User-defined ecosystems in health and social care

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Abstract

Purpose – People with complex health conditions must often navigate landscapes of uncoordinated public, private and voluntary health-care providers to obtain the care they need. Complex health conditions frequently transcend the scope of typical health-care service systems. The purpose of this paper is to explore and characterize such unique assemblages of actors and services as "user-defined ecosystems".

Design/methodology/approach – Building on literature on customer ecosystems, this paper introduces the concept of the user-defined ecosystem (UDE). Using an abductive approach, the authors apply the concept in an interpretive, qualitative study of ten families with special needs children.

Findings – This study uncovers complex UDEs, where families actively combine a broad range of services. These ecosystems are unique for each family and extend beyond the scope of designed service ecosystems. Thus, the families are forced to assume an active, coordinating role.

Research limitations/implications – This paper shows how to identify ecosystems from the user's point of view, based on the selected user unit (such as a family) and the focal value-creating function of the ecosystem for the user.

Social implications – This paper highlights how service providers can support and adapt to UDEs and, thus, contribute to user value and well-being. This can be used to understand users' perspectives on service and systems in health and social care.

Originality/value – This study develops the concept of the UDE, which represents a customer-focused perspective on actor ecosystems and contrasts it with a provider-focused and a distributed perspective on ecosystems. This study demonstrates the practical usefulness of the conceptualization and provides a foundation for further research on the user's perspective on ecosystems.

Keywords User-defined ecosystem, Health care, Social care, User unit, Customer-dominant logic, Health services

Paper type Research paper

Introduction

Service providers in the health and social care context frequently perceive service systems differently than the service users do (Hardyman *et al.*, 2019; Rossi and Tuurnas, 2021). Health and social care systems are traditionally planned with organizational considerations in mind (Callahan and Merrick, 2013), but the resulting systems can appear complex and confusing to the user (Schwaderer and Itano, 2007; Peel and Harding, 2014). Users are often forced to navigate a landscape of many separate, uncoordinated services to get the care they need (Gage-Bouchard, 2017; Vos *et al.*, 2018). This is particularly apparent in cases of multimorbidity, that is, when one person has multiple simultaneous chronic conditions (McSharry, 2014; Johnston *et al.*, 2019; de Bruin *et al.*, 2012) or in cases where families experience multiple social vulnerabilities (Goerge and Wiegand, 2019).

Indeed, health and social care systems tend to be ill-equipped to meet the needs of people with complex health or life situations, who may have to use many disparate services offered by multiple providers such as health centers, hospitals, rehabilitation providers, home care, pharmacies and social care (Banerjee, 2015; Johnston *et al.*, 2019; Hujala *et al.*, 2017). Despite this, health-care providers are often narrowly focused on the treatment of a specific illness and, thus, can fail to consider the overall subjective wellbeing of the patient (Lee *et al.*, 2013). In service and health-care research, the concept of the service ecosystem has served as a way to solve such problems (Sudbury-Riley and Hunter-Jones, 2021), analyzing service in terms of interacting systems

of actors (McColl-Kennedy *et al.*, 2020). Various perspectives and practices have emerged that define the role of the health-care customer/patient in the ecosystem, ranging from seeing the customer as a passive recipient of expert medical care to self-managed care where the customer is seen as an active partner in care (McColl-Kennedy *et al.*, 2017a).

However, in this paper, we argue that the choice of a particular actors' viewpoint on an ecosystem has consequences for how the content and boundaries of highlighted ecosystems are defined. The current paper presents holistic system thinking rooted in the user's subjective viewpoint as a way to identify and understand comprehensive actor ecosystems in health and social care. This comprehensive ecosystem encompasses not only medically orientated services but also services related to social care and support for everyday life. We characterize such systems as user-defined ecosystems (UDEs), referring to the often-unique assemblage of actors and services that users themselves combine and draw on to manage some area in their life. The purpose of the paper is to introduce, conceptualize and examine the concept of the UDE. We define UDEs as the user's perceived set of services, actors and elements that are relevant for the user's own work towards a goal or for a motive or particular life-theme. The UDE concept represents a customer-focused perspective on ecosystems, rooted in the assumptions within the customer-dominant logic (CDL) stream of research (Heinonen *et al.*, 2010; Tynan *et al.*, 2014; Heinonen and Strandvik, 2020). Thus, UDEs reflect an individualist ontology with the customer as the focal actor (Heinonen and Strandvik, 2018). This means that UDEs are systems centered on the users' personal concerns, reflecting the individual user's situation, sensemaking and idiosyncratic perspective (Kemppainen and Uusitalo, 2021). This differentiates them from provider-focused ecosystems, as described in early service research (Kingman-Brundage *et al.*, 1995; Grönroos, 2000), or later conceptualizations of distributed ecosystems, which reflect a collective viewpoint encompassing either dyads, networks or society (Vink *et al.*, 2021; Polese *et al.*, 2021; Vargo *et al.*, 2020) and which focus on co-creation and service-for-service exchange (Vargo and Lusch, 2017; Vargo *et al.*, 2017).

The paper applies an abductive approach with continuous iterations between theory and reality (Dubois and Gadde, 2002). Drawing on the customer-dominant tradition of service research (Heinonen *et al.*, 2010; Heinonen and Strandvik, 2020), we develop the concept of the UDE, rooting it in earlier conceptualizations of customer ecosystems (Heinonen and Strandvik, 2015, 2020). We apply the resulting conceptualization in an empirical study on families with special needs children. The qualitative study aims at answering the question "how do the parents of special needs children understand the ecosystem of services and actors that their family needs in order to care for the child?" Special needs families can be considered complex health-care service users, which allows us to study how the families interact with multiple services. In ten interviews with parents of special needs children, we mapped all services that the families used for the everyday care for their children, providing an overview of their UDE. These interviews enable an understanding of the array of stakeholders in the families' health and social care systems and the challenges that the families face when dealing with them.

The paper, thus, makes three main contributions to service research. First, it contributes to ecosystem research by delineating three distinct viewpoints on actor ecosystems: the provider-focused ecosystems perspective, the distributed ecosystems perspective and the user-focused ecosystems perspective. We show how each perspective provides a different starting point for identifying an actor ecosystem. We problematize the implicit assumption that ecosystems consist of a given set of actors (in dyads, networks or society) that are connected through some common principles that remain the same regardless of which actor's perspective they are studied from (Sharma *et al.*, 2020; McColl-Kennedy *et al.*, 2020). The paper, thus, contributes to literature on the systemic aspects of service by highlighting how different theoretical approaches will entail different starting points for identifying systems. Second, we contribute by developing the UDE concept, outlining the theoretical premises for identifying ecosystems from the focal user's perspective. Thus, we contribute by presenting the UDE as a way to delimit and identify customer ecosystems. Problematizing the nexus of the ecosystem by focusing on the customer highlights three distinct aspects of UDEs:

1 UDEs converge around the members of the a focal *user unit*;
2 users *subjectively determine* and *actively construct* their own UDEs; and
3 the scope of a UDE is set by its focal *value-creating function*.

