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Person-centeredness and Timeliness in the Process of Organizing Intensive Medical Rehabilitation in Public Health Care

Metropolia Ammattikorkeakoulu

Master of Business Administration

Health Business Management

Master´s Thesis

21.5.2021

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Title	Person-centeredness and Timeliness in the Process of Organizing Intensive Medical Rehabilitation in Public Health Care
Number of Pages	112 pages + 2 appendices
Date	21 May 2021
Degree	Master of Business Administration
Degree Programme	Health Business Management
Instructors	Eija Metsälä, Docent, PhD, RT, Principal Lecturer

The increased focus on quality of care has led to quality assessments now being increasingly common practice in health care settings, generally advising to target such structures or processes of care that have been associated with positive health outcomes and measures that are under the control of the health care organization responsible for care. In pediatric care, quality measurement generally refers to the assessment of the extent to which children receive quality of care in any of the six quality domains, being person-centeredness, timeliness, effectiveness, efficiency, equitability, and safety of care.

This research was undertaken as an extension to the development days held at the Helsinki Outpatient clinic for the Developmentally and Intellectually Disabled in October 2019, for the purpose of collecting baseline information regarding the organizing of intensive medical rehabilitation for pediatric customers. As a result, a quantitative study, based on historical, routinely collected data from 2018-2019 was chosen as the research method. Data collection was done using personnel data entries found in free writing format in the Pegasos data repository. Before data analysis, the data was manually converted into quantified data. It was the interest of the author to accurately describe the process and its different stages, while finding evidence of person-centeredness and timeliness of care in the process. The analyzed data sample consisted of 50 randomized processes of a pediatric pool of customers, who all had previously been through the process from start to end.

The results show evidence of person-centeredness and timeliness in the process of organizing intensive medical rehabilitation, although the level of these subcomponents of quality varied to some extent from process to another, in between the occupational groups, and in the different phases of the process. This variation was particularly reflected in the degree of direct rehabilitee involvement in the rehabilitation needs´ assessments, which was affected by the assessment method used by the different occupational groups. Caregiver involvement was rather low in all assessments made, as well as the degree of interdisciplinary teamwork. There were elements of cross-organizational collaboration in all assessments made, although the collaborative partner and the level of co-operation varied to some degree. Overall, the implementation of the rehabilitation negotiations indicated a higher level of person-centeredness throughout all processes, including high degree of rehabilitee and caregiver participation, interdisciplinary collaboration, and co-operation over organizational boundaries. In the timeliness measures, there was again more fluctuation.

Further research would be needed to gain more in-depth information about the true realization of person-centeredness and timeliness during the different stages of the rehabilitation planning process, especially from the rehabilitee and their caregiver perspectives.

Keywords	intensive medical rehabilitation, quality assessment, process management, person-centeredness, timeliness

Contents

1 Introduction

Intellectual disability (ID) refers to a person´s reduced capability to learn new skills and understand complex information, which often causes reduced ability to cope independently. ID is often diagnosed before adulthood and it has a lasting effect on one's development. (World Health Organization 2021.) The service needs for support of persons with ID vary greatly and require well-functioning service systems (Westerinen 2018: 6, 14). Rehabilitation, defined by the World Health Organization (WHO) (2020) as a set of interventions needed when a person is experiencing or is likely to experience limitations in everyday functioning due to ageing or a health condition, aims to support the best possible functional capacity of people in all everyday environments. With children and youth, rehabilitation supports the overall development and has far reaching implications for the child´s performance and participation in all aspects of life. (World Health Organization 2017: 1, 5.) Järvikoski (2014: 22), who cited Ward, Barnes, Stark and Ryan (2009) defined rehabilitation as a process, in which the key is for a disabled person to make plans and set goals that are important and suitable for their own circumstances. By this definition, rehabilitation is not a process done for a person, but a process that people themselves carry out under the leadership and support of professionals, family, and friends.

In Finland, intensive medical rehabilitation is rehabilitation organized by the Social Insurance Institution of Finland (Kela), in co-operation with public health care units responsible for care. Children are entitled to intensive medical rehabilitation if they have an impairment or illness that prevents them from participating fully in home, daycare, or school activities (Social Insurance Institution of Finland 2020: 7, 12.)

Among the units responsible for organizing intensive medical rehabilitation are the public outpatient clinics for the developmentally and intellectually disabled, who are obligated by the Act on Intellectual Disabilities 519/1977 to organize medical rehabilitation services for their customers (Ministry of Social Affairs and Health 2021, Social Insurance Institution of Finland 2020: 12-14). The rehabilitation services given under this Act are considered "special care" and the Act obliges the outpatient clinics to carry out such health assessments and treatments, which enable the preparation of rehabilitation plans, to be drawn-up as the basis for intensive medical rehabilitation (Act on Intellectual Disabilities 519/1977; Social Insurance Institution of Finland 2020: 13-14).

The Social Insurance Institution´s Rehabilitation Benefits Act 566/2005 10 § requires that rehabilitation arranged based on it corresponds to good rehabilitation practice (Social Insurance Institution of Finland 2020: 13-14; Paltamaa, Karhula, Suomela-Markkanen & Autti-Rämö 2011: 35). A good rehabilitation practice is based on person-centeredness, originates from everyday needs, applies an interdisciplinary approach, and is evidenced-based. It also embraces respect for individuality, correct timing, identification of challenges and strengths, application of knowledge and experience, participation of the rehabilitee and persons closest to them as well as cross-organizational collaboration. Effective rehabilitation requires that the different phases of the rehabilitation planning process be linked to each other seamlessly. (Paltamaa et al. 2011: 35-38.) These elements of good rehabilitation practice are comparable to the general dimensions of quality of care, which according to the Institute of Medicine (IOM) are “person-centeredness, timeliness, safety, effectiveness, efficiency and equitability” (AHRQ 2020). Among the core principles of good rehabilitation practice for children and youth are also person- and family-centeredness and timeliness of care, interdisciplinary team approach, and the integration of rehabilitation practices into the child’s everyday life environments, such as home, daycare and school (Kiviranta et al. 2016; Ministry of Social Services and Health 2017: 47).

Person-centeredness has been at the center of the many health and social services as it is associated with many benefits. It is a value in its own self but can also be considered as part of the effectiveness, cost-effectiveness, trust, and equality of care. (Jonsson, Pikkujämsä & Heiliö 2019: 82). Person-centered operating models have been associated with increased customer and employee satisfaction. The current legislation secures the foundations for person-centered care, but the act does not oblige or steer the public sector in a more person-centered direction in service offerings. (Virtanen et al. 2011: 8.)

Person-centered care is associated with a holistic, biopsychosocial, interdisciplinary approach and timeliness of care (Scholl, Zill, Härter & Dirmaier 2014: 5). It forms a partnership-based approach in which the care provider and the rehabilitee co-operate in the different stages of the rehabilitation process, both bringing their own expertise to support rehabilitation choices and decision-making (Paltamaa et al. 2011: 16; de Silva 2014: 9-10; Dukhu, Purcell & Bulley 2018: 2; Jesus, Bright, Kayes & Cott 2016: 1-2; Vaz, Jubilini & Queiroz 2017: 2). Timeliness of care means providing services in a timely manner, avoiding waiting times and harmful delays for those receiving and giving care (AHRQ 2020). It is also used to imply to the smoothness in providing care and services. (Ministry of Social Services and Health 2017: 40; Paltamaa et al. 2011: 226).

The increased focus on quality has led to quality assessments being increasingly common practice in health care, generally advising to target such structures or processes of care that are associated with desired health outcomes and measures that are under the influence of the care unit or organization in question. In pediatric care, quality measurement generally refers to the assessment of the degree to which children and youth receive high quality care in the quality dimensions defined by IOM (AHRQ 2018.) In quality evaluations, Donabedian's "structure-process-outcome" quality assessment framework still offers a valid tool for measuring quality in all health care settings (Berwick & Fox 2016: 4; Jonsson et al. 2019: 23). All three categories of structure, process or outcome can be used to measure any of the six quality domains of care (AHRQ 2018).

The purpose of this research is to evaluate person-centeredness and timeliness in the processes involving the organization of intensive medical rehabilitation for children and youth at the Helsinki Outpatient Clinic for the Developmentally and Intellectually Disabled. The aim is to prepare a description of the nature and degree of person-centeredness and timeliness visible in the different phases of the service process.

2 Quality and processes in rehabilitation

This part contains an introduction to the concept of quality, from the perspectives of person-centeredness and participation, teamwork and collaboration, and timeliness of care. In addition, there is an overview of the typical characteristics of a rehabilitation process as well as a description of intensive medical rehabilitation and children's good rehabilitation practice, to improve one's understanding of what constitutes quality in the processes of organizing rehabilitation. At the end, the most relevant theories, models, and tools needed in the assessment and measurement of person-centeredness and timeliness of care are introduced.

2.1 Quality of care

Quality is a complex and broad concept, which makes it also quite challenging to define. When defining quality, it is important to define it in its right context, and from the desired perspective, as it has a different meaning depending on the perspective taken. (Legido-Quigley, McKee, Nolte & Gliet 2008: 1.) Recent research regarding service quality has attracted growing interest among many public and private health care organizations

across the world, determined to explore its meaning and ways to measure it (Upadhyai, Jai, Roy & Pant 2019: 1).

In the recent quality measurement review by Upadhyai et al. (2019: 4-5), the authors cite an abundance of prior research and point out that even tough health care is also a service, it differs from other industries in the service sector and the concept of service quality is more challenging to define because of the different perspectives of the care provider, care receiver and the payer. It is common that care providers emphasize the delivery aspect of service, whereas care receivers generally assess services based on their own experience of the service received. The payer perspective tends to emphasize cost effectiveness of care as one of the most important aspects of quality of care. The authors also state that in the health care sector, service quality has often been assessed from the viewpoint of the service user, whereas the health care organization´s perspectives have been considered much less. (Upadhyai et al. 2019: 1, 3).

Martin, Charlesworth, and Henderson (2010: 227-228, 231, 240) also write about the many perspectives in health care quality definitions and state that the goal in all quality definitions should be to spot the differences in these perspectives. They also write about quality being a subjective issue, affected by people´s own experiences of care. Often, it is not enough to satisfy only some requirements, but not others. From the viewpoint of a quality chain, the quality of each element in a service process is likely to determine the quality of the entire chain.

The Institute of Medicine (IOM) has defined quality of care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge”. In this context, quality is the degree of adherence to established standards of care, based on prevailing knowledge and practices. (Kapoor 2011: 1.) The IOM has also provided one of the most influential frameworks for defining and assessing quality stating that the dimensions of health care are “safety, timeliness, effectiveness, efficiency, equitability and people-centeredness” (AHRQ 2020).

Rehabilitation services form an integral part of social and health services and the quality dimensionality applies there as well. To maintain high quality of intensive medical rehabilitation services, it is advised that the practices are organized in accordance with good rehabilitation practice (Social Insurance Institution of Finland 2020: 13), which has ele-

ments corresponding to the six quality of care dimensions. The good rehabilitation practice is rooted on evidence-based practice, which utilizes and combines information from scientific research, experiences of rehabilitation professionals and information received from persons receiving care and people closest to them. It places high value on person-centeredness, timeliness, and collaboration, which shows in respecting for each person's individuality, the right timing, the identification of the person's problems and strengths, the application of knowledge and experience, the participation and commitment of the person receiving care and their caregivers as well as the open co-operation and collaboration of the systems. A prerequisite for the effectiveness and efficiency of rehabilitation is the smooth rehabilitation process and its different stages. (Härkäpää, Kippola-Pääkkönen, Buchert, Järvikoski & Kallinen 2020: 16-21; Järvikoski 2014: 23; Paltamaa et al. 2011: 23, 35; Jeglinsky, Karhula & Autti-Rämö 2013: 2; Scholl et al. 2014: 5). In the following, the key dimensions contributing to high-quality rehabilitation are explained in more detail.

2.1.1 Person-centeredness and participation

In the literature, there are many ways to describe and refer to the concept of person-centered care. These terms include person, client, patient, consumer, user, individual and family, among others. The terms used to describe the care delivery include such as terms as -centered care, -focused care, -oriented care, -directed care and -driven care. (Registered Nurses' Association of Ontario 2015: 7.) Many of these concepts are used in part as synonyms to each other, but the terms have also been found to have some slight differences (AGS 2015: 1; de Silva 2014: 8; Jesus et al. 2016: 2). In the Finnish language, the term person-centeredness is most often referred to as "asiakaslähtöisyys", which is considered wider and more meaningful than the older and narrower concept of "asiakaskeskeisyys" (Virtanen et al. 2011: 18).

The concept of person-centered care is decades old, but it has gained more prominence over the years with its inclusion by the IOM as one of the six domains of quality (Davis, Schoenbaum and Audet 2005: 1). In health care today, being person-centered in the provision of health services is often associated with high-quality care (Waters & Buchanan 2017: 1). As a result, many health systems worldwide aim to provide better and more person-centered care and services, thereby affecting the way how services are being provided, managed, and financed. This trend is also reflected in the WHO´s "Global strategy on integrated people-centered health services 2016-2026". (Paparella

2016: 1, 5.) In the field of social care and learning disabilities, person-centered concepts have been around about a quarter of a century (de Silva 2014: 7). In Finland, person-centeredness has become the value base of all social and health services in the 21st century. (Virtanen et al. 2011: 9).

The IOM has defined person-centered care as “Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (AHRQ 2020). Person-centeredness in the provision of care services has meant that services are more tailored to meet the individual patient perspectives, with the goal to optimize the care experience. (Jesus et al. 2016: 1.) The IOM has also officially identified the key elements of person-centered care, which are 1) respect for patients’ values, needs and preferences, 2) provision of coordinated care, 3) provision of information, communication, and education, 4) provision of physical comfort, 5) provision of emotional support, and 6) involvement of caregivers (de Silva 2014: 7).

Person-centered practice is based on the fundamental idea that services must be organized not only based on organizational needs, but also to meet the needs of the individual being treated, requiring dialogue between the care provider and receiver. Dialogue is needed to ensure good understanding on how the needs of both parties could be best met with the available resources. As the dialogue and understanding improves, the service provider can gain “customer insight”, which is information and knowledge about the customer and their complex needs. Ideally, this knowledge can then be used in the continuous development, organization, provision, and management of social and health care services. (Virtanen et al. 2011: 9, 14, 18, 21.) Dialogue also helps in getting to know the person behind the patient and recognizing their individuality and specificity (de Silva 2014: 9).

Person-centeredness should not be mixed with the ideology to simply give people whatever they ask or want. It is more about interacting in the right way, paying respect, as well as regarding the service user as a professional in matters concerning his/her own care. At the very core of it is placing the person at the center of care planning and doing things rather “with” and “for” the person, than simply delivering something “to” the person. (Jesus et al. 2016: 1-2; Waters & Buchanan 2017: 3.) This kind of practice emphasizes equal partnerships between care providers and users in all phases of care, such as the planning, development, and assessment of care (Dukhu et al. 2018: 2).

Against this background, it is easy to understand that person-centered care is about active participation of the service user in all processes of care, thereby also facilitating

shared decision-making in matters involving care. It is the service provider´s responsibility to support the service user in the making of informed decisions about his/her care. It is also the provider's task to integrate the services into a smooth and continuous care path, mirroring the service user's perspectives. (de Silva 2014: 2, 9-10.) Waters & Buchanan (2017: 6) write about person-centered organizational culture and say that person-centered organizations embrace a value-base consisting of individualized, flexible, responsive, holistic, and solution-focused care that strives for continuity of care. A person-centered organizational culture is one that brings up the best in both personnel and customers. It places high value in appreciating and supporting personnel to empower them to perform their jobs better. In addition, it embraces a management style, which leads by an example of practicing person-centered leadership.

In rehabilitation settings, person-centeredness is seen as an essential ingredient in the implementation of timely, correctly targeted, and effective rehabilitation (Paltamaa et al. 2011: 23.). This is important, considering the change in population demographics of our aging societies and the resulting increase in health care service demand, combined with the limited public resources, which are all reasons causing pressure to renew services. Services must be made more effective, efficient, and productive, without forgetting quality. More person-centered service and operating models are seen as one way to contribute to this service reform. Person-centered care can increase the effectiveness and cost-effectiveness of care, as well as improve customer and employee satisfaction. (Virtanen et al. 2011: 7-8.)

In rehabilitation settings, a key element of person-centered is the active participation of the person receiving care in his/her own rehabilitation process (Paltamaa et al. 2011: 23). This requires collaboration between the provider and the person being cared for, starting from the assessment and the identification of the rehabilitation needs to the goal setting and the planning of appropriate rehabilitation measures. To be successful, health professionals must share information and power to facilitate these equal and consultative partnerships, in which both parties can bring their own expertise and to form a common vision and plan regarding the necessary rehabilitative measures. (Karhula & Salminen 2016: 5.)

A person-centered health system generally applies a biopsychosocial approach to the evaluation of care needs as well as to the provision of care, and this type of approach often includes collaboration with people closest to the service user (de Silva 2014: 9). The caregiver involvement in the context of rehabilitation can be divided into two broad

categories defined by Miles and Asbridge (2014: 1), which are the unpaid, informal carers, such as family, friends, and volunteers, as well as paid, formal carers, such as health and social care professionals.

Forming collaborative relationships are sometimes easier to be said than done. According to a recent research conducted in Southern Finland during end of 2020 and concerning the rated successfulness in the making of rehabilitation plans and related assessments for the intellectually disabled persons in public health care, the results showed that majority of caregivers and other closest persons to the disabled persons feel that they are more dissatisfied than satisfied with how the services are currently provided. In the answers of the respondents, some of the factors that were considered highly important in the successful making of the rehabilitation plan and related assessments included, but are not limited to, being on time (avoiding interruptions in therapies), working with the customer in a collaborative manner, open dialogue and sharing of thoughts between health professionals and customers regarding issues such as the necessity and the contents of the potential rehabilitation plans and recommendations as well as helping and guiding customers with their therapy applications. (City of Espoo 2021.)

2.1.2 Teamwork and collaboration

As previously stated, among the core components of person-centeredness is the cultivation of collaborative partnerships. This means the establishment of dialogue among the many levels in care relationships, including the relationship between the service provider and service user, relationships between health professionals within and across different disciplines as well as the relationship between the service user and their caregiver. (Mezzich, Appleyard & Ghebrehiwet 2014: 1.)

Dialogue and collaboration are necessary not only to foster care relationships, but also because of the growing complexity in the provision of care services (Singh, Kucukdeveci, Grabljevec & Gray 2018: 1). This is also in line with the shift from the traditional biomedical way of thinking towards the holistic, biopsychosocial approach to care, requiring greater understanding of the complexity of illness and health, and in turn demanding the involvement of health care professionals with varied skills, knowledge, and specialties to keep providing high-quality care (Mezzich et al. 2014: 2). Consequently, use of teamwork and interdisciplinary collaboration have become important approaches to providing care. There is evidence indicating that via teamwork it is possible to enhance quality of care

and improve outcomes of care, promote personnel satisfaction, and increase cost savings, as the use of teamwork is often associated with making decisions of better quality, coordinating actions and expertise in better ways as well as coping more effectively with complex tasks. (Valentine, Nembhard & Edmondson 2014: 1; Singh et al. 2018: 1.)

The promotion of teamwork stems from the belief that good teamwork can produce a combined effect, which is often larger than the sum of individual efforts. It is particularly true in rehabilitation medicine, where separate specialists and professions collaborate to direct treatments toward person-oriented goals. (Singh et al. 2018: 1.) In medical rehabilitation, there is a long tradition of co-operation and collaboration between different professions and disciplines. Teamwork has given means to gain good results in terms of treatment outcomes, thereby linking well-functioning teamwork to the delivery of high-quality care. (Lundgren & Molander 2017: 1.)

The concept of a health team can be used to describe groups of health care professionals, who each possess different skills and responsibilities, while still having shared objectives related to the outcomes of care. In the literature, there are several terms used to refer to these health care teams, including multidisciplinary, interdisciplinary, transdisciplinary, collaborative, interprofessional, cross-disciplinary and polydisciplinary approach. In most settings, the interdisciplinary team (IDT) approach seems to be the most appropriate for its inclusiveness. (Mezzich et al. 2014: 1.) It is also considered the most effective, collaborative, holistic and patient-centered teamwork model (Singh et al. 2018: 2; Greiner & Knebel 2003: 4; Körner 2010; 8-9). It is through an IDT approach, collaboration, and patient communication, that it is more likely to succeed in for example achieving the goals set regarding a person´s health outcomes (Fewster-Thuente & Velsor-Friedrich 2008: 3). The IDT approach as an interprofessional perspective may include the co-operation between physicians, nurses, therapists, social workers, and other health-related professionals. At the core of the IDT model is the person being cared for, who should be actively engaged in his/her own care. (Mezzich et al. 2014: 2.) The many stakeholders and perspectives included in the IDT approach also make it quite a complex process, requiring good communication, knowledge, and expertise sharing, to enhance the outcomes of care (Nancarrow et al. 2013: 1).

In rehabilitation settings, IDT practices often become evident in the ways, which the professionals from different fields co-operate and provide information on rehabilitation issues, while taking comprehensively into account the diverse needs and goals of the re-

habilitee. This is increasingly important when drawing up the rehabilitation plan and arranging rehabilitation (Paltamaa et al. 2011: 37-38). At a time of spiraling health costs, the IDT approach is also ideal to treat complex rehabilitation conditions and to maximize patient outcomes (Singh et al. 2018: 5), thereby playing a critical role in any quality improvement and cost reduction initiatives. In addition, use of interdisciplinary collaboration can eliminate errors and duplications in care as well as clarify roles (Fewster-Thuente & Velsor-Friedrich 2008: 5). The exact composition of a specialized rehabilitation team varies between clinical settings and between rehabilitees, as it is based on individual needs, which vary according to the person, their age, and their life situation. Also, the different care settings have an impact on IDT approach chosen, for example, an outpatient clinic providing care for persons with long-term conditions are likely to work differently than teams working in intensive care settings. (Singh et al. 2018: 2.)

Even if there are many benefits to team approach in health care, many organizations still lack effective teamwork practices. This may be caused by reasons relating to professional hierarchy or poor organizational support for teamwork (Mezzich et al. 2014: 2). Other barriers to IDT approach may include lack of time allotted for team members to collaborate, lack of role clarification and culture. These obstacles can be viewed from a domestic or local, organizational perspective as well as from a professional or an individual perspective. (Fewster-Thuente & Velsor-Friedrich 2008: 4-5.)

In Finland, the field of social and health services is a complex entity, with several public, private and third sector actors producing diverse services. Rehabilitation and services for the disabled are included as part of social services. The diversity of the field means that service provision requires specialists from several fields. (Virtanen et al. 2011: 11.)

The Social Insurance Institution´s updated Act from 2015 defines that therapies and interdisciplinary rehabilitation services must comply with good rehabilitation practice and be based on special expertise and necessary teamwork. In this context, teamwork includes both collaboration with the service user and people closest to him/her, as well as collaboration with other professionals and actors, who are important in the achievement of the goals set for the rehabilitation. (The Social Insurance Institution´s Rehabilitation Benefits Act 145/2015; Social Insurance Institution of Finland 2020: 7, 10, 13-14.) The goal of this type of teamwork is to emphasize the person’s own activity in his/her rehabilitation process and to guide and engage people closest to the person receiving care. This kind of collaborative practice promotes unified ways of working, makes rehabilitation

less therapy-centric and is associated with improved rehabilitation outcomes. (Social Insurance Institution of Finland 2020: 25-26.) It has been proven, that is challenging to achieve good rehabilitation outcomes, even in the most optimum circumstances, if the person receiving care does not commit to the goals set or if the immediate environment of the person does not support the entire rehabilitative process. This requires committed collaboration with the service user and people closest to him/her, from different contexts and environments. (Autti-Rämö & Komulainen 2013: 1.)

2.1.3 Timeliness and continuity of care

Timeliness and continuity of care are included in the essential elements of high-quality care (AHRQ 2016; IHI 2020). Timeliness and continuity of care can also be seen as key components of the vague concept of person-centeredness (OECD 2006: 14), including things like fast access to advise, care and treatment as well as smooth transitions in the processes of care (Paparella 2016: 2).

According to the IOM, timeliness means “reducing waits and sometimes harmful delays for both those who receive and those who give care” (AHRQ 2020). In practice, it refers to a health provider’s ability to provide care quickly after recognizing a need. In rehabilitation settings, timeliness can be used to refer to timely care as well as the continuity and overall smoothness of the entire rehabilitation process, which should be as seamless as possible. The process should cover all the necessary steps from the initial assessment and identification of needs to the planning, decision-making and service delivery as well as the monitoring and evaluation of the rehabilitation process and the making of adjustments to the process when necessary. (Ministry of Social Services and Health 2017: 40.) For the service user, it is important that the rehabilitation activities form a clear and comprehensible process. Potential delays, interruptions and duplications of activities that slow down the process and increase costs, should be avoided. (Ministry of Social Service and Health 2002: 9.)

Continuity of care is made of different components and it is perceived differently in different health care settings. Common to all settings are the two core elements and three types of continuity. The first element is a person´s experience of care, and the second is the continuity of care over time, also referred to as longitudinal continuity. The three types of continuity are informational, relational and management continuity, out of which the informational continuity refers to the appropriate use of information on previous health

care events, thereby enabling better planning of current care. Relational continuity refers to the care relationships between patients and providers, and management continuity refers to the provision of integrated care by many professionals under a shared management plan. All three aspects are equally important and affect the quality of care provided but tend to vary in their importance depending on situation. (Reid, Haggerty & McKendry 2002.)

Prompt health care is associated with many benefits. From the service user perspective, timely care may reduce emotional toll and improve the outcomes of care. From the provider perspective, timely care helps to eliminate frustration, bottlenecks and time wasted, thereby improving overall quality of care and care continuity. These benefits of timely care make timely care equally important as the care itself. (IHI 2020.)

2.2 Rehabilitation process

The starting point for a rehabilitation process is a person presenting to the health care system with a problem. As a result, people working within the health care system then start a standard problem-solving process (also known as “health care management cycle”), which typically involves the cyclical processes of collecting and analyzing data (i.e., carrying out rehabilitation assessments), planning actions (i.e., carrying out rehabilitation planning meetings), intervening (i.e., carrying out rehabilitation interventions), evaluating progress against the goals set and repeating the cycle if needed. The goal of the rehabilitation assessments is to improve one’s understanding of the person’s problem and the situation, particularly focusing on the nature and causes of the disabilities seen. This “diagnostic phase” of performing assessments typically takes much time and requires input from a range of specialties. It is often necessary to involve people in the assessments from outside health care and collaborate over organizational borders, to support the work of the core rehabilitation planning team. (Wade 2015: 4-5.)

Rehabilitation planning generally refers to the setup of rehabilitation planning meetings, also known as goal setting meetings or case conferences. In practice, this generally means the organizing of face-to-face meetings with the rehabilitee and people closest to them and may include cross-organizational collaboration. It is also a phase that generally requires considerable amount of time, including the preparation of the meeting, implementation of the meeting, and the necessary documentations to be done after the meet-

ing. In addition, time is needed for putting the agreed actions in practice as well as communicating and liaising with other organizations affected. Resources applied in these meetings, such as time and attendees, should be proportionate to the complexity of each individual case. (Wade 2016: 5-6; Wade 2015: 6.)

Rehabilitation interventions generally refer to support, reduction, or removal of the cause(s) of the problem (therapy), minimization of the effects of the problem, evaluation of progress against goals set and evaluation of the cycle if needed. It is normal for several interventions to be needed, which are often interdependent and sequenced, requiring actions undertaken by several people, requiring planning and coordination. (Wade 2015: 6-7.)

The rehabilitation process is known to differ quite significantly from other medical care processes in two ways. Firstly, the processes tend to involve many people and organizations, and therefore, require good communication and liaison between all parties for the processes to be effective and efficient. Secondly, the process emphasizes learning, both learning by the person and often by family members on how to achieve the goals set in the presence of altered or limited skills and abilities. (Wade 2015: 4.) Many of the complexities involved in the planning of rehabilitation interventions are often managed best by using the IDT approach. In comparison to medical teams, these rehabilitation teams usually involve a much broader range of collaborating professions, from inside and outside health care. The composition of the teams may also vary from specific rehabilitation teams to meta-teams, representing a group of specific teams. Most often persons, who have a long-term disability require collaboration on many levels and among many people and teams, which requires good sharing of knowledge to develop a unified management and rehabilitation plan. (Wade 2016: 2-3.)

2.3 Intensive medical rehabilitation

Intensive medical rehabilitation, previously known as medical rehabilitation for the severely disabled, settled into its present form by the law reform 145/2015 entering into force on January 1, 2016 (Härkäpää et al. 2020: 10). It is rehabilitation financed by the Social Insurance Institution of Finland, who has a legal obligation to arrange it, which is based on the Social Insurance Institution´s Rehabilitation Benefits Act 566/2005, in Finnish known as Laki Kansaneläkelaitoksen kuntoutusetuuksista ja kuntoutusrahaetuuksista or KKRL 566/2005 9 § ja 10 § (Social Insurance Institution of Finland 2020: 5).

The organization of intensive medical rehabilitation is the responsibility of those public health care units that are responsible for assessing the person's rehabilitation needs, planning and monitoring rehabilitation, and the continuity of necessary care during rehabilitation. Such units may be care facilities at different levels of public health care, such as health centers, hospitals, or outpatient clinics for the intellectually disabled. (Social Insurance Institution of Finland 2020: 12-14.)

The activities of the outpatient clinics for the intellectually disabled are based on the Act on Intellectual Disabilities 519/1977, and the services provided as special care include health care and rehabilitation services. In practice, this means that the outpatient clinics are responsible for the treatment and assessment of the state of health that enables the preparation of individual rehabilitation plans, as a basis for intensive medical rehabilitation. A rehabilitation plan drawn up by the private sector cannot be used as a basis for a rehabilitation decision unless the public health care provider has obtained the preparation of the rehabilitation plan as an outsourced service and has given its approval by signing or otherwise. (Social Insurance Institution of Finland 2020: 12-13.)

The process description regarding the organizing of intensive medical rehabilitation is presented in Appendix 1. The goal of intensive medical rehabilitation is to enable people to perform activities of daily living and to facilitate people's participation in everyday life activities. It is aimed at persons under the age of 65, who have been diagnosed an illness or disability and a related performance and participation restriction causing significant difficulties in performing activities of daily living and participating in everyday life situations and environments. It also requires that the performance or participation restriction results in a need for rehabilitation lasting at least one year. In addition, the performance or participation restriction must be so significant that the person has considerable difficulty in performing and participating in everyday activities at home, school, work or in other situations outside public institutional care. (Social Insurance Institution of Finland 2020: 2-3, 7.)

Intensive medical rehabilitation interventions may be used to support the learning of new or lost skills, or to strengthen existing skills, which support one´s functional ability. It does not cover rehabilitation related to the insured person's medical care or arranging rehabilitation based on passive interventions and treatments only, which do not involve any active performance nor participation of the insured. It is rehabilitation, which is arranged and implemented in close collaboration with the rehabilitees and people closest to them. The implementation is based on goals that are meaningful, relevant, and concrete for

the person, and enable them to better perform and participate in everyday life activities. In the goal setting and the assessments of rehabilitation needs, it is required that the assessments include a full evaluation of the factors affecting the insured individual's ability to function, such as medical health, body structures and functions, performance, and participation, as well as individual and environmental factors, which are factors included in the ICF framework (International Classification of Functioning, Disability and Health). The assessment of rehabilitation needs is advised to be carried out in co-operation with the customer and the unit responsible for care. (Social Insurance Institution of Finland 2020: 3, 6-10.)

The contents of the intensive medical rehabilitation are based on written rehabilitation plans, which are prepared in accordance with good rehabilitation practice. The plan is drawn up in the public health care unit responsible for the care of the individual and in collaboration with the individual and people closest to him or her. The plan is drawn up for a minimum of one year and a maximum of three years at a time, and then submitted free of charge to Kela. Rehabilitation plans are unique to each individual and consider rehabilitation recommendations and national rehabilitation guidelines and practices specific to the disability group. (Social Insurance Institution of Finland 2020: 10.) In the rehabilitation services for children and youth, Kela advises to use the recommendations of good rehabilitation practice published by the Finnish Pediatric Neurological Association (Social Insurance Institution of Finland 2019).

2.4 Good rehabilitation practices

The rehabilitation of children with disabilities must obey the obligations of the UN Convention on the Rights of Persons with Disabilities, in particular the articles concerning children, health, inclusion, and rehabilitation (Ministry of Social Services and Health 2017: 47). The Article 7 regarding children, contains the requirement, which states that "children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right." The Article 26 regarding the organization of rehabilitation services requires, that "…these services and programs: a) begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths; b) support participation and inclusion in the community and all aspects of society…". (United Nations 2006: 7, 16.)

Rehabilitation of children is included in the social and health care services that support the child's growth and development. Rehabilitation services are aimed at those children, who have diverse developmental difficulties, involving for example motor skills, speech and language, learning abilities, as well as social and interaction skills. Rehabilitation can be organized in inpatient and outpatient settings, and it can be either individually implemented or group based. (Ministry of Social Services and Health 2017: 47.)

In Finland, the organization and financing of rehabilitation for children belongs to the municipalities, which is based of Section 29 of the Health Care Act and Section 9 of the Kela KKRL. The rehabilitation of children can also be financed by an insurance scheme. (Ministry of Social Services and Health 2017: 47.) Health care units responsible for the organization of intensive medical rehabilitation for children include university and central hospitals, primary health care, government owned VALTERI schools and municipal special schools, and outpatient clinics for the intellectually disabled. The decision of the unit responsible for care is affected by the child's age and place of residence and by the need specified for rehabilitation. The outpatient units for the intellectually disabled are responsible for the planning of rehabilitation for people with an intellectual disability. (Kiviranta et al. 2016.)

Rehabilitation of children is based on guidelines regarding the good rehabilitation practice for children and youth, developed by the Finnish Pediatric Neurological Association in 2016. These guidelines are in line with the international guidelines and the general guidelines regarding good rehabilitation practice. They emphasize the use of the comprehensive ICF framework in the rehabilitation process, and state that rehabilitation should be based on scientific evidence and/or be based on the domestic guidelines regarding good rehabilitation practice. Good rehabilitation practice is also based on the principle of equity, is fair and just in nature, and considers the local resources and the different cultural and belief perspectives. (Kiviranta et al. 2016.)

Some of the essential components of good pediatric rehabilitation practice include timeliness, person- and family-centeredness, IDT approach, and the integration of rehabilitation practices into the child's everyday life environments, such as home, daycare and school. (Kiviranta et al. 2016; Ministry of Social Services and Health 2017: 47.) In practice, timeliness means that pediatric rehabilitation measures should begin as early as possible and be based on subjective needs, life situations and circumstances. Medical rehabilitation therapies usually focus on young children, children going to preschool and

primary school. The most important therapies used in medical rehabilitation of pediatric neurological diseases and injuries are physical therapy, occupational therapy, speech therapy, hydrotherapy, equine-assisted therapy (EAT), music therapy and neuropsychological therapy. At the start of school, the focus of the child's rehabilitation gradually shifts from medical rehabilitation to educational rehabilitation provided by school as well as towards various leisure activities. However, medical rehabilitation may still be needed during later school years, to support one's learning, functioning and independent coping, alongside other, educational rehabilitative measures. (Härkäpää et al. 2020: 14-15; Kiviranta et al. 2016; Ministry of Social Services and Health 2017: 47.)

Regarding person- and family-centeredness in pediatric rehabilitation, it is shown that it is especially important that children, their families, or other caregivers are involved in all phases of the rehabilitation process, from the planning and goal setting to the implementation and the evaluation of outcomes (Kiviranta et al. 2016; Ministry of Social Services and Health 2017: 47; Social Insurance Institution of Finland 2020: 4-5, 25-26). In an ideal situation, rehabilitative measures are in accordance with the child's own learning goals and objectives, which requires the active participation and hearing of the child in all phases of the process. The goals generally emphasize support for growth, development, and self-image as well as participation in activities of daily living but seen from the child's own perspective. (Kiviranta et al. 2016.) The goals should be meaningful and relevant, concrete, and achievable for the child, to facilitate his/her better functioning and participation. (Social Insurance Institution of Finland 2020: 10-11.)

