'I want support, not comments,'

children's perspectives on supports in their life.

Kathleen Mortier $^{a^{\ast}},$ Lore Desimpel a , Elisabeth De Schauwer a , and Geert Van Hove a

^aSpecial Education Department, Ghent University, Ghent, Belgium

Address:

Kathleen Mortier

H. Dunantlaan 1

9000 Gent

Belgium

kathleen.mortier@ugent.be

^{*} Corresponding author. Email: kathleen.mortier@ugent.be

Abstract

Supports are a major part of the daily lives of children with special educational needs who participate in general education schools. Little attention has been paid to how they experience supports. Six children and their peers who were interviewed appreciated supports because they remove restrictions in activities due to the impairment. However, the analysis also shows how these positive supports can have negative psycho-emotional repercussions, and that they are less focused on addressing disabling barriers. The children's accounts demonstrate the ambiguous and situated nature of supports, and need for the children to be able to direct supports as 'chief partners' in the inclusion process.

Keywords: children's experiences, supports, inclusive education, social relational definition of disability, support model.

We would like to express our thanks to Arthur, Louis, Mieke, Lies, Sharon, Nikki and their peers for sharing their experiences with us.

Introduction

The social model of disability allowed a shift in focus from a medical discourse of an individual's misfortune to a discourse of societal change and a human rights perspective. Acknowledging the significance of the social definition of disability, literature in the interdisciplinary field of Disability Studies also sheds light on some critical issues. Even though the rhetoric of the social model of disability was adopted decades ago, reality reveals the difficulty of translating the underpinnings of the social model into practice. Professional interest often remains focused on pathology instead of the universal experience of people (Nisbet 1992; Danforth 2004; Gabel and Peters 2004). Another topic of debate is that the focus on social barriers has overshadowed people's experience with the effects of impairment. Thomas (1999) argues for a social relational definition of disability which recognizes that apart from social forms of oppression (Disability), people also experience restrictions in activity and psycho-emotional effects as a consequence of their impairment. This paper will use this broadened definition to analyze the experiences of children with 'supports¹' in inclusive classrooms.

Considering the presence and potential impact of supports in the lives of children with Special Educational Needs, it is essential to gain insights into their experiences and perspectives concerning this issue. According to the Declaration of the Rights of the Child, all children, including children with a disability, have the right to give their opinions about issues of concern to them, and adults should listen to their opinions (Sinclair Taylor 2002). Children

¹In accordance with the AAIDD definition (Luckasson, 2002), 'supports' in this paper will be used to refer to support from an adult, support from peers, and support through adaptations and aides/devices.

are not included as research participants in most of the research (Allan 1999; Lewis and Lindsay 2002). Often parents are used to voice their children's perspectives. Even though parents know their children very well, their experience is not necessarily the same (Lewis and Lindsay 2002; Garth and Aroni 2003). Gibson (2006) points out that the 'voice' of children labeled with Special Educational Needs remains unheard. This "Culture of Silence" (Freire 1985) is linked with modernist education systems in which the 'other' is silenced.

"A barrier exists, a barrier of hegemony, modernist knowledge, preventing access to the child's subjective world. His/her subjective way of perceiving and understanding him-/herself and others, his/her subjective way of grasping what his/her needs are in relation to his/her education, ways in which variables impact on him/her and in turn are impacted upon by him/her, remain cloaked in a culture of silence. It is arguably this which prevents the realization of policy objectives and ideals of inclusive education." (Gibson 2006, p. 322) Recognizing the value of the children's 'knowledge' in the process of building inclusive schools, we listened to how they experience supports in their school environment. The purpose of this paper is to analyze the effects of supports on barriers of impairment and disability according to the perspectives of six children and young people with special educational needs, and their peers in general education schools in the Flemish speaking part of Belgium.

A number of studies show that supports are perceived by children as necessary and are linked with positive school experiences but also raise a number of issues that require consideration. Different kinds of supports are appreciated by students when they allow them to participate in class activities, help them keep up with the rest of the class, or stimulate social participation (Lightfoot, Wright, and Sloper 1999; Hutzler et al. 2002; Messiou 2002; Hemmingsson , Borell, and Gustavsson 2003; Curtin and Clarke 2005). Some students mention they do not like to be taken out of the class during fun activities. Students often do not like 'special' attention that can come with supports, they want to be treated the same as their classmates (Giangreco et al. 1997; Hutzler et al. 2002; Norwich and Kelly 2004; De Schauwer et al. 2009; Curtin and Clarke 2005).

