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Everyday Life Situations of School-Aged Children with Severe Disabilities: What are the Goals for the Future? An Exploratory Study

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Abstract: This study investigated present and future everyday life situations (ELS) in home, school, work, and leisure environments for a group of school-aged children with severe disabilities, including complex disorders and a combination of disabilities. The purpose was to explore universal ELS; clarify how the children can be supported in their development of autonomy; and to gather information on potential overall goals for interventions. To make data comparable, all reported ELS were linked to the International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY) and listed along with information on the setting. Both today, and in the future, recreational activities and participation in school or work were of highest importance, but few reported ELS involved directly interacting with other children. More ELS were predicted to occur outside the home and with a higher degree of autonomy. Therefore, interventions would be focused on the overall goal that children with severe disabilities take initiatives to become independent and to form relationships with others.

Keywords: Children, classification, disability, everyday life situation, ICF-CY, involvement, participation, special education.

Everyday Life Situations (ELS) are everyday activities that occur regularly in a child's natural environments. The ELS require more or less complex actions and affect the child's development [1, 2]. Even though desires for involvement in ELS seem nearly the same for all children, children with disabilities are usually at greater risk of limited social involvement [3-5]. Their involvement may be affected by peer relationship difficulties causing problems mastering the social tasks of gaining entry into peer groups [6]. In addition, children with Severe Disabilities (SD), including complex disorders and a combination of disabilities, need support to carry out daily activities. Therefore, they spend much time with adults and their involvement in ELS often becomes mandated by people around them [7-9]. To facilitate involvement, the children's networks need to intentionally support them in their development of self-determination and autonomy. To get knowledge of the ELS for school-aged children with SD and clarify how networks can support them in their development of autonomy, the current study intends to explore universal ELS for

children with SD occurring in present time and envisioned for the future.

INTRODUCTION

Involvement in ELS means participation. In the interactive health model International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY), participation is a key construct, described as children's involvement in life situations including a feeling of belonging and engagement [10, 11]. The construct incorporates taking part, being included and accepted in ELS but also having access to needed resources. Considering education, participation includes two elements, both related to functioning within a context [7, 12, 13]. First, it is about being in the school setting and attending activities. It includes availability of and access to everyday activities, which adults can ensure based on legislation and the belief that children should go to school every day. Secondly, participation is about engaging while being there, e.g. enjoying lectures and acquiring knowledge. It considers the intensity of children's involvement in activities and reflects how individual children manage and experience demands and events.

Essential parts of learning processes are participation and peer relationships. Therefore,

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occurring ELS are the most critical features of children's experiences during childhood [2, 14]. In school contexts, participation may include a positive interaction among and acceptance by classmates [15]. With respect to children's engagement and how environments constitute affective and motivational aspects of participation, e.g. enjoyment and preference, accommodations are often needed and the ELS should be accepted by the individual child [16-18]. In this regard, the adults must learn what matters most for each child to enhance engagement, support development and facilitate well-being. Everyday learning that is interest-based improves children's engagement also in other activities, making them prepared for different contingencies and gradually responsible for what happens around them.

Severe disabilities are complex and most often include secondary conditions. They might be predictors for developmental and learning difficulties, and for limited involvement. The disorder cerebral palsy (CP)¹, for example, may include epilepsy; hydrocephalus; visual disturbances; hearing difficulties; neurodevelopmental deficits; communication problems; and learning disabilities [19-21]. In a Swedish study of children with CP, aged 5 to 8 years, participation restrictions were related to mobility, education, and social relations [21]. Epilepsy was found in 35% and visual impairment in 20% of these children. The combination of visual disabilities; communication difficulties; motor impairments; and additional impairments have various names including profound intellectual and multiple disabilities; complex communication needs; or multiple disability visual impairment [21-24]. In the current study, a combination of disabilities is labelled as severe disability.