IDT approach becomes evident, as the attainment of the rehabilitation goals generally requires the integration of rehabilitation into everyday life environments such as home, daycare and school, which in turn requires good collaboration between the child, family, and professionals from different disciplines. This type of collaborative and even cross-organizational practice generally enhances the child's learning of new skills and helps in the transferring of the skills into everyday life situations. (Kiviranta et al. 2016.) In practice, this means that it is recommended that rehabilitation is carried out in whole or in part through home visits, kindergarten and school visits, or visits to other everyday life environments (Härkäpää et al. 2020: 14-15). Rehabilitation may also include separate guidance visits targeted to the family members or other caretakers of the person receiving care, to assist in the achievement of the rehabilitation goals (Social Insurance Institution of Finland 2020: 11).

Implementing timely, person-centered, and IDT approach to medical rehabilitation of children may sound like an easy task, but according to research, there are also challenges

involved in the realization of these approaches in practice. Salla Sipari's (2002: 31) research results showed that in the rehabilitation of children and youth, person- and family-centeredness can also be perceived as a burden. Interdisciplinary approach is based in part on statutory obligations, but this is not the case for all practical work. As a result, there is wide variation in the situations, configurations, formalities, and continuity of interdisciplinary teamwork for children, youth, and families. (Ministry of Social Affairs and Health 2017: 11.)

2.5 Quality and process management

In quality management, the objective is to make such products and services that meet the many customer needs and expectations, accepted standards, or both. The origin of quality management lies in statistical research involving processes, which started in the 1920s. Since then, it has transformed into an entire management philosophy, where processes have a crucial role. (Laamanen & Tinnilä 2013: 67-68.)

Organizations create and use quality management systems to better fulfil customer needs and expectations as well as to enhance the efficiency and effectiveness of their operations. Within a quality management system, an organization must have all necessary ingredients that enable them to identify, design, develop, produce, deliver, and support their product or service provision according to the customer need. This demands dynamic quality management systems, which adapt to changing requirements. The underlying principles supporting a good quality management system include involved leadership and engaged workforce, strong customer focus, continuous process management and improvement as well as fact-based decision-making. (Summers 2018: 46.)

Process management has emerged as a concept to improve the performance of many health care organizations, shifting focus from output characteristics, such as product or service, to process characteristics (Hellström, Lifvergren & Quist 2010: 1-2). Process-based organizations in health care have been associated with many benefits, such as improvements in service quality, efficiency, effectiveness, and cost reduction (Vera & Kuntz 2007: 1; Rohner 2012: 4).

The foundation of process management lies in an organization's ability to create value for its stakeholders and this value lies in processes (Laamanen & Tinnilä 2013: 52). There are several alternative approaches applicable in process management. Common to most, if not all, is the close connection of measurement and improvement, which act

as the two sides of the same coin, as it is challenging to make improvements without measurement. Measurement is the key to defining success in all changes. The challenge is that health care professionals often have limited time to collect and analyze data over time, which would improve their understanding of the processes and outcomes of care. (Nelson, Splaine, Batalden & Plume 1998: 1-2.)

Process management refers to identifying, describing, measuring, developing, evaluating, and improving important processes (Laamanen 2005: 155). It enables the processes of the organization to be clarified and reviewed, seeking to identify the functions, overlaps and bottlenecks that it manifests. In optimal situation, all parts of the process are in balance. (Parvinen, Lillrank & Iivonen 2005: 189-190.) Process management can strengthen an organization's continuous improvement strategy, support customer orientation and customer-driven operations, improve staff collaboration, increase one's understanding of roles and organizational goals as well as improve customer experience and satisfaction (Laamanen 2005: 156).

There are a few practical methods and approaches for improving quality and processes, such as quality assessments and audits, self-assessment, benchmarking, problem-solving, Statistical Process Control (SPC), Six Sigma, Lean Management (Lean), continuous improvement (Kaizen), Theory of Constraints (TOC), Quality Control Circles and ISO 9000 standards (Laamanen & Tinnilä 2013: 68). Selecting the right method depends on the situation at hand that one wishes to observe or study (Kapoor 2011: 1).

2.5.1 Quality assessments in health care and rehabilitation

In health care, many organizations are challenged by the aging societies, which increase the demand for services. That is why health care organizations are required to meet growing demand while also striving to maintain quality of care. (Rotter et al. 2017: 2.) Consequently, while health systems aim to maintain or improve quality of operations and services, quality and performance assessment are being increasingly carried out. These assessments have two principal purposes: external accountability and internal quality improvement (Gardner, Sibthorpe & Longstaff 2008: 1.) Based on these recent developments and the increased focus on person-centered care, there is now a lot of research being done in the field of quality and quality assessments (Upadhyai et al. 2019: 1).

Quality assessments refer to performance assessment and measurement, which is about producing knowledge as a raw material to assist organizational decision-making. In performance measurement, the results of measurement are compared with assumptions of performance, thereby supporting fact-based decision-making and organizational learning (Laamanen 2005: 18-19, 23.) In health care settings, performance can be measured at the policy or system level (such as regions, states), at the organizational level (such as clinics and hospitals) or at the individual level (such as physicians, therapists) (Ferlie, Montgomery & Pedersen 2016: 381). Quality assessments can be based on the six dimensions of quality of care introduced by the IOM and on Donabedian's organizational structure-process-outcome –model (AHQR 2016). The first step in health care quality assessments should involve the definition, of what is meant by quality in the given situation. Many problems are present at this fundamental level, due to the difficulty to define its meaning. (Donabedian 1966: 2.) Despite of these difficulties, quality assessments have gained importance among all stakeholders involved in the care provision and related processes, including the providers following the evidence-based practices, the care regulators setting the policies and the payers supervising the cost-effectiveness of care (Mainz 2003: 1).

The quality of health and rehabilitation services has traditionally been assessed in terms of structure, process, and outcomes (Jeglinsky et al. 2013: 2). This originates from the classic "structure-process-outcome" framework on quality of care developed by Avedis Donabedian in 1966. Even now many decades later, it still offers a valid framework for assessing quality of care in health care settings. (Berwick & Fox 2016: 4.) Donabedian's model can be used in combination with the quality-of-care dimensions identified by the IOM, which are people-centeredness, timeliness, effectiveness, efficiency, equity, and safety (AHRQ 2018). In all quality assessments in health care settings, the three areas of structure, process and outcome are important, although with different emphasis depending on context. Regarding the service provision for persons with learning disabilities, some say that the process aspect is the most important. (Martin et al. 2010: 262.)

In the Donabedian model, the structure (or input) perspective refers to the care settings and resources needed, such as material resources (facilities, capital, equipment, drugs), intellectual resources (medical knowledge, information systems) and human resources (health care professionals). (Donabedian 1966: 4-5; Legido-Guigley et al. 2008: 9-10.)

The process perspective refers to the use of the resources while giving and receiving care. This divides into patient-related processes (such as organizing care interventions)

and organization-related processes (such as managing waiting lists). (Legido-Guigley et al. 2008: 10.) The idea behind the process perspective is that by assessing the processes of care one can determine whether medicine has been properly practiced and whether “good” care has been applied. These judgements can be made based on evaluating the different phases and processes of care provision. (Donabedian 1966: 4.) As a direct quote by Donabedian, the question of performance and quality should be about “What goes on here?” instead of “What is wrong, and how can it be made better?” (Ferlie et al. 2016: 17).

The outcome perspective describes the effects of care and may include such final outcomes as mortality, morbidity, disability, and quality of life as well as intermediate outcomes, such as well-being and functional ability. Outcomes are poor measures of quality in situations where outcomes are only partially associated with the health services provided and may also be the result of other factors, such as lifestyle. (Legido-Guigley et al. 2008: 10-11.) Even so, Donabedian himself has claimed (1966: 3) that the validity of outcome as quality indicator is rarely questioned.

The Donabedian model underpins measurement for quality improvement. For improvement projects, it is often best to have all outcome, process, and structure measures in place, as they all have a different angle to measuring quality, and therefore, can be used to evaluate the success of a project from many perspectives. (NHS 2016.) According to Legido-Guigley et al. (2008: 10), even Donabedian himself argued that before assessing quality one must select the desired specification of quality and the desired perspective to be used in the quality assessment (practitioner, patient and/or health care system).

In Finland, the methods used to monitor the quality used in health care are not static, but develop as measurement methods are renewed (Association of Finnish Municipalities 2019:5). The challenge has been domestically, however, that measurements in the field of rehabilitation have been complicated by the lack of data resources to produce ”indicator data” on the start, targeting, content, duration and end result of customer processes. Monitoring rehabilitation services with comparable indicators has also been challenged by the heterogenity of the service system and the difficulty of finding standardized monitoring and comparison targets. (Hämäläinen, Kovasin & Räikkönen 2019: 226.) Therefore, there is no single standardized set of indicators that can be used for quality assessments, but measurement requires changing the selected perspectives and objectives to measurable elements and quality indicators (Mainz 2003: 1; Ferlie et

al. 2016: 382). The use of quality indicators also enables evaluation and monitoring of rehabilitation structures, processes and results (Westby, Klemm, Li & Jones 2016: 1).

2.5.2 Quality measurement and the use of quality indicators

In the context of health care, quality measurement cannot be achieved without the use of quality indicators (Mainz 2003: 1). According to Upadhyai et al. (2019: 10), there is no one-size-fits-all set of dimensions or measurement standards available. It is quite common that the chosen measurement methods in health care quality assessments lack the service provider perspective, which is important as the service user is often incapable to assess all aspects of service quality. The authors cited Brown and Swartz (1989) and stated that both perspectives are needed in all service quality evaluations to gain better understanding of care processes. Thus, there is now more demand to perform service quality assessments from the viewpoint of the service provider.

The use of quality indicators (QI) requires that the chosen quality perspectives and objectives be first translated into measurable components and indicators (Mainz 2003: 1; Ferlie et al. 2016: 382). QIs are standardized, evidence-based measures of health care quality, and they can be generic or disease-specific and relate to structure, process, or outcome of care. Structure indicators refer to the resources, whereas process indicators measure the quality of the inter-related patient actions taken by the care provider. Outcome indicators, such as the 5 D's being death, disease, discomfort, disability, and dissatisfaction are useful in situations where the outcomes affected by care can directly be measured. (Mainz 2003: 3.) QIs provide a measurable approach for quality assessments and allow the operationalization of practice guidelines and transformation of recommendations into actionable and measurable statements. In rehabilitation settings, QIs can be used to assess and monitor gaps related to the structures, processes, or outcomes of care. (Westby et al. 2016: 1.)

In the past, it appears that the three components of structure-process-outcomes are rarely analyzed in a comprehensive manner and that there have been many quality assessments done with the focus on structural measures of care only. Recently, however, there has been a shift in the focus towards the measurement of process and outcome. As an example, it has been acknowledged that quality improvement approaches should involve more person-centered models of care (Legido-Quigley et al. 2008: 10; Hanefeld, Powell-Jackson & Balabanova 2017.) Examples of structure and process measures that

can be used to assess quality of care can relate to resource allocation (in terms of time, place, and responsiveness to the needs of populations), resource application and use of time and resources (efficiency), avoidance of waste (economy), reduction of risk (safety), evidence-based practice (appropriateness), as well as continuity and person-centeredness of care. (Legido-Quigley et al. 2008: 11.)

Many health care improvement efforts require making changes in work practices and processes and to the ways in which service is being delivered. This involves the measurement of process performance, which can be challenging due to the existence of natural variation in processes, resulting in measurements yielding different values from time to time. (Benneyan, Lloyd & Plsek 2003: 1.)

Measuring person-centered care may be of interest by many groups, such as patient groups and clinicians, managers and service planners, quality assessors, regulators, and policy makers as well as researchers. The most common reasons for measuring person-centeredness include the need to assess service quality, the need to assess the success of a specific quality improvement initiative and the need to assess whether the services provided met the customers´ needs and preferences. (de Silva 2014: 11.) Finding objective measures for assessing person-centered care has been challenging (Fleming et al. 2006: 1). This is because it is a broad concept, which has many different components and subcomponents, such as shared decision-making, patient activation and participation as well as person-centered communication. Person-centered care can be measured in a variety of settings, although most research has taken place in hospitals. The main features generally being measured include definitions, preferences, experiences, and outcomes of person-centered care. In this context, measuring experiences relates to examining the extent to which care delivered was person-centered. (de Silva 2014: 8-11.)

Measuring person-centered care can be done using a holistic concept or using specific subcomponents. Majority of prior empirical research has focused on processes or experiences of person-centered care, such as the extent of patient involvement within a specific care encounter. (de Silva 2014: 12.) The holistic concept generally refers to care aiming to ensure that a person is an equal partner in his/her care. The selected subcomponents of person-centered care may include patient satisfaction/experience of care, patient engagement and level of active participation in the care process as well as empathy, compassion, and dignity. The behaviors supporting person-centered care include person-centered communication, support for self-management and collaborative decision-making. (de Silva 2014: 15-19.)

Different measures of person-centered care are used at varying points in a person's care paths or continuum. For example, when measuring experiences of person-centered care, it is best done during or after a care episode. Common research approaches have included the use of surveys, interviews, observation, as well as the review of patient records or other routinely collected data for evidence of person-centered care. Out of these approaches, the analysis of routine data can be used to evaluate the impact of a particular treatment or intervention, or to examine the care process itself. (Association of Finnish Municipalities 2019: 8; de Silva 2014: 8-9, 11-13, 15-19, 33.)

Regarding timeliness measures for care processes, one type of measure used to indicate the passing of time in delivery processes is known as cycle time, which is the time spent to realize activities. The cycle time of a process refers to a period from the beginning of the first activity to the end of the last activity, within a particular sequence of activities. Typical cycle times in service delivery are queuing time, service time, lead time, delivery time and total delivery time. (Laamanen & Tinnilä 2013: 101.)

Regarding time-based management of health care processes, there is one study published by Kujala, Lillrank, Kronström, and Peltokorpi (2006:3), who cited several authors (McCarthy et al. 2000; Fauman 2003; Sanmartin et al. 2000; Gardner 2003) and stated that many health care organizations generally measure and register time, but the measurements often lack a systematic approach or are excluded from the integrated patient processes partly due to inefficient and old-fashioned systems for collecting and processing time-related data. Kujala et al. (2006: 1, 3) also cited other prior research (Martin & Smith 1996; Propper et al. 2002 etc.) and stated that time-related studies in health care are mainly focused on waiting times or on the duration of individual medical procedures and they lack the total patient episode viewpoint, which compares to a customer order-to-delivery chain in industry. They pointed out that a patient episode refers to a patient perspective, while the term patient process refers to the care provider perspective. The researchers claimed that time-based management should focus on through put time of a patient episode and focus on minimizing the existence of all cost-adding and non-value creating components.

Regarding continuity of care, there are many ways to measure it and measures are chosen depending on the type of continuity that is relevant in each health care setting. The measure of informational continuity relates to the availability and completeness of documentation and other information transfer between care providers, and to the extent to which existing information is applied in decision-making by the service provider or service user. It differs from measures of management continuity, measures of compliance with

management protocols and measures regarding relational continuity. In this context, it is obvious that no single measure can capture the entire concept of continuity. Regarding informational and management continuity, there is also demand for new measures targeting the continuity of care across organizational and disciplinary boundaries. (Reid et al. 2002.)

Regarding quality measurements and QIs for the assessments of rehabilitation services, a study published by Johansen et al. (2019) included a systematic search for QIs used in all rehabilitation, not limited to diagnostic groups or study design. As a result, they identified several main themes for quality measurement, involving biopsychosocial assessments of patients and user involvement in the rehabilitation process. They also proposed several quality domains suitable for evaluating these main themes, such as interdisciplinary assessment of patients, patient participation in the entire rehabilitation process, procedures regarding rehabilitation planning and meetings. They also defined the common QIs relating to structure-process-outcome of rehabilitative care, which are presented in Table 1.

Table 1. Quality indicators used in rehabilitation settings, as suggested by Johansen et al. (2019).

Structure	Developing an individual rehabilitation plan, regular team meetings with patient, access to meetings with next of kin and external personnel, written individual plan for follow-up, patient participation in setting goals and planning the intervention, patient participation in evaluating the intervention, use of validated assessment instruments
Process	Initial health assessment, initial biopsychosocial assessment, individual written rehabilitation plan, participation in team meetings, access to meetings for next of kin and external personnel, individual plan for follow-up, external personnel were involved in planning follow-up, participated in setting goals, participated in planning the intervention, participated in planning follow-up
Outcome	Satisfied or very satisfied with rehabilitation, reached important goals, important improvement in physical, psychological, or social function, improvement in quality of life, no adverse events

3 Research purpose, aims and objectives

The purpose of this research is to evaluate person-centeredness and timeliness in the processes involving the organization of intensive medical rehabilitation for children and youth, by the Helsinki Outpatient Clinic for the Developmentally and Intellectually Disabled. The aim is to prepare a description of the nature and degree of person-centeredness and timeliness visible in the different phases of the service process.

The research questions are:

- How are the rehabilitation needs of the pediatric customers assessed in practice?
- How are the rehabilitation negotiations implemented in practice?
- What is the nature and degree of person-centeredness and timeliness in these two phases of the process?

For the operationalization of the research objectives, please see Appendix 2.

4 Helsinki Outpatient clinic

The Helsinki Outpatient clinic for the Developmentally and Intellectually Disabled is a single specialty clinic offering health and rehabilitation services for those Helsinki residents, who have been diagnosed an intellectual and/or developmental disability. One of the core services of the clinic is the planning and organization of intensive medical rehabilitation services, in close co-operation with the disabled persons and people closest to them. (Helsinki Outpatient clinic for the Developmentally and Intellectually Disabled 2018.) The clinic operates as a relatively small public business unit under the vast Helsinki Social Services and Health Division, under Family and Social Services Department, and under the Services for the Disabled (Helsinki Social Services and Health Care Division 2020).

On the central Helsinki city administration level as well as locally at the Outpatient clinic, business operations are monitored using the quadruple aim -model, where the four perspectives are customer experience and accessibility, personnel experience, effective-

ness, and productivity. In overall quality management, service development and improvement, the city suggests the use of the European EFQM-model and Lean thinking and its various tools. (City of Helsinki 2019: 4.)

The mission of the Outpatient clinic is to provide rehabilitation and guidance, which promotes the participation and maximum independence of the intellectually disabled customers. The customer relationship is based on intellectual disability diagnosis and Helsinki resident status. Clientship obtained may be either temporary or permanent, depending on the permanence of the intellectual disability diagnosis. Many customers obtain the clientship in their early childhood and youth and get a referral to the Outpatient clinic either from maternity hospitals, physicians from the Children's Hospital or school and preschool physicians. In some cases, client relationship is not established until adulthood, when the intellectual disability can be reliably confirmed. The number of customers has been increasing in recent years, reaching around 2400 at the end of year 2019. (Helsinki Outpatient clinic for the Developmentally and Intellectually Disabled 2015)

The clinic serves its customers and people closest to them in matters relating to intellectual disability, thus supporting other public, primary health care and specialized health care services provided by the city. The core services of the clinic include assessment and follow-up of rehabilitation needs, general guidance and counselling, implementation of individual and group therapies, provision of mental health consultations, assessments of medication needs, evaluation of need for assistive devices and/or home remodeling, etc.

The clinic forms an interdisciplinary work community, offering services from under one roof. In late 2018 and during 2019, the amount of full-time personnel contributed to 36 health care professionals representing five physicians, four health care and nursing staff members, six psychologists, six speech therapists, two occupational therapists, six physical therapists, five enhanced support workers, a sexual therapist, and an office secretary. The head of the clinic is a senior physician, who manages the operations with three middle managers, who represent the heads of psychology, physical therapy, and speech therapy. The management of the clinic reports to the higher levels of the Helsinki city social and health network. The work of all managers and employees of the clinic is focused on clinical customer work, and there is currently no administrative nor R&D staff members within the clinic's personnel.

The services of the clinic are provided either one occupational group at a time, as working couples, or using interdisciplinary teams. The first two often involve the performance

of health and functioning assessments, guidance, and consultations. Interdisciplinary teamwork often involves the organization of rehabilitation negotiations for the customers and people closest to them. The practices relating to the organization of rehabilitation vary to some degree according to the type and the funding mechanisms of the rehabilitation. The focus of this research is on the intensive medical rehabilitation for children and youth up to 17 years of age and it forms one of the core services of the clinic.

The actual work of the clinic's personnel takes place both at the clinic as well as on the field, working in customers' everyday environments, such as homes, daycares, schools, daytime activity centers and other settings. The work is very customer-oriented and there exists multidimensional cooperation with both internal and external stakeholders. External cooperation is often done with professionals from social services, maternity and child welfare, nursery schools, early education, education department and schools, primary health care, specialized health care (HUS), Kela, private companies providing rehabilitation services, assistive device clinics, organizations from the 3rd sector, sport clubs, etc.

5 Research methods

This research has been conducted as a quantitative study, based on the Act on the Secondary Use of Health and Social Data 552/2019. A quantitative approach was chosen based on the availability of pre-existing knowledge about the phenomenon of interest, which allowed the collection of highly structured, measurable data and the use of deductive approach, where it is proceeded from theory to practice (compare Bowling & Ebrahim 2005: 190). In practice, this meant that the author familiarized herself with the relevant theoretical background first, concerning the elements of quality and process management and assessment in health care, and then investigated through a set of scientific rigorous procedures and analytical methods, weather there were elements of quality subcomponents present in the rehabilitation organizing processes of the Outpatient clinic. The benefit of using this research method was that it allowed the production of factual and reliable data of the process under study.

The use of secondary health and social data in this study means that this research has been conducted by using existing data, derived from the electronic Pegasos data repository involving patient data. There were no other data sources used in the data collection.

In practice, this means that the data collected was originally collected for purposes other than this research. More specifically, the data was originally collected by the personnel of the Outpatient clinic, for the purpose of organizing intensive medical rehabilitation for the persons they were responsible for providing care for. In Finland, the secondary use of data for health care research has been supported by the Ministry of Social Affairs and Health and is encouraged by the Act 552/2019, which came into force in April 2019. (Ministry of Social Affairs and Health 2020). There is evidence, that this type of data derived from primary care usually works for the purposes of addressing specific research questions, in small-scale studies, which collect, analyze, or audit data from a single or selected group of practices (Bowling & Ebrahim 2005: 168).

5.1 Data collection and inclusion criteria

This research has been conducted in between late 2019 to May 2021, and it forms the master thesis of the author. The research process (see Figure 1.) started by the selection of the research topic and by the preparation of the research plan and related appendices during the first half of 2020. It continued with the application of the research permit and other required permits from the city of Helsinki during summer and fall 2020. A research consent was granted to the researcher in late 2020 by the Social and Health Care division of the city of Helsinki, and a collaboration agreement was signed by all parties involved, including the head of the Outpatient clinic, Metropolia University of Applied Sciences, and the researcher. Data collection and analysis was performed during first half of 2021.

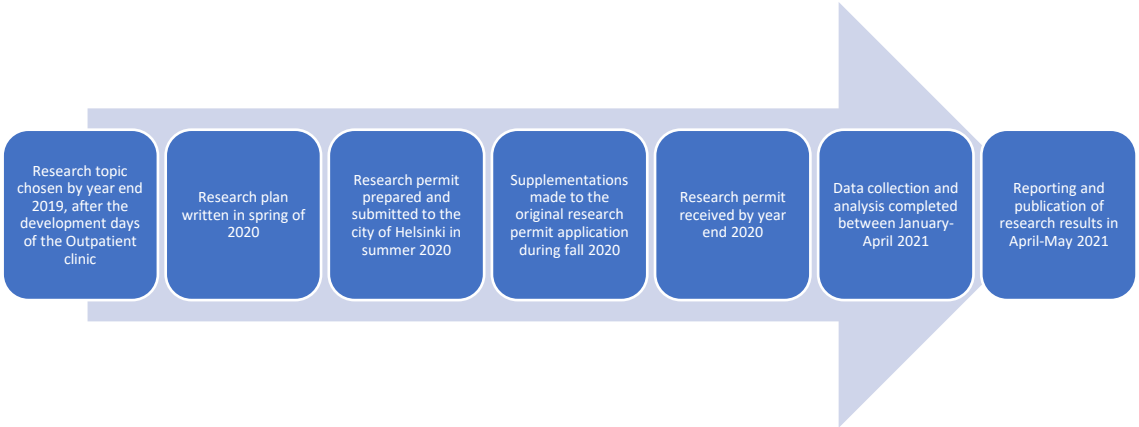

Figure 1. Research process.

Data collection was done retrospectively from data entries made in 2018-2019 and concerning data that was originally collected by the Outpatient clinic´ s personnel for organizing intensive medical rehabilitation for their pediatric customers. The given data collection period was chosen, as it was the time just before the outbreak of the Covid-19 pandemics, and it was the shared interest of the staff and the researcher to improve the understanding of the baseline situation regarding the clinic´s "normal" operations and practices, so that with the help of this improved understanding and sense making of the normal situation, it would be best possible to create "a knowing organization" and knowledge that would support later decision-making and organizational action, regarding the development of the process (compare to Choo 1998: 4).

The data collection was performed solely by the researcher and by using a researcher-designed data collection instrument (see Appendix 2). The use of the instrument allowed the accurate and objective inspection of the entire process and its different variables. During the data collection, the customer documentation that was originally collected in free writing format, was manually converted into quantified data. The variables included in this study mirror the fundamental elements of person-centered and timely care, such as the nature and degree of rehabilitee and caregiver involvement, cross-organizational collaboration, interdisciplinary teamwork, informational continuity as well as timeliness of service and continuity of care.

The data sample contained 50 randomly selected processes, forming a representative and agile subsample of the entire pediatric pool of customers of the Outpatient clinic. All persons, whose service processes were included in the data sample, had to meet the following inclusion criteria:

1) children and youth from birth and up to 17 years of age (adults excluded)
2) prior participation in the Outpatient clinic´s process involving the organization of the intensive medical rehabilitation, and possession of the related Kela rehabilitation decision, dated between January 1st to December 31st, 2019
3) availability of the Kela decision at the paper archives of the Outpatient clinic for use as the basis of the subsample calculation and for performing the random sampling

The total number of customers, who met the age inclusion criteria (from birth up to 17 years) and who had a documented Kela decision from 2019 in the paper archives of the Clinic, amounted to 289 rehabilitees. The random sample of 50 processes was calculated from this population. If some rehabilitees had more than one Kela-decision from

2019 in the paper archives, for example due to changes or add-ons made to the original rehabilitation plan, these decisions were counted as one and the same process, representing just one rehabilitee and/or process. Kela-rehabilitation processes of those rehabilitees, who were 18 years of age or older, were excluded from this study to the sample to represent only processes targeted for children and youth

5.2 Data analysis and reporting

After data collection, the data was analyzed by using SPSS and by utilizing mainly descriptive statistics, frequencies and crosstabulations. During the analysis, some of the data was recoded into new variables, to create for example appropriate age and day categories, to facilitate easier interpretations of the data.

During the data collection, analysis, and reporting, it became evident to the researcher, that there were some key background and process variables missing from the original data collection instrument. This concerned data regarding the number, duration and contents of the old rehabilitation plans as well as data regarding the initiation of the rehabilitation negotiations. Since this data was no personal data, but other background and process data, a decision was made to add it in the data collection and analysis, to allow relevant and appropriate description of the entire service process and the making of comparisons in between the old and the new rehabilitation plans. When analyzing and reporting results, data visualizations were added to support the comprehension of the results.

6 Results

In the following, the results of this master thesis study are presented. First, there is an introduction to the background data of the persons, whose rehabilitation planning processes were under study. After that, the reporting continues to cover the initiation of the rehabilitation meetings, the assessments of the rehabilitation needs, and the rehabilitation meetings held.

6.1 Background information

The information provided here includes background information about the children and youth in the data sample (n=50), regarding their age, daytime placements, and the contents and durations of their old rehabilitation plans. It serves as a background against which the rest of the research findings regarding the planning of the rehabilitation for the upcoming rehabilitation period are reflected.

The age of the rehabilitees ranged from 2-17 years. The mean age was 9,3 years and standard deviation for age was 3,8 years. The distribution of rehabilitees by their age is presented in Figure 2.

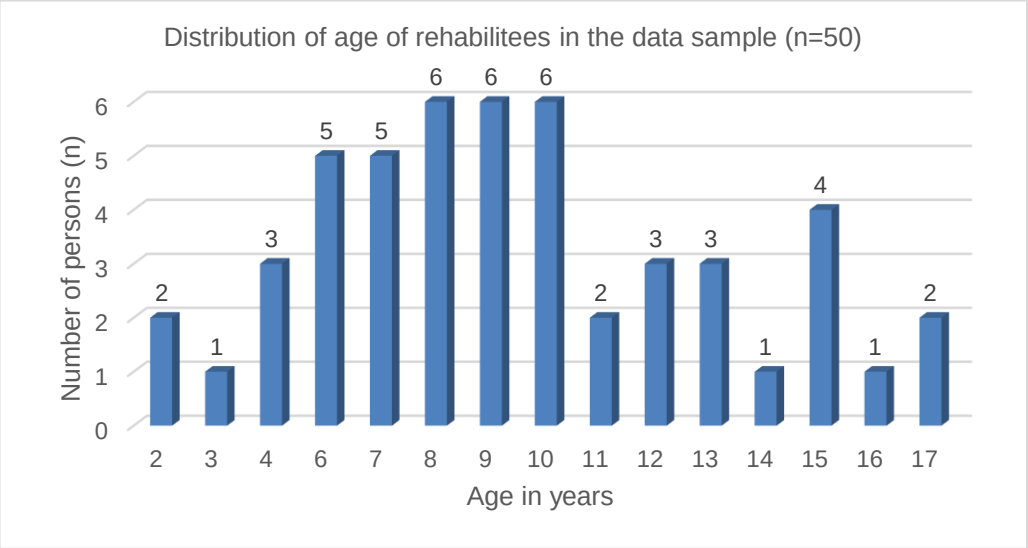

Figure 2. Distribution of age of the fifty rehabilitees, whose rehabilitation planning processes were under study in this master thesis.

To simplify the interpretation and the distribution of age, the rehabilitees were later grouped into four age categories (Figure 3.): infants and toddlers up to 2 years, children in early childhood from 3-5 years, children in middle childhood from 6-11 years and youth in early adolescence from 12-17 years. This classification is modified from age stages defined according to NICHD Pediatric terminology (Williams et al. 2012: 6). As it shows, over half of rehabilitees (n=30, 60%) belonged to the age group of 6-11 years and nearly third (n=14, 28%) belonged to the group of 12-17 years. Less than 10% belonged to the age categories of children up to 2 years (n=2, 4%) and 3-5 years (n=4, 8%).

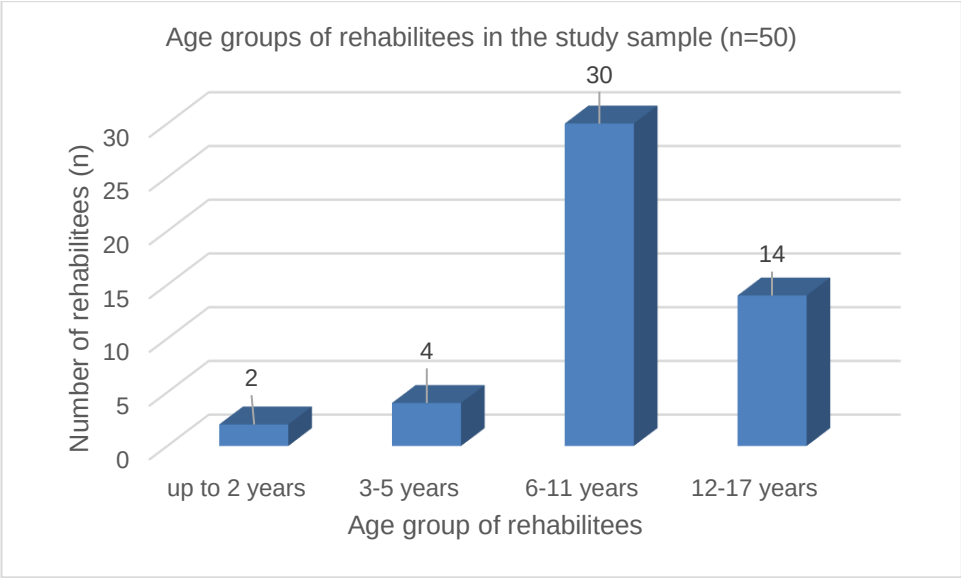

Figure 3. Distribution of age of rehabilitees in the study sample (n=50) using four age categories.

Regarding the daytime placements and activities of the rehabilitees (Figure 4.), majority of them were school-age children and children going to daycare.

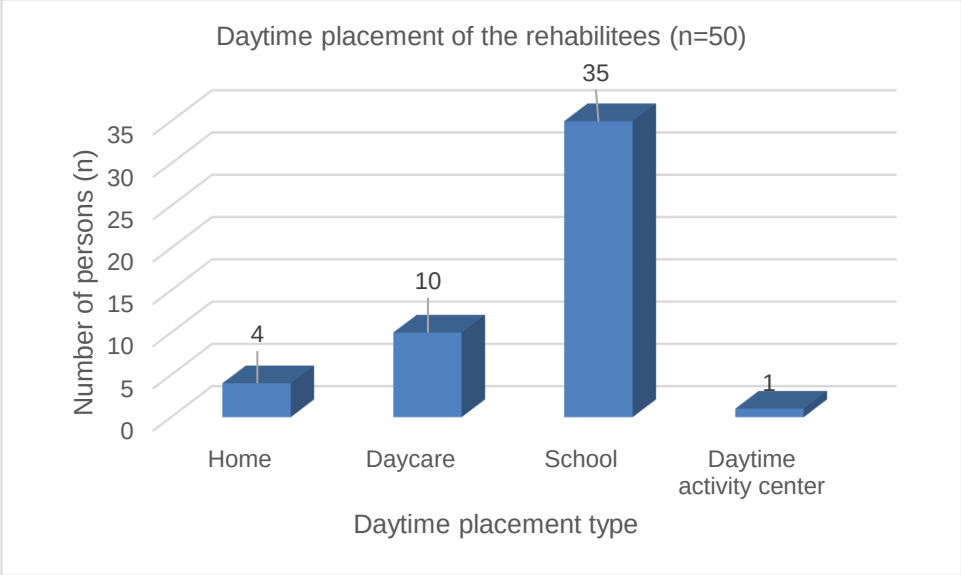

Figure 4. Daytime placement of the rehabilitees (n=50).

As it shows, the proportion of children and youth going to school during the day was 70% (n=35) and the proportion of children attending daycare was 20% (n=10). Four children (8%) were looked after at home (8%) during the day and there was one person (2%) going to the daytime activity center during the day.

Before the start of each new rehabilitation assessment and meeting process, most rehabilitees already had ongoing intensive medical rehabilitation, as shown in Figure 5. This

rehabilitation consisted mostly of physical therapy, occupational therapy and/or speech therapy, but could also include music, hydro, and equine-assisted therapy. The number of ongoing therapies varied from one rehabilitee to another, ranging from no therapies to three therapies at the most. The mean number of therapies was 1,56 and standard deviation was 0,76.