An issue that is addressed in several studies is the lack of say children have in the supports that are offered. How and when supports get organized is determined by adults with very little influence by children (Skär and Tamm 2001; Hemmingsson et al. 2003). Children want to be involved in choices about the type of supports they will get (Lightfoot et al.,1999). Building a good and close relationship with support persons is difficult and time consuming according to the students. The relationship is often experienced as unbalanced in the sense that the students are expected to open themselves up completely and have great trust while this is not reciprocal (Skär and Tamm 2001). There is the obvious risk of giving the students too much support and taking over their work. Students want to do as much as possible without help or adaptations (Lovitt, Plavins, and Cushing 1999; Broer, Doyle, and Giangreco 2005; Mortier et al. forthcoming).

Peers know that adult in-class support is for a particular student but they mention that they do call on the support person's help when that is allowed by the classroom teacher (Van Hove, Mortier, and De Schauwer 2005). Classmates acknowledge that supports and adaptations for the student with a disability have a positive effect on their learning as well (Fisher 1999). Also research on buddy programs show positive outcomes in terms of increased positive interactions and learning for the student with a disability as well as for the peer (Copeland et al. 2004).

Methodology

Participants

The participants of this study were children and young people² with a disability (n6) and their peers (n19). We conducted semi-structured interviews and focus groups. The children with a disability go to general education schools and were selected from a database of the parents movement 'Parents for Inclusion' and the Special Education Department of Ghent University. The selection was based on a combination of sampling procedures, such as purposeful sampling (a); convenience sampling (b, c, d) and maximum variation sampling (e, f, g) (Patton 2002). Participants were children:

- (a) with a disability in inclusive education
- (b) who are able to communicate verbally
- (c) in schools with a geographical spread that was feasible for the researcher
- (d) and families who hadn't recently been asked to participate in research activities
- (e) of different ages
- (f) of different gender
- (g) with varying needs for support

Each of the focus groups consisted of the student with a disability and four of his/her classmates. For variation purposes, two of the classmates were chosen by the child with a disability and two by the teacher. A brief description of the participants can be found in Table 1. The parents of the children with a disability were contacted by phone and received a letter describing the research project and the request to participate. After discussing it with their children, all the parents who had been contacted agreed to participate. The parents of the selected classmates were also asked for their informed consent.

² For this paper we will use the term children to refer to the participants (age 9-18)

Participants in	Participants focusgroups				
Student	Gender	Age	Strengths/Needs	Grade	Classmates
Arthur	М	9	A social boy, good at sports and using the computer. Need for cognitive and motor supports.	3 rd	4
Louis	М	9	Quiet boy, good at crafts and drawing. Need for motor and visual supports.	4 th	4
Mieke	F	11	Cheerful social girl, good at horseback riding and music. Need for learning and social supports.	6 th	4
Lies	F	12	Friendly girl who knows what she wants; loves dancing. Need for cognitive and social supports.	6 th	3
Sharon	F	15	Quiet girl, good at math and cooking. Need for social and cognitive supports.	2 nd secondary school (hairdresser)	4
Nikki	F	18	Creative young lady, good at drawing and foreign languages. Need for social, learning and motor supports.	6 th secondary school (office management)	0

Data collection

Interviews

Per student with a special educational needs, two semi-structured interviews took place. Each interview lasted about an hour. Most of the children were interviewed in school during class hours in a separate room. Nikki was interviewed at home and for Arthur the second interview was done in a familiar therapy room. For some the questions photographs were used as a way of enhancing motivation and response (Salmon 2001; Cappello 2005). The photographs

showed different supports for that student (Luckasson 2002) and were presented to the children with the question: 'what can you tell me about this photo?' The researcher asked additional questions based on the responses. The second interview gave the researcher a chance to focus on topics that had not yet been talked about or allowed to clarify things that remained vague during the first interview session.

Figure 1. Interview questions

-in separate document-

Focus groups

For each student with a disability, with exception of Nikki, a focus group was set up with classmates and took place at school. The focus group consisted of five participants. The student with a disability was included because the discussion concerns him/her. The focus groups were structured around the same topics as the interviews (except for questions about ideal supports) and the photographs were also used. The interviews and focus groups were audio recorded and transcribed verbatim.

