8 Skills for Growing Up and Ready Steady Go: Practical Tools to Promote Life Skills in Youth with Chronic Conditions

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8.1 Introduction

Youth with chronic conditions face the same challenges on their way to adulthood as their typical developing peers but encounter additional bumps in the road because of their chronic condition and its consequences. Becoming an adult—the transition into adulthood—requires the mastery of life skills (i.e. being able to perform adult roles). This transition occurs in several life areas, such as education and employment, interpersonal relationships and sexuality, finances and housing. As Binks et al. [1] noted, transition should be considered as a process rather than an event, and therefore each adolescent should be timely prepared for future roles. In fact, transition into adulthood ideally is a gradual shift, consisting of several steps to acquire age-appropriate life skills.

The importance of preparing youth for future roles requires a future-oriented approach in healthcare. Next to paying attention to symptoms and the treatment of the chronic condition, healthcare professionals need to tune to the specific developmental phase the young person goes through (see Chap. 5). This implies that addressing the development of autonomy and social participation (e.g. relationships with peers, education and leisure) becomes increasingly important for youth. Moreover, because the chronic condition impacts their development of autonomy and their opportunities to participate [2], young people with chronic conditions are at risk for overprotection by their parents [3, 4]. While young people with chronic conditions

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repeatedly stress the importance to discuss their future roles in the various life areas during healthcare consultations, these topics are often underexposed [3, 5, 6].

To open up discussions about developmental tasks and challenges during healthcare consultations, the use of comprehensive individual transition plans has been advocated [6–8]. Such plans help to regularly monitor the development of autonomy of youth in various life areas. Unlike transition readiness assessments that are more focused on medical management (e.g. disease knowledge) and assessment of treatment-related skills [9], individual transition plans are helpful to monitor the development of independence and autonomy, and as such can provide guidelines for action for young people, their parents and healthcare professionals. In this chapter, we discuss two specific examples of transition plans that facilitate the communication about the development of age-appropriate life skills from childhood to late-adolescence: the Skills for Growing Up (SGU) and the Ready Steady Go (RSG) tools. Since the developmental challenges are similar across chronic conditions, these tools are generic and can be used for all young people. The SGU, however, has diagnosis-specific adjustments. We elaborate on the theoretical framework, the content and structure of, and the first experiences with, and outcomes of these tools.

8.2 Theoretical Framework

The underlying concepts of both tools stem from the Basic Psychological Needs Theory, part of the Self-Determination Theory [10, 11], although not specifically mentioned by the developers. According to these, having autonomy, competence and relatedness are fundamental psychological human needs. In the Self-Determination Theory, autonomy refers to behaviour based on willpower and choice; competence refers to being able to master the environment; and relatedness means being connected with other persons in social constructs. In addition, having autonomy is essential for healthy functioning [12], and is a prerequisite for developing oneself as a motivated agent. It is important to distinguish between *executional autonomy* (being able to self-perform) and *decisional autonomy* (being able to make own choices) [13]. These principles are reflected in both the SGU and RSG. Both tools aim to support the development of competences (e.g. life skills). Youth are encouraged to take the lead, they are challenged to do certain things themselves (e.g. making a meal) or, if they cannot *do* it because of the disability or chronic condition, to take charge of it (e.g. deciding what has to be cooked). Relatedness is supported by addressing the importance of finding support when needed, developing friendships, intimacy and sexuality.

Although the development of autonomy is an ongoing process that onsets at a very young age, children need to have certain cognitive abilities to explicitly develop autonomy and reflect on it. Hence, the SGU can be used by children of 7 years or older, whereas the RSG is appropriate for youth of 12 years and older. Autonomy and acquiring competences are also corner stones in the Positive Youth Development (PYD) perspective [14] (see Chap. 2). PYD interventions focus on positive outcomes (i.e. self-advocacy, skill building and relationships with others). Both tools presented in this chapter can be seen as PYD-approaches because these support

