TALLINN UNIVERSITY OF TECHNOLOGY

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Designing a proactive service to disabled child's parents

Master's Thesis

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Author’s declaration

I confirm that I have constructed this Master’s thesis individually and that the current paper has not been presented by anyone before. All resources, viewpoints, citations, and other materials from other authors that have been used in this thesis have been referred to.

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Abstract

The aim and main research question of this Master's thesis is how to design a proactive service to disabled child's parents. The question is based on the analysis of current situation that shows it could be better for the parents of a disabled child, as accessing important information and arriving to different necessary services or benefits is complicated and needs a change.

There is a lot of information available on different websites, brochures and books, and also different services and benefits exist for disabled children. All these are provided by different organizations and for example to arrive to rehabilitation services necessary for a disabled child, the parents usually need to go through long application processes. These processes are consuming many resources, they are complicated, take a lot of time and effort, are often on paper, may bring negative emotions and sometimes do not give a result. It may also happen that information about some service or benefit does not even arrive to the family. From the aspect of disabled child, speed to arrive to the service and benefit is crucial as any delay may result in development delays, may influence the development of the child in general and situation of the whole family.

The new designed process, using agent-oriented modeling and the described functional and quality goals, helps the parents in their new and complicated situation with their disabled child, to receive useful information, access services and benefits faster and easier – online as a proactive e-service. This helpful, personalized and proactive process provides, according to the child's needs and according to the situation of the family, for example depending on the location or other factors, best calculated services and benefits, and of course information. This way the family does not need to search for it but the information will arrive to the family using sociotechnical systems that provides integrated service that fulfills most of the quality and functional goals described in the models.

Analyzed three case studies, conducted interviews with different stakeholders, such as medical and social workers, officers and parents, bring out many deficiencies in the current processes. It is shown that there is a need for change.

This Master's thesis contains theoretical part, literature overview, three case studies description, interviews with stakeholders, analyzes of interviews and to-be processes proposals for case studies. In the end, a proposal of a new integrated proactive e-service is made using agent-oriented modeling. The thesis finishes with conclusions.

The thesis is written in English and contains 103 pages, 8 chapters, 11 tables and 15 figures.

Annotatsioon

Käesoleva magistritöö eesmärk ja peamine küsimus on uurida, kuidas disainida proaktiivset e-teenust erivajadusega laste vanematele. Uurimusküsimus põhineb olukorra analüüsil, mis näitab, et hetkel kasutusel olevad süsteemid ja protsessid erivajadusega lapse vanematele vajaliku info leidmine ja erinevate teenuste või toetusteni jõudmine on konarlik ja vajab muudatust.

Infot ja teenuseid on palju, neid pakuvad erinevad asutused ning näiteks rehabilitatsiooni või taastusravi teenuseni jõudmiseks on vaja läbida erinevaid taotlusprotsesse, mis kulutavad erinevaid ressursse, on keerulised ajamahukad ja -kulukad, tekitavad negatiivseid emotsioone ja ei pruugi anda tulemust. Võib juhtuda, et info mõne teenuse või toetuse kohta ei jõuagi lapsevanemani. Erivajadusega laste seisukohalt on iga viivitus või mõne teenuseni mitte jõudmine aga takistus arengul, mis võib mõjutada otseselt lapse tulevikku aga ka kogu pere olukorda.

Disainitud uus protsess, milles on kasutatud ka agent-orienteeritud mudeldamist kvaliteedi ja funktsionaalsete eesmärkidega, võimaldab vanematel uues ja keerulises olukorras erivajadusega lapse jaoks jõuda info, toetuste ja teenusteni kiiremalt ja kergemat teed pidi. See abistav, personaalne ja proaktiivne protsess pakub vastavalt lapse vajadusele ja pere olukorrale olenevalt elukohast ning muudest faktoritest võimalikke teenuseid ja toetusi ilma, et perekond peaks neid ise otsima. Info jõuab vanemateni kasutades sotsiaaltehnilisi süsteeme, mis analüüsib olemasolevat infot, küsib seda vajadusel juurde ja teeb ettepanekud. Selline integreeritud teenus täidab enamuse mudelis kirjeldatud kvaliteedi ja funktsionaalsetest eesmärkidest.

Analüüsitud kolm protsessi ja läbi viidud intervjuud erinevate osapooltega nagu arstid, sotsiaaltöötajad, riigiametnikud ja lapsevanemad, toovad välja mitmeid puudusi olemasolevates protsessides. See näitab, et vajadus uue süsteemi järgi on olemas.

Magistritöö koosneb teoreetilisest osast, kirjanduse ülevaatest, kolme protsessi kirjeldusest hetkel, intervjuudest erinevate osapooltega ja nende analüüsist, protsesside arendusettepanekutest ning kasutades agent-orienteeritud mudelit uue proaktiivse e-teenuse disaini ettepanekust. Töö lõppeb kokkuvõttega.

Magistritöö on kirjutatud inglise keeles, 103 leheküljel ja sisaldab 8 peatükki, 11 tabelit ja 15 joonist.

Abbreviations

EC	*European Commission*
EU	*European Union*
ICT	*Information and Communication Tool*
ISO	*International Organization for Standardization*
IT	*Information Technology*
OECD	*The Organisation for Economic Co-operation and Development*
SKA	*Sotsiaalkindlustusamet (Social Insurance Fund)*
SKAIS	*Sotsiaalkindlustusameti infosüsteem (Information System for Social Insurance Fund)*
SKAIS2	*Sotsiaalkindlustusameti infosüsteem 2 (Information System for Social Insurance Fund)*
WHO	*World Health Organization*

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1 Introduction

The idea of this Master’s thesis is to analyze the current situation and the right to access information about services and benefits for a disabled child’s parents in Estonia; to give overview of state plans in this area together with some samples from other countries where proactive services are helping people in social questions; and to bring out ideas to plan and design a proactive service for parents who have a disabled child. From the authors experience and what comes out from materials read, once the family is in this new and complicated situation, today in Estonia there is no reliable and informative portal or collection of necessary information about services and benefits for disabled children, from where to read additional information and get support for applying for different services or any kind of help the family may need right after and during some time after their child is born and diagnosed.

In Estonia there are many different institutions, ministries and departments dealing with the issue of providing information and different services for disabled children and their family, but the information is spread between information systems and databases, and is very much office-related. Therefore, information is not shared between offices and there is no one complete portal from where to get all the necessary needed information that would proactively propose information about the child and family possibilities. It is stated that local government social worker should be the person to provide families the information they may need, but very often it depends on the will and motivation of this particular. An integrated proactive e-service could be a useful tool for the parent and also, for the social worker or future case manager to help the family to maintain or restore the normal family life and living standard.

Projects are in work during these years for developing better information systems to share already once collected information by the state in a very useful way. The system is far from simple and easy, but considering the information society possibilities, using databases that communicate with each other, the goal to be achieved should make data sharing and the whole life in this field easier both to the officer and also to the family. Finances given will be documented and the need of family is better presented. Parents will save their time and energy from searching for information and possibilities; the state will have overview of the needs and spending for the right thing; doctors will save their time to deal with medical questions mostly and the child will receive the needed help as early as possible.

The main research question this Master’s thesis is looking for answer is how to design a proactive service for a disable child’s parents? Some of the sub questions are what is the current situation with accessing existing services, what is missing at the moment and why this service is necessary.

