

Parents' Perspectives on Social Exclusion and the Development of Psychological Autonomy in Children with Disabilities

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Abstract

Psychological autonomy is increasingly understood as an important developmental aim, incorporating healthy self-esteem, resilient inner well-being, competence, and a sense of self-determination of one's life and choices. Psychological autonomy can be developed in children with disabilities, but to do so requires overcoming many barriers. This study examined parents' beliefs, attitudes, and practices in relation to the autonomy development of their disabled children. Lithuanian parents were interviewed (N=93) and data were analyzed qualitatively using an ethnographic method. The most salient findings were that parents struggled to define and support their children's autonomy in the face of the losses associated with their children's disabilities, the most salient loss being social exclusion. Social exclusion takes the form of hostile behavior, stigma, isolation, deprivation of adequate assistance, lack of vocational opportunities for disabled youth and young adults, and is aggravated by the poverty of families with disabled children. While some parents reacted to their children's disabilities with behavior that could be seen as overprotective, this response can be understood as an effort to exert control in a situation where the parents feel unsupported and without sufficient control over events. Most parents valued their children's autonomy and imagined needed social supports that could foster it.

Introduction

The purpose of this study was to improve scientific understanding of the development of disabled children's autonomy from the family's perspective, especially with regard to the problem of widespread discrimination against disabled children that results in the

phenomenon of social exclusion. Systematic interviews were conducted with Lithuanian families of disabled children, focusing on their children's development of autonomy, and the interview data were coded qualitatively. This study reports on the families' experiences. To understand the situation of disabled children it is important to understand the problem of social exclusion.

Social exclusion is gaining more and more interest as contemporary societies become more diverse and strive to remedy social inequalities. Many groups, including disabled people, experience social exclusion because of "deprivation, either of resources (such as income), or of social links to the wider community or society" (Scott, Marshall, 2005). Qvortrup (1999) points out that children as a social group in a society are in a paradoxical situation: On the one hand, throughout the 20th century, children's needs and rights as individuals have been encompassed with a growing concern by their significant others as well as in the psychological sciences, on the other hand exposed to an increasing indifference as a collectivity on the side of society. Children as social group in a society experience deprivation of social links to the community or society because they are not recognized as "social participants in society" (Kjorholt, 2004). Focusing on the development of autonomy may help disabled children to participate in the social life through self-realization, self-actualization and implementing their personal purposes.

To recognize children's participation in society we need to start with recognizing "children's culture" (Corsaro, 2005) or "imagined communities" (Kjorholt, 2004) that create a neutral space where either child or adult can enjoy a state of self-discovery – of being oneself. Kjorholt (2004, p. 38) points out

that respect for children as social participants does not diminish adult responsibilities. Moreover, it places new responsibilities on the adult community to structure children's environment, guide their behavior, and enable their social participation in ways consistent with their understanding, interests and ways of communicating. The idea that children are able to govern themselves through being responsible, independent agents demands that we know more about the phenomena of autonomy.

The definition of autonomy used here does not imply isolation from relationships; in fact, a key point is that collective actions and social context of family remain essential for the agency development process. Families play a unique role in the lives of persons with an intellectual disability, providing lifelong support and relationships. Families also often experience discrimination because of their association with a disabled person. This discrimination ranges from being denied access to public places, such as playgrounds and restaurants; the economic discrimination of being excluded from the labor market because of the need to care for the family member who has a disability; or restricted mobility because of exclusion from transportation (Inclusion International Organization). Therefore, the development of autonomy is important to consider from the perspective of family experience. Olsson and Hwang (2003) point out that the family's experience is very important, especially in the US and the UK, because the care and well-being of children, with or without disabilities, are seen almost exclusively as the individual family's responsibility.

Reviewing the Research

Social exclusion is a dynamic, multidimensional phenomenon. It is important to note that disability is never the only one and key reason for being excluded. While disability can lead to social exclusion if the disabled do not have access to the additional support and resources they need to have the ability to participate fully in community and public life, physical

and mental disability is just one of many factors that can lead to such social exclusion (Klasen, 2007). Whilst disabled children and their families may face specific barriers to social participation and inclusion, the needs of disabled children are often the same as the needs of other children (Clarke, 2006). Social exclusion is not an intrinsic part of a disability or impairment; rather, a particular set of circumstances increase the likelihood of social exclusion; deprivation can compound the situation (Don't Leave Me Out, 2004). Therefore, an analysis of social context, including the family's resources and attitudes, is important for understanding social exclusion.