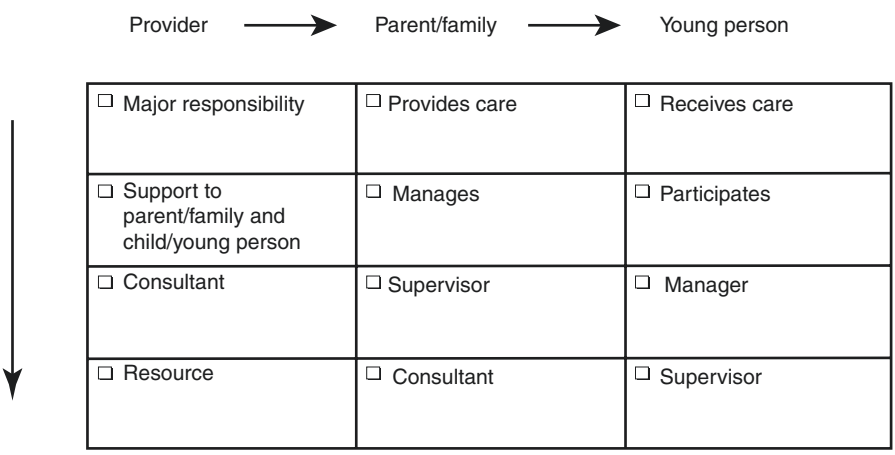

Fig. 8.1 Shared management model. (Growing Up Ready, Carie Gall, Shauna Kingsnorth, et al., Physical and Occupational Therapy in Pediatrics, 2006, reprinted with permission of Taylor & Francis Ltd, http://www.tandfonline.com)

normal development and promote the development of life skills. Also, both tools follow the framework of the Shared Management Model (SMM) [15]. The SMM outlines the gradual shift in responsibility for health, care and functioning from parents or caregivers to the child as he/she grows older (Fig. 8.1). The SGU and RSG align with this by proposing a stepwise approach to the development of competencies of youth across different ages.

8.3 Skills for Growing Up

The SGU approach was developed in Canada (Holland Bloorview Kids Rehabilitation Hospital) and was adapted for use in Dutch paediatric rehabilitation care (SGU-Dutch) [16, 17], paediatric nephrology (SGU-Nephrology) [18] and paediatric epilepsy care (SGU-Epilepsy) [3]. The tool is based on four key principles: (1) universality (encouraging family interaction about age-appropriate development), (2) family centredness, (3) shared management and (4) developmental approach [19].

The SGU consists of three (developmental) age-appropriate item lists: 'Getting started' (7–11 years), 'On my way' (12–16 years) and 'Almost there' (17 years or older). Additionally, there is a list for parents (not for the SGU-Dutch). Each item list in the Dutch version covers nine life areas: Me, Healthcare, Living and ADL (activities of daily living), Relationships, Education, Transportation, Sports, Leisure activities, and Employment (Fig. 8.2). All life areas contain items that represent age-appropriate knowledge, skills or activities per area (see Box 8.1). Per item, a young person can indicate whether he or she already possesses the mentioned knowledge, or skills or already performs the specific activity. Parents fill out whether or not they think their child already knows about the topics raised, masters the mentioned skills, and performs

Fig. 8.2 Life areas in the SGU. (With permission from: Hilberink et al. (2020). Focus on autonomy: Using 'Skills for Growing Up' in pediatric rehabilitation care. Journal of Pediatric Rehabilitation Medicine, 13, 161–167)

Box 8.1: Item Examples and Action Plan Format of the Skills for Growing Up Tool[a]

Me

'I can tell others what my condition is and what it practically means for my daily life' (12–16 years)

Healthcare

'I know what to do when I forget to take my medication' (12–16 years)

Relationships

'I spend time with my friends outside school' (12–16 years)

Education

'I know what to do to get an internship' (17+ years)

Work

'I know the influence of my condition on work' (17+ years)

Living and ADL

'I sometimes do chores at home' (7–11 years)

Transportation

'I travel by myself by public transportation' (17+ years)

Leisure activities

'I attend a camp, like school camp or soccer camp' (7–11 years)

Sports

'I can swim' (7–11 years)

Action plan

Step 1: I want to work on the following items:
[items scored with no]
Step 2: I will take the following steps to work on these items:
[description of steps to take]
Step 3: I will work on these items on:
[description of step] [date]
[a]Republished with permission of Sattoe et al. 2014 [18]

the tasks or activities independently. At the end of the list, youth can choose which items they would like to work on for the coming period and are stimulated to make an action plan accordingly. They can also write down any questions they have. The lists and action plans are discussed during consultations with healthcare professionals.

