9 On Your Own Feet: A Practical Framework for Improving Transitional Care and Young People's Self-Management

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9.1 Introduction

> *The basics of transition are simple and common to all diseases and conditions. Firstly, prepare young people and their families well in advance for moving from paediatric to adult services and ensure they have the necessary skillset to survive and thrive there. Secondly, prepare and nurture adult services to receive them. Thirdly, listen to young people's views (*Viner 2008*)*, p. 160.

These three "simple" recommendations have guided the *On Your Own Feet* research and innovation programs in the Netherlands from 2003 onwards. Worldwide, numerous researchers have addressed these basics of transition in care by studying different aspects of transition of care, such as young people's transfer readiness, their views and experiences as well as ways to improve healthcare practice. After an initial focus on the preparation of young people and on practices in pediatric care, attention is now shifting to include consideration for transition outcomes in young adulthood and stronger involvement of and collaboration with healthcare providers for the young adult population. Questions of what are the good practices to support young people in their transition have come up, and with this, a more conceptual question arose: what is successful transition? (Sattoe et al. 2017).

Different studies and numerous guidelines have proposed core elements, beneficial features, or statements on good transitional care and successful transition (Betz et al. 2016a; Colver et al. 2018; Fair et al. 2018; Foster et al. 2017; Got Transition 2014; Hergenroeder and Wiemann 2018; Mazur et al. 2017; National Institute for Health and Care Excellence (NICE) 2016; Schultz and

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Smaldone 2017; Surís and Akré 2015; White et al. 2018). Yet, a comprehensive overview of core elements and related good practices is still lacking.

This chapter deals with the experiences from the *On Your Own Feet* quality improvement programs during the past 10 years in the Netherlands, using a framework that encompasses eight key elements of transitional care described below. We provide an overview of suitable evidence-based interventions that nurses could apply during the preparation and follow-up of adolescents with long-term, chronic conditions in their journey to adulthood and their transfer from pediatric to adult care.

9.2 The *On Your Own Feet* Framework

Guided by the three basic recommendations of Viner (Viner 2008), we developed the framework for the national *On Your Own Feet Ahead!* quality improvement program in 2008 (Fig. 9.1). The framework addresses eight key elements of good

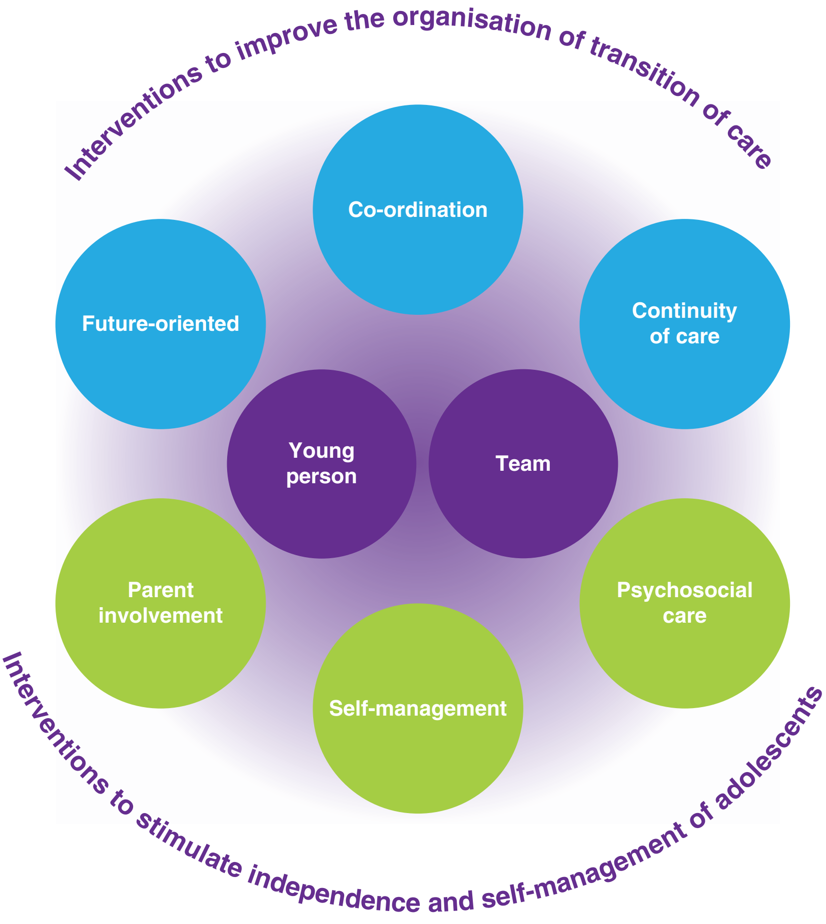

Fig. 9.1 Framework *On Your Own Feet* (www.opeigenbenen.nu)

transitional care, divided into three core categories: (1) interventions to improve the organization of care; (2) interventions to stimulate independence and self-management of adolescents; and (3) collaboration with young people (and their families) and within the multidisciplinary team of professionals, working both in pediatric care and adult care. Since children and young people should be supported in having their voices heard in matters that directly affect their lives (Coyne and Gallagher 2011; van Staa 2012), partnerships between professionals and young people are considered as vital for successful transitional care (Got Transition 2014; National Institute for Health and Care Excellence (NICE) 2016). This is why we placed collaboration between the young person and the multidisciplinary teams from pediatric and adult care at the heart of the framework.

The framework has been used in the Action Program *On Your Own Feet Ahead!* (2008–2012), in which 30 teams from Dutch hospitals and rehabilitation centers were guided in their improvement of transitional care. The framework was also used in the subsequent research projects, such as the *Self-management and Participation Lab* (SPIL) program (2012–2016) and the research and quality improvement initiative *Better Transition in Type 1 (T1) Diabetes* (2016–2018). In this project, 18 diabetes teams from 15 Dutch hospitals participated. The framework also served as base for the Transition Toolkit offered on the program website www.opeigenbenen.nu. Providing short descriptions of interventions, practice-based information on experiences, and references to scientific and professional literature, the Transition Toolkit serves as a guidance for useful and practical interventions for professionals working in Dutch adolescent healthcare. Documents are available for free downloads as much as possible. With over 50,000 unique views yearly, the website and the toolkit have found their way to widespread use in Dutch adolescent healthcare.

Recently, the framework was validated by comparing the core elements with recent reviews (Schultz and Smaldone 2017), international guidelines (Got Transition 2014; National Institute for Health and Care Excellence (NICE) 2016), consensus statements (Mazur et al. 2017; Surís and Akré 2015; White et al. 2018; American Academy of Pediatrics et al. 2002; Cooley et al. 2011; Betz 2017), and proposed beneficial features (Colver et al. 2018) for transitional care. The framework covers all key elements proposed in these documents. We present this analysis in the **Appendix** to this chapter. By focusing on organizational aspects such as co-ordination and continuity of care, combined with attention to self-management and active youth involvement, it seems to be even more “complete” than other frameworks. For example, self-management is not included as a core element of transition in the NICE guideline (National Institute for Health and Care Excellence (NICE) 2016), and the need for a holistic, integrative approach and attention to psychosocial issues is not specifically mentioned in the Six Core Elements of Got Transition (Got Transition 2014; White et al. 2018). Also, while most authors consider the active participation of the young people and the teams of both adult and pediatric care as vital elements of good transitional care, this is not always explicitly stated, like in (Colver et al. 2018; Schultz and Smaldone 2017). The framework also “fits” the overarching themes extracted in a review of transition experiences of young people with diabetes: (1) discontinuity of care, (2) renegotiating responsibility for condition management, and (3) psychosocial and practical issues (Sheehan et al. 2015).

It should be mentioned, however, that our framework is limited to the interactions between the young person (and his/her family) and the multidisciplinary team. It does not address the necessary preconditions in the wider socio-political context, such as:

- *Laws and regulations*: both national and international;
- *Quality standards*: a national quality standard providing norms for good quality (transitional) care/developmentally appropriate adolescent healthcare;
- *Information communication technology facilities*: a joint electronic health record that facilitates transition continuity of care by enabling patient data sharing;
- *Education and training* in adolescent healthcare issues both in interdisciplinary graduate and postgraduate educational programs;
- *Management*: a positive and stimulating environment for transition innovation, person-centered care and research;
- *Financing*: the reimbursement of joint consultations between pediatric and adult specialty or primary providers, extra attention for preparation and support for young people and their families for transition, standard provision psychosocial care.

Like in the Chronic Care Model (Bodenheimer et al. 2002), one could envisage such contextual factors to form an extra layer around the basic framework. Since our quality improvement programs targeted the (intermediate) team level only, this has not restricted the usefulness of the model in practice. In fact, our goal was to show professionals the way to initiate and to improve their transitional care arrangements, even in the absence of national policy guidelines and consensus statements.

In the next two sections, first, the national quality improvement programs conducted in the Netherlands are presented, using the framework described above. Then several key interventions are discussed, each connected to one of the core principles.