To describe children's functioning, one has to move beyond their disabilities. Previous research has established that functioning is affected by several interacting factors and that medical diagnoses provide information neither on functional status nor on involvement in ELS [10, 25-27]. Instead, functioning is dependent on the interaction between the child with children with SD and the environment. For example, with appropriate technical aids and/or personal support, a child with visual impairment could help in preparing meals and thereby not experience limited social

involvement in that specific ELS. As involvement is also a matter of getting access to activities, not least physically, children with SD become dependent on Social Support Networks (SSN).

The SSN around children with SD are extensive. They include persons with various roles including nurturing; supporting; educating; and decision making. According to Harty and colleagues [28], the SSN rarely include close friends but up to 65 adults with roles as parents; professionals, such as assistants; teachers; and health professionals in interdisciplinary teams in addition to peripheral partners, such as principals and other decision makers. Over a child's life, transitions change the SSN; natural environments; and ELS [29]. As the children's involvement in ELS is so often dependent on their SSN, low expectations of a the child's skills can inhibit development instead of being facilitating [30, 31]. Some adults might do everything for the child, which can cause learned helplessness. Instead, teaching the child to help himself is an active way to attain independence and autonomy. According to Tellevik and Elmerskog [23], this strategy can be encouraged by educating those in the SSN, using a teaching approach centered on social involvement.

The opportunities for social involvement, including integration and participation for all in the society, are core ideological principles in Swedish disability policy [32]. Ever since 1968, those children with SD have had the right to preschool (1-5 years) and special education in training schools (6-21 years). In addition, various support systems promote equality in living conditions for the children. Those systems should collaborate in identifying and prioritizing individual areas for development and thus for intervention. Although the National Board of Health and Welfare has issued a decree that requests professional collaboration, it appears weak or absent [33, 34].

With the purpose to improve the collaboration among parents and professionals in the SSN around school-aged children with SD in special education, a *Participation and Mobility Project* (P&M project) was conducted in Sweden during the years 2008-2011 [23, 35]. The project aimed to test a method to further develop and utilize the skills of the SSN including parents and professionals such as assistants in school and home; teachers; service providers in health care; and decisionmakers. To create conditions for responsible persons to plan, conduct, and evaluate interventions focussing on participation, specific ELS in which children with SD participated were investigated.

¹Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitations which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. 19. Rosenbaum P, et al. A report: the definition and classification of cerebral palsy. *Developmental Medicine & Child Neurology* 2007; 49(s109): 8-14. (p9).

In the P&M project, the SSN of children with SD were the direct participants whereas the children became indirect participants. The intervention consisted of in-service training conducted as three workshops with the use of a holistic, activity-based teaching approach centered on individual children's involvement in ELS [23, 35]. The training included five steps: determination of present ELS; future ELS with definition of main goals; prioritization of activities; implementation; and evaluation. As the participants were allowed to freely express ELS, the project results did not indicate any universal ELS for those with children with SD.

Purpose

The purpose of the current study was to build on the first two steps of the P&M project² to explore universal ELS for children with SD and how SSN can support the children in their development of autonomy. Future ELS were investigated to get knowledge on potential overall goals for involvement in ELS and thus of importance for decisions of interventions.

Ethical Considerations

Ethical approval was not applied for this particular study since data were taken from the earlier P&M project. Since that project had a teaching approach focusing on networks, and no interventions were provided, it did not involve sensitive personal information or physical encroachment on subjects or used any method that affected the subjects physically or psychologically. All participants had consented to the research. Parents gave their written, informed consent for participation including access to patient records and special educators' data [35]. Principals' consent were given for professionals in schools. Interdisciplinary team members were involved based on the parents' desires in addition to individual's consent to participate.

METHODS

The design was descriptive in nature. Children's ELS in home, school, work, and leisure environments were investigated based on information from SSN of seven Swedish school-aged children with SD 5-19 years. To make data comparable, the information was linked to the International Classification of Functioning, Disability and Health, version for Children and Youth (ICF-CY), using linking rules [10, 36].

ICF-CY

The ICF-CY was used as a framework providing a structure and language for the description of functioning and involvement in ELS, considering the impact of the environment on a child's functional status.

