

Global Health

Focus on autonomy: Using ‘Skills for Growing Up’ in pediatric rehabilitation care

Sander R. Hilberink^{a,b}, Anneke Grootoonk^c, Marjolijn Ketelaar^d, Ieteke Vos^e, Liselotte Cornet^f and Marij E. Roebroek^{a,f,*}

^aDepartment of Rehabilitation Medicine, Erasmus University Medical Centre, Rotterdam, The Netherlands

^bResearch Centre Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, The Netherlands

^cDepartment of Rehabilitation Medicine, Center for Rehabilitation, University Medical Center Groningen, Groningen, The Netherlands

^dCenter of Excellence for Rehabilitation Medicine, Brain Center Rudolf Magnus, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, The Netherlands

^eBlixembosch Rehabilitation Centre Eindhoven, Libra Group, The Netherlands

^fRijndam Rehabilitation, Rotterdam, The Netherlands

Abstract.

PURPOSE: Youth with disabilities face challenges regarding achieving autonomy. The ‘Skills for Growing Up’ tool was adapted for use in Dutch pediatric rehabilitation (SGU-D) to support development of autonomy. This study presents the experiences with the SGU-D tool.

METHODS: The SGU-D was implemented in 18 settings, of which 4 participated in the evaluation. Rehabilitation professionals were trained in the use of the SGU-D. In a qualitative study, participants were interviewed for their opinions regarding the tool.

RESULTS: Experience with the SGU-D was evaluated in 11 youth with disabilities, 11 parents and 8 rehabilitation professionals. They perceived the SGU-D as a helpful tool: i) to support development of autonomy, ii) to focus on future perspectives, and iii) to facilitate communication with family and rehabilitation professionals. Additional support from rehabilitation professionals on using the SGU-D was appreciated.

CONCLUSION: Youth with disabilities, their parents and rehabilitation professionals value the SGU-D as a practical tool for working on autonomy, and to identify important areas of development.

Keywords: Autonomy, youth, rehabilitation

1. Introduction

As youth with disabilities (hereafter referred to as ‘youth’) grow up, achieving autonomy is the main developmental task; however, this can be complicated by additional condition-related challenges. Late teenagers and (young) adults with physical disabilities lag behind in their development in several life areas [1,2]. Suboptimal outcomes have prompted pediatric rehabilitation

care to strengthen its focus on long-term outcomes regarding autonomy in societal participation and quality of family life. A useful approach is family-centered rehabilitation, which addresses the needs of youth and the family, and emphasizes the family’s involvement [3]. A future-oriented approach across the lifespan for children with neurodevelopmental disabilities is needed [4], accomplished by applying the life course health development model [5] to individuals with childhood-onset disabilities.

A future-oriented approach implies a focus on the development of autonomy and self-determination, to prepare youth for adult social roles. Autonomy and competencies or life-skills are fundamental human needs [6],

*Corresponding author: Marij E. Roebroek, Department of Rehabilitation Medicine, Erasmus University Medical Center, PO Box 2040, 3000CA Rotterdam, The Netherlands. E-mail: m.roebroek@erasmusmc.nl.

and are crucial for healthy functioning [7]. To support the development of autonomy and life-skills, interventions should not aim at problems or negative outcomes, but rather target the development of competencies, social connection and self-confidence [8] to improve the self-determination of youth. In this way, youth can gradually take over responsibilities of their caregivers to manage their health condition and its implications in daily life [9,10]. The ‘Skills for Growing Up’ (SGU) approach offers a practical tool to implement these theoretical concepts in clinical practice. The tool supports the development of autonomy in youth and encourages family involvement in pediatric rehabilitation. The SGU was originally developed in Canada and consists of three age-appropriate lists for youth, irrespective of the medical diagnosis [11]. After successfully piloting the Dutch version of the SGU (SGU-D) in the Netherlands [12], further implementation stagnated. The present study introduced an implementation strategy and evaluated a range of experiences with the SGU-D in pediatric rehabilitation.

