

# Families with special needs children consuming social and health care services – visible and invisible activities of daily life

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## 1. Introduction

Studying welfare services from the customer's point of view is a timely topic. Especially when the role of the customer is changing from a passive receiver into an active agent (e.g. Tuorila 2000, Deber et al. 2005, McColl-Kennedy et al. 2012). One of the key objectives of social and health services is to support and improve a customer performance in daily life. In other words, offer services that support the actions and activity that enhance wellbeing of a customer and/or help the customer herself to improve her own wellbeing. Thus, understanding the customer activity while using welfare services within the context of everyday life is a central topic.

Recently, customer-dominant service theories have begun to emphasize the significance of the services as part of customers' daily lives (see for example Heinonen et al. 2010; Mickelsson 2013). This enables a new understanding of the service system. The focus of customer-dominant research goes beyond the interaction between a service provider and a customer to cover also the customer's daily life especially functions that are not visible to the service provider but are significant to the customer (Mickelsson 2013).

This paper studies the customer's daily activities and the role of the social and health care services from the viewpoint of families with special needs children. It is typical for children with special care need to often require long-term social and health care services (Strickland et al. 2011). Because the children need many services rather intensively, they become an interesting subject for research.

Parents play central role in child's life and well-being (e.g. Shelton 1987). They can be pictured as captains of the team, which take care of and support that child. From the service providers' viewpoint, the active customer is the parent since any child less than 18 years old is not an independent actor in the eyes of the law, regardless of whether they are capable of looking after themselves. This makes the whole family an interesting unit to study.

The fact that the health and social care service system stresses the active agency of customers draws attention to this special context where the active agent is the parent (e.g. Järvikoski et al. 2012), not the child for whom the services are mainly offered. This demand for active agency creates tension between the role of the parent in taking care of their child and their role of active customer within the jungle of social and health care services. Caring for a child with special needs demands extra effort and activity from the parents (e.g. Nusrat et al. 2016). This may cause decreased wellbeing of the parent. It is critical for service providers to understand what kind of activity can be expected from families in this context and what is the role of services within their everyday life.

To support this trend of active agency, customers are offered, for example, multiple self-services or other services, enabled by the latest technology. With the help of these services customer can follow their own health (e.g. Lupton 2013) or manage their interaction with service providers via the Internet. Even though there are many good things and new possibilities in this trend, the activity which is required from customers should be examined more widely than from, for example, the perspective of remote or self-services. The use of welfare services is highly dependent on needs, capabilities and special situations, thus the significance of understanding the context of use. This aspect should be taken into account especially when planning and developing the services.

This study focuses on the activities of families with special needs children and their experiences with social and health care services, as well as educational services when they are mentioned in the interviews of the families. We aim to shed light on the interplay between a customer and multiple service providers as well as to the broader set of activities outside the traditional service context; activities that are supported by service providers, but mainly executed independently by the customer with little or no interaction with service providers, thus making them often invisible to the service providers. All the activities are viewed from the perspective of the customer's context, meaning that they are identified by the same context they belong to, in this case balancing everyday wellbeing. Hence, this study extends and deepens the understanding of context-related services (Mickelsson 2014) by utilizing the concepts of activity components (Leont'ev 1978) and customer activity levels (Heinonen et al. 2010). This paper builds upon the customer-dominant logic (CDL) view of service, where the primary focus is on the customer's life and activities that the service offering is related to (Heinonen et al. 2010).

## **2. Towards an active customership**

The term 'customer' has long roots in business economics. However, the use of the term has also become common in the instructions, statements and reports of the public social and health care services and the term has stabilized its presence as public sector's daily conversations even though citizens are still labelled as customers, patients or service users in Finnish legislation (Valkama 2012, 43,119; Virtanen et al. 2011, 15). In the discussion related to customership a concept of consumer has also been brought out (e.g. Tuorila 2000; Deber et al. 2005; Wald et al. 2007; McLaughlin 2009; Autio et al. 2012, 42). In the study of Valkama (2012, 149) the majority of the interviewees felt that the term "customer" reflected best their role in relation to the social and healthcare services. This may be because consumership usually entails a wide spectrum of opportunities for choice that is not at this moment possible (see e.g. Junnila et al. 2016, 4; Valkama 2012; Niiranen 2002, 68). In addition, there is usually a compulsory need or situation driving the acquisition of social and health care services, so consequently the acquisition is rarely well planned or executed due to a sudden impulse (Tuorila 2000, 39).

Even though this study uses the term 'customer', it pays attention to the special characteristics of the social and health care services: the customer is usually more dependent on these service producers than are customers of producers of other types of services, and the granting of the services is often based on the decision of a public authority (see e.g. Outinen et al. 1994, 59; Tuorila 2000).

