Destination unknown: Parents and healthcare professionals' perspectives on transition from paediatric to adult care in Down syndrome

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Abstract

Background: Transitioning from paediatric medical care to adult care is a challenging process for children, parents and healthcare professionals. The aim of this study was to explore the experiences, concerns and needs of parents of children with Down syndrome and of professionals regarding this transition.

Method: A qualitative study was performed using semi-structured interviews with 20 parents of children with Down syndrome and six healthcare professionals.

Results: We showed that parents and professionals have concerns during each of the three distinct phases of transition (preparation, transfer and integration). Data disclose specific concerns regarding communication, continuity of care and rebuilding trust. We propose a framework for the transition to adult care.

Conclusions: The transition in medical care for children with Down syndrome should be flexible, patient-centred and coordinated together with patients and parents. Only in ensuring continuity of care will individuals with Down syndrome not get lost in transition.

KEYWORDS
adult care, Down syndrome, paediatric care, qualitative research, service provision, transition

1 | INTRODUCTION

Down syndrome, known as trisomy 21, is a complex congenital condition with typical appearance, intellectual disability and increased incidence of various physical and mental disorders (Capone et al., 2018; Weijerman & de Winter, 2010). Improvements in medical and social care have increased the general health and survival of individuals with Down syndrome into adulthood (de Graaf et al., 2011; de Graaf et al., 2020). Therefore, active continuous health management throughout life is needed for prevention, detection, and treatment of impairments (Capone et al., 2018; Weijerman & de Winter, 2010).

Healthcare for these individuals is sometimes organised in multidisciplinary outpatient clinics (Santoro et al., 2021; Skotko et al., 2013; Tenenbaum et al., 2008). In the Netherlands, care for children with Down syndrome is coordinated by paediatricians running multidisciplinary outpatient clinics, so called ‘Downteams’ (Peters et al., 2020). Around the age of 18 years, children make the transfer (transition) to adult care providers. For adults with Down syndrome, the care is provided by the intellectual disability physician together with the general practitioner (GP) in the Netherlands (Coppus, 2018). The intellectual disability physician is a specialist in the treatment and support of adults with intellectual disabilities and complex health
needs. Care models in other countries have been reported in the literature, with no evidence that one model is more effective than others. In Belgium, children with Down syndrome visit a paediatrician and at the age of 18 are followed up by the Medical Genetics department (Elsing et al., 2017). In the United States, children might only see a paediatrician and transition to see an internist or family medicine physician (Bull & Committee on Genetics, 2011).

Healthcare transition is defined as the ‘purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented care systems’ (Blum et al., 1993, p. 570). Jensen and Davis (2013) have identified three distinct phases in healthcare transitions: (1) preparation, (2) transfer, and (3) integration. Previous studies have shown that successful transition reduces the possibility of inconsistent medical care that might lead to increased hospitalisation, costs, and poor health outcomes (Corkins et al., 2018; Dimitropoulos et al., 2019; Goralski et al., 2017). Consistent with these studies, it is our experience that children with Down syndrome and their relatives often face barriers such as limited available information and lack of transparency (White et al., 2021) when transitioning from the multidisciplinary paediatric healthcare system to adult care (van den Driessen Mareeuw et al., 2020), that is often less family-centred and less multidisciplinary.

Despite increasing scientific attention to the transition of care for children with intellectual disabilities in general (e.g., Burström et al., 2017; Both et al., 2018; McGovern et al., 2018; Peron et al., 2018), only a few studies have been conducted on the transition of care for individuals with Down syndrome. These studies show that the transition falls short in multiple instances (e.g., Coppus, 2018; Nugent et al., 2018). It has been found that (parts of) the medical history of patients is often lost during transition (Jensen & Davis, 2013) and only 30% of children with Down syndrome have a complete transition plan available (Bhaumik et al., 2011; van den Driessen Mareeuw et al., 2020). Without a plan, the transition to adult care is haphazard and inefficient (Nugent et al., 2018; Viner, 1999). Jensen and Davis (2013) showed that 48% of adolescents with Down syndrome are lost during the transfer to adult care, entailing a period of years without regular medical attention. Furthermore, Henderson et al. (2007) found that many adults with Down syndrome do not receive regular health checks that are formalised in (regional) protocols. However, this is also related to poor compliance with health guidelines by adults with Down syndrome as shown by various studies (e.g., Capone et al., 2018; Santoro et al., 2021). In addition, professionals also face barriers in organising the transition to adult care. For example, it is a time consuming process due to the involvement of multiple healthcare professionals from distinct healthcare institutions (Corkins et al., 2018; van den Driessen Mareeuw et al., 2020), healthcare professionals requiring more insight into the needs and wishes of parents and patients (Bindels-de Heus et al., 2013; Goralski et al., 2017; White et al., 2021), and professionals experiencing poor communication between paediatric and adult healthcare professionals (Goralski et al., 2017).