2. Methods

2.1. The SGU-D

The SGU-D aims to raise awareness on age-appropriate development, to facilitate communication between youth, parents and rehabilitation professionals, and to encourage a stepwise action plan. To establish a cross-cultural adaption of the SGU, the original items were first translated into Dutch language. Secondly, 45 persons (10 youths with disability, 10 parents, and 25 pediatric rehabilitation professionals) indicated whether each item was relevant (no/yes) and made suggestions for new items. Thirdly, an expert panel (1 parent, 2 teachers in special education, 3 allied healthcare professionals and 1 pediatric physician) further fine-tuned the items to Dutch cultural and healthcare practices. A total of four items were removed, and 60 items were added (e.g., addressing self-agency, sexual development and intimate relationships). Subsequently, The SGU-D includes three age-appropriate lists, with slightly different age categories as compared to the original instrument (to match national school ages): ‘Getting started’ (7–11 years) (43 items), ‘On my way’ (12–16 years) (61 items) and ‘Almost there’ (≥ 17 years) (50 items) [7]. In addition, the new tool included a different set of domains (to match with previously defined life areas of development into adult roles [1]), and an expanded



Fig. 1. Pictograms used in the SGU-D.

item-pool (e.g., addressing self-agency, sexual development and intimate relationships). The tool covers nine domains: ‘me’, ‘health care’, ‘relationships’, ‘education’, ‘work’, ‘living and activities of daily living’, ‘transportation’, ‘leisure activities’ and ‘sports’ (Fig. 1). Each domain contains a set of pre-structured items (e.g., “I can stand up for myself in the places I routinely visit (school, home, shops, library, sports club, online)”) (Domain: Me; List: Almost there). See Box 1 for example items of each list (the SGU-D Checklists are available from the corresponding author). Youth and their parents have ownership over the SGU-D. For each item, youth indicate whether the activity applies to their situation (yes/no). From the items they found relevant, they chose one to three items to work on, thereby creating a stepwise action plan. This action plan consists of three tasks: 1) I want to work on the following topics; 2) What I have to do to realize these topics; and 3) When do I take the steps to realize these topics. Youth and parents can set this action plan together, or – if needed – ask support from a healthcare professional.

2.2. Training local experts

Rehabilitation professionals (local experts) followed a two day implementation group training using relevant literature, implementation tools and guided practice. They had no previous experience with working with the SGU-D. The training was led by two experts (SH, AG) in collaboration with CP-Net, a national network of healthcare professionals, researchers and people with cerebral palsy and their parents. Each participating center issued two local experts. They coordinated the use of the SGU-D in their work setting, i.e. presented the tool during team meetings to equip their colleagues to introduce the SGU-D during contacts with youth and

Box 1
Example items for the nine domains of the three age-appropriate SGU-D lists

Domains	Getting started (7–11 years)	On my way (12–16 years)	Almost there (≥ 17 years)
Me	<i>I can stand up for myself at school and in my neighborhood</i>	<i>I know who I can go to if life gets tough</i>	<i>I think about how I can be independent in our family</i>
Health care	<i>I know my height and weight</i>	<i>I discuss the type of care I will need in the future with my doctor (transition clinic, adult care)</i>	<i>I can explain my medical history to others</i>
Relationships	<i>I sometimes play at someone else's home</i>	<i>I know what safe sex is and why it is important</i>	<i>I know about the influence my disability has on my sexuality</i>
Education	<i>I talk about what I want to be later on</i>	<i>I know what type of support and approach I need in order to do well in school</i>	<i>I know what I can say about my disability in an orientation interview or a job interview</i>
Work	–	<i>I am looking into a part-time job, volunteer work or regular work</i>	<i>I know what I wish to achieve in my (future) work and/or study</i>
Living and activities of daily living	<i>I pay attention to my appearance (I comb my hair, brush my teeth, wash, wear clean clothes)</i>	<i>I manage my daily care alone (choosing my clothes, washing)</i>	<i>I think about my future living situation</i>
Transportation	<i>I sometimes head out onto the street under supervision (walking, cycling)</i>	<i>I can travel on my own (bike, bus, train, subway, taxi)</i>	<i>I go out in traffic on my own (biking, scooter, car)</i>
Leisure activities	<i>I sometimes sleep over at my family's or friends' house</i>	<i>I go out with others (to the movies, to the city)</i>	<i>I can go on holiday by myself</i>
Sports	<i>I am part of a sports team</i>	<i>I exercise regularly (walking, biking, sports)</i>	<i>I maintain a healthy lifestyle and sufficient exercise: playing sports/working out, cycling to school/job</i>

Box 2
Topic list of the semi-structured interview with youth and parents

- Use of the SGU-D (*experiences, expectations, encouraging autonomy, action planning, ease of use*)
- What did you learn by using the SGU-D? (*domains, being proud of an achievement, developmental structure*)
- What were hampering factors to use the SGU-D?
- What were facilitating factors to use the SGU-D?
- Reflect on the impact of the SGU-D (*did it trigger you?*)

their parents. Up to three months after the training, local experts could consult one of the trainers by e-mail or telephone concerning the implementation. The local experts evaluated the training using a five-item questionnaire in a 5-points Likert scale ((1) totally disagree to (5) totally agree).