Interviewing children

Special attention was given to facilitate the interview process with children, to increase the quality and authenticity of the data, and to take particular situations into account.

- Before the researcher started interviewing, she did some class observations with the intention to get to acquainted with the child in his/her environment, to break the ice in contact with the child, and to gather ideas for questions (Einarsdóttir 2007).
- During the interviews the 'photo-elicitations' technique was used (Hurworth et al. 2005). The interviews were supported by pictures of different sources of supports in the child's school life. The photographs were taken during the observations and were

used as a starting point and support for the conversation about the themes. The photographs were also used to stimulate the children to talk as much as possible and to avoid the interview becoming too directed by the researcher.

- 3. The researcher also used adapted language according to the age and abilities of the participants. For each child the questions were adjusted in order to make them concrete and related to his/her specific situation (Lewis and Porter 2004).
- 4. With two of the participants the approach was individualized further after the first interview, which did not go very smoothly. Extra supportive elements were sought and put in place. For Arthur, the second interview was done in the presence of his speech therapist. She had a lot of insight into formulation of questions that would work for him. The interview took place at the time of his weekly therapy because he didn't like being pulled out of class activities. The second interview was also a lot more structured than the first. The researcher gave Arthur five pages with the different interview questions, each in a different color at the beginning of the interview. This way it was clear to him how many questions were done and how many more to expect. Some questions were abbreviated and multiple choices were offered. For Lies the second interview was also adjusted. During the first interview it became clear that, as a way of joking, she likes to tell things different than they really are. Therefore, a peer was invited to join the interview and to redirect the questions when necessary.
- 5. For Nikki, the researcher did the interviews at her home at the request of Nikki and her parents.

Table 2Data collection						
Child	Observations	Interviews	Focusgroups			
Arthur	3	2	1			
Louis	2	2	1			
Lies	3	2	1			
Mieke	2	2	1			
Sharon	3	2	1			
Nikki	2	2	0			

Table 2: overview data collection procedures

Data analysis

Interviews

We used the social relational understanding of disability by Thomas (1999, 2004) to do a deductive analysis (Maso and Smaling 1998) of the interview data because it provides a framework to look at which level, supports have a desired or undesired effect. A distinction is made between impairment and disability effects that people experience, each of which has two dimensions: factors and processes that restrict activity (barriers in doing), and processes that effect psycho-emotional well-being (barriers in being). Disability implies a form of social oppression.

	Restriction of activity	Impact on psycho-emotional well-being
Disability effects	Α	b
Impairment effects	С	d

Thomas (1999): 15

The interview transcripts were entered in a software program, Nvivo 8 (QSR International 2008). The data about supports were coded according to the type of effects and impact they related to in Thomas' analytical framework. The bulk of the results section rests on this analysis of the interviews with the children with a disability.

Focus groups

Because the focus group data did not only reflect the student with a disability's lived experiences, but mostly peers' opinions and experiences, an analysis with this framework did not seem appropriate. The focus group data were analyzed inductively by doing a line by line analysis of the manuscripts, identifying themes representing interviewees' perceptions of the different kinds of supports and comparing them across the cases to identify patterns (Patton 2002). There was continuous communication between the first and second author in the course of the analysis process.

Results

The children described themselves in terms of how they look, their place among their siblings, certain personal traits, things they like and do not like, and things they are and are not good at. Their preferences, interest and activities were very age and gender specific and up to date with current trends and popular culture. They were all positive about going to school and indicated personal preferences for certain activities, with recess often being a preferred part of the day. Becoming a gardener, a fireman, film director, ballet dancer, teacher, caretaker of little children, and director of a graphic design company were the professional dreams for the future.

Impairment effects

The children with disabilities who were interviewed mainly identified positive effects of supports (from peers, adults, adaptations and aids/devices) in removing restrictions in activity due to their impairment (c). The positive effects mentioned were: being able to participate in a more comfortable way in different class-activities (keeping up with the pace or working slower, following instructions, seeing things better, having access to materials), being able to have a better grasp of the content (receiving extra instruction, working at own level of competence, adaptations of tests or test circumstances), being able to participate in activities that involve physical action (keeping up with writing, participating in swimming, P.E., art, typing class), and finally, being able to have access and participate in the wider school community (walking more securely, participating in recess play activities, getting to classrooms). Even though the supports were effective at eliminating many barriers, the results also show that in some cases, support from an adult could cause restrictions in activity as well, such as not being able to participate and interact with other students, or in fun activities in the case of pull out support.