Third, we build on the findings of our empirical study to conceptualize how users determine, interpret and manage their own ecosystems, contributing to literature on the user's role in ecosystems.

The paper is structured as follows. It begins by shortly summarizing the development of service network and systems thinking within the service research discipline, indicating how these developments represent different perspectives on identifying systemic service. The paper then continues by defining the foundations for UDEs. Next, the paper presents a qualitative study of families with special needs children, leading to long-term use of multiple health and social care services. The paper concludes by discussing how the insights from the empirical study can inform a user-defined understanding of actor ecosystems in health and social care. This concluding section provides implications for practitioners as well as limitations and further research.

Three perspectives on ecosystems

Service research has witnessed a shift in its scope and focus, from the initial focus on a single organization delivering service to a recipient to the later understandings of service as collaborative processes in systems (Barile *et al.*, 2016). In this section, we describe three different perspectives for framing systemic service, namely:

1 a provider-focused ecosystem perspective;
2 a distributed ecosystem perspective; and
3 a user-focused ecosystem perspective.

The term "distributed" is used in Barans' (1964) sense of the word, referring to a system with no focal node, where each actor is equal in status to all others. In contrast, the provider- and

user-focused ecosystems are centralized systems with the provider or user in the middle. We use examples from health-care literature to illustrate manifestations of these three perspectives in a service context. In service research, the term "customer" is often used interchangeably with "user" and will, thus, be intermittently applied in this section.

The provider-focused perspective

Traditionally, service has been understood in terms of interactions between actors (Håkansson and Snehota, 1995; Grönroos, 1984; Ballantyne and Varey, 2006). From an initial focus on interaction in customer–provider dyads (Parasuraman et al., 1985; Solomon et al., 1985), the analytical frame of service research extended over time to incorporate more actors. Thus, researchers started to introduce concepts such as service systems, service ecosystems and service networks. Service systems were originally understood as the system of structures and processes that exist within a service organization (Normann, 1986; Kingman-Brundage et al., 1995; Grönroos, 2000) and analyzed using such concepts as the Service System Model (Grönroos, 2000). Consequently, the original view of service systems involved a strong intra-organizational focus, mostly concerned with how companies should manage service processes for service quality (Parasuraman et al., 1985; Fisk et al., 1993). This perspective entailed understanding systems from the provider's viewpoint, focusing on elements and actors within the provider's control. We suggest that such a perspective on systemic service can be denoted a *provider-focused ecosystem*. In practice, many organizations still view ecosystems in this way, for example, in terms of company-owned digital ecosystems (Dietz et al., 2020). In the health-care context, this viewpoint can be found in total quality health-care models, which study how quality could be delivered across units over the whole health-care organization (Lim and Tang, 2000; Talib et al., 2011). However, in service research, this perspective has increasingly given way to the larger scope of distributed ecosystems.

The distributed ecosystem perspective

With the development of the service-dominant logic (SDL) of marketing (Vargo and Lusch, 2004, 2008), the traditional conceptualization of service developed further, opening up new ways of defining and analyzing service as systems. Consequently, customers might be served by not only one service provider but also a whole ecosystem of providers that interact and collaborate to co-create the service provided to the customer (Tax et al., 2013; Akaka and Vargo, 2015; Vink et al., 2021). A service ecosystem is defined as a "relatively self-contained, self-adjusting system of resource-integrating actors connected by shared institutional arrangements and mutual value creation through service exchange" (Vargo and Lusch, 2016, p. 11). Thus, the focus is on mutuality and shared institutional arrangements, emphasizing a system that enables a service provision through service-for-service exchange (Vargo and Lusch, 2017). In health-care research, similar ideas have earlier been presented in terms of integrated health-care networks and systems (Lin and Wan, 1999) and later in terms of health-care ecosystems (Frow et al., 2019; Sudbury-Riley and Hunter-Jones, 2021). A person might, for example, need to use several service providers for knee surgery and related

physiotherapy or rehabilitation. Thus, the hospital providing the initial surgery and the private physiotherapist supporting the rehabilitation can coordinate as a system for the benefit of the customer.

SDL also inspired a new perspective on the role of the customer. Within the classic delivery-focused approach to service, the role of the customer (or user) was mainly to receive and consume the service. Later, however, researchers increasingly started to view service as a process of co-creation between the provider and customer (Payne Storbacka, and Frow, 2008). From this perspective, all the actors in a service system can, in fact, be understood as co-creating value, rather than simply delivering or consuming it (Vargo et al., 2008; Vink et al., 2021). Thus, the health-care user can be seen as being involved in a process of interaction and co-creation with a network of other actors: not just receiving health care but also actively contributing to it (Frow et al., 2016; McColl-Kennedy et al., 2017a, 2017b; Kim, 2019). From this perspective, value is understood as a system-level construct, co-created by multiple actors (Vargo et al., 2017). Thus, individual actors are best understood within their social or societal context (Tronvoll, 2017), and the use of an "individualist ontology" is discouraged (Simmonds et al., 2021, p. 102).

Consequently, we characterize this view of systemic service as a *distributed ecosystem* perspective, where all involved actors are to be viewed on equal terms (Vargo and Lusch, 2011), forming distributed systems that can be viewed on the micro, meso or macro levels (Danatzis et al., 2021). On the micro level, the nexus of a distributed system is on a set of focal relationships, such as physician–patient, patient–health-care team or patient–family member (parent/spouse/sibling) (McColl-Kennedy et al., 2020), whereas on the meso and macro levels, the nexus is on the links between different types of health and other organizations (Beirão et al., 2017). From this point of view, the main objective of managing a service ecosystem is to facilitate mutual value creation and service-to-service exchange (Vargo and Lusch, 2016), as well as striving for improved system wellbeing (Vargo et al., 2008; Beirão et al, 2017; Frow et al., 2019). Within the distributed ecosystem perspective, wellbeing is seen from a systemic viewpoint as either emerging on the micro level within dyads, on the meso level in communities or on the macro level in society as a whole (Finsterwalder and Kuppelwieser, 2020). An underlying assumption is that individual wellbeing is framed by wellbeing on the aggregate, system level (Leo et al., 2019).