2.3. Local implementation

The SGU-D was implemented in 18 settings of pediatric rehabilitation care, 9 of which were affiliated with a school for special education. Some settings organized group meetings for parents to introduce the SGU-D, and other sites provided written information. Generally, youth were informed in their classrooms or by their rehabilitation team and were asked to complete the SGU-D individually or together with their parent(s). Professionals actively encouraged the use of the SGU-D during therapy sessions and/or class meetings.

2.4. Evaluation study

A convenience sample of four settings participated in the evaluation study (three were affiliated to schools for

special education). A qualitative evaluation consisted of semi-structured interviews with pairs of youth without severe learning disability and parents, and rehabilitation professionals. All had their first experience working with the SGU-D during the study period. A convenience sample of 2 to 3 youth-parent pairs per center participated in separated face-to-face interviews with a research-assistant. Rehabilitation professionals were interviewed by telephone. The two interviews with youth and parents focused on whether and how they had benefited from the SGU-D. They were also asked what would help them to gain more benefit from the tool. Box 2 shows the topic list of the semi-structured interview. Two rehabilitation professionals per setting were selected; they were local experts or were trained by the local experts. In the telephone interviews, the rehabilitation professionals were asked to reflect on their role to encourage use of the SGU-D. All interviews were recorded, transcribed verbatim, and thematically analyzed. In the analysis, all transcripts were read to explore the data; data were allocated to the topics of the interview. Within each topic, themes emerged by means of an inductive process using open coding

Table 1
Evaluation of the training for local experts

Evaluation items	(totally) agree (%)
The training and literature explained the rationale of the SGU-D clearly	86
The training and literature provided clear information on how to work with the SGU-D	86
The training and literature provided sufficient information on how to implement the SGU-D	56
The training and literature were helpful to implement the SGU-D	71
The assistance on demand was helpful to implement the SGU-D	71

Table 2
Characteristics of the youths and parents

Youth	Age	Sex	Diagnosis	Parent	Age	Sex
Y1	8	M	–	P1	33	F
Y2	8	F	Cerebral palsy	P2	34	F
Y3	8	F	Filamin A deficiency	P3	36	F
Y4	10	M	Developmental coordination disorder	P4	42	F
Y5	11	M	Cerebral palsy	P5	40	M
Y6	12	M	Cerebral palsy	P6	–	M
Y7	13	F	Developmental coordination disorder	P7	53	F
Y8	13	F	Chromosome abnormality	P8	44	M
Y9	15	F	Spina bifida	P9	44	F
Y10	19	F	Cerebral palsy	P10	56	F
Y11	19	M	Cerebral palsy	P11	44	M

–: missing.

(i.e., themes arose from the collected data). Finally, themes addressing the same underlying construct were merged [13,14]. The Medical Ethical Committee of the Erasmus Medical Centre Rotterdam approved the study (MEC-2009-256); all participants provided informed consent.

3. Results

3.1. Evaluation of the training

The training consisted of two days separated by a seven-week interval. Ten teams attended the training in round-1 (15 professionals); 5 teams attended round-2 (8 professionals). Four other teams already used the SGU-D and were trained in the pilot study [12]. Among the course attendees were occupational therapists, social workers, psychologists and special education professionals. Overall, they evaluated the training positively (Table 1). Fifty-six percent considered the SGU-D sufficient to introduce in their own setting, indicating that professionals were trying to figure out what was the best way to incorporate the use of the SGU-D in daily practice. To meet the providers' needs, the second training day focused on implementation strategies, tailored to the local settings' organizational and clinical practices.

3.2. Evaluation of the SGU-D in daily practice

A total of 30 persons participated in the study: 11

youth (8–19 years; 5 with cerebral palsy; 4 girls), 11 parents (33–56 years; 7 mothers) (Table 2), and 8 rehabilitation professionals (3 occupational therapists, 2 rehabilitation physicians, 1 social worker, 1 teacher and 1 psychologist; 2 of them were local experts).