The ICF-CY coding system enables linkage of information to ICF-CY codes facilitating identification and comparison of data. Linkage can be made to any of four components consisting of chapters including categories listed hierarchically with increasing level of detail, identified by codes with an increasing number of digits [10, 37]. The four components are Body Structures with anatomical parts; Body Functions including physiological and psychological aspects; Activities and Participation defined as the execution of a task or action and involvement in life situations; and Environmental Factors with physical, social, and attitudinal elements [10].

For the purpose of the current study, the nine chapters in the ICF-CY component Activities and Participation, so called life areas, and the fifth chapter in the component Environmental Factors, specifically health services, were used to identify ELS (Table 1).

Participants

Children – Indirect Participants

A sample of included children with SD in the P&M project had been identified by the six special-needs advisors supporting this group of children at the National Agency for Special Needs Education and Schools (SPSM) [35]. The support offered by SPSM involves individual's learning, the work and activities of teachers, and organizational issues in schools. The advisors have broad knowledge of the pedagogical consequences of disabilities, and the knowledge and skills they offer complement the resources of the municipalities and schools. For the purpose of the P&M project, each advisor had been asked to identify children with SD in their area; inform the parents and school principals about the project; and ask them for consent to participate. Inclusion criteria were school-aged children with severe disability including visual and mobility impairments and receiving on-going support from the special-needs advisor. In addition, the children would be in a transition such as enter school; advance to a higher grade level; begin higher education; begin working; or move to independent living.

Eight children had been identified and initially recruited to the P&M project. However, as one set of

²Data from the first two steps of the P&M project were available for the current study as its second and third authors had been engaged also in the P&M project.

Table 1: Chapters in the Two ICF-CY Components Used in this Study

Code	Activities and Participation (d)	Code	Environmental factors (e)
d1	Learning and applying knowledge	e1	Products and technology
d2	General tasks and demands	e2	Natural environment and human-made changes to environment
d3	Communication	e3	Support and relationships
d4	Mobility	e4	Attitudes
d5	Self-care	e5	Services, systems and policies
d6	Domestic life		
d7	Interpersonal interactions and relationships		
d8	Major life areas		
d9	Community, social and civic life		

parents withdrew from the study at the end of the first year, the current study included seven children from six different regions of Sweden. They ranged in age from 5 to 19. Three of them were boys and four were girls.

The health status of the children are described below. Information on health conditions, i.e., diagnoses, vision, and intellectual status had been collected from parents and patient records. The SSN had described the children's functional status in terms of physical capacity, communication, and vision. This information was defined and labelled by the researchers as displayed in the appendix. For the purpose of the current study, the functional levels were consolidated into three levels: severe, moderate, and mild difficulty (see Appendix).

Health Conditions

Three of the children were born premature (week 29, 32, 33). All seven had congenital injuries or brain injuries acquired in infancy, which affect mental functions. Secondary diagnoses of CP were reported for six of the children: two in four children with tetraplegia³ and one in two children with diplegia⁴ had dystonic features⁵, which affect movement functions. Five of the children also had a diagnosis of epilepsy.

Functional Status

The seven children had multiple disabilities of varying functional levels (Table 2). Four of the seven children had moderate to severe difficulties in all four variables. In addition to physical impairments,

communication, and visual difficulties, four of the children had severe intellectual impairments and two children had mild intellectual impairments. Due to age, the preschooler was not assessed. One child walked with physical support and two children used electrical wheel chairs to aid in locomotion. Three of the children could easily communicate. All children had moderate to severe vision difficulties. The functional status of all seven children does well fit into the concept of children with SD.

Transitional Phase

One child was entering school for the first time, four were advancing to the next level of education, and two were terminating school to begin work (Table 2).

Social Support Networks – Direct Participants

Sixty-five adults were included in the seven networks (Table 3). The number of participants in each network varied from 5 to 13 (Md 10). The majority of adults, 55% (n=36), did not frequently meet the children, whereas 45% (n=29), including parents, personal assistants, and teachers, daily interacted with the children. The researchers learned that many more professionals worked with these children but did not have permission from their employers to participate.