This thesis is divided into eight chapters, starting with the introduction to the theme, explaining the research questions and methodology, followed by the theoretical part and literature review after what the need for this service is described through the viewpoint of a family with disabled child. Case studies and interviews are presented trough findings and discussion towards proactive service where the requirements' models for the future sociotechnical system are described to answer the research question and sub questions. The thesis is finished by the conclusions.

2 Research questions

This research will map the current situation of a family with a disabled child and access to information, services, allowances and benefits needed due to the disability of the child, to describe, how complex, outdated and time-consuming the situation is today. The thesis will analyze the possible developments in this field and will use agent-oriented modeling method for proposing and describing a sociotechnical system for a proactive service.

The main research question is:

- ✓ How to design a service for a disabled child's parents?

The sub questions supporting the main questions are:

- ✓ What is the current situation with existing services?
- ✓ What is missing for the family and what should be done to make the situation more comfortable for the family?
- ✓ Who will be the users of this service?
- ✓ Why is this service necessary?
- ✓ Where can parents find information about the service?

These questions are relevant because at the moment this kind of service or integrated service in one-stop point or portal does not exist. This service could help parents to reach for medical or health service faster, or to reach them at all, as now, some children and services for them never meet or they meet too late. Moreover, the situation of the family can be normalized through this service and through the help this service can provide. Families access information better and stress, negative emotions and obstacles will be exceeded, and the family could maintain the living standard and the medical staff could devote more time on medical issues instead of consulting the family on social questions and bureaucracy.

3 Research methodology

The research methodology used in this thesis is design science where the problems of design and solutions to it for describing human and organizational interactions, are presented via using qualitative and descriptive research, primary sources and agent-oriented modeling method. The qualitative methodology with interviews is used to get expert feedback and direct overview of the current situation and the descriptive research shows examples of case studies trough as-is situation and analysis of to-be models, including agent-oriented modeling method and the models.

Interviews to collect feedback from different parties involved, for example doctors and social workers, other parents and representatives of ministries and offices, are conducted and answers are analyzed either to support or resist the idea of the new integrated proactive e-service. Specialists were interviewed individually to map the situation, needs, developments and obstacles. The questions were adjusted according to the stakeholder to ask from their viewpoint about the shortages of current situation and if and how the new system would help them to either, do their work better as a medical worker, support to raise the child as a parent or manage the services better as the service owner, social worker or the case manager. The interviews give direct and qualitative feedback about the current situation, plans and need for changes.

In addition to interviews, three case studies of services a parent of disabled child may experience are described and analyzed. These services are mapped and in the part of findings, an agent-oriented modeling is used for describing the new designed sociotechnical system, to answer the research question of how to design a proactive e-service for disabled child parents. The case studies map as the services are at the moment, as-is, and the to-be models describe the future situation from the service user viewpoint for designing the new proactive service for the parent of a disabled child. Designing process will also take into account the emotional situation of the family and the state plans in general, possibilities of information systems and eHealth initiatives.

To map the current situation, in the theoretical part, an overview is given about the quality and proactivity of services and need for services for family who is in a situation when a disabled child is born or diagnosed. State plans for information society development and health care services development is given to see, how the idea of this Master’s thesis could fit in it.

Practical part of this Master’s thesis is mapping the current situation with case studies description as-is, with agent oriented modeling models and business modeler graphs together with descriptions of some services a parent has to go through for getting support for the child. And in the results, to-be models are created, both for sociotechnical system and business modeler, to support the main idea of his Master’s thesis about designing a proactive service for the parents of disabled child.

4 Theoretical background

In the following chapter, overview of a service, public service and more precisely the public e-service is given as well as service modelling and designing aspects. For example, description of important parts, the e-service should contain, the service owner should keep in mind and about the obstacles and possible outcomes are described. Also, some possible drawbacks are described and things to keep in mind when developing complex information systems. What an e-service should provide to the citizen compared to regular service and how to reach towards invisible and proactive public services to avoid situations where citizens who need help, do not know where to turn to and from where to get needed information. Taiwan and United Kingdom are brought out as role models with its state action plans towards proactive services and also, overview of obstacles that may come up are described.

The role of the state is to take care of its citizens and useful public e-services provided are important part of it. Some paragraphs in this chapter of theoretical background will give some insight in it, to show the importance of state activities to provide services, e-services and proactive services to its citizens for better interactions, sharing information and using the resources wisely.

4.1 The aim of service

To describe what a good service needs to contain and provide, it is important to know, what is a service and e-service in public organizations, especially in Estonia. The descriptions of service have specifically been created during the last years together with the rapid development of e-services and proactive services as the aim of public service during the last decades and years has moved towards e-services and activities around it.

Government Office of Estonia and Government of Estonia have by now also described the concepts of public service, e-service, proactive service and event-service. In this descriptions, the public service is described as a service that is provided in the public interest and that is funded from state or local government budget. Service also means supportive service (GO, 2014a). Marketing researchers Kotler and Keller describe in their book that, a service is any act or performance one party can offer to another that is essentially intangible and does not result in the ownership of anything. Its production may or may not be tied to a physical product. Increasingly, manufacturers, distributors, and retailers are providing value-added services, or simply excellent customer service, to differentiate themselves (Kotler, 2012).

By the explanation of the Government of Estonia, the public e-service is a service that an organization provides through any communication channel for a person to give the right to fulfill their legal obligation or for using their legal rights. A proactive service in their words is described as a service activated by the organization initiative presuming the will of the person and using the state information system compilations. A proactive public service is provided automatically or permission from the person is asked (Government, 2015).

The concept that governments in different countries are reaching towards is the event-service that should take place once a life event happens in somebody's life. Event-service is described as a public service that is provided by different organizations unitedly, to help the person comfortably fulfil his legal obligations and use his legal rights that incur with one event or situation in his life. Event-service connects several services that are connected to one life or business events so that for the user it seems as one smooth service (Government, 2015).

The essential for e-government projects are establishing a sensible and nationwide vision and strategy for creating service delivery and describe at a high level the provided services and providing a standardized framework for measuring the performance of IT investments and contributions (Sun, 2015).

4.1.1 The aim of public e-service

Public e-services are typically Internet-based services through which citizens and businesses can interact and exchange information with governmental agencies. These services are seen as means to fulfill three overarching objectives of e-government: to improve citizens' interactions with the government, to make governmental organizations more efficient and effective, and to increase the transparency of government and lead to a more democratic society (Lindgren, 2013).

Providing public services depends on the need to achieve the state functions or specific goals. The state needs to decide and provide wide scope of services in different fields. This has to be done effectively, keeping the cost reasonable and at the same time, keeping in mind the needs of citizens and multidisciplinary balanced development. The expectations for public services, such as the selection, availability, usability and quality, are high among citizens and companies. Public service needs to be delivered fast and with low administrative burden. The public service development has to rise the service quality and the effectiveness. Using the e-solutions, service delivery compared to usual service is up to 12 times faster and with higher quality (GO, 2014a).

The activity of public sector needs to be understandable. Citizens and companies have the right for information pertaining to them in the state administration. When going to „get a service ", it should be clear, what is the process and what the deadlines are, how far the process is (MEAC, 2011). Also, the "once-only" concept should be kept in mind, meaning that the state should ask information from the citizen once and later reuse this information without asking it again.

At the moment, www.eesti.ee is the gate for many services provided by public organizations in Estonia and this uses the x-road platform. But still it covers a small part of all services provided by the public sector. The mindset and actions are changing in a way that these services are turning into a proactive service – a service that is initiated by the state and not by the citizen. This type of services is also called invisible service (GO, 2014a).