Therefore, the aim of this study was to explore the experiences, concerns, and needs of parents of children with Down syndrome and of healthcare professionals, regarding the transition from paediatric to adult care in the Netherlands. We explore how both groups perceive the transition from paediatric to adult care in each transition phase. We present recommendations on optimal care for individuals with Down syndrome during the transition from paediatric to adult care.

2 | METHODS

2.1 | Study design and research team

The consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007) were used to design this qualitative exploratory study involving semi-structured interviews with parents of children with Down syndrome and with healthcare professionals (Appendix S1). Ethical approval for this study was obtained from the Ethics Review Board of Tilburg University [EC-2017.60t].

The research team consisted of two paediatricians from two different hospitals in the Netherlands with expertise in Down syndrome and transition of care (VB and JB), an endowed professor in the organisation of integrated care and health services research (BM), two master’s students with expertise in health service research and qualitative research (LB and JR) and a researcher with expertise in the organisation of multidisciplinary care for children with Down syndrome (VP).

2.2 | Participants

Recruitment of participants was carried out by two paediatricians based on purposive sampling logic. The purposive sampling technique is the deliberate choice of an individual and involves identifying and selecting individuals that are especially experienced in the phenomenon of interest (Patton, 2002). Using e-mail, face-to-face requests, and telephone, the paediatricians invited potentially interested parents of children with Down syndrome. Parents of children with Down syndrome were considered as potential participants when their child was maximally 3 years before the age of transition, when their child was in transition, or when their child had been in transition maximally 7 years previously (range of age 15–25 years).

Parents were asked to respond to the paediatrician within 1 month regarding their informed consent and their willingness for disclosure of contact details to the first author (VP). The first author (VP) contacted the participants and scheduled the interviews together with LB and JR. The healthcare professionals were recruited via telephone and face-to-face requests by the paediatricians in the study team. When the healthcare professionals gave consent for their contact details to be disclosed, the first author (VP) contacted the professionals and scheduled the interviews together with LB and JR. Written informed consent from all participants was obtained prior to participation.

2.3 | Data collection

To let the participating parents of children with Down syndrome feel at ease, they could choose between a home visit or a hospital visit for
the interview. All interviews with healthcare professionals took place at the hospital. The interviews were conducted by JR and LB and took place between March 2019 and December 2019.

The semi-structured interviews lasted 45 to 60 min and involved open-ended questions regarding the perceived difficulties and concerns in relation to the transition from paediatric to adult care (Appendices S2 and S3). The interviews were audio-recorded and transcribed verbatim. Data saturation happened after 20 interviews, as no new themes emerged from the data gathered between interview 19 and interview 20. Generally, reaching saturation, meaning that new interviews do not yield new data on the interview topics, is considered sufficient for validity (Guest et al., 2006). For the sake of completeness, the researchers agreed to perform the remaining scheduled interviews (one interview with a paediatrician, one interview with an intellectual disability physician, four interviews with parents). All interviews were included in the dataset. Participants were asked to review their own transcript to improve the reliability of our interpretations. This was done to check for accuracy and resonance with the experiences of the participants (Birt et al., 2016). No changes were made to the transcripts.

2.4 | Data analysis

A thematic analysis of the content was carried out (Braun & Clarke, 2006). Analysis began with the coding of three interviews independently by two researchers (LB and JR), using the initial coding scheme that was developed based on theoretical constructs. The codes were discussed between three researchers (VP, LB and JR) until consensus was reached. This resulted in a final version of the coding scheme which was used to code all the interviews. Codes were grouped into themes and, while doing this, we discovered that themes belonged to each of the respective transition phases. To get more detailed information about the complete transition process, the themes were sorted according to the three transition phases as identified by Jensen and Davis (2013).