One element that was prominent throughout the data is that children with special educational needs gave descriptions of supports that were very specific and situational. They were able to specify exactly for which part of the activity they need what kind of help and under which circumstances. They also communicated personal preferences about supports in their lives. Five out of the six students preferred a support person of the same gender. Some of them preferred support from an adult in the class and others out of the class. Some preferred peer support because peers were often more readily available (while adults are often wrapped up in other activities), for certain other things they preferred adult support because it was more secure.

"The buddy wants to take off my coat and put it on the hanger, but I want to do that myself. (...)I only need help starting off the zipper and only when I put my coat on." (Louis)

The peers also considered supports to be positive for their classmate, but also for themselves. They acknowledged that the student with special educational needs, should have supports and think it is good that different options are available. However, conversation between the student and support person can hinder the peers' concentration. The peers say they like being involved in providing support. A few comments were made about the time investment. In one situation there was mention of jealous reactions regarding the received support. These disadvantages were brought up by some of the students but were never acknowledged by the whole group.

"I used to think, wow Mieke is sometimes lucky that she does not have to do P.E., because it can be, huh, boring... but then I think, Mieke is not that lucky because sometimes she has to do more annoying things than I do." (peer Mieke)

"Then you can also with someone else, if he needs supports, or later when you want to become a teacher, do that too." (peer Arthur)

The supports that had positive effects on removing 'barriers in doing' due to impairment effects (c) can at the same time imply a negative impact on psycho-emotional well-being (d). In the interviews with the children with a disability these 'barriers in being' were expressed by the children as a normal part of their daily reality. They did, however, make those issues subordinate to their need for supports. None of the students chose to address them or discuss them with the people in their lives. We will explore some of the areas of tension that the children were struggling with.

Control-freedom

"What I find annoying is that they say 'your bag is too heavy', but that is not true. I want support, not comments." (Mieke)

All the students with a disability in the study experienced supports as additional control. Some of them had to sit in the front of the class (for reasons that they understood and thought were good) but did not like to never be out of sight of the teacher. Also the physical proximity of the support persons, which prevents one from chatting, fiddling around or spacing out, was tiresome. Another form of control was the comments from peers or adult support persons about their work, their grades, etc. One student felt it was unfair that the teacher and parents get more quickly informed about things that her peers are able to keep to themselves. She also experienced her dependence on an assistant for mobility as a loss of opportunity to get out in the world and experiment.

Dependence-Independence

"I want to do it [about math and reading] alone and by myself. I rather do it by myself."

(Arthur)

All the students in this study felt that they get too much support. Not in terms of devices and adaptations but support from adults and also support of peers was described as 'excessive'. The issue of unwanted help was raised over and over again in the course of the interviews. The children stressed the importance of getting supported for things that are difficult and not for things that they can do (even if it is only part of the task or the activity). Another point they made was that their support needs evolve as they get older and become more independent. One student mentioned the importance of being able sometimes to try something when you want to before you get assistance to do it. Also for the oldest student, reaching the highest possible level of independence was a major personal goal. Getting too much assistance enhances a feeling of inadequacy, the feeling that you cannot do it yourself.

Same-difference

"Everyone is allowed more time. So in fact, it is the same for everyone." (Nikki) The children were very aware of exactly of what was the same and what was different between them and their classmates in terms of support systems. It was always mentioned if similar accommodations had been made for other students. In this sense adaptive devices were not always experienced as positive when they made them stand out, like adapted tables, chairs, walkers, or tricycles. Computers were not experienced as stigmatizing. The children stressed the importance of keeping activities as normal as possible. They preferred accommodations that the teacher made and that were along the same lines as what was (or would be) allowed to the peers. Also, the way things look was considered important in this context. Support from adults was considered more stigmatizing compared with support from peers, especially if the support person exclusively gave assistance to him/her and was sitting close by. One of the children wanted to make sure that peers knew she was not getting privileges when she was getting physical therapy during P. E. classes but that she had to work hard too.