4.1.2 Proactive services

Proactive e-governance is citizen-centered where services are orchestrated in a way that the user does not have to be aware of or navigate through bureaucratic structures. The citizen only has to react at key points. Automated workflows take care of the sequencing of agency request and actions (Linders D. L.-P.-M.).

Once the information to provide public service exists in the state information system and it is presumed that the person would like to get the service, the organization develops a proactive service together with authority managing the database. The information about the service needs to be easily accessible and released, for example in the state portal www.eesti.ee in Estonia or any other relevant self-service portal. The person should not have to submit his data again after first entry to the database but there needs to be an option to renew the data. The organization gives information about the progression and deadline of the service (Government, 2015).

Compared to Estonia’s success stories in information technology in e-government and e-governance, there are some countries where e-solutions have taken the format of proactivity towards the citizen. These are some case studies and samples to move towards to. As the concept of e-government and e-governance are relatively new and no handbooks exist for creating the huge systems on state level, these samples can be taken as a role model to look at. In Taiwan, it has taken three state level action plans for several years and real actions accordingly, to make the fourth action plan ideas into reality. Taiwan is now providing proactive services to its citizens and benefits from it. Also United Kingdom has had a straightforward and strict plan to develop the e-services and government websites to be reactive.

4.1.2.1 Taiwan from pull to push and United Kingdom progress

Governments of leading countries explore the ways to harness, besides efficiency, information technology innovations how to change the delivery of public services and how to solve public problems. For example, Taiwan’s fourth e-government strategy is committed a lot to “proactive” service and information delivery. E-government as the facilitator of good governance. The mentality of service delivery has changed from “pull” to “push” model. Meaning that the citizen must not seek for government information but the government proactively and smoothly delivers the service to the citizen on the moment the service is needed. These services are built around and according to the need, location, situation, life events and preference of the citizen. The services are personalized and citizen intervention is kept minimum (Linders D. L.-P.-M.).

The same direction has been for United Kingdom (UK) for more than a decade. UK released their first e-government action plan for the years 1999-2001 by the National Audit Office. In 2002 the progress on e-government was examined and it was followed by a report with Government on the Web II. The Office had three core objectives: to make the UK the best environment in the world for e-commerce by 2002, to ensure that everyone who wants it has access to the Internet by 2005, to make all government services available electronically by 2005. The initial plan to have 100% of services online by 2005 was filled 75% by the end of the period. The progress so far had been made through developing the websites and in encouraging the development of e-services across government. The proportion of agencies allowing users to fill-in and submit forms on line has improved from one in seven to one in four. The Cabinet Office also claims that its new government portal, www.direct.gov.uk has been a success (Bennett, 2009).

The next strategy in UK, E-Government strategy 2005-2011 was released in November 2005. The Cabinet Office published Transformational Government, Enabled by Technology. The six-year strategy set out how effective use of technology to deliver services designed around the needs of citizens and businesses can make a real difference to people’s lives (Bennett, 2009). UK has made several important steps towards better e-government besides having action plans and actions taken accordingly. For example, a website www.data.gov.uk was launched to the public in 2010 to offer free access to UK government data. Also, in the same year, the new coalition government announced the appointment of a new UK Digital Champion, with the mission to focus on encouraging as many people as possible to go online, and to improve the convenience and efficiency of public services by driving online delivery. This was part of government's drive to increase transparency and accountability. And to replace outdated paper based systems for patient notes and prescriptions, there is a critical stepping stone taking place in helping the National Health System go digital by 2018 (EC, 2014).

Departments need to work together in delivering more public services built around the needs of the citizen’. As the world of ICT is relatively new and there are no clear tutorials, the leading countries try to share their experiences and lessons learned. The paths the governments follow to achieve the goals take many forms to see what finally works and what not. In this area, Taiwan is infusing strategically ICT into everyday operations of the government to provide more effective public services and therefore, better quality of life for citizens. It has taken around 15 years from e-government vision to reality, through three national ICT plans. The first plan was the implementation of a government network infrastructure, “Taiwan Online” 1998–2000, with basic information and communication infrastructure. Second one was the promotion of online government services and “one window” service integration, “e-Taiwan”, 2001–2004, that meant digitization and online service delivery that made available accessing government from home, services were integrated and accessible from one window. The third action plan was the advancement of ubiquitous access through a range of channels, from computers to cell phones to kiosks, “m-Taiwan” and “u-Taiwan”, 2005–2011. This led to web 2.0 interactivity together with mobility and as a result, government was accessible anytime, anywhere.

The last and current, fourth action plan of e-government in Taiwan is providing proactive services to citizens, intelligent Taiwan, social, cloud and big and open data that get together and act as proactive service delivery and smarter government. The services are built and designed around the citizen and his needs.

In the center of this is the e-government portal *My E-Gov* that provides one-stop window to citizens to access government information and services. This integrates the customer interface but not integrating back-end processes. The systems detect, when or where a service becomes relevant and then automatically initiate its delivery, uses data to proactively tailor the government’s menu of services to the individual needs etc. Citizens perform the role of partner rather than customer in the delivery of public services. (Linders D. L.-P.-M.).

The government then guides the user through the services. This is especially important when considering the vulnerable populations in accessing needed services such as social welfare and healthcare that need interactions between several organizations and levels of government (Linders D. L.-P.-M.).

In Taiwan, citizens select their baseline profile and then customize the service. The service can collaborate also with private sector and the owner is National Development Commission. Customers are citizens as individuals. The upgrade will transform the service into a digital “Life Dashboard” that manages all government records and contains also secure payment possibility showing the financial transactions with government. The services included also in this e-service are base also on location, not only on personal characteristics and preferences. This way the whole government fits in the pocket (Linders D. L.-P.-M.)

There will of course remain still segment of population who will lack reliable access to e-services. For this Taiwan has a plan to provide door-to-door services where the services provided at the counter are delivered home by servants, social workers, using a service-station computer, tablet or smartphone. These servants work also using their mobility by informing about issues they meet during their work. The customers will not be only the ones without tools but also citizens with disability, elderly and low-income households (Linders D. L.-P.-M.).

This shows how governments are realizing better how e-government improves administrative efficiency and many steps are taken to improve delivering e-services to citizens. These two samples from two countries show, how complicated these developments are and how different can be the progress although the action plans may be well formed.

4.1.2.2 E-government 2.0

For providing better and more proactive services, governments are deploying Web 2.0 and the architecture is referred to as e-government that links citizens, businesses, and government institutions in a seamless network for resources, capabilities, and information exchange. The shift from Web to Web 2.0 means a shift from a medium in which information is transmitted and consumed to being a platform which content is created, shared, remixed, repurposed, and passed along. Web 2.0 technologies transform themselves from government-oriented to citizen-oriented organizations. It also acts as a catalyst to transform the administration of government by replacing traditional ways of working with new, more efficient and effective processes, structures, and lines of communication. It removes boundaries, promotes openness, transparency and user participation. E-government ether equalizes access to government and its services in the information-rich environment or increases the barriers to participate for those in the information-poor environment (Sun, 2015).

4.1.3 Public e-service obstacles

There are many obstacles that make understanding and accessing public services complicated. To start the first biggest obstacle to the service user is that the information about necessary services is available on many different websites as the services are provided by different organizations. Between the organizations, there are different standards for giving service, sharing or designing information materials, channels for providing information etc. What makes users also confused, may be that the way public services are presented on the webpages has very different style, there are many different documents and forms in use that makes also the electronic document exchange complicated. It must not be forgotten that there are also still many people who cannot access Internet and computer to use the public e-services (in 2014, 21% of Estonians did not use Internet) (PRAXIS, 2013).