3 | RESULTS

The study sample consisted of 26 participants (20 parents of 20 children with Down syndrome and six healthcare professionals (Table 1)). During analysis, themes arose that contained the most relevant experiences, concerns, and needs of parents and healthcare professionals. We have structured the results section according to the three transition phases of Jensen and Davis (2013) (preparation, transfer, and integration) and the respective themes identified per phase.

### 3.1 | Preparation phase

In the Netherlands, paediatric outpatient clinics organise multidisciplinary team appointments for children with Down syndrome, including a visit to medical, paramedical, and nonmedical specialists, all on the same day. When the child becomes an adult, transition from multidisciplinary paediatric care to less multidisciplinary adult care is made. However, this transition is not a standard feature of all the paediatric outpatient clinics. Consequently, the transition of care is discussed on an ad hoc basis between the paediatrician and the intellectual disability physician, resulting in ill-prepared individuals, parents, and healthcare professionals.

#### 3.1.1 | Consistency

The preparation phase starts with the transition being discussed by the paediatrician during a multidisciplinary team appointment. The paediatricians stated that they only start to discuss transition with parents when the child is approximately 17 years old, and that a formal transition protocol was not available. A Dutch guideline on the medical management of adults with Down syndrome is under development and the transition to adult care is an essential part of this guideline. For the time being, each paediatrician organises the transition to adult care in its own informal way, as such reinventing the wheel for each patient. Some start the transition at the age of 14, whereas others start the transition at the age of 17: ‘Since there is no protocol readily available, I have created my own workaround. However, for each patient I deviate from this workaround given the patients’ circumstances, resulting in inefficient work’ [Paediatrician 2]. Parents also recognise the issue of lack of consistency, finding it hard to collect information from parents whose children had already finished the transition: ‘It feels like every patient trajectory is unique. Each parent that I have spoken about the transition tells a completely different story’ [Paediatrician 2].

#### Table 1 Demographics of participants

| Parent of children with Down syndrome (N = 20) | Healthcare professional (N = 6) |
|---------------------------------------------|--------------------------------|
| Gender of parent (female; male) 17; 3 | Gender of healthcare professional (female; male) 3; 3 |
| Children with Down syndrome (N = 20) | Occupation healthcare professional |
| Gender of the child (female; male) 8; 12 | Intellectual disability physician 3 |
| Age of child in years (mean, SD) 20.05; 3.66 | Paediatrician 3 |
| Healthcare professional (N = 6) | Employer healthcare professional |
| Occupation healthcare professional | Care organisation for people with intellectual disabilities 3 |
| Intellectual disability physician 3 | Hospital 3 |
| Paediatrician 3 | Work experience healthcare professional |
| | 0–10 years 1 |
| | 10–20 years 4 |
| | 20–30 years 1 |
different story’ [Parent 9]. This shows that the outcome of the transition is different for each individual and their parents.

3.1.2 | Communication

Parents expressed the view that little information was available about the organisation of adult care. They indicated that they would like to receive more information, not only verbally, but also in terms of brochures or checklists instead of them having to figure out everything themselves. The lack of communication resulted in negative feelings towards the transition: ‘... it [healthcare transition] overwhelmed me’ [Parent 13]. The paediatricians also admitted that they did not have any material to share with parents: ‘I do not have any information or brochures about the transition to adult care that I can give to parents’ [Paediatrician 1]. Parents said they felt nervous about the healthcare transition or were unwilling to engage because they were uninformed and, therefore, concerned about the process. One parent stressed that: ‘The first time I heard about transition I found it very difficult, and I did not know what to do. This was quite problematic because I only had one more year before the transition would start’ [Parent 11]. If the parents had been informed a few years earlier, they could have prepared their children and themselves better.

3.2 | Transfer phase

The actual transfer is a one-time event and involves several individuals: paediatrician, intellectual disability physician, the individual with Down syndrome, and parents. However, since there is no transition protocol or guidelines available, there are several possible approaches to transition from paediatric to adult care.

