

Working relationally to promote user participation in welfare services for young disabled children and their families in Iceland

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ABSTRACT

Despite the avowed aims of the Icelandic legislation to provide family-centred and inclusive services, families raising disabled children commonly express their experiences of fragmented services provided more on the terms of the service providers than the users. This article is based on data derived from an on-going qualitative multi case-research in three municipalities in Iceland. The aims of the paper are 1) to identify the main contradictions that explain tensions and dilemmas within the service system as experienced by the parents, and 2) to suggest potential solutions for improving practices in accordance with family-centred inclusive policy and enhanced user participation. The cultural-historical activity theory was applied as an analytical framework. Three activities central to the wellbeing of the children and their families were identified as the unit of analysis, and contradictions within the activities were located and classified by following the expansive learning theory. Based on our findings we propose Edwards's three 'gardening tools' of relational practices as innovative and appropriate concepts for the necessary changes needed. By utilising these tools, the disabled children and their families are brought to the forefront and the professionals enhance their expertise in partnership with all stakeholders.

Keywords

disabled children, family-centred services, preschools, relational practices, service development, cultural-historical activity theory

INTRODUCTION

During recent decades a family-centred approach has become prominent in welfare service policy worldwide (Espe-Sherwindt, 2008) and has consequently had an impact on legal provisions and practice in Iceland (Arnadóttir & Egilson, 2012; Egilson, 2010). However, it is commonly expressed by parents of disabled children that there is a mismatch between the aims of the welfare legislations and the service provision that appears in practice i.e. in service-based solutions lacking collaborative efforts between service providers and service users (Lundeby & Tøssebro, 2008; Ytterhus, Wendelborg & Lundeby, 2008; Egilson, 2015). Bailey, Raspa & Fox (2011) highlight the essentials in a family-centred approach and draw particular attention to how families should be seen as partners in making decisions about goals and activities in matters affecting them and their children. Although not compulsory in Iceland, the vast majority of all children at 2–6 years of age (disabled or not) attend preschool full time. This is both an educational issue for the child and a practical issue for the families, as it enables both parents to work outside the home, as is customary in Iceland. Inclusive schooling, also referred to as ‘education for all’, is the prevailing school policy. Preschools are funded and administrated by the municipalities and governed by the Preschool Act no 90/2008 (Lög um leikskóla [The Preschool Act], 2008) and school authorities are obliged to provide special services as needed. The amount of time for special education in the preschools is allocated on the grounds of ‘type’ and ‘severity’ of impairments according to psycho-medical diagnosis. Additional services are provided by specialists, either employed by the municipalities or self-employed. Those working privately get paid from the national health insurance according to rules based on the number of clients served. A recent external audit of the Icelandic system on inclusive education (European Agency for Special Needs and Inclusive Education, 2017) reveals the need for guidance for all stakeholders on how inclusive practices should be monitored and evaluated in line with national legislation and policy.

This article is based on data derived from on-going multi-case research on services for young disabled children (2–6 years) and their families in Iceland (Ingólfssdóttir, Egilson & Traustadóttir, 2017). The aim of this part of the project is 1) to identify the main contradictions that explain tensions and dilemmas within the service system as experienced by the parents, and 2) to suggest potential solutions for improving practices in accordance to family-centred inclusive policy and enhanced user-participation.

CULTURAL-HISTORICAL ACTIVITY THEORY AS AN ANALYTICAL FRAMEWORK

Historically it is well known that taking new ideas or theories into practices can be complicated. New paradigms call for changes when implementing new forms of practice that may cause discrepancies and tensions hindering the development of the relevant practices. Cultural-historical activity theory is a theoretical framework that helps to understand and analyse human activities in their social contexts (Engeström, 1987; 1999; 2001; 2016). Based on Vygotsky (1978), who suggested mediated activity for researching individual-societal interaction in context, Engeström (1987) put forward a model of an activity system for use as an analytical tool to explore the relations between individual

and community in human activity. The model describes the structure of an activity system in a triangular diagram (Figure 1).