Public e-services have the potential of improving the quality of work and life for many people in our society. Public e-services also have the potential of unintentionally excluding citizens from public services, or making work unnecessarily complicated for service providers in governmental organizations. For those reasons, the development of public e-services must not be left to chance. They must be thoughtfully and skillfully developed and implemented in order to live up to their potential. Part of such thoughtful and skillful development and implementation involves an understanding of who are affecting, or are affected by, the public e-service (Lindgren, 2013).

In Estonia, information society is for all Estonian citizens. Special attention is paid towards integrating social groups with special needs, regional development and supporting initiatives. Access to Internet and the content should be with any device used (MEAC, 2013c).

One more problem is when developing public service in Estonia is that the service does not have to have an owner at the moment. An owner is usually the one who is responsible and has the full view over the service and who is responsible for the service and development. The volume, content and quality is not mapped. There is no overview of the current situation – where, how many and at what level the services are provided, through what channels and how many these services are used, what are the used resources and how much does it all cost. The minimum requirements of how the service should look like, what should it provide and at what level, the speed, user friendliness, preciseness, understandability, translations, etc. are not set over the country. Public service impact assessment indicators are uncertain. Some public organizations have completed it, but not all and this makes the situation more complicated to control and map (MEAC, 2013b).

Surveys show that around half of projects of e-service fail with regard to the initially set standards, keeping the budget or timeline. Even more are found to fail to meet the end-user’s expectations. The main reasons, barriers and drivers, to e-government development and the e-services, to keep in mind and not to make the same mistake again could be for example design-reality gaps, missing focus, content issues, skill issues, execution issues, regulatory issues, external factors, missing user satisfaction. Factors may also be organizational power, politics, education, project management issues, ambiguous business needs and unclear vision, security and privacy, finance and operational costs, ICT and system development process. From all factors, the organizational power and politics are considered to be the most important for e-government project failure (Anthopoulos, 2016).

The barriers that come up with e-governance can also be structural or cultural. With structural, there may obstacles from government side, for example legal aspects, lack of finance, shortage of human resources and skills, political and management support is limited, there is lack of coordination and technology. From citizen side, there may be lack of technological devices and little knowledge of computers and Internet, time and innovation integration. For cultural barriers, the government may face resistance to change and interference with bureaucratic failure. For citizens, there may be just lack of interest, not enough faith and negative image towards government or resistance to technology (Meijer, 2015).

In Estonia, for many public services and the users, the language becomes a problem – most of the websites are not translated to English or Russian language. The websites are in Estonian and if, then usually just part of the information is translated, if at all. The logic of public e-service should be different from the service that is on the paper form – here often the public organizations do not provide good quality e-service by simply putting the service paper form online. There is not enough information provided to the citizen about the condition or standing for example about the application – when is the deadline of processing, steps of processing or any intermediate steps. So far the option to give feedback is not common and if it is possible, organizations collect different level and kind of feedback, also there is not enough cooperation between ministries and no service-centered view. Each public service is connected to other public services (MEAC, 2013b).

Modelling and designing a good public service, many aspects need to be kept in mind. In the following paragraphs, this will be described.

4.2 Designing public services

Providing public service should be the priority of public organization and the need of persons should be the starting point of modelling the service. Responsibility should be set on state level to better organize the horizontal cooperation between organizations and keep the principles and requirements under control (MEAC, 2013b).

Designing and implementing a public e-service that fulfills its intended purposes has proven difficult regarding designing and implementing public e-services that citizens want to use. A reoccurring problem with public e-service implementation seems to be an imbalance between the supply and demand of the e-service meaning that public e-services are developed even when there is no perceived need for them amongst the intended users (Lindgren, 2013).

Government services are different from commercial services offered online or offline by traditional for profit firms, as many government services must be used. Many of these services have been designed according to common sense or common practice, without paying attention to quality as defined by the customer, resulting in poor design and user dissatisfaction (Venkatesha, 2012).

A good public service has to find and present balance between two „sides": the organization and the user. Both are equally important – from one side to the client or user and the other that is valued and necessary for the organization. Trough designing and developing the service, the organization and processes are more effective, the service is automated and human factor is involved just a little. The service is easy and comfortable to use and this brings out positive emotions in the user when it is easy and comfortable to use with thought-through design, the user has control over using the service that is accessible from all devices and at all times (Simson, 2014).

Transforming traditional public services into e-government services, brings cost-effective delivery of services, integration of services, reduction in administrative costs, a single integrated view of citizens across all government services and faster adaptation to meet citizens' needs (Venkatesha, 2012).

It is believed that public organizations can create public value for citizens through assuring high efficiency of their operation, providing convenient channels to access public services, saving time and money, and promoting greater interaction between citizens and their governments. Perceived public value and perceived ease of use are significant determinants. Ease of use has significant positive impact on perceived public value – the easier the service to use, the more beneficial and valuable citizens perceive it. There is a positive relationship between trust and perceived public value and perceived ease of use (Al-Hujran, 2015). Trust is important part of e-government as citizens are concerned about their privacy and misuse of their personal information.

Developing a self-service is not only software development but developing a service. It is important to know, understand and learn – what the customer needs. Here, a helpful tool is the user participation in developing e-services. Holgersson and Karlsson have described three so-called schools how user participation is explained and how it could be used in developing and designing e-services. These are user-centered design, participatory design and user innovation (Holgersson, 2014). The key is in the hands of service content specialists, not only the information technologists. To know the needs of the customer or client, there are several methods for screening. One good way is to make interviews to get to know positive and negative experiences when using (this/a) service and to ask quite specific questions. It should be kept in mind to consider the advice clients give and to make the necessary changes not to disappoint clients (Trinidad, 2014).

The main emphasis is not only to automate the traditional public service processes trough implementing the new ICT systems or add new online service delivery channel but it is rather improving transparency, accountability and governance of the public sector services. Through this, the government performance can improve. There will be new public value for citizens and businesses. The success of e-governance is dependent upon citizens' adoption and use of e-government services (Al-Hujran, 2015).

Ministry of Economic Affairs and Communications has issued several guidelines for developing good e-services. There it is pointed out that to enhance the development of public services – catalogue of services of where, what kind and what level public services are provided needs to be visible and easily accessible on the webpage of the organization. Also, portfolio management is applied and every service and channel should have an owner who is responsible of it and keeps control over the processes. To have e-services running well, development projects management should be enhanced and this all should follow developed strategies and action plans. (MEAC, 2013c).

Unified electronic contact point is necessary (as www.eesti.ee, eHealth, entrepreneur portal or similar) depending on the field and the interoperability should be ensured (MEAC, 2013b). It has been pointed out that there is need for nation-wide local governments information society competence center in Estonia as current distributed organizations cannot replace it. We are in a situation where we should not talk about the need to use information and communication technologies but we should use these tools for work-processes and modelling the services (e-Governance Academy, 2011).

Life event services should be based on principles that they are managed process-based. The services are dependent on the area, interest of the person, age, services used before etc. The goal is to make the communication with the state as smooth and easy as possible. Citizens do not have to know the structure of state organizations; which public administration provides which service. Service user is interested only in the service itself. Service provider should pay attention to which part of the life-event service they are responsible of, what is the cost and what are the citizen actions when using the service (MEAC, 2013b).

Proactive service is not initiated by the user but by the organization and the goal of the organization should be to move towards proactive services where the system informs the client of some service automatically and the client either can accept the provided service or if it is initiated automatically, the client can disturb the service delivery only if he wants to decline from it. For the service provider the main question will be from where to get the necessary data – from own databases or from other information systems to start the service. It is important to think through if the data asked from the client is enough and necessary to start the service or it is possible to take the data from already existing information (Trinidad, 2014).