While the aforementioned SGUs are developed for youth with normal intelligence, youth (with or without epilepsy) with a mild intellectual disability can use the SGU-ID (intellectual disability). The SGU-ID has two age-appropriate item lists: 'Getting started' (7–13 years) and 'Almost there' (14 years or older). These lists consist of fewer items and items are phrased vernacular compared to the other SGU tools. Rotterdam University of Applied Sciences and Rijndam Rehabilitation provide the Dutch SGU lists for free at: https://www.opeigenbenen.nu/professionals/transitie-toolkit/tool_groei-wijzer/, and at: https://www.rijndam.nl/innovatie-onderzoek/productcatalogus-voor-zorgprofessionals/e-learning-hoe-werk-ik-met-de-groei. An e-learning has been developed to support professionals in child rehabilitation in using the SGU-Dutch https://www.free-learning.nl/modules/groei-wijzer-in-derevalidatie/start.html.

The SGU tools aim to encourage the communication about the development of autonomy and life skills between youths and parents and between youths, parents and the healthcare professionals. In other words, it aims to hold up a mirror to show what constitutes 'typical' age-appropriate development and to make a stepwise action plan according to the chosen life skills. Therefore, the SGU is not a checklist to measure ones 'life skills' status', but rather a communication tool to promote discussion about autonomy and empowerment of youth with chronic conditions. In Box 8.2 an illustrative case of a consultation with a boy and his mother is presented.

Box 8.2: Application of the Skills for Growing Up Tool: An Example
A few days ago, Eli and his parents came to the children's rehabilitation centre for consultation. Recently, he turned 18 years old and he is planning on pursuing further education. He will be transferred to adult rehabilitation soon. Before the consultation, both Eli and his mother filled out the Skills for Growing Up lists. In the past few years in rehabilitation care, attention has been given to Eli's development of independence and autonomy, but the therapists felt that Eli has not been able to show his potential. They gave him and his parents the Skills for Growing Up lists to facilitate interaction between them about his

development. Eli filled out the list together with his mom and came up with some points he would like to work on. During consultation, the therapist asked him about this, but before Eli could respond his mother took over. Quickly the conversation evolved between his mother and the therapist and was *about* Eli instead of *with* him. Eli's mother for instance complained about him sleeping way past breakfast time in the weekends, and about him being busy on his phone all the time. The therapist noticed that Eli was not feeling comfortable to say anything and turned the conversation. He explained that things that parents see as problems are not always problems for their children. Actually, wasn't Eli's behaviour appropriate for his age? After this was clear, the conversation about Eli's future could start. The therapist asked him again and Eli told him that he would like to live independently after finishing his vocational education. He said the Skills for Growing Up lists encouraged him think about what would be needed for him to live independently and how he could take the lead. He, for example, mentioned that he could make his own breakfast instead of waiting for his mother. Together with the therapist Eli developed an action plan to work on his independency in household activities, starting with making his own meals. He actively thought about the right time to start doing this and about who he could ask for help if needed. This conversation made his mother aware of amount of help she and her husband offered Eli. She admitted that Eli's behaviour was common for his age and that he should get more room to try to do things. Instead of his parents solving everything for him, Eli should be encouraged and facilitated to take care of himself. For Eli's parents, the consultation with the Skills for Growing Up list helped them to put the choices and wishes of Eli before their own. For Eli, the consultation with the Skills for Growing Up list lead to a conversation about becoming independent and eventually resulted in a tailormade action plan. He became aware of the fact that, while he is not ready to live independently yet, he could take the lead in working towards independency in small steps. He is the one who has to take action, but he can always ask for help if needed.