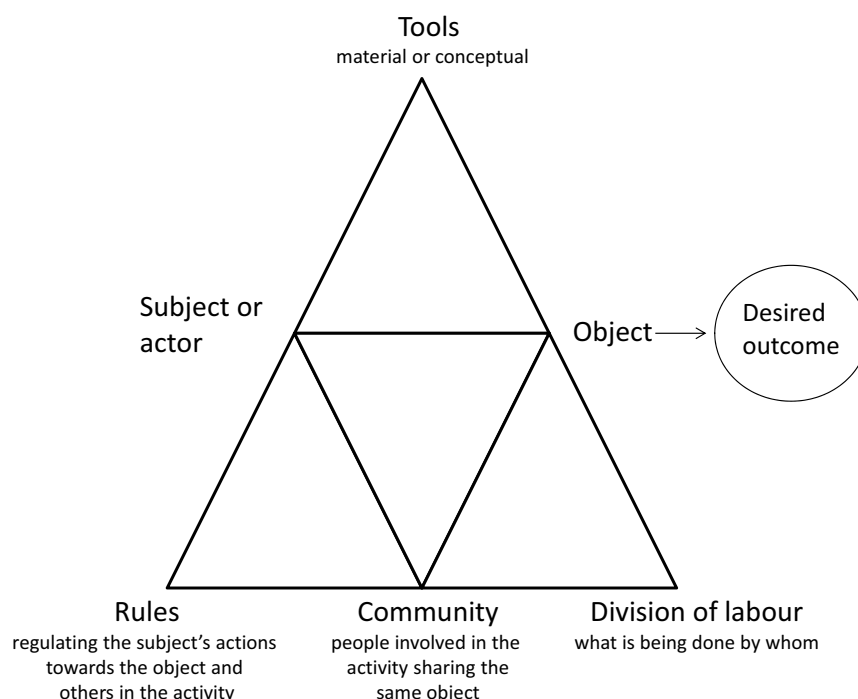


Figure 1. The structure of a human activity system (Engeström, 1987, p. 78)

The *subject* refers to an individual or a group whose agency is chosen as the point of view in the analysis. The *object* is the target of the activity system and the *outcome* is the goal or the ends towards which activity is directed. The subject's relationship with the object is mediated by use of different types of *tools* afforded by the culture, which can be both material and conceptual. The *rules* refer to the set of norms and conventions that regulate the activity, the *community* consists of the people involved in the activity who share the same object, and the *division of labour* mediates the hierarchy of labour and division of tasks between its members. Since activities are always related to other activities, Engeström (2001) suggested two interacting activity systems to be the minimum unit of analysis.

According to this theory, contradictions are present in every collective activity system, causing tensions, problems and dilemmas that disrupt the activity. Contradictions are understood as challenges that practitioners need to deal with, and identifying these contradictions may open up opportunities for the development of practices. To clarify the way in which practitioners collaborate to overcome contradictions, Engeström (2001) developed the 'expansive learning theory' and presented a model of the *expansive learning cycle* (Figure 3) for analysing and supporting development. The expansive learning cycle directs analysis of step-by-step evolution of activities (Engeström 2016).

THE RESEARCH

This paper is part of an on-going qualitative multi-case research (Creswell, 2008) focusing on services for young disabled children (2–6 years of age) and their families in Iceland (Ingólfssdóttir et al., 2017). It is a theory-led research (Simons, 2009) based on family-centred theory (Bamm and Rosenbaum, 2008; Dunst, 2002) and the Nordic relational view on disability (Tøssebro, 2004). The research was conducted in three different municipalities in Iceland. Each case included two to four children, their families (eight families in all) preschool professionals, service counsellors and external experts (see table 1). Case study A was carried out in Reykjavík, by far the largest municipality in Iceland. Case study B was conducted in a rural municipality that is composed of several small communities with aggregated 8,000 inhabitants. *Case study C* was undertaken in a municipality in North Iceland with 18,000 inhabitants that has been widely regarded as a model in integrated welfare services. These three different municipalities were selected because they provided the opportunity to reflect on services in diverse locations with respect to population and geographical region, since preschools and the affairs of disabled children are run by the municipalities. Since previous Icelandic research has focused mostly on children and families in urban and suburban areas (Bjarnason, 2009; Arnadóttir & Egilson, 2012), more families were selected from the rural municipality than from the other two municipalities.