4.3 Sociotechnical systems and agent-oriented modeling in service design

Sociotechnical systems started to develop more when using computers became widespread. Traditionally these systems and the design has concerned more development of work systems in individual organizations. Today the challenge is to extend this across several organizations where complex tasks need solving by number of different organizations which work together. The approach of sociotechnical systems has been a common currency in the world of work and work systems in which many people have a role to play and the tasks are large, which means division of work between people and procedures between them is important and should be well planned (Eason, 2014).

These sociotechnical systems, that contain both, a social aspect and a technical aspect, need to be responsive, dependable and secure. Large software systems that are needed to run society are integrated in the existing systems. Software engineering approach should make them cope autonomously in changing environment and take advantage of new features. The book The Art of Agent-Oriented Modeling presents approaches for modeling complex systems consisting of people, devices, and software components in changing environments. Several characteristics need to be considered when developing these systems such as complexity, distributed, time-sensitivity, uncertain and unpredictable environment and open. Also, a list of attributes is desirable, for example the software needs to be adaptable, as it needs to reflect the change, it also needs to be intelligent, efficient, purposeful and understandable. The agent-oriented modeling uses as well quality goals and functional goals that help to describe the developed and designed sociotechnical system in a better and clearer way (Sterling & Taveter, 2009).

The main elements that make the socio-technical system include (Maguire, 2014):

- ✓ The collective operational task where the system undertakes the operational delivery of the overall task objectives.
- ✓ Social and technical sub-systems in which the complete task performance is undertaken by human resources in the social system using technical resources in the technical system and where the two are ideally co-optimized.
- ✓ The attribute of being an "open system" which is influenced by the environment and so has to adapt as environmental conditions change.
- ✓ The idea of being an unfinished system that needs to be flexible enough to deal with new demands in the short term and where there is provision to review and refine the system as these demands become confirmed as new requirements.

Understanding the task connections and involvement to a large task is at the heart of a sociotechnical systems analysis. These systems have been used also for predictive work, to understand, what may be the impact of change through some task added in the system. This way the unexpected and unwanted consequences may be avoided. Sociotechnical systems work with two kind of resources: human resources and technical resources. For humans, as they have motives, emotional states and roles outside of work, then motivation to work and job satisfaction and well-being at work is important as it has impact (Eason, 2014).

The goal for organizations is to move towards computerized information systems for all users to access keeping in mind that the system should speak the language of user. The systems should be planned and thought through well as it is not always possible to set up pilot projects, using and creating scenarios technique shows great success. Dealing with complex electronic documentation is an integral part of much contemporary professional work (Wastell, 2014).

Over the last decade, changes in health information technologies have been substantial. New forms of those technologies have been introduced, such as electronic patient record systems, virtual wards, mobile and assisted living technologies, etc. This has brought many changes to manage work and healthcare delivery of services for patients. These big initiatives will increase in the future due to demographic and other population trends. At the same time, it has been shown that these systems perform poorly and sometimes fail as the projects are big and there is no traditions and experience in developing these kind of systems. Obstacles come when the new system is not compliant with existing system and technically incompatible giving negative impression to the users, the cost of implementation is high, the data quality is inadequate and if there are tensions in relationships between stakeholders for example software developers, suppliers, managers, medical workers. Healthcare sociotechnical systems are complex and need to be tailorable, and scaled to local requirements. But health care professionals see the need for new technologies to support their work, to make their work tasks more efficient and safer (Waterson, 2014).

Good design of electronic documentation systems is critical due to the limitations of the digital medium. Reading time compared to paper is around 30% longer and the understanding of the content is not as good as reading from a paper (Wastell, 2014). When developing a new system, a question may come if to design organization’s own application to meet all the necessary requirements or to obtain an off-the-shelf application and adapt this (Maguire, 2014). Nowadays as the user interfaces are highly developed, people own their own technology that is more advanced, flexible, faster and customized compared to a new system designed. This may bring satisfaction and may not fill all expectations. Especially at deployment time and the users may feel the system is not supporting their work. During usability design, it is important that it is related to socio-technical context. For some users the system may be better understandable than for others. Usability needs have to be mapped well, many of the principles and guidelines are written down also in ISO 9241 (Maguire, 2014).

Technology design is affected by relations between organizations, the organization relations between departments, group functioning, career, roles, tasks and skills in the designing system. Technology design affects the same list of things in the using system. With the increasing use of technology integration, the difference between two working levels – the work system level where the sociotechnical ideas were developed and applied, and the organizational level with contingency theory, has become less relevant (Klein, 2014).

We are moving toward future where the work we do is more and more mediated by computer-based technologies, so it is important that future work-systems are designed keeping with co-optimization, otherwise people know their task only the way technology represents it to them. This inhibits the use of human learning and adaptability. The use of sociotechnical systems theory in designing systems is important as it helps to develop better and useful systems that bring benefits to all stakeholders (Eason, 2014).

4.4 Service design and quality of service

For the past years, service design and quality of public service have been a concern and many steps to improve it have been taken. Public institutions have started to evaluate themselves – the quality of service provided and how it is delivered to the user. This paragraph will bring some insight into elements of designing a good public service and also what should be kept in mind to develop good quality services.

E-services are used by public organizations as a means of creating benefits for both citizens and government. The driving forces behind transformations from paper based services to e-services come from both inside and outside of governmental organizations. The introduction of systems for automatic handling of information and Internet-based services is seen as a way of making public administration more effective and efficient. Simultaneously, there is a pressure from citizens and businesses on governmental organizations to go on-line. (Lindgren, 2013).

The quality of service is defined as measure to the extent to which the provided service corresponds to the expectations of the clients (Sa F., 2016b). The main goal towards the client is to improve the usability and availability of the service. As a result of the characterization, the services are detailed, thought through and refined. For the organization, the main objectives are better use of resources and capacity building. As a result, having services that are described generalized way (GO, 2014a).

E-government has to use the information system, technologies, configuration and the media, with the purpose of changing or adapting their administrative processes instead of only automating services and publication. The goal should be maximizing the quality of the interaction by promoting their services and information, pro-activity, with their citizens, companies, other government bodies and everyone (Sa F., 2016b). It is important to measure the quality of the service.

When designing the service information architecture, there are many aspects and good tutorials written with many samples and guidance to make the self-service visible for the client. Here the ease of navigation plays the main role. Once the client has logically signed in, the desktop should be as comfortable as possible to use with important topics presented visibly, for example the deadlines, personal services, etc. Information needs to be delivered in an understandable way and the goal should be just a click away (Trinidad, 2014).

Citizens expect quality public services and the technology used to deliver it makes no exceptions. Sa, Rocha and Cota have created a model that is capable of globally evaluating the quality of services in a local online e-government context. Based on the literature review, they analyzed, identified and defined 16 dimensions of e-government services that are divided into four domains: *technical* (usability, design, technical quality), *organization* (customer support, alternative channels, transparency of actions, complaints, customization, politician's role, e-Governance), *safety* (privacy, safety, reliability, delivery) and *information* (information quality, task information) (Sa F., 2016b).

The ability to measure the quality of the service is a prerequisite to obtain high quality level of the service. There are several sides to pay attention to, to keep the level high. Sa, Rocha and Cota presented a list of dimensions for an electronic local government quality model that is based on literature review where approaches for electronic and e-government service quality were deeply analyzed.