Box 3 shows goals formulated by the youth using the SGU-D. Overall, youth reported that they benefited from the SGU-D, and the parents found the tool helpful. Three main themes emerged from the interviews: i) the SGU-D as a supportive tool, ii) becoming aware of future prospects, and iii) facilitating communication. Subthemes included: i) youth achievements by using the SGU-D, ii) future plans (employment, education, hobbies) as well as parents' consideration of the potential of their child, and iii) interactions between youth and parents, including parents' hopes, expectations, and values, and how to best to communicate with healthcare professionals.

3.2.1. Supportive tool

Youth showed appreciation for the SGU-D in open responses: "I liked it because it gave me a clear picture". Another commented that the SGU-D gave him "grip". In addition to being helpful, the tool was considered "fun and important". Youth remarked that it helped them to undertake more activities (e.g., learning to swim, doing chores at home). The SGU-D was perceived as an aid. Parents acknowledged the SGU-D too: "My son now goes to the neighbors by himself, which he didn't do before". The SGU-D provided in-

Box 3
Using the SGU-D: Goals formulated by youth to work on

Going to a club of the church	Getting pocket money	Taking care for own things
Going to the cinema	Learning to prepare meals	Shopping
Getting morning routine	Doing groceries	Travelling alone
Becoming less dependent on parents	Getting an own bank account	Laying the table
Staying the night with friends	More self-decision at home	Ordering the taxi
Speaking to the doctor myself	Riding a bicycle	Choosing a new study
Packing my bag	Making friends	Doing homework myself
Learning to swim	Doing chores at home	

sight into age-appropriate development, which helped to focus on specific skills to be learned. For younger children (\pm 8–12 years), the SGU-D encouraged them to relate with peers (“*I have learned to make friends*”), while older ones focused more on school (“*I still do homework thanks to the SGU-D*”). The premise that the SGU-D allows the youth to have the initiative to select their goals and make an action plan was valued (“*It helps me to figure out what I find important*”), since they could personalize and prioritize the items they wanted to achieve. Making an action plan helped them to maintain an appropriate focus.

3.2.2. *Becoming aware of future prospects*

Youth and parents indicated that the SGU-D helped them to become aware of what they found important in the present and the future: “*Now I have more insight into my future expectations... it’s very useful to think about yourself*”. The SGU-D also helped parents: “*It was an eye-opener, I could now see all those points about what my son can and cannot do*”. Some realized that their child had more potential than they had previously thought. Often parents realized that they automatically did things for their child, and helping was not always a consciously made decision. A rehabilitation professional said: “*In younger children I see that parents say ‘Oh yes, that is an important thing to talk about’*”. Thus, the SGU-D triggered less limiting future expectations in both youth and parents. Rehabilitation professionals noticed that, especially in older youth, youth and parents held different perspectives. The rehabilitation professional helped to clarify the future perspectives and to address wishes and worries about the future (for both youth and parents). Such attitude fits the premise that the SGU-D is not intended to be used as a type of “examination” and rather as a tool for individualized development.

3.2.3. *Facilitating communication*

Youth reported that the SGU-D helped them to talk about important issues with their parents. Also, some parents appreciated the SGU-D as a communication

tool, not only with their children but also with rehabilitation professionals: “[The professionals] *help to set goals so rehabilitation and the home situation closely work together. This helps to achieve the goal*”. Other parents indicated that they no longer used the SGU-D after filling it out once. The SGU-D helped youth to discuss things they found important with professionals: “*Maybe therapists should create more room to talk about the goals I achieved or want to achieve. It is important to discuss these things together*”. A professional noted: “*And what I notice when you explain what that SGU-D is, and why it is so important to also think about that future whether they are 17 or whether they are 8, then they are all very open and inclined and they really see the importance of it. You also have great conversations*”. Some youth and parents indicated that they needed more help from a rehabilitation professional in order to make an action plan: “*Filling in the SGU-D together with a rehabilitation professional is a good idea*”. In particular, converting a goal into actual steps of action seemed to require more support: “*I want to make a goal out of it. The help from a professional would be welcome!*”. Rehabilitation professionals recognized that some youth and parents needed additional explanation about the SGU-D. The pre-structured response categories targeting whether an activity applies to his/her situation and he/she masters the skill (yes/no) were sometimes hard to score and some parents added one or more response options (e.g., ‘Can do it partially’).

4. Discussion

The present evaluated the use of the SGU-D in pediatric rehabilitation practice. Youth, their parents and rehabilitation professionals appreciated that the SGU-D supported the development of life-skills and autonomy. The tool helped them to raise awareness on the future prospects of youth and supported them to make an action plan to achieve personal milestones. The tool seemed to improve communication on these topics, be-

tween youth, their parents, and rehabilitation professionals.