As discussed earlier, term 'customer' is still quite multi-layered and varied (Kaatrakoski 2016, 167). In spite of the versatile nature of the term, understanding customer needs and aiming towards customer-centered approach has become an objective for the social and

health care services (see e.g. Walden 2006; Kaarakainen & Syrjänen 2012, 39; Kaseva 2011, 5). The challenge lies in the planning and production of need-based services with decreased resources, but there also is a huge potential to produce better services (Tuulaniemi 2011, 279).

In this study we want to emphasize the recent change in the concept of a customer that is the transformation of a customer from a passive recipient into an active actor (see e.g. Shilling 2002; Virtanen et al. 2011, 15; Autio et al. 2012). This means to the customer that she has an increased responsibility for her own health and general wellbeing. The change is often justified on the grounds of social responsibility or sometimes it is built into a service system. In other words, to be entitled to the service – that is to become a customer – the citizen has become active (Valkama 2012, 56.) Furthermore, the system can be seen offering excessive welfare protection, leading to a situation where the customer expects or even demands that the society solves problems which are supposed to be the responsibility of the customer (Valkama 2012, 53; see also Valkenburg 2007, 29-30; Bauman 1998, 36-41).

Other reason driving the transformation is service providers' desire to control costs, to increase the ability to respond to the customers' needs and to improve quality. These all increase the need to transform the customer into an active participant that can be seen as customer taking part into decision making concerning the care or participating the development of services. (Tritter 2009.)

Addressing the requirements for activity demanded by service providers requires know-how and resources from the customer. This puts service providers in the situation of needing to balance between demands for activity and customer competences and resources in such a way that customer's resources and capabilities are not used up in the detriment of independent initiative and action (ref. Tuorila 2000, 36). Even though the customers are more active, interested in their rights and role as a service user (Koivisto 1994; Kinnunen 1995; Tuorila 2000, 37), for example, weakened health or wellbeing must be taken into account as it has a significant effect on the possibility to be active.

When examining customer activity and services role in it, we have to take into consideration that this activity has also been facilitated and accelerated by recent technological development. The Internet provides practically limitless opportunities to look for information. Customers of health services in particular are expected to independently advance their personal health with this increased information available (e.g. nutrition and health related blogs and services providing information on diseases and symptoms) and with well remote or self-diagnostics services (e.g. online doctoral services, sensors planted under skin) (Simborg 2010; Autio et al. 2012). Technological solutions have facilitated improved medical care (Ghulam ym. 2006), the participation of customers in service development (Freire & Sangiorgi 2010) as well as better utilization of customer knowhow (Nambisan 2002, 2009).

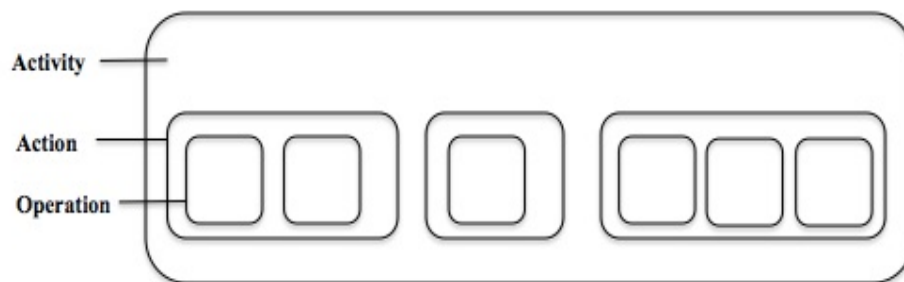
### **3. From a service-centered approach towards understanding the activities of the customer**

In recent years, there has been an increased interest in understanding the more active role and activities of the customer. In discussions related to Service-Dominant logic (Vargo and Lusch 2004, 2008; Gummesson et al. 2010) the customer is seen, for example, as an active actor and co-producer, who creates value with his or her own activity (Lusch & Vargo 2006). Cova and Dall'Aglio (2009) see the customer as a working customer who adds cultural and effective elements to service offerings. Prahalad and Ramaswamy (2004) see the

phenomenon of customer activity as the co-opting the consumer's competence into the production process.

According to Mickelsson (2014, 14) customer activity is a central marketing concept, and he has endeavored to develop a more detailed definition of it. According to him, for example, the 'solution-based' approach presented by Sawhney (1999, 2006) examines activity from the customer point of view but does not clearly define what is meant by the term activity. In practice-theory based research (see e.g. Holttinen 2010, Korkman 2006) the focus is also the customer and her daily activities, but such research focuses on socially formed and shared behaviors but not the activity itself (Mickelsson 2014, 14).