9.3 Quality Improvement Programs for Transitional Care

Two quality improvement programs conducted between 2008 and 2018 (*On Your Own Feet Ahead!* and *Better Transition in Diabetes*) applied the Breakthrough Series improvement and implementation strategy using the principles of the Plan–Do–Study–Act (PDSA) cycle (Institute for Healthcare Improvement (IHI) 2003). The Breakthrough strategy helps organizations close a gap between what is known and what is done by creating a structure (the Quality Improvement Collaborative) in which organizations can easily learn from each other and from recognized experts.[1]

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[1] A Breakthrough Collaborative is a structured 10–12 month program, designed to help organizations come together to achieve sustainable change in a specific topic area. The collaborative is structured into a series of learning events where teams commit to coming together to learn improvement theory and share their work, interspersed with action periods where change ideas are tested in PDSA-cycles by teams (IHI, 2003). The learning collaborative strategy has also been used in US programs to improve transitional care (Got Transition; White et al. 2018).

Table 9.1 Overview of the two national quality improvement programs conducted in the Netherlands (2008–2018)

	On Your Own Feet Ahead!	*Better Transition in T1 Diabetes*
Period	2008–2012 (three rounds)	2016–2018 (one round)
Action period per round	12–15 months	12–18 months
# participating teams/ healthcare organizations[a]	22/22[a]	18/15[b]
Chronic conditions	Various[c]	DM1
Nurse project leaders	15/22 (72.7%)	11/15 (73.3%)
Evaluation research	Yes (prospective)	Yes (retrospective)
Aim of the research	To establish the effects of the action program on transitional care provision as perceived by adolescents, parents, and professionals	To gain insight into the added value of a transition clinic (and other essential elements of transitional care) compared to direct hand-over care
Transitional care arrangements present at start of the program	No	Yes, in about half of the teams
Active participation of young people	Encouraged, not centrally organized	Youth panel conducted site visits and played an important role in the program
Funding	Dutch healthcare insurers' innovation fund; Dutch Kidney Foundation; and the NAD (National Action program Diabetes	Fund NutsOhra and Diabetes Fund
Financial contribution required from teams	€ 10,000 each in round 2 and 3	None required

[a] Additionally, 8 rehabilitation centers participated in the program adding up to 30 teams

[b] Due to hospital merges, several teams worked in different locations while resorting under one organization. A total of 18 teams were involved in the quality improvement program (15 hospitals), of which 15 teams (in 12 hospitals) participated in the research

[c] Teams working with adolescents with diabetes mellitus type 1 ($n = 11$), chronic kidney diseases and transplantation ($n = 4$), juvenile idiopathic arthritis ($n = 2$), cystic fibrosis ($n = 2$), congenital urological conditions ($n = 1$), HIV ($n = 1$), and neuromuscular disorders (one home ventilation support team)

Our programs were short-term learning systems that brought together multidisciplinary teams from hospitals and rehabilitation clinics all over the Netherlands that volunteered to seek improvement in transitional care. Using the framework, participating professionals based their actions on perceived bottlenecks in care delivery (Fig. 9.1). Table 9.1 provides information on both programs.

9.3.1 Action Program *On Your Own Feet Ahead!*

In the Action Program *On Your Own Feet Ahead!* (2008–2012), 30 teams participated in three rounds (one pilot round and two dissemination rounds) with 10 teams each. These teams had been carefully selected for their intrinsic motivation. Professionals were not reimbursed for their time investment. Eight of the 30 teams came from rehabilitation clinics and 22 from hospitals. The rehabilitation teams are not included here as their care provision and transition services differ from hospital transitional care services. Professionals from both pediatric and adult care were represented in most teams, while nurses and nurse specialists played leading roles in over 70% of teams. At baseline, before the start of the Action Program, none of the participating hospitals or rehabilitation centers had transitional care arrangements in place and preparation for transfer and collaboration with adult healthcare was virtually nonexistent (van Staa et al. 2015).

During the first meeting at the start of each round, teams evaluated the care provided by them and developed a specific plan of action using the framework. Professionals discussed their individual self-evaluation of the teams' performance on the eight core elements of the framework until consensus was reached upon the goals they wanted to achieve. During the one-year program, the teams implemented local interventions with support from consultants from the first step (setting goals) to the final step (evaluating the effects of efforts to improve care) of the program. Co-creation with patients and parents was strongly encouraged. In addition, team members participated in national learning sessions in which team building, collaboration, and dealing with barriers in the local settings were addressed and experts (both professionals and patients) shared their experiences with improving adolescent care. During the program, professionals were supplied with formats, instruments, and descriptions of interventions. A toolkit with descriptions of suitable and promising interventions was made available on the project's website (www.opeigenbenen.nu).

The Action Program *On Your Own Feet Ahead!* was evaluated by an independent research team. Findings from this research project demonstrated that transitional care interventions may improve the organization and co-ordination of transitional care and better prepare adolescents for the transition to adult care within a 1-year period. By setting specific goals based on perceived bottlenecks, the Breakthrough strategy helped to improve transitional care delivery (Nieboer et al. 2014). The use of a bottom-up approach, meaning that teams developed their own plan of action and decided which interventions suited their situation best, seemed to be a key aspect because it augmented professionals' autonomy and ownership with respect to the selection, testing, and adjustment of interventions to local settings. Strong features of this strategy are the efficient use of participating experts and the exchange of best practices among the participating teams (Schouten et al. 2008).

The evaluation study established that, at the start of the Action Program, adolescents rated current care significantly worse than did parents on opportunities to make their own decisions and be seen without parents present (Sonneveld et al. 2013), using the Mind The Gap scale (Shaw et al. 2007). Adolescents also rated healthcare providers' current social skills like talking, listening, showing understanding, and honesty lower than did parents. Adolescents were more satisfied than their parents about transitional care process aspects such as co-ordination and communication between providers, but both groups indicated that the care process offers most room for improvement (biggest gap scores, i.e., differences between "best care" and "current care"). Providers reported other input in their evaluation of the project, such as adolescents' lack of responsibility regarding self-care and parents' difficulties with ceding control to their children. According to providers, shortcomings in the care process with respect to guidelines, protocols, and co-ordination were most prevalent (Sonneveld et al. 2013).

After the 1-year period, the professionals indicated improvement on all bottlenecks for transitional care (Table 9.2, taken from (Nieboer et al. 2014)), while patients reported that transition programs effectively improved some aspects of the organization of care. Improvements were reported in providing opportunities for adolescents to visit the clinic alone and to decide who should be present during consultations. These improvements were closely linked to the core interventions implemented in most hospital teams (e.g., encouraging independent consultations). Since not all implemented interventions are directly noticeable for patients, changes in the system of care delivery are known to be experienced first by professionals, followed by patients (Nieboer et al. 2014). The patient surveys after 1 and 2 years indeed demonstrated that the number of adolescents reporting independent behaviors during consultations increased significantly and that more non-medical topics were being discussed (van Staa et al. 2015).

Table 9.2 Bottlenecks in transitional care perceived by professionals participating in the Action Program *On Your Own Feet Ahead!* ($n = 72$), (Nieboer et al. 2014)

	Mean (SD) at T0	Mean (SD) at T1	Change (T0–T1) (SD)	*p*
No joint mission between pediatric and adult care	3.4 (1.0)	1.8 (0.6)	1.6 (0.9)	<0.001
Parents have trouble ceding control to adolescents	3.1 (0.7)	2.6 (0.6)	0.5 (0.7)	<0.001
Lack of co-ordination between pediatric and adult care	3.0 (0.8)	1.8 (0.4)	1.2 (0.8)	<0.001
Adolescents take too little responsibility for self-care	2.9 (0.7)	2.5 (0.5)	0.4 (0.6)	<0.001
Lack of resources for joint care services	2.7 (0.9)	1.8 (0.6)	0.9 (1.0)	<0.001
Psychosocial problems of adolescents	2.7 (0.5)	2.5 (0.5)	0.2 (0.5)	0.027
Non-compliance of adolescents with therapy	2.7 (0.7)	2.4 (0.5)	0.3 (0.6)	<0.001
Social participation of adolescents	2.3 (0.6)	2.2 (0.6)	0.2 (0.5)	0.005

SD standard deviation, *T0* beginning of *On Your Own Feet Ahead!* quality improvement program, *T1* 1 year later

Only data from respondents who completed the questionnaire at both T0 and T1 were included in the analyses

9.3.2 Better Transition in T1 Diabetes Project

Five years later, the *Better Transition in T1 Diabetes* project (2016–2018) applied a similar bottom-up approach for inducing and sustaining change. The main difference was that three teams had already participated in the Action Program, while several others had already implemented transitional care interventions such as transition clinics before the program started. The evaluation study of this program did not aim to demonstrate effects of the program, but rather to provide evidence about the effectiveness of certain transitional care interventions.