Procedure

Given the procedures used during the P&M project, the two first steps were to determine the ELS in which the children were involved. During the first workshop, teachers carefully defined the construct of ELS and draw attention to the variety of possible ELS. Home, school, work, and leisure were specified as spheres of activity [23]. Thereafter, each child's present ELS and where they occurred were jointly identified, named and listed by the SSN. This was followed by a determination of the future ELS that were envisioned

³Tetraplegia is the most severe type of CP characterized by bilateral spasticity predominating in the upper limbs, almost always in association with severe mental subnormality and microcephaly 20. Aicardi J, Bax M. Cerebral Palsy, in Diseases of the Nervous System in Childhood, Aicardi J, Ed. Mac Keith Press: London 1998; pp. 210-244.

⁴Diplegia is defined as a type of CP in which the lower limbs are much more affected by spasticity than the arms. (20. Ibid. p217).

⁵Dystonic CP is characterized by sudden, abnormal shifts of general muscle tone, often exhibiting abnormal movements. (20. Ibid. p221).

Table 2: The Children’s Functional Levels and Transitional Phases (see Appendix for Description of Levels)

	Child A	Child B	Child C	Child D	Child E	Child F	Child G
Age	19	16	5	18	17	16	12
Physical capacity	Severe	Severe	Moderate	Severe	Moderate	Severe	Moderate
Communication Expressing	Severe	Moderate	Moderate	Mild	Mild	Severe	Mild
Communication Understanding	Moderate	Moderate	Moderate	Moderate-Mild	Mild	Severe	Moderate-Mild
Vision	Severe	Severe	Severe	Severe	Severe	Severe	Moderate
Transitional phase	Begin work	Advance to next grade level	Enter school	Begin work. Living on his own	Advance to next grade level	Advance to next grade level	Advance to next grade level

Table 3: Participants in the Social Support Networks

	Network A	Network B	Network C	Network D	Network E	Network F	Network G	Sum
Parents	2	1	2	1	1	1	1	9
Personal assistants	1	3	2	3	2	1	0	12
Teachers	0	2	0	2	2	1	1	8
Special-educators	1	2	4	2	0	2	2	13
Professionals in interdisciplinary teams	1	2	3	2	3	2	0	13
Decision-makers	2	1	1	0	0	0	0	4
Principals	0	0	1	2	2	0	1	6
Sum	7	11	13	12	10	7	5	65

by the SSN as important for the children’s involvement. Thinking beyond the present, the envisioned future ELS were added to the lists.

To enable participants to further define ELS, the SSN were asked to complete the lists within a three month timeframe. This occurred while they, supported by the special-needs advisors, decided how to improve involvement of the child, i.e., while they prioritized activities.

Data Analysis

The initial analysis step was to link data to the ICF-CY. The first author assigned all listed ELS, submitted from each SSN, to the most detailed code using linking rules by Cieza *et al.* [36]. Thereafter, the three authors discussed the linkages. Any changes were made by consensus based on common knowledge of linking processes; the purpose of the P&M project; and the functioning of the children. During discussions, a coding scheme was created [38] including ambiguous

expressions of ELS and the following consensus-based considerations additional to the linking rules:

Intention

The intention of an ELS was considered, e.g. “math” was linked to Learning to calculate (d150), “planning the school day” to Carrying out daily routine (d230), and “playing the piano” was linked to Acquiring skills (d155). ELS intended as treatment, e.g. “music therapy”, “pool training”, “using a standing aid”, and “going to the occupational therapist” were coded as Health services (e580). “Rest” was coded as a leisure activity (d920) in a home environment, however, it was coded as a treatment (e580) in school settings because children with multiple disabilities often need time to stretch during school time. When an ELS occurred in several environments, it generated more than one ICF-CY code.

Age

Play activities, e.g. “rocking in a swing”, were viewed as a Major life area (d8) for the pre-schooler but

as Recreation (d9) for the older children. In addition, 'ride a moped' and 'travel by car' were coded as Recreation (d9) when offered as entertainment for children unable to drive themselves due to age or functional status.