This research relies on Mickelsson's (2013, 539) definition of the customer activity, according to which customer activity is "a discrete sequence of behavior that through its outcomes aims at creating or supporting some type of value in the customer's life or business". The definition is based on activity theory which examines human behavior through motives and goals (Leont'ev 1977, 1978; Engeström 1999). According to Leont'ev (1989), the behavior of people can be divided into different action components, which can be further divided into separate operations (Picture 1.) According to Mickelsson (2014, 81-82) the different components of activity are not separate but rather different parts of the same phenomenon which is examined from different abstract levels. The interpretation is based on the researcher's or practitioner's own more or less consistent understanding of the entire activity.



Picture 1. Activity, Action and Operation (Leont'ev 1978; Mickelsson 2014)

In his own research, Mickelsson (2014, 89) has identified three different approaches for studying the activity: activity can be interpreted as based on a single event, as the context in which the activities are associated, or activities that occur in different contexts but share the same motivation for action. This study focuses on context-related activities.

Heinonen et al. (2010) have presented a Customer-Dominant logic, in which the starting point is the everyday life of the customer and the integration of services in it. The model widens the perspective from interaction between a customer and a service provider to consider also those activities that are not directly visible to the service provider. According to them, customer activities can be divided into three different types or levels: *Core activities*, *Related activities* and *Other activities*. Hence, the customer experience or value is dependent on what happens on all these different levels (Heinonen et al. 2010; Mickelsson 2013, 538).

Activities that are seen as *core activities*, relate in one way or another to the use of the elements provided by the service provider. Hence, *a core activity* is such an activity that the service provider can influence, such as interaction or use of service. (Mickelsson 2013, 538.) *Related activity* is related to the same value-adding process as the *core activity*, but they are

invisible to the service provider (Heinonen et al. 2010). Grönroos and Voima (2012) call this type of activity as customer value-adding process. What is significant here is that although service providers have little or no visibility of these activities, they are important factors in the creation of value to the customer (Mickelsson 2013, 538). The activities include, for example, the collection of information about services and communication with other related actors. *Related activities* can also be supplemental activities that the customers do prior to using the service. (see Mickelsson 2013.) Such supplemental or complementary activities can be, for example, calling taxi before going to the restaurant.

*Other activities* are activities that influence value creation indirectly. Such activity is, for example, activity that does not relate to the service but around which the activity has to be organized. These activities do not directly affect the process of creating value, but they affect the structure in which services are provided by, for example limiting the scheduling of services. (Heinonen et al. 2010; Mickelsson 2013, 539.)

The definition of customer activity by Mickelsson (2013, 2014), activity components (Leont'ev 1978) and the concept of customer activity in Customer-Dominant logic (Heinonen et al. 2010) are all suitable approaches for the study of services targeted at families with special needs children. First of all, families with special needs children need and use different services than families with normal children. Since the role of the services is a significant part of everyday life, research and understanding of the activities from the viewpoint of everyday life can open new perspectives for services planning and provisioning.

Second, the objective of services is to support and ease the everyday life of families. Of course, in individual services such as healthcare services, the main goal may be to cure the patient, but when considering welfare services as a whole, it can be assumed that families aim to pursue a good and well-functioning everyday life. Hence, all activities in the everyday life of a family, even those related to other services, have significance on the formation of daily lives.

Thirdly, since the daily life of a family with a special needs child differs from the daily life of the so called “normal” family, the understanding of the context is especially important. Hence, a Customer-Dominant logic, which emphasizes that in order to understand customer-driven value creation of services, the service provider must understand customer’s everyday activities and how the services support the life of the customer (Heinonen et al. 2010), provides a solid theoretical basis for service research.

#### **4. Data and methodology**

The experiences of special needs child or families with special needs children have often been examined and studied by focusing on the diagnosis the person has (for example ADHD or development disability). Because families with special needs children share the need for long-term and diverse services (Strickland et al. 2011), the amount of services in use was set as a key criteria for families to be selected to this study. Regardless what kind of diagnosis the child has. The objective is to study the so called “heavy users” of services by which we mean that the families have to use at least four different services due to the special needs of their child or children. Similar criteria have been used for example in a joint study by City of Oulu, The Social Insurance Institution of Finland, The Finnish Innovation Fund Sitra and private health care providers (2015).

The data has been conducted among families living in The Hospital District of Helsinki and Uusimaa in Finland. The data collection was planned and coordinated by the first author of this paper. The criteria set for the child was the age – less than sixteen years old – and she/he had to live at home. The parent who had taken main responsibility for interacting with service providers and child's medical examinations, care and therapy was selected as the interviewee. In this study, all interviewees were mothers.

Ten narrative interviews were conducted. Most of the interviewees were between ages of thirty and fifty: only one was over fifty years old. Three of the ten families had two special needs children. Most families had used services for over five years. Three of the interviewees were able to work full-time, others had made adjustments to their work or studies due to the special needs of the child/children. Interviews lasted approximately 1-2 hours.