The user-focused perspective

In addition to the distributed perspective, where the focus is on actor-to-actor interaction, mutuality and co-creation, researchers have also argued that customers use service beyond the control and field of vision of individual service providers (Gummesson, 2006; Heinonen et al., 2010; Mickelsson, 2013), in what can be characterized as the customer's sphere of value-creation (Grönroos and Voima, 2013; Heinonen et al., 2010). In the customer sphere, the provider has limited influence and the customer is more in control of the service process, acting according to their own goals, motives and life themes. Thus, service providers may unknowingly be involved in a user-focused ecosystem where the customer includes the provider into a private value-creating process that requires the input of

many different actors. Building on the customer-dominant view of service (Heinonen *et al.*, 2010), such user-focused systems have been labelled customer ecosystems (Heinonen *et al.*, 2013; Heinonen and Strandvik, 2020).

The user-focused perspective takes its starting point in the users' processes and the user's own subjective understanding of what is valuable and helpful (Heinonen and Strandvik, 2015; Seppänen *et al.*, 2017). Thus, the user's goals for engaging with a set of actors and services that form an ecosystem is to enable wellbeing for themselves and for other relevant parties (Heinonen and Strandvik, 2020). The ecosystem consists of services, actors, elements and technologies that are identified – and delimited – from the point of view of the user's own value-creating process (Heinonen and Strandvik, 2015). This value-creating process can generally be understood in terms of a series of events that is part of the user's work towards something, be that a goal, outcome or some ongoing concern in their life or business (Gummerus, 2013). Note that this represents a wider viewpoint than, for example, jobs-to-be done, which focuses more narrowly on a task that is to be carried out (Christensen *et al.*, 2016). Hence, this perspective views service and value from the user's individual and idiosyncratic viewpoint, emerging as an expression of the user's logic (Heinonen and Strandvik, 2018). Thus, CDL diverges from SDL by embracing an individualist ontology and emphasizing the primacy of the customer role (Heinonen and Strandvik, 2018).

Crucially, users' value-creating processes often go beyond the scope of touchpoints and interactions in planned service processes (Heinonen *et al.*, 2010; Grönroos and Voima, 2013; Mickelsson, 2013). This, in combination with the idiosyncratic nature of users' value-creating processes, means that users' personal ecosystems are likely to have different contents than collectively defined ecosystems do. From a user-focused perspective, the goal of health care is subjective wellbeing, defined as "people's evaluations of their lives – the degree to which their thoughtful appraisals and affective reactions indicate that their lives are desirable and proceeding well" (Diener *et al.*, 2015, p. 234). Thus, wellbeing is seen as evaluated by the users themselves.

This third perspective on systemic service is nascent and developing. In health care, the idea of user-focused ecosystems is relevant in care for the elderly, for example, where users may need to use a wide range of separately managed health and social care services to live their everyday lives in a satisfactory

manner (Béland and Hollander, 2011). In the public management context, Kinder *et al.* (2020, p. 3) have characterized these types of systems as "personalized configurations of cross-disciplinary services" that individual service users themselves pull together for their own benefit. The key issue of the user-focused perspective is that it is the user who defines the ecosystem, based on their own subjective and self-chosen criteria for goal achievement. Thus, it does not reflect a collective, shared viewpoint, as in the distributed ecosystem. Rather, it reflects the users' subjective viewpoint on which are the relevant actors in an ecosystem. This distinguishes the UDE from distributed ecosystems, which highlights co-creation and service-for-service exchange.

We argue that ecosystems can be identified according to the previous three perspectives – either as a system seen from the service provider's viewpoint (i.e. a provider-focused ecosystem), a system based on a shared, collective viewpoint (i.e. a distributed ecosystem) or a system anchored in a focal user's viewpoint (i.e. a user-focused ecosystem). Table 1 summarizes these perspectives. In the first perspective, the delimiting problem concerns how a focal provider can organize systems by means of asserting direct control or influence. In the second perspective, the delimiting problem concerns how actors in a network can interact to co-create a service and value. Within the third perspective, the delimiting problem concerns how a particular customer involves other actors and elements into their own value-creating processes. Thus, the three perspectives in Table 1 can serve as different starting points for studying systemic service. It is important to note that these three perspectives do not exclude or supplant each other but rather offer complementary starting points for understanding the content and organization of systemic service.

The next section operationalizes the user-defined perspective by delineating the main features of UDEs.

Identifying user-defined ecosystems

To study user-focused ecosystems, we build on the concept of the customer ecosystem (Lipkin and Heinonen, 2022), which has been defined as "systems of actors, resources, and elements that are relevant to customers and linked to each other through different kinds of relationships" (Heinonen and Strandvik, 2020,

Table 1 Focus and content in three perspectives on ecosystems

Type of system	1. Provider-focused ecosystem	2. Distributed ecosystem	3. User-focused ecosystem
System content	*Provider-defined system of centrally coordinated units* (Normann, 1986; Kingman-Brundage *et al.*, 1995)	*Distributed system of interacting actors* (Vargo and Lusch, 2016; Simmonds *et al.*, 2021)	*The focal user's personally determined system of providers and other actors* (Heinonen *et al.*, 2013)
System objective	*Ensuring service quality and efficiency* (Parasuraman *et al.*, 1985; Fisk *et al.*, 1993)	*Co-creating value, service-for-service exchange* (Vargo *et al.*, 2008; Vink *et al.*, 2021)	*Supporting or enabling the focal user's value-creating process* (Heinonen and Strandvik, 2015)
Who defines service and value?	*Service and value are defined and orchestrated by the provider* (Kingman-Brundage *et al.*, 1995)	*Service and value are collectively co-created in systemic interactions between actors* (Vargo *et al.*, 2017)	*Service and value emerge as an expression of the focal user's logic in engaging with their own ecosystems* (Heinonen and Strandvik, 2018)
Health and social care examples	*Total quality management in health care* (Lim and Tang, 2000; Talib *et al.*, 2011)	*Integrated health care networks and systems* (Lin and Wan, 1999; McColl-Kennedy *et al.*, 2020)	*Personalized configurations of care services* (Kinder *et al.*, 2020, current article)

p. 75). Such systems could be operationalized and studied in many different ways. The simplest way to capture customer ecosystems, however, is by studying users' own perceptions of their systems, that is, to approach them as UDEs. Thus, the customer ecosystem concept resides on a higher level of abstraction than the UDE concept, which encompasses elements that users themselves can perceive. These perceptions are likely to incorporate only a subset of all the elements in the full customer ecosystem. We, thus, define a UDE as *the user's perceived system of services, actors and elements that the user understands as relevant for their own work towards a goal, for a motive or for a particular life-theme.* Building on CDLs ideas presented in the previous chapter, we characterize user-defined systems as idiosyncratic, dependent on the selected user and reflecting the individual users' value-creating process. We, thus, propose that the identification and delimitation of a UDE is dependent on two factors:

1 deciding on the *user unit* at the center of the system; and
2 on the *value-creating function* of the ecosystem (i.e. what specific value-creating process it supports).