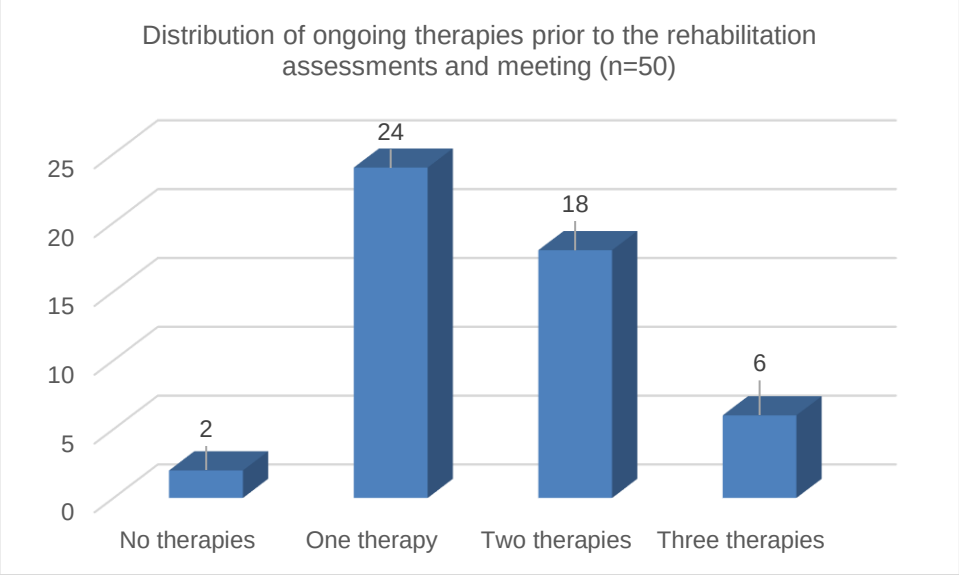

Figure 5. Distribution of the number of therapies among the rehabilitees, prior to the start of rehabilitation planning for the upcoming rehabilitation period.

As it shows, nearly half of the rehabilitees (n=24, 48%) had one ongoing therapy and just over third of rehabilitees (n=18, 36%) had two ongoing therapies before attending their upcoming rehabilitation assessments and rehabilitation negotiations. Minority of participants had either three ongoing therapies (n=6, 12%) or no therapies at all (n=2, 4%).

Starting from Figure 6., these different forms of ongoing therapies are presented one by one, starting with physical therapy and hydrotherapy, as a special form of physical therapy. This information about the individual therapies was included as a benchmark measure of sufficiency of the assessments of rehabilitation needs undertaken, contributing to the need-based, person-centered service.

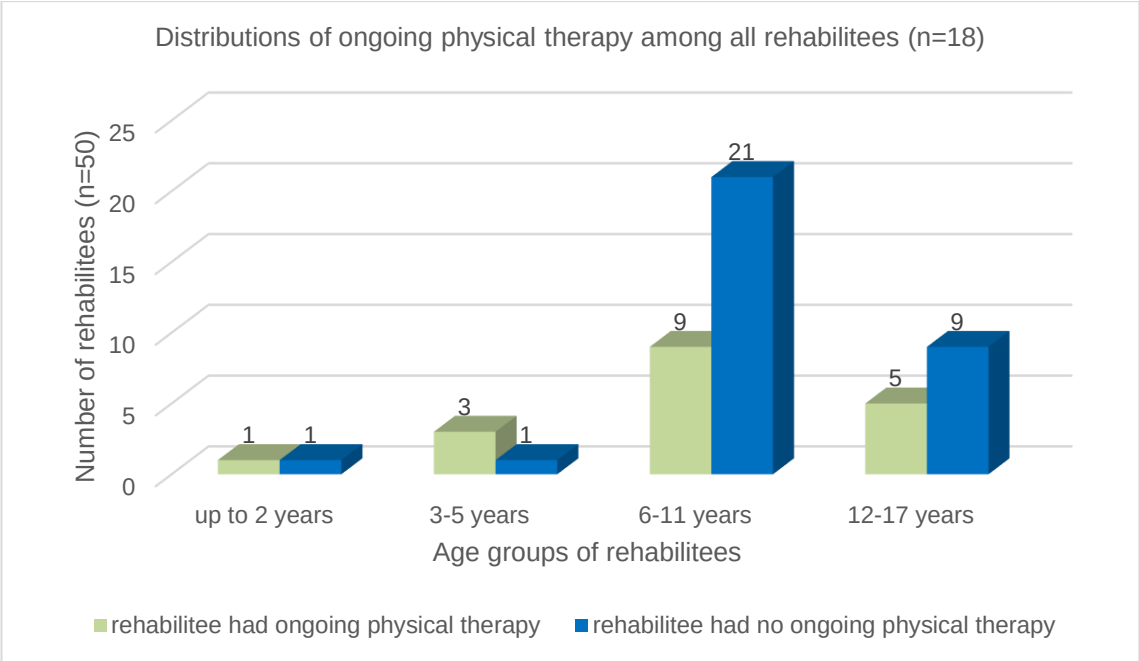

Figure 6. Distributions of ongoing physical therapy as a part of the rehabilitees´ intensive medical rehabilitation, prior to the assessments of further rehabilitation needs.

Out of the fifty persons in the data sample, there were 18 persons (36%) having physical therapy and 32 persons (64%) not having it as their intensive medical rehabilitation prior to their participation in the rehabilitation assessments and rehabilitation negotiations. Majority of the persons having it were between 6-11 years old (n=9, 50%) and 12-17 years old (n=5, 27,8%). In the younger age groups, there was only one person in the first age category (5,6%) and three persons (16,7%) in the 3-5-year age group having physical therapy.

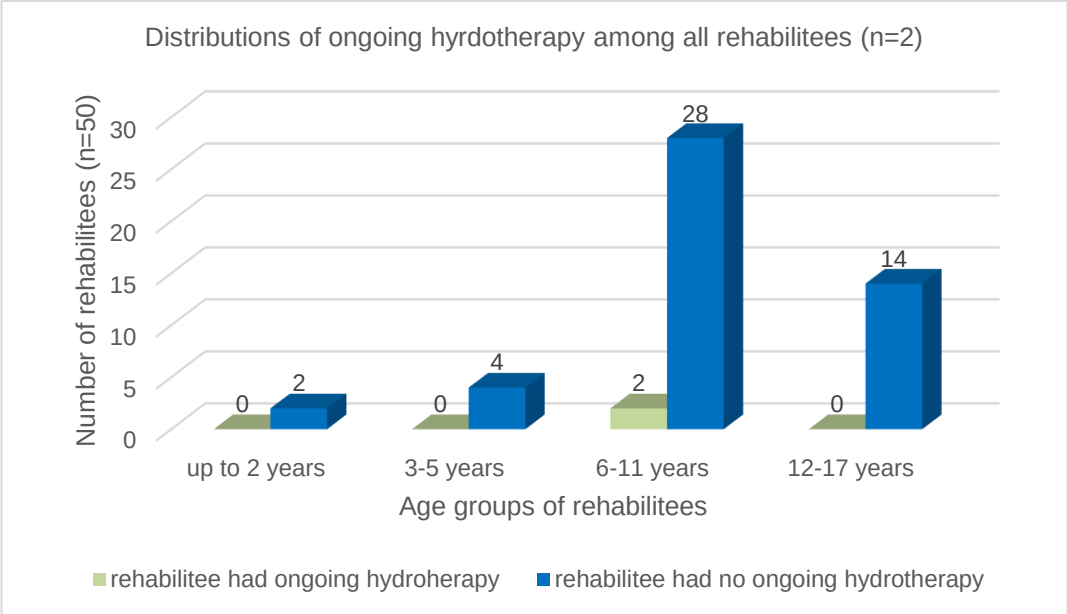

Figure 7. Hydrotherapy distributions by age groups, prior to the start of the assessment phase.

As shown in Figure 7., there were only two in 50 persons (4%) having hydrotherapy prior to their participation in the rehabilitation assessments and rehabilitation negotiation. Hydrotherapy was present (n=2) in only one age group, i.e., 6-11 years. In one of these two cases, hydrotherapy was ongoing as a side-therapy with physical therapy and in the other case, it was ongoing parallel to physical and occupational therapy.

Figure 8. shows the distribution of ongoing occupational therapy per all rehabilitees in the data sample. In total, there were 19 persons (38%) having occupational therapy prior to their participation in the rehabilitation assessments and rehabilitation negotiations later in the year.

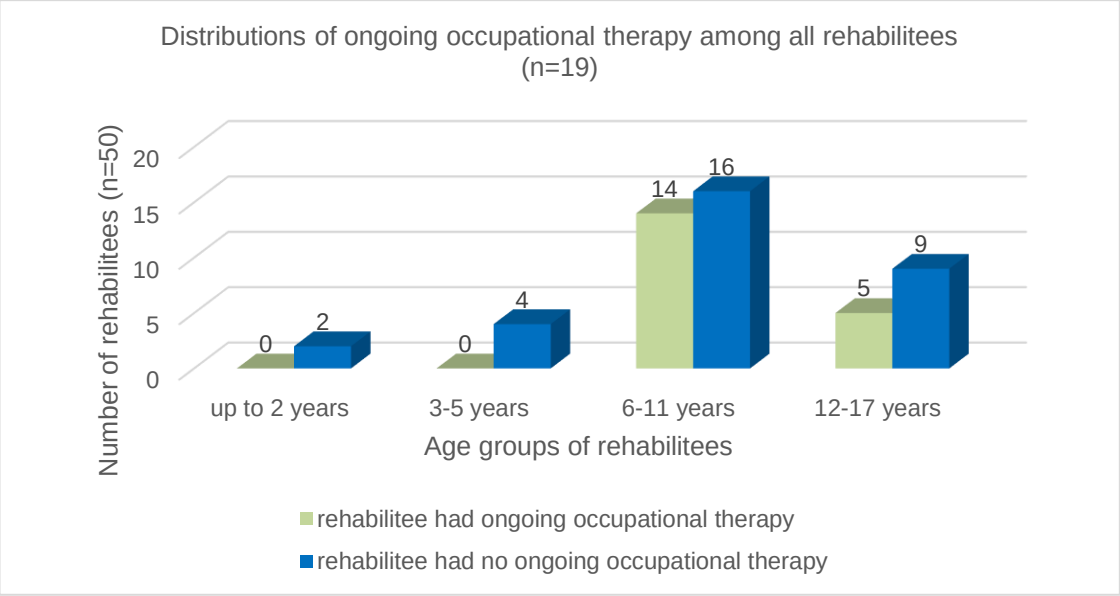

Figure 8. Distributions of ongoing occupational therapy among rehabilitees prior to the start of the new assessment and rehabilitation planning process.

Majority of the persons having occupational therapy were 6-11 years old (n=14, 73,7%). There were also five persons (26,3%) between 12-17 years of age having occupational therapy, but none in the two youngest age groups.

Next, there is a summary of the ongoing equine-assisted therapy (EAT) amounts of the rehabilitees in the data sample (Figure 9.). EAT is a special form of therapy, which can run as its own form of intensive medical rehabilitation, or as a sub-therapy under physical therapy or occupational therapy.

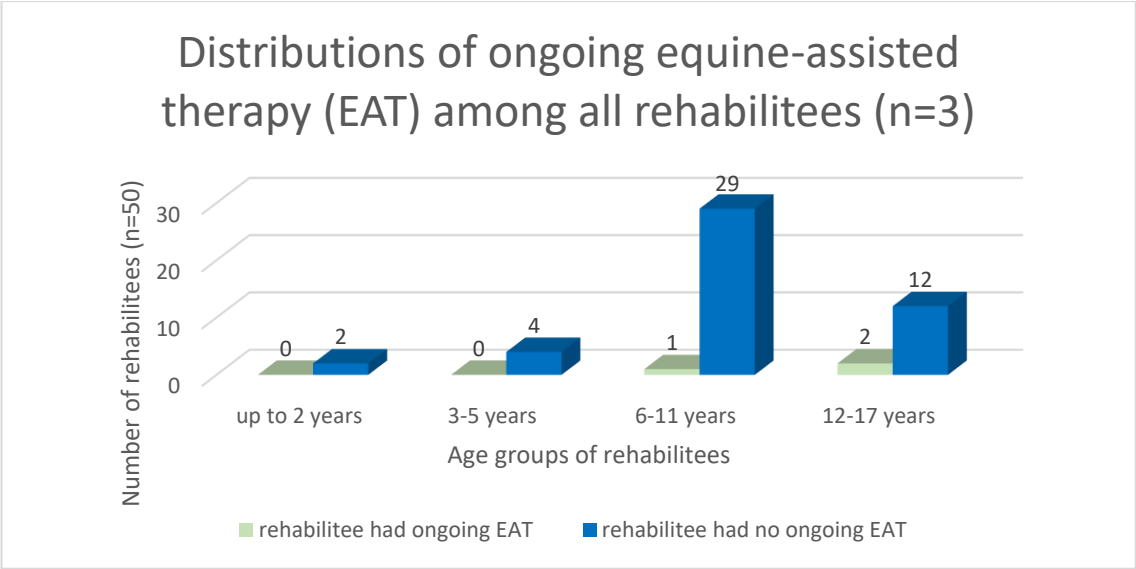

Figure 9. EAT distributions prior to the start of the assessment phase.

As it shows, there were three persons (6%) having ongoing EAT as their intensive medical rehabilitation prior to the assessments made, and two of these persons were in the age group 12-17 years and one in the age group 6-11 years.

Regarding the ongoing speech therapy distributions before the assessments undertaken, these are presented in Figure 10.

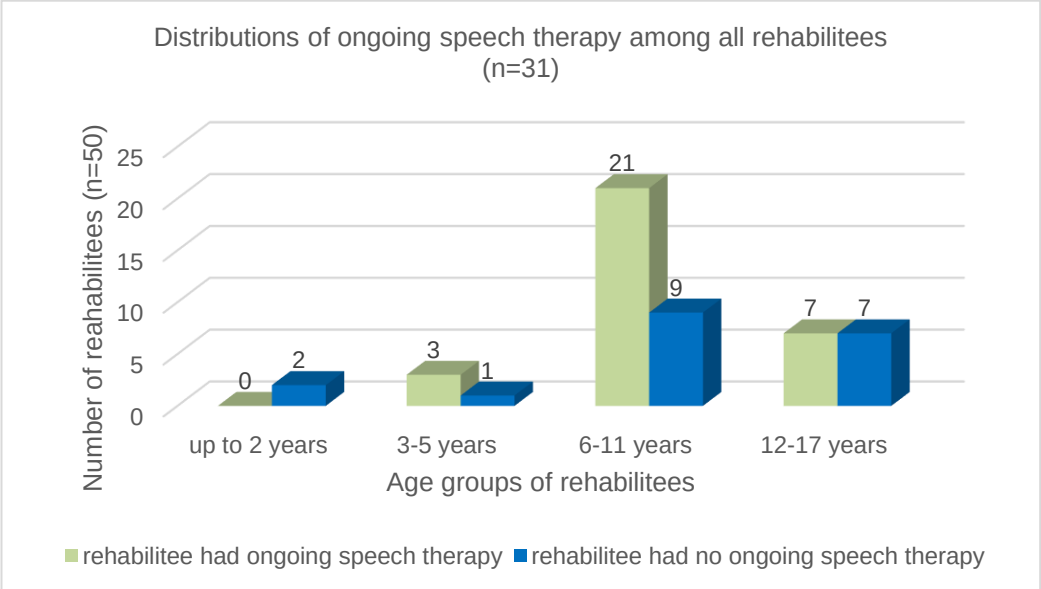

Figure 10. Distributions of ongoing speech therapy as a part of the rehabilitees´ intensive medical rehabilitation, prior to the assessments made.

There were 31 in 50 persons (62%) having speech therapy prior to their participation in the rehabilitation needs´ assessments and rehabilitation negotiations. Majority of these

persons were between 6-11 years (n=21, 67,7%) and 12-17-years of age (n=7, 22,6%), while in the younger age groups, there were only three persons in the 3-5-year age category having speech therapy (9,7%).

Out of the fifty persons in the data sample, there were five persons (10%) having music therapy as their ongoing intensive medical rehabilitation, before the assessments and negotiations held. These persons belonged to the two of the eldest age groups, as detailed in Figure 11., showing that there were three persons in 6–11-year group and two persons in the 12-17-year group having music therapy.

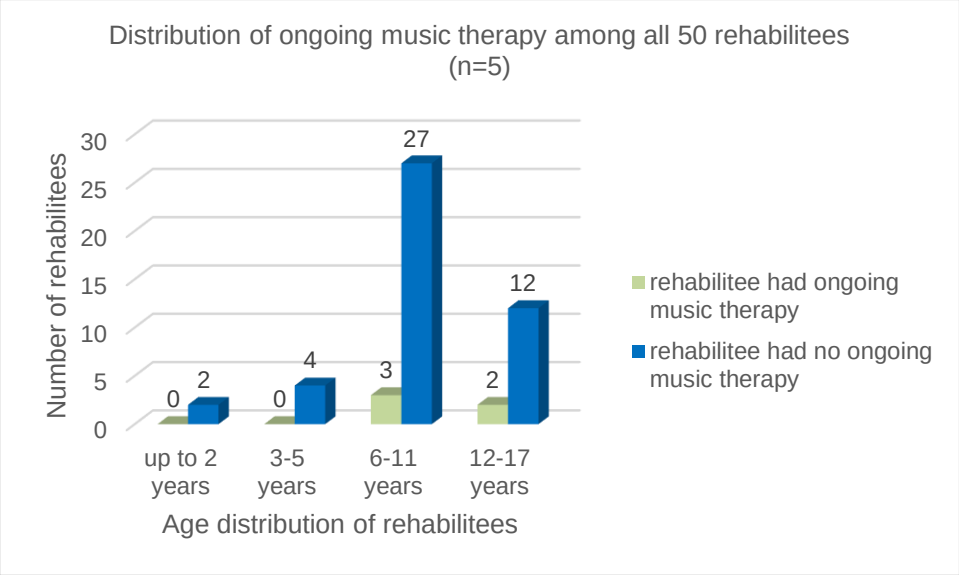

Figure 11. Distribution of ongoing music therapy among all rehabilitees in the study sample.

After knowing the distributions of the ongoing therapies among all rehabilitees, next there is an overview of the lengths of the old rehabilitation plans of the rehabilitees, which were valid before and during the rehabilitation assessments and meetings held, the plans ranged from no plan at all to 2-year plans. (Figure 12).

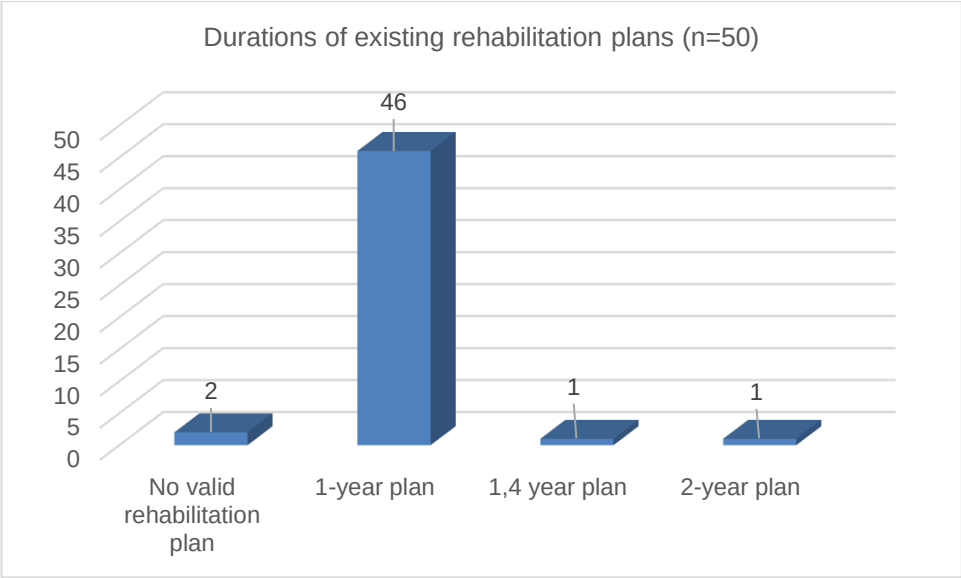

Figure 12. Durations of the existing rehabilitation plans in the study sample, prior to any rehabilitation assessments made or rehabilitation meetings held.

Majority of the rehabilitation plans had been made for 1 year (n=46, 92%). There was one person (2%), whose rehabilitation plan was for 1 year 5 months and another person (2%), where the plan was for 2 years. Out of the 46 persons with a 1-year plan, one had different lengths for different therapies at the time of the assessments and rehabilitation meeting. There were only two persons (4%), who had no prior rehabilitation plan prior to the new rehabilitation assessment and meeting process. One 11-year-old had been having two therapies previously, but partly funded by the city of Helsinki and partly at own cost. One 2-year-old had no rehabilitation plan documented but had been participating in the special rehabilitation program called “vartu”, before attending the rehabilitation meeting.

Regarding the expiry months of the old 48 rehabilitation plans, nearly every fifth of them (n=12, 25%) expired in December 2019. Other common rehabilitation plan expiry months in 2019 were July (n=7, 14,6%), January (n=5, 10,4%) and May (n=5, 10,4%), as shown in Figure 13.

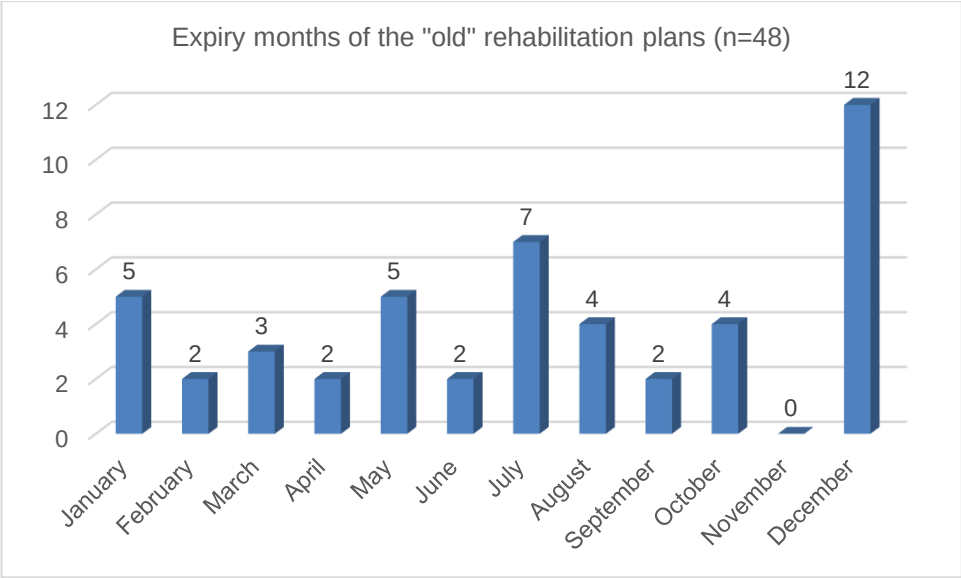

Figure 13. Expiry months of the “old” rehabilitation plans, prior to the rehabilitees participating in their rehabilitation needs´ assessments and rehabilitation negotiation meeting later in the year.

Next, the research findings concerning the assessments of rehabilitation needs are presented one therapy at a time, while reflecting the practices against the principles of person-centered and timely care.

6.2 Assessments of rehabilitation needs

Before looking at the research results, the term assessment used in the context of this study is defined. Assessments were considered any proactive inquiries made by telephone or by visiting the rehabilitee in-person, which produced some relevant information concerning for example the status of the rehabilitee, the progress in the ongoing therapies, or other valuable, rehabilitation related information gained through conversations with the rehabilitees and/or people closest to them. In addition, another assessment category titled “other assessment methods” was added later, to represent the few internal and external consultations held during the assessment phase.

The reason for the distinction between phone calls and visits was that it allowed the evaluation of direct and indirect rehabilitee participation, thereby providing information about rehabilitee involvement in their own assessments. Assessments made by telephone were later divided into phone calls targeted to parents and providers, as those two categories fit all assessment calls documented by the personnel. There were no phone calls reported to the rehabilitees, so this group was excluded from this category.

The in-person visits were divided into appropriate groups, based on the location of assessments. All the assessments were carried out by the therapists and psychologists of the Outpatient clinic, who are the persons responsible for the making of the rehabilitation recommendations for the rehabilitees, as members of the rehabilitees´ interdisciplinary rehabilitation teams.

First, there is an overview of all assessments made, and after that, the assessments are presented in more detail, one therapy and health professional group at a time, including assessments undertaken by physical therapists, occupational therapists, and speech therapists. Since there are no in-house music therapists working at the Clinic, the music therapy assessments described in this study relate to the assessments made by the clinic´s in-house psychologist.

Table 2. gives an overview of the total number and nature of assessments made in all therapies both individually and combined, in relation to the number of persons who were assessed per each type of therapy.

Table 2. Distribution of total number and nature of rehabilitation needs´ assessments made, per each type of therapy, performed by all the health care personnel of the Outpatient clinic.

	Type of therapy / number of persons assessed (n)					
Nature and number of assessments made	**Physical therapy and Hydrotherapy / 23 persons**	**Occupational therapy / 21 persons**	**Equine-assisted therapy / 3 persons**	**Speech therapy / 38 persons**	**Music therapy / 4 persons**	**Total number of assessments made (n)**
Number of assessments made by telephone (n)						
to parent	8	3	3	16	1	31
to provider	12	16	3	24	3	58
Total:	***20***	***19***	***6***	***40***	***4***	***89***
Number of in-person assessment visits (n)						
Home visit	8	1	-	6	-	15
Group home visit	1	-	-	-	-	1
Daycare visit	4	3	-	8	-	15
School visit	6	4	1	24	-	35
Daytime activity center visit	-	-	-	-	1	1
Visit to Outpatient clinic	1	-	-	-	-	1
Visit to therapy provider premises	2	-	1	-	-	3
Pool visit	1	-	-	-	-	1
Horse stalls	-	-	-	-	-	0
Total:	***23***	***8***	***2***	***38***	***1***	***72***
Total number of assessments (n)	***43***	***27***	***8***	***78***	***5***	***161***
Other assessment methods used						
Internal consultation	-	2	-	-	1	3
External consultation	-	-	-	-	1	1

In the following, there are more detailed descriptions of the assessments made per each health professional group and per each therapy.

6.2.1 Physical therapy and hydrotherapy

In total, there were 23 persons (46%), who were documented some form of assessment done by the physical therapists of the Outpatient clinic, before the rehabilitation negotiations. These included all those persons, who had ongoing physical therapy (n=18), out of who also two had ongoing hydrotherapy. On top of that, there were five more persons assessed based on new assessment needs. The assessments included both proactive phone calls to parents and therapy providers as well as in-person visits to homes, group homes, daycares, schools, therapy provider premises and therapy pools.

Next, there is a breakdown of how the total number of assessments done to the 23 rehabilitees by physical therapists, divided between phone calls and in-person visits. Assessments done by telephone (Figure 14.) were documented for 14/23 persons. Out of the persons called, eight persons were inquired about once and six persons twice. Nine out of the 23 assessed rehabilitees were not made any assessment inquiries by telephone.

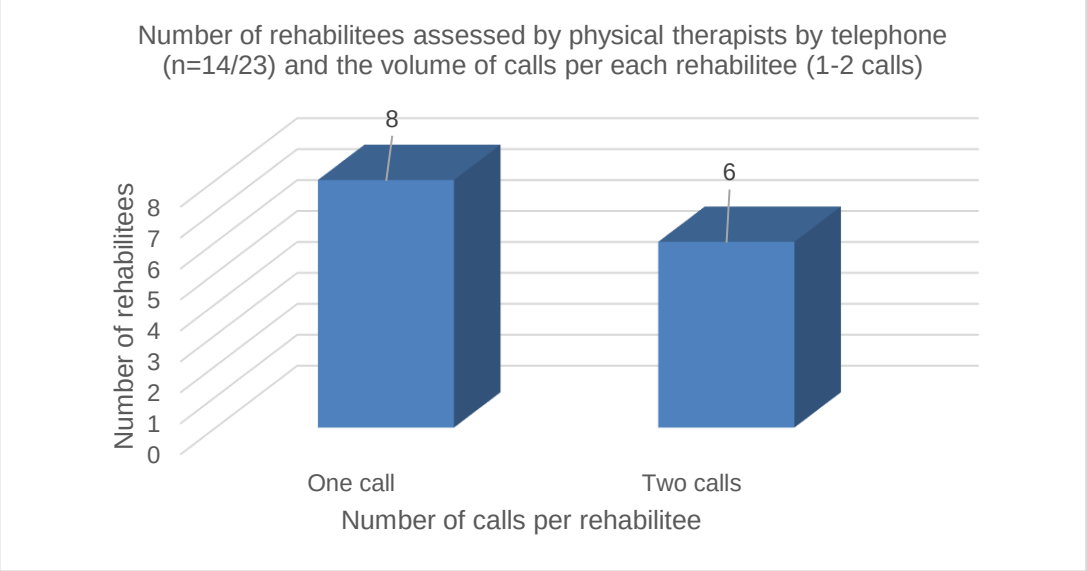

Figure 14. Number of persons assessed by telephone and the volume of these assessments.

Regarding the distribution of assessments made in-person in different life settings (n=18), over half of these assessments (n=14) involved one onsite visit and minority two

(n=3) or three onsite visits (n=1) per rehabilitee (Figure 15.) Out of all the 23 persons assessed, there were five persons, who had no assessments made in-person.

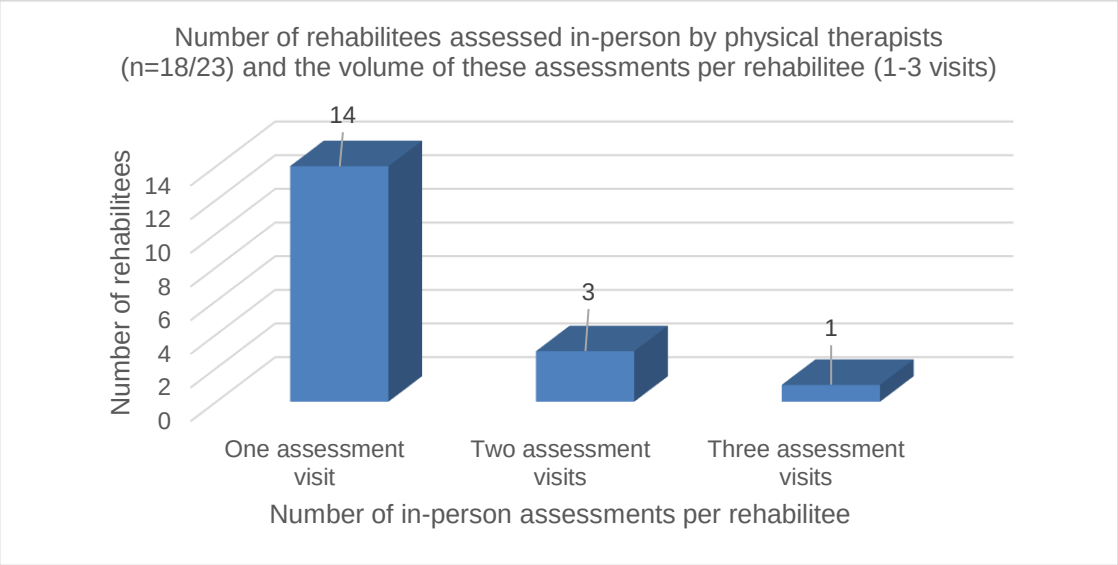

Figure 15. Number of persons assessed in-person and the volume of these assessments.

Next, a closer look is taken at the nature of the telephone assessments (Figure 16.) and visits made in-person (Figure 17). The total amount of assessment phone calls (n=20) was divided into calls to therapy providers (n=12) and parents (n=8). Since there were 14 persons whose assessments involved phone calls, the number of calls per rehabilitee ranged from 1-2 per rehabilitee, as shown previously in Figure 14.

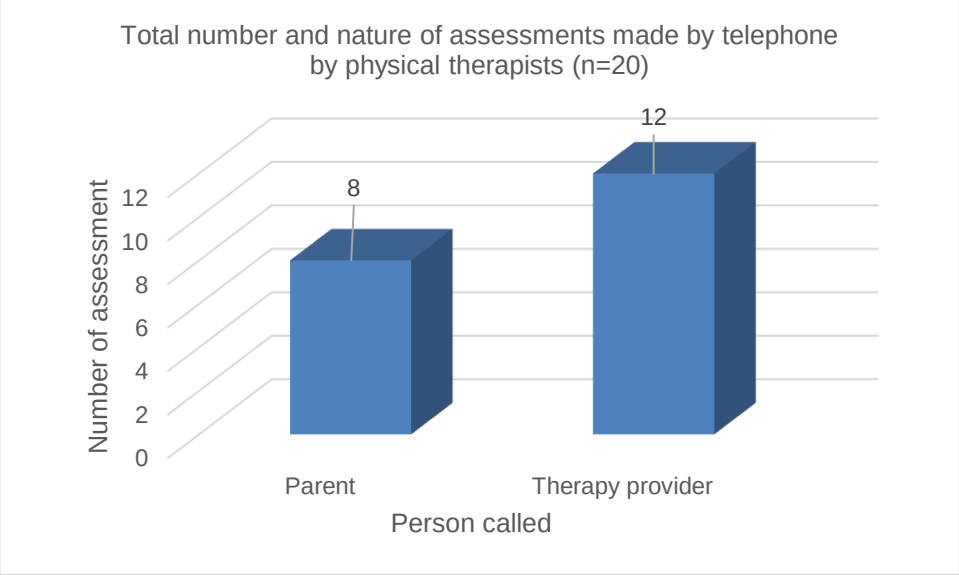

Figure 16. Total number and nature of assessment phone calls made from physical therapy.

The nature and number of assessments done in-person to everyday life settings of the rehabilitees, are presented next in Figure 17.

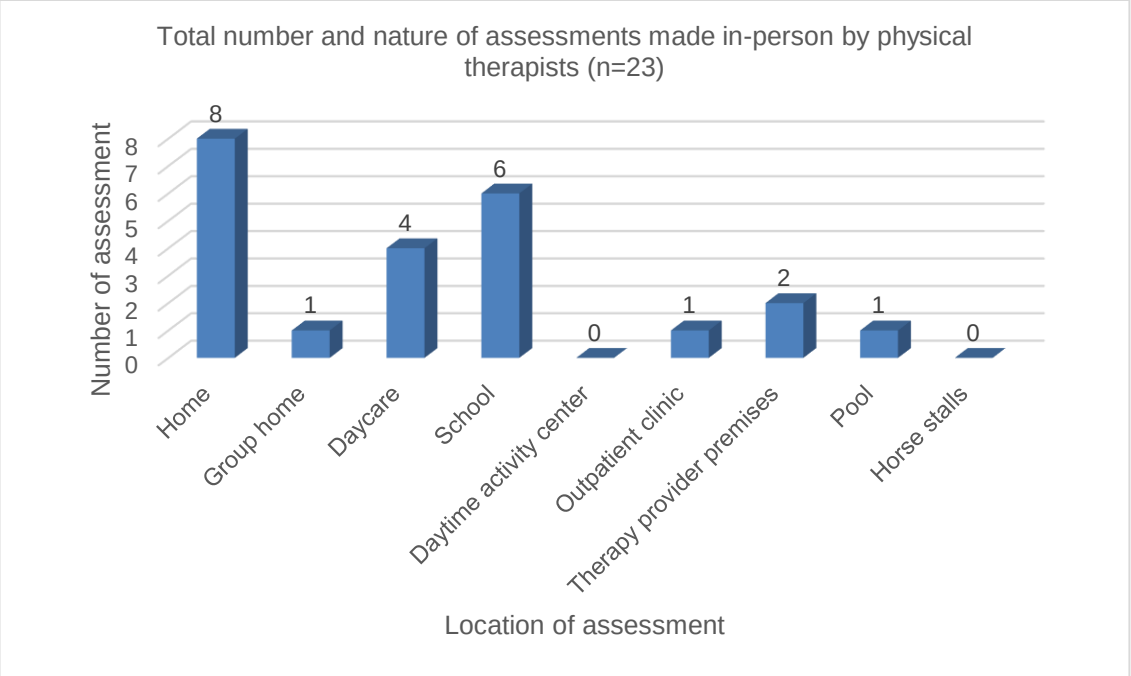

Figure 17. Total number and nature of assessments made in-person from physical therapy.

As it shows, there were in total 23 assessment visits made from physical therapy. The number of visits per each visited rehabilitee (n=18) varied from 1-3 visits, as shown previously in Figure 15. Majority of the visits were home, school, and daycare visits.

Out of all rehabilitees, who were assessed in-person (n=18), all persons having ongoing physical, or hydrotherapy were assessed in collaboration with the rehabilitees´ physical therapy providers (n=14), as shown in Figure 18. There were two assessments performed as own, independent visits, without the involvement of a physical therapy provider nor a colleague. There were also two assessments done to two “vartu”-program rehabilitees, out of which one included a home visit with a speech therapist colleague and a home visit with a physical therapy provider, and the other a home visit with a speech therapy colleague and an independent visit.

