cake—are the first to be cut. I don't want to call transitional care a luxury, but it's not acute care where blood flows if you don't provide it. That's why I don't easily free up nurses to do transitional care."

Lack of reimbursement

Transitional care is not reimbursed, even though healthcare professionals do spend considerable time on it.



Time spent on transitional care per young person with ID and co-occurring problems

N=150

Lack of policy

- **65%** of respondents reported that there is no **institution-wide transitional care policy** for young people with ID and co-occurring problems.
- At the **departmental level,** a care pathway or protocol is also often missing **(57%).**

N=157

The **Dutch Quality Standard – Young people in transition from pediatric to adult care** does recommend such policies. Average awareness of this guideline was reported as **3.05** on a scale from 1 (not at all familiar) to 5 (very familiar).

N=195

3

Problems in providing optimal care: transitional care requires a personalized approach, but professionals do not always experience the flexibility needed to achieve this.

Transitional care requires a personalized approach that responds to the specific needs and capacities of young people and their parents. According to healthcare professionals, such personalization is particularly needed in the following areas:

Topics to discuss	What topics should be addressed, and at what point in time
Who to involve	What disciplines should be included in the transition plan
Care needs	What support the young person requires
Timing of transfer	What the right moment is to move to adult care
Form of transfer	What form the transfer should take (e.g., phone, digital, warm handover)
Time investment	What amount of time is needed to find follow-up care
Parental support	What level of support parents need during the transition process
Communication	What communication is needed, and with whom (parents and/or the young person)
Meeting structures	What role informal meetings, alongside formal consultations, should play in ensuring a smooth transition

A personalized approach is possible insofar as **administrative** and **financial structures** permit.

Only **30%** of respondents reported applying a flexible transfer age; in **51%** of cases, transfer usually occurs at age 18. This may indicate organizational and/or structural limitations to implement personalized transitional care in practice.

N=156

Barriers and facilitators in transitional care

Healthcare professionals were asked to what extent the following factors act as barriers or facilitators in the provision of transitional care. Average ratings of the factors are shown in orange.

- Contracts with health insurers
- Referral procedures
- Feasibility of adequate transitional care

Pediatrician: "I regularly get reprimanded for keeping a patient over the age of 18. But when it comes to growth, endocrinologists often have little expertise. For a late bloomer, I prefer to continue care until the child has fully grown. But that's not allowed, because the insurance company will complain about it. I believe this should be handled with much more flexibility."

Pediatrician: "I simply cannot find a follow-up provider for this patient, it is terrible. I have already been working on it for six months now. The ID physician says: 'No, that's too much emergency care.' This is a major problem for many ID outpatient clinics. When children move to residential care facilities, there is an emergency service. But for those who remain at home — which is often the case — you are dependent on the ID outpatient clinic. And then an epileptic seizure is only allowed to happen between 9 a.m. and 5 p.m. on weekdays."

Nurse practitioner: "Of course, I would be very much in favor if transitional care were actually funded. At the moment, this type of care is all delivered for free. Everyone agrees it is important, but I have to plan it carefully into my own schedule, because it cannot be included in my regular outpatient clinic schedule; that is considered 'clinic contamination'."

- Support for healthcare professionals
- Continuing education and training
- Knowledge and expertise of professionals
- Availability of necessary resources
- Awareness of the importance of transitional care
- Scientific evidence base for transitional care

- Team processes: willingness
- Intention/motivation of professionals
- Willingness of parents/caregivers to support the process

Social worker:
"It is also about parents truly being partners in care. In the past it was very much like: well, we decide what will happen, and then we inform you, and then you can agree. And now it is really: well, this is what we see, what do you see, and what are we going to do about it together?"

ID physician:
"If you say: 'Patient X used to see you in your clinic, and now I'm facing this problem. Did you ever encounter this, and how did you handle it?' They are never unwilling; they are always open to think along with you."

N=130

Practical recommendations

The research results show that healthcare professionals know what constitutes good transitional care, but its implementation is not straightforward. Three main issues hinder practice:

1. Referral procedures are difficult due to limited availability of professionals
2. Continuity of care is fragile due to lack of policy, time, staff, and funding
3. Providing personalized care is challenging due to inflexible systems.

Motivation of professionals and involvement of parents act, on the other hand, as facilitators.

To improve the continuity and quality of transitional care for young people with intellectual disabilities (ID) and additional physical and/or mental challenges, improvements are needed at three levels:

System Level
Transitional care requires time, coordination, and alignment. Without reimbursement, this care quickly drops off the agenda, especially during staff shortages. Therefore, ensure structural funding for transitional care. Stable financing makes transitional care a standard part of the care process and should allow flexibility to provide person-centred care that reflects the needs and preferences of the young person and their family.

Organizational Level
Integrate transitional care into policy, scheduling, task allocation, and administrative systems. Do not treat it as an "extra"; consider it an integral part of care. Encourage collaboration between professionals and include transitional care in discussions with health insurers.

Practice Level
Collaborate, coordinate, and actively seek each other out. Transitional care requires team responsibility and a named worker to safeguard continuity. Ensure warm handovers, involve the young person and their family, and build sustainable networks with colleagues in both pediatric and adult care. Small investments in communication and coordination can make a big difference in the experience and outcomes of the transition for young people.

Recommendations for health insurers and policy makers

- Ensure structural funding for transitional care
- Allow flexibility for personalized care

Recommendations for healthcare organizations

- Develop an organization-wide policy for transitional care
- Embed transitional care in schedules, policies, and systems
- Promote and facilitate collaboration
- Integrate transitional care into contract negotiations with health insurers

Recommendations for healthcare professionals

- Collaborate actively
- Assign a named worker
- Invest in network building

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