Each interview started by loosely utilizing the auto-driving method presented by McCracken (1988), which helps to establish and concretize those experiences that can be challenging to bring up in an interview or in a form of a narrative. As the objective was that the interviewees to tell about their experiences from rather long period of time, even from fifteen years ago, they were asked to first draw a picture of their family and then list the services they use around that picture.

Then the interviewees were asked to describe their own and their family's experiences about four wider topics: 1) getting the services, 2) managing the services as part of their daily lives, 3) participating the planning of the services and 4) using digital services. Interview questions were open-ended, but additional questions were asked when necessary in order to direct the conversation within the four wider topics. Final amount of transcribed text was fairly large, approximately 270 pages.

When reading the narratives, small "mini"-narratives started to rise within the wider subject topics. Based on these mini-narratives different meta-themes such as "acting as the contact person" and "the effect of the services to the daily lives" were noted. First coding of the data took place in fall 2016 with Atlas.ti-software. Altogether 941 citations were found and they were divided into 15 categories. One observation at this stage was that one of the key topics – Participating the planning of the services – did not come up strongly in the narratives of the interviewees, but experiences related to it were incorporated into other themes.

Extracts from different narratives that were similar to each other were combined as one category (Lieblich et al. 1998). The number of extracts under different categories varied: some included a great deal of descriptions and some less. There was also some overlapping within categories.

The mini-narratives under categories were analyzed and they indicated that using multiple services requires a great deal of time and effort from the family and that affects the family's efforts to balance their daily lives. However, it was difficult to analyze what kind of activities exactly require time and effort and therefore the data was recoded and this time the objective was to identify different types of activities that can be found in narratives. In the end, there were 1196 coded citations and 45 categories. However, in addition to different type of activities, categories also included several rich descriptions on special cases which were saved separately for further analysis.

The data included different levels of activity descriptions: from concrete phone call – mentions to more general mentions about finding and applying for services. In addition,

some factors that either hamper or ease the activities were identified and saved for further analysis.

After recoding, the data was categorized by loosely following the way Mickelsson (2014) did categorization in his analysis on practice-theoretical studies where he utilized the activity components (Leont'ev 1978). After that all the identified activities were categorized based on the concept of customer activity (Heinonen et al. 2010; Mickelsson 2013) where *core activities*, *related activities* and *other activities* are grouped together. Here is an example of the categorization done for *core activities*:

CORE ACTIVITIES		
Activity	Action	Operation
Applying for services	Acquisition of statements and other additional clearances	Taking contact to get a statement
		Discussions related to the statement
		Delivering statements (physically or virtually)
	Visits to e.g. daycare or school	
	Filling in and sending applications	Asking for instructions
		Writing applications
		Collecting statements and other necessary appendix
		Delivering application virtually, personally or by postal service
		Re-filling application if decision has been negative
		Visiting professionals
Interaction with professionals	Discussions on the content of service	
	Discussions with professionals	
	Child's examinations, evaluations, control and followup meetings	
	Therapy sessions	
	Medical care visits in hospital	
	Visits in school/daycare	
	Courses	
	Fitting ancillary appliances	
	Scheduling	Finding out the timing of different visits and
		Negotiating the timing of visits with multiple professionals
	Cancelling other agreed but overlapping services	
	Updating the family calendar	
	Keeping in mind all vacation periods of the professionals	
	Informing child's weekly schedule or changes in it to school/daycare/taxi	
	Sharing information in person	
	Copying/scanning documents	
	Sending papers personally, by postal service or by email.	
Advising and supervising professionals	Offering information/fixing wrong information	Finding and figuring out necessary information (e.g. Law)
		Sharing information with professionals
		Correcting wrong information
	Helping to interpret the Law	
	Supervising professionals' work	Calling, sending SMS or email to professional to ensure he/she is doing her work.
		Visiting professional personally
Claiming rights	Making child protection notice (on own family)	
	Making a letter of request to service provider	
	Making a letter of request to the board of social and healthcare services	
	Sending an appeal to provincial government	
	Seeking own rights from Supreme Court	

Table 1. Activities, actions and operations within *core activities*

As the current definition of the concept of customer activity is interpreted from the perspective of one service, it was modified to better fit the situations, where the study covers multiple services (Table 2.) Interaction between the customer and the service provider as well as customer's visible activities are still emphasized in the *core activities*. In *related activities*, customer activity stresses the independent use or utilization of services but the role of interaction between the customer and the service providers lessens thus making the customer activity less visible to service providers. In *other activities*, the use of the services is low, but the motivation or goal of the activity is the same as in *core* or *related activities*.

