Preprint[1]

Facilitating and hindering factors in the realization of disabled children's agency in institutional contexts - literature review

Johanna Olli[a]*, Tanja Vehkakoski[b] and Sanna Salanterä[a]

[a] Department of Nursing Science, University of Turku, Turku, Finland;
[b] Department of Education, University of Jyväskylä, Jyväskylä, Finland
*Corresponding author. Email: jmolli@utu.fi

Disabled children's opportunity to act as agents may be compromised because adults have the power to choose who are entitled to express agency. Disabled children spend much time in institutions and with professionals of different fields. The aim of this literature review was to find out which factors facilitate or hinder the realization of disabled children's agency in institutional contexts. As data we used 19 research articles and analyzed them with inductive content analysis. Key factors relate to professionals' attitudes towards diversity, children and themselves as well as professionals' communication skills and institutional factors that enable the child to have an influence or prevent it and which give or do not give room for children's peer relationships. Rethinking the child and adult view and learning dialogical communication are recommended in the education of all fields that work with disabled children.

Keywords: disabled children, agency, professionals' attitudes, communication, literature review

Points of Interest

- Disabled children are not always given the opportunity to influence their own affairs.
- This article combines knowledge from 18 earlier studies about professionals working with disabled children in school, health or social care.
- Professionals can help the child to have an influence on her/his own affairs by respecting diversity and children as individuals, by noticing their (professionals') own influence on children and by developing their (professionals') own communication skills
- The structures of institutions and society also need developing in order to enable the child to have an influence and to allow space for children's peer relationships.
- Essential for the future education of all professionals working with disabled children: emphasizing child-centred attitudes and better communication skills

Introduction

Due to the contributions of childhood studies, children have been increasingly considered as active 'beings' and social actors with their own values and rights instead of only 'becomings' and objects of adult goals (e.g. James & James 2004, Mayall 2002). From this perspective, researchers have become interested in examining children's agency and its realization in various institutional settings, such as schools (Rainio 2010), day-care centres (Vandenbroeck & Bouverne-De Bie 2006) and hospitals (Alderson et al. 2005).

The concept of agency may be defined in various ways. Some researchers connect the concept to power and consider it as something that only some people have (Ahearn 2001). For example, according to Bandura (2001), the preconditions for the agency of an individual are the individual's capacities for intentionality, forethought, self-reactiveness and self-reflectiveness. In these kinds of definitions agency has been considered a problematic concept when speaking of small or disabled children, because it has been questioned whether cognitive competence and autonomy as prerequisites of agency are actualized with them. The same interpretation appears in the Convention on the Rights of the Child (UN 1989), where the right to express her/his own views is assured only to the child who is capable of forming those views. Likewise, the Convention on the Rights of Persons with Disabilities (UN 2009) advises giving due weight to children's views in accordance with their age and maturity. Human right conventions thus promise many rights to children, but at the same time the conventions give adults the power to decide who can use those rights. That places small children with cognitive impairments in particular in danger of the disablist presuppositions of adults (Priestley 2003) without giving them the possibility to be heard (Davis & Watson 2000).

In this review the need for agency, or the need to have an influence on other human beings through communication, is understood as part of every human being's essence. According to Mayall (2002), an 'agent' is a person whose interaction makes a difference. The concept of agency is therefore differentiated from the concept of 'actorness', which is confined only to the description of acting, not the consequences (Mayall 2002). In this review agency is seen as a feature in all human beings and the realization of agency as dependent on interactions with other people. Thus, in

interaction a child's agency is realized when her/his need to have an influence is taken into account and responded to. Other peoples' inability to understand a child's self-expression or unwillingness to let the child have an influence may restrict the child's agency from being realized, but it does not eliminate the existence of agency.

Agency may be seen both as an intrinsic value like other human rights and as an instrumental value whose consequences are significant both for the disabled child and society. Important consequences for the child are the actualization of meaningful decisions in her/his life   (Davis&Watson 2000, Loijas 1994, Mandich et al. 2003), an increase of self-confidence (Franklin & Sloper 2008, Lightfoot & Sloper 2003, Mandich et al. 2003), control of her/his own life (Loijas 1994) and the experience of being valued (Franklin & Sloper 2008, Kelly 2005). In addition, the realization of agency might increase the child's sense of belonging to a community (Mandich et al. 2003, Milner & Kelly 2009), diversify the child's social relationships and strengthen her/his integration into society (Loijas 1994). From society's point of view, the realization of children's agency is related to the prevention of social exclusion because a lack of influence is related to exclusion from society (Lämsä 2009).