Table 1: Overview of participants and data sources in the case studies

	Case (a) Reykjavík, the capital		Case (b) Rural municipality			Case (c) Municipality in North Iceland		The study as a whole (across cases)
Child details	Child one and two Twin boys; Four years; Intellectual impairment and ADHD	Child three Boy; Two years; Intellectual impairment (Downs syndrome)	Child four Girl; Three years; Intellectual impairment (Downs syndrome)	Child five Girl; Five years; Physical- and intellectual impairment	Child six Boy; Five years; Mild intellectual- physical- and speech impair- ment	Child seven Boy; Seven years; Autism spectrum disorder	Child eight Boy; Four years; Severe intellectual, physical and speech impairment	Child nine Boy; Five years; Mild intellectual physical- and speech impair- ment; ADD
Family and community details	Live with father and stepmother; One older sister; Both parents work out- side the home; Attends a local preschool. Attend local preschool.	Lives with both parents and two older brothers; Both parents work out- side the home; Attends a local preschool.	Lives with both parents. Both parents work outside the home; Attends local preschool.	Lives with both parents and two older sisters; Father receives disability benefits; Mother works outside the home; Attends a local preschool.	Lives with mot- her & stepfather; Both parents work outside the home; Attends local preschool.	Lives with both parents and three siblings; Both parents work outside the home; Attends local preschool.	Lives with both parents and younger sister; Father works outside the home, mother a university student; Attends pre- school nearby a reha- bilitation centre.	Lives with both parents. Half-brother stays with the family every second weekend; Both parents work outside the home; Attends a local pre- school.
Specific data sources	Interviews: Father; Fat- her & stepmother; Observation: Team mee- ting (parents, teachers and service coordinator from the local service centre).	Interview: x2 with both parents.	Interview: Both parents.	Interviews: Mother; Preschool social pedagogue; Head of pre- school; Observations: Story time at pre- school; Home.	Interview: Mother; Service coordinator; Observation: Team meeting.	Interviews: Mother; Pre- school teacher; Observation: Home; Review: Indivi- dual education plan.	Interviews: Mother; Father; Special educa- tion teacher; Head of preschool; Speech therapist; Observations: Pre- school playtime and mealtime, Language training session, Team meeting; Review: Individual education plan.	Interviews: Mother x2; Special education teacher; Head of pre- school; Observations: Pre- school playtime and mealtime, Language training session, Team meeting; Review: Individual education plan
Generic data sources for municipality	Interviews: City special education project leader; Head of advisory preschool*; Advisory preschool spe- cial education coordinator; Speech pathologist Pre- sentation of services: Advisory preschool Arrangements of disabled children's services within advisory preschool Documents from city's official website: Information on family- and educational ser- vices, reports and official rules	Interview: Municipality service consultant Review of documents from municipality's official website: Information on family- and educational services, reports and official rules	Interview: Municipality service consultant Review of documents from municipality's official website: Information on family- and educational services, reports and official rules	Interview: Municipality service consultant Review of documents from municipality's official website: Information on family- and educational services, reports and official rules	Interview: Municipality service consultant Review of documents from municipality's official website: Information on family- and educational services, reports and official rules	Interviews: Municipality preschool special educa- tion counselor; Municipality family service manager Review of documents from municipa- lity's official website: Information on family- and educational services, reports and official rules	Interview: Parent-counsel- or operating nationwide Documents: Icelandic laws and regulations on social and educational services for disabled children and families; UN-CRPD	

*A preschool that specialises in serving disabled children and provides advice to other preschools in Reykjavík

The participating families were selected by the local special education counsellors aiming at diversity with regard to intellectual and/or physical impairment, number of siblings in the family and societal circumstances. The children were 3–7 years of age when the research took place and all had attended preschool from when they were about two years old. All the children received special education within the preschools according to the prevailing rules for allocation, and all received additional specialised services outside the school such as speech therapy or/and physiotherapy. The authors were in no previous contact with the children or their families. The limited number of cases has to be considered when drawing conclusions from this study, as well as the fact that the participants were proposed by the local counsellors in each municipality.