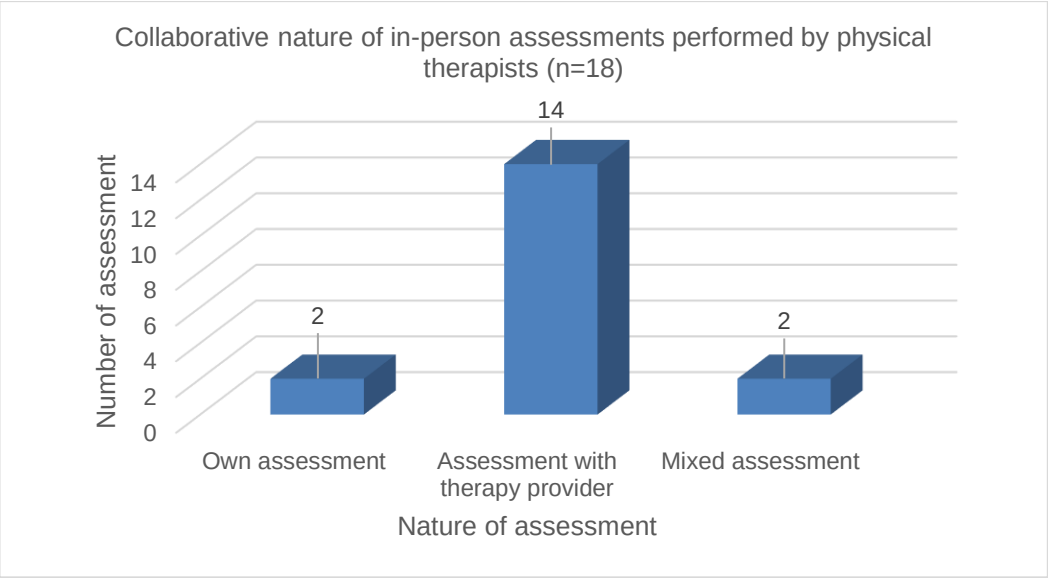

Figure 18. Collaborative nature of the assessments made in-person by physical therapists.

Next, there is a more in-depth description of the persons present during the in-person assessments made by physical therapists, including both internal and external representatives (Figure 19.). The notion stating “not applicable” indicates that the type of representative given was not an option for that rehabilitee, due to reasons like being at day-care instead of school, living at home instead of group home, or not having physical therapy ongoing at the time of the assessment made. These reasons would naturally result, as not applicable alternatives, from the viewpoint of the rehabilitee.

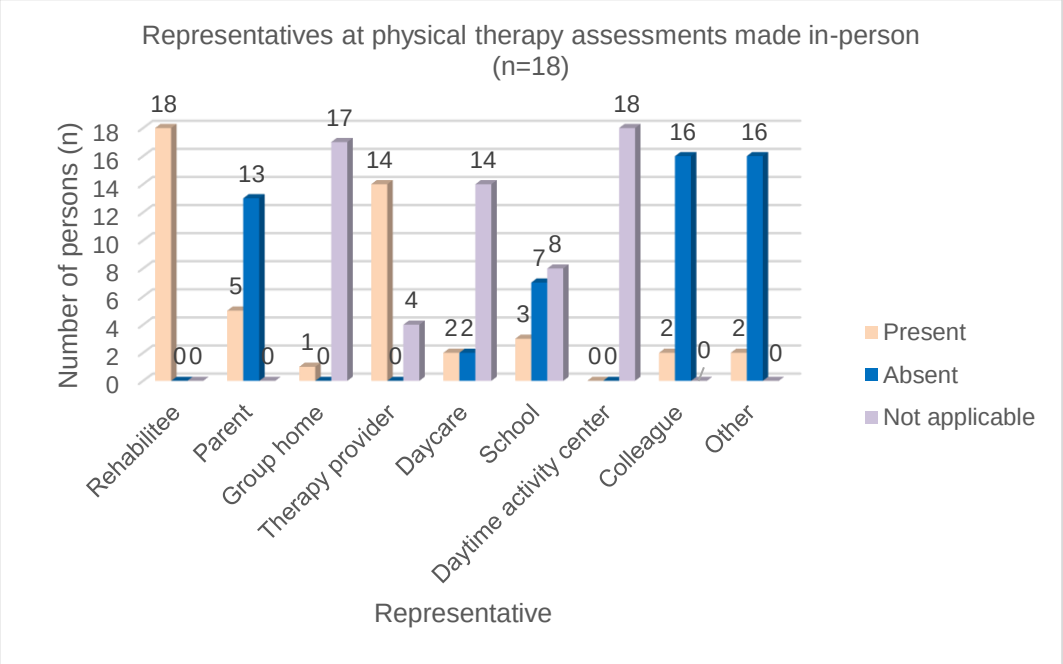

Figure 19. Description of the representatives, who were present or absent at the in-person assessments carried out by physical therapist.

As it shows, all in-person assessments (n=18) were performed with the rehabilitee present, showing high person-centeredness from the perspective of rehabilitee involvement. Parents of the rehabilitees were present in about a third of all in-person assessments made (n=5/18), showing lower engagement and involvement during the onsite assessments. Since most children and youth resided at home, group home personnel had a minority representation in these figures, showing only one representation out of 18 assessments.

Regarding the collaboration over organizational boundaries and participation of the private physical therapy providers in the in-person assessments, they were present in all 14 applicable cases, and absent from those four assessments where the rehabilitee had no ongoing physical therapy.

Regarding daycare and school personnel participation in the assessments done in daycare and school settings, daycare personnel was present in two and absent in two cases (out of four applicable cases). The representation of daycare personnel included early childhood education teachers and daycare assistants. School personnel was present in three and absent in seven cases (out of 10 applicable cases) and their representation involved only the teachers of the rehabilitees. None of the rehabilitees, who were assessed in-person by physical therapists, spent their days in a daytime activity center. There was no cooperation done with social workers or translators during the physical therapy assessments. The involvement of “others” in the assessments included other pupils from school settings.

Regarding interdisciplinary cooperation, two out of the 18 in-person assessments were made together with a colleague, and in both cases, this involved the Outpatient clinic´s speech therapist. This is natural, concerning the clinics early rehabilitation program called “vartu”, targeted for families with young children with special needs, which is service typically provided by a physical and speech therapist as a working couple.

To conclude, all rehabilitees receiving physical therapy (n=18) or hydrotherapy (n=2) under the old rehabilitation plan, were assessed by telephone or by in-person visits before their upcoming rehabilitation negotiations, showing high responsiveness to the need to assess them before the renewal of the rehabilitation plans. Out of all persons assessed (n=23, 46%), majority (n=18, 78,3%) were assessed in-person and minority (21,7%) using a phone call inquiry only, targeted to the parent or the therapy provider. Out of the 18 persons assessed in-person, majority (n=14, 77,8%) were paid one visit. The rehabilitees

were present in 100% of the assessments made in different life settings, showing high level of rehabilitee involvement. The level of parental involvement remained below 30% in all in-person assessments. A common assessment method was the use of collaborative visits to different therapy settings with the private therapy providers. Collaboration with other external personnel, such as daycare and school personnel remained lower, between 30-50%. There was no co-operation done with the social workers or translators during the assessments and the level internal, interdisciplinary teamwork remained low (11,1%).

6.2.2 Occupational therapy

Next there is an overview of the number and nature of the assessments made by occupational therapists. In total, there were 21 persons (42%), who were assessed by an occupational therapist before the rehabilitation meetings. These included all but two of the 19 persons having ongoing occupational therapy at the time. For the ones missed, one was documented that the assessment was based on the written feedback report received from the private occupational therapy provider, and for the other it was documented, that there was no assessment made due to lack of time. From the ones who had no ongoing occupational therapy, three persons were assessed based on varying reasons, such as parent´s wish for assessment, horse-riding therapy trials and having had a period of occupational therapy financed by the city of Helsinki. The assessments included telephone calls mostly to the therapy providers and a few parents as well as in-person visits to homes, daycares, and schools.

Next, there is a breakdown of the number of assessments done to the 21 persons by the occupational therapists, dividing them between phone calls and in-person visits. Assessments done by telephone were documented for 15/21 persons, as shown in Figure 20. Majority of persons were made only one assessment call (n=11) and minority two calls each (n=4). There were 6 in 21 persons, who had no telephone inquiries documented during the occupational therapy assessments made.

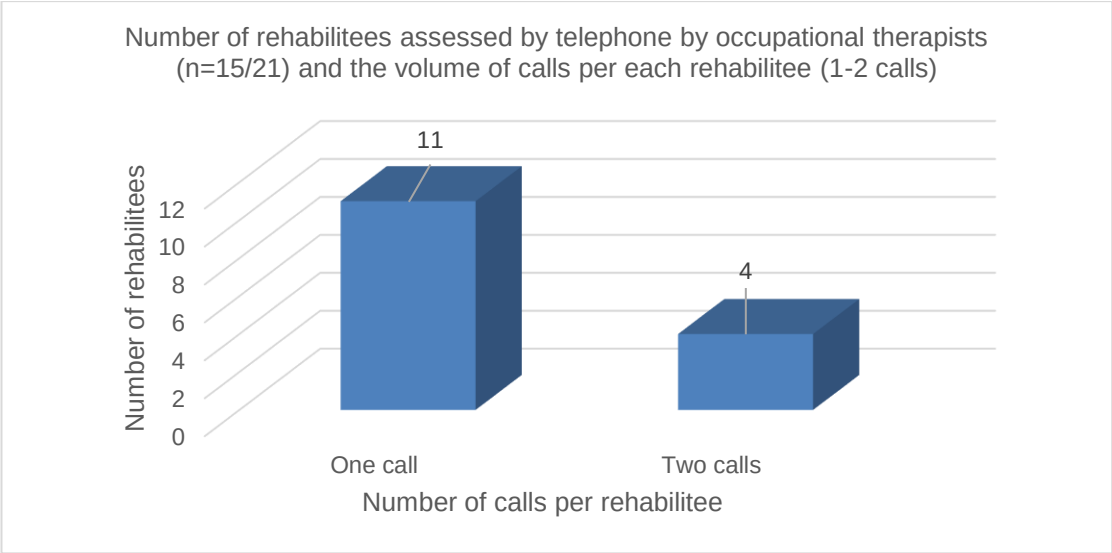

Figure 20. Number of persons assessed by telephone and the volume of these assessments.

Regarding the distribution of assessments made in-person from occupational therapy (n=7), majority of these involved one onsite visit per rehabilitee (n=6) and minority two onsite visits per rehabilitee (n=1), as shown in Figure 21. Out of all the 21 persons assessed, there were 14 persons (66,7%), who had no assessments made in-person.

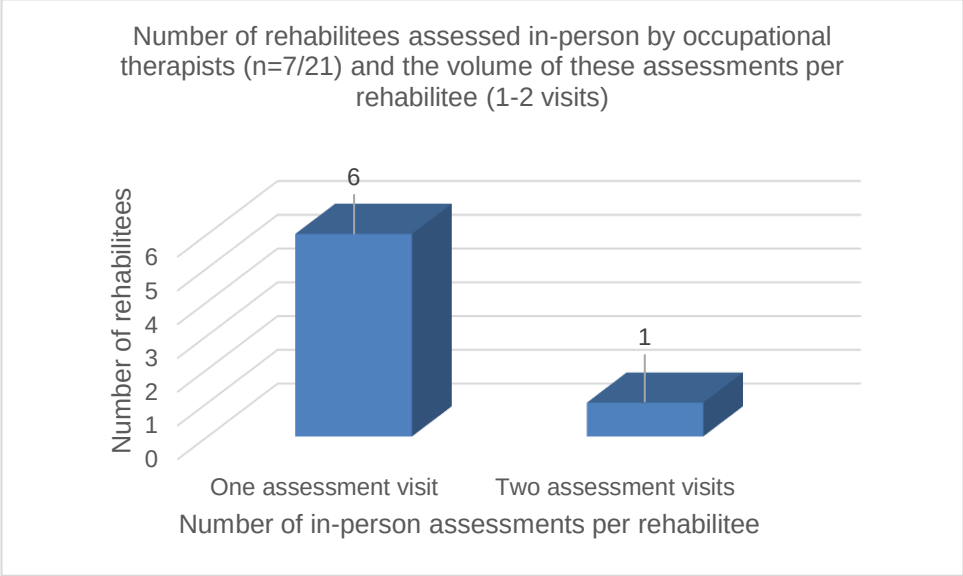

Figure 21. Number of persons assessed in-person and the volume of these assessments.

Next there is a closer look taken at the nature of the calls and visits made from occupational therapy. As shown in Figure 22., majority of the telephone assessments were targeted to the therapy providers (n=16/19), and minority to the parents (n=3/19) of the rehabilitees. Since the total number of calls made from occupational therapy amounted

to 19, and there were 15 persons assessed by telephone inquiries, the number of calls per rehabilitee ranged from 1-2 per person.

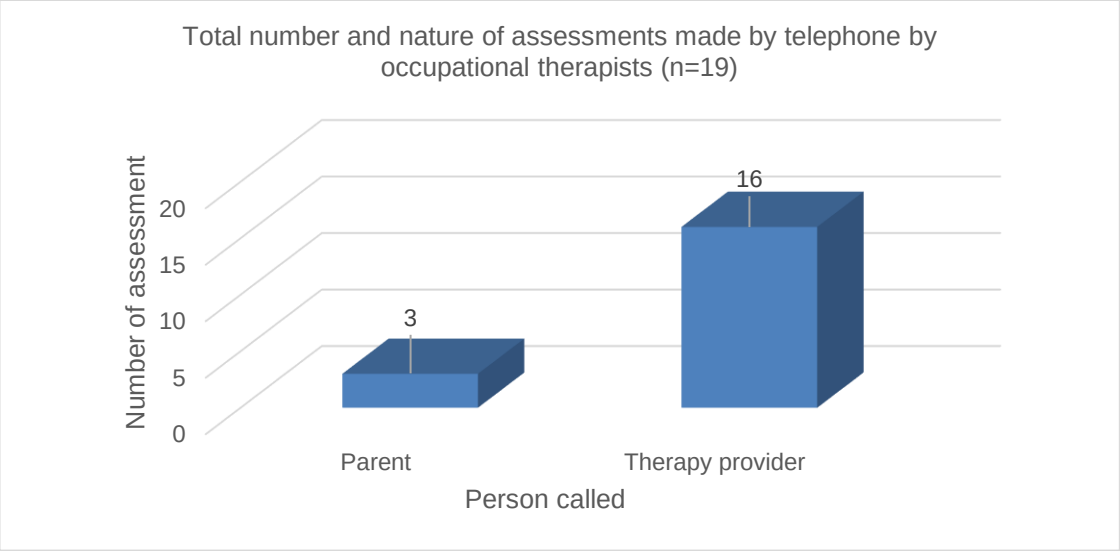

Figure 22. Distribution of the number and nature of assessment calls made from occupational therapy.

Next, the nature and number of assessments done in-person, by the occupational therapists in different settings are presented in Figure 23.

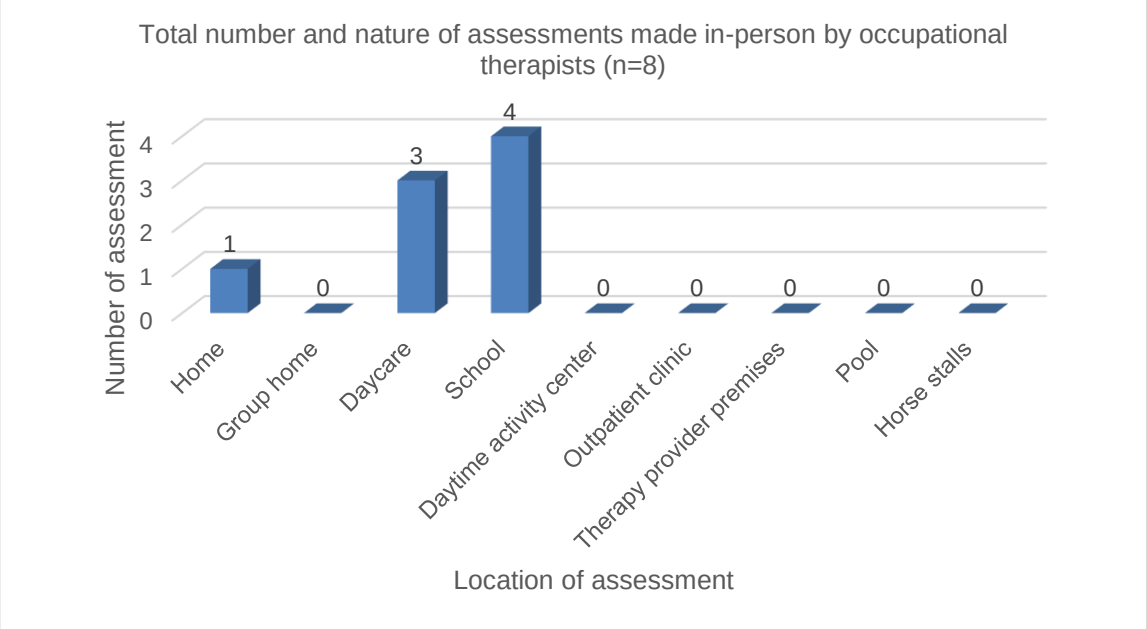

Figure 23. Total number and nature of assessments made in-person from occupational therapy.

As it shows, there were in total 8 assessment visits made from occupational therapy. The number of visits per each visited rehabilitee (n=7) ranged from one (n=6) to two (n=1)

visits, as shown previously in Figure 21. Visits were done to schools, daycares, and homes.

On top of the assessment calls and visits, there were also two cases, where the assessments involved other form of collaboration, being internal consultations among colleagues.

Out of the seven rehabilitees, who were assessed using the in-person visits to different life settings, two were assessed in co-operation with the occupational therapy providers and two with colleagues. There were three assessments carried out as own, independent activity, but including discussion with a representative from the rehabilitee´s daily environment, as shown in Figure 24.

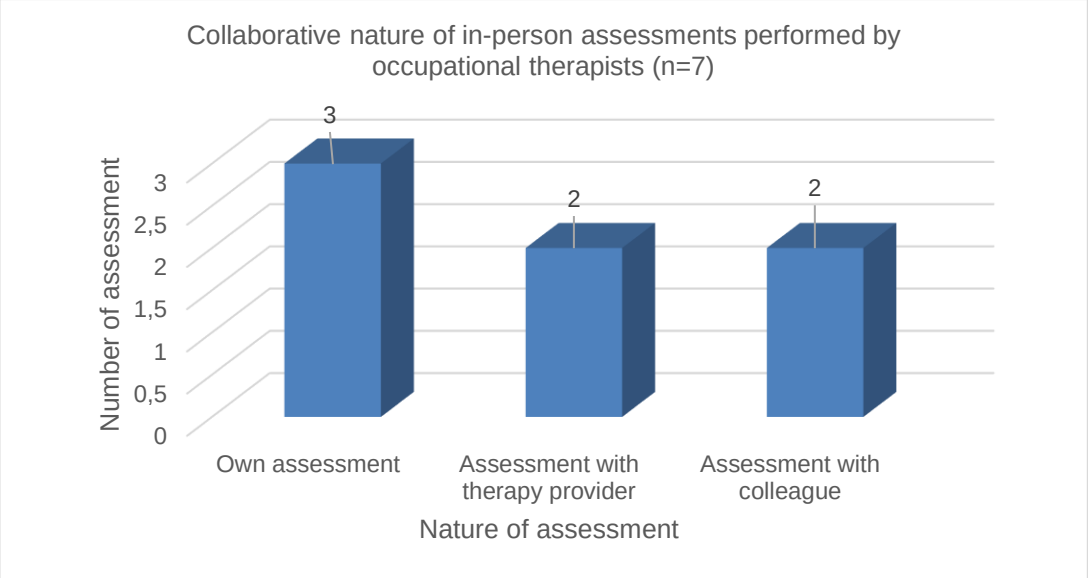

Figure 24. Distribution of in-person occupational therapy assessments by their nature.

Next, there is a more in-depth description of the persons, who were present or absent at the occupational therapy assessments made in-person, including both internal and external representatives (Figure 25.). These figures also distinguish weather each participant is applicable for each rehabilitee.

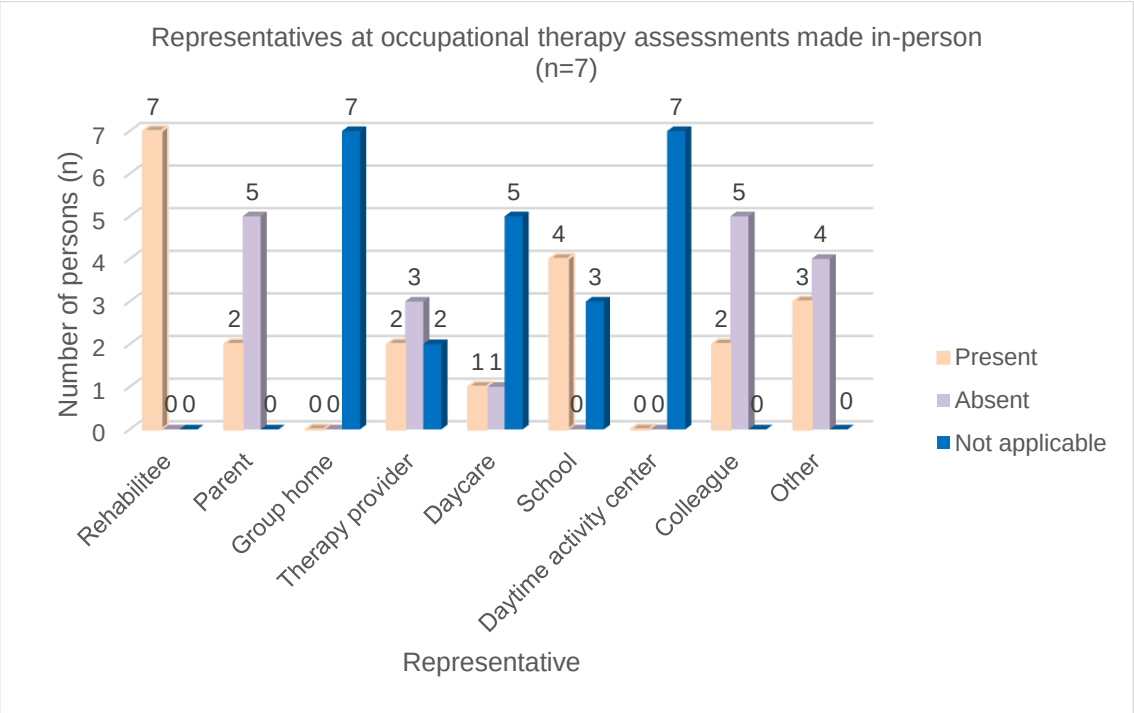

Figure 25. Representation of the people present or absent in the occupational therapy assessments made in-person.

As it shows, all in-person assessments (n=7) were performed with the rehabilitee present. Parents of the rehabilitees were present in about a third of all in-person assessments made (n=2/7). Group home personnel had no representation in these figures, as all rehabilitees resided at home.

Occupational therapy providers were present in two out of seven cases, absent in three cases out of seven cases, and the remaining two persons had no ongoing occupational therapy at the time of the assessment, thereby showing as not applicable.

Regarding daycare and school personnel participation in the assessments done, out of the seven rehabilitees assessed, two were children going to daycare and five going to school. Hence, the involvement of daycare personnel remained low, showing presence and absence one time for each, rest being non-applicable. The representation of daycare personnel included an early childhood education teacher. School personnel was present in all four assessments made in school settings. School personnel representation included teachers (n=3) as well as teacher and assistant (n=1). None of the assessments were undertaken in daytime activity centers, thereby showing zero representation. Neither was there any cooperation with social workers or translators during the occupational

therapy assessments. There was some representation of “other” people in the assessments (n=7), being other children from daycare (n=1) and other pupils from school settings (n=6).

Regarding interdisciplinary cooperation in the occupational therapy assessments, this remained at 28,6%, indicating that two out of the seven assessments were made collaboratively with Outpatient clinic´s occupational therapy student interns. There were no in-person visits done with other therapists with different specialty fields.

To conclude, out of all the rehabilitees having occupational therapy (n=19, 38%) under the old rehabilitation plan, all but two were assessed before their rehabilitation meetings. Assessments were performed to 21 persons in total (42%), and majority of them (71,4%) were assessed by telephone and minority (33,3%) using an in-person visit, indicating more indirect rehabilitee involvement than direct. Also, family involvement in the in-person assessments remained at 28,6%, and assessments by telephone were made to the private therapy providers more often than the parents. The collaborative assessment visits made together with the therapy providers were limited to two of the seven in-person assessments made. Collaboration with daycare personnel was done in 50% of the assessments made in daycare settings, but school personnel was involved in 100% of assessments made in school settings. There were no assessments made by occupational therapists in daytime activity centers and there was no co-operation done with the social workers or translators during the assessments. The level of internal teamwork remained low.

6.2.3 Equine-assisted therapy

Regarding the assessments of EAT needs, all assessments were done by the clinic´s physical therapists, and there were no assessments made in the actual therapy settings (i.e., horse stalls). In the first of the three cases, EAT was the only ongoing intensive medical rehabilitative therapy for the customer, performed under a licensed physical- and EAT therapist. Assessment was done by the physical therapist of the Outpatient clinic, by telephone calls to the parent and the therapy provider, thereby having no direct rehabilitee contact nor involvement in the assessment phase.

In the second case, EAT ran parallel to physical therapy and occupational therapy. It was provided to the rehabilitee by a private physical- and EAT therapist, and therefore, was assessed by the Outpatient clinic´s physical therapist, via phone calls to parent and the

therapy provider. In addition, the physical therapist had met with the customer in-person during an earlier school visit, thereby showing some evidence of direct rehabilitee involvement in the assessment.

In the third case, EAT ran parallel to physical therapy and it was assessed by the clinic´s physical therapist by phone calls to parent and physical therapy provider and by in-person assessment at the physical therapy provider premises, again showing evidence of rehabilitee involvement and participation, although not in the actual EAT setting.

To conclude, rehabilitative needs assessments involving the three persons having ongoing EAT were assessed by telephone discussions with parents (n=3) and therapy providers (n=3) as well as visiting the rehabilitee in person at school and in physical therapy settings. Therefore, approximately 2/3 of the assessments undertaken were done in-person, but in other than the EAT therapy settings, showing approximately 70% of direct rehabilitee involvement. The involvement of parents and EAT therapy providers was realized through the telephone assessments. Because of the nature of the assessments made, there was no involvement of other parties in the EAT assessments made.

6.2.4 Speech therapy

Next, the number and nature of the assessments made by speech therapists is described in detail. In total, there were 38 in 50 persons (76%), who were assessed by a speech therapist before the rehabilitation negotiations and all but one of the 31 persons having ongoing speech therapy at the time, were assessed before the rehabilitation negotiations. This left 8 persons who had an assessment made, without ongoing speech therapy. The assessments included telephone calls made to parents and to therapy providers as well as in-person visits to homes, daycares, and schools.

Next, there is a breakdown of the total number of assessments done to the 38 persons by the speech therapists, dividing them between phone calls and in-person visits. Assessments done by telephone were documented for 27 out of 38 persons (71%), as shown in Figure 26. About half of these persons were made one assessment call (n=14) and another half two calls each (n=13). There were 11 in 38 persons (28,9%), who were not used any phone calls for assessment purposes.

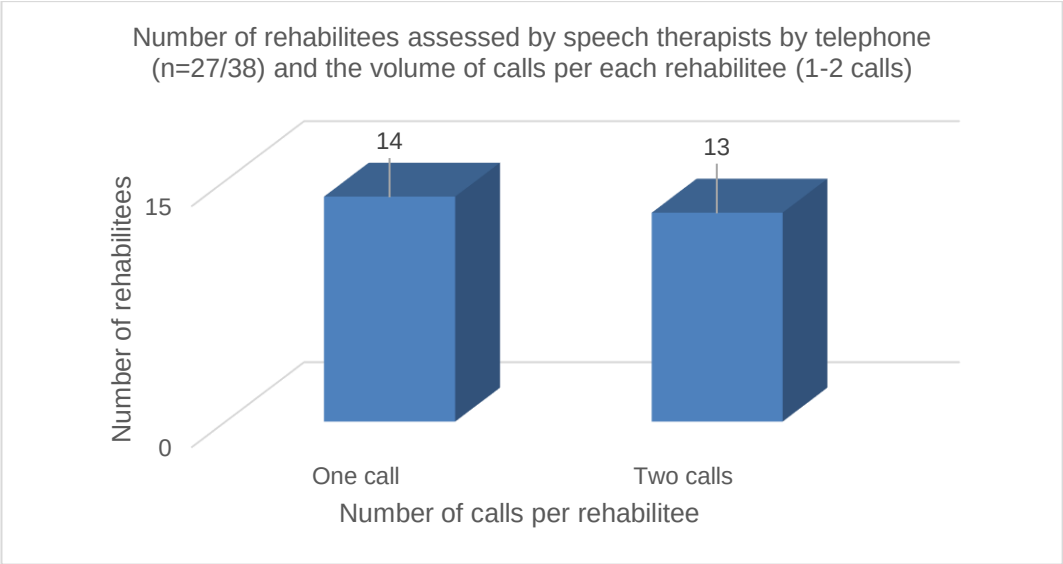

Figure 26. Number of persons assessed by telephone and the volume of these assessments.

Regarding the distribution of assessments made in-person from speech therapy (n=32), majority involved one onsite visit (n=27) and minority either two (n=4) or three (n=1) on-site visits per rehabilitee (Figure 27.). Out of all the 38 persons, who were assessed, there were 6 persons (15,8%), who had no assessments made in-person.

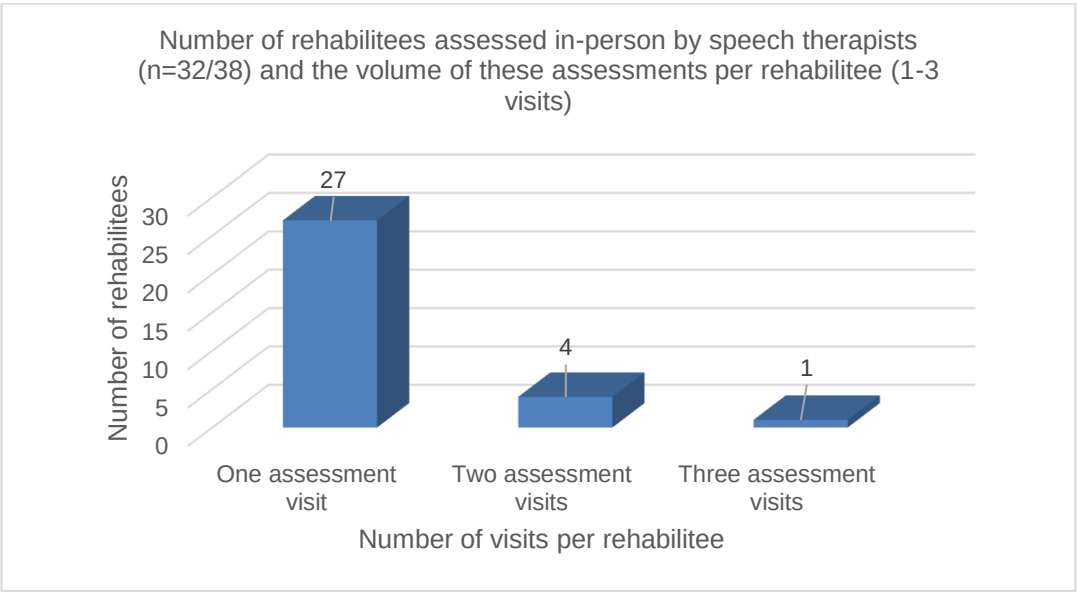

Figure 27. Number of persons assessed in-person and the volume of these assessments.

Next there is a closer look taken at the nature of all assessment calls and visits made from speech therapy. Phone calls were targeted to both therapy providers (n=24/40), and parents (n=16/40) of the rehabilitees, as shown in Figure 28. Since the total number of calls made from occupational therapy amounted to 40, and there were 27 persons

assessed using telephone inquiries, the number of calls per rehabilitee ranged from one call (n=14) to two calls (n=13) per rehabilitee.

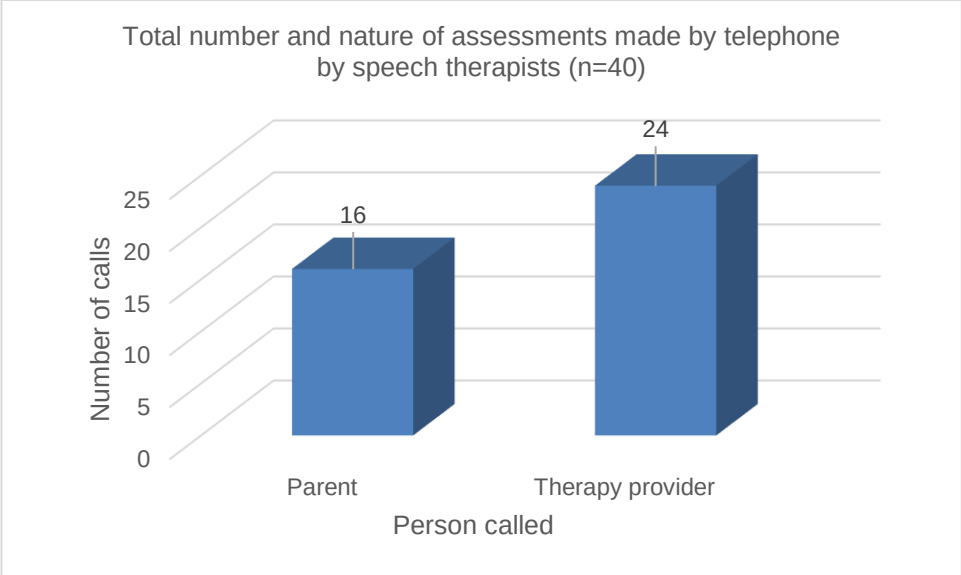

Figure 28. Total number and nature of assessment calls made from speech therapy.

Next, the nature and number of assessments done in-person, by the speech therapists in different life settings are presented in Figure 29.

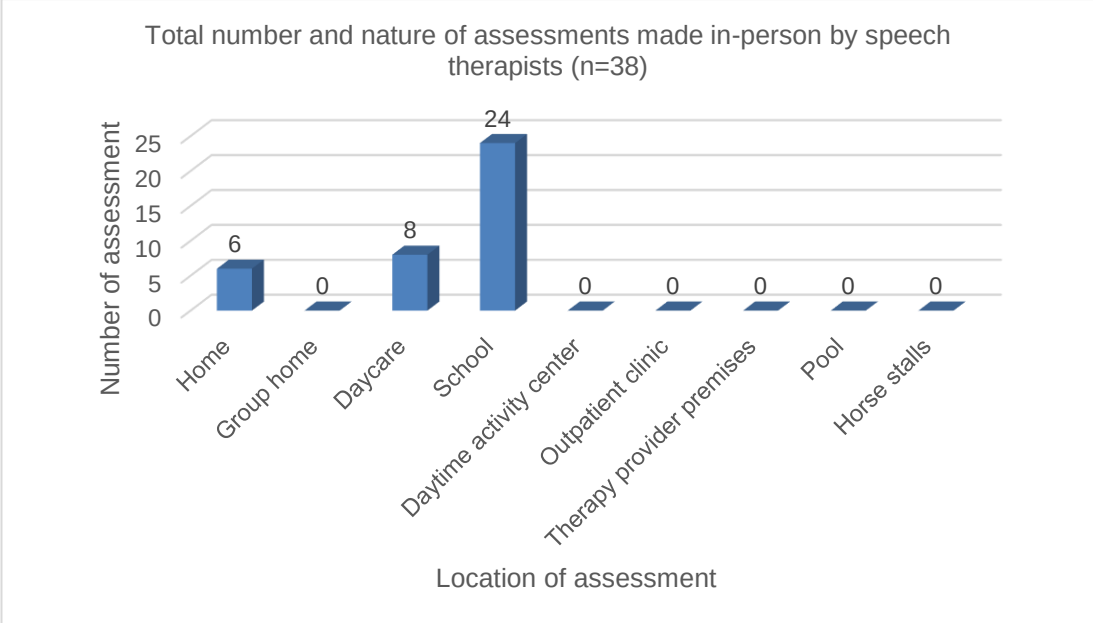

Figure 29. Total number and nature of assessments made in-person from speech therapy.