This review discusses studies which have examined disabled children's agency in relation to professionals working with children in different kinds of institutional contexts. As we illustrated earlier, living both as a child and a disabled person at the same time increases the risk of that child's agency not being realized. In addition, disabled children spend more time than other children in special institutional contexts (e.g. health care and habilitation/rehabilitation) and in institutions common to all children (e.g. day care and school); they spend more time with professionals and under their surveillance (Rehm & Bradley 2006, Watson et al. 2000). This puts a great responsibility on professionals to facilitate these children's agency. This review seeks answers from the literature to the question of what factors facilitate or hinder the realization of disabled children's agency in institutional contexts.

Methods

In order to find studies about disabled children's agency, we carried out several searches in the following databases: Cinahl, Medline, Eric, PsycINFO, Sociological abstracts, SocIndex and Ebsco Academic Search Premier. Our search

words were different combinations of the following: child*, disabilit*, developmental delay*, impair*, participation, involvement, agent, agency, inclusion and child's/children's perspective*/view*/experience*/attitude*. The searches demonstrated that it is extremely hard to find articles about agency because the word 'agency' has several meanings and because many articles concerning children's agency do not use the concept of agency. The search was made more challenging by the fact that we wanted to find studies conducted from the children's point of view. We approved as data for this review only two articles (Garth & Aroni 2003, Spitzer 2003) from those searches. Other articles included in the data were found by hand search from lists of references, conference presentations, recommendations from others or from searches carried out for other purposes. All the data was from the 21st century, although no time limitations were set.

For the final data set we selected out of all the articles found by different channels those 19 articles (Table 1) that passed the following inclusion criteria: 1) the article is about an empirical research study, 2) the study has primarily sought children's point of view through interviews and/or observation of children's and professionals' interactions and 3) the study examined disabled children's life at least partly in an institutional context. In seven articles parents and in ten articles professionals were also interviewed. However, children were the primary informants in all the studies. The majority of the studies were located in the school context, but there were also studies from different health and social care contexts. Detailed descriptions of the contexts, participants and data collection methods are seen in Table 1. We approved as data only studies which trustworthiness could be evaluated on the basis of a thorough description of their data collection and analysis methods (see also Patton 2002).

The data was analysed by inductive content analysis. All the expressions in the results sections of articles which described the actions of professionals that affected children's agency (in compliance with the above definition of agency) were underlined. The expressions were condensed into concise phrases which were grouped by similarity. These groups were given descriptive names and called subcategories. Connectable subcategories were merged into main categories (attitudinal factors, communicational factors and institutional factors), and two themes were constituted: facilitating and hindering factors.

Table 1. Description of the data.

Authors & year	Country	Participants	Data collection	Methodological approach	Context
Alton-Lee et al. 2000	New Zealand	15 children (0-1 class pupils) 1 professional	Observation (C, Pr) with audio/video records Interview (C, Pr)	Case studies	School
Beresford et al. 2007	United Kingdom	100 children (2-19 yrs) (parents)	Interview (C) Observation (C)	Qualitative research	Health/ social care
Cameron & Murphy 2002	United Kingdom	12 young people	Interview (C)	Pilot study	Speech and language therapy service
Cocks 2005	United Kingdom	Children (age not known) Professionals (48 situations during 12 months)	Observation (C, Pr)	Ethnography	Respite care + play and leisure setting
Connors & Stalker 2003	United Kingdom	26 children (7-15 yrs) 38 Parents	Interview (C, Pa)	Qualitative approach	Health, education and social services
Davis & Watson 2000	United Kingdom	>300 children (11-16 yrs) Professionals (14 schools)	Observation (C, Pr) Interview (C, Pr)	Ethnography	School
Davis & Watson 2001	United Kingdom	>300 children (11-16 yrs) Professionals (14 schools)	Observation (C, Pr) Interview (C, Pr)	Ethnography	School
Davis & Watson 2002	United Kingdom	>300 children (11-16 yrs) Professionals (14 schools)	Observation (C, Pr) Interview (C, Pr)	Ethnography	School
Davis et al. 2000	United Kingdom	Children (11-16 yrs) Professionals (1 school)	Observation (C, Pr) Interview (C, Pr)	Ethnography	School
Franklin & Sloper 2008	United Kingdom	21 children (5-18 yrs) 24 parents 76 professionals	Interview (C, Pa, Pr)	Case studies	Social services
Garth &	Australia	4 children (6-	Interview	Qualitative pilot	Health care