Therefore, a controlled study was undertaken to gain insight into the added value of a transition clinic/transition program compared to usual (= direct hand-over) care (without a transition program) (Sattoe et al. 2016). The study employed a mixed-methods design and involved a range of qualitative and quantitative research efforts to evaluate outcomes of all participating diabetes teams (Table 9.3). In the quantitative study, all patients who had transferred to adult care 2–4 years prior to data collection were recruited to participate which involved a retrospective chart review of their medical records two years before and two years after transfer and completing a survey about their transfer experiences. Approval was obtained from all hospital ethics review boards; participants were informed about the goals of the research and those willing to participate in the study gave consent. One hospital withdrew from the program due to staff shortages and for logistical reasons; two hospitals did not participate in the research, leaving 12 hospitals in the study. Several organizations had recently merged and provided care at varied locations with different teams of healthcare providers. All multidisciplinary teams consisted of both pediatric and adult care providers: involving a total of 165 professionals. Of these, 62% worked in pediatric care and 53% in adult care; 30 professionals worked in both settings. Among the professionals, there were 102 diabetes specialist nurses or nurse specialists, 50 medical specialists (including pediatricians and endocrinologists), 30 dieticians, and 17 psychologist or social workers. In two-thirds of the teams, the local project leader was a nurse.

In the first phase of the evaluation study, a national survey administered to 156 professionals (63% nurses) working with young people with diabetes in 58 different clinics (43% worked in adult care; the rest in pediatric care) revealed large

Table 9.3 Data collection methods applied in the *Better Transition in T1 Diabetes* program ($n = 12$ hospitals involving 15 teams of healthcare providers)

Qualitative	Quantitative
Semi-structured interviews with healthcare professionals ($n = 41$) working in pediatric and adult care	Retrospective chart review of medical records involving all young people transferred in 2012–2014, collecting data 2 years before and 2 years after transfer ($n = 321$)
Intake-interviews plus documents and protocols collected in all teams	Online survey distributed among all young people involved in the chart review (response $n = 180$)
Observations of 57 consultations in outpatient (transition) clinics (both in pediatric and adult care)	

differences in the design and execution of transitional care in the Netherlands (Bronner et al. 2017). This was confirmed by the participating hospitals. A clearly defined format for a transition clinic was nonexistent in these hospitals. We carefully researched the transitional care arrangements in each team at the start of the program by rating their quality of care on the eight core elements of the framework as identified previously. Input for this evaluation came from the review document and oral information that all teams had provided with the initiation of the program, interviews with professionals both in pediatric care and adult care (n = 57), and observations of consultations of adolescents in both settings (n = 41). Fifteen different transition routes could be detected (in three hospitals, different routes existed in different locations). Results of the analysis are shown in Fig. 9.2, which presents the mean scores of the teams on each core principle, with 1 indicating "minimal care" and 4 "excellent care" (Peeters et al. 2019b).

In almost all teams there was room for improvement, coinciding with their own judgments in the team plans designed for participation in the project. Teams that used systematic interventions for transitional care (see next section) received higher scores. Overall, teams received highest scores for organizational aspects such as continuity and co-ordination of care; while the lowest scores were given for investments in youth participation, future-orientedness of care, and involvement of

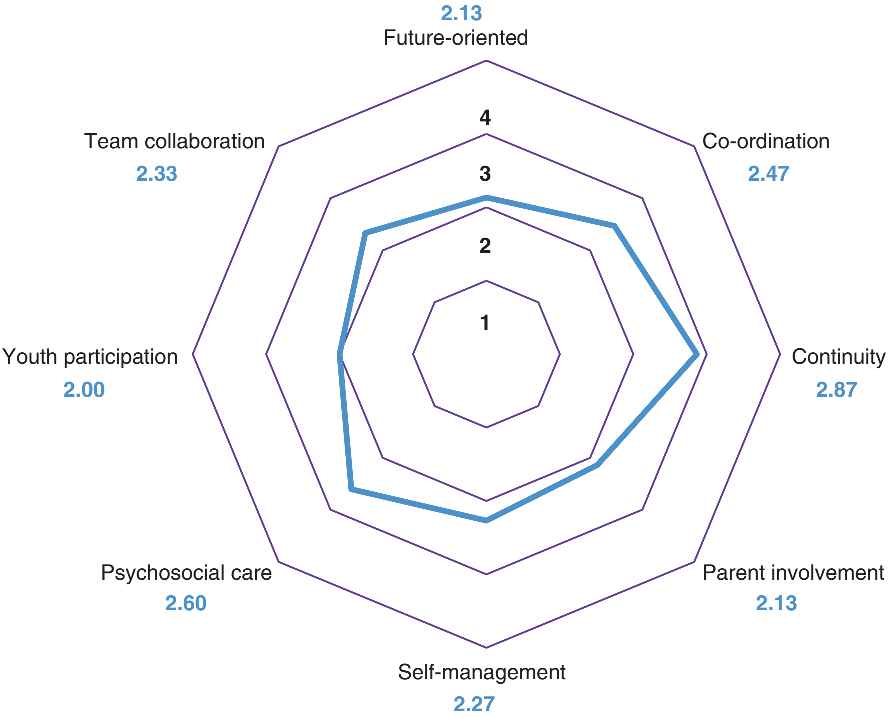

Fig. 9.2 Scoring of essential elements of transitional care in 15 teams at the start of the *Better Transition in T1 Diabetes* program: based on documents, interviews, and observations of clinical encounters

parents; attention to self-management and to psychosocial issues scored in the medium range. Making young people partners in care seems the highest priority for achieving optimal transition.

Summing the scores of all eight core principles (minimum = 8; maximum = 32), the highest score was 26 and the lowest 10 of the participating teams. More in-depth analysis of team scores was conducted by dividing the teams into two groups (those with a score ≥ 19; *n* = 7, versus those with scores ≤18; *n* = 8) and found no correlations with young people's experiences in transitional care as calculated with the overall On Your Own Feet—Transfer Experiences Scale (van Staa and Sattoe 2014). The only difference was found in the sub-scale "Experiences with preparation for transfer": young people cared for by teams that invested more in transitional care assigned higher scores than did those from teams that invested less (mean scores on a scale from 1 to 5: 3.2 ± 0.8 vs 2.9 ± 1.0; $p = 0.023$). There was no difference in the general satisfaction with the total process of transition from pediatric to adult care: the mean score was 7.0 (SD ±1.5) on a scale 1–10. Figure 9.3 presents the scores of the Transfer Experiences Scale of young people in the study ($n = 169$). Of all subscales, the appreciation of "Preparation for transfer," "Youth Involvement" (in the decisions surrounding transfer of care), and the experienced "Alignment" (between pediatric and adult care) scored lowest, indicating that these areas deserve priority (Peeters et al. 2019b).

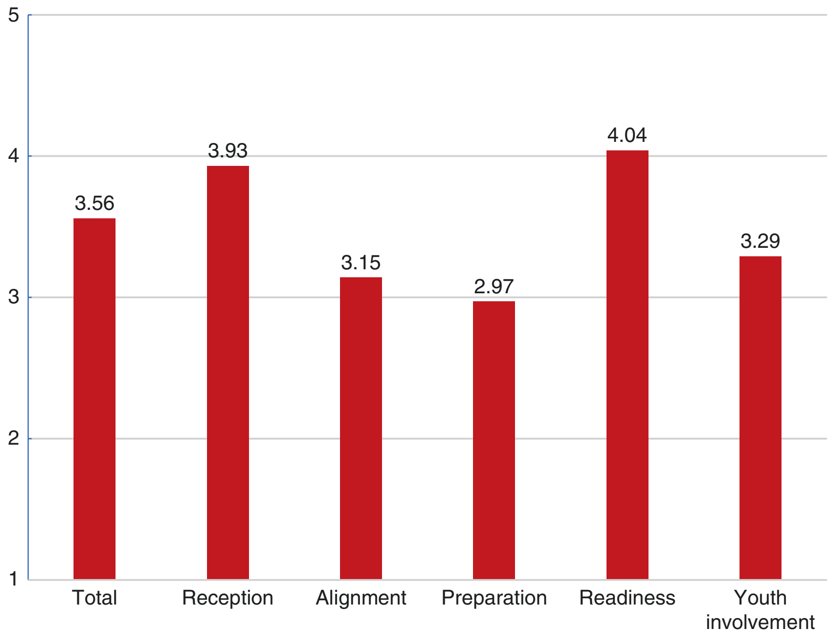

Fig. 9.3 Mean scores of Transfer Experiences Scale (including 5 subscales) of young people with T1 diabetes ($n = 169$) (Peeters et al. 2019b)

9.4 Interventions for Transitional Care

In the quality improvement programs, *Action Program On Your Own Feet Ahead!* and *Better Transition in T1 Diabetes*, teams implemented new interventions or working ways to improve transitional care. In the Framework *On Your Own Feet* (Fig. 9.1), we distinguished three types of interventions:

1. Interventions to enhance youth participation and team collaboration;
2. Interventions to improve the organization of care;
3. Interventions to stimulate independence and self-management.