Out of the 32 rehabilitees, who were assessed in-person and onsite, majority (n=23, 71,9%) were assessments conducted as own, independent activity (n=3/23) and involving discussions with those representatives, who were present at the assessment setting

(n=20/23). Minority of the assessments were made solely in cooperation with the rehabilitees´ speech therapy providers (n=3), solely in an interdisciplinary manner with colleagues (n=3), or by using a mixed method, which involved the use of both independent visits and visits with the therapy provider or a colleague. These distributions are visualized in Figure 30.

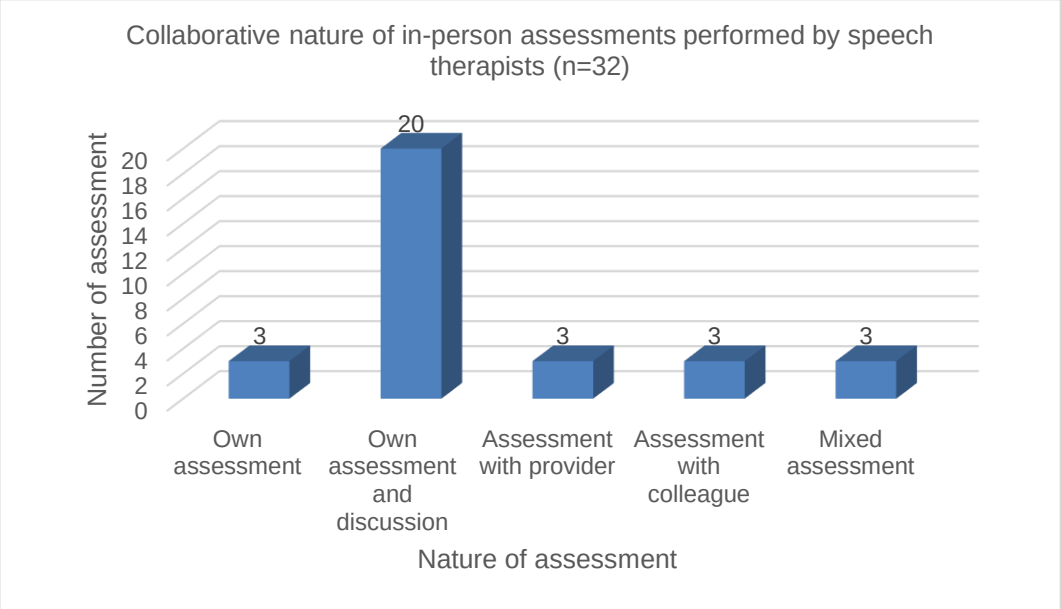

Figure 30. Collaborative nature of the speech therapy assessments made in-person.

Next, there is a more detailed description of the persons present or absent at the speech therapy assessments made in-person, differentiating both the internal and external representatives (Figure 31.).

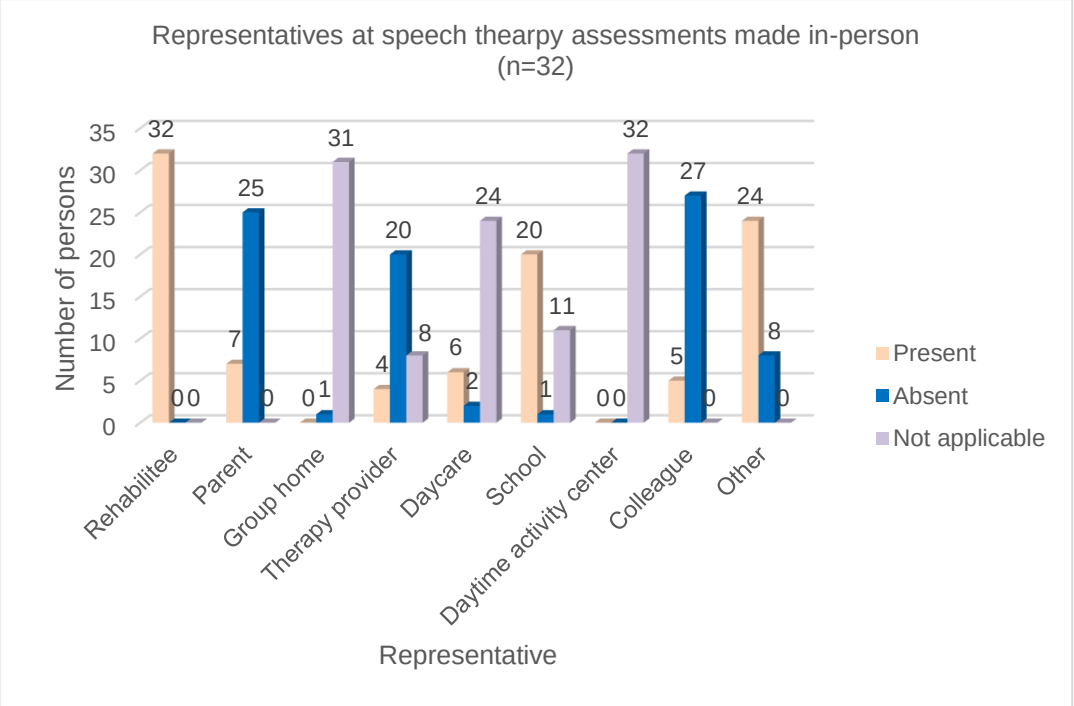

Figure 31. Representation of the people, who were present at the in-person assessments performed by the speech therapists.

All in-person assessments (n=32) were performed with the rehabilitee present. Parents of the rehabilitees were present in about every fifth (n=7) of the in-person assessments made. There was no group home involvement documented in one of the assessments made in a group home setting.

Speech therapy rehabilitation providers were present in four cases (12,5%), absent in 20 cases (62,5%) and the remaining eight persons had no ongoing speech therapy at the time of the assessment, thereby showing as not applicable.

Regarding daycare and school personnel participation in the assessments done in those settings, daycare personnel was present in six assessments and absent in two, whereas school personnel was present in 20 assessments and absent in one, rest were considered as not applicable. The representation of daycare personnel included the presence of the early childhood education teacher (n=3), assistant (n=1) and teacher and assistant (n=2). School personnel representation included teachers (n=12), assistants (n=2) as well as a combination of teachers and assistants (n=6). None of the rehabilitees assessed were in daytime activity centers during the day, thereby showing zero representation. Neither was there any cooperation with social workers or translators during the

speech therapy assessments. Persons categorized as other people present in the assessments (n=24) included other children from school settings/classmates (n=18), daycare children (n=4), siblings (n=1) and a nurse (n=1).

Regarding the level of interdisciplinary cooperation in the speech therapy assessments made, there were five out of 32 in-person assessments made in co-operation with colleagues (15,6%), out of which two visits were made as working pairs with the physical therapist (involving “vartu”-customers), two with an occupational therapist, and one with a student intern.

To conclude, out of all the rehabilitees having speech therapy (n=31, 62%) under the old rehabilitation plan, all but one person was assessed before their rehabilitation negotiations. Assessments were done to 38 persons in total (76%), and majority of them were assessed in-person (84,2%) and minority using a phone call inquiry only (15,8%). Given this nearly 85-15% split between in-person visits and telephone inquiries, the rehabilitee involvement and participation in their speech therapy assessment was high. Regarding family involvement, this remained at 21,9% of all in-person assessments, although there were also several assessments by telephone targeted to parents during the assessment phase. Regarding co-operation with the speech therapy providers, much of the collaboration was done by the telephone assessments and less of it were collaborative visits (12,5%). Collaboration with daycare personnel was done in 75% of assessments made in daycare settings and collaboration with school personnel was done in 95% of assessments done in school settings, showing high level of cross-organizational collaboration. There were no assessments made by speech therapists in daytime activity centers. Neither was there any co-operation done with the social workers or translators during the assessments. The level of internal collaboration and interdisciplinary teamwork remained at 15,6% of all in-person assessments made.

6.2.5 Music therapy

Out of the five persons having ongoing music therapy, four were assessed by the Outpatient clinic´s psychologists before the rehabilitation negotiations (Figure 32.). The number of assessments ranged from 1-2 per each assessed rehabilitee. The assessments included phone calls to parents (n=1) and therapy providers (n=3) as well as one in-person visit to a daytime activity center, showing evidence of both direct and indirect rehabilitee involvement, limited amount of parental involvement and limited collaboration

over organizational boundaries. One of the assessments also involved an internal discussion among colleagues and another a consultation of an external music therapist, showing a small degree of interdisciplinary teamwork.

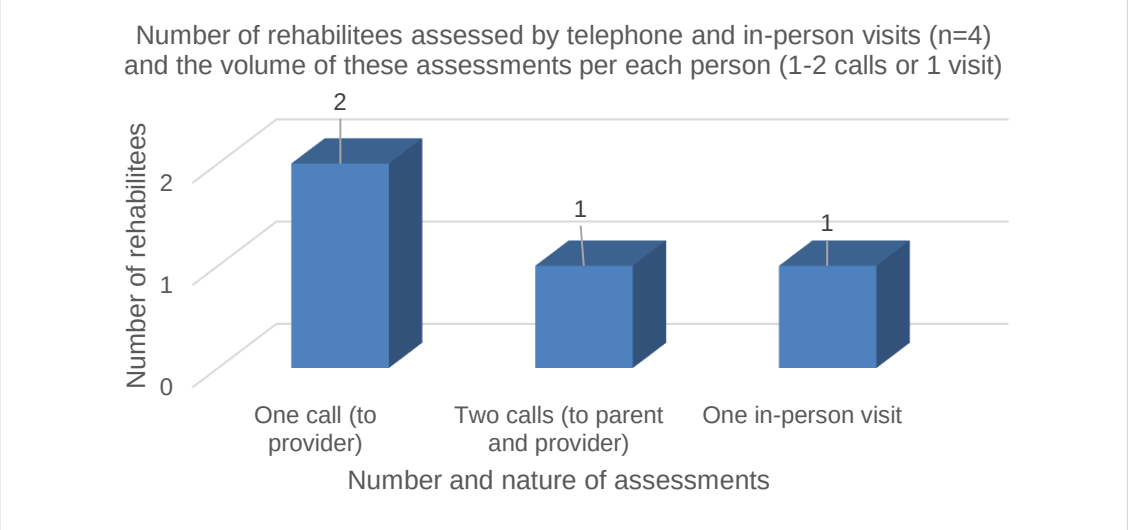

Figure 32. Distribution of music therapy assessments made by the psychologists via phone calls and in-person visits.

After describing the assessment practicalities of the Outpatient clinic, next there is an overview provided regarding the implementation of the rehabilitation negotiations.

6.3 Implementation of rehabilitation negotiations

In this section, there is an overview regarding the implementations of the rehabilitation negotiations, starting with the scheduling of an appointment and ending with the mailing of a ready-made rehabilitation plan to the customer.

6.3.1 Scheduling

The initiation of each new rehabilitation negotiation begins by the scheduling of an appointment for the rehabilitation negotiation to take place. This is an activity most typically coordinated by the nurses of the Outpatient clinic. After scheduling the appointment, an invitation letter is mailed to the rehabilitees and their caregivers, to inform them of their upcoming rehabilitation meeting. These letters contain information about the scheduled time and place as well as a “preliminary information sheet” in the form of a short questionnaire to be filled out by the rehabilitees and/or by people closest to them before the

rehabilitation meeting. The mailing date of the invitation is then typically entered in the rehabilitee´s health records in the Pegasos data repository, showing evidence of the service provided and action taken. The date of the scheduled meeting is then also entered in the calendars of the relevant Outpatient clinic personnel. In addition, the necessary external parties, such as the social worker or translation services, are then also typically informed of the scheduled time and place of the meeting.

In the following, the appointment scheduling and invitation mailing is described in more detail first, before moving on to the results of the rehabilitative needs assessments. A differentiation was made here in between the number of invitations sent per each rehabilitee and the timeliness of sending these invitations. This was made to reflect the person-centeredness in the form of flexibility and responsiveness of the clinic to the individual rehabilitee needs and requirements, such as openness to appointment rescheduling to better accommodate customer wishes. The timeliness aspect was included to inform how much time in advance the customers and their caregivers were notified about their upcoming rehabilitation negotiation meeting as well as to show how much time the Clinic´ personnel had for preparing the necessary customer assessments, prior to the scheduled meeting. In addition, it later facilitated the measurement of the lengths of the entire processes.

First, there is analysis of the number of invitations sent. As outlined in Figure 33., most rehabilitees and their families were sent one invitation letter to the rehabilitation meeting (n=37, 74%).

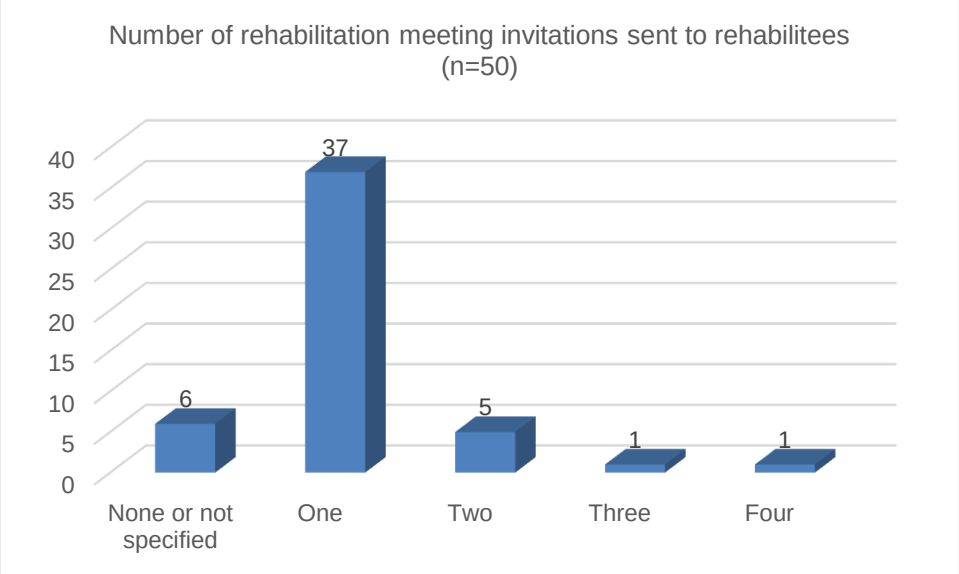

Figure 33. Number of invitations sent to rehabilitees, as a notification of their upcoming rehabilitation meeting.

In six cases, this information was either not specified (n=5 out of 6) or there was a different invitation procedure in use (n=1 out of 6, concerning the early rehabilitation program “vartu”-practices, where invitations to rehabilitation meetings are done mostly verbally due to closer, regular contact to families). In five cases, there were two invitation letters sent to the families, mostly due to customer related reasons reported, varying from: 1) client had lost the first invitation, 2) client had been “no-show” for the first rehabilitation meeting, so another meeting was scheduled, and family notified, 3) due to customer reasons, 4) family cancellation of first appointment due to fall holiday and 5) cancellation and rescheduling due to holiday. In one case, three invitations were sent due to ambiguities resulting from that there were no active Kela-therapies ongoing for the client, so the initially established meeting was cancelled and postponed, and then later rescheduled twice by the client. Also, in one case four invitations got sent to rehabilitee due to several appointment changes initiated by the parent of the rehabilitee.

Next, there is a description of how much time in advance the invitation was first sent to rehabilitees prior to their scheduled rehabilitation meeting date. On average, the mailing time of the first invitation letter was 61 days prior to the rehabilitation meeting, standard deviation being 20 days. In other words, rehabilitees, and their caregivers as well as the personnel of the Outpatient clinic had approximately 60 days (give or take 20 days) to prepare for the meeting. At the minimum, invitation was sent 14 days prior, and at the most, 140 days before the rehabilitation meeting.

Instead of looking at the invitation mailing dates one by one, the days were later grouped and now presented using five categories: up to 30 days, 31-60 days, 61-90 days, 91-120 days, and 121 or more days (Figure 34.), due to the high variance in the number of days and to facilitate better comprehension.

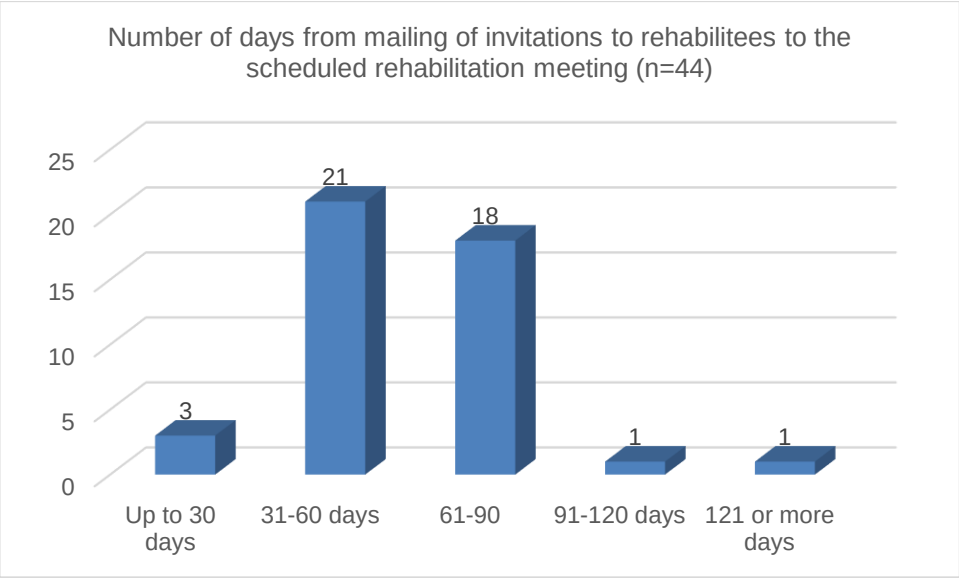

Figure 34. Amount of time in between the rehabilitation invitation mailing date and the actual rehabilitation meeting date, expressed in number of days and ranging from 14 days to 140 days.

As it shows, the most common day groups were 31-60 days (n=21) and 61-90 days (n=18), accounting for 88,6% of all cases. Three rehabilitees had up to 30-day notice about their upcoming rehabilitation meeting. In two cases the invitation was mailed either 91-120 days or more time before the actual rehabilitation meeting took place. It is worth noting, that these given numbers do not consider and differentiate those cases, where there were changes made into the original rehabilitation meeting time, weather it was postponed or not. Therefore, it only shows the actual dates in between the first invitation sent and the actual date that the rehabilitation meeting took place at the Outpatient clinic.

To conclude, most rehabilitees and their caregivers in this data sample (74%) were sent one invitation letter to notify them about their rehabilitation meeting. There was great variance in the timeliness of the first invitations sent (n=44), ranging from 14 to 140 days. On average, the mailing time of the first invitation letter was approximately 60 days, give or take 20 days, prior to the rehabilitation meeting.

Next, the monthly distribution of the negotiations is presented in Figure 35., showing that October was the busiest month with ten rehabilitation negotiations. This makes sense because most rehabilitation plans of the fifty rehabilitees were drawn-up for a full calendar year starting from January 1st and ending December 31st, and the negotiations are typically scheduled to occur approximately two months before the expiry of the old rehabilitation plan, i.e., October. Negotiations scheduled for other months throughout the year 2019 divided more evenly, other busiest months being April (n=7), August (n=6), May (n=5) and June (n=5).

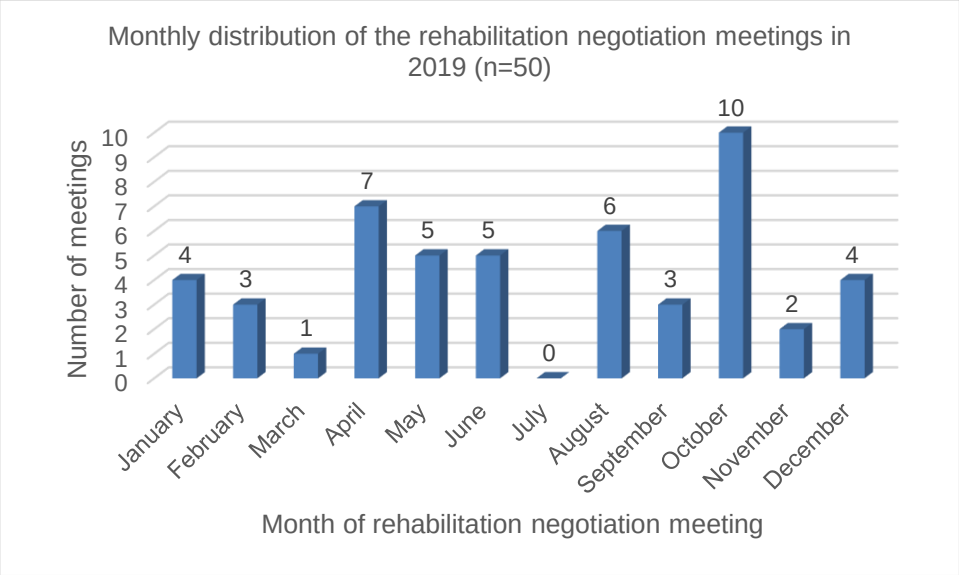

Figure 35. Monthly distribution of rehabilitation meetings in 2019.

Next, there is a description of the external and internal participants, who attended the rehabilitation negotiations.

6.3.2 Participants

Those participants who came to the rehabilitation negotiations from outside the Outpatient clinic were referred to as external participants. This group included the rehabilitee himself/herself, parents or grandparents, group home personnel, therapy providers, daycare, school or daytime activity center personnel, translators, and social workers. A category titled as “other” was also included, to represent other external representatives in the meeting. The participants coming from within the clinic were referred to as internal participants and these persons included physicians, psychologists, physical therapists, occupational therapists, speech therapists, and student interns.

First, the total volume of participants is looked in more detail in Figure 36. As it is shows, the total number of participants per each meeting (n=50) ranged from four (n=2) to eleven persons (n=2), but in most meetings there were either six (n=13), eight (n=10) or five persons (n=8) present. On average, there were seven persons present at the meetings, with a standard deviation of approximately 2 persons.

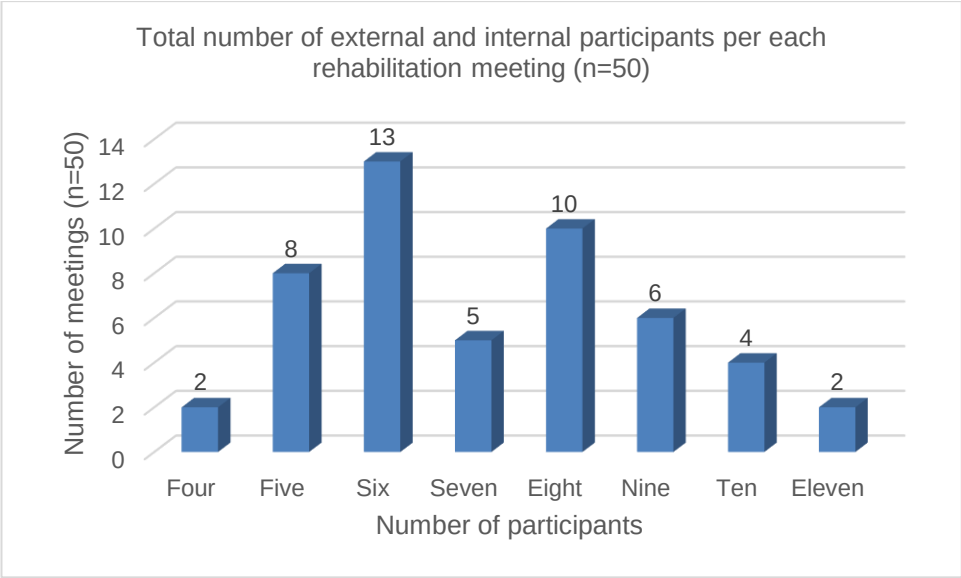

Figure 36. Distribution of total number of participants.

Knowing the total volume of all participants, next there are ranges and averages given specifically for external and internal participants (Table 3.). The number of external participants ranged from 1-7 persons and the average number of persons coming to the meeting from outside the clinic was four, give or take one person. The number of internal participants to the meetings ranged from 1-5 persons, and the average number of internal participants was three professionals, give or take one person.

Table 3. Number and nature of participants in the rehabilitation negotiation meetings in the selected data sample (n=50) from 2019.

Number and nature of participants	N	Min	Max	Mean	Std. Dev.
Total number of external participants	50	1	7	3,98	1,20357
Total number of internal participants	50	1	5	3,16	0,99714
Total number of both external and internal participants	50	4	11	7,14	1,82958

Next, the representations and distributions are looked in more detail, starting with the external and then moving onto the internal representations.

6.3.2.1 External participants

Regarding the distribution of the external participants (see Figure 37.), in 38% of negotiations there were four persons (n=19), and in 30% of negotiations there were three persons present (n=15) from outside the Outpatient clinic. Also, there were more often either five (n=6) or six (n=6) external participants present, rather than just one (n=1) or two

(n=2). At the most, there were seven external participants present, also representing a minority (n=1).

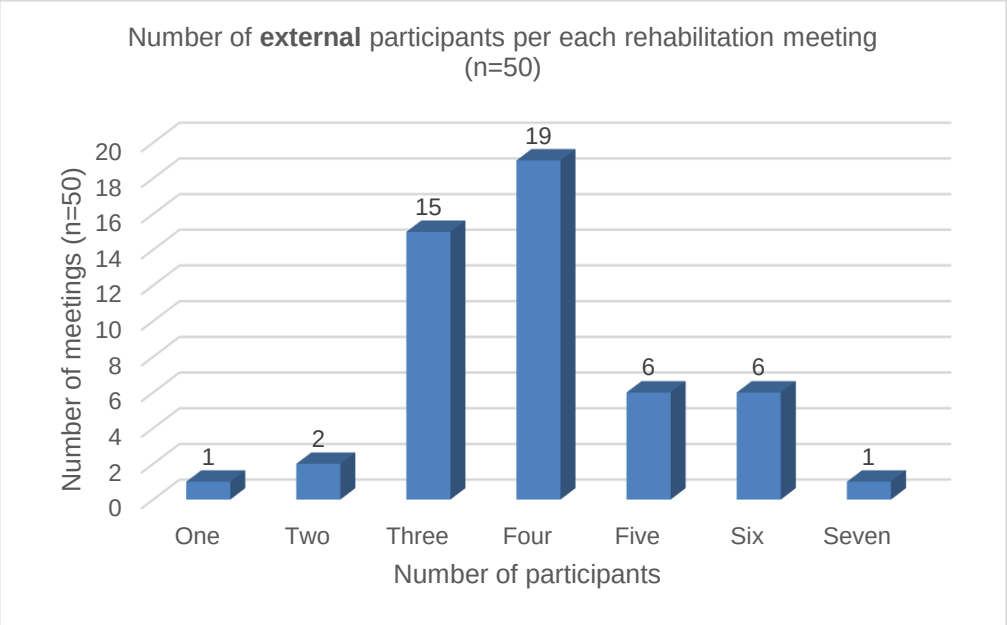

Figure 37. The distribution of the number of external participants to the rehabilitation negotiations.

Out of the fifty meetings, the rehabilitees themselves were present in 46 meetings and absent in 4 meetings, giving an attendance of 92% and absence of 8% (see Figure 38). Regarding these participations, in one meeting the rehabilitee was present only part of the meeting, but in rest, full-time presence was indicated. Regarding the four absences, there was one meeting held without the rehabilitee, who had previously met with the physician of the clinic before the rehabilitation meeting.

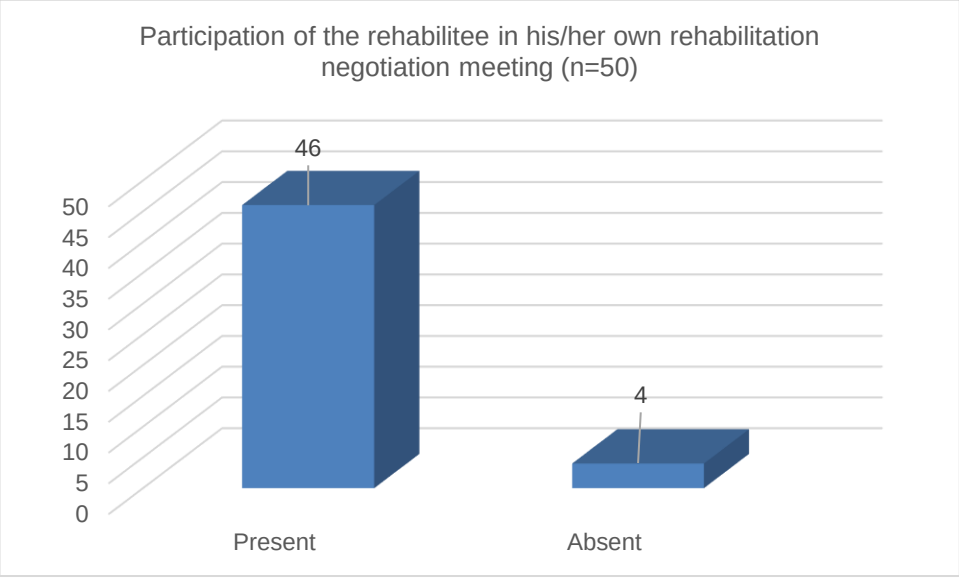

Figure 38. Participation of the rehabilitee in his/her own rehabilitation negotiation meeting.

Regarding the participation of the parents of the rehabilitees, mothers were present in nearly half of the meetings (n=24), both parents were present in 42% of meetings (n=21) and fathers alone were present in 8% of meetings (n=4), as detailed in Figure 39. There was also one meeting with a grandparent present.

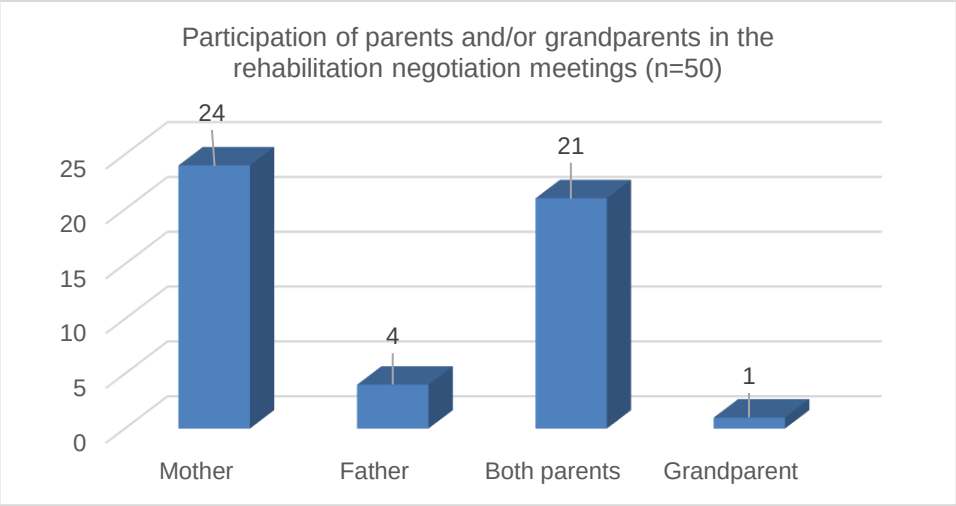

Figure 39. Participation of parents and/or grandparents in the negotiations.

Regarding other caregiver participation, out of the three rehabilitees living in a group home setting, there were participants from group homes in two out of three negotiations, giving an attendance of 67% (Figure 40.).

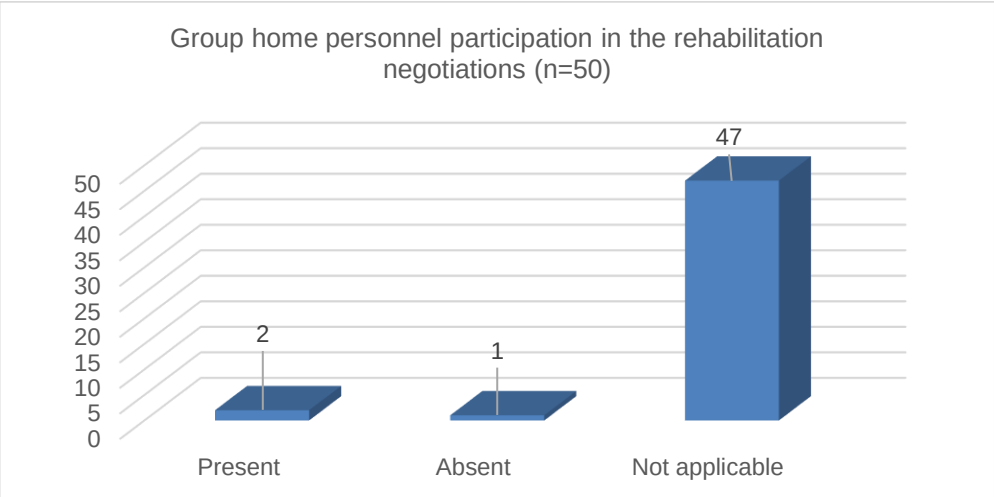

Figure 40. Participation of group home personnel in rehabilitation negotiations.

Regarding therapy provider participation in the negotiations, there were in total 49 rehabilitees (98%) in the study sample, who had at least one type of therapy and at the most

three ongoing therapies, prior to their scheduled rehabilitation negotiation. The participation rates of those therapy providers is described in Figure 41.

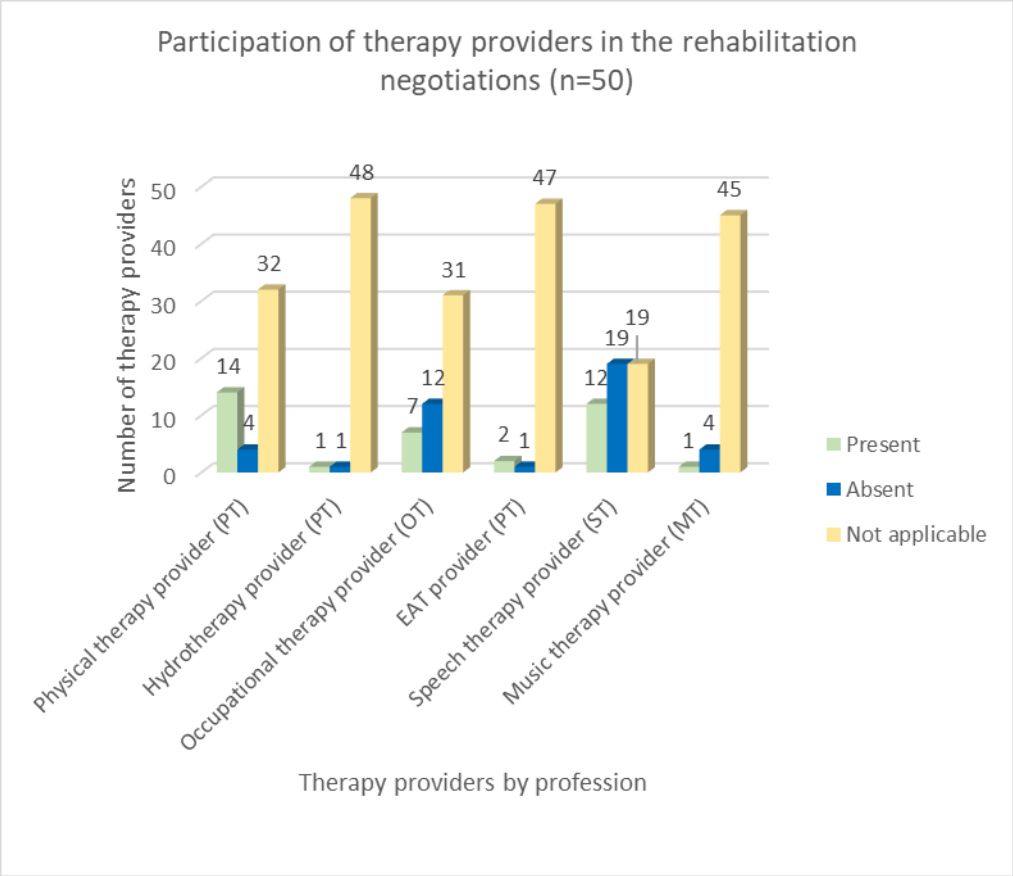

Figure 41. Participation rates of the therapy providers in the rehabilitation negotiations.