Sclater and Piper (2001) point out that to address the issue of children's social exclusion in a context of welfare we need fundamental changes in the direction of a more psychodynamically informed view of personhood and a new image of the child to inform policies. Ridge and Miller (2000) point out that exclusion should be addressed much more from a child-centered perspective. Bloch and colleagues (2003) point out that neo-liberalism relates child welfare with discourses of autonomy, independence, flexibility, and choice. Children are too often portrayed as victims and incapable of the self-determination that is essential for autonomy. Instead, one can focus on the capabilities for self-determination and autonomy that children do experience and express.

Exclusion should be considered as a dynamic process and a multidimensional phenomenon. Micklewright (2002) points out that social exclusion *can happen*, but does not necessarily happen, when there is a combination of the circumstances as follows: low income, poor housing, restricted participation within mainstream services, bad health, family breakdown, etc. Suffering from the circumstances listed above does not necessarily equate with being socially excluded. This draws our attention to the importance of allowing persons to experience freedom from adverse circumstances, thereby effectively shaping their own destiny and helping each other (Sen, 1999).

Fostering autonomy for children would help them to be more motivated to respond to adverse circumstances with resilience. In fostering autonomy for disabled children, the development of self-determination is assumed to play a crucial role. In 1988, the USA Office of Special Education and Rehabilitation Service developed a self-determination initiative to focus on system-wide activities that would help individuals with disabilities have more input in the decisions that affect their lives. Many studies (Sands, Doll, 1996; Wehmeyer, 1999; 2000; Wehmeyer, Palmer, 2000; Wehmeyer, 1996; Wehmeyer, Metzler, 1995; Doll, Sands, Wehmeyer, Palmer, 1996; Ward, 1996) investigated ways to promote and maintain *self-determination* skills for disabled children, adolescents and youth.

Thus far, not everyone would agree that autonomy is the most suitable concept to express the notion of children's self-determination, or agency. I chose the concept of autonomy because it is more broad and directed to children's development, instead of the concept of social participation, which has been gaining increased popularity. Kjørholt (2004, p. 104) argues that the concept of social participation expresses the idea of sharing responsibility and creating interdependence, when a "competent child ... is given the right to participate in society on a par with adults" More suitable for capturing the diverse competencies of disabled children is the concept of autonomy, which has been reconceptualized recently towards a greater focus on "*interdependence*" (Reindal, 1998).

Autonomous individuals possess qualities of independence, self-direction, self-determination, self-governance, and self-care. A central paradigm change occurred when autonomy started to be considered not as a function of what one can do for and by oneself, but rather of accepting responsibility, and making decisions, for oneself in the framework of social connectedness and closeness (Crittenden, 1990; Turnbull, Turnbull, 1996, 2001; Field, Hoffman, 1999; Erwin, Brown, 2003; Wehmeyer, 1996; 1999; 2000; Doll, Sands, Wehmeyer, Palmer,

1996). This notion contradicts the earlier one that was based mostly on the view of developmental psychology and considered autonomy as a developmental endpoint, synonymous with psychological maturity and personal fulfillment either for non-disabled or disabled children (Colman, 2001; Sutherland, 1989; Hill, 1989; Harriman, 1980). Thus, universal stages of development a-priori deny disabled children possibilities for autonomy. Therefore, it is important to consider autonomy as distinct from biological immaturity, and rather as linked with societal and value-based considerations. Thus, the autonomy of disabled people has started to be evaluated as a social construction.

Moreover, together with the introduction of the social model of disability (Oliver, Sapey, 1999; Barnes, Oliver, Barton, 2002; Albrecht, 2004), the experience of disabled people in relation to personal autonomy has been considered. It is reasonable to consider the possibilities to experience autonomy for people with disabilities in relation to social exclusion as restricted access to public space and public roles, barriers faced in private realms (e.g. family) mediate opportunities for choice making; decision making; problem solving and self-determination that are dimensions of autonomy.

Subjects and Methods

Methods of Data Collection

A qualitative approach was used to collect empirical information. A semi-structured individual interview was conducted with parents of children with disabilities.

Methods of Data Analysis

A content analysis was carried out to process the interview data obtained. The process of interpreting data is very subtle because there is no one right way to go about it (Denzin & Lincoln, 1998). Therefore, interpretations are presented together with empirical material so that the reader can "participate" in a process of interpretation.