8.4 Ready Steady Go

The RSG tool was originally developed in the United Kingdom and is a continuation of previously developed individual transition plans for young people with rheumatoid arthritis [20]. It has been translated into French, Spanish, Dutch, Portuguese, Thai and Japanese [21]. The tool aims to prepare youth for the transfer to adult care, to support the development of autonomy, and to empower youth in order to improve long-term outcomes [22]. Although not explicitly mentioned as an aim of the RSG, some introduce the tool as a way to improve therapeutic adherence [21]. In contrast to the SGU, the RSG has not been not adjusted for specific diagnose groups and should be considered as a generic tool that can be used across different chronic conditions.

The RSG consists of four age-appropriate item lists: Ready (11/12–14 years), Steady (14–16 years), Go (16–18 years) and Hello (18–25 years). Each item list used in paediatric care covers eight domains: Knowledge (about the chronic condition and therapy), Self-advocacy (speaking up for yourself), Health and lifestyle, Daily living, School/career/your future, Leisure, Managing your emotions and Transfer do adult care. The list used in adult care (Hello) does not address transfer to adult care anymore and thus has seven domains. Items consider knowledge, skills and activities in the different domains (see Box 8.3). Recently, Easy Read versions of the Ready Steady Go lists have been developed [23].

The working way is the same as for the SGU: youth report per item whether or not they possess the mentioned knowledge, skills or perform the activities. There is, however, an extra column per item asking whether the young person wants to know more about this particular item. At the end of the lists they can write down anything else they wish to discuss with their healthcare provider. The lists are discussed during consultations with healthcare professionals. Youth are also encouraged to make an action plan, although this is not specifically mentioned on the RSG lists. If preferred, they could do so in collaboration with parents and/or healthcare providers during consultations. The University Hospital Southamptom/NHS provides the original RSG materials for free: http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx. Rotterdam University of Applied Sciences also provides the Dutch RSG materials for free at: https://www.opeigenbenen.nu/professionals/transitie-toolkit/tool_ready-steady-go/. The RSG tool is, just like the SGU, a communication tool to foster empowerment and autonomy in young people with chronic conditions, not a questionnaire to measure transition readiness.

Box 8.3: Item Examples of the Ready Steady Go Tool

Knowledge

'I am confident in my knowledge about my condition and its management' (Go)

Self-advocacy

'I feel ready to start preparing to be seen alone for part of the clinic visit in the future' (Ready)

Health and lifestyle

'I understand the risks of alcohol, drugs and smoking to my health' (Ready)

Daily living

'I can make my own snacks/meals' (Steady)

School/career/your future

'I am managing at college/work e.g. getting to and around, nature of work, friends etc.' (Hello)

Leisure

'I can use public transport and access my local community e.g. shops, leisure centre, cinema' (Hello)

Managing your emotions

'I am happy with life' (Go)

Transfer to adult care

'I am aware of the plan for my medical care when I am an adult' (Steady)

8.5 Experiences of Youth and Their Parents

Youth and their parents report positive experiences with both tools and mention several benefits of their use. Since these overlap between the RSG and SGU tools, we will discuss them without distinguishing between the specific tools. First, youth and parents agreed with the content of the item lists and in general felt that all life areas or domains in the lists were appropriate and relevant for them [3, 18, 21, 22]. However, a small group of youth in one study doubted the relevancy of the tool and reported that filling out competency lists reminds them of school work and doing exams, which is not a positive thing [3]. Another study found that the value youth attached to the tool correlated with age and youth's self-efficacy. Younger persons and those with lower self-efficacy seemed to appreciate the tool more [17].

Second, young people felt that the tool helped them in communication and interaction with both their parents and healthcare professionals [3, 16]. It made it possible for them to share their wishes, expectations and what they thought is important. According to healthcare professionals parents also mentioned that the tool supported their interaction with their child [18]. This was also found in another study where parents indicate that the tool made it easier for them to discuss transition-related topics with their children [24].