Activity/Definition	Original definition (Heinonen ym. 2010, Mickelsson 2013)	Modified definitio; from the viewpoint of multiple services
<b>Core Activity</b>	Interaction with provider's service elements	Interaction with service providers is in significant role
<b>Related Activity</b>	Interaction with other providers, learning about service context, communicating about service context, other connected activity	Activity is supported by services, but the role of interaction is smaller and/or random
<b>Other Activity</b>	Other unrelated activities that influence the customers' value creating process	Other activities that have the same context-based motivation, but the role of services is minimal or nonexistent.

Table 2. Definition of the levels of customer activities from the viewpoint of multiple services (see Heinonen et al. 2010, Mickelsson 2013).

Besides the previously described categorization, a categorical-content analysis was executed in order to interpret and describe the types of activities found.

This analysis includes both social and health care services as well as educational service providers regardless of whether their sector (public, private, third sector). Educational service providers were included, because they were an integral part of the narratives and the interviewees felt that they play a significant role in the family's life. Because the objective of the study is to understand customers' activity and the role of the services in their daily lives, the services play a significant role, not the service provider itself. There were situations when interviewees didn't even remember who is providing the service, it was just critical to understand that how the service works.

## 5. Preliminary findings

Preliminary findings are based on a categorization according to the above activity models and categorical-content analysis. We describe the core, related and other activities (Heinonen et al. 2010, Mickelsson 2013) and different activity components (Leont'ev 1978) that were identified based on the interviews. Their visibility and/or invisibility from the service providers' point of view will be discussed.

### 5.1 Core Activities

*Core activities* include: applying for services, interaction with professionals, advising and supervising professionals, and claiming rights. All three activity components (Leont'ev 1978) can be found within these activities except for claiming rights where only activity and action components were found. In addition, interaction with professionals included some actions that could not be divided into smaller activity components, that is operations. One possible interpretation can be that, for example, different types of visits are common activities or to the interviewees, therefore complementary explanations are not considered necessary.

#### 5.1.1 Applying for services – intensive work for customership

Characteristically in welfare services such as in the social services, specialized medical care or special educational support – one has to meet certain criteria in order get the service. First, the customer has to find out and understand the criteria, then have an assessment or examination done by a professional, then get a statement based on the assessment and finally send the assessment with the application form to the authority (a simplified description).



We can identify several actions related to the above description: acquisition of statements and other additional clearances, visiting e.g. the daycare/school, filling in and sending applications, and negotiations on the content of the service. Different types of evaluation or examination visits to professionals fit in this activity, but as those visits often belong within a larger context of service usage, we included them under *Interaction with professionals*.

It is important to take into account the context of the customers when evaluating the application for services. First of all, customers use multiple services so the activity with the actions and operations related to it multiply each time a new service is applied for. Over time families dozens of services, meaning that applying for services -activity requires a significant amount of time and resources. Especially in situations where the family has no previous experience in applying for services, the process may require an unreasonable amount of work:

*“..the disability allowance granted by the Social Insurance Institution of Finland (Kela), I counted that it has required at least 80 hours of work from me just for the writing and all the additional work that does not change my child’s situation in any way, I just had to prove it.”*  
– Rita, a mother of a quadrupled child

Another characteristic of the services is that many of them are granted only for a limited period (e.g. for a year). This means that the customer has to re-apply for the services on a yearly basis. In some of these cases the customer has to go through the same process from assessments/evaluations to filling in papers, almost from scratch. This process is required even if there have been no changes in a customer’s situations.

The interviewees also described that the application process may require them to apply personal pressure in order to be heard. In some cases, it may become clear during the application process that the benefit of the service is not worth the effort. Families have also experienced situations where the application process takes years of effort in order to get a suitable service.

When evaluating the visibility of the actions and operations from the service providers’ point of view, all of them should be fairly visible to the service providers as they require a lot of interaction from both the customer and the service provider. However, it may be that service providers have not paid much attention to the amount of work and time they require as one application may take tens of hours of work. Thus, customer experience of value (Heinonen et al. 2010) is surely decreasing when the families feel that the service system is not supporting their wellbeing, but instead adding pressure and stress by requiring time and effort.

### **5.1.2 Interaction with professionals – working with them**

Interaction with professionals includes a wide range of multi-level actions. Also the length of the action may vary from a few minutes to several days or weeks. We have distinguished interaction with professionals from applying for services based on the aim behind the activity: the main motivation for interaction is to maintain existing and established relationships. In some situations, the activities may overlap, especially where the purpose of an examination of the child is both to apply for a service and to get a more general understanding of the child’s situation.