Aroni 2003		12 yrs) 6 parents	(C, Pa)	study	
Higgins et al. 2009	New Zealand	9+13 children (primary & secondary school pupils) Parents Professionals (2 research projects)	Observation (C, Pa, Pr) Interview (C, Pa, Pr)	Ethnography + action research	School
Kelly 2005	United Kingdom	32 children (2-16 yrs) 32 parents 16 professionals	Interview (C, Pa, Pr)		Social service
Komulaine n 2005	United Kingdom	Children (2-8 yrs) Professionals (2 settings, several situations during nine months)	Observation (C, Pr)	Ethnography	Day nursery + assessment centre
Lightfoot & Sloper 2003	United Kingdom	23 children (13-20 yrs) 13 professionals	Interview (C, Pr)		Health service
MacArthur et al. 2007	New Zealand	7 children (11-14 yrs) Parents Professionals (3 days/month during 3 years)	Observation (C, Pa, Pr) Interview (C, Pa, Pr)	Ethnography	School
Nind et al. 2011	UK	3 children (4 years) Parents Professionals	Observation (C, Pa, Pr) Interview (Pa, Pr) Documents	Qualitative case studies	Early childhood settings, home
Spitzer 2003	US	5 children (3-4 yrs) Parents Professionals (several months)	Observation (C, Pa, Pr) Interview (Pa, Pr)	Ethnography	School, therapy, home
Watson et al. 2000	United Kingdom	>300 children (11-16 yrs) Professionals	Observation (C, Pr) Interview	Ethnography	School

		(14 schools)	(C, Pr)		

Note: C = children/young people, Pa = parents, Pr = professionals

Facilitating and hindering factors of disabled children's agency

The realization of disabled children's agency in institutional contexts is facilitated and hindered by factors related to professionals' attitudes, professionals' communication skills and institutional factors (Table 2). Next, we will analyse these factors on the grounds of the studies selected as the data of this review.

Attitudinal factors

Professional's attitudes towards diversity

Professionals may look at diversity with respect or regard it as a negative deviation from 'normality'. Looking at the different needs and habits of children as a learning challenge in one's own professional practices (Higgins et al. 2009) is an example of an attitude which facilitates the child's agency. In contrast are professionals' expressions that build the otherness of disabled children, e.g. 'They are not like us' (Davis, Watson & Cunningham-Burley 2000).

According to Davis and Watson (2000), building otherness is due to the use of normative and supposedly objective criteria. This places the burden of continuously proving their competency on the children (Davis & Watson 2000, Higgins et al. 2009). In addition, normative-oriented and professional-centred ways of thinking might be barriers to understanding a child's personal way of thinking (Spitzer 2003) when the child's own interpretations of situations, instructions or equipment such as the toys used in tests are not accepted as valid (Komulainen 2005).

A normative idea of diversity may also lead to an emphasis on similarity, so that similar behaviour is demanded of every child, instead of seeing the complexity and skill of the child's actions in relation to the individual child (Spitzer 2003). Considering similarity as a prerequisite for belonging in a group may hinder the realization of the child's agency (MacArthur et al. 2007). Emphasizing similarity may

Table 2. Facilitating and hindering factors in the realization of disabled children's agency in institutional contexts

FACILITATING	CHALLENGING
Attitudinal factors	
Valuing diversity	Seeing diversity as a negative deviation from normality
Valuing the child - seeing the child as the subject of her/his own life - seeing the child as an individual - concentrating on the child's strengths	Undervaluing the child - seeing the child as an object of professionals' actions - seeing the child through her/his impairment - concentrating on the child's limitations
Taking into account the influence of professionals' own actions, the situation and the environment	Interpreting problems as always caused by the child's impairment
Communication factors	
Using dialogical communication - having a willingness to create a relationship with the child - changing the power relationship - engaging in a communication process where the meanings and discussion subjects are negotiated	Communicating on professionals' terms - keeping a distance with the child - maintaining the power relationship - holding on to presuppositions or professionals' chosen discussion subjects and presupposed meanings
Solving communication problems by developing professional skills - seeing problems as dependent on the situation and the professionals' skills - reacting to the content of the child's message - using communication methods which enable the child to express her/his own views	Not solving the professional's communication problems at all - seeing problems only as caused by the child's impairment - reacting only to the way that the child's message is expressed - using communication methods which makes the expression of the child's own views impossible
Institutional factors	
Institutional structures enabling the child to have an influence - seeing the child as a client - having enough time to listen to the child - depending on societal values and decisions grounded on respecting diversity and the child's views	Institutional structures preventing the child from having an influence - seeing only parents as clients - not having enough time to listen to the child - depending on societal values and decisions emphasizing quick changes, measurable results and cognitive competence
Establishing a social order which gives room for children's peer relationships	Establishing a strict social order directed by professionals

also lead to illogical reasoning in which disability is seen as the only difference and characteristics such as gender are ignored (Watson et al. 2000).