Socialization

Independent of the environment, all ELS related to interaction with others were linked to Interpersonal interactions and relationships (d7).

Transportation

The destination was considered, e.g. "going to school by bus" was given the code for Using transportation (d470) and Maintaining educational programme (d8201).

A second analysis step was used to list the natural environments where the present ELS took place and where future ELS would take place according to the SSN. As one ELS could appear in two or more contexts, the number of environments became more than the number of ELS.

In a final step, the ELS were reviewed according to how they were formulated by the SSN to determine if they solely considered how the child executed a task or also how involved the child seemed in the ELS.

RESULTS

Present ELS

Altogether 259 linkages reflected present ELS (Figure 1). Treatments were defined by 27 linkages (11%) and related to the environmental factor of Health services (e580). The remaining ELS were distributed

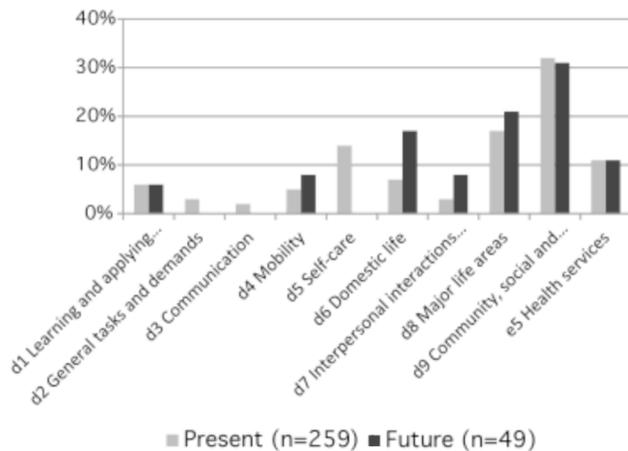


Figure 1: Distribution (%) of present and future ELS across ICF-CY chapters.

across all life areas defined by the Activities and Participation chapters.

Most ELS were associated with three of the nine Activities and Participation chapters: Self-care (d5; 14%), such as toileting, dressing or eating; Major life areas (d8; 17%), such as play, education or work; and Community, social and civic life (d9; 32%), such as recreational activities. Less ELS were associated with General tasks and demands (d2; 3%), such as daily routines; Communication (d3; 2%); and Interpersonal interactions and relationships (d7; 3%), such as relating with peers.

Future ELS

Altogether 49 linkages reflected future ELS that the networks envisioned (Figure 1). As for the present ELS, 11% concerned treatment, i.e., Health services (e5). No linkages were made to General tasks and demands (d2); Communication (d3); or Self-care (d5). Proportionally, more linkages were made to Mobility (d4), e.g. managing to enter the school building; Domestic life (d6), e.g. "acquiring a place to live"; Interpersonal interactions and relationships (d7), e.g. having coffee with a friend; and Major life areas (d8), such as working.

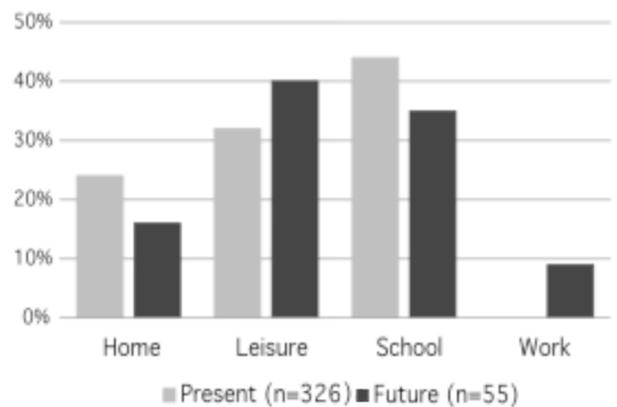


Figure 2: Distribution (%) of present and future ELS related to environment.

When analyzing the natural environments where the ELS occurred, more envisioned ELS related to leisure time (Figure 2). In the future, work became a natural environment, whereas less envisioned ELS related to home environment and school.

The review of how the ELS were formulated suggested a changed focus, from the execution of a task or action to involvement in ELS with increased independence (Table 4).