3.2.1 | Approaches to transition

Parents and healthcare professionals recognised three approaches of transition to adult care. The first approach was described as a ‘warm handoff’ in which the paediatrician, the intellectual disability physician, and the parents with their child were physically together at the actual moment of transition to adult care and discussed the entire medical situation. The second approach was characterised as a ‘cold handoff’ in which the paediatrician, the parents and their child were physically together and only briefly met the intellectual disability physician without discussing medical information. The paediatrician and intellectual disability physician then had a separate meeting to discuss medical details. The last approach was basically a ‘general handoff’ in which the paediatrician transfers all the child’s documentation to the intellectual disability physician. Then, the first time the child and parents visited the intellectual disability physician they discussed this documentation. Parents expressed a preference for a warm handoff because they felt more comfortable with this type of transition. One parent argued that this would help to reduce the amount of repetition: ‘If I am being honest, I would prefer a warm transfer since this tells so much more than just some data. This also saves me from re-telling the same story’ [Parent 12]. Another parent stressed that a warm handoff would help to involve their child during this important moment of their life: ‘I think this [warm handoff] is the best way to get to know each other and in this way the children can also be involved because the doctor can ask her questions’ [Parent 3]. The paediatricians also said that they saw added value in a warm handoff: ‘You go through a whole process with these people [children with Down syndrome and their parents]. These people have been visiting me [paediatrician] and the Downteam for so long that it is good that a summary is given of what has happened in the past, the points that you think should receive extra attention and that parents also hear that we are passing that on’ [Paediatrician 1]. However, parents also realised that this warm handoff might be difficult to realise in terms of time, planning, and costs: ‘I prefer having a warm handoff, but I do understand that this [warm handoff] is not always possible: time, planning, and money-wise’ [Parent 2]. The paediatricians highlighted that they were pessimistic about the actual realisation of a warm handoff given certain barriers: ‘Yes on paper the warm handoff might sound like the best solution, but in practice it might turn out different. Payment systems and hospital policy might hinder us in the actual realization of this kind of transition’ [Paediatrician 3]. Healthcare professionals emphasised that they tried to fully accommodate patient preferences, but that this was simply not always possible due to constraints: ‘Sometimes we are limited by the system; if there is no incentive to organize a warm handoff, my manager will not be happy with me organizing such a complicated meeting’ [Paediatrician 2].

3.2.2 | The need for coordination

Professionals stressed the importance of good coordination in the process of transition to adult care. This is especially important because the paediatrician often acquires an overview of the complexity of different health problems facing the child with Down syndrome and helps to coordinate the health care needed. Lack of coordination could lead to increased health risks for children with Down syndrome. Good coordination could prevent conflicting treatments or unnecessary duplication from multiple healthcare professionals. One parent emphasised this: ‘My son has a variety of unexplained and unexplored health issues. The paediatrician is well aware of this, but I am hesitant about who will take this responsibility in adult care’ [Parent 1]. According to parents, healthcare professionals should have connections with actors outside the medical field such as school and social services. In summary, coordination of healthcare is of great importance for individuals with Down syndrome, especially during the transition.

3.3 | Integration phase

In contrast to paediatric care, most adult care does not take place in a multidisciplinary setting. Most parents mentioned that their grown-up
child visited an intellectual disability physician at a care facility for people with intellectual disabilities. Some parents also mentioned that their GP served as the main healthcare professional for their grown-up child. Parents and professionals expressed a range of concerns about this phase.

3.3.1 | Rebuilding trust

According to parents, it took a long time to get to know the intellectual disability physician and that, at the outset, they needed to provide additional information. This medical and personal information had got lost during the transition so parents felt that they had to start all over again: ‘There is no communication between organizations it seems. When visiting another care provider, I need to tell the same story every time’ [Parent 7]. Personal contact in which the intellectual disability physician or GP had the medical history of the patient and showed interest in the patient, also beyond the medical aspects, would contribute to a feeling of comfort and safety in the new setting. This could potentially lead to improvements in the continuity of care for these patients.

3.3.2 | Continuity of care

Parents and healthcare professionals also stressed the need for continuity of care. Their experience was that many changes in care providers impeded good coordination of care and the establishment of an essential trusting relationship. Parents often mentioned that before their child turned 18, they had limited contact with their GP because they considered the paediatrician as their ‘main’ physician. The GP is therefore less involved in the care of children with Down syndrome under the age of 18. This was confirmed by one of the paediatricians ‘Many parents try to avoid the general practitioner during childhood’ [Paediatrician 1]. After the age of 18, children and parents can no longer rely on the assistance of a paediatrician who simply must bow out of the care arrangement. As a result, continuity of care is not guaranteed, and parents often end up feeling lost in the transition process. Both paediatricians in the study believe that appointing a person who coordinates the transition might solve this.