Professionals' attitudes towards subjectivity

Seeing children through personal and cultural ideas of normality and diversity (Davis & Watson 2001) may cause children to be treated as objects instead of subjects (Davis & Watson 2001, Komulainen 2005) with their own views on issues of their lives and with the will to affect those issues. According to Davis and Watson (2000) a child's agency is facilitated by professionals' willingness and ability to believe the child and act on what the child says. Franklin and Sloper (2008) show that it is significant for children to see their opinions as making a difference in professionals' actions or even an institution's structures. When sharing their opinions does not affect their issues, the realization of children's agency is hindered (Franklin & Sloper 2008, Kelly 2005).

The realization of children's agency is facilitated by the possibility to choose their actions and company based on their own interests, not by adults' assumptions (Cocks 2005, Franklin & Sloper 2008). Franklin and Sloper (2008) emphasize that it is not only ideal for children to participate when deciding big issues, but also when deciding small issues such as the menu at a child's institution. However, quite often children are not heard when practices concerning them are planned (Davis & Watson 2001), even though professionals' and children's objectives do not always coincide (Komulainen 2005). A child's personal matters may also be discussed in the presence of the child as if she/he were not there (Watson et al. 2000), or her/his privacy may be violated, e.g. by speaking about the child's personal matters in front of her/his schoolmates (Kelly 2005, Watson et al. 2000).

Regarding children primarily as individuals, instead of looking at a child through her/his impairment or a label attributed to her/him facilitates children's agency (Davis & Watson 2000). Also, concentrating on the child's strengths and expecting her/his best effort facilitates agency (Higgins et al. 2009). Adults' belief in a child's competency empowers her/him to make decisions concerning her/his life (Davis & Watson 2000, Nind et al 2010). To this end, Kelly (2005) states that professionals should not only see the services they offer as important, but other

aspects of the child's life as well. However, professionals may have prejudices about the impacts of an impairment on the child's life and always see her/him through her/his impairment (Davis & Watson 2002). This may lead to interpreting the child's behaviour that expresses agency (such as disagreeing with adults) as caused by her/his impairment and as punishable, even though the same kind of behaviour from non-disabled children is ignored or is interpreted as a positive expression of agency (MacArthur et al. 2007).

Children feel that professionals' overprotecting practices are an underestimation of their abilities (Davis & Watson 2001) as well as that too low expectations hinder the realization of their agency (MacArthur et al. 2007). Underestimation may be caused by a professional's views on what a child can or cannot achieve in the future (Davis & Watson 2000) or their views that the child's repetitive activity (such as flicking materials) is not a meaningful action, but a symptom of her/his impairment (Cocks 2005, Spitzer 2003). Choice making that is essentially related to agency may be prevented by a professional ignoring the choice-making ability of a child (Davis & Watson 2000).

Professionals' attitudes towards the influence of their own actions and the environment

Davis and Watson demonstrate (2000), how the realization of children's agency is facilitated when their competency is seen as situated and fluid. In that kind of cases professionals pay attention to the influence of the situation and the context, and do not see all of the children's problems as innate (cf. Komulainen 2005) and caused by their impairment (Davis & Watson 2000). For example, in Davis' and Watson's study (2000) one child's intended exclusion from 'mainstream' school, ordered because of the child's problematic behaviour, was cancelled when professionals observed the situation with an open mind and discovered that the child's behaviour was not due to his impairment but to other children teasing him.

Professionals may also be incapable or unwilling to evaluate their own actions and their influence on the child or to question their own interpretations of the child's behaviour (Davis & Watson 2000). For example, if only adults' chosen alternatives are given when a choice is to be made, the child may not want to choose any of the alternatives. Professionals may interpret this as the child not being able to choose,

even though the alternatives were too limited to choose among (Komulainen 2005). Their view of 'communication difficulties' as a quantifiable, measurable and pathological phenomenon (Komulainen 2005) only focus on the child's communication skills, even though situations interpreted as a child's problem in understanding may be due to the professional's insufficient skill of expressing herself/himself in a way that is understandable to the child (Connors & Stalker 2003, Davis & Watson 2002).

Communicational factors

The dialogicality of communication

There is evidence that communication which facilitates the realization of the child's agency is grounded on the professional's willingness to create a relationship with the child, to change traditional power relationships and to be flexible (Davis & Watson 2001). In contrast, keeping a distance from or ignoring the child hinders the child's agency (Davis & Watson 2002) because the child may feel that the professional does not like her/him and the child may be scared of her/him (Kelly 2005).

Dialogical communication is grounded on supposing that a child's action has a meaning and on avoiding presuppositions of what that meaning is for the child (Davis & Watson 2002). According to Spitzer (2003), understanding the meaning may require seeing the action as meaningful to the child even though it may seem meaningless to an adult. This requires engaging in a communication process in which meanings are negotiated (Davis & Watson 2002) by communicating directly with the child, asking questions and allowing her/him to ask questions (Garth & Aroni 2003). If the child is not allowed to have an influence on the subjects discussed, she/he cannot raise issues which are important to her/him (Lightfoot & Sloper 2003). Professionals' eager prompting may also restrict the child's communicative space (Nind et al. 2010).