Out of the 18 persons having ongoing physical therapy at the time of the meeting, there were 14 meetings with the physical therapy (PT) provider of the rehabilitee present (77,8%) and 4 meetings with the PT provider absent (22,2%). For hydrotherapy, the numbers were one therapy provider (PT) present and one absent, out of the two applicable cases. For occupational therapy, these figures were 7 therapy providers present and 12 absent out of the 19 applicable cases, giving attendance of 36,8% and absence of 63,2%. For EAT, there were 2 therapy providers (PT) present, and one absent, out of the three applicable cases. For speech therapy, the numbers were 12 speech therapy providers present and 19 absent out of the 31 applicable cases, giving attendance of 38,7% and absence of 61,3%. For music therapy, there was one therapy provider present out of the 5 applicable cases.

When looking at the total attendance and the combinations of attendances of these different therapy providers in the 50 rehabilitation meetings under study (Figure 42.), it shows that there were 1-3 therapy providers present in 28 out of the 50 meetings (56%),

out of which only PTs were present in 11 meetings, only OTs were present in 3 meetings, only STs were present in 8 meetings, and only MTs were present in 1 meeting. Meetings, where there were at least two different therapy providers present (e.g., PT and OT), added up to 4 and there was only one meeting with 3 therapy providers present.

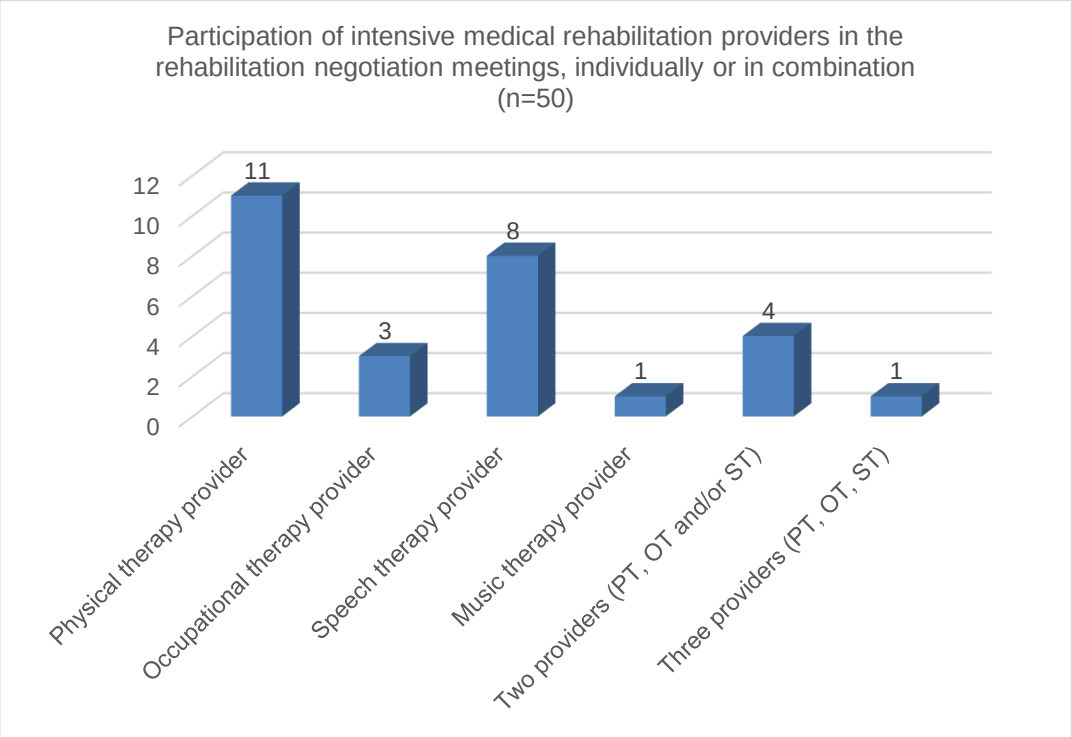

Figure 42. Therapy provider attendance rates in the rehabilitation negotiations.

In Figure 43. there is a description of the participation of daycare, school, and daytime activity center personnel in the negotiations, distinguishing the applicable and non-applicable cases in these figures.

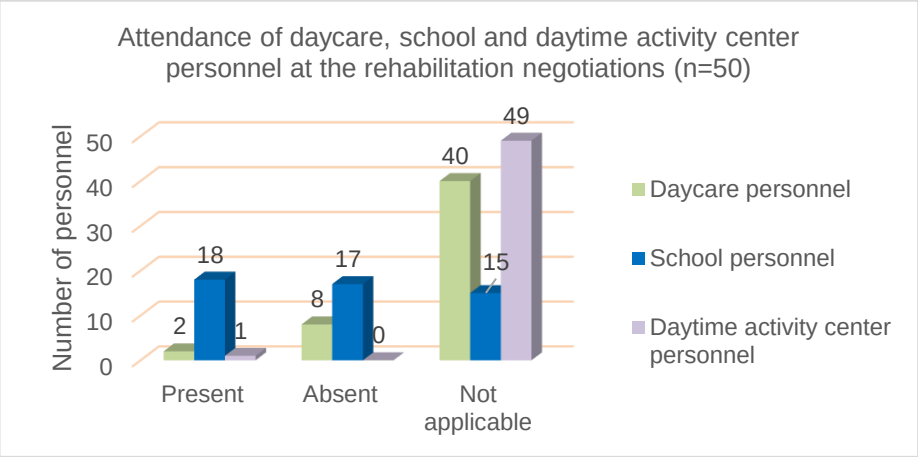

Figure 43. Daycare, school, and daytime activity center personnel attendance.

Out of the ten rehabilitees going to daycare during the day, daycare personnel attended two of their negotiations, the attendees representing early childhood education teachers (n=1) as well as a teacher and an assistant (n=1). Out of the 35 rehabilitees going to school during the day, there were 18 persons (51,4%) having school personnel attending their negotiations. In majority of times (n=17), the school representative was the teacher of the rehabilitee and in one case it was an assistant and an afternoon club instructor. There was only one rehabilitee going to a daytime activity center during the day and for this person´s negotiation, the daytime activity center service manager and instructor attended the meeting.

Regarding co-operation with other external members, social workers attended 18 (36%) and language translators 4 (8%) out of all meetings, as shown in Figure 44.

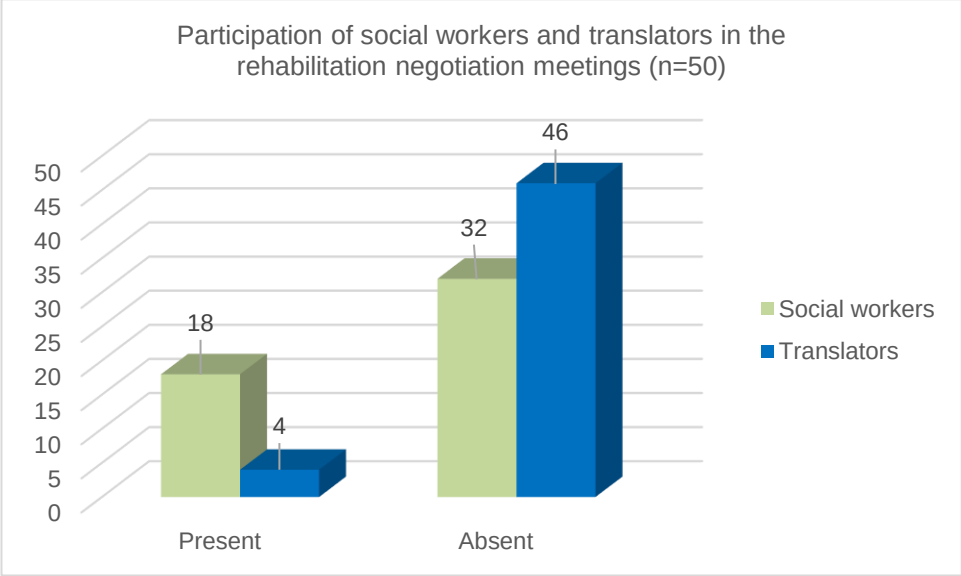

Figure 44. Participation of social workers and translators in the rehabilitation negotiation meeting.

In the category “other representatives” there were siblings (n=6) and a special family worker (n=1), attending a total of 7 out of the 50 meetings (14%).

To conclude, there was high variance in the number of external participants in the rehabilitation meetings, but overall, there generally was a good number of representatives, ranging from 1-7 persons and on average, being four persons. Rehabilitees themselves were present in 92% of meetings, and parents or grandparent in 100% of meetings, showing high involvement and participation in the rehabilitation planning. There was a limited number of persons living in group home settings, and therefore, group home attendance remained at 2 out of 3 meetings. Regarding the level of collaboration over

organizational boundaries and the attendance of the therapy providers, there were 1-3 therapy providers present in 56% of meetings. Physical therapy providers had the highest, nearly 80% attendance percentage, whereas occupational and speech therapists had 36-38% attendance. For other, less frequent therapies, the attendance of hydrotherapy providers was 50% and 67% for EAT providers. For music therapy, the representation of the therapy provider remained lowest, at 20%. Daycare personnel had an attendance of 20% and school personnel attendance of 51%. Given the pediatric nature of the data sample, there was only one person having daytime activity center participation in his/her rehabilitation meeting. Social workers of the rehabilitees were present in 36% of all meetings and language translators showed a small presence of 8%.

6.3.2.2 Internal participants

Next there is a description of the internal participants to the negotiations, starting with the total number of professionals attending the meetings (Figure 45.) As it shows, most often there were either four (n=16), three (n=15) or two (n=14) staff members present at the negotiations. At the most, there were five staff members in the meetings (n=4), and at the minimum, there was only one internal representative present (n=1).

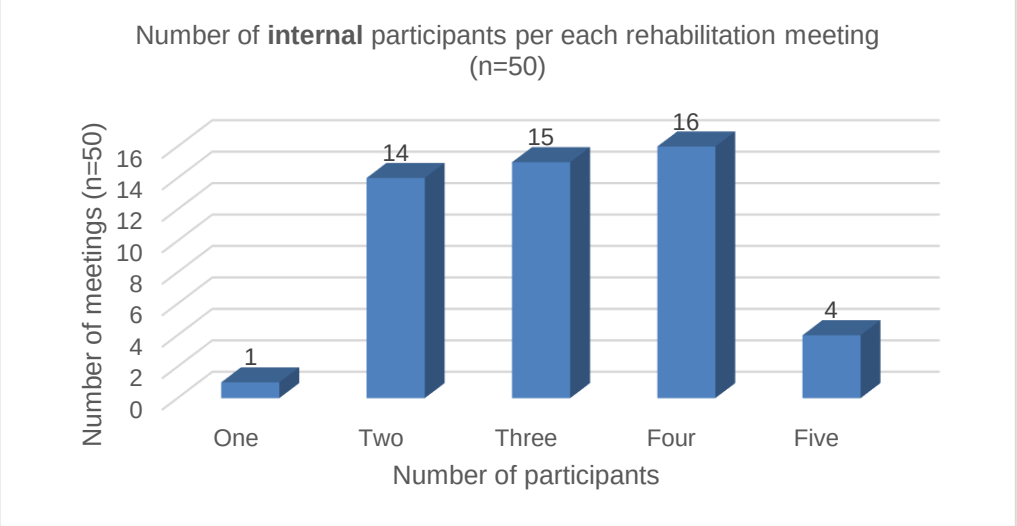

Figure 45. The distribution of the number of internal participants to the rehabilitation negotiation meetings held in 2019 (n=50).

Next, the distribution of internal participants to the negotiations is viewed based on occupational groups (Figure 46.). There was a physician present in all but one meeting

(n=49), a psychologist present in 15 meetings, a physical therapist present in 29 meetings, an occupational therapist present in 24 meetings, a speech therapist present in 39 meetings, and a student intern present in two meetings.

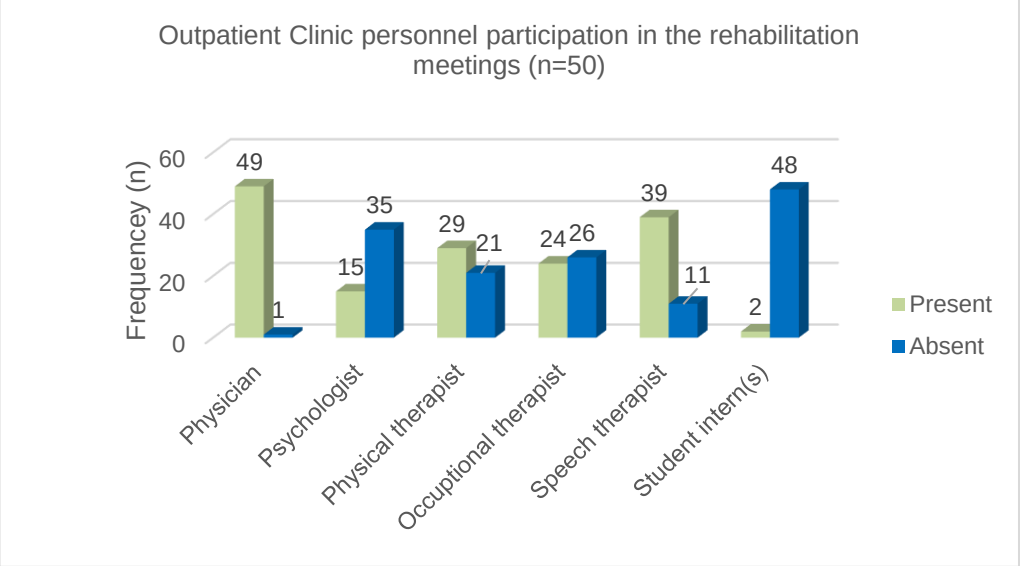

Figure 46. Internal participation in the rehabilitation meetings.

Next it is being distinguished, how the internal participants measured against the ongoing therapies of the rehabilitees. These numbers are presented one health professional group at a time, starting with physical therapists (Figure 47.).

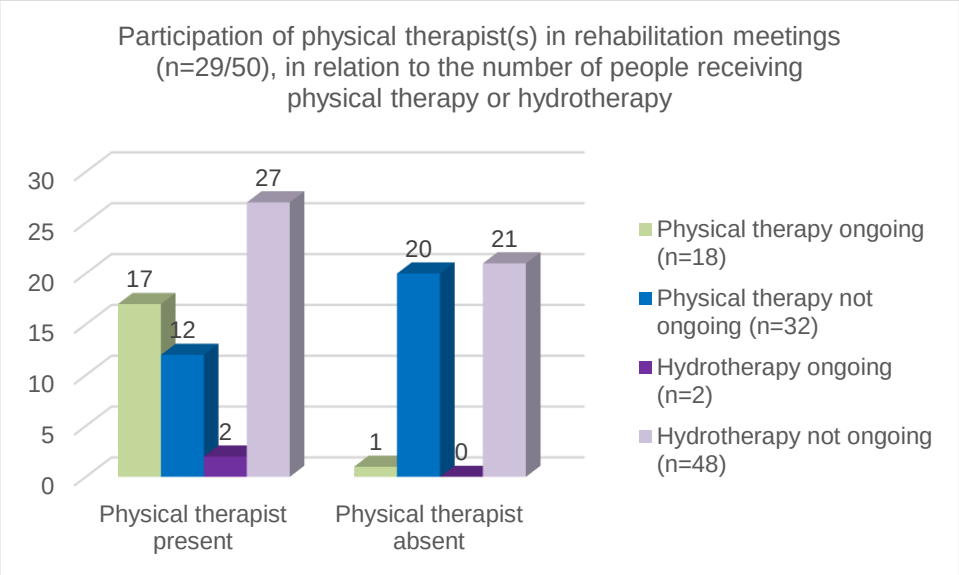

Figure 47. Participation of the physical therapists in the rehabilitation negotiations.

Physical therapists attended a total of 29 negotiations (58%), out of which there were 17 persons having ongoing physical therapy and 2 persons having ongoing hydrotherapy.

Among the 21 meetings missed by the physical therapist, there was one rehabilitee having ongoing physical therapy, but none having hydrotherapy.

Regarding the attendance of occupational therapists, similarly, Figure 48. shows, that there were in total 24 meetings with the occupational therapist present (48%), out of which 17 rehabilitees had ongoing occupational therapy. Out of the meetings missed, by an occupational therapist, two rehabilitees had ongoing occupational therapy.

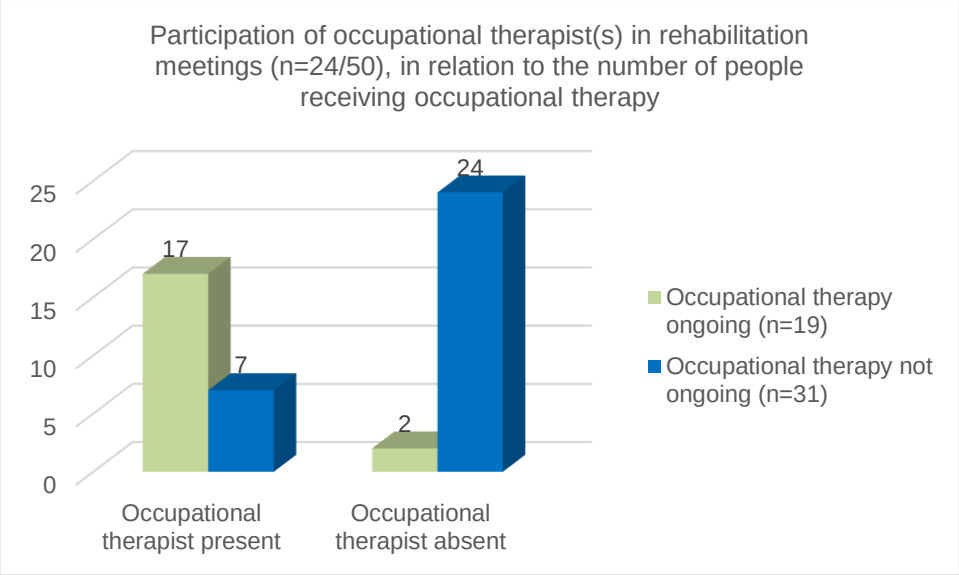

Figure 48. Participation of occupational therapists of the Outpatient Clinic in the rehabilitation negotiation meetings (n=24/50), and in relation to the ongoing occupational therapy.

Regarding EAT, there was an internal physical therapist present in 2 out of 3 three applicable times, as shown in Figure 49.

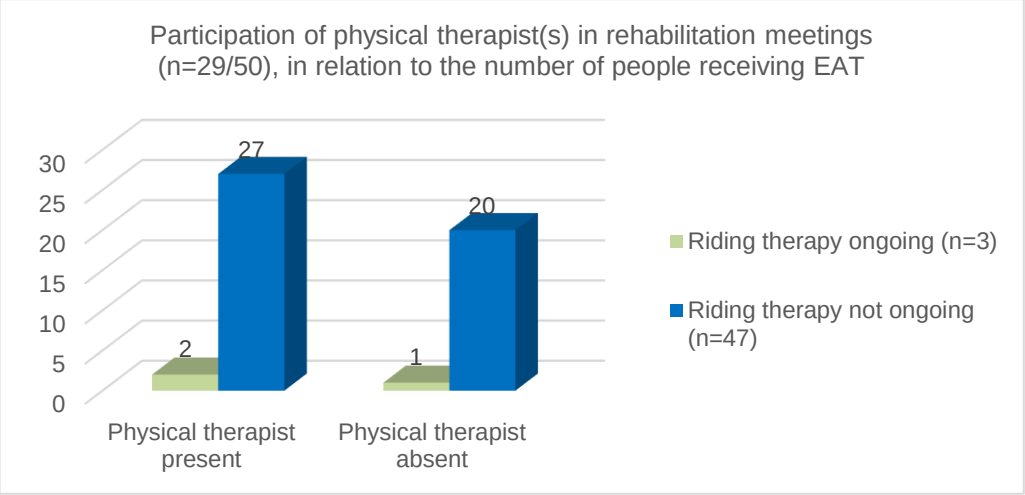

Figure 49. Participation of physical therapists in the meetings, in relation to the ongoing EAT.

Regarding the participation of the speech therapists, they attended a total of 39 meetings (78%) out of which 29 rehabilitees had ongoing speech therapy. Out of the meetings missed, there were two persons having speech therapy, as shown in Figure 50.

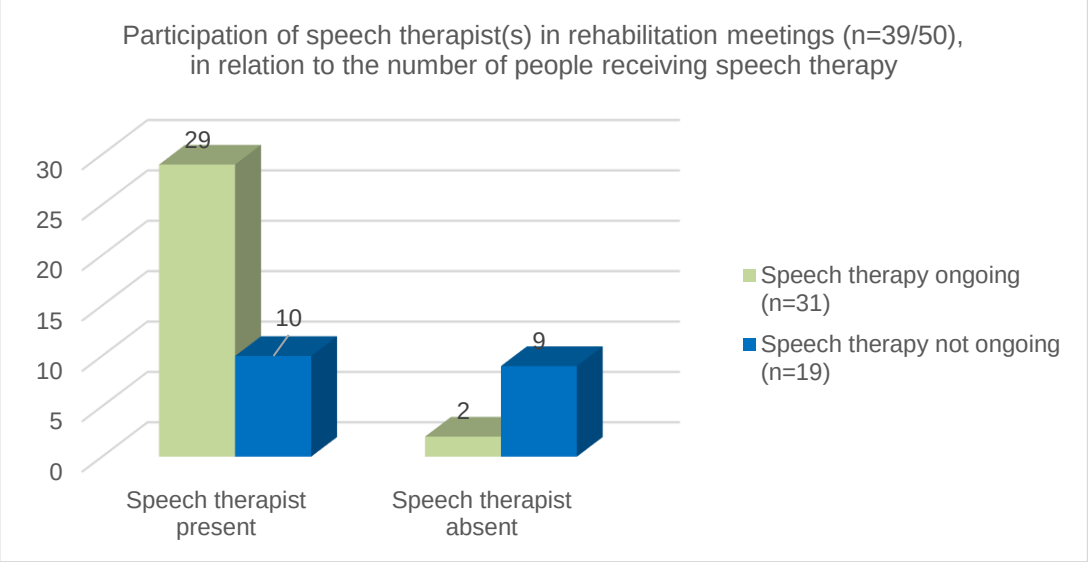

Figure 50. Participation of internal speech therapists in the rehabilitation negotiations.

Regarding music therapy and participation of the internal psychologists in the negotiations, these are outlined in Figure 51. As it shows, there were 15 rehabilitation meetings with a psychologist present (30%), out of which there were four persons having ongoing music therapy. Out of the 35 meetings missed by the psychologists, there was one rehabilitee having ongoing music therapy.

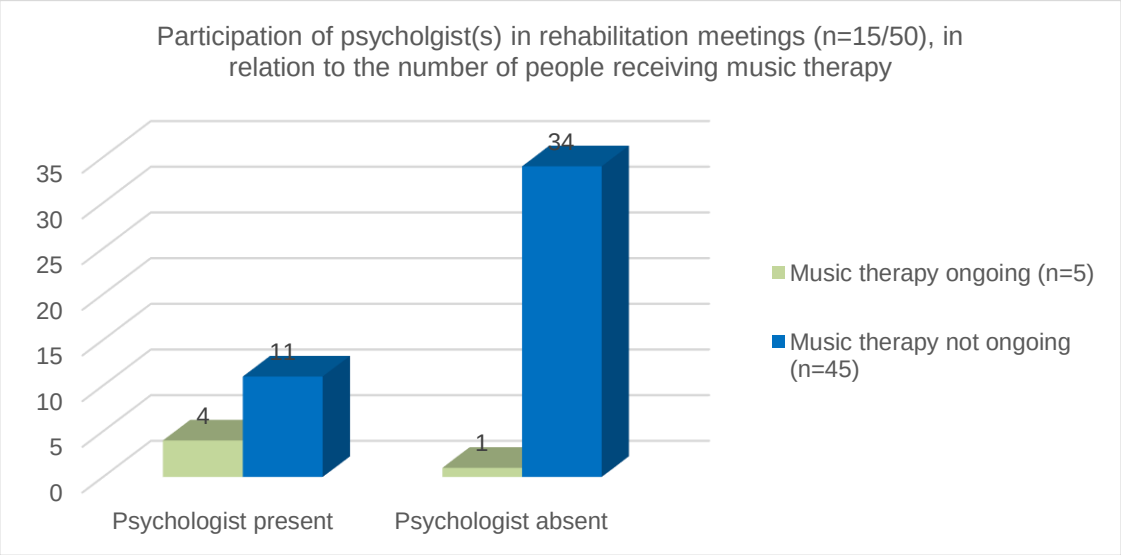

Figure 51. Participation of internal psychologist in the rehabilitation negotiations, and in relation to ongoing music therapy.

To conclude, the number of personnel attending the meetings ranged from 1-5 persons, and on average was three persons, give or take one person. There were five internal participants in only four meetings (8%) and one internal participant in only one meeting (2%), representing minority. Physicians were present in 49/50 meetings, facilitating the drawing-up or renewal of the rehabilitation plan for the rehabilitees. Psychologists were present in 30% of meetings, covering majority of persons having ongoing music therapy (n=4/5) and contributing to “right” meetings. Therapists attended majority of meetings, where they were needed to make recommendations regarding the continuation or termination of those therapies in question. Therapists also present in several negotiations, where the rehabilitee had no ongoing therapy. Based on these internal representations, it can be concluded that the degree of interdisciplinary teamwork varied from one meeting to another, but overall, was realized in more cases than not.

6.3.3 Availability of therapy feedback

Next there is a description of the “on-time availability” of the therapy provider feedback reports. This was chosen as a quality indicator relating to the concept of informational continuity and continuity of care, being important elements of person-centered care and good rehabilitation practice. In practice, this means that the therapy providers of the rehabilitees are required to write a therapy feedback report near the expiry of each of their client´s ongoing rehabilitation plans, where they describe the past rehabilitation period with its contents and outcomes as well as make suggestions and recommendations for future rehabilitation needs and objectives. This report is then typically delivered to the rehabilitee and their caregivers, to Kela, and to the Outpatient clinic, for the collaborative planning and decision-making concerning the new rehabilitation period. In Figure 52., the availability of these therapy feedback reports at the time of the rehabilitation negotiation meeting are viewed in more detail.

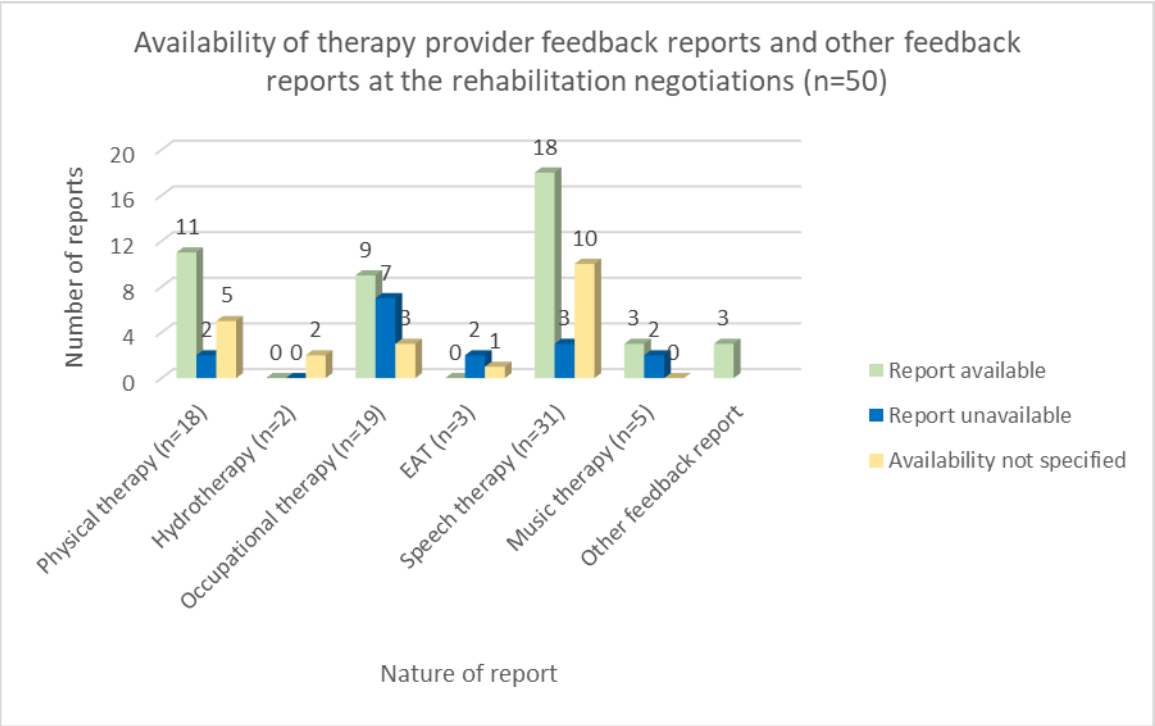

Figure 52. Availability of therapy feedback reports at the rehabilitation negotiations, indicating timeliness of information exchange between the organization responsible for care and the private therapy providers responsible for executing the rehabilitation.

Physical therapy feedback reports were submitted on time in 11 cases, submitted late in two cases, and in five cases this information was not clearly documented. For hydrotherapy, there was no information indicating the arrival of the feedback reports. For occupational therapy, there were 9 feedback letters received on time, 7 received late, and 3 not specified. For EAT, the corresponding numbers were none returned on time, two returned late, and one not specified. For speech therapy, 18 reports were returned on time, three returned late, and ten not specified. For music therapy, three reports arrived on time and two arrived late. In addition to the therapy feedback reports, there was one feedback report delivered for use at the negotiation from the private sector (Rinnekoti), one concerning an EAT trial and one from daycare. Based on these figures, there were gaps in the data, and the continuity of care and informational continuity was realized only to a limited degree.

6.3.4 Rehabilitation recommendations

Next, there is a description of the contents of the new rehabilitation recommendations made for the upcoming rehabilitation period, based on the negotiations held, prior assessments made, and feedback reports received from the therapy providers. Based on

these recommendations, the rehabilitees are then responsible for applying the recommended therapies from Kela, which is done by filling out a rehabilitation application and submitting it to Kela together with the newly made rehabilitation plan (B-statement) and other necessary statements (provided by therapists who have recommended therapies).

First, looking at all therapy recommendations made on a general level per each rehabilitee, these ranged from zero (n=1) to four therapy recommendations made (n=1). Approximately half of the rehabilitees (n=27) were recommended one therapy and a third (n=15) two therapies. There were six persons who were recommended three therapies in total. (Figure 53.)

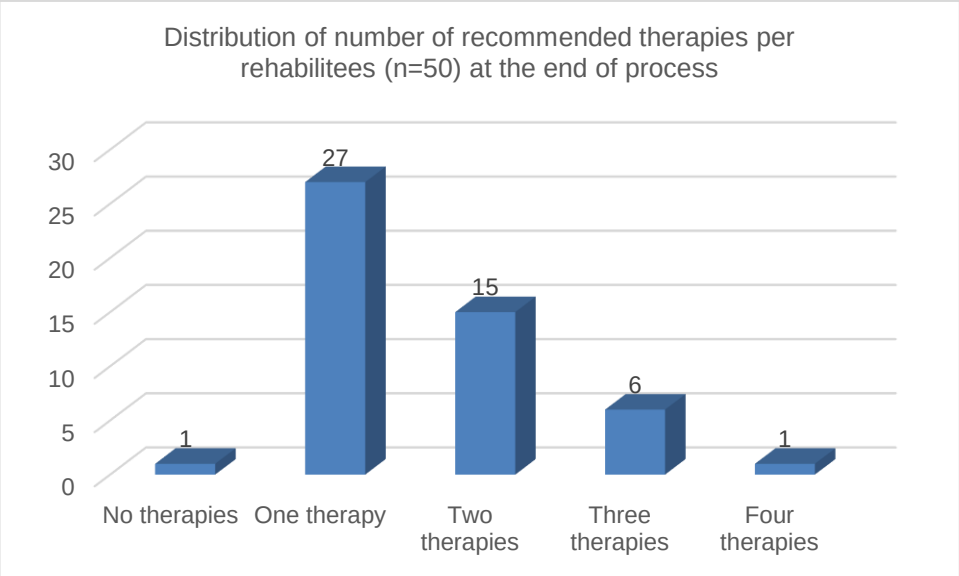

Figure 53. Distribution of the recommended number of therapies per rehabilitee.

In addition to therapy recommendations, there were other rehabilitation related recommendations were made to six persons out of all. These included referrals for the rehabilitees and their families to participate in adaptation couching courses (n=2), communication/support sign teaching lessons (n=3), and a mix of these two (n=1).

Next, the newly made recommendations are divided based on each type of therapy, differentiating the cases in which therapy was recommended to continue, not recommended to continue, or whether it was recommended to start as a new therapy for a person (Figure 54.)

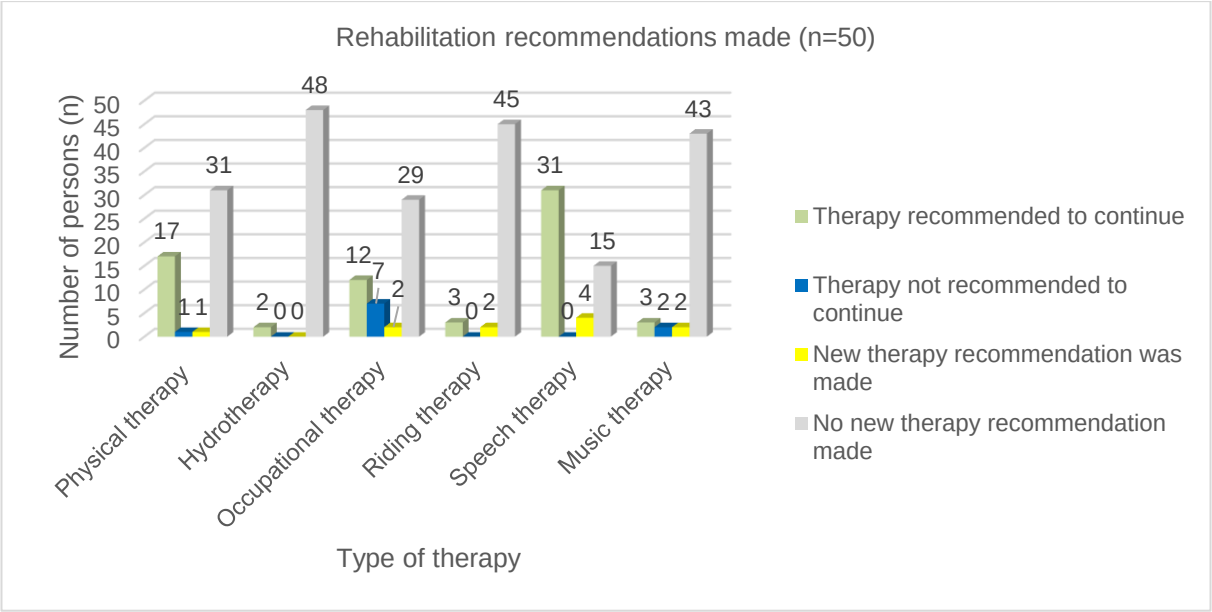

Figure 54. Rehabilitation recommendations made, in relation to initiation, continuation or termination of therapies.

As it shows, physical therapy was recommended to continue for all but one rehabilitee (n=17) and there was one person, who had it recommended based on the assessments and negotiations. Therefore, the total number of rehabilitees, who were recommended physical therapy remained at 18 (36%). For hydrotherapy, it was recommended to continue to two persons, who had it ongoing previously. For occupational therapy, there were 12/19 persons who were recommended a continuation of it, and two persons, who were recommended it as new. For riding therapy, all three persons having it at the start were recommended a continuation of it, and two more persons were recommended it. For speech therapy, all 31 persons were recommended a continuation of it or had it ongoing at the time of the rehabilitation meeting, and there four persons, who had it recommended as new. For music therapy, there were three out of five persons who were recommended a continuation of the therapy and two new recommendations were made.