These two factors are crucial for distinguishing user-defined systems from distributed ones: By accepting that these are variables and serve as a methodological choice to be made, we can start studying users' individualized ecosystems. This idea is visualized in Figure 1.

The first factor that delimits the UDE is the user unit. In service research, Heinonen and Strandvik (2018, p. 4) have characterized a customer unit as "the unit making choices regarding what to acquire/purchase to achieve its own goals". The unit could, for example, be a family or a group of consumers acting collectively, such as a group of friends visiting a restaurant. The idea of many users forming units has in business research earlier been discussed in terms of co-consuming units (Kylkilahti *et al.*, 2016), relational units (Epp and Price, 2011), usage centers (Kleinaltenkamp *et al.*, 2017) and families as customer units (Epp and Price, 2008; Gummerus *et al.*, 2021). In a health-care setting, a similar idea has been suggested in terms of the link between primary and secondary customers (Leino, 2017) and to some extent also through the idea of family-centered care (Davidson *et al.*, 2017).

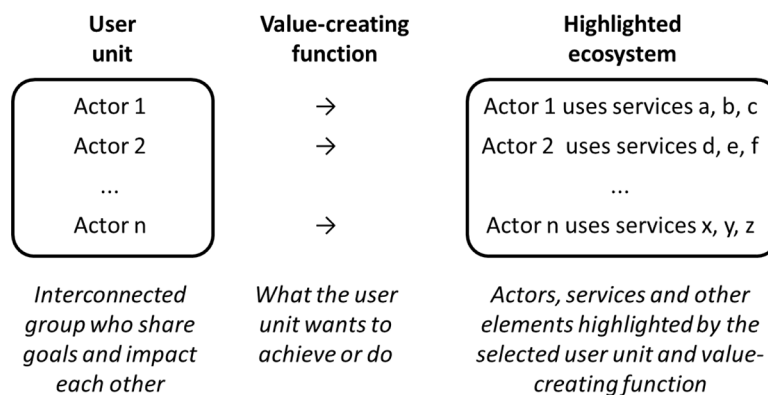Thus, we define a *user unit* as an interconnected group of people who share goals and directly impact each other in terms of everyday service use, choices and support. We propose that a UDE reflects the viewpoint of *one particular user unit*. The UDE consists of the individualized, unique set of actors and services that the members of a particular user unit perceive as relevant for their own value-creating process. The constellation of people in the user unit delimits the scope of the ecosystem: One actor may be connected to a particular set of elements, while another actor adds to this set by means of their own connections. Thus, for example, a married couple, where one party has fallen seriously ill, can form a user unit. Both people are involved in treating the illness and are affected by its events and outcomes. The person who has fallen ill sets the initial scope of the UDE by means of their insurance and assigned doctors, for example, while the spouse may bring in additional actors and elements in terms of discussions with helplines, acquaintances, etc. However, as people differ in their goals, contexts and general circumstances, all user units can be expected to have unique UDEs.

The second factor, the value-creating function, refers to what the user unit collectively wants to achieve or do (Christensen *et al.*, 2016; Heinonen and Strandvik, 2020). We propose that the scope of actors and elements that are involved in the UDE depends on how one defines its value-creating function. In health care, this could be considered narrowly as the actors or services involved in a linear process to treat a specific illness or condition (Schildmeijer *et al.*, 2019) or, from a wider perspective, as the actors involved a set of everyday events that relate to maintaining or improving a person's health on a more general level (Riebe *et al.*, 2005). Thus, the value-creating function of an ecosystem can be defined according to the user's ultimate goal (Woodruff, 1997). Depending on which goal or theme we choose, a specific set of actors or services will be highlighted, excluding others. Further, this means that a single user unit may maintain many overlapping ecosystems that relate to different, interrelated user goals. For example, there may be one ecosystem that supports everyday mental health, another supporting childcare and a third for treating a particular illness. These ecosystems are partly overlapping, and all contribute to the general subjective wellbeing of the user unit.

Research methodology

Having proposed factors that can be used to identify UDEs, we apply them in a study carried out in the context of Finnish health and social care. We follow an abductive approach to

Figure 1 The configuration of a user-defined ecosystem

User unit	Value-creating function	Highlighted ecosystem
Actor 1	→	Actor 1 uses services a, b, c
Actor 2	→	Actor 2 uses services d, e, f
...		...
Actor n	→	Actor n uses services x, y, z
Interconnected group who share goals and impact each other	*What the user unit wants to achieve or do*	*Actors, services and other elements highlighted by the selected user unit and value-creating function*

explore UDEs, using both deduction and induction in our analysis (Dubois and Gadde, 2002). The Finnish social welfare and health-care system provides a fruitful empirical setting given its broad range of service providers and service offerings. In Finland, the social welfare and health-care system is publicly arranged and funded by government-subsidized municipalities. However, other actors, such as private enterprises and non-governmental organizations, also provide similar and supporting services. Consequently, the provision of public health and social care in Finland has become fragmented and often faces challenges in meeting the needs of the population (Keskimäki *et al.*, 2018). How these diverse service providers can be organized to cater for a functioning health-care system is an increasingly important issue.

Our study is conducted in a complex health-care service setting focused on families with special needs children. It aims to understand how the parents perceive the constellation of actors (service providers, caregivers, families, etc.) that they work with to care for their child. This empirical setting is extremely delicate. According to Statistics Finland (2019), about 8% of all Finnish schoolchildren need special support, making their care a significant societal issue. Moreover, special needs children have a long-term need for multiple services (Caicedo, 2014), enabling the study of complex UDEs. Importantly, the user unit (i.e. family of the special needs child) represents several actors with important responsibilities. The parents of special needs children are forced to be active and invest significant amount of time and effort in coordinating complex sets of services (Kuo *et al.*, 2011). In addition, the situation of a child impacts the everyday life of the whole family, causing care needs among other members (Niemelä *et al.*, 2016). Family members have been shown to adjust their shared and individual activities to satisfy the everyday needs and demands other family members (Bernheimer and Keogh, 1995). Thus, special needs families can be expected to operate as user units with shared goals, unified in their concern for the whole family's wellbeing. We aimed at answering the following research question: "how do the parents of special needs children understand the ecosystem of services that their family needs in order to care for the child?"