Participants

In total, 130 families participated in the interview. For the analysis, 93 families were chosen. Interviews were conducted in Lithuania during 2005. The sample was selected based solely on the criterion of whether parents were caring for a disabled child. Accordingly, the sample includes parents of all ages, both genders, diverse marital status, residences, and children's ages, genders, and types of disability. Families had children with disabilities ranging in age from newborn to eighteen years old, and lived in the biggest cities (N=38) or smaller cities and rural settings (N=55). Parents reported the disabilities of their children as follows: children with mobility-related disability (N=15), mentally retarded children (N=21), children with both mental retardation and mobility-related disabilities (N=20), children with either vision or hearing impairments (N=14), children with severe, multiple disabilities (N=5), and children with developmental disabilities (N=12). These families were recruited by contacting kindergartens, schools, rehabilitation centers, early intervention agencies, and community-based programs providing services to the families of children with disabilities.

One of the limitations of this research sample is that mostly mothers were interviewed. Very few parents agreed to participate in interviews. This problem is faced by other researchers as well, at least as has been reported in Lithuania (Butkeviciene, 2001, Alisauskiene, 2002). While analyzing children's autonomy development, this situation may be favorable because it reduces the bias that could result from men's biases in favor of autonomy: researchers suggest women are less likely to emphasize autonomy because "women have historically been the care providers, it is suggested that they are less likely to promote unrealistic view of independence" (Shakespeare & Watson, 2001, p. 560).

Measures

A semi-structured interview was developed by the author of the article to collect information about the parents' views regarding the ability of their disabled child to become independent, self-sufficient, and autonomous. Also, the respondents (participants) were asked to fill demographic information sheets to collect information about parent's gender, marital status, education, place of residence, etc. and about their child's age, disabilities, and gender. The plan of the interview was based on a theoretical analysis of scientific studies of children's disability and autonomy in family contexts (Turnbull, Turnbull, 1996, 2001; Field, Hoffman, 1999; Erwin, Brown, 2003; Wehmeyer, 1996; 1999; 2000; Doll, Sands, Wehmeyer, Palmer, 1996; Solberg, 1997; Cook, Brotherson, Weigel-Garrey, Mize, 1996).

Results of the Research

Parents's Concepts of Autonomy and Disability

The parents who were interviewed said that their concept of autonomy is based on a view of a non-disabled child. Those parents say that autonomy is impossible without health. Mostly parents strongly link together the child's health and the possibilities of being independent:

"Independence lies in good health. If since the beginning there's no good health, independence is difficult to be expected."

Parents tend to thoroughly mark the discrepancies between healthy and handicapped children:

"My boy's thinking is dysfunctional, therefore he doesn't feel the responsibility like the healthy children do."

"I hope for her to become more independent, but she won't be like her peers."

This tells us that parents who have the challenge of understanding, accepting, and responding to their child's disability, may be inclined to see their children in terms of impairment, rather than first and foremost as a child (see also, "Don't Leave Me Out," 2004). Parents' acceptance of their child's disability is distinguished by the parent's difficulty accepting the consequences of the disability as it might restrict the child's autonomy development:

"You may jump over it (mentally), but this requires a lot of effort of not thinking about him being unable to recognize and count money, being naïve."

As M. L. Wehmeyer (1996, p. 130) points out, as family members move toward acceptance, they may maintain attitudes that are barriers to the development of autonomy. One such attitude is viewing the disability as a problem, which may convey a message to a child that he/she and the disability are indistinguishable. Also, parents feeling a sense of loss about their children's disability often see their disappointed aspirations not in terms of their children needs, but rather in terms of their dashed hopes as parents:

"My daughter will never achieve more than I succeeded in doing."

"My son will never achieve what I dream about."

The sense of loss is compounded because parents seem to have difficulty knowing what it is reasonable to aspire to in terms of their child's development of autonomy. Parents often talk about a large gap between the child's actual possibilities and the conditions to realize them:

"I have never stressed disability and that was a big mistake, because the boy couldn't understand, that he won't be able to become a policeman when grow-up. I had said he wouldn't be able to become who he wants to, and he kept asking me "why". One day my patience

broke down and I said to him "you are an invalid". This was very painful for both of us, we cried – one in one room, another in another one." (1026)

"A handicapped person may be responsible, have a job and do it properly, but the attitude of our society towards the handicapped is very improper, because it is thought that these people are incompetent and worthless. I think, the handicapped can perform a very responsible job, and sometimes they can accomplish much more than the healthy, only we need to trust them more." (1025)

Lack of Opportunities and Assistance in Society and Children's Autonomy Development

Clarke (2006) underscores what the parent above mentioned, which is that for disabled children who encounter low aspirations of professionals and parents, the lack of opportunities in society can be considered to be an interpersonal barrier to personal autonomy and social inclusion, potentially over the life course. Parents need help in challenging negative attitudes and low expectations, and this process is an important element in ensuring social inclusion and autonomy development.