Third, youth report that use of the tool made them more aware of their independence and future prospects and stimulated them to make conscious efforts to obtain independence from their parents [3, 16]. Parents share the positive note about awareness, although some mentioned that the tool could also be confronting. For example, one parent mentioned that before filling out the item list he or she never thought about the future of his/her child with epilepsy, while he/she did think about the future of his/her other children without epilepsy. The tool was an eye-opener for this parent [3]. The benefit of increased awareness was also mentioned by parents of young people with end-stage kidney disease [18] and by parents of youth treated in rehabilitation care [24]. Finally, youth and their parents in general found both instruments to be supportive tools to develop autonomy and acquire life skills, and to achieve developmental milestones in small steps [16]. For example, young people with type 1 diabetes explicitly appreciated that the steps to independence start at an early age [25].

However, there are also some areas of concern. One study showed that youth with spina bifida following special education, seemed to have more problems with understanding the items and filling out the lists on their own. These young people were also less satisfied with the tool compared to those not following special education [26]. The same was true for youth with significant learning needs in another study [21]. To counter this, perhaps the version for young people with mild intellectual disability (SGU-ID) [27] or the specially developed 'Easy Read' versions of the RSG or the RSG version for use on a tablet [21] can be used. Another critique is that answering in 'yes' or 'no' dichotomy is not always easy. Often 'sometimes' is also the right answer and this might hinder the use of the tool [26], although adding a third answer category could also complicate the use of the tool if young people are more inclined to choose the 'safe' 'sometimes' option.

8.6 Experiences of Healthcare Professionals

Overall, healthcare professionals appreciate the tools and their aims [3, 6, 16–18, 22]. Depending on the setting, the tools are used by different disciplines. In paediatric somatic care, this is most often the (specialized) nurse [3, 18, 21]; in paediatric rehabilitation care, it depends on the local organization: sometimes it is the occupational therapist who uses the tool, in other centres a social worker, psychologist, or special education professionals [16].

Healthcare professionals report different benefits of using individual transition plans such as the RSG and the SGU. The first is that it creates awareness in all parties involved [6, 16, 18]. In professionals, particularly, it helped them to be more focused on the young person (instead of the parent or carer) and to employ a more holistic approach that provides room to discuss difficult topics during healthcare consultations [6, 16, 18]. Professionals treating youth with type 1 diabetes, for instance, experienced that young people experienced a lower threshold to speak up about subjects when using the RSG [25], and professionals working with the SGU-D in paediatric rehabilitation care noticed improved communication with youth [16]. Furthermore, professionals valued that the tool helped them to start raise awareness about autonomy development and self-management from an early age and that it stimulated youth and parents to take small steps in this development [18]. Also, healthcare professionals reported that use of the tools fostered family interaction about development of autonomy and independence [6, 16, 18].

However, in one study professionals also mention a point of attention. Although they all agreed that all life areas included in the SGU-N are important, some felt hesitant to discuss non-medical issues with young people [18]. They were wondering if their roles should extend beyond the medical domain to areas such as living and transportation. Other obstacles both for SGU and RSG relate to implementation and are discussed in the next paragraph.

8.7 Implementation Issues

Although the experiences with both tools are generally positive, the implementation in routine daily care remains a challenge. In case of the RSG, implementation is hampered by the workload of the healthcare teams [21]. Similarly, the use of the SGU-N has been found time-consuming which hindered its use [18]. This has been attributed to the lengthiness of the lists of the SGU-N. Also, professionals did not have enough time to review the lists, because youth and parents did not bring them to consultations [6, 18]. To counter the logistic problems, more user friendly digital forms of the lists, for example an App, would be useful [18], as has also been mentioned for the RSG [21]. Another issue is that it is important keep track of the topics that have been dealt with, which requires maintaining good documentation in the EPR [21]. Some nurses using the tool implemented electronic checklists to do so [6], but there are no standardized ways or recommendations for good documentation of the process.