Data collection and analysis

In line with the case-study approach, we drew on multiple sources of information including in-depth interviews, participant observations and document analysis (Creswell, 2008). A review of policy documents was carried out, including laws and regulations regarding disabled children and families. Data also consisted of documents published on the local government websites and websites of individual preschools, which provided rich information related to policy and preschool services. Twelve semi-structured in-depth interviews with parents were conducted (six with mothers alone, two with fathers alone and four with the parents together) and twelve interviews were carried out with professionals from diverse disciplines. In addition to the interviews, nine participant observations were conducted: six participant observations in the preschools, and three at meetings concerning the children, in order to gain a comprehensive overview and insights that cannot be obtained solely by speaking with people (Simons, 2009). The observations created an important opportunity for comparing and contrasting information with data obtained in the interviews.

The interviews were recorded, transcribed and analysed according to deductive within-case and cross-case analysis (Creswell, 2008; Simons, 2009), with the prior described features of family-centred services and the social-relational view on disability as a framework. During the entire process of analysis an effort was made to focus on the quality of the statements made by participants rather than the quantity of ideas presented (Patton, 2014). Initial categories and themes were identified by reading the transcribed data and selecting expressions that manifested family-centred services. In the second round of analysis, main categories were formulated by combining initial sub-categories. Final conceptualisations were generated through parallel investigation and comparison of the main categories. During this phase the main topics were compared within and between municipalities in order to detect similarities and differences between the three cases, as expressed by the parents and professionals. Unexpectedly, there was a high convergence between all the three cases on what worked well for the children and their families and what did not. The differences obtained were based on individual experiences rather than geographical location. The parents in all three municipalities valued their child's preschool and praised the preschool staff for good interaction and support. However, the parents found other parts of the services detached from this main service unit, such as physical and speech therapy services, which were mostly provided at the specialists' venue.

THE UNIT OF ANALYSIS IN THE LIGHT OF THE EXPANSIVE LEARNING THEORY

In analysing the services for disabled children with regard to family-centeredness and inclusive practices, we identified three activity systems central to the children’s wellbeing: the family, the preschool and the external services of specialised experts as the unit of analysis (Figure 2).