Parents' and professionals' low expectations may be related to a lack of real opportunities for young people with disabilities, since as they grow into adult lives the lack of employment and vocational opportunities are very great obstacles for autonomy development. Transition planning and support for young disabled people moving into adulthood is very important for reducing social exclusion (Russell, 2003) and developing autonomy. Exclusion may offer a useful label for the fate that awaits some children who suffer from various disadvantages in childhood which threaten their capability to achieve in the future (Micklewright, 2002). As the young adult and her/his parents become discouraged, unfortunately dim future prospects and

opportunities deepen social exclusion. It is vitally important to improve life chances for young disabled people.

Parents always have the active task of filling the huge gap between their child's possibilities and the competencies required by society. Gray and Jackson (2002, p. 10) describe "the deviance-competence hypothesis," which has relevance in that the more competencies that are attributed to a person, the more deviance is tolerated, and vice versa: The fewer competencies that we attribute to a person, the less accepting people tend to be of deviance and therefore, of the child's mistakes in the course of developing competence. Because of limited vocational possibilities and inadequate community living arrangements, some families may be left with few choices for giving the adult son/daughter with a disability more freedom and independence.

Families Cope with Social Attitudes and Facilitate Children's Autonomy at Home

Thus, young adults with disabilities experience continuing dependency upon families. Parents consider young adult sons or daughters with disability as being responsible. But, they necessarily restrict the scope of responsibilities to the home environment.

"My son is fully able to take care of himself, he is able to prepare meal for himself, clean the room, look after the younger brother."

"He is tidy, can make meals. I train what his abilities allow me to. By comparison with peers, our son is less mature only in a physical sense."

While in fact there are less vocational opportunities for young adults with disabilities, this fact about society may be conflated with pessimism about the person's developing autonomy. The conclusion that children with disabilities inevitably have limited opportunities may be related to the lack of recognition that social assistance is important as a possibility for developing

autonomy, and social and vocational services can be considerably enhanced, with corresponding increases in the autonomy of people with disabilities.

Acceptance of assistance is a part of every person's life course, including that of a disabled person. It may be that assistance for disabled people is more visible, and therefore parents are afraid of "a stigma attached to such assistance" (Litvak., Enders, 2001, p. 726). The parents interviewed imagined in more positive ways the way their children's autonomy could be developed through accepting assistance in a specific context. One parent commented,

"He could be independent while living in a community of the handicapped."

Rothman (2003, p. 116) points out that it is important for disabled children and adults to have contact with people with the same disability in order to normalize their experiences, as a step towards self-acceptance. The experience in a community for disabled children can help a person to know her/himself in more positive ways. For example, deaf parents of a deaf child might interpret their child's first signs not merely as the beginnings of communication, but as the continuation of a linguistic and cultural heritage that makes them proud that their child is deaf. In such a family, disability (if that even continues to be an appropriate term) is celebrated rather than lamented (Corker, 1996; quoted in Ferguson, 2001, p. 388).

Acceptance by society of the importance of assistance for persons with disabilities could help to prevent social exclusion by making it possible for disabled people to carry out their daily lives and participate as citizens. But in their current situation, only a few parents have positive expectations of having any help or assistance. They note that helping relations don't diminish the autonomy of a handicapped child.

"He has enough autonomy (...) he only needs assistance. But if he won't have

a good assistant, he won't be able to do anything by himself (...) He could be living on his own staying away from home (...) what he needs is an assistant."

"He can be partly independent. He himself can care about his everyday needs, but in other matters he needs an assistant."

Unfortunately, denying assistance hinders the disabled youth's autonomy development and deepens the social exclusion of the disabled child and her/his family.

"Independence for us is unreachable (...) Independence is not possible because of the wheelchair and because of the weak hands."