Dimensions from the literature review they found are: emotional appeal, customer support, alternative channels, reliability, deadline compliance, design, service availability, e-participation, task information, innovation, online integrity, politicians' role, customization, privacy, information quality, technical quality, complaints, safety, transparency of actions, usability, advantage or online services, website access speed, processing speed (Sa, 2016a). These dimensions are found to be important in when providing a quality public service. The list of potential dimensions can be used when evaluating local government or any other public or private services (Sa, 2016a)

Simson (Simson, 2014) points out many of these in his handbook needs from organization: positive image such as having the stylebook, clear and compact representation of information, using modern technologies; informing the public by sharing information about all the services provided by the organization as much as the client needs for independent use and also to find as well very rarely used services, informing public also trough using blogs and social media; e-service as self-service/competence center by presentation of necessary information; achieving effectiveness trough implementing mindset of Internet first, using push and pull strategies (Simson, 2014).

Based on Sa, Rocha and Cota research and interviews in finding potential dimensions for a local e-government services quality model by local government experts, representatives and users some more dimensions could be added to the list that are important when designing good quality public e-services to citizens (Sa, 2016a). These additional dimensions are described in Table 1.

Table 1. Additional dimensions for an electronic local government quality model

Dimension	*Description of the dimension*
Process management	correctly implemented and designed internal processes to enable an aligned provision of services
Interoperability	multiple electronic services integration and sharing in a single portal in a transparent way for citizens. Available services should share resources to simplify their use and access
Accessibility	equality of access including people with physical disabilities
Compatibility	the services should be developed so that no matter what technology is used; the service is accessed independently
Variety of services offered	services should be still available in all varieties considering everybody's need

All these dimensions described in Table 1 and the ones described in a paragraph before were then re-divided by Sa, Rocha and Cota between four main domains, service-, information-, management- and technical quality are described in Table 2.

Table 2. Re-divided dimensions for an electronic local government quality model

Domain	*Description of the domain*
Service quality	aspects that directly impact the service effectively provided
Information quality	quality and content of the information made available to users
Management quality	aspects concerning internal specificities
Technical quality	technical aspects of the service provision that mean ease of use, web design and speed

When the service owner or the one responsible of service development starts to redesign the service, these four domains with subdomains described in Table 1, Table 2 and a list presented, need to be remembered and used.

Some needs from users what they expect from a good quality service are as described below (Simson, 2014):

- ✓ Automated service and the process is easy to use.
- ✓ Simplicity when using the service, using simple language and understandable structure, user friendly user interface.
- ✓ Control over using the service and creating trust for users.
- ✓ Service accessibility and possibility to use the service 24/7 and different devices.
- ✓ Standard solutions.
- ✓ Safe environment including safe authentication and avoiding digital signing.
- ✓ Using several services in one place and using one organization has one domain.
- ✓ Positive emotion trough trustable design and blending with the stylebook.

Besides the good service, it is important to measure the usability and get feedback from the user’s experience. For this, the organization should map, what they want to know from the user’s experience to develop the service even better (Simson, 2014).

Holgersson and Karlsson have described in their survey that citizens' willingness to participate in e-service development is actually high. Factors that affect their degree of willingness to participate are: use of public e-services, satisfaction with public e-services, personal incentives, available time, social commitment, and earlier experience of systems development. The main factors for non-participation are knowledge about public authorities, knowledge about IT, and knowledge about systems development. Finally, the main reason for citizens not to participate is lack of time, often in combination with a low general interest in public e-services. But in conclusion, it should be made available that citizens, who are interested and have resources, can participate in e-services development (Holgersson, 2014).

It is important for the user, how convenient is the service and the quality of it not from which office or state level is the service provider. Public service developers at the moment are missing a useful toolbox from where they could get information in a fast, interactive and comfortable way to develop and run the service. Also, there is no control of how many and at what level the existing services are provided, through which channels and from where to get information about them. It makes the development and cooperation complex if this is not described. For the end user this means that services are not accessible easy and comfortable. Steps are taken and actions described for raising the service usability and to change the officers view into the customer’s view and to test cooperation in developing services (GO, 2014b).

An important aspect for these actions described in this paragraph is having vocabulary to describe the services, for example EU initiative Core Public Service Vocabulary (CPSV) can be a base for having one that fits all public institutions, including local governments (GO, 2014a).

Besides all the plans and good projects created and brought into reality, it may matter little how good a service is according to the supplier – it is the consumer who decides the quality of the service (Lindgren, 2013).

5 Literature overview

The state, public organizations and administrations providing information, services and benefits play important part in raising a disabled child who needs medical care and extra help compared to a healthy child. The ministries in Estonia have made many great action plans and state development plans in many areas, including social topics and especially health of disability and disabled child. These plans rely on European Union and European Commission eHealth action plans and strategies (EC, 2016a).

The system of providing information at the moment is not ideal and does not satisfy the parent, but when analyzing the future plans, things are in process to improve the existing system or to create even new ones. We live in an interesting time in the sense of information technology and the enormous possibilities that we can achieve when using the collected data and matching it together with knowledge, science and experience. The ideas of personalized medicine, telemedicine and prevention instead of dealing with the result are taken into account when developing state information systems for health care.

Overview of some Estonian state development and action plans and eHealth global plans are brought out in the next parts of this thesis and paragraph to show, how the current situation is mapped and what is planned to be improved during the next years. Also, overview of tutorials and handbooks and important aspects of cost management in eHealth projects is presented.

5.1 eHealth history and plans in Estonia

We are all future-oriented as that is the place where we spend the rest of our lives. But it has been proved for centuries that fortune tellers are not always right and failure is not because of low will but the complexity of the problem. Health care is a national problem and this needs to be solved unitedly in the whole Estonia. This is the base for sustainability and competitiveness. With IT projects and solutions there appear also many isolated and replicative solutions. Combining individual and single solutions in the system makes it all more complicated and there is a threat that there is no clear unified picture (Port, 2010).

Since regaining independence in 1991, the Estonian health system has undergone two major shifts: first, from a centralized, state-controlled system to a decentralized one; and second, from a system funded by the state budget to one funded through social health insurance contributions. The state is responsible for development and implementation of overall health policy, including public health policy, and for supervision of health service quality and access. Its main function is regulation (Jesse M, 2004).

The health system that is overseen by the Ministry of Social Affairs and its agencies as the State Agency of Medicines, the Health Board, that is responsible for supervising healthcare providers, ensuring communicable disease surveillance and enforcement of health protection legislation, and the National Institute for Health Development responsible of research and development agency in public health. The financing of health care is mainly organized through the independent Estonian Health Insurance Fund. The eHealth Foundation operates the national eHealth system, which is an information exchange platform that connects all providers and allows data exchange with various other databases. This and other eHealth solutions are seen as tools to improve efficient use of health resources by reducing paperwork and duplication, and to improve medical statistics. Use of e-solutions is part of an overall national initiative to develop innovative electronic solutions to provide improved access to public services. Estonian eHealth system that was launched in 2008 is a platform that has a number of e-solutions such as electronic health records, e-prescriptions, digital image archive, patient portal, e-laboratory, e-emergency care solutions and statistics modules enabling information exchange with other e-systems. Patients can access their medical records and digital prescriptions through a patient portal and be better informed (Lai T, 2013).

eHealth development goal in Estonia is to ensure that different levels and service providers, the services are seamlessly interwoven with each other. Citizens health related questions are dealt comprehensively and the data, not a person, is sent by and between professionals (GO, 2015c).

