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Thinking relationally: Disability, families and cultural-historical activity theory

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Abstract

It is commonly expressed by parents of disabled children within the Nordic region that there is a mismatch between the official aims of the welfare state and the services provided. In an attempt to explore ways to improve welfare services for disabled children and their families this article proposes three social-relational approaches to disability, family, and service systems which combined may create a basis for new and dynamic ways of working with families. The first approach is a relational understanding of disability, the second a family-centred theory characterized by partnerships with parents, and the third a cultural-historical activity theory emphasizing inter-organizational learning as a method to develop services. Developing ways to fulfil the welfare states' promise of equality and human rights for all is particularly relevant now when all the Nordic countries are currently striving to meet the demands of the new UN Convention on the Rights of Persons with Disabilities.

Introduction

Modern trends in welfare services are characterized by ideas about freedom, equality and solidarity, aiming at equal opportunities for each member of society. These principles are also clearly outlined in the new UN Convention on the Rights of Persons with Disabilities (UN CRPD) (United Nations 2007), signed by 154 nations including all the Nordic countries (as of September 2012). The welfare state plays a key role in achieving such civil liberties. As the Nordic countries have a long tradition of community focus in welfare services, these human rights perspectives regarding disabled people have been found for several decades in welfare policies and

legislation in those countries (Abrahamson, Boje and Greve 2005, Greve 2007, Ólafsson 2005). Nevertheless, it is commonly expressed by parents of disabled children within the Nordic region that there is a mismatch between the goals of the services and the service provision (Jónsdóttir 2003, Tøssebro and Lundeby 2002). Furthermore they find services to be incidental, incompatible and uncompromising (Bjarnason 2010, Egilson 2011, Lundeby and Tøssebro 2008, Ytterhus, Wendelborg and Lundeby 2008). Additionally, many parents complain about not being listened to and having to fight for their statutory rights (Bjarnason 2010, Jónsdóttir 2003, Lundeby and Tøssebro, 2008). This seems to be the case despite the clear intentions of the welfare

state to provide individual support and modified solutions. Given the above findings of the research literature on services for disabled children and their families there is an obvious need for new approaches if the promises of the welfare services are to be fulfilled.

In this article we present three theoretical approaches to disability, family and service systems, and argue that these can, in concert, create the basis for new forms of welfare services for families of disabled children. The three approaches are: First, a social-relational understanding of disability which has been developed during the past few decades where, instead of viewing disability as a medical condition, it has emerged as a socio-political category (Goodley 2011, Traustadóttir 2003, Tregaskis 2002). The second is a family-centred theory which highlights partnership with parents and focuses on the family's role in decision-making about their child's needs (Bruder 2000, Dunst and Trivette 1996, 2005, Espe-Sherwindt 2008, Law et al. 2003). And thirdly a cultural-historical activity theory (CHAT) which emphasizes inter-organizational learning as a method to develop services that can incorporate multiple perspectives and voices, and meet new interactive demands, trends and official goals (Engeström 2001). Here below we explore these approaches in-depth in an attempt to analyse how, if combined, these social-relational and dynamic approaches can advance our understanding of disability, family and welfare services. This is particularly relevant when all the Nordic countries are currently working towards meeting the demands of the new UN Convention on the Rights of Persons with Disabilities for equality, solidarity, participation, dignity and autonomy.

Social-relational views on disability

Within the field of disability research the conceptualisation of disability is widely debated and one can find a plethora of definitions. In the minds of many the concept "disability" has changed from being a medically-defined classificatory concept, signifying an abnormality or malfunctions of the body or mind, to being seen as a socially produced phenomenon (Altman 2001, Thomas 2004) or as a relative construct emerging out of interaction between impairment and societal surroundings (Shakespeare 2006, Tøssebro 2004). Since the 1970s, the disability movement has aimed at moving the gaze from the impaired body to the important role of the surroundings, and the fact that societal barriers restrict the participation of people with impairments (Oliver 1990, Barnes, Mercer and Shakespeare 1999). This has succeeded in shifting debates about disability from bio-medically dominated agendas to discourses about politics, citizenship and accessibility (Gustavsson, Tøssebro and Traustadóttir 2005). These definitions presume that disability may be defined either in a person-oriented or in a situation-oriented way where the individual or personal "tragedy" understanding of disability is often referred to as the medical model opposed to the social-relational understanding of disability typically referred to as the social model.