Below, we present the most frequently chosen (nursing) interventions, connected to the key principles of the framework (Table 9.4). We briefly discuss the experiences and evidence coming both from the literature and our experiences with these interventions.

9.4.1 Interventions to Enhance Participation and Collaboration

Participation in transitional care concerns various actors and levels: collaboration of professionals with the young person and the family (partnering), but also *within* the multidisciplinary team and *between* the pediatric and adult care teams. By placing the young person and the team in the core of the framework, the importance of collaboration with the young person as a partner in healthcare is emphasized.

9.4.1.1 Youth Participation

Mirror Meetings

According to the NICE guidelines, young people and their parents should be involved in the service design, delivery, and evaluation of transitional care (National Institute for Health and Care Excellence (NICE) 2016). Our research into experiences with transfer showed that young people were least satisfied with how they had been involved in the decisions surrounding the transfer. They were also critical about their preparation for transition and of their reception in adult care (Fig. 9.3). Active youth participation in the organization of their care is a vital element in improving transition services. But what is an effective and efficient strategy to include the patient's perspective?

In the *Better Transition in T1 Diabetes* program "mirror meetings" were held, which were found to be a powerful tool to encourage teams to listen to young people's voices. A mirror meeting is described as a group discussion in which several young people who have recently transferred to adult care share their experiences with transition. Healthcare providers from both pediatric and adult care were invited to listen but were not supposed to interfere or give judgments about what they heard. The conversation was led by an independent moderator who invited the young people to share their experiences. Only in the second part of the meeting, healthcare

Table 9.4 Overview of frequently chosen interventions to improve transitional care using the *Framework On Your Own Feet*

	Young person	Team	Future-oriented	Co-ordination	Continuity	Parent involvement	Self-management	Psychosocial care
Young person	Mirror meeting	Mirror meeting						
Team		Multidisciplinary consultation meetings/transition policy		Multidisciplinary consultation meetings/transition policy				
Future-oriented			Transition protocol/clinical pathway	Transition protocol/clinical pathway	Transition protocol/clinical pathway	Transition protocol/clinical pathway	Transition protocol/clinical pathway	Transition protocol/clinical pathway
Co-ordination		Transition co-ordinator		Transition co-ordinator	Transition co-ordinator			
Continuity		Transition clinic	Transition clinic	Transition clinic	Transition clinic			
Parent involvement						Parent information/course	Parent information/course	
Self-management	Individual transition plan (Ready Steady Go)		Individual transition plan (Ready Steady Go)			Individual transition plan (Ready Steady Go)	Individual transition plan (Ready Steady Go)	Individual transition plan (Ready Steady Go)
Psychosocial care	PROMs							PROMs

providers were invited to ask non-judgmental questions (de Wit et al. 2008). The purpose of the mirror meetings was to inform both pediatric and adult healthcare providers about the value and needed improvements of the transfer experience.

In this project, a group of 12 young people with T1 diabetes underwent training to participate on a youth panel to share their transition experiences with pediatric and adult healthcare providers. They visited the hospitals in pairs while the team would invite some of their own patients as well. Before a meeting, teams fed the moderator with questions about what they would like to hear from young people. These questions were briefly discussed by the moderator with the young people before entering the mirror meeting. The procedure and some suitable questions for the group discussion are provided in Box 9.1.

Box 9.1: Designing a Mirror Meeting in Transitional Care

(de Kruif-Hoek et al. 2018)

Participants

- A variety of young adults who have experienced the transfer to adult care
- The multidisciplinary teams from pediatric and adult care
- An independent and experienced moderator

Design

- Maximum of 1.5 h
- Patients are invited to sit in an inner circle; healthcare providers in a semi-circle around them.
- Content: the moderator introduces the topics and asks the patients to reflect on their experiences. There are no restrictions, patients are free to express their feelings and voice their opinions. After the mirror meeting, professionals are invited to ask (non-judgmental) questions.

Examples of questions related to transition experiences

- How did the transfer to adult care go?
- What was your best/your worst experience?
- What differences do you experience between pediatric and adult care?
- Was the transfer announced timely?
- What is your opinion about the moment you transferred? How did you participate in the decisions?
- How was your preparation for transition to adult care?
- What role did your parents play? What has changed since you moved to adult care?

Examples of questions related to interventions and transitional care

- What do you see as “dos” and “don’ts” for healthcare professionals?
- What are we supposed to do with your parents?
- What is the most important advice you would give us to deal with young people who do not attend hospital apppointments?

- How do you feel about group consultations/about meeting fellow patients?
- What is the best way for us to communicate with you (face-to-face, e-mail, WhatsApp, etc.)?
- How much attention would you like us to pay to psychosocial issues?
- How do you like seeing the dietician/the psychologist? What is a good frequency for such consultations?

The power of this approach lies in the direct interaction between patients and providers. A "mirror meeting" provides professionals with direct (and often unfiltered) feedback about the experienced care or about gaps in care provision. Using this interactive approach, professionals cannot escape listening to young people's voices, this method helps to create awareness of young people's lived experiences and a willingness to change. The presence of professionals when patients tell their stories or share their opinions is seen as a crucial factor for success (de Wit et al. 2008).

At the same time, young people also formulated clear recommendations for improvement and often provided compliments and shared positive experiences with the teams. They talked freely about the professionals who had helped them and about the interventions they particularly appreciated. We noticed that it worked well to invite different young adults: those who had attended a transition clinic as well as those who had felt "lost in transition." A mix of young people treated in the hospital visited combined with adolescents treated elsewhere provided a safe atmosphere and triggered discussions among the youth participants as well.

The teams invariably felt that the mirror meetings helped them to become more sensitive to young adults' preferences, while they also acknowledged that there was no such thing as "one size fits all." A diabetes nurse commented: *"The young people's message was loud and clear, and their advices were definitely useful. It was clear that they valued empathy and professionals that listen well and take them seriously"* (de Kruif-Hoek et al. 2018).

Interestingly, the young people as well voiced that the mirror meeting had been useful for them. They were surprised to hear that fellow patients had different experiences and judgments about care, and they were also impressed by the commitment of the teams to invest in the conversation. One young person who participated in several mirror meetings said: *"My admiration for my diabetes nurse has definitely grown. I had never anticipated that her job could be so difficult!"* and another one expressed: "*It's so special to learn that everyone is working so hard to improve care for us and that they are willing to listen to us" (*de Kruif-Hoek et al. 2018*).*

Independent Consultations

The content and quality of patient-provider communication is decisive for young people's transition readiness and constitutes an important aspect of developmentally appropriate care (van Staa et al. 2015). One way to deliver developmentally appropriate care and to involve young people in their own healthcare is the use of independent consultations, i.e., routine service appointments during which healthcare professionals mainly talk with the young people themselves and parents are not present (all the time). There are different models of independent consultations (van Staa et al. 2015). One is the "split-visit model" in which young people start the consultation alone with the healthcare professional, while parents join later. Young people are then asked to summarize the conversation they had with the professional for their parents. Another model excludes parents completely from the routine consultations, as they are no longer invited to participate. Yet another model includes separate consultations of young people with the nurse, while parents see a social worker at the same time, followed by joint consultations of young people and their parents with the doctor.

In the Action Program, positive experiences with independent consultations were reported (van Staa et al. 2015). The split-visit model was mainly used; it proved easy and quick to implement. Healthcare professionals reported that applying the split-visit model activated young people and helped them to become more independent and to take responsibility for their own healthcare. An important advantage was also the possibility for young people to talk about subjects they did not want their parents to know (i.e., it enhanced confidentiality). Professionals also received positive feedback from young people confirming this. At the same time, parents did not feel excluded. The evaluation study also showed that independent consultations increased adolescents' independent behaviors and involvement, and that more non-medical topics, such as future education, intimate relationships and sexuality, and transfer to adult care, were addressed during consultations. The intervention was evaluated positively, but professionals did mention that one should be flexible in applying it and that parents should not be totally excluded. Teams mostly implemented independent consultations with young people after the age of 16, although some also successfully experimented with split-visits for younger adolescents from 12 years up.[2]

9.4.1.2 Team Collaboration

Multidisciplinary Team Consultation Meetings/Shared Vision on Transition

One of the proposed beneficial features for successful transition is having an interdisciplinary, co-ordinated team of health professionals from pediatric and adult care who work together and communicate about their respective working ways, treatment protocols, and care procedures (Colver et al. 2018; National Institute for Health and Care Excellence (NICE) 2016). Team performance may be facilitated or hindered by the team climate, which refers to professionals' shared knowledge and perceptions of the types of behavior and action that are rewarded and supported by the team's policies, practices, and procedures (Goh

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[2] The Dutch Act on the Medical Treatment Agreement (WGBO) provides the legal basis for seeing adolescents alone after the age of 16, as young people are then expected to make medical decisions on their own. Between 12 and 16, treatment agreements are to be made by involving both parents and the young person, while legally under the age of twelve, the responsibility lies with parents.

et al. 2009). Cramm and colleagues (Cramm et al. 2014) investigated team climate in the teams participating in the Action Program *On Your Own Feet Ahead!* and concluded that team climate was positively related to high-quality transitional care over time.