To capture the user's viewpoint on ecosystems, we chose an interpretive, qualitative approach with in-depth interviews (Belk *et al.*, 2013). We wanted to gain an understanding of the phenomenon in real-life settings and obtain insight which is difficult to attain with numeric data (Ospina *et al.*, 2018). We delimited the users by two criteria. First, to highlight the role of the family, the special needs child had to be under 16 years old and living at home. Second, to ensure that we capture a complex situation, users had to have experience of using more than four services related to the special needs of the child. There were no selection criteria for diagnosis.

This type of user group arguably constitutes a rare population, which imposes challenges for sampling (Faugier and Sargeant, 1997). An open call to participate in the study was published in eight Facebook groups for Finnish parents or families with special needs children. Members of the groups were encouraged to forward the message to other peer networks. This "snowballing" method involves recruiting informants through the networks of members belonging to a primary network and is a recommended technique for reaching

a rare population (Baltar and Brunet, 2012). It resulted in access to ten families with special needs children. This sample size corresponds with other qualitative studies of special needs families (Mason and Pavia, 2006; Avis and Reardon, 2008). We asked to interview the parent who had taken the main responsibility for interacting with care-related service providers. This turned out to be the mother in every case, which is common in studies focusing on families with special needs children (Leiter *et al.*, 2004; McCann *et al.*, 2012). The children in the families had various diagnoses such as cerebral palsy, development disability, quadriplegia and autism spectrum disorder. Many of them also had multiple other symptoms or challenges. The ten families provided rich insight into their use of different services, and as themes started repeating across cases, we did not recruit further families.

Data collection

The interviews lasted 1–2 h and were conducted either in the home of the interviewer or interviewees or at their workplace, depending on what suited the interviewee best. After sharing information about the study objectives and collecting general background data, interviewees were asked to draw a picture of their family and, around them, write down all the services they use as a consequence of having special needs children. This task provided an initial sketch of the UDE and served as a type of visual auto-driving method (McCracken, 1988) that helped elicit experiences that might be challenging to express directly as a narrative. Research has indicated that different types of visual techniques may help interviewees to recall and reflect on situations that might be overlooked using traditional interrogative techniques (Dodds *et al.*, 2018).

Although the interview topics were predetermined, the interviews resembled informal discussions (Eriksson and Kovalainen, 2016, p. 83). The ensuing interviews focused on four main themes:

1. applying for and getting services for the child;
2. managing the services as part of their daily lives;
3. participating in the planning of the services; and
4. using digital services.

The participants were also encouraged to share stories about events related to service usage. The aim was to produce insights that we could not acquire with other methods (Wattanasuwan, 2012) or anticipate beforehand (Eriksson and Kovalainen, 2016, p. 95).

Table 2 provides an overview of the interviewees and their families. To ensure confidentiality and anonymity, personal information was removed, interviewees were assigned pseudonyms and their ages were categorized into age brackets (Eriksson and Kovalainen, 2016, p. 55).

All interviews were audio-recorded with permission and transcribed afterwards. Of the total 260 pages of transcribed text, approximately 160 pages were found to be relevant for the study at hand.

Analysis

The interviews and data analysis were conducted by one of the authors, who had extensive experience in long-term use of multiple social and health-care services because of caring for a

Table 2 Overview of the interviewees

Interviewee (pseudonym)	Interviewee age group	Number of special needs children per age group (< 7 years)	(7–16 years)	Other children	Number of years of service use
Camilla	41–50 years		1	Yes	6–10 years
Leena	31–40 years	2		Yes	6–10 years
Veera	41–50 years	1	1	No	≤ 5 years
Taina	31–40 years		1	Yes	6–10 years
Rita	31–40 years	1		No	≤5 years
Marika	31–40 years		1	No	6–10 years
Erja	41–50 years		2	No	11–14 years
Olivia	41–50 years	1	1	No	11–14 years
Katri	41–50 years		1	Yes	11–14 years
Satu	51–60 years		1	Yes	11–14 years

special needs child themselves. This provides the ability to immerse in the phenomenon and embrace its complexity (Ospina *et al.*, 2018). Researchers have argued that such expertise and pre-understanding is beneficial when conducting qualitative research in hard-to-reach populations (Elliot *et al.*, 2002). Repeated readings of the data were undertaken to acquire a holistic understanding of the situation of the users and to make sense of their everyday life and service use experiences (Goulding, 2005). The data were then subjected to thematic analysis (Joffe and Yardley, 2004), applying deductive coding to identify services, user units and value-creating functions in the respondents' UDEs, as well as inductive coding to find emergent themes from respondents' stories of using the services.

Thus, the process can be characterized as abductive (Dubois and Gadde, 2002). Services were identified based on the respondents' recollections. To identify services across cases, two researchers analyzed the respondents' descriptions and compared their interpretations until reaching agreement on how to denominate the different services. Findings were then analyzed to identify services per person in the user unit and categorized according to the type of actor responsible for organizing the services. The expert researcher then worked on identifying emergent themes in service use, highlighting and labelling text passages that expressed similar themes. These were then checked by the other researcher for consistency.

Findings

Special needs families as user units
The first theme emerging from the data concerned the complex interdependencies between the family members in terms of caring for the child. Caring for a special needs child is demanding in itself, and the whole family is affected. Leena talks about simultaneously caring for two special needs children but not getting any other support than physical therapy services:

> [...] I just cried, saying that this will not work, the whole thing is doomed, we can't manage with the children. And I said, what if I have to give them up? I can't do it anymore.

Many of the families had at times experienced life as complete chaos, and several of the interviewees perceived that they were not able to respond to the additional demands that services often set on the family, such as therapeutic exercises. Indeed, the respondents perceived the scope of the services as too narrow, only considering a single condition in one particular family member and, thus, not contributing to the overall subjective wellbeing of the family. Many respondents expressed wishes to be treated as a family by the service providers, hoping that providers would understand their everyday challenges and provide care beyond merely treating physical conditions. For example, Marika was taken into hospital because of exhaustion and depression and asked for home help services when returning home:

> [...] but they said no: 'Home help service in this kind of situation [...] it's only for families in crisis.' And we asked them, what are we then? I'm hospitalized because of exhaustion and depression and the father is taking care of Marko [special needs child], isn't that a kind of family crisis? 'No, you're not getting help'. Oh, ok.