Shakespeare (2006) argues that an understanding of the social model which focuses solely on societal barriers has become an obstacle to the further development of the disability movement and disability studies and suggests to always look upon disability as an interaction between

the individual and structural factors. This view accords with the main idea behind one of the definitions now commonly accepted, the so called Nordic relational view on disability as articulated by the Norwegian scholar Jan Tøssebro (2004). He describes disability from the viewpoint of the deep-set notion of social equality and human rights within the Nordic societies, resulting in three main assumptions. (1) Disability is a person-environment mismatch that occurs because the environment is not adapted to accommodate the whole range of people, (2) disability is situational or contextual, meaning that specific individual limitations can become disabling or not due to concrete situations and (3) disability is relative, as the cut-off point in impairment-based disability definitions is to some extent arbitrary. Tøssebro (2004) further combines this relational view on disability to the interplay between the person and the societal surroundings and to the notion of equal rights and opportunities which are at the core of the Nordic welfare states. This environmentally relative definition views disability as constituted both by impairments and the disabling environment in which the person lives, and acknowledges that disability is physically based but socially produced. In practice this means that segregated, standardized solutions are not acceptable, and efforts should be made to allocate integrated and individualized services. This understanding also helps determine people's real needs and how these can be met. However, despite widespread acceptance of the social-relational understanding of disability in Nordic scholarship and policy, it has served primarily as a guiding philosophy rather than a basis to develop service practice (Gustavsson, Tøssebro and Traustadóttir 2005). We argue

for the importance of better integrating the social-relational and dynamic understanding of disability into services and suggest the benefits of combining this approach with other social theories, in particular family-centred theory, in order to contribute to improved services for children with disabilities and their families.

Family-centred theory

The transition from medically focused to person- and family-centred models of service delivery has its roots in the ecological systems theory of human development outlined originally by Bronfenbrenner (1979). Although this is a generally accepted approach, services seem to have tendencies to be more child-focused, taking the form of a specialist concentrating on the child alone. This professional work is typically controlled by the processes of diagnosis as is often the case in educational and therapeutic circumstances. In this context scholars have drawn attention to how parents of disabled children have been affected by research that pathologises their children's condition instead of acknowledging disability as constantly shifting, always moveable and social in character (Goodley and McLaughlin 2008). Recognising the socially constructed nature of parenting explains why parents of disabled children resist normative modes of feeling about their kids or dealing with everyday life as they seek out productive alternatives according to their needs and lived experiences. It is evident that a child focused approach alone does not lead to a constructive change if the parents' views and needs for support and information are overlooked (Turnbull, Turbiville and Turnbull 2000).

Consequently, it seems essential to search for empirically useful strategies for conceptualization and characterisation of the complex social processes in serving families raising a disabled child.

Family-centred services

Currently there is an overall agreement in welfare policies and legislations that the family is the most desirable place for disabled children to grow up in, and disabled children are entitled to attend mainstream schools and leisure activities with their nondisabled peers. This is in line with the UN Convention on the Rights of the Child (United Nations 1989), the Salamanca Statement and Framework for Action on Special Needs Education (United Nations 1994) and the UN CRPD (United Nations 2007). Furthermore it is an expressed goal within the Nordic welfare state that families with disabled children shall have access to coordinated and flexible services, adapted to their needs as interpreted by the parents and where parents are met as partners by the professionals (Arbeids- og sosialdepartementet 200, Félagsmálaráðuneytið 2006).

Family-centred theory is a philosophy and method of service delivery for children and parents that emphasizes partnership between the parents and service providers. It focuses on the family's role in decision-making concerning their child and recognizes parents as experts on their child's status and needs (Bruder 200, Dunst and Trivette 1996, 2005, Espe-Sherwindt 2008, Bamm and Rosenbaum 2008, Law et al. 2003). Here the terms "parents" or/and "family" refer to all the important adults in a child's life. Furthermore family-centred theory takes the interplay between the person and the immediate surroundings into

consideration. This process is affected by the relations between these settings and by the larger contexts (Turnbull and Turnbull 2001). The family is regarded as the basic social unit, the main educator, supporter and shaper of each person. Family-centred services also emphasize the recognition of the uniqueness of each family in terms of lifestyle, experience and culture which affects its view on disability, parental role and services (Law et al. 2003, Turnbull, Turbiville and Turnbull 2000).