Enhanced personal bonds and integration between adult and pediatric services seem key conditions to improve team climate, communication, and collaboration between providers from pediatric and adult care. The professionals interviewed in another Dutch study recommended having more staff exchange, holding multidisciplinary team (MDT) consultation meetings about patients before and after transfer, and setting up joint clinics (van Staa et al. 2011).

In the Netherlands, collaboration between pediatric and adult care teams is still in its infancy, as is visible from the existing culture gap. Our national, cross-sectional online survey (2016) among healthcare professionals working in adolescent diabetes care ($n = 156$) showed that 57% shared a common vision on transition in pediatric and adult care. Still, MDT consultation meetings around a patient's transfer were not a standard part of transitional care (Bronner et al. 2017). The *Better Transition in T1 Diabetes* study confirmed this: at the start, many teams reported they struggled with the involvement of pediatric and adult care providers, developing joint policies and services. In their assessment of transfer experiences, young people were critical of the perceived "alignment" between pediatric and adult care (Fig. 9.3 (Peeters et al. 2019b)).

This underpins the importance of implementing of MDT consultation meetings for patients who are being transferred. These proved helpful in aligning policies and creating ways between pediatric and adult care providers as well as reaching agreement on the objectives of transition and building of commitment.

9.4.2 Interventions to Improve the Organization of Care

In the Netherlands, diabetes professionals marked no-show (loss to follow-up or dropout[3]) and therapy adherence as the most serious challenges in their care provision (Bronner et al. 2017). A cohort study (6-year follow-up) among some 500 young people with various chronic conditions showed that after reaching adulthood, 25% had dropped out of special care (van Staa and Sattoe 2014). The transition period seems most liable to dropout or no-show. A controlled cohort in Dutch rheumatology care (3-year follow-up) indicated a dropout rate[4] of 22% in patients under transition, higher than in pediatric (3%) and adult care (10%) (van Pelt et al. 2018). In our diabetes study, 30% of young people missed at least one consultation in the 2 years before transfer; this increased up to 42% in the 2 years after moving to adult care (Peeters et al. 2019b). Several interventions aim to address continuity and coordination of care in the transitional period.

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[3] A complication is that often different definitions of dropout are being used. Also, non-attendance of consultations is not always recorded in electronic health records.

[4] Dropout was defined as: not attending the clinic for two consecutive visits.

9.4.2.1 Future-Oriented

Transition Protocol/Clinical Transition Pathway

A written transition protocol is a useful tool to organize planned, developmentally appropriate, and holistic transitional care. It enables the integration of various transition interventions into routine clinical practice (Walter et al. 2017). An example of a clinical transition pathway, developed by a rheumatology nurse specialist, is provided in Fig. 9.4 (Walter et al. 2018).

Important elements that should be incorporated into the design of the transition protocol to enable a smooth and gradual transition towards more responsibility and independence for the young person are:

- Start of preparation for transition in early adolescence (starting from 12 years[5]; 14 years at the latest);
- Focus on the development of self-management skills and independence using an individualized transition plan involving both patients and parents (see below);
- Meeting adult care professionals prior to the transfer.

As such, the transition protocol or clinical pathway encompasses all elements of a person-centered approach that addresses both medical, developmental and psychosocial aspects of care for the young person and his/her parents. It describes how to guarantee co-ordination and continuity of care (Table 9.4). These necessary elements are well described in the NICE guideline on transition (National Institute for Health and Care Excellence (NICE) 2016).

In our experience, the development and implementation of transition protocols are a team activity, with nurses and nurse specialists in the lead. A Dutch study (Walter et al. 2018) showed that the implementation of the clinical transition pathway developed by a nurse specialist led to a substantial improvement of patient care during the transitional process (see Fig. 9.4 (Walter et al. 2018)). The dropout of care rate declined from 35% to less than 5% and high scores were assigned on satisfaction with transition. High scores on the self-reported self-efficacy scale suggested a higher level of confidence of young people to have achieved enough skills to successfully manage their disease and underpinned the importance of addressing the development of self-management skills (Walter et al. 2018). Still, our survey about transitional care in diabetes revealed that written transition protocols are not often present in clinical practice and that preparation generally started quite late, around 16 years, or only within the year before transfer (Bronner et al. 2017), implying that implementation of transition protocols is still not widespread.

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[5] Depending on the age where children move onto secondary education: in the Netherlands this is around 12–13 years; in the UK this is usually around the age of 11.

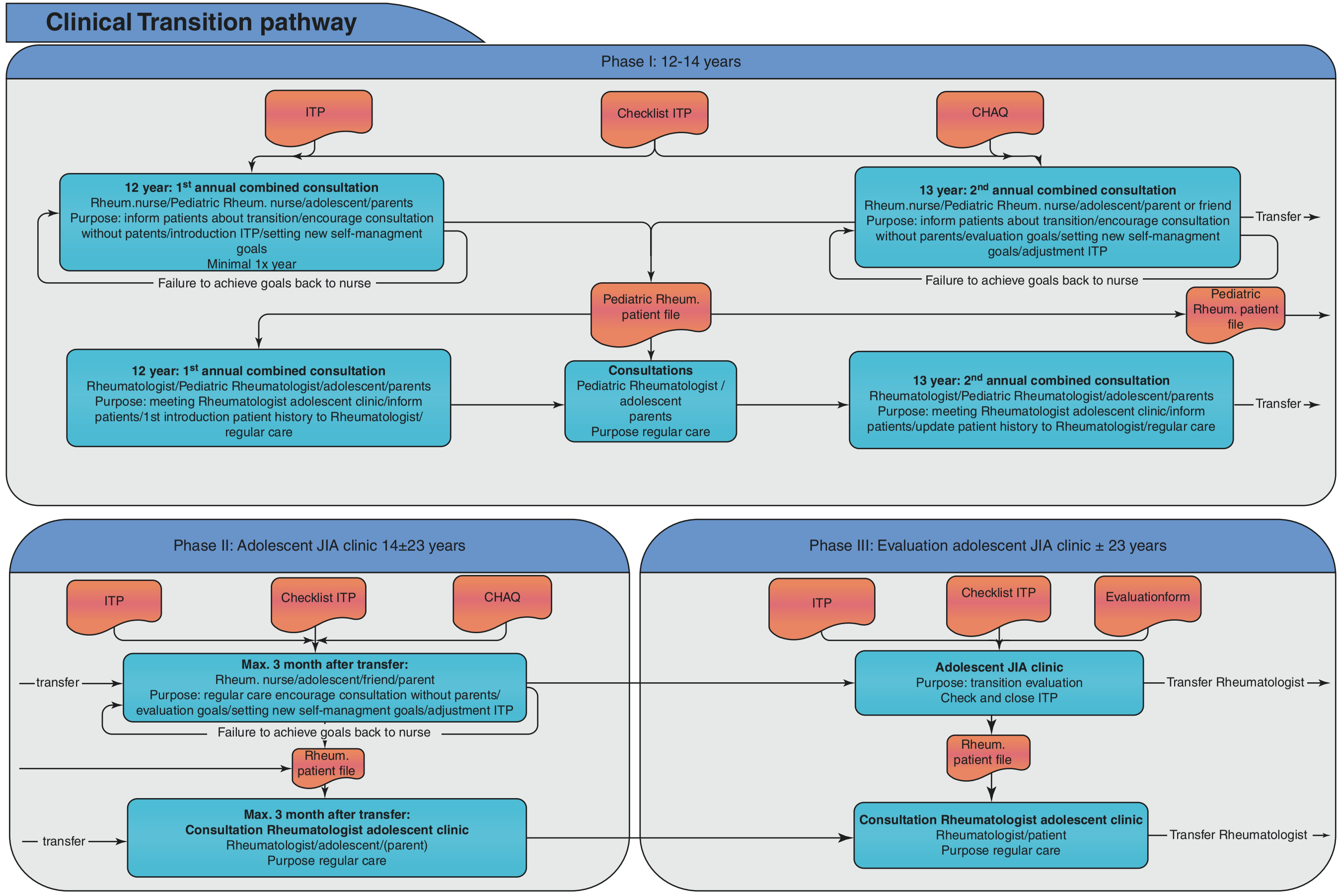

Fig. 9.4 Clinical transition pathway for adolescents with juvenile-onset rheumatic and musculoskeletal diseases (Walter et al. 2018)

9.4.2.2 Co-Ordination

Transition Co-Ordinator

Another essential intervention to improve the organization of transitional care is appointing a transition co-ordinator (Colver et al. 2018; Foster et al. 2017; National Institute for Health and Care Excellence (NICE) 2016). This could be dedicated nurse or other healthcare professional given the following position responsibilities (Colver et al. 2018; Schultz and Smaldone 2017; Betz and Redcay 2005):

1. to liaise between adult and pediatric teams to ensure the co-ordination of care and support;
2. to facilitate the communication and collaboration between pediatric and adult care;
3. to implement the transitional protocol or clinical pathway;
4. to manage the logistics around transition and transfer;
5. to ensure the provision of appropriate materials for health promotion, or individual transition plans;
6. to schedule appointments and following up if appointments were not attended.