Marika's account indicates how the child's condition impacted the whole family, causing additional service needs to manage everyday life. This was echoed by Olivia, who felt that it is not adequate to treat family members as separate users: A child with long-term illness impacts the whole family, and therefore, the family should be seen and treated as a whole. Indeed, situations where families had experiences of being recognized as a unit were mentioned as positive ones.

Value-creating function and ecosystem scope
The second theme emerging from the data concerned the scope of the identified ecosystems. The central value-creating function behind the identified ecosystems was to care for the child. Overall, the interviewees themselves indicated that their underlying goal was to manage the whole family's everyday life while caring for their special needs children. The respondents described how their families, as a consequence of having a special needs child, had a long-term need to use a wide variety of services. In total, the respondents mentioned 57 different publicly funded, and seven private (or non-profit) social or health-care services. This proportion of public and private services was to be expected, as in Finland Government-funded local municipalities have the main responsibility for organizing the services, while some of the publicly funded services are outsourced to the private sector. Of the identified services, most were directed at the special needs children, but many were directed at other (or all) family members. For example, Leena

mentioned 24 different health and social care services, of which 12 were directed at the older special needs child and 2 at the younger. The ten remaining health and social care services were used by the whole family or by one of the parents. The Appendix at the end of this paper lists all of the health and social care services each family had used over several years. The appendix reveals the variability and scope of the identified sets of services, indicating how the ten families maintained unique ecosystems.

The respondents applied multiple labels when talking about the services they used, and sometimes, many different denominations were used. The parents struggled to remember, describe or distinguish the exact denominations of all the services within the UDE, as expressed by Leena:

> They [the hospital] called me and asked if I had visited a certain hospital unit, and what had happened there? I didn't recognise the unit name, and asked them if it was on the third floor? They began wondering if mom's too tired to know where she's been? I said, I've visited so many places, I can't remember all their names.

Leena had visited multiple hospital care units with her son and listed them all as separate services or places of care, indicating perceived disparities even within a single provider. Similarly, Katri felt that she became responsible for combining the different hospital units into a coherent whole, that is, a hospital offering. The parents were sometimes even forced to decide whom trust in cases where there were differing opinions between doctors from different units.

The parents mentioned not only health and social care services but also other special services and support provided by the educational or early childhood care division, as well as by other actors such as peers, friends and families, who were perceived as contributing to overall care. The role of educational services was especially apparent in Camilla's case.

Her son's school had organized many of the rehabilitation services usually organized by the social and health-care system. By identifying and including all relevant services from the user's perspective into the UDE, the number of services used increased to up to 45 services per family. In general, however, the parents felt that there was very little communication or coordination between the different types of services, regardless of who provided them. Olivia expresses her wish for improvement:

> It would be wonderful if […] the healthcare provider, and therapists, and daycare, and me, and the municipal disability worker […] we would all get the same information at the same time and could comment. But that's not possible in our municipality.

Challenges in engaging with the ecosystem

The third emergent theme concerned challenges in engaging with the ecosystem. The interviews indicated that using a large number of services threatens to disrupt everyday activities. Services are usually only available at limited times and have to be coordinated with the rest of the family's life. Katri explained the challenges of integrating service usage into the family's timetable:

> This week Vesa [older special needs child] has an appointment with the school doctor. So on top of all the other doctors and whatever he has to meet the school doctor. Then, we have a school meeting about personal learning and rehabilitation planning. And I don't just manage my own calendar – I also have to make sure that the speech therapist, occupational therapist and teacher are available for the meeting. Well, we have set a date but I'm not sure the speech therapist can come. Whatever – it's an ongoing thing. And then we have all these day care related discussions, and all kinds of other meetings. That's how it is – when you solve one thing, something else needs to be arranged. And that's probably what I find most stressful.

Thus, use and engagement with uncoordinated and disparate services were seen as demanding, challenging and time-consuming,

Figure 2 A family unit's user-defined ecosystem (Marika)
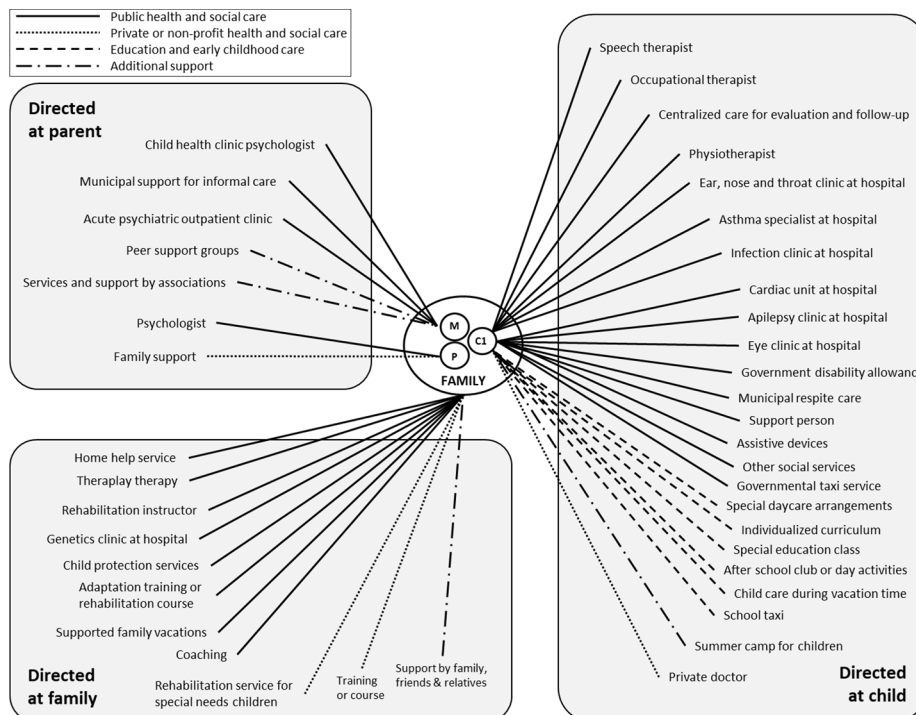
especially when they entail complex application processes and inconvenient timetables. However, Veera states that everyday life would be a disaster without all the support and services. This highlights the significance of the services and their centrality for everyday life, highlighting the need for them to integrate smoothly into the family unit's everyday activities.

The uniqueness of the ecosystems

Besides a few commonly used services, all ecosystems were individual and unique. Figure 2 represents a single family's UDE. The figure visualizes Marika's perceptions of her family's ecosystem as a centralized network where the family is placed in the middle. All the services of the UDE are shown connected to a member (or members) of the family or to the family as a single unit. "M" represents the mother, "P" both parents and "C1" the child.