Thus, the basic principles of family-centred theory support the relevance of making every effort to recognize the parents' views on their own affairs. Acknowledging this leads to increased attention to environmental circumstances in conjunction with disability and how it affects the life of the child and its family. These family-centred values in service delivery are highly regarded by parents of disabled children but are yet to be fully understood and developed in practice (Bamm and Rosenbaum 2008, Egilson 2011). Bruder (2000) argues that research in early childhood practices during the past decades has provided a foundation for the growth and development of interventions aimed at minimizing the impact of a child's delay or impairment and promoting his or her competence which should be the main focus within services. Bruder also refers to Dunst, Trivette and Jodry (1997) when she argues that the processes that influence early learning and development are produced by the interaction of the environments experienced by a child and the characteristics of the people within these environments.

Family-centred early intervention

During the last decade there have been increased arguments for an early interven-

tional approach in children's services in Nordic policymaking in pre-school education (Lov om barnehager 2005, Rammepplan for barnehagens innhold og oppgaver 2006, Sérkennlustefna leikskólasviðs Reykjavíkurborgar 2009). Dunst (2000) claims that the field of early intervention adopted family-centred theory as its philosophical foundation in the 1990s. Accordingly the "third generation model" of early intervention takes into account knowledge about environmental factors when conceptualizing and structuring intervention and family support as can be noted in Nordic strategy plans for services (Arbeids- og sosialdepartementet 2005, Félagsmálaráðuneytið 2006). The conceptualization of family-centred early intervention framework is based on an ecological model of human learning and development along with family systems theory (Turnbull and Turnbull 1990) arguing that individuals cannot be understood in isolation, but rather as a part of their family as the family is the emotional unit. Families are seen as systems of interconnected and interdependent individuals, none of whom can be understood in separation from each other, and therefore the child, parent, and family function as a complex social unit (Bowen 1978). This approach to early intervention has a close resemblance to the relational view on disability in that it acknowledges the relevance of the interplay between the individual and the societal surroundings that may need to be changed, instead of emphasizing solely on the cure or adjustment of the child.

The term "parent-professional partnership" is at the core of family-centred theory and has therefore become a widespread term within service policy and early intervention (Dunst and Trivette 1996, Turnbull, Turbiville and Turnbull 2000).

Working in partnership means that there is a close cooperation between two or more parties having specified and joint rights and responsibilities which is often contractual (Kagan 1991). According to Armstrong (2005) partnership implies mutual respect, complementary expertise, and a willingness to learn from each other. However, recent Nordic research indicates that although "partnership" is a commonly used term in legislations and policy guidelines, it is generally loosely defined, if at all (Sæmundsdóttir and Karvelsdóttir 2008, Christiansen 2010). Therefore limited guidance is given to the interlocutors within services regarding the motives and preferred methods in practice (Árnadóttir and Egilson 2012). Thus, it can be asserted that despite the overall calls and agreement for parent-professional partnership within welfare policies, it seems like there is little awareness or understanding about what it means in real situations and how it should be performed.

As parents often hesitate to carry forward their wishes, and professionals overlook to ask both parties, parents and professionals are confused about how to handle their cooperating roles. To avoid discrepancies between the expectations of the partners, services need to be performed in a co-configured manner. Nummijoki and Engeström (2010) present the hallmarks of co-configuration work according to the Cultural-Historical Activity Theory, CHAT,

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when they emphasize “the client’s active and continuous contribution to the shaping of the product service” (p. 49). Further they describe how co-configuration requires new kinds of agency from both the client and the service provider who must be willing to change the shape of the service and experiment with new patterns of provisions when a need arises. Traditionally, learning is understood as changes in the subject, for example in the behaviour and cognition of the learners. Contrary to this, CHAT regards expansive learning as manifested primarily in changes in the object of the collective activity. This is explained below where we turn to CHAT as a relational and dynamic utility which is suitable for applying the system’s approach in services to families of disabled children.