The health care system in Estonia connects many stakeholders and parties (patients, medical staff, health insurance board, ministries, hospital, medical companies, pharmacies, families, employers, IT system developers and owners, health IT system, etc.). It is important to know and understand everyone’s needs and possibilities, who benefit from the new systems. The needs of system users should be discovered and mapped (Port, 2010).

In Estonia, several documents exist for eHealth plans. There are *eHealth development goals 2020* and *eHealth Strategic Development plan*, that is part of *National Health Plan 2009-2020*. In the strategy, the focus is on e-services related activities and the activities towards e-state principles and implementing innovative solutions, interoperability of service providers and enhancing information exchange. eHealth strategy is supporting also the *Vision of Information Society* and *Development Plan of Estonia 2020* implementation and smart specialization approach on supporting Estonian economic growth. eHealth strategy covers technological and organizational fields that are connected to health data or providing services from distance using e-channels. This is called eHealth systems and under it there is Health Information System by national database and other information technology equipment and implementations that are processing health related data (GO, 2015c).

For the implementation of the strategy, there is a need to develop base-capability and innovation in health services, relying on technological opportunities, on the following five focus areas (GO, 2015c):

- ✓ High quality health data and the infrastructure of health data so that data-capture is quality and the data processing is effective from the first formation point until reaching different users. This is the base when using the same collected data again for precise and effective decisions on treatment and developing innovative e-services. At the moment, this conception in Estonia does not exist but is in progress by developing standards and classificatory for definitions and lists. Secondary use of data can be used for example together with health related compensations, supports, permits and responsibilities.
- ✓ Human centered and personal medicine where people are active in managing their health condition and where provided services are personalized and precise. The health related services are given and organized according to each person's needs and therefore preventive, predictable and involving approach is implemented in health care. The goal is towards complete health information collection and use to provide synchronized and smooth service connecting different service providers under the same responsibility dealing with the same case.
- ✓ Complete approach to each case and organizational cooperation, meaning interrupted and complete health service provision, that is possible through all steps of health service from prevention until rehabilitation. This will be possible because the health service providers and patients have complete overview of the health condition and action plan by different parties. Health services are integrated to social- and labor-services. It is important for reducing inefficiency and to improve service-experience, which at the moment are a challenge due to low information exchange when coordinating services. As a goal, the resources will be used effectively, time is used wisely and the satisfaction in health, welfare and employment area rises as there will be better opportunity to provide health related benefits and supports. At the moment the information is exchanged via x-road but the services are not connected and integrated. SKAIS2 is under development.
- ✓ Health services performance and capability of analysis for planning and managing decisions on all levels and it is possible to measure and analyze the performance.
- ✓ Developing distance services to make the health system services more cost-effective and available.

Among the principles, it is stated that the data is organized as health-events and not from the viewpoint of who pays for the service, but from the substantive viewpoint. Defining the health-event is the base for functional e-service. The data needs to be reusable and machine readable for interoperability. E-services create new value through what they improve the service quality and in long term, raise quality of life, save time, money and gain years lived healthier (GO, 2015c).

Social support services should be accessible with unified standards and no matter from which local government. It would be important to have all supports and benefits under one system, to use the resources wise and on the principle "best for citizen". Personal budget idea could work well, so that everyone who has the right for supports, can use it for the things he needs the most (Touchpoints, 2015).

The goal could be that by the year 2020, all citizens of Estonia would consider provided e-services to be accessible, easy, not burden, understandable and transparent. On the other side, the service providers should ensure the service to be safe, effectively and cost effective. To accomplish certain level of providing public service, there should be a basis for public service management, taking into consideration the state information system and possible opportunities. Considering the aging of Estonian population, we are soon facing a situation where we have more people who need services and less who can provide the services. This may be one of the reasons to think about better e-services development (MEAC, 2013b).

5.2 eHealth global goals

Since the millennium, the progress in information technology have changed the way services are delivered, planned, organized and offered. In public area, there is huge growth in the citizen's expectation for faster and better access to information, higher quality for medical services and treatments, support for disabled peoples living and their lifestyle management. eHealth is an umbrella term that describes the use of information technology, electronic communication and the use of all the data that is collected, stored and delivered in electronic way for all necessary purposes, besides patient's treatment also for academic and research (Domenichiello, 2015).

WHO defines eHealth as the use of information and communication technologies for health. In its broadest sense, eHealth is about improving the flow of information, through electronic means, to support the delivery of health services and the management of health systems (WHO, 2012).

eHealth has tremendous opportunities to rise the quality and safety of health care, to make it more efficient and responsive to needs, reducing mistakes and besides providing better health, also lower the costs. Despite all this, the application of information technology systems has not been so quick as in other sectors. It may be that this is due to the complexity of the system with so many stakeholders with many participants who need to access, process and exchange information and process sensitive personal data (Domenichiello, 2015).

The goals of European Union in the field of health and health care cover several parts that are involved. The idea is to improve citizen's health by making life-saving information available using eHealth tools and not only in member states but also between countries. Also, to make these tools more effective, user-friendly and widely accepted. This means involving professionals and patients in the strategy, design and implementation. An important goal is also to increase the quality of healthcare and access to it by making eHealth part of policies (EC, 2016a).

Adoption of eHealth in Europe is an area of interest to many stakeholders. The European Union, through its executive body the European Commission, has been a very active stakeholder in promoting the digital agenda in health in recent decades. Since 1989, the EC has invested over 1 billion euros in over 450 eHealth projects. The work includes action plans for eHealth, directives and guidelines related to eHealth, sponsored eHealth projects, benchmarking activities and commissioned research. The primary care sector has been a particular focus of interest as it is where most patients have their routine encounters with the health system and where the greatest volume of health services are provided (Brennan J, 2015).

In the sense of eHealth, it refers to tools and services using information and communication technologies that can improve prevention, diagnosis, treatment, monitoring and management. It can benefit the entire community by improving access to care and quality of care and by making the health sector more efficient. eHealth includes information and data sharing between patients and health service providers, hospitals, health professionals and health information networks; electronic health records; telemedicine services; portable patient-monitoring devices, operating room scheduling software, robotized surgery and blue-sky research on the virtual physiological human (EC, 2016a).

5.3 Cost management of e-services

Cost management of e-government and e-governance projects is a big part of the whole public service process. It is important to think in advance, what the project brings and what value it gives. Some measurements are developed and for example, DG Information Society and Media in European Union has developed a measurement framework in eGovernment Economics Project (EC, 2006).

The model is built around three value drivers of efficiency, democracy and effectiveness. They are elaborated in a way that besides quantitative financial impact; it also includes more qualitative impacts. It is said that the measurement should include also impact that is directly financially measurable, tangible and also measured intangible way that cannot be directly measured financially – to distinguish as well the qualitative and quantitative measures (EC, 2006).

Efficiency value driver generates financial and organizational value with cashable financial gains, better empowered employees, better organizational and IT architectures. The democracy value driver generates political value with openness, transparency and accountability, and participation. The last of three, the effectiveness value driver generates constituency value with reduced administrative burden, increased user value and satisfaction, and more inclusive public services (EC, 2006).

E-services have positive impact as using e-services, it helps to save time and deal with government in a more accessible way. It has been pointed out also, that the e-services should be made more intuitive and easier to involve more those possible users who have less skills with using computers and Internet. In general, Estonian government has reached to good time and significant money savings, although the calculations are complex (PRAXIS, 2013).