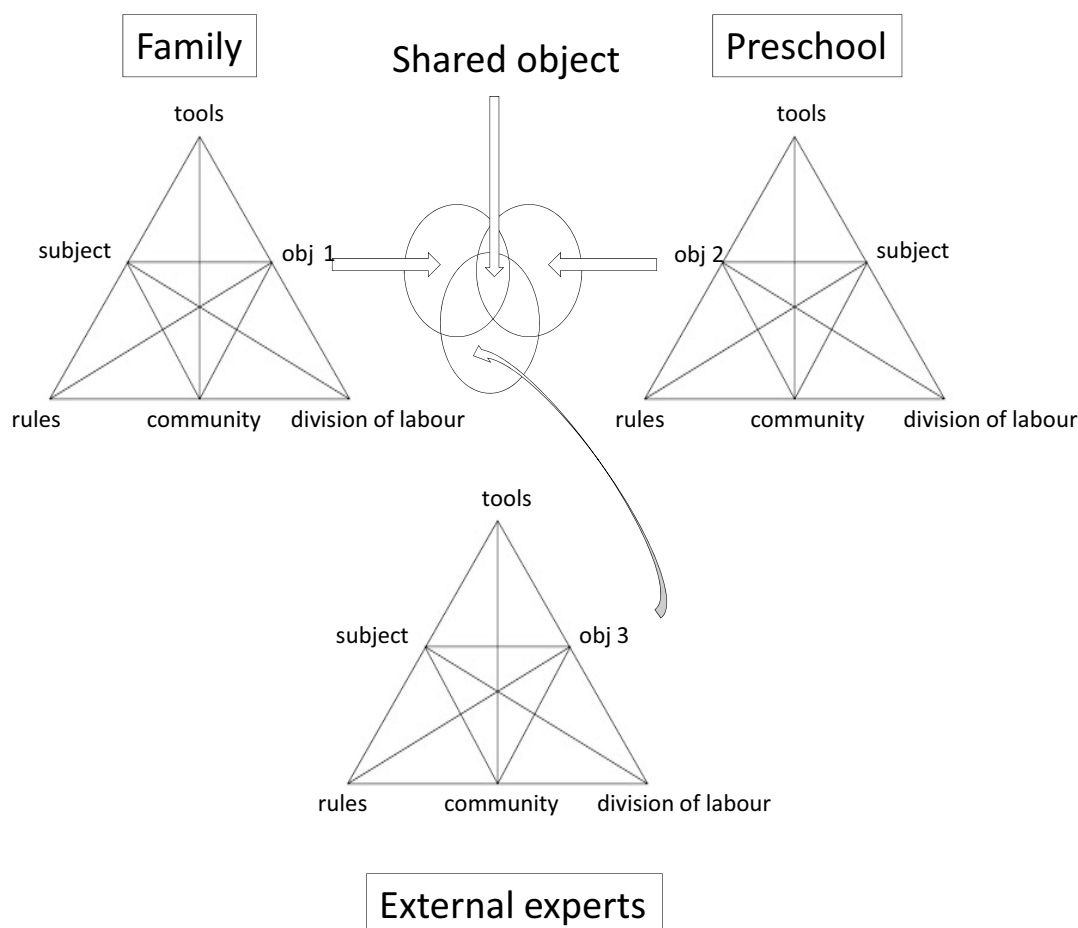


Figure 2. Three interacting activity systems as the unit of analysis (Adapted from Engeström, 2001)

The family is seen as an activity with parents being the subject, the upbringing of their child the object, and the long-term welfare of the child as the outcome. In the preschool’s activity system, the preschool practitioners are the subject and the children’s education and development the object. In both activities, the desired outcome of the activity, i.e. the goal, is children’s wellbeing. The family and the preschool clearly share a common object, being the upbringing of the children with the common goal to support their wellbeing. Most children participate in these two activity systems. However, in the case of disabled children there is often an additional activity involved consisting of the therapies and treatments they receive from external experts. According to our data, this activity calls for most attention since the way this activity system and its practices causes disruptions in the lives of the families, especially the children’s and the mothers’. Our data suggests, however, that chan-

ges within these practices (the activities of the external experts) are emerging as some therapists/experts have developed their occupational practices in line with new ideologies and are now seeking opportunities to work more inclusively in collaboration with the other two activities. This situation – when some practitioners start to doubt the old model and find the need for changing their practice – is identified as the *needs state* in the expansive learning theory, and the first step of contradictions that need to be attended to and worked with for the expansion of organisational learning (Figure 3).