An important step towards broader implementation of the tools is that their use is recommended in clinical guidelines; for example, the SGU is recommended in the treatment guideline for children with cerebral palsy [28]. Still, it is not always easy to convince professionals to value the more holistic approach and the needed change in healthcare delivery [18, 21]. Professionals questioned whether it is their task to monitor more generic life skills development, and felt that the medical domain is primarily where their tasks lay. Also, traditionally, professionals are used to a more directive role in healthcare, whereas the use of the SGU or RSG asks for a coaching role of professionals. In case of the SGU-N for instance, some professionals regretted that the tool was not supposed to be used as a checklist or an assessment [18]. This is in line with the issue of ownership mentioned by van Staa et al. [6]. They explained that some professionals viewed individual transition plans as something that young people themselves own. They felt the main aim is to empower these young people. Other professionals, however, felt the lists should primarily benefit the healthcare teams.

8.8 Perceived Effectiveness

Studies of the effectiveness of individual transition plans such as the SGU and RSG are scarce. Yet, the few studies that did research the outcomes of these tools, mostly show promising results. Adolescents using the SGU-N for instance, reported a higher frequency of discussions of non-medical topics [6]. In general, youth felt the tools helped them to become more independent, to plan their future and to prepare for their transfer to adult care [6, 16]. For the RSG, Cable and Davis [29] also noted a trend towards more talking about non-medical topics that were found important by young people. Nagra et al. [22] found that professionals had a more holistic approach and that it was easier to address sensitive topics during consultations when the RSG was used. Two studies also found some effects of the RSG on clinical outcomes. Use of the tool lead to better outcomes for young people after renal transplant [21] and was associated with a lower number of emergency room visits in young people with type 1 diabetes [29]. One quantitative controlled study did not find any significant short-term effects of the SGU-E on different outcomes, such as communication or self-management. However, the authors mention that this could be due to the lack of power of the study [3]. Finally, van Staa et al. [6] emphasized that despite an increase in discussions of non-medical topics, gaps between how important topics were rated by adolescents and how often these were discussed were still existent. They conclude that there is ample room for improvement in the application of individual transition plans.

8.8.1 Recommendations

1. Individual transition plans like the SGU and RSG are useful in practice, but it is recommended to tailor use of such tools, i.e. to select the right tool for the right person. There are for instance Easy Read versions for people with mild intellectual disabilities.

2. Professionals might benefit from proper guidance when implementing SGU or RSG to have a clear view on ownership of the tool and to prevent hesitation in discussing topics with young people. For both the SGU and the RSG there is an e-learning (in Dutch) available for professionals (https://www.free-learning.nl/modules/groei-wijzer-in-de-revalidatie/start.html and https://www.free-learning.nl/modules/readysteadygo/start.html). It is recommended that the whole healthcare team together works on an implementation plan before starting to work with either tool. Questions they should address in such a plan are for instance:
   (a) Who of the team will work with the tool?
   (b) When and how often will the tool be used?
   (c) Will the separate lists for parents also be used?
   (d) How can the tool be provided to young people and their parents? (On paper or digital)
   (e) How will action plans or agreements be documented and by whom?
   (f) How will results be shared among the team members; also during transfer to adult care?
   (g) Who will use the tool in adult care?
3. Good documentation of the process is important for the tools to be useful. It is recommended that teams develop a standardized way of documentation to be implemented in the electronic health record.
4. Finally, the paper form of the tools is time-consuming and brings logistic problems. Therefore, the integration of the SGU and RSG in electronic platforms used in healthcare is recommended. In the Netherlands for example, both tools are implemented in KLIK PROfile, which is an effective web-based application for the use of patient reported outcomes and experiences for monitoring [24, 30, 31].

8.9 Conclusion

Individual transition plans such as the SGU and RSG are useful tools to open up discussions about developmental tasks and challenges of young people with chronic conditions during healthcare consultations. Since these tasks and challenges are similar across conditions, the use of such generic tools seems appropriate. Young people, their parents and healthcare professionals all value the use of the tools and feel that it helps young people to become independent and to prepare for the future. They particularly appreciate the attention for generic developmental challenges. Furthermore it increases awareness and provides guidelines for all involved parties. Yet, effects on autonomy development are not underlined by effect studies yet. Also, the use of tools like the SGU and RSG requires flexibility and tailoring in clinical practice. However, attention for autonomy development is part of developmentally appropriate healthcare for young people and this is precisely what tools as the SGU and RSG foster.

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