As such, the transition co-ordinator can ensure continuity of care during transition and after transfer to adult care, and thereby contributes to deal with the challenge of loss to follow-up or dropout of young people. This is a serious problem, identified in various studies as discussed above. A transition co-ordinator works best as a named key worker who is known to the young persons and their parents, and who they can easily contact or go to in the case of problems of co-ordination or misunderstandings. The best results are probably gained when the transition co-ordinator occupies a central position in clinical care and works on both sides of the transition, thereby personally “bridging the gap” between pediatric and adult care. Nurses seem to be in an excellent position to fulfill this role (Betz and Redcay 2005).

9.4.2.3 Continuity

Transition Clinic

A transition clinic is often advocated as best practice to provide continuity in transitional care (Sattoe et al. 2016). At a transition clinic, professionals from pediatric care and adult care are both involved in the delivery of outpatient transitional care. Models of transition clinics differ in the daily routines and used protocols. While some models focus on organizing a smooth transfer to adult care, others have a broader approach including the transition to adulthood and psychosocial wellbeing (Betz et al. 2016a). Nevertheless, the shared core element is the collaboration between the pediatric and adult care departments. This often includes multidisciplinary team consultation meetings around transfer (see above) and joint consultations wherein young people are seen by professionals from both settings at the same time. A key feature of transition clinics is that young people meet their future adult care provider(s) before the actual transfer to adult care.

In the past years, there has been an increase in the number of evaluation studies of transition clinics implemented in a variety of care settings and for a variety of conditions such as T1 diabetes (for example, (Levy-Shraga et al. 2016)), cystic fibrosis (CF) (Gravelle et al. 2015), inflammatory bowel disease (IBD) (Yerushalmy-Feler et al. 2017), epilepsy (Geerlings et al. 2016), rheumatology (Stringer et al. 2015), nephrology (McQuillan et al. 2015), and so forth. Most of these studies show some positive health outcomes and improved follow-up rates of young people after transfer, but the evidence is inconclusive, the setup of these clinics is often not well described and the outcomes are often not compared to usual (direct hand-over) care. The number of controlled evaluations of transition programs and transition clinics is still scarce, as is demonstrated in a review on components of interventions that improve transitions to adult care for adolescents with T1 diabetes (Schultz and Smaldone 2017).

An overview of selected studies and proposed outcomes of the evaluation of transition clinics is given in Sattoe et al. (2016), where a controlled evaluation study protocol for the added value of transition clinics is presented. Using this protocol for the evaluation of a CF transition clinic in the Netherlands, healthcare professionals reported that the intervention helped to better prepare young people and their parents for their transition and transfer (Peeters et al. 2019a). The professionals themselves benefitted because the transition clinic encouraged them to work together (e.g., in joint consultations). They also felt that the quality of care had improved, because they obtained a more holistic view of the transferring patient and working ways were aligned across pediatric and adult care. Having a dedicated transition co-ordinator was found to be an important facilitator. At the same time, positive effects on healthcare use and clinical outcomes were difficult to support (Peeters et al. 2019a). So, while some beneficial features of transition clinics have been identified, the optimal design for transition clinics remains unclear. The operationalization of "joint care" and the optimal interval at which transition clinics are to be organized are yet to be reported. Also, empirical testing is warranted to investigate whether transition clinics may be less effective in realizing successful transition than dedicated adolescent clinics, where adolescent health specialists see young people aged 15–25 over a longer period. Furthermore, in the Netherlands, the organization of transition clinics is seriously constrained by a lack of funding and reimbursement of joint care initiatives, a shortage of dedicated professionals trained in adolescent health, and the absence of a national policy or standard for transitional care.

9.4.3 Interventions to Stimulate Independence and Self-Management

9.4.3.1 Parent Involvement

Information and Education, Individual Transition Plans, Parent Group Support

While transitional care focuses on strengthening the young person's independence, empowerment, and involvement, the parents, too, need to be involved. Parents should not be excluded from their child's care during the transition period and may need support in transferring responsibilities for treatment and self-management to their offspring (van Staa et al. 2011). Their involvement concerns not only what happens during clinic visits (the presence and role of parents during consultations), but also what happens at home (the management of the young person's health and life) (Colver et al. 2018; Surís and Akré 2015). While young people do want to be in the center of attention, they need their parents to support them in health-related and other decisions (Peeters et al. 2014). Timely preparation for the transition and repeated discussions about new roles and responsibilities with respect to self-management are essential elements in developmentally appropriate care for young people (National Institute for Health and Care Excellence (NICE) 2016).

Self-management interventions that address the parents' role often apply educational methods and/or skills training; they usually include both separate and joint sessions (Sattoe et al., 2015). Examples of educational methods are informational sessions, parenting courses, and written materials. Particularly skills building programs using instruments such as Ready Steady Go (Nagra et al. 2015) and Skills for Growing Up (Sattoe et al. 2014; Hilberink et al. 2018) are known to contribute to a successful transition towards adulthood and adult care (see below). These programs often provide specific instruments for parents. The instruments are to be used as conversational tools that encourage young people and their parents to discuss developmental and psychosocial issues with each other, and to increase the parents' confidence to "let go" and the young people's confidence to take up new tasks and responsibilities.

A brief group education program on parenting may be supportive to parents. An example is the so-called "Los Vast" program, a 3-session course recently developed for Dutch parents of adolescents with diabetes. Under the guidance of a child psychologist they discuss challenges, developmental issues, and useful approaches to support their children in becoming autonomous in diabetes management (www.diabetesgroeimodel.nl).

The role of parents in transitional care is still ambiguous. In pediatric care, their presence and importance are undisputed, sometimes even to the expense of the young person, while in adult care they often feel excluded. Parents acknowledged that leaving pediatric care is a logical step for their child, but the parting with familiar surroundings proved harder for them than for their child, who often displayed a positive "wait-and-see" attitude (van Staa et al. 2011). Our research among diabetes care professionals showed that interventions focusing on parenting skills and involvement of parents in transitional care are not often applied (Bronner et al. 2017).

9.4.3.2 Self-Management

Individual Transition Plans: Ready Steady Go and Skills for Growing Up

A person-centered and holistic approach is necessary to support young people in their transition. Professionals' attention should go beyond medical aspects and also address typical development and challenges of young people in their transition to adulthood. Developmentally appropriate care is essential to build young people's self-efficacy and to foster their transfer readiness. These goals can be realized by using tools that focus on building skills for independent living and self-management (i.e., enhance self-efficacy), formally known as individual transition plans. These are self-management action plans filled out by young people that are subsequently discussed with their healthcare providers and parents. Developing such a plan raises the awareness of all involved of the impact of the condition on all life domains and the need for structured planning of independence development. It also encourages talking about social functioning and participation—vital aspects of adolescent health (Sawyer et al. 2007; Sattoe 2015). So, ideally such plans encourage young people to think about their future and to set their personal goals for gaining more autonomy in different life domains (e.g., healthcare, education, relationships, etc.). Parent versions of the plans will support the parents in gradually shifting their co-ordinating role to their child (van Staa et al. 2015). Furthermore, since competency-building, as part of the transition process, continues well into young adulthood, the use of self-management action plans will likely need to continue in adult care.

The basis for such transition programs is generic (non-disease-specific), while some programs include disease-specific items. An example of a generic individual transition program is *Ready Steady Go*, developed in the UK and widely distributed within the NHS (Nagra et al. 2015). Dutch versions of the Ready Steady Go instruments have been made available in the *Better Transition in T1 Diabetes* program. *Ready Steady Go* includes an instrument for use in young adult care (the “Go” instrument). *Ready Steady Go* builds on extensive experience with individual transition plans used in English rheumatology care (McDonagh et al. 2015) and with the *On Trac* program in Canada (Moynihan et al. 2015). Before, in the Action Program *On Your Own Feet Ahead!* several teams have implemented individual transition plans. Our evaluation study showed predominantly positive experiences with the introduction of such plans, although there were problems with logistics and the intervention was considered time-consuming. Still, adolescents reported that over time there was indeed a shift to more non-medical topics being discussed during consultations. The most important advantage was that such self-management action plans served as a conversational tool to open discussions with young adults, parents, and healthcare professionals about developmental tasks and challenges (van Staa et al. 2015).