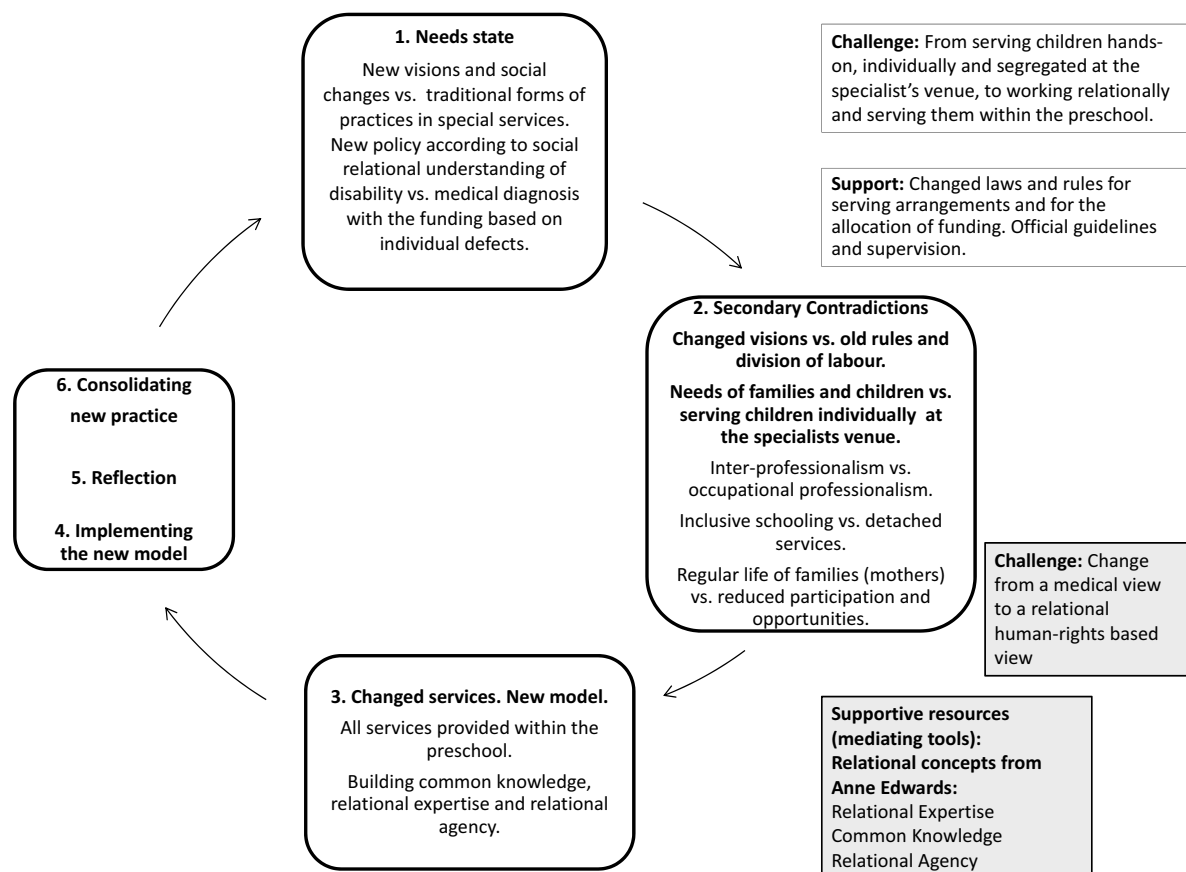


Figure 3. The expansive learning cycle (Adapted from Engeström, 2001)

Following the theory, expansive learning is predicated upon a progression from individuals questioning the state of the art in current practice through the modelling of new forms of practice (see Table 2). The theory of expansive learning puts the primacy on the collective community learning for the creation of new culture (Engeström, 2016, p. 36). In the case of our research, the service users (the children and their families) and the professionals construct a new co-owned object, (children's upbringing) with the shared goal of the welfare of the children and families according to new policy ideals. This implies that the contradictions identified in our research can, if addressed, become a source of change in the services in Iceland. In order to better understand how, when and why interacting activity systems develop, close attention to the four levels of contradictions, identified in Table 2, is essential (Engeström, 1999).

LEVELS OF CONTRADICTIONS AND CORRESPONDING LEARNING ACTIONS

Primary contradictions: tension between the old and the new

Despite the avowed aims of the Icelandic legislation to provide family-centred and inclusive services, the data from all the three cases demonstrated fragmented services being provided more on the terms of the service providers than the users. This is due to the mismatch between the policy ideals, representing family-centeredness and inclusion on the one hand, and the rules for the allocation of services based on the psycho-medical diagnosis of impairments on the other. In the research, a father of prematurely born twins reported how his family was directed to two different institutions for further diagnoses due to their slightly different IQ outcomes in the primary assessments of his sons. The reason was the different roles of the institutions according to the severity of impairments. This is an example of how the fact that eligibility for specialised services is primarily decided on the basis of child's diagnosis rather than the actual need for support. The paradigm change described before requires services to better align with the needs and wishes of the service users.

The previously mentioned discrepancy between policy and service actions is caused by the primary contradiction, which is the fundamental contradiction that keeps the activity system in constant tension. It surfaces in everyday contexts, in various forms and in other levels of contradictions.

Table 2. Levels of contradictions and corresponding learning actions (adapted from Foot, 2014)