This visualization shows how the members of the user unit connect to a distinct set of individual and shared services, highlighting the complexity of UDEs. From the user's point of view, the boundaries of designed service systems are irrelevant, as the user tries to manage a complex ecosystem that reaches beyond any designed systems. For example, the role or meaning of medical services directed at the child may change when used concurrently with other services as part of everyday life. The Appendix presents all ten UDEs. It shows that each family maintains their own unique ecosystem, ranging from Camilla's high emphasis on educational services, all the way to the complex arrays of health-care services used by Marika and Katri.

Discussion

In this article, we explored UDEs, which represent users' unique configurations of service and other actors that they use to achieve their own goals or to manage some area in their life. The UDE concept was developed based on ideas in the customer-dominant tradition of service research, which assigns primacy to the customer viewpoint (Heinonen *et al.*, 2010; Heinonen and Strandvik, 2018). We propose that the UDE is able to capture a user-focused perspective on the systemic aspects on service, different from the traditional provider-

focused ecosystems perspective, where the emphasis is on the provider's internal control (Normann, 1986; Kingman-Brundage *et al.*, 1995). Because of its underlying individualist ontology, the user-focused perspective also differs from a distributed ecosystems perspective, where the emphasis is on service-for-service exchange and co-creation between a given set of actors (Vargo *et al.*, 2008; Vargo and Lusch, 2011; Vink *et al.*, 2021).

To explore the features of UDEs empirically, we studied a complex situation of service use. In the empirical study, the user was not a single person but a family, representing a user unit with the shared goal of managing the whole family's everyday life while caring for their special needs children. The case served not only as a means to deductively show the viability of the proposed UDE model but also as a way to inductively discover themes in how users manage and interact with their UDEs. In the next sections, we discuss the theoretical and managerial implications of our findings and the UDE model.

Theoretical implications and further research

Table 3 summarizes contributions to service research, suggestions for further research and managerial implications. The first UDE feature concerns the focal user unit and how the selected user unit has direct implications for the highlighted UDE. Our study showed the difference between a subset of services used by a special needs child and the larger set of services used by the family as a whole (Figure 2). The notion of a collective user unit is not new as such (Kylkilahti *et al.*, 2016; Kleinaltenkamp *et al.*, 2017), but the link between how the user unit is defined and the emergent ecosystem is new. In service research, the structure of an ecosystem has been determined by understanding which actors are involved in co-creating a service (Akaka and Vargo, 2015; Vink *et al.*, 2021), but researchers have not considered how the selected user unit might have implications for the scope of a highlighted ecosystem. Thus, future research could explore the link between selected user unit and the highlighted UDE.

The second feature concerns the subjectively determined and constructed nature of UDEs. The study showed that users made sense of their own health and social care systems according to their personal logic, goals and memories.

Table 3 Key features of the user-defined ecosystem: contributions, research suggestions and managerial implications

UDE features	Contribution to service research	Suggestions for further research	Managerial implications
User unit	UDEs converge around user units, which consist of several interlinked actors who may use services together or separately	● What types of user units exist in various settings? ● What is the link between selected user unit and the highlighted UDE?	● The relevant user unit might be hidden and needs to be determined and recognized
Structure of ecosystem	The UDE is actively constructed and subjectively determined by users The user unit makes sense of ecosystems based on their own goals, activities and contexts	● How do users construct their UDEs in different contexts? ● How do users' sensemaking and logic influence the way they understand and interact with ecosystems?	● The user-defined ecosystem is different from the provider's designed service ecosystem ● Everyday activity patterns frame UDE use Users can face challenges in combining different services to achieve goals
Value-creating function of ecosystem	The identification of a UDE is dependent on the selected value-creating function Selecting a value-creating function is a conscious methodological choice	● What is the relationship between selected value-creating function and the scope of the identified UDE?	● A focal service may belong to many different, parallel ecosystems, depending on the selected value-creating function ● Roles in the ecosystems will vary accordingly

The various services relevant for care for the child had a real impact on everyday life, and the users made sense of the services in relation to the family's day-to-day activities. Thus, the structure of the UDE is subjectively determined, based on the user's own sense-making (Kemppainen and Uusitalo, 2021) and logic (Heinonen and Strandvik, 2020). However, this feature is not only a question of how users may perceive a designed service ecosystem differently than intended, but also – and more importantly – that users actively construct their own ecosystems, adapting them to their own goals and circumstances. Consequently, the user's ecosystem and its nature are idiosyncratic and largely hidden from providers and other external actors. In ecosystem research, users have been assigned an active role in co-creating health-care service (Frow et al., 2016; McColl-Kennedy et al., 2017b), but the current study adds to this by indicating that structure of the UDE itself is highly dependent on the user's own activity of pulling together and coordinating many services, especially in complex life situations. In our study, this was evident in the mothers' struggles to identify and apply for services and, also, in how they were forced to actively manage a multitude of different service actors. Further research could study how users construct, interact with and make sense of their own UDEs.

The third feature of the UDE is its value-creating function. From the user's point of view, the desired outcome of engaging with an ecosystem is user value, that is, when the user unit is able to carry out their own desired processes to satisfaction (Grönroos and Ravald, 2011). In our study, the stated value-creating function was to manage the whole family's everyday life while caring for special needs children. For this, the families engaged in a wide set of services and actors perceived as relevant for accomplishing the value-creating function (Appendix). Similar to how user unit selection serves as a methodological choice with implications for the UDE, the selection of value-creating function also is a choice. In health-care research, systems typically encompass the actors co-creating the treatment of a particular illness (Brodie et al., 2021; Schildmeijer et al., 2019). From a subjective wellbeing perspective, however, or in complex health conditions, the value-creating function is broader than the treatment of a single condition and will, thus, incorporate additional actors. In our study, this complexity became apparent in how respondents wished that providers would understand their situation more broadly, recognizing the wider set of actors involved. Thus, we contribute to service research by indicating that the scope of a highlighted UDE is variable and dependent on the selected value-creating function. This differs from how service research typically sets the scope of ecosystems, focusing on collaboration around a specific service (Akaka and Vargo, 2015; Sklyar et al., 2019). Future research could further explore the relationship between the selected value-creating function and the highlighted UDE.