3.3.3 | Holistic approach

Parents pointed out that the intellectual disability physician mostly talked about health and medical aspects, whereas the paediatrician also paid attention to other considerations. For example, one parent mentioned: ‘Because my child is never sick, the paediatrician always asked about her overall well-being and other things that my child finds important. I miss that with the intellectual disability physician’ [Parent 20]. If the intellectual disability physician or GP were to have the full medical history and showed personal interest in the patient, it would contribute to a feeling of comfort and safety. This could potentially lead to improvements in the continuity of care for these patients. Parents did not question the skills and knowledge of the professionals, but it was rather the approach towards their grown-up child. The intellectual disability physicians argued that they know how to treat the patient, but since the transition to adult care is ill-structured, they felt they were starting with a disadvantage. The intellectual disability physicians argued that they try to provide patient-centred care, but that they need to ask medical health questions to ‘check’ the patient and therefore have less time for other aspects: ‘I only have limited time during a visit with the patient in which I have to perform the mandatory checks. Unfortunately, a lot of time is already ‘wasted’ with those checks leaving less room for other issues’ [Intellectual disability physician 1].

4 | DISCUSSION

The aim of the current study was to explore the experiences, concerns, and needs of parents of individuals with Down syndrome, and those of healthcare professionals, regarding the transition from paediatric to adult care. We provide healthcare professional- and parent-driven data, allowing us to provide recommendations for the transition from paediatric to adult care based on the three transition phases (preparation, transfer, and integration).

Although the needs of individuals with intellectual disabilities and their parents during the transition of care have been recognised (Both et al., 2018; van den Driessen Mareeuw et al., 2020), only a limited number of studies have incorporated their perspectives. Our study shows that the perspectives of parents of children with Down syndrome is aligned with the perspective of healthcare professionals and provides a fresh and comprehensive view on this topic. As such, we address the call from recent studies to provide patient- and parent-driven data in addition to professional-driven data (Corkins et al., 2018; White et al., 2021).

Continuity of care was highlighted by professionals and parents as one of the central themes deserving more attention. The importance of continuity of care is confirmed in previous studies (Dyke et al., 2013; Haggerty et al., 2003; Miller et al., 2009). Acknowledging the nature of complex chronic health conditions, such as Down syndrome, various forms of continuity can be considered for transitions models facilitating transition from paediatric to adult care. Haggerty et al. (2003) identified three types of continuity that exist in almost all healthcare settings: informational, relational, and management continuity. Based on our empirics, we recognise these three types of continuity and relate them to each of the transition phases showing how a well-organised transition can improve continuity of care. For example, relational continuity is recognised in the preparation phase, during the ongoing years of relationship between paediatric care providers, parents, and patients and is highly valued by the parents. However, this relational continuity is at risk when parents are not informed at an early stage about the upcoming transition. Both parents and professionals are aware of the importance of early preparation for transition (Both et al., 2018; Peron et al., 2018), while our empirics show that
Early transition preparation does not usually happen. This early transition preparation can be realised, for instance, by an information session for parents in the pre-transition group, when children with Down syndrome are around the age of 16, or by the provision of brochures and leaflets with information on healthcare transition. A lack of management continuity has been observed because the paediatrician, GP, and intellectual disability physician all have separate care plans, separate electronic records, and work in different institutions. The literature suggests that management continuity can be realised by means of written healthcare transition protocols that are applicable to all involved healthcare professionals (Miller et al., 2009).

Informational continuity was observed in the transfer phase. Our participants indicated their belief that a warm handoff would lead to enriched information transfer and would kick-start the relationship with the adult healthcare provider. When a warm handoff is not feasible, the paediatrician and adult care provider should at least discuss each patient together or develop a comprehensive format for the referral letters (Coppus, 2018). This would ensure that no information is lost during transition and would result in information continuity.

To ensure continuity of care before, during, and after the transition, and to make the overall transition process more transparent, we propose the use of a framework for the transition from paediatric to adult care that follows Figure 1. Our framework is based on our empirical findings and substantiated by scientific literature on care models for healthcare transitions in chronic conditions (e.g., Both et al., 2018; Goralski et al., 2017).