The Cultural-Historical Activity Theory (CHAT)

Activity theory has a long history within Soviet psychology, drawing on Vygotskian notions of tool mediation and socio-cultural-historical theories of learning (Engeström 2001). Vygotsky’s followers identified the *activity* as the fundamental unit of analysis. Leont’ev (1981) also indicated that *activity* is a system with its own structure, its own internal transformations, and its own development. An activity has a motive and refers to a goal-oriented hierarchical system of actions and operations, mediated by cultural artefacts or tools. A fundamental assumption of CHAT is, therefore, that activities cannot be analysed meaningfully in isolation from their social contexts (Sannino 2008).

Since 1987, Yrjö Engeström has been working on a conceptual model of an activ-

ity system which can serve as an analytical tool to explore the relations between individual and community in any kind of human activity. His formulation of the structure of human activity system is described in a triangular diagram (Figure 1).

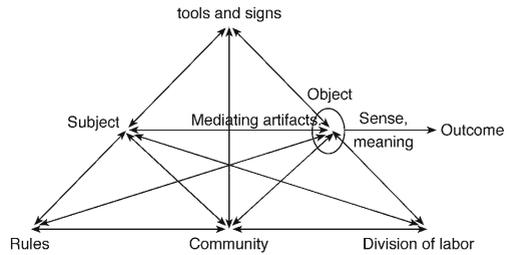


Figure 1. The mediational structure of an activity system (Engeström 1987: 78).

The *subject* refers to the individual or a group of individuals whose agency is chosen as the point of view in the analysis. The *object* refers to the ends towards which activity is directed. The object is the target of the activity within the system. The subjects act on the object by tools, giving the activity a specific direction. The mediation occurs through the use of many different types of tools, material tools as well as mental tools, including culture, ways of thinking and language. The *instruments (tools)* mediate relationships between the subject and the object. The *rules* refer to the set of norms and conventions that regulate the relationships between community and object, and *division of labour* mediates the hierarchy of labour and division of tasks between its members. In this context, the child and family can be seen as the subject of an activity and their welfare as the object. To be able to analyse such complex interactions and relationships, a theoretical account of the constructive elements of the system under investigation is needed. As

cultural-historical activity theory has evolved through three generations of research, it is seen as a feasible theoretical framework for such a unit of analysing. Within activity theory conceptual tools have been developed to better understand dialogue, multiple perspectives and voices, and networks of interacting activity systems (Engeström 2001). To be able to analyze such complex interactions and rela-

tionships as between families of disabled children and the educational system a theoretical account of the constitutive elements of the system under consideration is needed. In analysing those, the basic model described above is expanded to include minimally two interacting activity systems with a collective meaningful object jointly shared or constructed by the activity systems (Figure 2).

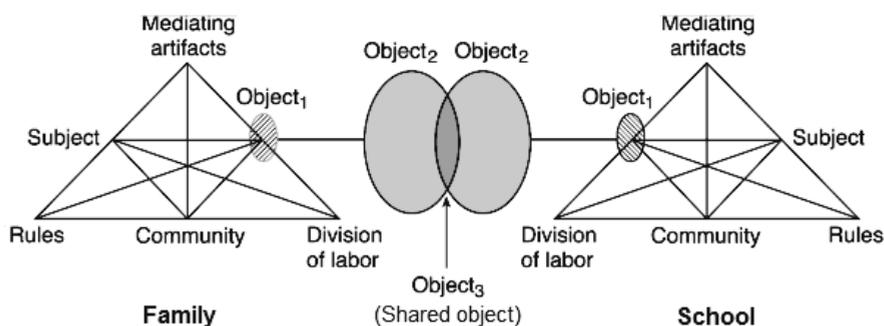


Figure 2. The school and family; two interacting activity systems.