Solutions to communication problems

As mentioned above, seeing communication problems as a shared problem facilitates the realization of children's agency. Davis and Watson (2002) state that if the professional refuses to change her/him first impression about a failure in communication as the child's fault, the communication will not evolve into dialogue. Sometimes a new opportunity for dialogue is needed and apologizing to the child is necessary if the professional's behaviour has been patronizing (Davis & Watson 2002). According to MacArthur et al. (2007), communication may also fail if professionals respond only to how the child expresses the message (such as with a loud volume), not to the content of the message.

To be able to facilitate the children's agency, professionals need knowledge about and the ability to use alternative and augmentative communication (AAC) such as signing, picture communication and communication devices. Insufficient AAC skills hinder the child's agency if the child does not talk or uses talking only as a part of hers/his communication   (Beresford et al. 2007, Kelly 2005). Instead, a child's agency is facilitated when she/he has the opportunity to choose among several methods of communication e.g. play, projective techniques, drawing or emotion cards (Kelly 2005) or gaze, action and speech (Nind 2010). According to Cameron & Murphy (2002), good features for a communication technique which makes it easy to ask the child's opinion are the following: the child enjoys using it, using it is not grounded on right or wrong answers, answers can be altered and the child is allowed to use as much time with it as she/he wants. In addition, it is useful to take photographs of the result of the conversation so that it is easy to later return to it (Cameron & Murphy 2002). If no concrete instruments for communication can be found, the professional can facilitate the child's agency by learning to infer the meanings of the child's actions from observed cues and from knowledge of hers/his history, or what she/he senses from the child's participation in the activity (Spitzer 2003).

Institutional factors

The child's clientship

There is evidence that many institutions are structured so that the children are approached through her/his parents or a professional responsible for the child. These 'gatekeepers' may facilitate the realization of a child's agency if they think that the child has relevant opinions and feelings which should be taken into account in the professionals' meetings such as the care plan reviews (Kelly 2005). However, they might also prevent professionals from approaching the child in order to ask her/his opinion (Franklin & Sloper 2004). According to Garth and Aroni (2003), children do value being present when issues relating to them are being discussed even if they may not understand the entire discussion.

In some institutions it is unclear if the client is the child, the parents or both. This structural unclarity sometimes places professionals in a difficult situation if they want to facilitate the child's agency. When a decision regarding professional practices needs to be made, parents are often the only ones asked about matters concerning the needs of the child even though they do not always allow the child's opinions to influence their decisions (Kelly 2005). Sometimes professionals feel forced into the role of a conciliator between the child and her/his parents (Franklin & Sloper 2004), and at times they comply with the parents' wishes, e.g. pressuring the child to go to an unpleasant respite care (Kelly 2005).

Institutional factors and the child's possibilities to have an influence

Institutional factors may hinder the realization of children's agency if children's participation in decision making is not embedded in the culture of an organization (Franklin & Sloper 2008). Moreover, the cultural atmosphere of the institution affects how easy it is for professionals to listen to the child (Davis & Watson 2000).

Essential to the children's agency are circumstances where children can empower themselves (Davis, Watson & Cunningham-Burley 2000) instead of structural solutions in which the child feels different and incompetent and which the child cannot influence (Higgins et al. 2009). For example, MacArthur et al. (2007)

describe a structural solution that ignores the child's opinion placing a girl who has a physical impairment in a class where all the others are boys with 'challenging behaviours'. In that class the girl was bullied and found learning difficult. Another example of hindering the child's agency is giving her/him equipment which she/he does not want to use because it separates her/him from other children in an unpleasant way (MacArthur et al. 2007).

One institutional factor that hinders children's agency is professionals' lack of time (Beresford et al. 2007). As Franklin and Sloper (2008) have noticed, many professionals need more time than usual to observe a child, prepare material in an alternative communication form or to co-operate with adults familiar with that child's style of communication.

Furthermore, wider societal decisions have effects on children's agency. This includes, for example, institutional funding (Davis & Watson 2001, Franklin & Sloper 2008) and national targets in school – if a teacher wants to meet those targets, she/he can only have a few children with learning difficulties in her/his class (Davis & Watson 2001). According to Franklin & Sloper (2008), other factors related to society's structures are rapidly changing environments and the requirement for quick results. These requirements do not take into account that listening to the child's view may produce significant results even if the results are not visible in the short term. (Franklin & Sloper 2008).