It starts with the preparation phase (when the child is around the age of 16) where paediatricians should explain the forthcoming transition to children with Down syndrome and their parents. The age of 16 is debatable, since our empirics and previous research do not provide conclusive evidence for the age at which transition should start (e.g., Bull & Committee on Genetics, 2011; Got Transition, n.d.; Goralski et al., 2017; Mahan et al., 2017; van Cleve et al., 2006). It is important that this is not simply an announcement, but rather a two-way conversation where paediatricians make clear what the transition entails, why it is necessary, what the consequences are, and where the parents can retrieve information and ask questions. This explanation must be given verbally, but it is also advisable to give relatives a brochure or pamphlet that provides additional information on preparing for the transition and signposts healthcare professionals/organisations who will be able to provide care when their child becomes an adult. This is important because children and parents themselves should be the ones who decide which professional or organisation is responsible for their care (Goralski et al., 2017).

In the transfer phase, it is important that the medical and personal information from the paediatrician is transferred to the adult care provider, and that parents are aware which information is being transferred. It is desirable to communicate expectations clearly, for example, that the role of the GP will increase. We propose that there might be a possible role for a transition coordinator who guides transition of care. This professional would have an up-to-date overview of the complexity of different health problems of the child with Down syndrome, an overview of the different healthcare providers involved, and help to find the healthcare needed. Literature shows that the presence of a coordinator who coordinates the entire process increases the chance of the transition’s success (Bindels-de Heus et al., 2013; Dimitropoulos et al., 2019; Goralski et al., 2017; van den Driessen Mareeuw et al., 2020; Viner, 1999; White & Cooley, 2018). In the integration phase, communication with the GP needs to intensify. It is essential for the success of the transition of care that GPs and the intellectual disability physicians communicate regularly. Without frequent communication, overlap or gaps in healthcare provision can
arise (Peters et al., 2020) which does certainly not enhance continuity of care. Finally, it is important that the parties involved evaluate the transition to improve future transitions and ensure that all the necessary information about patients is transferred. This will enhance the continuity of care even further.

4.1 | Strengths and limitations

Our study focused on the transition from paediatric to adult care for individuals with Down syndrome in the Netherlands. This provided the opportunity for an in-depth analysis of the way the transition is organised in the Netherlands and resulted in a detailed understanding of the organisation of transition to adult care. To the best of our knowledge, previous literature provides limited evidence of how the transition is organised in other countries. As a result, it is unknown whether the findings from the Netherlands are generalizable outside of this setting. Future research should investigate the transition of care and explore whether our proposed warm handoff is feasible in other countries. Although we tried to involve parents of children with Down syndrome from as many different backgrounds as possible, all parents still came from the same region (North-Brabant) and most parents were current and past patients of the paediatricians in the study team. Additionally, all healthcare professionals interviewed had experience with Down syndrome care provision and worked in the same, large, region in the Netherlands but at different healthcare institutions. Therefore, our sample of six healthcare professionals might not be representative of the experiences and concerns of parents and healthcare professionals caring for individuals with Down syndrome in other parts of the world. Nevertheless, previous research has shown that the organisation of care for individuals with Down syndrome is fairly similar throughout the Netherlands (Peters et al., 2020). In addition, parents were considered as proxies for children with Down syndrome in our study. Although parents are often used as proxies in paediatric care, differences between children and their parent proxy have been reported (Eiser & Varni, 2013). To fully capture the transition to adult care, future research should not only include parents and healthcare professionals in other regions in the Netherlands, but also include the perspectives of individuals with Down syndrome. In addition, we recommend performing a follow-up study to show whether our proposed framework is feasible in current healthcare provision for individuals with Down syndrome. If this study proves to be successful, this framework could also be applicable for individuals with intellectual disabilities like 22q11.2 deletion syndrome (Tobia et al., 2018). It might also prove useful for people going through similar multisystem manifestations such as congenital heart disease (Burström et al., 2017).

5 | CONCLUSION

We show that parents and healthcare professionals have concerns during each phase of the transition, especially regarding communication with patients, continuity of care, and rebuilding trust. We provide a framework for the transition from paediatric to adult care and highlight that the transition should be flexible, patient-centred, and developed with the involvement of individuals with Down syndrome and their parents. Only in doing so, can we ensure continuity of care and guarantee that individuals with Down syndrome do not get lost in transition.

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DATA AVAILABILITY STATEMENT

Data cannot be shared publicly because the data contain potentially identifying or sensitive patient and healthcare professional information that cannot be de-identified. Data are available upon request from the Ethics Review Board of Tilburg University (contact via erb@tilburguniversity.edu) for researchers who meet the criteria for access to confidential data.

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