Levels of contradictions	Characteristics of contradictions	Corresponding learning action
Primary	Mismatch between policy and practice. New visions on disability and human rights vs. old forms of practices based on medical views.	Questioning – Needs state. New ideas call for new forms of practices. Services need to move from provision on the terms of the specialists or the system to being on the terms of the service user.
Secondary double bind	Psycho-medical diagnosis as the main predictor for the allocation of services vs. the rights for family-centred services according to needs. Fragmented services reducing quality of life for disabled children and families.	2A Historical analysis – The paradigm shift from medical view on disability to social-relational views. 2B Empirical analysis The paradigm change calls for new solutions. Develop new forms of family-centred practices in accordance with new views on disability, official aims of services, inclusive schooling, regulations and the emerging implementation of the CRPD.
Tertiary	Arises when a more developed activity is introduced into the central activity system such as: A new model is emerging, characterized by relational professionalism aiming at monitoring and controlling professional work according to the needs and wishes of the service users vs. professionalism led by the professions according to the old model based on the medical view.	Modeling the new solution. Rethinking practices by rethinking expertise and multi-agency practices. Relational expertise, common knowledge and relational agency being the central concepts in a new model. Examining the model. Implementing the model on a systemic level requires change of rules; regulations on a systemic level in accordance to new policy and law. Evaluating process.
Quaternary	Occurs between central activity and neighbouring activities, triggered by tertiary contradiction.	Consolidating new practice. Questioning – the spiral goes on.

According to Foot (2014) the primary contradiction is not only continually present, but also serves as a foundation for other levels of contradictions. Furthermore, she claims that even if attempts to resolve the other levels of contradictions are temporarily successful, the primary contradiction remains. The levels of contradictions and corresponding actions are outlined in Table 2.

Secondary contradictions: tensions between rules for expert practice and ordinary life of children and families

The parents we interviewed were unanimous about the difficulties they encountered when striving for an appointment with fully booked specialists, which forced them to accept any appointment slot offered. Usually it was the mother's role to take the child to the therapists and, consequently, all the mothers taking part in the research had been compelled to reduce their working hours or change their occupations to be able to bring their children to the specialists. Thus, the service arrangements disrupted their personal and family circumstances both in terms of career and financial income, quite apart from disturbing the children's routines. This indicates that services are provided on the specialists' terms – the old policy contradicting the new, which presumes that needs of children and the families are at the forefront. The allocation of funds for specialised services is primarily decided on the basis of the 'severity' of the child's diagnosis, running in opposition to the new policy, which declares that the services should be provided on the bases of the actual need for support expressed by the families. However, the data reveal an emerging trend of both diagnostic measures and services in accordance with the new family-centred and inclusive policy.

A mother of a young girl with Down's syndrome felt 'lucky' as the impairment her daughter has is well known. She added that they [the family] were guided along a prepared path designed for families with children with Down's syndrome. Furthermore, parents of children diagnosed with autism reported how they were offered a choice of highly structured behaviour therapy provided individually within the preschool by specially trained (para-) professionals. Since the rules for the allocation of services are based on diagnosis, parents and preschools tend to strive for psycho-medical diagnosis of children (often against their own better judgment and conviction) as it gives access to financial resources. This is against the spirit of the prevailing law favouring family-centred services, where the will and preference of the service-users and their individual needs for assistance are supposed to be at the forefront.

Tertiary contradictions: new forms of practices cause fragmentation in services where some practitioners have changed their practice while others fall behind

An example of an emerging new model of practice in the specialists' services was reported by one of the participating mothers. She explained how she had managed to influence her son's services when a physical therapist accepted to alter her usual service to accommodate the mother's wishes. Instead of bringing the boy to the therapist's premises, the therapist went to the preschool to work with the boy. In the mother's opinion this was the ideal

arrangement as it had a minimal effect on her son's school routine and she herself did not have to break up her workday to drive her son to the session with the therapist. Additionally, it gave the preschool staff an opportunity to extend their knowledge. Unfortunately, this therapist went on a maternity leave and the new therapist did not accept to continue this arrangement. This can be identified as a tertiary contradiction between developed practices in accordance to new views versus traditional modes of practice that does not take new understandings and policy into account.

In all three municipalities the preschool administrators were open to the idea of providing specialised services at the school premises in accordance with the spirit of the law, but evidently the lack of official rules, relevant guidelines and supervision prevented this. Furthermore, the specialists' working conditions and even professional preferences appeared to stand in the way at times. An experienced speech therapist expressed her views on this by saying: 'Professionals need to look into and reconsider their own practices and stop just acting according to their own convenience'. A special education consultant was unequivocal when she said she envisioned that the specialist services would be transferred into the preschools and included in everyday activities. She continued, however, by describing the obstacles, such as the limited number of specialists working within the school system and increased emphasis on individual behaviour therapy. These are signs of tertiary contradictions motivating new dynamics for developing family-centred services in an inclusive way.