The management of children's peer relations

Children's agency can be realized in a flexible and changeable social order in which professionals give children room to create their own relationships as Cocks (2005) describes in her study. Professionals may think that children need constant direction when creating and maintaining friendships, but studies have shown that this is an incorrect assumption (Cocks 2005, Watson et al. 2000). Instead, being under the constant surveillance of adults might keep disabled children from joining their peer group (Connors & Stalker 2003, Kelly 2005, Watson et al. 2000), as might restrictions set by adults such as forbidding the child from visiting their friends (Kelly 2005). When the professional who assists the child steps back, it gives the child space to be part of the peer group (MacArthur et al. 2007). Children's agency can be facilitated by

giving them the freedom to choose their own roles in their peer group and to choose companions who share their own interests, not those with similar assumed skills or a similar lack of skills (Cocks 2005).

Sometimes facilitating a child's agency requires professionals to create opportunities where the child can be accepted by other children. For example, situations may be organised for children to make their own decisions in a peer group which is facilitated but not led by a professional (Davis & Watson 2000). Cocks (2005) demonstrates that often opportunities for children to share experiences with others who have a shared history are dependent on adults' organizational decisions. Higgins et al. (2009) describe how children's agency may also be facilitated on occasions where children's 'becoming visible' to each other is made possible, e.g. a drama project arranged for both disabled and non-disabled children. Likewise, resisting segregating practices may facilitate a child's agency because the child does not miss the activities of her/his own group (Higgins et al. 2009).

In a group of children a child's agency may be facilitated by offering the child a role that allows other children to notice her/his strengths first, not her/his impairment. A professional can give a child the responsibility of teaching something she/he already knows or of otherwise helping other children (Alton-Lee et al. 2000, Connors & Stalker 2003, Higgins et al. 2009). If a child is being bullied, the professional can make educational, i.e. indirect, interventions in which the child is not a passive object, unlike in disciplinary, i.e. direct, interventions (Alton-Lee et al. 2000). As MacArthur et al. (2007) demonstrate, professionals may also support the child in defending herself/himself against bullying.

Discussion

In this review we sought facilitating and hindering factors in the realization of disabled children's agency in institutional contexts. Significant factors seem to relate either to professionals' attitudes and communication or to the structural and cultural factors of institutions and society. Underlying all of these factors appears to be professionals' attitudes towards children's diversity and individuality and towards

their own contribution in working with the child. Conceptions of disability, childhood and professionality are strongly intertwined.

Health, social and educational sciences have made an attempt to substitute professional-centred, behaviouristic and paternalistic ways of thinking with more child-centred or child-originated and more constructivist theories which aim to empower the client. Yet it seems that the old models live on in the practices of the care and education of disabled children. In this review the data on professional practices concerning agency did not differ according to field (health, social or educational), but differences were found between institutions and individual professionals in all fields. Common to those professionals who facilitated children's agency seemed to be seeing disability in line with the social model of disability and seeing childhood in line with the new sociology of childhood. Also common to them seemed to be that their professional self-efficacy was so strong that they could confess ignorance and could engage in unpredictable dialogue with a child. Listening to and understanding a child seems to require giving up a power relationship in which one person places oneself above another and knows better or acts on her/his behalf. As Sieppert and Unrau (2003) state, children's possibility to influence issues in their own lives may stop where adults think they know what is best for the child and professionals think they know what is best for the client.

In this review the concept of agency is defined somewhat differently from previous research (e.g. Ahearn 2001, Bandura 2001), as agency is seen here as a feature of all human beings, the realization of which is dependent on interactions with other people. This led to seeing agency where it would not have been seen with other definitions (e.g. in children with severe cognitive impairments). As data for this review we chose only studies in which children had been heard and their own perspectives valued. Probably due to this, all of the articles aimed at promoting children's agency and identifying best practices for communicating with children. Some of the articles used the same data as other articles (e.g. all of Davis and Watson's articles used the same data, and Higgins et al. and MacArthur et al. partly used the same data), but we included them because every article had some new insights.

Results of this review have been systematically drawn from results of the original studies, and only this discussion section goes beyond the references. However, as always in qualitative studies, we as researchers were the instrument that

processed the data and therefore it is useful for the reader to know also something about us (Patton 2002). Our professional and academic experience of the institutional situation of disabled children served as the background for our interpretations: one of us has worked as a nurse with disabled children in a hospital, another has researched professionals' attitudes towards disabled children, and the third is an experienced researcher of sick and healthy children's nursing care. Our academic backgrounds consist mainly of nursing science and special education (both of these with a history of emphasizing the medical model of disability), but two of us also have knowledge of disability studies and childhood studies.