Consideration-self-determination

"I sometimes say no, I want to do that myself. Then the buddy says, no I want to do that and then I say, no, I want to do that. Sometimes they do not want to listen and sometimes they do (...) I often say nothing because I think they will be angry with me, that is why I don't say anything" (Louis)

The children's accounts show how they continuously consider other people's feelings. One boy described that when the support person arrives at school he feels torn between going to greet him and continuing to play with his friends (which is what he implied he would like to do). The children also indicated they do not want to be a burden to their fellow students, their teachers, and their parents. Some showed preference for peer buddy systems instead of solely spontaneous peer support because it ensures that the 'work' is divided over different peers. But one of the students would never even tolerate having such a system, which would 'force' peers to help her. When new peers or adults support them, they had to explain things over and over again so that person feels at ease. In cases of unwanted help or comments they did not like, they usually did not dare say anything about it out of fear of a 'strange' reaction or hurting the other persons' feelings because they mean well. They also want to maintain a positive relationship to ensure they get the support they need the next time around. One of the participants with limited cognitive and communicative abilities expressed a similar frustration but in her case it resulted in conflict and using bad language with either peers or adult support persons.

Hardship-evolution

"I have to work the whole time with him [support person] and I do not like that and I said: "No, I do not want to see you anymore, Mr. Jack." (Lies)

The children repeated throughout the interviews that certain supports (extra instruction/ therapy or using certain devices) were good for their development but that they can be hard and are things that they dread doing or using. Working hard on something was okay as long as the content was interesting. Some students also felt it is hard to get support from an adult on days when they get out of the wrong side of the bed, or just do not feel like working.

Disability effects

"I prefer boys [to be his buddy], but I can not choose that." (Louis) "I was sitting there all by myself on the playground. And that hurts, and you also notice in yourself that that really breaks you at certain moments" (Nikki) The data contained experiences with barriers in doing and being in due to disability. Those were referred to in terms of incidents but not as daily life occurrences. The supports were not very effective in dealing with these situations.

The student's participation in activities of his or her choice was sometimes limited or impossible (a). Playing along on the playground was experienced as a barrier by a couple of the students. They were just not invited to participate or peers decided the game would be too rough. Two students shared the experience of sometimes being forgotten by the peer buddy and thus not being able to participate in the next activity. One of the students in secondary school was not welcome in certain classes because of her level of competence. During these times she would work independently in a different room on worksheets that her support person or her mother provided. Her work often did not get reviewed. She also was not allowed to participate in exams.

There were also examples of the psycho-emotional impact of disability which was caused by painful reactions, insensitive behavior of others, and lack of choice regarding supports (b). A student mentioned having to hide her level of work or certain adaptations that were made for her to participate in exams to avoid jealousy among the other students. This student also talked extensively about a time in which she was socially excluded from the class group due to a falling out with a peer who used to support her all the time but then stopped doing so when she did not show gratitude. This situation led to bullying for a while, to the extent that she did not want to go to school anymore. This was resolved over time but she remembered not finding the appropriate help to get out of this situation. A number of people were very willing to listen to her problems, but nobody would do anything she considered helpful, and in some cases they made things worse. Inappropriate behavior and comments in the adult or peer support relationship such as saying 'poor you', holding hands, getting picked up, or rubbing the head, were resented strongly by the children in the study.

And finally, even though the children had clear ideas about their own preferences regarding supports, none of them had been able (or encouraged) to express any choice in whom or how and for what they received support.

Conclusion & Discussion

The images the children presented of themselves were very similar to those of same-age peers. As in the study of Connors and Stalker (2007), impairment or disability did either not come up or was only referred to indirectly when asked describing things that they are not good at or that are difficult. This could indicate a discrepancy between the image that children have of themselves, defined by sameness and the image that others have, more based on difference. It could also mean that the children don't see 'disability identity' as useful at this point in their lives.

The children with a disability in this study were mainly positive about supports in their school life. This is consistent with other research on children's perspective about supports (Lightfoot et al.1999; Curtin and Clarke 2005). Similarly, the perspectives of the peers on supports were positive. Peers were understanding towards the different types of supports because they recognize it helps their classmate with a disability. These findings about the peers' perspective coincide with those in other studies (York & Tundidor 1995; Allan 1997; Fisher 1999; Van Hove et al. 2005).