The descriptions of mothers reveal multiple actions related to the activity of interaction: discussions, examinations, medical care, therapy sessions, school/daycare visits, courses,

taking ancillary appliances into use, scheduling and sharing information. Only the latter ones, scheduling and sharing information, include recognizable operations, thus making them an interesting subject for analysis and interpretation. Mothers described the actions by explaining even the small units of operations they have to execute in order to reach the goal of the action. With the rich explanation they wanted to show how much time, effort and even know-how the work requires.

Families have multiple reasons for visits, for example, examination of the child's situation and regular check-ups or follow-ups. Examinations and assessments typically occur in situations where there are new symptoms and doctors try to determine the reasons behind the symptoms. These situations may require families to spend days or weeks in the hospital or polyclinic. Leena describes the situation of her family in the following way:

*“..we have spent all together 10 weeks there, either with father and one child, father and three children. Or there have been father and mother, one child who is under examination. Then there have been mother and three children. Then they have come to our house to evaluate our living at home, so there has been all possible combinations.”* – Leena, mother of two special needs children

This citation shows how much time and effort, for example, examinations may require from families. Leena described later on in her interview that she had to resign from her work because her employer was not able to grant her enough days off in order to participate in this examination period. Thus, families are forced to make economical sacrifices for the sake of family well-being.

There are several operations included in scheduling, hence unveiling the amount of work one action may require in the daily lives of families. Mothers mentioned many operations, such as finding out when a certain visit takes place and agreeing with multiple professionals about the timing, cancelling other activities (e.g. taxi), paying attention to holiday seasons when scheduling, informing about the child's weekly calendar or changes in it to the different professionals.

One interesting observation is that, for example, scheduling requires a lot of interaction with professionals and therefore it is a visible action to service providers. However, that fact that action is done in interaction with multiple professionals, the amount of work is difficult to acknowledge just from the viewpoint of one service provider. To understand the action, it has to be viewed from the customer's view and see how the interaction takes place within the whole service system. That way, the invisible amount of work becomes visible. And again, family is seen as the active unit which coordinates whole experience of daily life.

The same observation can also be made regarding the action of information sharing: the operation of sharing is visible to the provider with whom the customer is interacting with in a certain situation, but extent of the operations when multiplied by the number of different services or professionals may not be visible to anyone – not even family itself.

### **5.1.3 Advising and supervising professionals – working for them**

One possibly surprising observation was that mothers face situations where they have to advise and supervise professionals on their own work. In this kind of situations, a mother has to take some of the tasks that belong to the service system onto herself. These kinds of actions are, for example, offering valid information or correcting false information, advising on the interpretation of laws and instructions, and ensuring that the work that has to be done

from services side gets done. These kinds of actions are reminiscent of the work of a supervisor or manager in the service system. As Zwick et al. (2008) have argued in business life marketing managers is using customers as a source of competence and put them to work (Prahalad and Ramaswamy 2000; also Cova & Dalli 2009). It seems that in social and health care services, families with the special needs children, are serving and working for the system. They do invisible work for their visible services, but the system is unable to recognize the required invisible work. Nor reason for it.

We have categorized this ‘working for system’ as *a core activity*, as the interaction with service system itself is significant. However, it should be noted that especially the operational level of this activity is most likely invisible for the service providers.

#### **5.1.4 Claiming rights – fighting for customership**

Claiming rights includes actions that aim to either overturn denying decisions or otherwise demonstrate that the family is not satisfied with the decision. There are multiple ways to execute this action, but there is one common denominator – when the family is forced to do this action, it always means that acquiring that service will take more time than expected and make the whole application process more difficult. Rita describes her experience in the following way:

*“The first time I applied for the disability allowance, it took me 8 months [...], I made two or three letters of realignments and some adjustments in it. And the same person tried to deny it three times, saying that these expenses are not this way, there is no diagnosis for strabismus, all this kind of strange things.”* – Rita, a mother of a quadrupled child

Claiming rights -activity does require interaction with service providers, but since some of the letters of realignment are sent to other institutions (such as provincial governments), some of the actions are invisible to the service providers.

#### **5.2. Related activities**

*Related activities* emphasize the independent activity of the customer. The customer may utilize the services, but the interaction with service providers is significantly less than in *core activities* thus making these activities less visible to the service providers.

##### **5.2.1 Finding and figuring out**

Finding and figuring out things independently, almost without any help from professionals, shows up as an activity that takes a lot of time and energy from the family. The actions vary greatly from case to case and depending on the family’s situation. However, a large part of these actions are related to the acquisition of information about the child’s circumstances and available services, and information on how to facilitate everyday activities is also often sought. The acquiring of information on services can vary from calling professionals and searching the web and to visiting schools or kindergartens.