These recommendations indicate that there were different amounts and types of intensive medical therapies recommended, based on rehabilitative needs´ assessments and negotiations held, showing responsiveness to the varying needs and objectives of the pediatric rehabilitees, thereby providing evidence of person-centered care. However, this list of number of therapies and their types does not alone reveal, whether they were considered the right type of therapies for the rehabilitees, according to the rehabilitees themselves or their caregivers. However, since majority of therapies, which had been ongoing previously were also continued, indicates that the therapies had been needed and effective, as they were recommended a continuation of it. Only on few occasions,

the therapies were discontinued, and in some of these cases, it was also planned action, as they had initially been titled as “ending periods” of those therapies. This was particularly true in occupational therapy, where most therapies were also discontinued out of all.

6.3.5 Number and duration of rehabilitation plans made

Next there is a description of the number and durations of the newly made rehabilitation plans. These plans are also then compared to the number and duration of the “old” rehabilitation plans of the study sample. As outlined in Figure 55., there were in total 49 new rehabilitation plans made, and the plans ranged from 1-2 years in duration. Majority of the plans were drawn up for a 1-year period (n=45), also representing the mean duration. There was only one person having a 1,5-year-plan made and three persons having a 2-year plan made. Out of the 50 rehabilitees, there was only one person left without a new rehabilitation plan, meaning no therapy recommendations were made for the upcoming year.

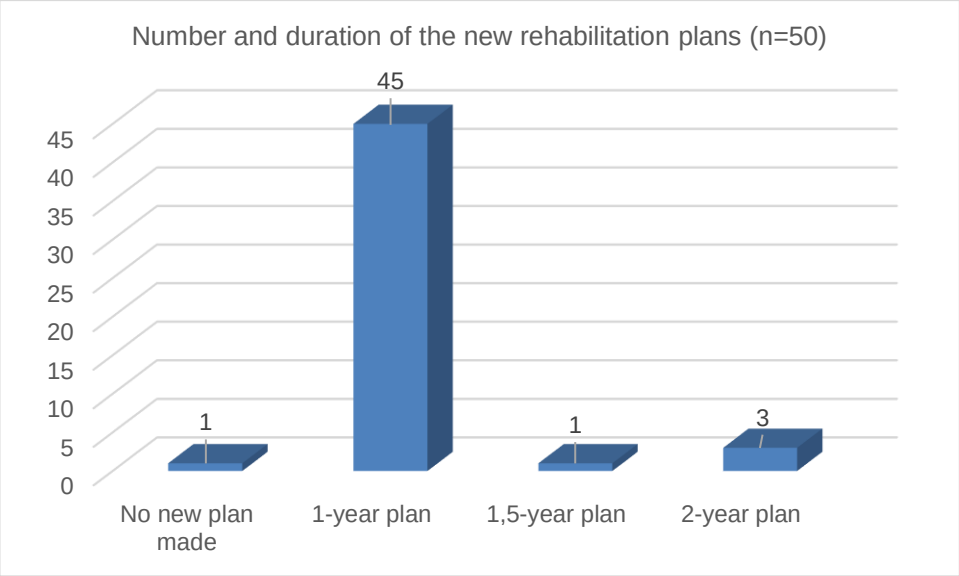

Figure 55. Number and durations of the new rehabilitation plans made.

Table 4. provides a comparison of the durations of the old and new rehabilitation plans.

Table 4. Comparison of duration of the old and new rehabilitation plans (i.e., B-statements).

Existence and duration of "old" rehabilitation plan (n=48)	Existence and duration of "new" rehabilitation plan (n=49)				
	No new plan	1-year new plan	1,5-year new plan	2-year new plan	Total
No plan	0	2	0	0	2
1-year plan	1	41	1	3	46
1,4-year plan	0	1	0	0	1
2-year plan	0	1	0	0	1
Total	1	45	1	3	50

Judging by the numbers there were only small changes made to the lengths of the plans, as most persons still had a 1-year plan made. There was a slight increase in the 2-year plans made, which tripled from 1 to 3. Given these figures, it can be concluded that in pediatric intensive medical rehabilitation, it is common to draw up plans for one year at a time, rather than 2-3 years. More regular follow-up allows the health care organization responsible for care (i.e., the Outpatient clinic) to monitor the growth and development of the disabled child and/or youth more closely. From the customer point of view and from the person-centeredness perspective, more regular controls may provide the rehabilitee and their caregiver a sense of added safety, knowing that their child´s/youth´s development is monitored more often.

6.3.6 Issuance of the B-statement

After each rehabilitation negotiation, a new rehabilitation plan (i.e., B-statement) is issued if there are therapy recommendations made. The plan is prepared by the physician of the health care organization responsible for care and then mailed to the rehabilitee, with other necessary attachments, such as recommendations from therapists, whose therapies are recommended. The rehabilitee then submits these statements together with their own rehabilitation application to Kela. Kela then uses the application, B-statement and other relevant statements for their own processing and decision-making.

Figure 56. outlines the timeliness in the issuance of B-statements by the Outpatient Clinic. No information was collected about the issuance of other, non-rehabilitation specific statements, such as disability allowance related C-statements nor “free-form” statements (titled locally as “V-statements”).

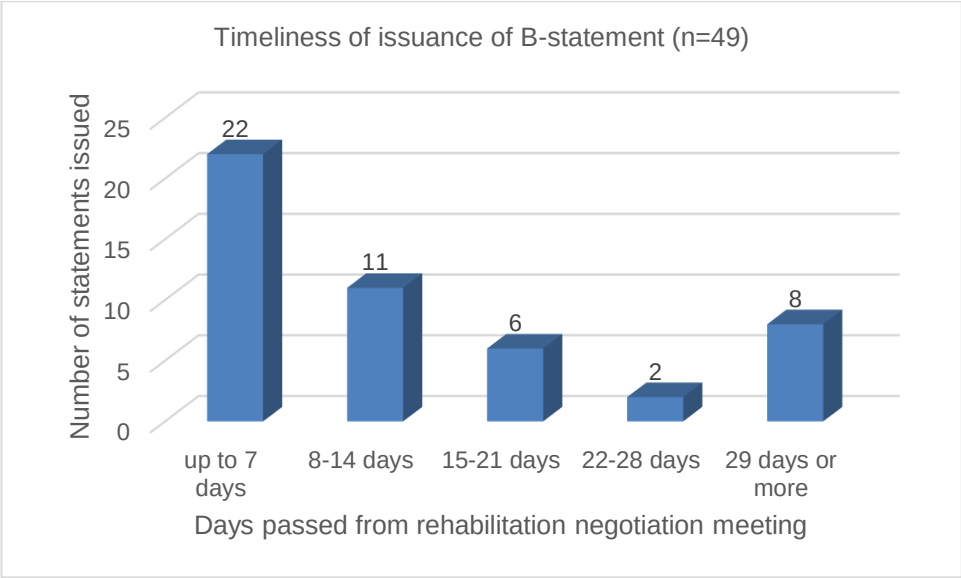

Figure 56. Issuance of B-statements by the Outpatient clinic´s physicians, post-rehabilitation negotiation, indicating the timeframe in which the statements were issued after the meeting.

As it shows, in 22 out of 49 cases (44,9%), the B-statement was issued within seven days. In 11 cases (22,4%) it was prepared within 8-14 days, and in 6 cases in 15-21 days. There were two times where it took 22-28 days and eight times where it took about a month or more time. There was only one negotiation, which did not result in drawing-up the new plan, as all therapies were discontinued. The fluctuation of the time between the negotiation date and the preparation date of B-statement is shown in Figure 57.

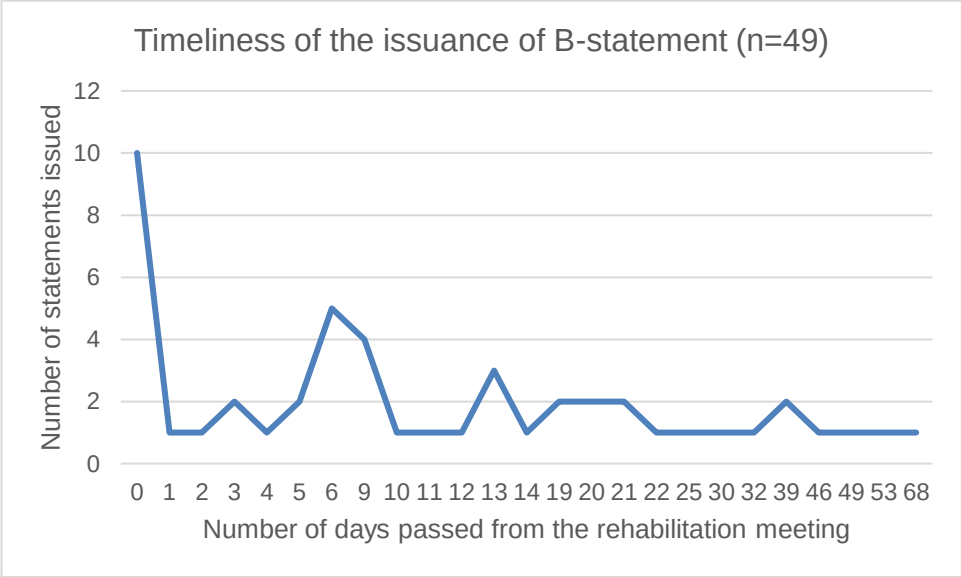

Figure 57. Fluctuation of time between the rehabilitation negotiation and the issue of B-statement.

On a positive note, B-statements were issued nearly real-time, on the day of the negotiation in 10 out of 49 times. On a negative note, there were eight times where there was

a 1-month or more delay in the issuance of the B-statement. Given these figures, there was variance in the number of days it took to issue the B-statement. It ranged from same day issuance to two months post-rehabilitation negotiation. About half of all B-statements were issued within a week of the rehabilitation meeting, and out of them, 20% were issued nearly real-time, on the same day as the meeting was held.

6.3.7 Mailing of statements

After the preparation of the B-statement and other necessary (therapy-specific) statements, the documents are collected and mailed to the rehabilitees and/or their legal guardians or other caregivers. After mailing the documents, the mailing date is entered in the patient records, as evidence of service provided. At times, this mailing is replaced by families choosing to pick up statements directly from the clinic, thereby avoiding mailing procedure and potential mailing related delays.

The mailing date of statements and/or notification of parents about statement pick-up, was included in the data collection, to measure both person-centeredness and timeliness of the process from both the clinic´s and the customer´s perspectives. From the clinic´s perspective, it shows how quickly the papers were processed locally and sent forward to the customer. From the customer perspective, it effects the total waiting time. The main objective here would be to avoid unnecessary hold-ups and delays of statements, thereby allowing the customer to proceed smoothly and timely with their own therapy application. The mailing time, however, does not directly tell how fast the customer received the papers in the traditional paper post, due to possible delays, strikes etc. in mail services, but it does give a relatively good indication.

The mailing time, or other notification given to families, was calculated from the date of issue of the B-statement, as this naturally affects the time it can be mailed. Figure 58. outlines the mailing times, which ranged from zero (n=8) to 26 days (n=1), with the zero days indicating that the statement(s) were mailed on the date of issue.

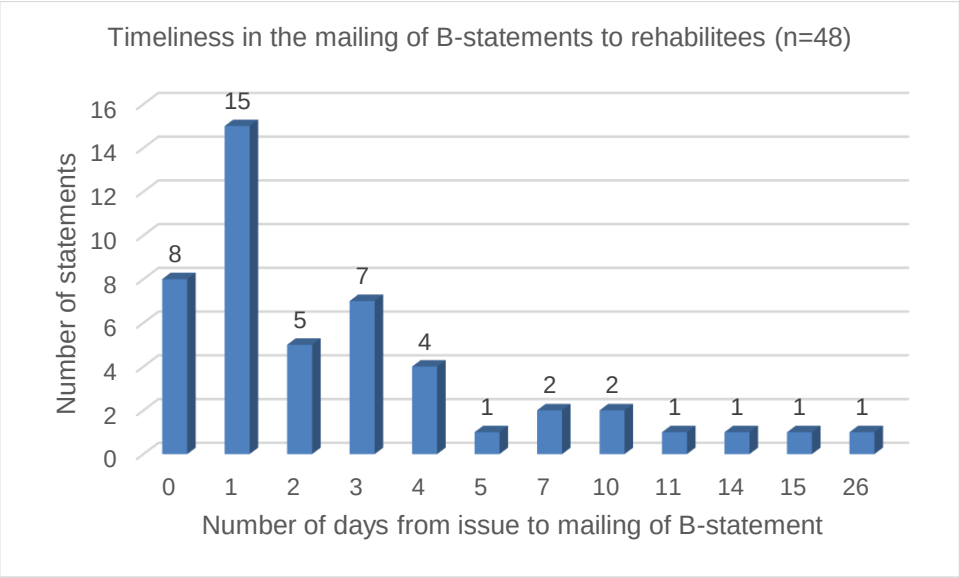

Figure 58. Pass of time between the issue and mailing of statements to customers.

As it shows, majority of statements were mailed to rehabilitees within four days after the issue of B-statements. The mode, being the most common mailing day of the statements was one day post-negotiation (n=15) and the median was 2 days, indicating quick response and service delivery times. However, as the data indicates, there were also some delays in the mailing times. In nine cases the mailing time extended from five days to up to 26 days, thereby affecting the mean number of days being 3,5.

6.4 Length of process

Next, the cycle times of the entire processes are described, starting from the mailing date of the first invitation and ending with the mailing date of the newly made rehabilitation plan. Based on the 43 processes (86%) in which the cycle time could be calculated, the cycle time was on average 77,7 days, with the standard error of mean being 4,3 and standard deviation being 28,1 days. The minimum length of the process in this data sample was 13 days and maximum length was 161 days, giving a wide range of 148 days. Median (the middle value) was 75 days and the smallest most frequent number of days (mode) was 56 days. In total, there were seven missing cases for this measure, caused by no data entries made about mailing of invitation to six rehabilitees and one person not having a new rehabilitation plan made at the end.

As shown in Figure 59., over half of the 43 processes (n=24) were completed in 61-90 days. On a negative note, there were seven processes (16,3%), where it took 91-120

days to complete and three processes (7%) taking 121 days or more time. On a positive note, there were nine processes in total, lasting either 31-60 days (n=6) or up to 30 days (n=3).

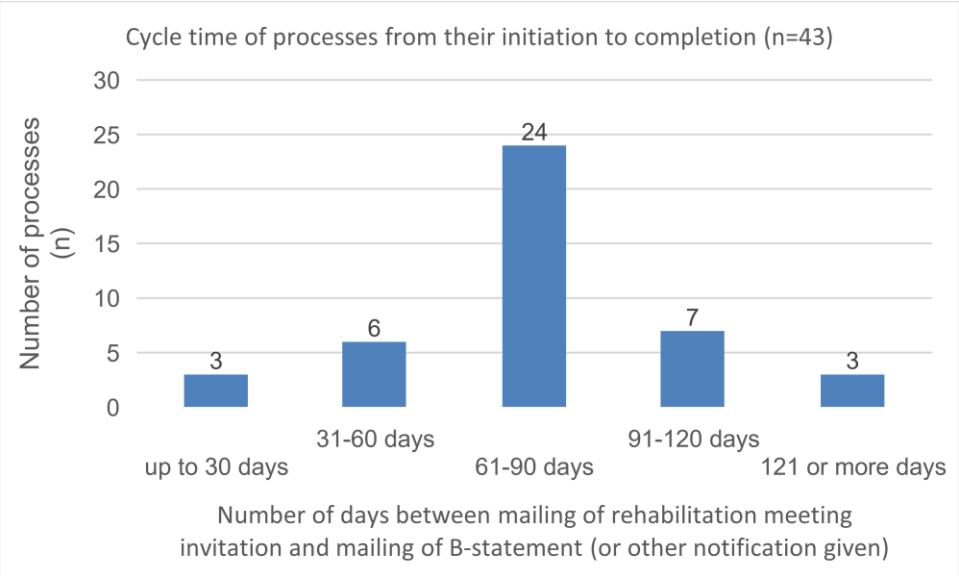

Figure 59. Process cycle times indicating time from initiation to completion of process.

Based on these process cycle times, it can be concluded that there was great variance in the durations of the processes. Majority were completed in 2-3 months of time, but at best, the process was completed in a month. At the most, it took 3-4 months or more time. There was no significant correlation found between the month of the rehabilitation meeting and the length of the entire process.

Since the above durations only tell the total length of the process, and not whether the process was finished “on time” from the customer perspective (i.e., before the expiry of the old rehabilitation period and the recommended starting time of the new rehabilitation period), another critical timely measure was added, namely “the leftover time” after the completion of the clinic´s process, for the customer to proceed with his/her therapy application, to indicate the timeliness of the process completion for the customer.

6.5 Leftover time post-process

Knowing what the implementations of the rehabilitation processes looked like in practice, next it is looked at weather this was done in a timely manner, so that the rehabilitees were left with enough time to proceed with their therapy applications before the expiry of

their ongoing rehabilitation plans and before the start of their newly drawn up rehabilitation plans. From the person-centeredness and timeliness perspectives, it is important to avoid causing delays or interruptions of ongoing or starting therapies, which could be non-beneficial or even at worst, harmful, to the rehabilitees. Ideally, rehabilitees and their caregivers are left with adequate time for preparing their therapy applications, collecting necessary statements, and forwarding all documents to Kela officials for further processing and decision-making.

This aspect of timeliness was measured by counting the number of days that remained between the date of issuance of B-statements and the starting dates of the rehabilitees´ new rehabilitation periods (Figure 60.). For this purpose, the date of issuance of B-statement was chosen over the mailing date of the statement (or other notification about its readiness), because it was more frequently given variable across all 50 processes.

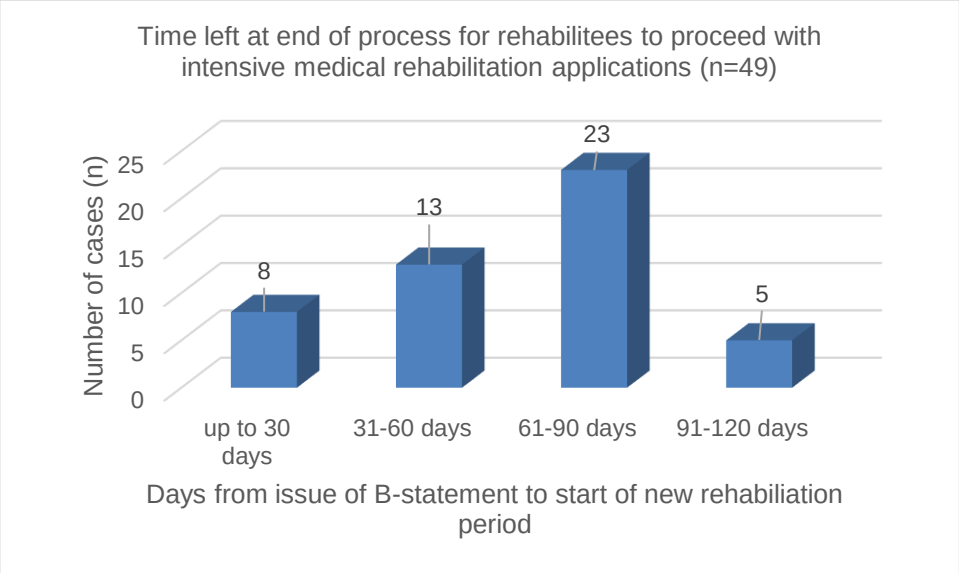

Figure 60. Timeliness of process, indicating the “leftover time” that the rehabilitees had left after the process completion at the Outpatient clinic, for applying the necessary therapies through Kela, prior to the start of the new rehabilitation plan.

As shown above, there was high variance in the amount of time left for the rehabilitees to proceed with their therapy applications, prior to the start of their new rehabilitation plan period. In nearly half of all cases (n=23), rehabilitees were left with 61-90 days to proceed and roughly in every fourth case (n=13,) they were left with 31-60 days to proceed. However, there were nearly ten persons (n=8), who were only left with up to 30 days to proceed, prior to the start of their new rehabilitation plan. On the contrary, five persons were left with extensive 91-120 days to proceed. Out of all 49 processes, the mean number of days left in between the two dates was 58 and the standard deviation was 27,3 days.

When looking at the specific numbers of “leftover time” more closely (Figure 61.), the days ranged from zero (n=2) to 115 days (n=1), with the zero meaning that the rehabilitees had no time at all in between the issue of B-statement and the start of the new rehabilitation plan. A closer look at the two processes showing zero days in between the expiry of the old and start of the new plan revealed that one of them was caused because of customer reasons and the other because of bottlenecks in the clinic´s practices.

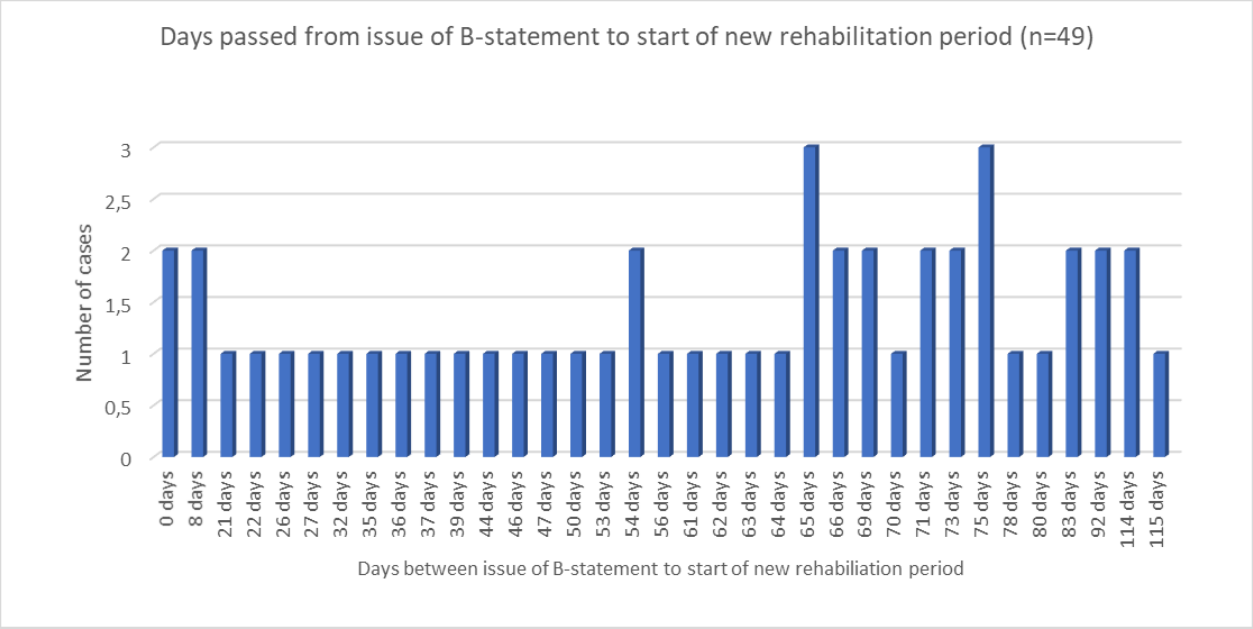

Figure 61. Time left for rehabilitees to proceed with their therapy applications, prior to the start of the new rehabilitation plan periods, excluding the mailing time of the statements.

In addition to the two persons having no leftover-time, there were two persons having only 8 days left and four persons having 20+ days left to proceed before the start of their new rehabilitation plan, thereby causing likely delays and hold-ups in the activation of the new plan. Rest of the persons were provided service with better timeliness, since five persons were left with 30+ days, three persons 40+ days, four persons 50+ days, seven persons 60+ days, five persons 70+ days, two persons 80+ days, one person 90+ days, and two persons 110+ days at the end of the process.

Given these leftover-times and the suggested minimum 36-day rehabilitation application processing time for Kela (36-day estimate was used as a benchmark and was based on Kela´s online application processing time calculator, calculated on 23 April 2021) (Kela 2021), it can be concluded that majority of the rehabilitees were left with sufficient processing time, equaling to, or exceeding the 36 days (n=39/49, 79,6%). On the other hand, 20,4% of the rehabilitees were left with insufficient, 0-35 days amount of time to proceed,

causing likely delays and hold-ups in the activation of the new plan, thereby putting the customers at risk for having an interruption in their rehabilitation. These numbers, however, mirror only Kela´s processing times from April 2021, and do not consider their annual busy seasons, such as December and January, which could nearly double the processing times (Haapala 2021).

6.6 Summary of results

Regarding the age and background of the rehabilitees, whose service processes were examined in this master thesis (n=50), majority were 6-11 and 12-17 years of age and attended either school (70%) or daycare (20%) during the day. Before the start of the rehabilitation assessments and negotiations, majority of the rehabilitees had either one (48%) or two (36%) ongoing therapies running under their *old* rehabilitation plans. Majority of these plans (92%) were made for 1-year in duration, and the most common expiry months of those plans were December (25%) and July (15%).

Regarding the assessments of rehabilitation needs for the purpose of making the *new* rehabilitation plans, these were done in all therapies **directly**, by visiting rehabilitees mostly at daycare, school, or home, as well as **indirectly**, by assessment phone calls targeted to therapy providers and parents. Overall, the volume of direct versus indirect assessments and their nature varied between therapies/professional groups. The proportion of direct assessments was 84% in speech therapy, 78% in physical therapy (including hydrotherapy), 67% in EAT, 33% in occupational therapy and 25% in music therapy. In all therapies, over half of the assessment phone calls were made to the therapy providers (over parents), and there were no assessment calls made to the rehabilitees themselves. However, there was 100% rehabilitee participation rate achieved in all assessments done in everyday life settings. The participation rate of caregivers in the assessments was limited to 20-30% in the mainstream therapies (physical, hydro, occupational, and speech therapy). The nature and level of cross-organizational collaboration varied between professional groups and depending on the assessment method used. The level of collaborative visits with the therapy providers was highest among physical therapists (100%) and lowest (17%) among speech therapists, whereas assessments made by occupational therapists and psychologists (for music therapy) involved more phone calls than visits. The volume of collaborative discussions with daycare and school personnel during the assessment visits was 50-70% of all applicable

daycare visits and 30-100% of all applicable school visits. Regarding the level of inter-disciplinary teamwork, assessments carried out as working couples amounted to 10-15% of all assessments, indicating rather low level of IDT and involving mostly assessments of customers participating in the early rehabilitation program (vartu) of the clinic. There was no co-operation done with the social workers or translators during the assessments. Out of those rehabilitees having ongoing therapies, vast majority were assessed on-time before their rehabilitation negotiations.

Regarding the rehabilitation negotiations, these were initiatied by mailing the negotiation invitation to the rehabilitees. In 74% of all reported cases, there was one invitation letter mailed to the rehabilitees and their caregivers, and nearly 90% of all letters were sent either 31-60 days or 61-90 days before the scheduled rehabilitation negotiation time. Majority of the negotiations were scheduled for the month of October (n=10) and April (n=7). In the 50 negotations held, the total number of internal and external participants ranged from 4 to 11 persons, but on average, there were seven persons present at the meetings, give or take two persons. Regarding the external participants, rehabilitees themselves participated 92% of all meetings. Also, parent(s) or grandparent attended 100% and group home personnel two out of three (66%) of negotiations held, showing high degree of participation. Therapy provider attendance ranged from the lowest attendance rate of 20% in music therapy to the highest of 80% in physical therapy. Daycare personnel attended 20% and school personnel 51% of all applicable meetings. Social workers´ attendance contributed to 36% and translators´ 8%. Other external participants included the siblings of the rehabilitees and a family worker. Regarding the internal participants, this ranged from one to five professionals per negotiation, with the mean being three participants, give or take one person, thereby showing evidence of higher degree of IDT approach than what was achieved in the assessment phase. Physicians were present in 49/50 meetings, facilitating the drawing-up or renewal of the rehabilitation plan for the rehabilitees. Psychologists were present in 30% of meetings, covering majority of persons having ongoing music therapy and contributing to “right” meetings. Therapists also attended majority of meetings, where they were needed to make recommendations regarding the continuation or termination of those therapies in question. Therapists were also present in several negotiations, where the rehabilitee had no ongoing therapy. Regarding the on-time availability of the therapy providers´ feedback reports regarding the ongoing therapies, this varied between therapies, and the information was not always specified in the data entries.

Regarding the therapy recommendations made in the negotiations, majority of the rehabilitees were recommended one (54%) or two therapies (30%). Regarding the durations

of the newly made rehabilitation plans, 90% were made for 1-year period. There was variance in the timeliness measure in the preparation of the B-statement post-negotiation. Approximately half were issued within a week from the negotiation and another 22% within 8-14 days from the negotiation. The rest took from 15-28 days (n=8) to 29 days or more (n=8). Majority of the statements were mailed between the day of issue and up to 4 days after its issue, most frequent mailing day was the day after its issue indicating fast, timely service. The variance in the entire process cycle time starting from the mailing of the first invitation and ending to the mailing of the statements varied from process to another, although roughly 50% were completed in 2-3 months of time. At best, the process was completed in one month´s time, and at the most, it took 3-4 months or more time to complete. Regarding the time that was left for customers to apply for the recommended therapies from Kela after the process completion at the clinic and before the indicated start of the new rehabilitation period, nearly 80% of rehabilitees were left with sufficient processing time, equaling to, or exceeding the minimum of 36 days required by Kela (as of April 2021 benchmark) (Social Insurance Institution of Finland 2021).

7 Discussion

Next, the research results are analyzed through the lens of person-centered and timely care, including the core principles of rehabilitee and family involvement, cross-organizational collaboration and interdisciplinary teamwork, informational continuity as well as timeliness and continuity of care.

7.1 Rehabilitee involvement

It is known that one of the core principles of person-centered care and service, also in rehabilitation settings, is the active engagement and participation of the service user in his/her processes of care and shared decision-making in matters involving care (Silva 2014: 2, 9; Paltamaa et al. 2011: 23). Therefore, including this measure of rehabilitee involvement also in this study and in the different phases of the rehabilitation planning process was critical.

Concerning direct and indirect rehabilitee involvement in their rehabilitation needs´ assessments, the direct participation ranged from the highest of 84% in speech therapy to the lowest of 25% in music therapy assessments made in-person. In other therapy assessments (physical and hydrotherapy, occupational therapy and EAT), the direct rehabilitee participation varied between 67-78%.

In physical therapy and hydrotherapy, majority of rehabilitees were assessed in-person (78,3%), with the rehabilitee present 100%. The proportion of assessments made by telephone remained low, at 21,7% and the calls were targeted to parents and therapy providers, not the rehabilitees themselves. In occupational therapy, the level of in-person assessment remained lower (33,3%) and the volume of assessment phone calls to the therapy providers and parents was higher (71,4%). But there too, rehabilitees were present in 100% of all assessments made in-person (n=7). In EAT assessments, direct rehabilitee participation was realized in two out of three cases (66,7%) and rest were indirect phone calls to parents and therapy providers. The onsite assessments were limited to other than the actual EAT therapy settings, but still showed evidence of direct rehabilitee involvement. In speech therapy, majority of the assessments were done in-person (84,2%) and with 100% rehabilitee presence, and minority indirectly using assessment phone calls (15,8%). This nearly 85-15% split between direct and indirect assessments referred to the highest rehabilitee involvement and participation out of all. In music therapy, assessments were performed by the clinic´s psychologists to four out of five rehabilitees having ongoing therapy, using both phone calls to parents and therapy providers, as well as one in-person visit (25%), showing limited amount of direct rehabilitee involvement.

Knowing the direct and indirect participation levels of the rehabilitees in the assessments, it can be concluded that the level of direct rehabilitee participation varied between therapies and occupational groups, based on the assessment methods used. It is not under the scope of this study to define the factors contributing to this variance, and so, it would be worth another research to determine these factors. It is the best guess of the author, that the differences are partly staffing and personnel resource related, as the relative volume of direct assessments (by in-person visits) was the highest in speech and physical therapy assessments, where the number of personnel was also the highest. Similary, the relative volume of indirect assessments (by telephone) was the highest in occupational therapy, where the number of personnel was the lowest. Another potential factor contributing to this variance can be the preference of the different occupational groups to use different types of assessment methods. Given the limited sample size (n=50) and the large differences in the proportions of the different ”ongoing” therapies

per rehabilitee, thereby affecting the volume of assessments made, there is also the possibility, that these results concerning rehabilitee participation do not reflect the entire population. For example, the number of rehabilitees having ongoing EAT at the time of the assessments was limited to three persons, and the number of persons having music therapy was limited to five persons. Therefore, it is difficult to make definite conclusions based on the small number of persons assessed. A larger sample size with different proportions in therapies and related assessments, could have given different results regarding rehabilitee involvement.

Regarding rehabilitee participation in the rehabilitation negotiations (n=50), the rehabilitees were present in 92% of the meetings (n=46), showing high level of engagement and participation. This is in line with the central element of person-centeredness in rehabilitation planning, which emphasizes the active participation of the person receiving care in his/her own rehabilitation process at all phases (Paltamaa et al. 2011: 23). However, the attendance percentage alone does not directly indicate how involved the rehabilitees with their disabilities were in the meeting and the discussions held there, and weather they were able to express their own needs and perspectives there. However, the presence of both the rehabilitee as the service user and the personnel as the service provider, enable and facilitate dialogue, collaborative planning, and decision-making, at least to a certain degree. More research would be required to examine, weather the participation alone did allow the forming of dialogue and consultative partnership, where both parties could bring their own expertise and form a shared vision and plan regarding the necessary rehabilitative measures. (compare to Karhula & Salminen 2016: 5.)

7.2 Caregiver involvement

Participation of families and other caregivers in the planning of care and rehabilitation form another central aspect of person-centered health care system, which aim to take a holistic approach to assessing needs and providing care, often requiring collaboration with the people closest to the person being cared for. (de Silva 2014: 9.) Through collaborative practice with families and other immediate environments it is possible to support the entire rehabilitative process and to improve rehabilitation outcomes (Autti-Rämö & Komulainen 2013: 1; Social Insurance Institution of Finland 2020: 13-14). Also, according to a recent study conducted in Finland about the service paths for the developmentally and intellectually disabled, the results confirm that the collaboration done with caregivers during the making of a rehabilitation plan is highly valued (City of Espoo 2021).

Therefore, including this measure into this study was meaningful. In the following, the caregiver involvement in the rehabilitation assessments and negotiations is discussed by using the two broad carer categories defined by Miles and Asbridge (2014: 1).

Regarding the rate of parents´ involvement in the assessments of rehabilitation needs in the *mainstream* therapies, parents were physically present in 27-28% of the assessments made in-person for physical therapy, hydrotherapy, and occupational therapy. For speech therapy, the presence of parents was slightly lower, 22%. Regarding the rate of parents´ participation in the assessments of the less common therapies (EAT and music therapy), there were no collaborative assessment visits done with parents. Regarding parents´ involvement in other form of assessments, parents were made a total of 31 proactive assessment phone calls from all therapies, amounting to 35% of all assessment calls made, showing that majority of calls were targeted to therapy providers, instead of parents.

Regarding the participation of other caregivers of the rehabilitees, this was limited to group home personnel, which was physically present in one of the assessments made by a physical therapist in a group home setting. In other therapies, there were no assessments made in group homes, thereby involving no group home participation.

Regarding the participation of the caregivers in the rehabilitation negotiations, at least one of the parents or both parents were present in 49 out of 50 meetings, and in the one meeting missed, there was a grandparent present. Group home personnel attended two out of three applicable meetings, giving a participation rate of 66%. Due to the small number of children and youth residing in group home settings, it is difficult to generalize and draw any definite conclusions about the participation levels of group home personnel in the rehabilitation negotiations.

It can be concluded that there was great variance in caregiver involvement in the different phases of the service process. It was high during rehabilitation negotiations, when parent(s) or grandparent attended 100% and group home personnel two out of three (66%) of the negotiations held. This indicates that parents were highly involved in the planning of intensive medical rehabilitation for their child/youth, which is in line with the philosophy of person-centered care, aiming to form collaborative partnerships, and to place families at the heart of all decisions (de Silva 2014: 6). Due to the small representation of rehabilitees living in group home settings, it is impossible to make any generalizations re-

garding the level of participation of group home personnel, although they did show involvement in rehabilitation planning of the persons they cared for. Overall, this measure of parental and other caregiver attendance to the negotiations does not directly tell, what the level of active dialogue was in the meetings, and weather the needs and expectations of parents and other caregivers were heard.