Another competency-based tool, the *Skills for Growing Up tool*, was developed for use in rehabilitation settings in Canada, but has been modified for use in rehabilitation, nephrology, epilepsy, HIV, and CF care in the Netherlands (Sattoe et al. 2014; Hilberink et al. 2018). Healthcare teams participating in the Action Program also implemented this tool. Evaluation studies showed that it enabled professionals to discuss psychosocial and developmental topics in a more structured way and to put young people in the lead. Creating awareness about the transition process and shift in autonomy and fostering family interaction in this matter were other important benefits mentioned by professionals (Sattoe et al. 2014; Hilberink et al. 2018).

Propagating the use of competency-building programs such as *Ready Steady Go* and *Skills for Growing Up* contrast differently from the use of Transition Readiness Assessments in the following aspects: (a) focus on one-time measurement, (b) psychometric properties, and (c) detecting gaps between self-care beliefs, skills, and transition planning (Sawicki et al. 2011; Zhang et al. 2014). Moreover, transition readiness assessments are predominantly concerned with medical self-management tasks and tend to ignore the wider challenges in social participation. While we do not deny the importance of measurements and detecting mismatches, we feel that a focus on youth involvement and holistic self-management support is even more important in view of the high risk of discontinuity of care in the transitional period. The outcomes of several instruments make clear that nurses play an important role in working with self-management action plans, confirming their central role in encouraging adolescent responsibility for self-management and preparing them for transition to adult life and adult care (van Staa et al. 2015).

9.4.3.3 Psychosocial Care

Routine Measurement of PROMs, such as Quality of Life

Attention for psychosocial issues is a critical part of transitional care. Timely referral of young people to psychosocial care (e.g., a psychologist or social worker) is important to prevent psychosocial problems from escalating. Routine measurement of psychosocial patient-reported outcome measures (PROMs) is helpful in monitoring. One web-based application that allows for systematic monitoring of Health-Related Quality of Life (HRQoL) in children and young people with chronic conditions is the KLIK PROfile (Haverman et al. 2013). Before regular consultations, the young person fills out the web-based HRQoL questionnaire at home (or elsewhere). The results are summarized in a “PROfile” to which the healthcare professional has access. If deemed necessary, the professional can address issues during the consultation and act accordingly. An evaluation study showed that for young people with juvenile idiopathic arthritis the use of this application led to more attention to psychosocial topics during consultations (Haverman et al. 2013). The intervention was evaluated positively by all involved. In pediatric oncology, a controlled evaluation showed that in the group not using the application (i.e., the control group), the professionals were less likely to identify emotional problems (i.e., anger and fear) as compared to the intervention group (Engelen et al. 2012). No effects were found on the number of children referred to psychosocial care. The KLIK PROfile is a helpful tool for systematic monitoring HRQOL in pediatric practice, without lengthening the duration of the consultation (Engelen et al. 2012).

9.5 Priorities for Research and Training

Despite the increase of studies and recommendations on successful transitional care practice, many issues remain to be addressed and the current evidence on which components of transition programs work best is still weak (Schultz and Smaldone 2017). First, relevant outcome measures need to be identified by improving the evidence based on models of care. Currently, there is a lack of agreement on sensitive and relevant outcome measures of transition and little is known about predictors as reflected in the use of multiple outcomes in evaluation studies (Le Roux et al. 2017). The underlying issue here is that there is no clear definition of “successful transition”. However, having an agreed “core transition dataset” for routine practice in pediatric and adult care would help inform and foster future research initiatives, facilitate a standardized approach in transitional care, and enable comparative assessment of care (Foster et al. 2017). Another important issue would be the need for long-term follow-up to establish "successful transition" in the wider perspective of young people reaching their full potential instead of just looking at "not being lost to follow-up" after transfer (Sattoe et al. 2017; Surís and Akré 2015).

Secondly, it is important to acknowledge the complexity of transitional care interventions in evaluation studies. An intervention is considered complex if it requires cultural and behavioral changes from professionals and/or patients, involves several (levels of) organizations and/or different professionals, aims at affecting different health and other outcomes, and requires flexibility and tailoring in its execution (Craig et al. 2008). These elements are all present in transitional care programs. Careful evaluation is therefore required, using a mixed-methods design comprising both a qualitative evaluation of the process and a quantitative measurement of transition outcomes (Sattoe et al. 2016). This approach enables us to gain insight into what works and for whom (Sattoe et al. 2015).

A third research priority is establishing the cost-effectiveness of transitional care programs. Our research has shown that deficient financing of interventions or lack of resources is a barrier to implementation and use of available transitional care interventions (Nieboer et al. 2014; Peeters et al. 2019b). Insight into the costs and benefits of establishing transitional care programs is necessary to inform health policy, and to secure sustainable funding and the impact of transition guidelines and recommendations in daily practice.

Finally, in many European countries, including the Netherlands, pediatric staff—both nurses and doctors—have no formal training in adolescent health issues and are ill-equipped to deal with issues and health problems such as substance use, sexual health, psychiatric problems of adolescence, and transition to adult care. Thus, competency-based training in developmentally appropriate adolescent healthcare deserves priority (Cramm et al. 2014). This also applies to professionals working in adult care who too are often inadequately trained in dealing with adolescent health issues. Since nurses are placed in an excellent position to provide self-management support, they are particularly challenged to define what developmentally appropriate self-management support would entail.

9.6 Key Recommendations for Practice

Considering the current state-of-the-art of knowledge, the consensus as expressed in recent standards and guidelines (Foster et al. 2017; Mazur et al. 2017; National Institute for Health and Care Excellence (NICE) 2016; Surís and Akré 2015; Betz 2017), and the lessons learnt in the *On Your Own Feet* research and quality improvement programs, ten key recommendations directly related to our framework can be formulated.

1. Young people should have access to high-quality, co-ordinated transitional care, delivered through partnership with healthcare professionals, young persons and their families, and addressing needs on an individual basis.

2. The transition process should start as early as possible, in early adolescence or directly after the diagnosis in adolescent-onset disease.
3. There needs to be direct communication between the key participants during the process of transition. Before and after the actual transfer, there should be direct contacts between pediatric and adult teams.
4. Individual transition processes and progress should be carefully documented in the medical records and planned with young people and their families.
5. Every service providing care to young people with chronic conditions must have a written, agreed, and regularly updated transition policy.
6. There should be a clear, written description of the multidisciplinary team involved in transitional care, locally and in the clinical network. The team should include a designated transition co-ordinator.
7. Transition services must be focused on the young person, be developmentally appropriate, and address the complexity of young people's daily lives and developmental challenges.
8. There must be a written transfer document available to all participants in the transition process including young people and their parents.
9. Healthcare teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent care and childhood-onset diseases.
10. There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for young people entering adult care.

9.7 Conclusion

In our quality improvement programs, nurses played a pivotal role as team leaders, designers, and implementers of transition interventions, and as connectors of pediatric and adult services. Indeed, nurses are in a unique position to involve adolescent patients in decision-making, encouraging their independence and responsibility for self-management, and by well preparing them for the transfer to adult care (Betz 2013; Betz et al. 2016b). Therefore, the nursing role in adolescent care deserves to be expanded. An important challenge in developmentally appropriate care in adolescence is the gradual shift in responsibility from the parents to the young person. Useful interventions proved to be: asking the parents not to be present for part of the consultation and using self-management action plans. At the same time, parents may also need support in the process of transferring responsibilities to their children. Young people's needs should be explored at the crossroads of medical, role, and emotion management; therefore, attention should be paid to medical as well as psychosocial needs. Routine monitoring of quality of life can provide insight into psychosocial functioning and needs, and facilitate these being discussed. Having said this, holistic support for young people growing up with chronic conditions should ideally be provided in multidisciplinary teams that work together across the boundary of pediatric and adult care—for instance, in the form of joint transition clinics. Nurses working on both sides and functioning as transition co-ordinators could guarantee that self-management support is provided all the way from pediatric into adult care.

The *On Your Own Feet* Framework encompasses all elements discussed above and is, therefore, suitable for use in evaluating current transitional care efforts and providing directions for change. Preconditions in the wider socio-political context, such as a national quality standard, adequate financing, ICT facilities, professional education, and training and management support, need to be fulfilled to realize sustainable developmentally appropriate adolescent healthcare.

9.8 Useful Resources

- **Website and Toolkit *On Your Own Feet*** (in Dutch) www.opeigenbenen.nu
  This website is part of the *On Your Own Feet* research and innovation program of Rotterdam University's Research Center Innovations in Care. It provides information for young people with chronic conditions about several subjects (Me, Healthcare, Living, Relations, Education, Mobility, Sports, Leisure, Work, Parents). Healthcare professionals will find the Transition Toolkit here (www.opeigenbenen.nu/professionals/transitie-toolkit). It offers formats and descriptions of useful transition interventions. The website also presents research findings and a list of publications.