Table 4: Examples of how Everyday Life Situations were Formulated by the Social Support Networks

	“Life area”	Present	Future
d1	Learning and applying knowledge	Math; playing the guitar	Can choose what to do based on weekly planning
d2	General tasks and demands	Checking today’s schedule	---
d3	Communication	Singing	---
d4	Mobility	Going to school	Can find the way using the electrical wheel chair
d5	Self-care	Eating; brushing teeth	---
d6	Domestic life	Baking; shopping	Invite someone for coffee; stay in one’s own home
d7	Interpersonal interactions and relationship	Seeing peers	Interact with a friend
d8	Major life areas	Attending group activities	Participate in activities in the school yard; engage in work
d9	Community, social and civic life	Listening to music	Participate in sports; go to the pub

DISCUSSION

In this exploratory study, members of Social Support Networks (SSN) of children with Severe Disabilities (SD) have expressed their views about the Everyday Life Situations (ELS) in which children are involved at present time and will be in the future. The information provides data on how networks can support children in their development of autonomy and can provide guidance for long-term intervention goals. The seven children in the current study ranged in age from 5 to 19 years of age, and all had mobility, communication, and visual impairments. Their self-care activities were foreseen by their SSN to become more automatic and not considered as an ELS in itself in the future. It became obvious that participation is context-related and that the children’s social inclusion is dependent on the SSN.

For children with SD – as for all children - SSN are essential for their physical and social development and everyday functioning. Children with severe CP, however, may need help to prevent participation restrictions effected by hindering environmental factors such as limited access to objects and events [39]. For the children included in the current study, their SSN identified recreational activities and participation in school or work as being of the highest importance both in present time and in the future. However, few included ELS involved interaction with other children. It was envisioned by the SSN that over time more activities will occur outside the home and with a higher degree of autonomy. Therefore, interventions should be focused on teaching children with SD to take the

initiative to become more autonomous and better able to relate to classmates and friends.

Among environmental factors, also society’s social attitudes, including low expectations on the children’s abilities or self-determination, may constitute participation restrictions [30, 31, 40]. Most of the present ELS were expressed as the execution of tasks, i.e., less complex actions such as morning routines; eating; sleeping; and dressing. The network members also mentioned treatment elements such as ‘using a standing aid’ as an ELS without adding any activity performed when standing, or ‘listening to music’ without explaining the context or the relation to peers. One reason can be, consistent with Raghavendra and colleagues [24], that children with SD often attend different activities than other children. This may likely be due to the adult’s focus on training which may limit a child’s interaction with peers. In special needs education, often children are moved to activities determined and organized by adults. This suggests low expectations of each child’s possibilities to express opinions and participate in an active manner [30, 31]. Given that the same activities are likely to be of interest for children with SD as for other children [3], and that peer relationships are critical to promote any child’s development [2], the SSN surrounding children with SD should promote the establishment of peer social interactions.

Social interaction requires that children know and apply their own strengths, preferences, and limitations. Most often, children with SD need support of significant adults to become involved in a degree that is consistent

with their abilities [41]. All children's capacity of making choices emerges across the life span. When they are capable to stand up for themselves and their rights, they can help create a satisfying way of life [42]. Findings in the current study show convincingly that the SSN were aware of the increasing degree of autonomy. Their envisions for the future indicated a desire to help the children gain independence and provide opportunities to be involved in ELS.

Children's involvement in ELS is a determinant of well-being and life satisfaction and an important factor defining quality of life [43]. Within a group of children with disabilities, involvement may vary due to type of impairment and abilities but also due to the kind of activity, interest and contextual conditions [31, 44]. If the adults believe that children can achieve, it is likely that the children's adaptation to everyday demands improves [45, 46]. One of the children in the current study, for example, was later allowed to use an electrical wheel chair during school days. It significantly improved her autonomy and independence, and made her free from having an adult close to her all the time. She could draw attention when needed but decide by herself where to move. For children with SD, this opportunity of self-determination also provides understanding of what happens in school; why certain demands are repeated every day; and how to relate to the other children. In the end, it will most likely increase their experience of involvement.