Regarding the participation levels of the caregivers in the rehabilitation assessments, this remained much lower, in comparison to the attendance to the negotiations. There was also therapy-specific variance in the volume of collaboration done with parents and group home personnel, including both assessments made by telephone and by in-person visits. Factors contributing to the low level of parental involvement in the assessments can be timing and location related because assessments are done during the regular workdays and working hours of the week, and as the results show, mostly in daycare and school settings, when parents themselves are most likely occupied at work. Factors hindering the participation of group home personnel were that there was only one assessment made in group home setting. However, there were several assessments done by phone calls between the clinic´s therapists and the parents, thereby partly compensating for the lack of face-to-face assessment sessions. There were no assessment phone calls documented to be targeted to the group home personnel. Unfortunately, it is not under the scope of this study to be able to determine if the level of caregiver involvement in the assessments undertaken is adequate or not. This would require another study, investigating parents´ perspectives to this matter.

7.3 Cross-organizational collaboration

Person-centered care is known for its holistic approach utilizing teamwork (Scholl et al. 2014: 5), which often results in the crossing of organizational and sectoral boundaries, as well as collaboration with professionals from different specialties and sciences. The same goes for the organizing and providing of rehabilitation services for the disabled, being a diverse field and requiring specialists from many fields, including social services (Virtanen et al. 2011: 11). Against this background, it was important to include the measure of cross-organizational collaboration into this study.

In the rehabilitation planning for the customers of the Outpatient clinic, the cross-organizational, collaborative partners included therapy providers, daycare, school and daytime activity center personnel as well as social workers and translators. Next, the

level of this collaboration over organizational boundaries is discussed, analysing the two phases of rehabilitation assessments and rehabilitation negotiations separately.

In physical therapy and hydrotherapy assessments undertaken, co-operation with the therapy providers was done through collaborative visits and phone calls targeted to the therapy providers. Collaborative visits took place in 100% of all applicable processes (n=14), meaning that if there were rehabilitees having ongoing physical therapy, assessments were done as collaborative visits with the physical therapy providers. Regarding the assessments made by telephone (n=20), 60% were targeted to the providers and rest to parents. Regarding other cross-organizational collaboration, daycare personnel was involved in 50% of the assessments made in daycare settings and school personnel was involved in a third of assessments made in school settings. There were no assessments performed in daytime activity centers, and neither was there any co-operation with the social workers or translators during the assessments done by physical therapists.

Regarding collaboration over organizational boundaries in occupational therapy, co-operation was done with the therapy providers mainly through the telephone assessments (n=16), and 84,2% of all calls were targeted to the providers instead of the parents. There was only limited amount of collaborative assessment visits made, as the therapy providers were only present in two and absent in three out of the seven applicable assessments made in-person. Regarding other cross-organizational collaboration during the assessments performed from occupational therapy, daycare personnel was involved in half of the assessments made in daycare settings and school personnel was involved in all assessments made in school settings. There were no assessments made in daytime activity centers, and there was no co-operation done with the social workers or translators during the assessments done by occupational therapists.

Regarding cross-organizational collaboration in speech therapy assessments, co-operation with the speech therapy providers was done in moderation and it divided between telephone assessments and collaborative visits. Out of the 32 assessments made in-person, the therapy providers were present in four assessments only, resulting in involvement of 12,5%. Regarding assessment calls targeted to the therapy providers, there were 24 calls made in total to the therapy providers, amounting to 60% of all calls made, the rest of calls targeted to parents. Regarding other collaboration, daycare personnel was involved in 75% of the assessments made in daycare settings and school personnel was involved in and discussed with, in 95% of assessments made in school settings. There were no assessments made by speech therapists in daytime activity centers, and

there was no co-operation done with the social workers or translators during the assessments carried out by speech therapists.

Regarding cross-organizational collaboration in the music therapy assessments, there was some co-operation done with the private music therapy providers using telephone conversations, and an external music therapist was consulted upon need.

To conclude, the amount and nature of cross-organizagtional collaboration varied from process to another and between the different therapies assessed. Marjoity of collaboration occured in the mainstream therapies, as summarized in Table 5. The distribution of the calls to the therapy providers over parents ranged from 60 to 84%, with most calls made from occupational therapy. The amount of assessments made in collaboration with the therapy providers was the highest in physical therapy and lowest in speech therapy. The proportion of assessments done in collaboration with daycare personnel ranged from 50-70% and with school personnel from 30-100%.

Table 5. Summary of the nature and proportions of the collaboration during the rehabilitation needs´ assessments made in the mainstream therapies.

	Assessed therapy		
Nature and proportions of cross-organizational collaboration	**Physical and hydrotherapy**	**Occupational therapy**	**Speech therapy**
Calls to therapy providers	n=12/20, 60%	n=16/19, 84%	n=24/40, 60%
Visits with therapy providers (proportion expressed in relation to rehabilitees having ongoing therapy)	n=14/14, 100%	n=2/5, 40%	n=4/24, 17%
Collaborative visits with daycare personnel	n=2/4, 50%	n=1/2, 50%	n=6/8, 75%
Collaborative visits with school personnel	n=3/10, 30%	n=4/4, 100%	n=20/21, 95%
Collaborative visits with daytime activity center personnel	-	-	-

Next, looking at the cross-organizational collaboration of the rehabilitation negotiations. Regarding the attendance of the therapy providers in the rehabilitation negotiations, there were 1-3 therapy providers present in 56% of the meetings (n=28). When matching the therapy provider attendances to the ongoing therapies for these rehabilitees, the attendance of physical therapy providers to the meetings was nearly 80% and for hydrotherapy the attendance was 50%. For occupational therapy, the attendance of the therapy provider was nearly 37% and for EAT the attendance of the therapy provider was nearly 67%. For speech therapy, the attendance was nearly 39% and for music therapy

it was 20%. Given these numbers, there was high variance in the attendance of the therapy providers, with the physical therapy providers showing highest attendance percentage, and music therapy providers showing the lowest.

Regarding the participation of daycare, school, and daytime activity center personnel in the rehabilitation meetings, daycare personnel had an attendance of 20%, representing early childhood education teachers and daycare assistants. School personnel attendance to meetings amounted to 51%, representing mostly teachers of the rehabilitees. Given the pediatric nature of the data sample, there was only one person having daytime activity center personnel participation in his/her rehabilitation meeting, representing their service manager and instructor. Based on these figures, it can be concluded that school personnel were represented more frequently than daycare personnel in the rehabilitation meetings of the pediatric clients of the Outpatient clinic.

Regarding the involvement of other cross-organizational partners, social workers of the rehabilitees were present in 36% of all meetings. Language translators were only present in 8% of all meetings, even though there is a growing number of multinational customers at the Outpatient clinic, whose native language is other than Finnish. Based on these numbers of the data sample, it can be concluded that there was some collaboration done with social workers, but translator services were required less frequently.

To conclude, the level and nature of cross-organizational collaboration in the different phases of the rehabilitation process vary according to the daytime placement of the rehabilitee, the nature and number of ongoing therapies for the rehabilitee and the slightly different assessment practices used by the occupational groups of the Outpatient clinic. Common to all assessments was that majority of the assessment phone calls were made to the therapy providers (over the parents), facilitating collaboration in the form of verbal information exchange between health professionals. Majority of the assessment visits took place in daycare and school settings, although home visits were also common in physical therapy and speech therapy, thereby showing evidence of both cross-organizational and family involvement. On the other hand, there was limited collaboration done with personnel from daytime activity centers, which fits the pediatric profile of the customers. The collaboration with the social workers and translators was done only during the rehabilitation negotiations, and to a limited degree.

Factors, that could potentially allow or hinder the participation of the cross-organizational members to the rehabilitation assessments or negotiations can vary from staffing and

personnel resourcing issues (e.g., social workers, daycare, and school personnel) to Kela compensation issues (therapy providers). Secondly, the selection and invitation of the participants, especially involving the rehabilitation meetings, is generally the task given to the rehabilitees and their caregivers. Therefore, these numbers regarding the participants to the rehabilitation negotiations can reflect the willingness or the forgetfulness of the rehabilitees and their caregivers to include or exclude some of these external parties in the meetings. Regarding the participation and collaboration with the social workers and translators, these persons are generally invited by the Outpatient clinic, based on need expressed by the rehabilitees and their caregivers.

7.4 Interdisciplinary teamwork

Despite the legal obligations for teamwork (The Social Insurance Institution´s Rehabilitation Benefits Act 145/2015; Social Insurance Institution of Finland 2020: 13) and the many benefits obtained through interdisciplinary collaboration, many organizations lack teamwork (Mezzich et al. 2014: 2), and therefore, it was interesting to examine the extent to which it occurred in the processes under study.

Looking at the degree of interdisciplinary teamwork in the rehabilitation assessments, it remained rather low. In physical therapy and hydrotherapy assessments, assessments done with a colleague remained at 11% of all assessments. In occupational therapy, two assessments involved some form of internal discussions in an interdisciplinary manner and two out of the seven assessments were made together with the clinic´s occupational therapy student interns. There were no other assessment visits made in an interdisciplinary manner with colleagues representing other specialties. The EAT assessments did not include any internal collaboration with colleagues, as all assessments were carried out as own, independent activity or in co-operation with therapy providers. In speech therapy assessments, collaboration remained at 16%, meaning that 5 out of 32 in-person assessments were carried out in co-operation with a colleague, representing a minority practice. In music therapy, internal collaboration was limited to one internal discussion, and one external consultation. This low level of teamwork is in line with previous research findings indicating that many health care organizations have barriers to teamwork, such as lack of time to collaborate, lack of role clarification and culture (Fewster-Thuente & Velsor-Friedrich 2008: 4-5). It would require more in-depth research to find out what the causes were in the case of the Outpatient clinic.

Next, looking at the level of teamwork and internal participants at the rehabilitation negotiations, overall, the number of professionals attending the meetings ranged from 1-5 persons, and on average, was three persons, give or take one person. Most commonly, there were either four (32%), three (30%) or two (28%) health professionals attending each meeting. At the most, there were five professionals attending 8% of meetings and at the least, only one professional attending one meeting (2%). Based on these figures, it can be stated, that majority of the rehabilitation meetings were carried out in an interdisciplinary manner, thereby showing evidence of person-centered care. Out of all 50 meetings held, a physician was present in 98%, a psychologist in 30%, physical therapist present in 58%, occupational therapist in 48%, speech therapist in 78% and student intern(s) in 4% of the meetings.

When assessing the meeting participants from the perspective of the personnel representatives needed there, from customer and his/her ongoing therapy point-of-view, physical therapists were present in 29 meetings and absent in 21 meetings, and in the meetings missed, there was one rehabilitee having ongoing physical therapy. Occupational therapists were present in 24 meetings and absent in 26 meetings, and in the meetings missed, there were two persons having occupational therapy at the time, but no representation of the clinic´s occupational therapist in the meeting. For EAT, there were three persons having ongoing EAT running parallel to physical therapy at the time of the meeting, and the clinic´s physical therapist attended the meeting in two out of the three cases (66,7%). Speech therapists were present in 39 meetings and absent from 11 meetings, and in the meetings missed, there were two persons having ongoing speech therapy. Regarding the participation of the clinic´s psychologists in the rehabilitation meetings, they were present in 15 meetings and absent from 35 meetings, and in the meetings missed, there was one person having ongoing music therapy.

Based on these internal representations, physicians were present in all but one case, giving an excellent rate of attendance, as well as facilitating the drawing-up or renewal of the rehabilitation plan for the rehabilitees. Psychologists, on the other hand, were only present in 30% of meetings, but these meetings covered majority of the persons having ongoing music therapy. Therefore, psychologists contributed and participated in the meetings where they were needed to make recommendations for the continuation or termination of music therapy. Regarding the attendances of the physical, occupational and speech therapists, they also attended majority of those rehabilitation meetings,

where they were needed to make contributions and recommendations regarding the continuation or termination of those therapies. There were only a few occasions, where the therapists missed a rehabilitation negotiation, where the rehabilitee had ongoing therapy. Given these high rates of interdisciplinary collaboration during the rehabilitation negotiations, it shows that there were less barriers for teamwork taking place in the Outpatient clinic setting, than in comparison to the assessments made in various locations.

7.5 Therapy feedback reports

Organizations embracing person-centered care typically have a value-base of consisting of solution-focused care and continuity of care (Buchanan 2017: 6). One aspect of continuity of care is informational continuity, which means the use of relevant information to make current care appropriate. (Reid et al. 2002). For the purposes of this study, the appropriate measure of informational continuity was the “on-time” availability of the therapy feedback reports, provided to the Outpatient clinic by those private therapy providers of the rehabilitees, who were providing and implementing therapies at the time, under the “old” rehabilitation plan. Ideally, these reports enable relevant and timely information exchange between the public organization responsible for care (the Outpatient clinic) and the private sector (therapy providers), which is needed in addition to the rehabilitation assessments and negotiations, for the purpose of making person-centered and timely rehabilitation recommendations for the upcoming, “new” rehabilitation periods of the rehabilitees.

Based on the information available in the Pegasos data repository, therapy feedback reports were available for use at the rehabilitation negotiations in approximately 40-60% of all meetings. However, given the gaps in the data, resulting from that this information was not always documented by the personnel of the Outpatient clinic, full analysis on the on-time availability could not be made.

7.6 Timeliness of service

In the following, the timeliness of the previously presented processes of the Outpatient clinic are discussed, to see whether there was prompt action versus potential delays, smooth actions versus interruptions, or possible duplications of activities that might slow

down the process and cause poor continuity of care, which should be avoided (compare STM 2002: 3, 8-9). This information helps to detect any bottlenecks in the processes and in the continuous development of the process, provided by the clinic, who is responsible for the coordination of services into an integrated and seamless pathway, that strives for continuity of café (de Silva 2014: 2, 9).

The first timeliness measure of this study was the measure of notification time to the customers about their upcoming rehabilitation negotiation, in other words, the sending of the invitation letter. There was great variance in the timeliness of the first invitations sent, ranging from 14 to 140 calendar days. However, the most common notification times were 1-3 months prior to the rehabilitation negotiation, accounting for nearly 90% of all cases. Based on these findings, it can be concluded, that majority of the customers were left with sufficient notification time of their upcoming rehabilitation negotiation. Also, given the small rate of appointment cancellations and rescheduling of appointments, majority of customers also accepted the initially suggested rehabilitation negotiation time. With the handful of customers, who wished to reschedule due to varying reasons, the clinic showed flexibility and ability to accommodate to individual customer wishes.

Given these mainly acceptable, yet highly variable notification times towards the customer, a question arises: What could be the cause of this variation? Is it because this activity is not an automated process, but rather a manual procedure carried out by the health care personnel of the clinic, thereby not representing a standardized set of automatic mailing dates but rather causing high variance?

Another timely measure of the process was the issuance of the rehabilitation plan, i.e., the B-statement, after the rehabilitation negotiation was held. As the data showed, there was high variance in the number of days it took to issue the B-statement. This shows that the process is not carved in stone as a standardized practice, but rather, varies from one process to another and between physicians, who write the statements. A positive finding was that about half of the B-statements were issued within a week of the rehabilitation meeting, and out of them, 20% were issued nearly real-time, on the same day as the actual rehabilitation meeting took place. However, there were still several statements written relatively late, increasing waiting times for the customer, and thereby causing delays in the entire process and potentially customer dissatisfaction. From the timeliness perspective, it would be worth finding out the reasons for these hold-ups and eliminating these delays in the future, to ensure speedy service and the reduction of wait-times and harmful delays, as well as to maintain higher quality of service (AHRQ 2020). This would

be also in line with the findings of a recent research published by the city of Espoo, concerning the service paths targeted to the developmentally and intellectually disabled persons and people closest to them. Their results indicated that in rehabilitation planning and in the making of rehabilitation plans, timeliness, or the lack of it contributes a great deal to the customer satisfaction and/or dissatisfaction. Any delays and the causing of interruptions in therapies should be avoided, adding to the experience of customer satisfaction. (City of Espoo 2021.)

The third timely measure was the mailing time (or other notifications made to customers) of the prepared statements, such as the B-statement and statements prepared by therapists to the customers, post-meeting. Majority of statements were mailed between the day of issue and up to four days after its issue. The most frequent mailing day was the day after its issue (n=15, 31,3%), indicating fast, timely service to the customers. There was, however, also some variance in the mailing times and there were nine times, where it extended from five days to up to 26 days, causing delays in the process.

Regarding the total cycle times of all process, there was great variance in this measure, although over half of all processes were completed in 2-3 months of time. At best, the process was completed in one month´s time, and at most, it took 3-4 months or more time to complete. There was no significant correlation found between the age of the rehabilitees nor the month of the rehabilitation meeting and the length of the entire process.

The different lengths of the processes may have resulted in different consequences to the customers, depending on when their current rehabilitation plan was expiring and when the recommended new plan was about to start, pending Kela approval. On the positive note, the quick 1-month process is more likely to allow the customer to proceed with their rehabilitation application in due time, thereby causing less delays and increasing the risk of interruptions in the therapies. On the negative note, lengthy processes caused by the few bottlenecks in the processes are more likely to delay the entire rehabilitation application process for the customer, putting them at an increased risk for having interruptions in the therapies in between the expiry of the old and the start of the new rehabilitation period, which is known to cause great harm and dissatisfaction to the customers (City of Espoo 2021).

Since the previous measure of the process length did not tell the entire truth from the customer perspective, another timeliness measure being the “leftover-time” for the customer, was added. It means the amount of time that was left to customers for further

rehabilitation application proceedings with Kela, after the process was completed at the Outpatient clinic and in between switching from the old to the new rehabilitation plan.

The results show, that nearly 80% of the rehabilitees in the data sample were left with sufficient processing time, equaling to, or exceeding the minimum of 36 days required by Kela (as of April 2021 estimate of minimum processing time), and therefore, does not account for all cases and all times of year (Social Insurance Institution of Finland 2021). On the contrary, this means that 20% of the rehabilitees were left with insufficient amount of time to proceed, ranging from zero days to 35 days, increasing the risk for delays and hold-ups in the activation of the new plan, and thereby putting the customers at risk for having interruptions in therapies.

Concerning the average rehabilitation application processing times of Kela, and the sufficiency or non-sufficiency of the times that were left for customers after the project completion at the clinic, it is impossible to say reliably and accurately, weather the left-over times were enough and for how many persons in total, as the Kela processing times of today are only current estimates, and do not reliably reflect the back-dated situation from 2019. In addition, the current processing times given by Kela also do not reflect and consider the natural, annual variance of processing times, especially during the busy months, such as December and January, which according to a Kela´s representative (Haapala 2021) could nearly double the processing time of rehabilitation applications.

7.7 Ethical questions

Any research using electronic patient data registry and records needs to consider patients' rights and issues of data protection and confidentiality (Bowling & Ebrahim 2005: 167, 185). This study has been carried out following all elements of good research practice, including responsible acting with the data in all phases of the study.

This research complies with the research ethics in the humanities and social and behavioral sciences, set forth by the Finnish National Board on Research Integrity TENK in 2019. These include respecting the dignity and autonomy of human research participants, respecting material and immaterial cultural heritage and biodiversity, and conducting the research in a manner, which does not cause harm, damage or significant risk to

the study participants, communities, or other subjects of research. (Finnish National Board on Research Integrity TENK 2019: 50.)

Due to the nature of this research, which was based solely on the secondary use of health data derived from one single data registry, no ethical review statement was required from the Finnish National Board on Research Integrity TENK, and it was possible to deviate from the principle of collecting informed consents from the data subjects (being the process owners and/or their legal guardians) before the data collection. However, the conduct of this research required a research consent from the city of Helsinki and was subject to the EU´s General Data protection Regulation (GDPR). This required the preparation of the research plan together with the privacy statement and related impact assessment, thereby ensuring appropriate security of personal data and to identify, evaluate and control the risks involved in the processing of personal data in all phases of the research. The impact assessment was needed in particular because of the deviation in the principle of the informed consent. The data collection conserning personal data was limited to the very minimum, necessary amount of data concerning the data subjects, as the main focus was in the analysis of the process itself, not the persons owning these processes. Data collection, analysis and reporting were carried by following the elements of GDPR and Data Protection Law 1050/2018 (Arene 2018).

While carrying out this research, all European principles of research integrity (Arene 2018) were also followed, containing such elements as honesty and openness in communication during the research, reliability on behalf of the researcher when collecting and analyzing the research materials as well as objectivity and impartiality when reporting the research results. It was the sole responsibility of the researcher to perform the collection and the analysis of the data, thereby increasing the likelihood for producing unified interpretations of the data. Biased interpretations have been avoided based on the fact, that the data of those processes, which were included in the data sample, were historically documented for other purposes than this research, so none of the data collected could have been falsified or altered by anyone for the purposes of this research.

7.8 Reliability and validity

Validity of reserach indicates the extent of the research to which it is able to investigate the phenomenon of interest, that it was initially intended to investigate (Hiltunen 2009). Regarding the validity of this research, the researcher aimed to enhance internal validity

(i.e., interpretability and factors affecting outcomes) by carefully collecting the data with a custom-designed data collection instrument, which matched the needs and objectives of the target organization, and then by rigorously analyzing the data. As a result, it was possible to produce a very detailed description and sense-making of the process and its different phases, ”as it was” in 2018-2019, also allowing the evaluation of its nature and degree of person-centeredness and timeliness to a certain extent. However, to gain more in-depth information and different perspectives, for example regarding the human experiences (e.g. experiences of the rehabilitees and their caregivers), a different research approach would be needed, since the data gained simply from health registry can only provide more superficial data, leaving many questions unanswered. For this purpose, the use of surveys, interviews or other data collection methods would be preferred. The benefit of using a registry approach in this study was, however, that in order to produce reliable and accurate information regarding the baseline of the care processes carried out in the past, it would have been impossible to collect this data simply by relying on memory of the customers nor the personnel of the Outpatient clinic. It is hoped that the information produced by this research can be used in the further development of this process. The external validity (i.e., the extent of generalizability) of this research may remain limited given the small, but well representative sample size of 50 processes.

Reliability of research indicates how reliably and consistently the applied research approach or measurement method measures the desired phenomenon (Hiltunen 2009). Regarding reliability, the researcher aimed to improve the internal reliability and consistency of the study by applying consistent a data collection, analysis, and interpretation, so that any other researcher could come to the same research results. Regarding the external reliability, it is the aim, that any researcher could reproduce a similar study, and by using the same data collection instrument.

8 Conclusions

The results of this descriptive, quantitative research based on historical, routinely collected data from 2018-2019 confirm that there were elements of both percen-centeredness and timeliness in the process of planning of intensive medical rehabilitation for pediatric customers at the Helsinki Outpatient Clinic for the Developmentally and Intellectually Disabled. However, the level of person-centeredness and timeliness varied

from process to another and in the different phases of the process. In particular, there was a large amount of variance in the level of person-centeredness evident in the phase of the rehabilitation needs´ assessments. In the phase of implementing the rehabilitation negotiations, on the other hand, there was evidence of higher level of person-centeredness and its different subcomponents overall, although there was some variance in the timeliness of the process.

Regarding ideas for further research concerning the assessments of rehabiltation needs. In the future, if the degree of rehabilitee participation in the assessments is to be increased or made a more standardized practice, the underlying factors affecting both high and low rehabilitee involvement should be further examined and solutions matched to either strengthen or improve them. For example, if the low degree of rehabilitee involvement is simply caused by the need to assess rehabilitees indirectly by using telehone calls instead of in-person visits due to lack of time, more personnel resources should be provided to those areas, where needed. Regarding the level of carer involvement in assessing rehabilitation needs, it also requires further research to determine if the needs of the parents and other caregivers were heard to the extent required. For this purpose, carers could be directly approached and inquired about their satisfaction or dissatisfaction towards the assessments made and methods used. If the carers would like to be more present in the assessments done in the future, more collaboration with carers should be done to determine the best assessment practices, which suit both the customer and the Outpatient clinic. Regarding the level of cross-organizational collaboration and interdisciplinary teamwork during the assessments, if these are to be further increased, the collaborative partners and personnel should be consulted about the factors facilitating and/or hindering it, and then solutions matched to those views.

Regarding further research ideas concerning the implementations of rehabiltiation meetings and its aftermath, it would be interesting to investigate, wheather the customers were satisfied with the outcomes of the meetings or weather there was room for improvement, and the areas requiring improvement. For example, information regarding the number and nature of participants to the meetings does not directly tell if the customers felt that these were the right persons to attend the meetings. In addition, regarding the fluctuations in the lengths of the entire process and in the amount of left-over time post-process, it would be worth further research to examine, how many smooth transitions or interruptions there were in the therapies, and to learn ways to either strengthen the quick, timely practices and how to prevent bottlenecks and timely delays in further processes in the future.

There were some limitations to this study. Firstly, the data was limited to a sub-sample of 50 processes of the entire pool of processes. Therefore, generalizations concerning the entire populatio cannot be made. In addition, the data was manually collected from the Pegasos health data repository, and there were some gaps in this data, as it was originally collected for other purposes than this study. However, the data covered a predominance of the themes under study, and therefore, it can be expected that the information included in the analysis is likely to ensure that all key topics were captured and discussed.

The benefit of using routinely collected patient data and having only one person collecting and analysing the data ensures that all available data was collected and processed in a systematic manner, limiting subjective, individual perspectives, and aiming to provide objective and accurate description of the data.

The author of this research worked at the time of the study at the Outpatient clinic as a physical therapist. The practical knowledge of the different elements of the process helped the author in the planning of the process indicators and measures as well as in the preparation of the data collection instrument. The author worked in an objective manner through out the study, eliminating any subjective perspectives, ensuring that all analysis is based on the reserach results, not on person opinons. The author reports no conflicts of interest and there was no funding received for this master thesis research.

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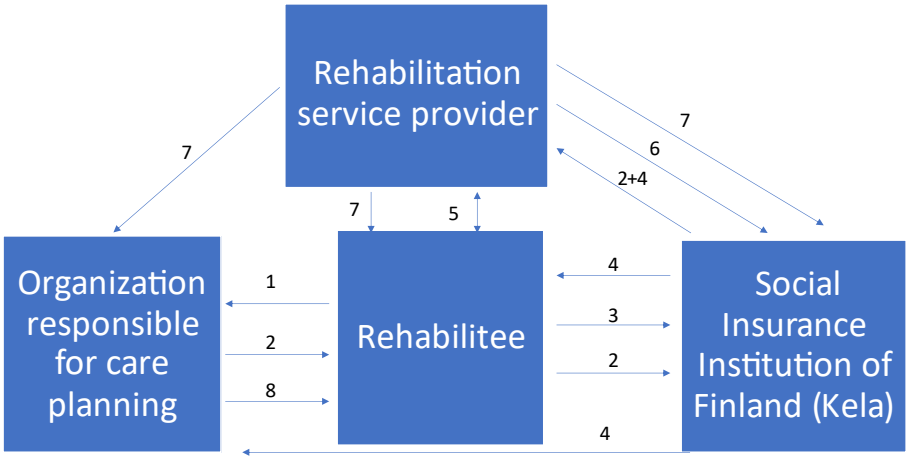
Process description concerning the planning of intensive medical rehabilitation (vrt. Paltamaa et al. 2011: 30)



1. **Physician (compare to rehabilitation negotiation)**
2. Rehabilitation plan (in Finn. Kuntoutussuunnitelma)
3. Rehabilitation application
4. Rehabilitation decision
5. Participation in various types of therapies as part of intensive medical rehabilitation and/or other rehabilitation and adaptation training courses for groups of people with specific medical diagnoses
6. Invoicing
7. Therapy feedback reports (in Finn. Kuntouspalautteet)
8. **Assessment and the making of new recommendation and new rehabilitation plan, upon need**

BACKGROUND INFORMATION	VARIABLE	CLASSIFICATION OF VARIABLE	DESCRIPTION AND ANALYSIS METHODS OF RESEARCH	ARGUMENTATION AND BASIS FOR INCLUDING THIS VARIABLE IN THE RESEARCH
Description of age of rehabilitees	Age as an indicator of age group	scale	key figures (such as averages, standard deviation, range) and graphical description	Finlex 145/2015; Hämäläinen, Kovasin & Räikkönen 2019: 138; Social Insurance Institution of Finland 2020: 6-7; Kiviranta et al. 2016.
Description of the life situation, i.e. daytime placement of rehabilitees (home, group home, daycare, school, daytime activity center)	Daytime placement as an indicator of life situation (affecting locations of rehabilitation needs´ assessments)	nominal	categories, frequences, percentages and visual presentation of data	Hämäläinen, Kovasin & Räikkönen 2019: 138; Social Insurance Institution of Finland 2020: 10, 14, 39-40; Kiviranta et al. 2016.
Description of duration, expiry months and number and nature of ongoing therapies under the old rehabilitation plan, before new assessments and negotiations	Distribution of duration, expiry and therapies under the old rehabilitation plan (affecting assessments of rehabilitation needs)	nominal	categories, frequences, percentages and graphical presentation of data	Finlex 145/2015; Hämäläinen, Kovasin & Räikkönen 2019: 138; Social Insurance Institution of Finland 2020: 10-11; Kiviranta et al. 2016.
RESEARCH QUESTION 1: How are the rehabilitation needs of the pediatric customers assessed in practice?	**VARIABLE**	**CLASSIFICATION OF VARIABLE**	**DESCRIPTION AND ANALYSIS METHODS OF RESEARCH**	**ARGUMENTATION AND BASIS FOR INCLUDING THIS VARIABLE IN THE RESEARCH**
1.1. Description of the total volume of assessments and their distribution among all occupational groups	Total number of assessments performed and number of assessments performed by each occupational group (physical therapists, occupational therapists, speech therapists and psychologists)	scale	key figures (such as averages, standard deviation, range) and graphical description	Finlex 145/2015; Hämäläinen, Kovasin & Räikkönen 2019: 110, 141, 146, 193; Ministry of Social Affairs and Health 2017: 40; Social Insurance Institution of Finland 2020: 1-2, 8-10, 14, 27; Paltamaa et al. 2011
1.2. Description of assessments completed on time before the rehabilitation negotiations and in relation to the ongoing therapies (defined by the old rehabilitation plans)	Number of persons assessed on time, showing evidence of person-centeredness, timeliness and continuity of care	scale	key figures (such as averages, standard deviation, range) and graphical description	AHRQ 2018; 2018b; IHI 2020; Hämäläinen, Kovasin & Räikkönen 2019: 140, 226; Ministry of Social Affairs and Health 2002: 3, 8-9; Paltamaa et al. 2011: 35
1.3. Description and breakdown of assessment methods and settings used (assessments by telephone or by in-person visits to homes, group homes, daycares, schools, daytime activity centers, therapy provider practices, Outpatient clinic, pools, horse stalls and other)	Nature and volume of different assessment methods and settings used, showing evidence of rehabilitee and carer involvement, collaborative environments	nominal	categories, frequences, percentages and graphical/visual presentation of data	Kiviranta et al. 2016; Social Insurance Institution of Finland 2020: 1-3, 13-14, 40
1.4. Description of those persons involved in the assessment visits	Nature of internal and external participants present in the assessments, showing evidence of rehabilitee and carer participation, cross-organizationl collaboration, interdisciplinary teamwork	nominal	categories, frequences, percentages and graphical/visual presentation of data	AHRQ 2018; 2018b; de Silva 2014: 2, 7; Finlex 145/2015; Karhula & Salminen 2016: 5; Hämäläinen, Kovasin & Räikkönen 2019: 110, 143, 149; Härkäpää et al. 2020: 20; Kiviranta et al. 2016; Ministry of Social Affairs and Health 2017: 10; Ministry of Social Affairs and Health 2002: 3; Mauk 2012: 55; Mezzich et al. 2014: 1; Paltamaa et al. 2011: 23, 35-38; Social Insurance Institution of Finland 2020: 1-3, 10, 13-14, 27; Scholl et al. 2014: 5; Singh 2018: 5
RESEARCH QUESTION 2. How are the rehabilitation negotiations implemented in practice?	**VARIABLE**	**CLASSIFICATION OF VARIABLE**	**DESCRIPTION AND ANALYSIS METHODS OF RESEARCH**	**ARGUMENTATION AND BASIS FOR INCLUDING THIS VARIABLE IN THE RESEARCH**
2.1. Description of the initiation of the rehabilitation negotiation, i.e., number of invitations sent and amount of notification time given	Number of invitations sent and notification times given, indicating care coordination and responsiveness to customer needs and timeliness of service	scale	key figures (such as averages, standard deviation, range) and graphical description	Social Insurance Institution of Finland 2020: 12-14
2.2. Description of the monthly distribution of rehabilitation negotiations	Number of negotiations held in different months, indicating busy/quiet months and mirroring these against Kela processing times	nominal	categories, frequences, percentages and graphical/visual presentation of data	Social Insurance Institution of Finland 2021a
2.3. Description of the persons present at the rehabilitation negotiations	Nature of internal and external participants present in negotiations, showing evidence of rehabilitee and carer participation, cross-organizationl collaboration, interdisciplinary teamwork	nominal	categories, frequences, percentages and graphical/visual presentation of data	AHRQ 2018; 2018b; Autti-Rämö & Komulainen 2013: 1; de Silva 2014: 2, 7; Espoo 2021; Finlex 145/2015; Hämäläinen, Karhula & Salminen 2016: 5; Härkäpää et al. 2020: 20; Kovasin & Räikkönen 2019: 110, 143, 149; Kiviranta et al. 2006; Ministry of Social Affairs and Health 2017: 10; Ministry of Social Affairs and Health 2002: 3; Social Insurance Institution of Finland 2020: 1-3, 10, 13-14, 27; Mauk 2012: 55; Mezzich et al. 2014: 1; Paltamaa et al. 2011: 23, 35-38; Scholl et al. 2014: 5; Singh 2018: 5
2.4. Description of the number of persons involved at the rehabilitation negotiations (internal and external)	Number of participants present in the negotiations	scale	key figures (such as averages, standard deviation, range) and graphical description	see 2.3.
2.5. Description of the on-time availability of therapy providers´ feedback reports and other feedback letters at the negotiations	Nature and proportion of feedback reports available at the negotiations, indicating level of informational continuity, continuity of care	nominal	categories, frequences, percentages and graphical/visual presentation of data	Paltamaa et al. 2011; Social Insurance Institution of Finland 2020: 1-2, Reid et al. 2002
2.6. Description of the number and duration of the newly drawn up rehabilitation plans	Number of new rehabilitation plans made and their duration in years	scale	key figures (such as averages, standard deviation, range) and graphical description	Finlex 145/2015; Ministry of Social Affairs and Health 2017: 10; Social Insurance Institution of Finland 2020: 10-11; Kiviranta et al. 2016
2.7. Description of the nature and number of therapy recommendations made, in relation to the initiation and/or continuation of therapy	Nature and number of therapy recommendations made	nominal	categories, frequences, percentages and graphical/visual presentation of data	Social Insurance Institution of Finland 2020: 10-11; Kiviranta ym. 2016
2.8. Description of the timeliness in the issuance and mailing of statements, i.e. the time taken to issue B-statement and mail it to the rehabilitees	Number of days from the negotiation to the issue of B-statement and number of days from the issue of B-statement to the mailing of all statements to the rehabilitee, contributing to timeliness of service, continuity of care	scale	key figures (such as averages, standard deviation, range) and graphical description	Espoo 2021; Social Insurance Institution of Finland 2020: 72-73
2.9. Description of the duration of the processes from their initiation to completion	Number of days between the mailing of negotiation invitation and the mailing of statement(s), indicating timeliness and smoothness of service, continuity of care	scale	key figures (such as averages, standard deviation, range) and graphical description	AHRQ 2018; 2018b; Espoo 2021; IHI 2020; Hämäläinen, Kovasin & Räikkönen 2019: 140, 226; Ministry of Social Affairs and Health 2002: 3, 8-9; Paltamaa et al. 2011: 35
RESEARCH QUESTION 3. What is the degree and nature of person-centeredness and timeliness in these two phases of the process?				
This question will be answered based on answers from the previous questions.				