Thomas's (1999) social relational model allowed us to look at the effects of supports more closely, which led to some important findings about what it means for children to have supports in their lives. Almost all of the supports were aimed at dealing with barriers to activity as a consequence of their impairment. Although the data also reveal incidents of social oppression (disabling barriers), the supports were less focused on dealing those issues. The availability of supports as a whole, however, was one of the deciding factors for all of these students in overcoming the disabling barrier of getting access to the school of their choice.

The children with a disability worded the ambiguous nature of supports when describing their experiences. Being able to distinguish between 'effects on doing' and 'effects on being', resulted in the observation that a positive support can, at the same time, restrict his/her activities and negatively affect his/her psycho-emotional well-being. Areas of tension that the children were struggling with as a direct consequence of receiving supports aimed at reducing impairment effects were: control-freedom, same-difference, independencedependence, consideration-self-determination, and hardship-evolution. They did not want extra control or too much support. They felt uncomfortable standing out or having to consider other people's feelings despite of their own and they did not like having to work very hard (in one-on-one situations with adults) on dull content. The children understood the doubleedgedness of supports well. Throughout the interviews they nuanced their comments about the impact on their being with comments about the usefulness of the supports. Even though the sample in this study is limited, these direct insights highlight the importance of supports in children's lives on the one hand, but also the huge challenge of getting it right when looking at it from the child's perspective. This perspective calls for further research. The excessive amount of adult surveillance in the lives of the children (Watson et al. 2000) was also experienced by the children in this study. The conclusion of Middleton (1999) that children with impairments experience a great deal of avoidable disadvantage is supported by the data of this study. The data reveal how typical supports can have negative consequences

and risk enhancing disabling effects that the students, from their position, art not able to challenge.

Evolution in conceptualization of supports from a 'care model' to a 'support model', as conceptualized in the field of intellectual disability (Thompson et al. 2009), will be fundamental in addressing some of the issues that were pointed to by the children who were interviewed. Thompson and his colleagues (2009) make a distinction between supports and support needs and also look at desired outcomes. 'Support needs' are in most situations addressed as a normative or objective need, but there is also a felt need, expressed need or demand, or a comparative need. These authors note that support needs originate in a mismatch of competency and demands within the environment, and not in the type of impairment, which was the case for the students in the study. They suggest that through the thoughtful planning and application of individualized supports, improved personal outcomes, such as more independence, better personal relationships, enhanced opportunities to contribute to society, increased participation in school and/or community settings, and a better sense of personal well being/life satisfaction, can be achieved.

The accounts of the children in this study illustrate that they know very precisely what they need and what they do not need, what they like and what they do not like and why.

And more, what was experienced as an impairment or disabling barrier was varied across the different participants. Similarly, in research of Simmons, Blackmore, and Bayliss (2008) the situated nature of disability, inclusion and exclusion was revealed. Children should have the chance to evolve from being a recipient of supports to becoming an agent of their own supports. Being allowed to, and learning how to direct supports, will be an essential element of their quality of life in childhood as well as in adult life.

Any adult or peer arranging supports, or supporting the child should become very much aware of the possible negative psycho-emotional impact of supports. They should get the opportunity to be sensitized about the individualized and situated nature of supports and about the 'support model.' Middleton found that young people with a disability want adults who stick up for them, see them as individuals, have a sense of humor, are good listeners, are not embarrassed by their impairment, will talk about being disabled, talk about their abilities (rather than make the assumptions about what they can or cannot do), support and encourage achievements, do not take control away, do not impose ideological beliefs, help them develop social skills, help them to meet other children, both disabled and non-disabled, do not trivialize their concerns, are honest and straightforward, make them feel safe (in the sense of trustworthy), do not gossip about them, do not smother them, notice when they are unhappy, do not act on information without consulting them, do not pity, humiliate or abuse them, do not make promises they cannot keep.

Only with adults who assume this kind of sensitivity and understanding in relationship with the child or young person, true partnerships can be established. A mother of a son with a disability reflects that in the few cases that real partnership was established between the professional support person and themselves, it was her son who was in the role of 'chief partner' with the rest of them going alongside him in their different roles (Murray 2000). Supports are intended to contribute to the quality of life or greater opportunities for being, belonging and becoming of the children with a disability in our schools and societies (Shalock, Gardner, and Bradley 2007). Listening to children as chief partners and taking their advice seriously can be a way to avoid possible negative consequences and pursue the personal outcomes that they value.