Provided that circumstances are favorable, children with SD can act autonomously within a social framework. With the psychological capacity to make choices and get networks to help them compensate for impaired physical capacity, they can obtain their goals [30, 31]. A good illustration is a child with severe disability who could not handle tools by himself but decided to create an animal from wood during craft class. After asking his personal assistant to get a piece of wood and begin sawing, the child leaned against the assistant and most likely viewed himself as fully participating in that activity. It is consistent with Perenboom and Chorus [47] that "Performance in itself does not necessarily refer to participation, while not performing does not necessarily mean that someone is not participating. For instance, participation is also being in control" (p587).

Findings raised the question why few ELS included direct interaction with other children or were chosen by the children with SD. One plausible answer is that adults provide 'scaffolds' for children's experiences

throughout childhood and therefore arrange ELS that they determine will facilitate child development [30]. However, in addition to having fun and being in control, doing and being with others are elements of participation that most likely facilitate learning and development [2, 17]. As children with SD usually have little contact and no friendships with children without disabilities, they most often communicate with adults and seldom with persons of the same age [28]. Therefore, they need adult support to start interacting with peers and to introduce friendships. Planned and supported relationships among children with disabilities would be the optimal start. In parallel, other children would be coached on how to best interact with children with SD.

Findings also raised the question why so few of the present ELS reflected independent actions although two of the children already were in their late teens. One explanation to this observation could be that interaction or self-selected free activities are not traditionally prioritized in special education. Today, however, the use of Augmentative or Alternative Communication methods (AAC), such as Talking Mats or pressure contacts could support children's selection of activities or desires for peer participation more easily than in the past [48, 49]. Using AAC in school settings can allow children to indicate their desires and influence the way they dress; in what situations they want to participate; or which children they want to see. Most likely, such communication opportunities may make the children's experiences of ELS move from *attend* to *engage* in the activities and support their interactions with other children.

The two dimensions of participation, attend and engage, can be applied to different ecological levels from the degree of participation of a child in a certain ELS in the micro-system to the input of school curricula in the macro-system. Clearly, the network-child interaction is an intrinsic part of the degree to which a child attends school but also part of the degree to which a child engages in specific activities [13, 29]. Therefore, connections among individuals in a child's network are needed to share experiences and agree on what demands to put on the child in different ELS, and how to have the child involved, as regulated on national level. The Swedish Education Act, introduced in 2011 [50], is built on the United Nations Convention on the Rights of the Child [51]. This act includes consideration of the best interests of the child (art. 3) and to children's right to freely express their own views in all matters affecting them (art. 12). To fulfill those

intentions, children of all ages should be involved in planning and decision making that concern them. As this is not explored in the current study, it is left for future research to investigate how the rights of the education act are applied in special education.

The ELS reported by the networks were mainly correlated with the later chapters in the ICF-CY component Activities and Participation: Self-care (d5); Major life areas (d8); and Community life (d9). The first three chapters showed low representation: Learning and applying knowledge (d1); General tasks and demands (d2); and Communication (d3). These findings support those in previous studies [1, 7, 26], indicating that the first chapters include basic skills that are important across areas of functioning and constitute prerequisites for involvement in most life situations.

For the purpose of the current study, the ICF-CY worked as the framework for identifying ELS in which children with SD participate. In concordance with the ongoing debate about the construct of participation as context-dependent and closely related to socially and culturally defined roles [7, 15, 52], the findings showed a strong connection between the children's participation and the social environment. As people around children with SD most often mandate their involvement in ELS, it is a challenge for the adults to support the children by acting as facilitators of participation rather than barriers. By this, the adults should help the children to activities in a social context since performing single activities are not part of social participation. In special education, the ICF-CY framework can also be used as a diagnostic tool to assess multiple domains to assist in identifying special education needs [27, 53, 54]. The ICF-CY sees disability as a product of activity limitations and participation restrictions that are influenced by environmental and personal factors in addition to impairments. It pinpoints the important role of SSN on children's functioning and participation in ELS.