- **Ready Steady Go**
  Ready Steady Go is an English generic transition program to help young people to gain the knowledge and skills to manage their condition, which helps them to gain the confidence and skills to move to adult services (Nagra et al. 2015). Ready Steady Go has been implemented in the UK National Health Service and is available for free downloads: www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx

  Dutch versions: www.opeigenbenen.nu/onderzoek/projecten/readysteadygo

- **Skills for Growing Up/Growing Up Ready**
  The *Skills for Growing Up* tool is based on a method developed in a Canadian rehabilitation setting, *Growing Up Ready*. It helps young people to acquire the knowledge and skills needed to manage their condition. The tools have been modified for use in Dutch rehabilitation and hospital settings (Sattoe et al. 2014; Hilberink et al. 2018), and are available here: www.opeigenbenen.nu/professionals/transitie-toolkit/tool-groei-wijzer/

  The original *Growing Up Ready* tools are available here: hollandbloorview.ca/programsandservices/ProgramsServicesAZ/Growingupready

Appendix

Framework 'on your own feet ahead'	Six core elements of healthcare transition (Got Transition 2014; White et al. 2018)	Key elements for, and indicators of, a successful transition (Surís and Akré 2015)	NICE guideline on transition (National Institute for Health and Care Excellence 2016c)	Proposed beneficial features (Colver et al. 2017)	Consensus statement on successful transition (Mazur et al. 2017)	Components of interventions that improve transitions to adult care (Schultz and Smaldone 2017)
Future-oriented	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through transition processes The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool, and self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14–16	Starting planning transition at an early age (and at least 1 year before the transfer boundary) If developmentally appropriate, seeing the adolescent alone at least for part of the consultation	Ensure a smooth and gradual transition Collaboration between paediatric and adult care providers Start early (13 years at latest) Make a transition plan Meet adult care providers in advance (a transition clinic could help to facilitate this) Provide information about services and support available in adult care	Meet adult team before transfer: this could be in a joint clinic where paediatrician and adult physician consult together; or the adult physician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult physician Promotion of health self-efficacy: the clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition Written transition plan, which should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services The young person should have a copy of it and it should be updated	A structured, written policy involving child and adult healthcare providers. This should be available to adolescents and their family or caregivers Starting to create a healthcare transition plan as early as possible, for example, by the age of 14 or below or at least one year before the transfer itself The transition process and timing should be individualized	Transition clinics can provide a tailored approach to young adults, addressing issues specific to this age group

(continued)

Framework 'on your own feet ahead'	Six core elements of healthcare transition (Got Transition 2014; White et al. 2018)	Key elements for, and indicators of, a successful transition (Surís and Akré 2015)	NICE guideline on transition (National Institute for Health and Care Excellence 2016c)	Proposed beneficial features (Colver et al. 2017)	Consensus statement on successful transition (Mazur et al. 2017)	Components of interventions that improve transitions to adult care (Schultz and Smaldone 2017)
Co-ordination		Assuring a good co-ordination (such as timing of transfer, communication, follow-up, remaining available as a consultant, etc.) between paediatric and adult professionals	Appoint a named worker to coordinate the transition care and support	Key worker: a single person known to the young person whom they could easily contact or go to if there were any problems of co-ordination or misunderstandings that needed to be sorted out Transition manager for clinical team who facilitates good working relationships between adult and child services; ensures that there are appropriate materials available for things such as health education or the transition plan; and monitors whether the young person has a suitable appointment in adult services and whether the appointment is kept		A transition coordinator may be helpful in optimizing clinic attendance. They could provide assistance with scheduling appointments and following up if appointments were not attended

Continu-ity	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12–14. The policy is publicly posted and familiar to all staff The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet), and paediatric clinicians communicate with adult clinicians, confirming paediatric provider's responsibility for care until young adult is seen in the adult practice The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience	Identifying an adult provider willing to take on the young patient before transfer Patient not lost to follow-up	Ensure a smooth and gradual transition Collaboration between paediatric and adult care providers	Age-banded clinic: an intermediate clinic setting such as a young person's clinic or a young adult team	A structured, written policy, involving child and adult healthcare providers Continuity of care and cooperation, i.e. using common medical guidelines, keeping proper medical records, and performing follow-up evaluations Continuity of financing	

(continued)

Framework ‘on your own feet ahead’	Six core elements of healthcare transition (Got Transition 2014; White et al. 2018)	Key elements for, and indicators of, a successful transition (Surís and Akré 2015)	NICE guideline on transition (National Institute for Health and Care Excellence 2016c)	Proposed beneficial features (Colver et al. 2017)	Consensus statement on successful transition (Mazur et al. 2017)	Components of interventions that improve transitions to adult care (Schultz and Smaldone 2017)
Young person	The practice ensures equal representation of youth and families in strategic planning related to healthcare transition	Including young person’s views and preferences to the planning of transition	Involve young people and their caregivers in service design, delivery and evaluation of transition care Transition support must be developmentally appropriate Transition support must be strengths-based		Procedures should be available to adolescents and their family or caregivers, and should allow for some flexibility, depending on the adolescent’s developmental stage as well as the expectations and needs of the patient and relatives Active participation of the adolescents and the parents or caregivers should be sought The transition process and timing should be individualized	

(Multidisciplinary) team	The practice has incorporated transition into its plan of care. All clinicians are encouraged to partner with youth and families in developing transition goals and updating and sharing the plan of care. Clinicians are also encouraged to address needs for decision-making supports. The practice has a vetted list of adult providers and assists youth in identifying adult providers		Collaboration between paediatric and adult care providers Meet adult care providers in advance (a transition clinic could help to facilitate this)	Age-banded clinic: an intermediate clinic setting such as a young person's clinic or a young adult team Meet adult team before transfer: this could be in a joint clinic where paediatrician and adult physician consult together; or the adult physician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult physician Co-ordinated team of which the members need to work together and communicate well together, and demonstrate to the young person that this is happening. Co-ordination of appointments on the same day demonstrates this	Adequate staff training and sensitization to the needs and concerns of adolescent patients Interdisciplinary teams	

(continued)

Framework 'on your own feet ahead'	Six core elements of healthcare transition (Got Transition 2014; White et al. 2018)	Key elements for, and indicators of, a successful transition (Surís and Akré 2015)	NICE guideline on transition (National Institute for Health and Care Excellence 2016c)	Proposed beneficial features (Colver et al. 2017)	Consensus statement on successful transition (Mazur et al. 2017)	Components of interventions that improve transitions to adult care (Schultz and Smaldone 2017)
Parent involvement	The practice ensures equal representation of youth and families in strategic planning related to healthcare transition	Discussing with patient and family about self-management	Involve young people and their caregivers in service design, delivery and evaluation of transition care	Appropriate parent involvement in their child's care, but with changing responsibilities. Involvement concerns what happens in the clinic (parent being present or not and who does the talking) and also discussions at home about the young person's health and how to manage it	Active participation of the adolescents and the parents or caregivers should be sought	

Self-management	The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool, and self-care needs, and goals are incorporated into the youth's plan of care beginning at ages 14–16	Discussing with patient and family about self-management If developmentally appropriate, seeing the adolescent alone at least for part of the consultation		Promotion of health self-efficacy: the clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition and the young person is asked "*Have you received enough help to increase your confidence in managing your condition?*" Holistic life-skills training for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed	The extent to which the adolescent has acquired some skills for self-management should be taken into account	Psychological support may help youth learn how to balance their multiple priorities as well as cope with challenges such as understanding how their illness affects their self-image and avoiding becoming isolated from their social circles

(continued)

Framework 'on your own feet ahead'	Six core elements of healthcare transition (Got Transition 2014; White et al. 2018)	Key elements for, and indicators of, a successful transition (Surís and Akré 2015)	NICE guideline on transition (National Institute for Health and Care Excellence 2016c)	Proposed beneficial features (Colver et al. 2017)	Consensus statement on successful transition (Mazur et al. 2017)	Components of interventions that improve transitions to adult care (Schultz and Smaldone 2017)
Psychosocial care		Although having a holistic approach to prepare young people for adulthood was not unanimously considered as essential or very important, it is an important part of transition. In fact, it seems that the consensual elements in the study of Surís and Akré (2015) are mainly limited to health outcomes	Using a person-centred (holistic) approach Involve primary care (general practitioner)	Written transition plan, which should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated Holistic life-skills training for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed	Young patients should not be transferred until they have the skills to function in an adult service and have finished growth and puberty. The extent to which the adolescent has acquired some skills for self-management should also be taken into account, as well as their own expectations Adolescent patients with chronic conditions have specific needs that go far beyond treating their condition. These concerns are usually better addressed by an interdisciplinary team	Transition clinics can provide a tailored approach to young adults, addressing issues specific to this age group including taking responsibility for their diabetes, experimenting with drugs or alcohol and managing diabetes away from home. Transition clinics can also give adolescents/young adults an opportunity to meet with providers of different disciplines

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