IMPLICATIONS FOR SERVICES

Based on our analyses directed by Engeström's theory of expansive learning, we are able to suggest which changes need to be implemented in order to develop inclusive family-centred welfare services for disabled children and their families. *Firstly*, we refer to the problems and dilemmas faced by the families, especially mothers, when policy ideals on the one hand and the provision of services on the other do not combine to provide services in a family-centred inclusive manner. Our analyses suggest a need to change the rules for the allocation of financial resources for specialised services, and to adopt official guidelines for new approaches in professional practices in accordance with family-centred inclusive services. *Secondly*, we refer to the importance of pursuing relational practices between all inter-related activity systems. This is the key change needed to overcome the current contradictions within the welfare services, especially when striving for family-centeredness and inclusive practices. Inclusive practice in preschool education requires making adjustments, modifications and individualised accommodations in instructional methods so the disabled child can fully participate in play and everyday learning activities with their peers (Grisham-Brown, Hemmeter & Pretti-Frontczak, 2017). Hence, inclusive practices call for professional collaboration and transfer of knowledge across professional boundaries. In this context, we find the cultural-historical approach to collaboration within and across practices as introduced by Edwards (2017) well suited to promote the development of welfare services, better to comply with the merits of family-centred theory and inclusive practices. The three fundamental concepts in her theoretical contribution are: *relational expertise* (including the parents as experts), *common knowledge* and *relational agency* to

support both professional and organisational development (see Figure 3). These concepts are labels Edwards has given to the aspects of the expertise exercised by professionals who accomplish effective inter-professional work to bolster children and families (pp. 7–12). She refers to those three concepts as *gardening tools* that have been used to build, nurture and sustain the expertise needed for collaborations across professional boundaries. The first and overarching concept is *relational expertise*, which is the capacity to work with others on complex tasks, involving a joint interpretation of the work ahead as well as a joint response. Relational expertise is therefore an additional form of expertise that augments specialist expertise and makes fluid and responsive collaborations possible. The second concept, *common knowledge*, acts as a mediator of relational agency in the sense that through common knowledge, practice can be oriented towards coherent goals of interacting activities. Professionals learn from one another and therefore common knowledge is created in interactions in sites of intersecting practices (Edwards, 2017, p. 10). Lastly, the third gardening tool, *relational agency*, is the capacity of professionals from different practices to align with the thoughts and action of one another, in this case the families, preschool professionals and external experts all drawing on the resources they offer to strengthen their purposeful responses in order to act in line with the objectives of family-centred services and inclusion.

CONCLUSION

The high convergence between all three cases on what worked well for the children and their families, and on what caused tensions and dilemmas, draws attention to the commonly expressed contradictions between policy ideals and the services as enacted in practice. The emerging paradigm change followed by changes in the views on disability calls for systemic development in professional thinking and provision of services. The necessary changes require official guidelines from the authorities about the working arrangements that conform to the ideology, within existing laws and conventions. In our view this demands new solutions and the will and capacity of service providers to interact intensively across professional boundaries with the families of disabled children. The existing rules for the allocation of resources and the working conditions of external experts motivate them to follow a process of identifying the impairment and its limitations, aiming at taking the necessary action to improve the position of the individual disabled child, often without looking at the wider context. This has produced a service system in which an authoritarian service provider prescribes and acts for a ‘passive client’ irrespective of his or her actual needs and wishes. In order to develop new ways of practices for better complying with the aims of family-centred services, inclusion and other human rights perspectives, we suggest changes in rules on how the welfare authorities allocate resources in order to support a relational turn in expert practices. Our proposition is that by utilising the *gardening tools* of relational practices, the disabled children and their families will be brought to the forefront and professionals will be able to enhance their own expertise in partnership with all stakeholders. According to the expansive learning theory, the next step in the learning cycle would be to develop a new service model by rethinking practices and expertise. Based on the characteristics of the contradictions identified in this research and the sug-

gested learning actions to develop the services, multi-agency practices with relational expertise, common knowledge and relational agency will be central concepts in our future work aiming at the enhanced participation of disabled children and their parents.

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