Although these actions may entail interaction with service providers, they emphasize the independent action of the customer. The fact that these actions do not focus on only one service, but rather the customer goes through a variety of sources or professionals to get the information she needs or has to understand the specifics of a particular case. Leena describes the acquiring of information in the following way:

*“...collecting information and acquiring information, it’s really slow when you are not professional yourself so that you know where to search for information, or when it is not your field at all. And then, so, sharing that knowledge is a big part of that, which my job is to share things like diagnosis, epicrisis and so on. And I should also know to who I need to share it. And my task is sort of take a stand for what this means to his/her unit, with my own knowhow.”* – Leena, mother of two special needs children

Considering that the public authorities have responsibility to give information and guidance to customers and that there is limitless amount of information available in the Internet, it is surprising to observe that this action is challenging. Mothers describe that, for example, the dispersed information and the reluctance of professionals to help forces them to spend a lot of time and effort with this action.

### **5.2.2 Participating peer support**

Families participate in peer support to strive to strengthen their own know-how and understanding or increase their resources. Participation takes place in both virtual and physical communities. Although peer support was often referred to, operations-components were hardly found. Instead, the information provided by peer support was considered significant, especially in situations where the child has a rare diagnosis or information about symptoms is hard to find. Therefore, this activity overlaps with Figuring and Finding out – activity.

For some interviewees, suitable peer support has proved to be a difficult task despite the large number of peer support groups available provided by different associations or available within Facebook. For others, participating peer support was described as an activity that they would like to do, but because of all the other previously listed activities take so much time and effort, mothers felt that they did not have enough time for this.

### **5.2.3 Training, giving medical care and using ancillary appliances at home**

One characteristic of families with special needs children is that the home is a place where a lot of action takes place: different types of training, giving medical care and using ancillary appliances. We included this activity into *related activities* because the actions related to it are usually guided or directed by a service provider, meaning that a service provide gives instructions, provides ancillary appliances and when necessary comes home to guide and help the action. However, the responsibility of the action falls on the shoulders of the parents and actions are most often integrated into families’ everyday lives. Therefore, the time and effort required for the actions and operations may remain invisible to the service providers although the importance of the activity, for example, for the child’s rehabilitation is significant, as Veera explains:

*“..of course, any kind of therapy is the same that the same practices are trained here at home, we get so called homework from them. Because otherwise it’s not like speech therapy, like some oral motorics areas, that if we do no nothing here at home those five to ten times would not accomplish anything.”* – Veera, mother of two special needs children

Within this activity, interaction with service providers often focuses on the initial stage, that is getting a service or for example during annual control. Families receive many instructions because even many basic functions – such as learning to speak – requires a lot of guidance and training like Taina describes:

“Yes, we do a lot, we have received millions of lists, games and books and appliances and systems that we have acquired and played and done tons of r- and d-practices and word-practices at one time. We use pictures and we have tons of lists that he.. now that have learned to read, so we are practicing these basic things. Nothing comes naturally.” – Taina, mother of a special needs child.

*Related activities* take place mainly outside of the premises of service provider, in this case at home (also through internet). On one hand, the service provider guides or helps the activities, and in that way activities are visible – even if they happens somewhere else. On the other hand, the activities are carried out by the family, and that work is invisible for the service provider. Yet, both actors recognize the significance of *related activities* alongside the *core activities*.

### **5.3 Other activities**

Apart from the fact that different services and the usage of services play a major role in the everyday life of families with special needs children, these children require more attention and support from parents for growth, personal development and everyday life activities than normal children. When categorizing *other activities*, we aimed to find descriptions and mentions of actions/operations that somehow deviated from the everyday activities of a normal family. Thus, we identified actions and operations that do not occur in everyday life or where certain normal everyday life actions require much more support or work from the child or the parent. *Other activities* are invisible for the service provider, yet, influencing considerably to family’s everyday life.

#### **5.3.1 Acting as personal helper**

One aspect of actions and operations *related to other activities* is that they are somehow related to supporting the child’s personal activities and wellbeing. Therefore, we decided to name it ‘acting as a personal helper’. Actions included in this activity are: guiding and supporting the child’s activities, controlling the child’s behavior and handling transportation (to daycare, school, therapies and so on).

Guiding and supporting the child’s activities can entail anything from helping the child to eat, drink, use the toilet, going to the shopping mall, or acting as a personal assistant in his/her interest groups. Controlling the child’s behavior can also require a fare amount of time and effort; for some families it is enough that the family learns to use pictures when communicating with the child, but sometimes a very challenging child can make a family’s life extremely stressful, like Marika describes: “..he [Marko] threw things and he hurt himself and us and every hour he had for sure ten ferocious attacks.” Later in the interview she said that there was no way to make any preventive work, because all that she could do was to “extinguish the fires”, such as controlling the ferocious attacks.