Finding data for this review was challenging, which speaks to how rarely disabled children have been researched from the point of view of agency. All the data was found from the 21st century, so this perspective is quite new and has been the focus of only a few research groups. Especially rare has been research on small children with cognitive impairments in the health care context, even though health care is in many countries the first stop for interventions for these children. Specifically, small children's views are often ignored even in contexts where there are specific systems for listening to children (such as the family group conference, Heino 2009). It would be important to regard disabled children's human worth and human rights as similar to others from the very beginning. As Cocks (2000) states, segregating disabled children in their own institutions and treating them as passive objects of adults' interventions reflects the fact that people see passive adulthood as suitable for them.

In future it would be significant to emphasize child-centred attitudes and dialogical communication in the basic and further education of all professionals working with disabled children. These are enabled only if professionals can see children as both competent and incomplete, as Cocks (2006), Komulainen (2007) and Lee (1998) suggest. It would be essential for professionals to see incompleteness and fallibility also in themselves – and yet, at the same time, to be able to value themselves and their professionality. This is related to seeing aspects shared with all human beings (such as the need for agency) in both children and in professionals and seeing diversity as a richness in all of us. It might be useful to see that changing professional practices towards facilitating children's agency would also have positive outcomes for professionals: their professional behaviour changes when they realize that they do not always know what is important to children – and that children have

much to say that is worth listening to (Karlsson 2009, Lightfoot & Sloper 2003). Most essential would be, however, to concentrate on agency as an intrinsic value, i.e. a universal human right, because seeing agency as an instrumental value gives adults too many opportunities to speculate about who will benefit from it and who will not.

References

Alderson, P., Hawthorne, J. & Killen, M. 2005. The Participation Rights of Premature babies. The International Journal of Children's Rights 13, no. 1-2: 31-50.

Ahearn, L. 2001. Language and agency. *Annual Review of Anthropology* 30:109–37.

Alton-Lee, A., Rietveld, C., Klenner, L., Dalton, N., Duggins, C. and Town, S. 2000. Inclusive Practice within the Lived Cultures of School Communities: Research Case Studies in Teaching, Learning and Inclusion. *International Journal of Inclusive Education*, 4, no. 3: 179–210.

Bandura, A. 2001. Social Cognitive Theory: An Agentic Perspective. *Annual Reviews* 52: 1-26.

Beresford, B., Rabiee, P. & Sloper, P. 2007. *Priorities and Perceptions of Disabled Children and Young People and Their Parents Regarding Outcomes from Support Services.* York: The University of York. Social Policy Research Unit.

Cameron, L. & Murphy, J. 2002. Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities.* 30: 105-112.

Cocks, A. 2000. Respite Care for Disabled Children: micro and macro reflections. *Disability & Society* 15, no. 3: 507-519.

Cocks, A.J. 2005. 'The Peer Groups of Children with Learning Impairments', in D. Goodley and G. van Hove (eds.) *Another Disability Studies Reader? Including People with Learning Difficulties*, 75-91. Antwerpen: Garant Publishers.

Cocks, A.J. 2006. The Ethical Maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood* 13, no. 2: 247–266.

Connors, C. & Stalker, K. 2003. *The Views and Experiences of Disabled Children and Their Siblings.* London and Philadelphia: Jessica Kingsley Publishers.

Davis, J. & Watson, N. 2000. Disabled children's rights in every day life: Problematising notions of competency and promoting self-empowerment. *The International Journal of Children's Rights* 8, no. 3: 211-228.

Davis, J.M. & Watson, N. 2001. Where Are the Children's Experiences? Analysing Social and Cultural Exclusion in 'Special' and 'Mainstream' Schools. *Disability & Society* 16, no. 5: 671-687.

Davis, J. & Watson, N. 2002. Countering stereotypes of Disability: Disabled Children and Resistance. In M. Corker & T. Shakespeare: *Disability/postmodernity: embodying disability theory*, 159-174. London: Continuum.

Davis, J., Watson, N. & Cunningham-Burley, S. 2000. Learning the Lives of disabled Children. Developing a Reflexive Approach. In P. Christensen & A. James: *Research with Children. Perspectives and Practices*, 201-224. London / New York: Routledge Falmer.

Franklin, A. & Sloper, P. 2004. *Participation of Disabled Children and Young People In decision-making within Social Services Departments*. Interim Report. The University of York.

Franklin, A. & Sloper, P. 2008. Supporting the Participation of Disabled Children and Young People in Decision-making. *Children & Society* 23, no. 1: 3-15.

Garth, B. & Aroni, R. 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.

Heino, T. 2009. *Family Group Conference from a Child Perspective*. Nordic Research Report. Report 13/2009. Helsinki: National Institute for Health and Welfare. http://www.thl.fi/thl-client/pdfs/da905b95-70f6-4db8-9d82-91b74fe55ed0

Higgins, N., MacArthur ,J. & Kelly, B. 2009. Including disabled children at school: is it really as simple as 'a, c, d'? *International Journal of Inclusive Education* 13, no. 5: 471-487.