Bibliography

- Allan, J. 1997. With a little help from my friends? Integration and the role of mainstream pupils. *Children & Society* 11, no. 3:183-193.
- Allan, J. 1999. Actively seeking inclusion. Pupils with special needs in mainstream schools. London: Falmer Press.
- Broer, M., M. Doyle, and M.Giangreco. 2005. Perspectives of students with intellectual disabilities about their experiences with paraprofessional support. *Exceptional Children* 71, no.4: 415-430.
- Cappello, M. 2005. Photo interviews: eliciting data through conversations with children. *Field Methods* 17, no. 2: 170-182.
- Connors, C. and K. Stalker (2007). Children's experiences of disability: pointers to a social model of childhood disability. *Disability & Society*, 22, 19-33.
- Copeland, S., C. Hughes, E. Carter, C. Guth, J. Presley, C. Williams, and S. Fowler. 2004.
 Increasing access to general education. Perspectives of participants in a high school peer support program. *Remedial and Special Education* 25, no. 6: 342-352.
- Watson, N., T. Shakespeare, S. Cunningham-Burley, C. Barnes, M. Corker, J. Davis, and M.
 Priestley. 2000. *Life as a Disabled Child: A Qualitative Study of Young People's Experiences and Perspectives*. Final Report to the ESRC. Department of Nursing Studies,
 University of Edinburgh: Edinburgh.
- Curtin, M., and G. Clarke, G. 2005. Listening to young people with physical disabilities' experiences of education. *International Journal of Disability, Development and Education* 52, no. 3: 195-214.
- De Schauwer, E., G. Van Hove, K. Mortier, and G. Loots. 2009. 'I need help on Mondays, it's not my day. The other days, I'm ok.' Perspectives of disabled children on inclusive education. *Children and Society* 23, no. 2: 99-111.

- Danforth, S. 2004. The "postmodern" heresy in special education: a sociological analysis. *Mental Retardation* 14, no. 6: 445-458.
- Einarsdóttir, J. 2007. Research with children: methodological and ethical challenges. *European Early Childhood Education Research Journal* 15, no. 2: 197-211.
- Fisher, D. 1999. According to their peers: inclusion as high school students see it. *Mental Retardation* 37, no. 6: 458-467.

Freire, P. 1985. The politics of education: culture power and liberation. London:Macmillan.

- Gabel, S., and S. Peters. 2004. Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability and Society* 19, no. 6: 585-600.
- Garth, B., and R. Aroni. 2003. 'I value what you have to say'. Seeking the perspective of children with a disability, not just their parents. *Disability & Society* 18, no. 5: 561-576.
- Giangreco, M., S. Edelman, T. Luiselli, and S. MacFarland. 1997. Helping or hovering? Effects of instructional assistant proximity on students with disabilities. *Exceptional Children* 64, no. 1: 7-18.
- Gibson, S. 2006. Beyond a 'culture of silence': inclusive education and the liberation of 'voice'. *Disability and Society* 21, no. 4: 315-329.
- Hemmingsson H., L. Borell, and A. Gustavsson. 2003. Participation in School: School
 Assistants Creating Opportunities and Obstacles for Pupils with Disabilities. *Occupation, Participation and Health* 23, no. 3: 88-98.
- Hurworth, R., E. Clark, J. Martin and S. Thomsen. 2005. The use of photo-interviewing: three examples from health evaluation and research. *Evaluation Journal of Australasia* 4, no.1/2: 52-62.