Managerial implications and limitation

The approach outlined in this paper can help managers understand the role of the services they control, in relation to other relevant, hidden services and actors within the UDE. However, our findings also indicated that managers first need to understand the relevant user unit, which also might be hidden from an external actor's perspective. Only after recognizing the user unit is it possible to start uncovering the UDE. This allows managers to discover how their preconceived notions of an ecosystem may differ from the UDE. By understanding the role and position of their service in a UDE, managers may better be able to support their users' everyday value creating processes. Moreover, a focal service may have different roles in different, parallel UDEs, depending on what focal value-creating function it supports. By understanding UDEs, service organizations can discover which other actors they might need to collaborate or communicate with or simply acknowledge in their dealings with the user. Health-care professionals can use insights about individual user ecosystems in planning patient-centered care, which is to be built on "deep respect for patients as unique living beings, and the obligation to care for them on their terms" (Epstein and Street, 2011).

The presented approach can be used for mapping services in complex care contexts where users require many different types of care and support, such as in mental health care (McGorry, 2007), multimorbidity (Banerjee, 2015), cancer care (Grunfeld et al., 2004; Hardyman et al., 2019) or dementia care (Draper et al., 2009). These contexts present situations where users are in not only need of physical care focused on treating a particular condition but also need different types of psychosocial care to increase their subjective wellbeing. The development of information technology also makes it increasingly viable for providers to record patients' unique UDEs and then adapt individual treatments to the features of such ecosystems. Providers can also support increased user value and wellbeing by assisting users in understanding and managing their own UDEs. Managers can use aggregated insights into users' individual UDEs to identify generic user segments that can be used to plan work on the meso and macro levels. Insight into UDEs may be beneficial for managers in other contexts as well, such as complex hobbies, home ownership and improvement or other areas where users need to combine the services of many actors within their own, unique situation.

This study was mainly limited by interviewing only mothers in special needs families. Thus, future research could gain a more complete view of special needs families' customer ecosystems by also interviewing other relevant family members. Another limitation is that the study was carried out in a country with comprehensive public health and social care. Future studies could focus on how user units manage their customer ecosystems in countries where health care is mainly private and whether this leads to further challenges for users with complex health situations.

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Appendix

Table A1 Services from different actors used by the families

C1 = first child, C2 = second child, M = mother, F = Family and P = parents

Services offered by different actors	Camilla	Veera	Taina	Rita	Leena	Erja	Olivia	Katri	Satu	Marika
Public health and social care										
Intensive or special care at delivery ward at hospital					C1			C1		
Family social work					F					
Home help service			F							F
Infant interaction unit					F					
Child health clinic psychologist		C2 and M	C1							M
Rehabilitation clinic		C1						C1		
Family counselling centre	F						F			
Sensory motor rehabilitation group		C2								
Speech therapist	C1	C1	C1	C1	C1	C1	C2	C1	C1	C1
Occupational therapist	C1	C1 and C2	C1	C1	C1	C1	C2	C1		C1
Physiotherapist		C2		C1	C1	C1 and C2	C1 and C2	C1	C1	C1
Riding therapy						C1		C1		
Music therapy									C1	
Theraplay therapy										F
Centralized care for evaluation and follow-up	C1	C1	C1	C1	C1 and C2	C1	C2	C1	C1	C1
Rehabilitation instructor							F			F
Psychologist										P
Emergency care or operation at hospital					C1	C1		C1		
Intestinal care at hospital					C1					
Ear, nose and throat clinic at hospital					C1			C1		C1
Genetics clinic at hospital					C1					F
Neuropsychiatric care at hospital			C1 and M				C1			
Psychiatry clinic at hospital					C1		C1	C1		
Neurology clinic at hospital					C1 and C2		C2	C1	C1	
Asthma specialist at hospital										C1
Infection clinic at hospital										C1
Cardiac unit at hospital										C1
Epilepsy clinic at hospital									C1	C1
Eye clinic at hospital						C1		C1		C1
Orthopedic care at hospital						C1			C1	
Rare diseases center at hospital							C1			
Pediatric arthritis care at hospital							C1			
Phoniatrics clinic at hospital								C1		
Psychiatric family ward at hospital					F					
Cleft palate and craniofacial centre at hospital						C1	C1	C1		
Governmental disability allowance	C1	C1	C1	C1	C1	C1	C1 and C2	C1	C1	C1
Governmental sickness allowance					M					
Youth outpatient clinic	F and M									
Sleep school					F					
Municipal support for informal care		M		M	M	M	M		M	M
Municipal respite care					C1		C1	C2		C1 and F	C1
Child protection services, such as babysitting					F	F			C1	F
Tax relief			M							
Support person					C1		C1			C1
Municipal car allowance					M					
Adaptation training or rehabilitation course					F		F	F	F	F	F
Assistive devices					C1		C1	C2		C1	C1
Sign language teacher										F
Acute psychiatric outpatient clinic							M			M
Supported family vacations										F
Governmental housing allowance										F
Municipal home renovation support						F				F
Other social services (e.g. diaper service, clothing allowance)						C1			C1	C1
Governmental taxi service						C1		C1		C1
Rehabilitative daycare, free						C1	C2			
Case manager									F	
Coaching (at home)										F
Private or non-profit health or social care										
Private neuropsychologist	C1									
Private doctor				C1						C1
Private psychiatrist					M					

(*continued*)

Table A1

C1 = first child, C2 = second child, M = mother, F = Family and P = parents										
Services offered by different actors	**Camilla**	**Veera**	**Taina**	**Rita**	**Leena**	**Erja**	**Olivia**	**Katri**	**Satu**	**Marika**
Rehabilitation service for special needs children (non-profit)							F			F
Training or course organized by non-profit organization					F					F
Family support organized by church										P
Sibling course (non-profit)						C2				
Total health and social services	8	11	9	13	24	21	22	17	16	35
Services offered by different actors (continued)	Camilla	Veera	Taina	Rita	Leena	Erja	Olivia	Katri	Satu	Marika
Education and early childhood care										
Special daycare arrangements		C1	C1		C1 and C2		C2	C1		C1
Individualized curriculum	C1	C1		C1		C1	C1 and C2	C1	C1	C1
Special education class	C1	C1	C1			C1		C1	C1	C1
Special education school	C1					C1		C1		
School psychologist	C1									
Music therapy	C1									
Occupational therapy	C1									
Speech therapy	C1									
School counselor	C1									
Personal assistant for child	C1			C1		C1	C1		C1	
After-school club or day activities		C1	C1						C1	C1
Child care during vacation time		C1							C1	C1
School taxi	C1	C1	C1				C2	C1	C1	C1
Other special educational services						C1				
Additional support										
Peer support groups/networks in Facebook	M	M	M	M	M	M	M	M	M	M
Information/support by associations (e.g. autism association)		M				M		C1	F	M
Summer camp for child										C1
Support by family, friends and relatives	F	F						F		F
Total amount of services offered by different actors	20	20	14	16	27	28	28	25	24	45

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