Reindal (1998) notes that educational system and practices for many years have been influenced by a modernist/liberal ideal of personal autonomy, with great emphasis on independence and self-help strategies, including caring for oneself without assistance (dressing, washing, cooking, etc.), and the ability to work independently. Having special needs and lacking self-support skills means not being able to manage life on one's own. Furthermore, Litvak and Enders (2001, p. 715), while talking about support systems, point out that independence does not mean being able to do everything for oneself; rather, it means being in control one's supports. The parents interviewed agreed, saying for instance:

"He could live on his own under supervision of another person, i.e. social worker."

Children with disabilities can compensate for the low expectations and stigma in wider society if they can experience the self-determination which is essential for autonomy (Turnbull, Turnbull, 1996, 2001; Field, Hoffman, 1999; Erwin, Brown, 2003; Wehmeyer, 1996; 1999; 2000; Doll, Sands, Wehmeyer, Palmer, 1996). Families can

structure their home environment to ensure their child's earliest opportunities for choice, control, and privacy that are very important for children's autonomy development (Cook, Brotherson, Weigel-Garrey, Mize, 1996). Children always have a strong desire to own, control, and occupy space (Solberg, 1997). Research findings suggest that when children can participate in the selection of toys, furnishing, equipment, or color schemes for their rooms or play spaces, autonomy and feelings of self-worth and confidence can be enhanced. The parents interviewed noted that they put a lot of effort into structuring the family home environment so that their disabled child could reach the toys, and, for example, in this way to communicate her/his choice of games:

"We asked the child himself where to set shelves, table, bed in his room. For me his choice to arrange things in a room was not acceptable but I said nothing <...> most important is that such arrangement is comfortable for him".

As the above parents exemplify, enlisting the disabled child's opinion about how to organize her/his environment is an important element of advancing the child's self-determination and autonomy. The child's participation in organizing her/his environment helps the child define his/her self-identity, develop self-control, and strengthen his/her individuality and sense of belonging to a group through acting independently.

Some children with disabilities face barriers to achieving greater levels of independence in their home environments because of overprotective parents (Clarke, 2006). For example, some parents say that they keep things on a high shelves that the child cannot reach without the assistance of an adult, because they fear it is unsafe for the child to reach everything by himself. It seemed likely, in listening to these parents, that they felt a greater need to take control in the form of closed or locked doors, things placed on the highest shelves and out of

reach, etc. because of the loss of control connected with the many stressors involved in caring for a disabled child in a context of social exclusion and without adequate social supports.

Those parents who note that children are capable of exerting some control in their home environment also enhance children's possibility to be independent outside the home environment. But parents report that it is difficult for the children with disabilities to experience independence outside the home environment, mostly because of negative attitudes from other people, who can be not only insensitive but even hostile and cruel:

"My girl is not motivated to go into the city alone because she is almost blind, and when she asks for the people to say the number of the bus they say: "are you blind that could not see?" and she feels too frustrated to admit she is blind or to ask again <...> But if she does not, then she catches the wrong bus and gets lost in the city."

"My teenage boy sitting in a wheelchair always wanted to come back home alone from the school. And I let him to do that despite that I wondered very much. <...> and one day teenagers they pushed his wheelchair against his will down the hill on the road home. It was terrible."

Optimally, siblings can help children with disabilities experience more control outside of their homes. Most parents said that siblings protected their disabled brother or sister. Gauvain (2001) points out that sibling interactions play a significant role in cognitive development, including skills related with autonomy development such as problem-solving. For example, younger children observed and imitated the problem-solving behaviors of their older siblings more than they observed or imitated the behaviors of their peers who were working on the same task.

Conclusions

Autonomy development for children with disabilities is closely related to conditions of social exclusion. Families with disabled children face many challenges that, combined, result in social exclusion: Negative attitudes, physical barriers, lack of assistance in the home and outside of it, and lack of opportunities for young people moving to adult lives. All these factors deepen the social exclusion of disabled children and their families, and make it difficult for the children to develop autonomy, which in turn deepens dependency and social isolation. In addition, caring for children with disabilities is costly and the family's poverty can also deepen their social exclusion (Sletten et al., 2004).

"Valued recognition" (Hertzman, 2002) is essential for diminishing social exclusion. The development of self-determination skills of children with disabilities would help to know them as capable to solve problems, make decisions and choices that are important for children's social participation in a society, and would help children with disabilities to experience "valued recognition" among their peers. While a disability is generally not produced by human choice, the restrictions on children's autonomy development are socially constructed in the forms of social policies and attitudes such as stereotypes and stigma – and thus are changeable by making different choices. Therefore, we need to constantly examine how we can structure our society to increase the autonomy of individuals with disabilities.

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