James, A. & James, A. 2004. *Constructing Childhood. Theory, Policy and Social Practice.* New York: Palgrave Macmillan.

Karlsson, L. 2009. To construct a bridge of sharing between child and adult culture with the Storycrafting method. In H. Ruismäki & I. Ruokonen (Eds.): *Arts Contact Points between Cultures, 1st International Journal of Intercultural Arts Education Conference,* 117-128. Research Report 312. Helsinki: University of Helsinki. Department of Applied Sciences of Education. https://helda.helsinki.fi/bitstream/handle/10138/14969/RR312_verkkoversio.pdf

Kelly, B. 2005. Chocolate . . . Makes You Autism': Impairment, Disability and Childhood Identities. *Disability and Society*, 20, no. 3: 261–275.

Komulainen, S. 2005. The Contextuality of Children's Communication Difficulties in Specialist Practice: A Sociological Account. *Child Care in Practice*, 11, no. 3: 357–374.

Komulainen, S. 2007. The Ambiguity of the Child's 'Voice' in Social Research. *Childhood* 14, no. 1: 11-28.

Lee, N. 1998. Towards an immature sociology. *The Sociological Review* 46, no. 3: 459-482.

Lightfoot, J. & Sloper, P. 2003. Having a Say in Health: Involving Young People with a Chronic Illness or Physical Disability in a Local Health Services Development. *Children & Society* 17, no. 4: 277–290.

Loijas, S. 1994. *Rakas rämä elämä. Vammaisten nuorten elämänhallinta ja elämänkulku. (The life-course and control of own life of young disabled people.*) Raportteja 155. Helsinki: Stakes.

Lämsä, A-L. 2009. *Tuhat tarinaa lasten ja nuorten syrjäytymisestä. (A thousand stories about exclusion among children and young people.*) Acta Universitatis Ouluensis E 102. Oulu: Faculty of Education, University of Oulu.

MacArthur, J., Sharp, S., Kelly, B. & Gaffney, M. 2007. Disabled Children Negotiating School Life: Agency, Difference and Teaching Practice. *International Journal of Children's Rights* 15, no. 1: 99-120.

Mandich, A.D., Polatajko, H.J. & Rodger, S. 2003. Rites of passage: Understanding participation of children with developmental coordination disorder. *Human Movement Science* 22, no. 4-5: 583-595.

Mayall, B. 2002. Towards a Sociology for Childhood. Thinking from children's lives. Maidenhead.: Open University Press.

Milner, P. & Kelly, B. 2009. Community participation and inclusion: people with disabilities defining their place. *Disability & Society* 24, no. 1: 47-62.

Nind, M. Flewitt, R. & Payler, J. 2010. The social experience of early childhood for children with learning disabilities: Inclusion, competence and agency*, British Journal of Sociology of Education* 31, no. 6: 653-70.

Patton, M. Q. 2002. *Qualitative research and evaluation methods.* 3rd edition. Rev.ed of: Qualitative evaluation and research methods. Thousand Oaks: Sage Publications.

Priestley, M. 2003. *Disability: a life course approach*. Cambridge: Polity Press.

Rainio, A. 2010. *Lionhearts of the Playworld -An ethnographic case study of the development of agency in play pedagogy*. Studies in Educational Sciences 233. Helsinki: University of Helsinki. http://helda.helsinki.fi/handle/10138/19883

Rehm, R. & Bradley, J. 2006. Social interactions at school of children who are medically fragile and developmentally delayed. *Journal of Pediatric Nursing* 21, no. 4: 299-307.

Sieppert, J.D. & Unrau, Y.A. 2003. Revisiting the Calgary Project Evaluation: A Look at Children's Participation in Family Group Conferencing. *Protecting Children* 18, no. 1-2: 113-118.

Spitzer, S. 2003. With and Without Words: Exploring Occupation in Relation to Young Children with Autism. *Journal of Occupational Science* 10, no. 2: 67–79.

UN 1989. *Convention on the Rights of the Child.* United Nations. http://www2.ohchr.org/english/law/crc.htm

UN 2006. *Convention on the Rights of Persons with Disabilities.* United Nations. http://www.un.org/disabilities/default.asp?id=259

Vandenbroeck, M. & Bouverne-De Bie, M. 2006 Children's Agency and Educational Norms: A tensed negotiation. *Childhood*, Vol. 13, no. 1: 127–143.

Watson, N., Shakespeare, T., Cunningham-Burley, S. Barnes, C., Corker, M., Davis, J. & Priestley, M. 2000. *Life as a Disabled Child: a qualitative study of young people's experiences and perspectives.* Final report to the ESRC. Edinburgh: University of Edinburgh, Department on Nursing Studies. http://www.leeds.ac.uk/disability-studies/projects/children.htm