- Hutzler, Y., O. Fliess, A. Chacham, and Y. Van den Auweele. 2002. Perspectives of children with physical disabilities on inclusion and empowerment: supporting and limiting factors. *Adapted Physical Activity Quarterly* 19, no. 3: 300-317.
- Lewis, A., and G. Lindsay. 2002. Emerging issues. In *Researching children's perspectives*. Lewis A. and G. Lindsay (Eds.), 189-197. Buckingham: Open University Press.
- Lewis, A., and J. Porter. 2004. Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities* 32, no. 4: 191-197.
- Lightfoot, J., S. Wright, and P. Sloper. 1999. Supporting pupils in mainstream school with an illness or disability: young people's views. *Child: Care, Health and Development* 25, no. 4: 267-283.
- Lovitt, T., M. Plavins, and S. Cushing 1999. What do pupils with disabilities have to say about their experience in high school? *Remedial and Special Education* 20, no. 2: 67-76.
- Luckasson, R. 2002. *Mental Retardation: definition, classification, and systems of supports*. 10th ed,. Washington: American Association on Mental Retardation.
- Maso, I., and A. Smaling. 1998. *Kwalitatief onderzoek: praktijk en theorie*. Amsterdam: Boom.
- Messiou, K. 2002. Marginalisation in primary schools: listening to children's voices. *Support for Learning* 17, no. 3: 117-121.
- Mortier, K., G. Van Hove, De Schauwer, E. FORTHCOMING. Supports for children with disabilities in regular education classrooms: an account of different perspectives in Flanders. *The International Journal of Inclusive Education*.
- Middleton, L. 1999. *Disabled children challenging social exclusion*. Oxford: Blackwell Science.

- Murray, P. 2000. Disabled children, parents and professionals: partnership on whose terms? *Disability and Society* 15, no. 4: 683-698.
- Nisbet, J. 1992. *Natural Supports in School, at Work, and in the Community for People with Severe Disabilities*. Baltimore: Paul H. Brookes.
- Norwich, B., and N. Kelly. 2004. Pupils' views on inclusion: moderate learning difficulties and bullying in mainstream and special schools. *British Educational Research Journal* 30, no. 1: 43-65.
- Patton, M. 2002. *Qualitative research & evaluation methods (3rd ed.)*. Thousand Oaks: Sage.
- Shalock, R., J. Gardner, and V. Bradley. 2007. Quality of Life for People with Intellectual and Other Developmental Disabilities. Washington: The American Association on Intellectual and Developmental Disabilities.
- Simmons, B., T. Blackmore, and P. Bayliss. 2008. Postmodern synergistic knowledge creation: extending the boundaries of disability studies. *Disability and Society* 23, no. 7:733-745.
- Sinclair Taylor, A. 2002. The UN convention on the rights of the child: giving children a voice. In: *Researching children's perspectives*. Lewis A. and G. Lindsay (Eds.), 21-33.Buckingham: Open University Press.
- Skär, L., and M. Tamm. 2001. My assistant and I: disabled children's and adolescents' roles and relationships to their assistants. *Disability & Society* 16, no. 7: 917-931.
- Thomas, C. 1999. *Female Forms. Experiencing and understand disability*. Philadelphia: Open University Press.
- Thomas, C. 2004. How is disability understood? An examination of sociological approaches. *Disability and Society* 19, no. 6: 569-583
- Thompson et al. 2009. Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and developmental disabilities* 47, no. 2: 135-146.

- Van Hove, G., K. Mortier, and E. De Schauwer. 2005. *Onderzoek inclusief onderwijs*. Orthopedagogishe Reeks, 23. Universiteit Gent.
- York, J., and M. Tundidor. 1995. Issues raised in the name of inclusion: perspectives of educators, parents and students. *Journal of the Association for Persons with Severe Handicaps* 20, no.1: 31-44.

Figure 1

Interview questions

- Can you introduce yourself? (prompt questions: age, siblings, hobby's, strengths, weaknesses, preferences)
- Can you tell something about school? (prompt questions: how long, fun things and less fun things)
- 3. What are things that help you participate at school?
- 4. Questions with photos of different supports (peers, adults, devices)
 - a. Can you tell me something about what you see on the photo? + additional questions to clarify how the support is organized according to the student
 - b. Can you tell me what you find good about it?
 - c. Can you tell me what you don't find good about it?
- 5. Are there other supports at school?
- 6. Do you find that you have enough supports?
- 7. What does it mean to you to have supports in your life? (refer to elements of question4)
- 8. Are you always helped with the supports you get?
- 9. Do other children or people sometimes react to the fact that you have supports?
- 10. What are your preferences about [different supports]?
- 11. What would ideal supports look like for you?

Focus group questions

- 1. Can you tell me something about the supports at school for [name of the student]?
- 2. Questions with photos about different supports

- a. Can you tell me how that works?
- b. Can you tell me what you find good about it?
- c. Can you tell me what you don't find good about it?
- 3. What does it mean to you to be a buddy?
- 4. What kind of things do you pay attention to?
- 5. Do others react to the fact that there are supports for [...]