In the present study participants appreciated the role of professionals to better benefit from the SGU-D. Since the introduction of the SGU-D in the Netherlands, some diagnosis-specific SGU-Ds have also been developed for youth with epilepsy [15] and with chronic kidney disease in a hospital setting [16]. Youth with kidney disease and their parents indicated they needed additional support with making an action plan to work on selected goals. The need for additional support is yet another reason for professionals to focus on family empowerment and involve youth and parents as partners of the rehabilitation team. A successful strategy to support youth and families is solution-focused coaching, rather than hand over solutions. A coaching approach facilitates engagement, empowerment and participation of the youth and their families [17,18] and is recognized as best practice in pediatric rehabilitation [19]. The combination of a solution focused coaching approach and the SGU-D seems to encourage family empowerment.

The present results and feedback demonstrate that youth, parents and rehabilitation professionals in pediatric rehabilitation generally experienced the SGU-D as a supportive tool to increase autonomy in youth. In the Netherlands, its use is recommended in the treatment guideline for children with cerebral palsy [20]. As only half of the trained rehabilitation professionals considered the training by itself to be sufficient to successfully implement the SGU-D in daily practice, an e-learning module for rehabilitation professionals was recently launched to better equip professionals to coach youth and parents working with the SGU-D. This module can be incorporated in pediatric rehabilitation medicine training to assist professionals to use the SGU-D in daily practice and to support and empower youth with disabilities and their families in achieving autonomy and developing life-skills.

The SGU-D contributes to raising awareness among youth and professionals for the development of life-skills and leads to more youth-parent and youth-professional desired discussions about participation [21]. The key is to adopt a life-course approach, since development is an ongoing and dynamic individual process, in many different and changing contexts which requires adaptability. Hence, providing opportunities to learn and facilitating experiences in real life from a young age onwards is necessary to develop the life-skills for current and future roles [22]. The SGU-D can help to identify personalized goals and to offer such opportunities.

4.1. Limitations

This qualitative study aimed to provide insight into the experiences with the SGU-D of youth with disabilities, parents and healthcare professionals. The incorporation of these three perspectives is a strength of the study. A limitation is that we did not perform paired-analyses to explore specific differences between youth and their parents, since our main aim was to use these perspectives for evaluating the experiences with the tool. Second, the sample size did not allow in-depth age-specific analysis corresponding to the age-appropriate SGU-D lists. Overall, the themes that emerged from the present results were similar to those found in youth with epilepsy [15]. Third, positive experiences with the tool do not necessarily reflect its effectiveness. Considering the relative low intensity of use and the diverse and personalized content of the SGU-D, selection of relevant outcome measures, design and follow-up period is a challenge. Future research should combine the e-learning (e.g., education on coaching to improve the support for professionals to work with the tool) and the use of the SGU-D, and evaluate outcomes such as self-determination and self-efficacy [23] and personalized outcomes (e.g., Goal Attainment Scale [24]) to establish the effectiveness of the tool.

5. Conclusion

Youth with disabilities, their parents and rehabilitation professionals generally found the SGU-D to be a practical tool to focus on autonomy and life-skills from a young age onwards. The tool facilitates discussions about autonomy between youth, parents and professionals. Implementation of the SGU-D would likely be beneficial in many pediatric rehabilitation care settings and is therefore recommended.

Acknowledgments

The authors thank the youth, their parents and the rehabilitation professionals of De Hoogstraat Rehabilitation (Utrecht), Merem Rehabilitation Centre De Trappenberg (Huizen), Scheper Ziekenhuis (Emmen) and Rijndam Rehabilitation (Rotterdam) for their participation in the study. We thank the following research assistants for interviewing the youth and their parents: Jitske Boerkamp, Jennifer van der Cammen, Bo Duijvestijn, Esma el Haddadi, Gul Kibiroglu and

Ebru Toker (School of Health Care Studies, Rotterdam University of Applied Sciences). We thank Heidi van Heijningen-Tousain (Research Centre Innovations in Care, Rotterdam University of Applied Sciences) for interviewing the rehabilitation professionals. We thank Johanna Children's Fund (JKF) (2013/0051-193), Rotterdam Children's Rehabilitation Fund Adriaanstichting (KFA) (13.10.01.2013/0051) and Foundation Beatrixoord North-Netherlands.

Conflict of interest

Authors report no conflict of interests.

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