Transportation of children to different places may be a major factor impacting daily time management. There may not be a suitable daycare or school near the family’s home, so parents drive the child to more distant places. This is especially in the case when there’s no possibility to use or get a taxi service. For example, carrying and driving a child with quadriplegia become challenging just because of his weight. In addition, parents have to take the child with special needs always with them when leaving the house because s/he cannot be left alone like normal children who learn to be alone already at 5-6 years.

When talking about special needs children, it should be noted that children may not even learn all the functions and actions needed in everyday life, and then parents stay as personal helpers for years until the teenage years or even into adulthood.

## Conclusions

In our analysis we have utilized both activity components (Leont'ev 1978) and the concept of customer activity (Heinonen et al. 2010; Mickelsson 2013) in a similar way as Mickelsson (2014). In addition, we have applied a category-content approach (Lieblich et al. 1989) when interpreting our preliminary findings.

These findings indicate that this type of combination of activity research is useful in bringing out new information and perspective on everyday activities and service experiences of families with special needs child. By utilizing activity components and the concept of activity it is possible to recognize and describe activities, actions and operations related to and required by services. Moreover, these tools enabled us to analyze which of the activities are visible or invisible to the service providers. When the activity analysis focuses on the contextual activity (Mickelsson 2014) – in this case the pursuit of equilibrium of everyday activities – it is possible to concentrate only on activities that are characteristic of the family with special needs children.

Applying for services and interacting with the professionals are the key activities of *the core activities*. They included multiple mentions of actions and operations and special attention should be put into the how time- and resource consuming those actions are. This is especially the case when actions which are not very visible to the service providers, such as acquiring statements and requests for clarification. When we relate the identified activities to the context – in our case the families with special needs children have multiple services to apply for - the workload increases each time a new service is added (e.g. Zwick et al. 2008, Cova & Dalli 2009). And every time the amount of invisible work increases.

Perhaps one of the most surprising interpretation was that parents typically have to take the role of a supervisor, that is to ensure that the professional does his or her job, and in some cases parents even have to advise the professional in his or her job. This way, parents become half-professionals when they are forced to work for the professionals.

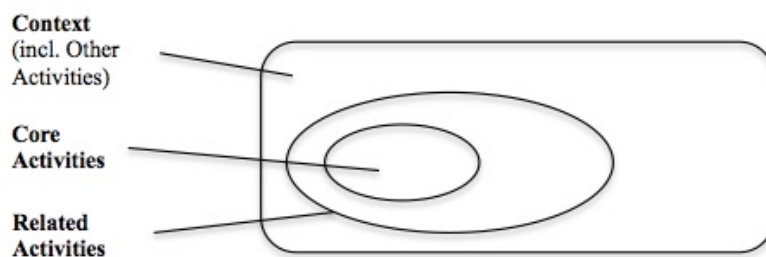
In addition, actions and operations related to interaction with professionals often spread across many different service providers, whereby it is difficult for one service provider to see and understand the total amount of work required from the family. Therefore, interaction should be viewed from the viewpoint of the customer and her activities with multiple services, not from the viewpoint of one service provider.

*Related activities* emphasize the responsibility of finding out necessary information and figuring out the services. Parents seek information from many sources and for many purposes. Considering how much information is available, for example, in websites, the acquisition of suitable information is surprisingly difficult and requires a lot of time and resources.

Home-based training, nursing and using ancillary appliances is usually guided by professionals, but is handled independently at home, as part of families' everyday life. In these actions, the context can be particularly important because even training for eating or speaking can take years and requires a lot of effort on a daily basis from the parents.

*Other activities* included mainly various actions that support the child him/herself such as transportation and personal guidance. It may be that this category includes less actions and operations because they do not require interaction or help from services which was the focus of this study. On the other hand, we can ponder whether the everyday life of families is so loaded with interacting and using the services, that there is not much “*other activities*” in there. However, this implies that there is a need to study and understand the context even more deeply and in similar customer groups.

We have aimed to analyze and interpret the activities of families with special needs children in their own context. When analyzing the *other activities*, we pondered whether this category could be or should be included as part of the context itself. Then the concept of activity would then need to be modified in the following way:



Picture 2. The context-related activities (modified Mickelsson 2013, 538)

According to the picture, the aim would then be to study and especially to describe both the context – in our case the combination of characteristics of the family with a special needs child and *other activities* – and context-related *core and related activities*. This is to be considered as the research proceeds.

Other topic to study as the research proceeds are the factors that appear to make it more difficult for customers to act such as the inability or reluctance of the professionals to provide information. Related to that, we have also identified factors that help the customer’s own activities. The integration of these two factors into the study of activity may provide an opportunity to create a framework or model to be used in the strategic development of services.

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