LIMITATIONS

In the current study, data were initially collected during the first workshop included in the P&M project. The SSN had at that occasion recently become acquainted with the constructs of participation and ELS. This might explain the frequency of ELS expressed as performance of tasks, e.g. morning routines; eating; sleeping; and dressing, and the functions required to carry out those tasks or

interventions such as using a standing aid. At this initial phase in the holistic teaching process, the present ELS might have been expressed based on what the members of the networks knew that they accomplished with the children rather than on what it meant for the children in terms of participation. Besides, the construct of participation is not entirely clear. The definition is under debate and the interactions with others, including a subjective experience, is not completely ruled by the ICF-CY definition "involvement in life situations" [7, 15]. When linking information, we focused on the children's social roles in the different environments, which might have raised our expectations on social involvement rather than performance of tasks.

Other limitations include: the small sample size; the wide age range; and missing information from professionals who did not participate due to their employers' wishes. Therefore, universal ELS for children with SD could not be established and only tentative conclusions can be drawn.

CONCLUSION

This exploratory study indicates that recreational activities and participation in school or work are of the highest importance for children with severe disabilities. However, their social support networks seemed to pay little attention to what the present ELS mean for the individual child in terms of interaction or relationships. Over time, ELS were expected to more frequently occur outside the home with a higher degree of autonomy. Therefore, the overall goal for interventions would be that the children with severe disabilities, as much as possible take the initiative to become independent and form relationships with other children. To obtain this goal, the support of the social support network is essential.

Further research should include a larger sample size and examine the opinions of various SSN with respect to the age of the child and their functional status.

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Appendix: Functional Levels of Disability

Level of disability	Physical capacity*	Communication expressing*	Communication understanding*	Vision** Visual acuity, field, performance and diagnosis
1	Severe disability, whole body affected - head, arms, legs (poor balance, legs and arms seriously affected)	Body language - general moods only expressed through whole or part of body or voice, i.e., smile, cry, tense body, relax	Responds to situations, i.e. shows pleasure or displeasure of music, touch, smell proximity to others but no specific gesture or word receives a consistence response	Blindness/Total visual impairment. Worse than 0.05
2	Severe disability in legs and arms (not able to walk and not able to eat by her/himself)	1-20 gestures, signs, words, picture symbols, objects of reference	1-20 gestures, signs, words, picture symbols, objects of reference	Severe visual impairment. Worse than 0.1 but equal to or better than 0.05
3	Severe disability in arms (not able to eat by her/himself). Minor disabilities in legs (able to walk)	21-100 gestures, signs, words, pictures, symbols, objects of reference	21-100 gestures, signs, words, pictures, symbols, objects of reference	Moderate visual impairment. Worse than 0.3 but equal to or better than 0.1
4	Minor disabilities in arms (able to eat by her/himself). Severe disability in legs (not able to walk)	Above 100 signs, words, picture symbols, objects of reference but not normal communication according to age	Above 100, signs, words, picture symbols, objects of reference but not normal communication according to age	Mild visual impairment. Worse than 1.0 but equal to or better than 0.3
5	Minor disabilities in legs and arms (able to walk and eat by her/himself)	Can make some daily needs known by other means	Can make some daily needs known by other means	No visual impairment
6	No disabilities in arms. Minor disabilities in legs (able to walk).	Normal communication according to age	Normal communication according to age	Not applicable
7	Minor disabilities in arms (able to eat by her/himself). No disabilities in legs	Not applicable	Not applicable	Not applicable
8	No physical disability that limit participation in activities	Not applicable	Not applicable	Not applicable

Ref: * Tellevik *et al.*, 2009, **ICD-10.

For the purpose of this study, the functional levels were consolidated:

Physical capacity (1-8): 1-3 = severe, 4-5 = moderate, 6-8 = mild difficulty.

Communication (1-6): 1-2 = severe, 3-4 = moderate, 5-6 = mild difficulty.

Vision (1-5): 1-2 = severe, 3 = moderate, 4-5 = mild difficulty.

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