From this standpoint meaningful transfer only takes place through interaction between two or more collective activity systems. For example, the school engages in collaborative interaction with the family, resulting in both parties learning from each other. Transfer is not based on the transition of knowledge only, but is rather a culmination of collaboration capable of producing new theoretical concepts and solutions to problems or tasks that lack ready-made answers (Engeström 2001). As stated by Tuomi-Gröhn (2007) such a process is multidirectional and multifaceted and has a dynamic nature. It can give an applicable approach to explain how new knowledge, activities, and practices are created collaboratively and facilitate moving towards an identified goal. These ideas provide a

ground for a rich belief in parent-professional partnership within welfare services.

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The contradictions that emerge may be created by different views on disability, unbalanced power-relations or misleading views on the shared objects resulting in the manifestation of tertiary contradictions between the central form of the activity and

a new version of it. Tertiary contradictions appear when a culturally more advanced object and motive is introduced into the activity. Such a contradiction can arise when practitioners within welfare-services are to adopt new ideas such as regarding disability as a relational construct or incorporating a family-centred approach without believing in them. Therefore, the new ideas might be formally implemented by the authorities, but internally resisted by the vestiges of the old activity. By recognizing this and working collaboratively with the internal forces, the activity system gradually transforms into a more advanced form. As a result, the tensions are likely to prompt the creation of new approaches in services as to make them function more cohesively in favour of all the participants. Human activity is also affected by the communicative use of language and the production of activity is a key determining factor of human mind and action. In other words, discursive exchanges do not only stem from activity but also generate and regenerate activities through the agentive initiatives of those involved. Sannino (2008) argues that the relationship between the activity and the communicative sign system may be grasped by focusing on the way interlocutors experience talk in a conversation. In her view the gap between conversation and activity is intimately connected to the structure-agency problem.

CHAT is not a predictive theory but a conceptual framework within which different theoretical perspectives may be employed. Thus, linking the Nordic relational view on disability to family-centred theory and further describing welfare services as interacting activity systems makes it possible to utilize the activity theory model as an analytical tool to explore and

analyse its intra related elements. Activity theory describes the activity systems as constantly working through tensions within and between its elements, and this can shed a light on the believed mismatch between the aims and the implementation of welfare services. Potentially it can also support moving the tenets within the Nordic relational understanding of disability from the theoretical level to a practical guiding ideology in accordance with the aims and demands of the UN CRPD. As activity systems take shape and get transformed over lengthy periods of time, their problems and potentials can only be understood against their own history. Furthermore history itself needs to be studied as local history of the activity, its objects and the theoretical ideas and tools that have shaped the activity. Thus, welfare services aiming at being family-centred need to be analyzed in connection with the history of their local situation in relation with the global history in order to better understand the views and concepts related to human rights, ideas about equality, disability, procedures and tools employed and accumulated in the local activity. Therefore the features of CHAT can draw the attention of researchers and professionals to the complex context of disability, families and services that otherwise might be missed.

Conclusion

The promise of the Nordic welfare state about freedom, equality and equal opportunities for all its citizens has been difficult to fulfil when it comes to disabled children and their families. This calls for new efforts on behalf of the welfare states to develop new initiatives in services for this group.

This is particularly relevant at current times when all the Nordic countries are working towards meeting the demands of the new UN Convention on the Rights of Persons with Disabilities which calls for the fulfilment of all human rights for all disabled people. This new human rights treaty highlights a particular need for the protection and advancement of human rights for two groups: Disabled women and disabled children. In this article we have suggested three theoretical approaches to disability, family and service systems, and argued that these, if employed in concert, have the potential to create new forms of welfare services for families of disabled children. The move towards a more family-centred approach in services is already evolving in the Nordic countries through new trends in understanding disability and more dynamic ways of working with parents. In keeping with CHAT, welfare services aiming at enhancing their practices need to take history and the external reality into account

along with up to date theories. Organisational changes geared towards parent-professional partnership require new forms of negotiated professional practice which is argued for in this article. Without a substantive understanding of societal surroundings and the historically changing character of the work performed in a given organisation, theories of organisational and professional learning are likely to remain too general and abstract to capture the emerging possibilities and new forms of learning.

Combining the social-relational view on disability, family-centred theory and CHAT is an attempt to deconstruct objects such as “parent”, “disability”, “professional” and “services” and their interrelations and connections with the external environments. It is argued that utilising these three relational, dynamic, discursive and inter-dependent approaches can create a much needed fruitful and dynamic ways in working with families.

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