The service evaluation model created by Government Office final report about Integrated Portfolio Management of Public Services brings out service evaluation model with 38 indicators that play role. These indicators are for example from service cost side impact area: cost for personnel, direct and indirect costs, total expense of the service, the average time spent, removing some channel cost. The return of investment impact indicators is payback period, the net present value, internal rate of return, financial sustainability. In addition, other impact areas are service capacity, quality of service, service costs and support staff, service activity goals and the quality of organization management (GO, 2014a).

OECD brings out a short table for the nature of benefits – either it is with direct financial impact; nonfinancial impact or indirect benefit trough good governance. The benefits come from reducing costs, economic burden and the possibility to use the savings on other projects and services; taking advantage from the investment trough interoperability, sharing data and reusing for developing proactive services; raising legitimacy by raising general trust and security in government; supporting growth by contributing to business environment and opportunities (PRAXIS, 2013).

Cost of measuring is an important factor and it should be taken into account already at the development phase of the service. Later it is usually difficult to implement it. At the moment, many information systems are developed without it and this makes it difficult to monitor many existing services (GO, 2014a).

5.4 Guidelines and tutorials for e-services and self-service systems

During the last years, Ministry of Economic Affairs and Communications in Estonia has worked on and out several guidelines for developing and designing better public e-services and self-service portals. Also several surveys, handbooks and analysis are conducted. These useful materials are freely available on the ministry website and have many samples described in the books that are presented in an easy reading way for any public organization to develop its own online environment for providing services (MEAC, 2016c). To develop good public services bases on a good will of every public organization and the management ideas and goals. There is no legislation that could force or punish public organizations in their services development but the ministry has done a lot from their side, to make the process for designing good and better e-services.

The ministry has released following documents: Public Services Green Paper; E-services design handbook; Process analysis handbook; Administrative burden calculator; Indicators for measuring usability; Customer feedback system project; Analysis of payment options; Integrated Portfolio Management of Public Services; Framework for self-service environments; The analysis and strategy of information governance; E-state charter; Prototype for describing and displaying public services; Vision for public sector websites; Model for evaluating the means of document exchange; Analysis and concept for cross-institutional service - Copernicus satellite data distribution center (MEAC, 2016c).

These documents are at the moment a good base for developing and designing new and existing e-services into better ones and also into proactive service. Based on these materials and other state plans, actions are taken towards completing the state action plans that were described in the first part of this paragraph.

6 Disabled children and the need for services

What happens to the family once a disabled child is born or diagnosed, what obstacles the family faces, the situation of siblings, economic and relations is described. All these parts of family life are much dependent on the accessibility and availability of necessary services. In addition to service modelling and design, the situation of the family where a disabled child is growing, is given – how the family copes with the situation, what are the needs from services and what does the statistics show about the current situation in disabled children, access to information and services.

When a baby is born, the parents feel overwhelming happiness. Many dreams and future plans are made and visions of life full of first moments when the child is growing and developing. Unfortunately for many families, life has given extra task and responsibility, if a disabled child is born or after some time, diagnosed due to some illness or accident. From the moment a family is informed about it or knows about child disability, the future dreams collapse. A time starts when the whole family has to build a new world that has many obstacles. Some steps forward can be taken individually as a family, but there are steps that need external help, from close family, from friends and of course, from professionals.

During the first weeks and months, family members have difficulties of understanding, what will happen and therefore, getting the right and necessary information is extremely important. This information can lead to better outcomes for the disabled child to get necessary medical help and also for the family, to turn back to as normal family life as much as it can be possible in this situation.

6.1 Disabled child in family

Every disabled child is special and needs individual approach. Disabled child in family also influences the dynamics of the family and support for the parents and close ones need to be present as well. The family needs many services and help to manage (Rääk, 2014). And these services should arrive to the child and family as easy as possible using the information technology possibilities.

The diagnosis and the way it is presented influences the parents. After the diagnosis is known and announced to the parents, they need to take action – what to do next, how to continue with life, how to cope with it and what the future brings. Parents need support and co-operation as they need to re-evaluate their life and reframe priorities. After the diagnosis, multidisciplinary approach to care is needed. A team including physicians, genetics, nurses, pharmacists, nutritionists, social workers, therapists, extended family and friends as well as support for the family (Graungaard, 2006), (Riley C., 2015). Parents want to see the child's possibilities and not disabilities. Information and communication in this area needs to be individualized according to the case. The initial experience with health professionals has lasting and major influence on the child's parents ability to continue with their child's situation and for this, good guidelines facilitate the communication process between all stakeholders (Graungaard, 2006).

Families are the closest social unit around a disabled person and they develop their own norms and ideals, seek to meet the medical, social, emotional and financial needs of their members. When the family has a child with special needs, the family is constantly undergoing significant changes to create an ongoing and functioning family system. The so called normal functioning is disrupted, families learn, adapt, re-examine, re-negotiate all what is around them – the routines, rituals, identity and so on. These changes involve extended period. Families want to feel "normal" and continue doing everyday rituals and social activities. They even attempt to increase their well-being by using the limited energies wisely (Mason, 2006).

Families with a disabled child face numerous complex issues and it can be overwhelming to become expert in all fields the family has contact with, for example legal issues, primary care, organizing and planning specialist meetings and rehabilitation, take care of everyday responsibilities and other siblings, work and not to forget, also relationship with the partner and family. Coordinated care by health care system needs to be improved to keep these families from depressions and becoming isolated (Riley C., 2015).

It has been identified, that there is lack of counseling and therapy, coping with the future, support and so forth. Common reactions by parent when they get to know about their child disability include protectiveness, revulsion, grief, anger, shock, guilt, embarrassment, inadequacy of reproduction and rearing. Parental function is limited to providing information. Parents are not brought to the decision-making process as parent is taken as a passive client and is not involved, although should be (Case, 2000).

Parents appreciate getting information from talking to people in addition to written information, information and guidance by people "who know". When there are leaflets on shelves, parents often do not find and read them. Parents need information faster but information arrives slowly. After the parents have contacted public administration and a social worker – they discover several benefits they were not aware of and almost one year later (Pain, 1999). Parents who have a disabled child have said an advisor who has similar experience is useful and it would be necessary to have this person around the family once the family hears about their child's disability for the first time. When being in crisis, the family receives help and support since the beginning. The advice is free of estimations, based on mutual understanding. This person is the source of power, person who understands and listens (TPIK, 2012).

Parents are significantly less sociable after the birth or diagnosis, due to lack of time, energy or opportunity to socialize. Common theme is that the life of the parent revolves around the child. Families believe that they have only received useful help or advice from the parents of other disabled children, whereas they are significantly unlikely to receive useful advice from doctors, health visitors, social workers, speech therapists, support groups and midwives. Professionals may even avoid telling the full picture of the disability in order to reduce the stress of the situation. This may occur lack of professional knowledge regarding the practical implications of disability for the family. Some say that intensive interactions can have direct bearing upon parents' emotional recovery from the trauma of diagnosis. Parents want to play direct part in their child's treatment and to be involved in therapy. Counselling helps parents to express and clarify their feelings and understand their reactions and reactions of others (Case, 2000).

Family with a child with special need utilize internal (family and relatives) and external resources and support systems (Riley C., 2015). It is suggested to take part of support group activities where families with similar life events act as a source of information as they can give relevant advice and support. Besides this, help and work provided by different organizations and their websites is important source for next steps (Riley C., 2015).

6.1.1 Parenting stress

Many parents face parenting stress – what the parent expects and the disappointment of not getting what was expected due to the developmental or other delay. Stress in general is defined as individuals emotional and behavioral response to some unpleasant event and where the level of stress negatively affects the individual's behavior and functioning. Parenting stress includes pieces of personality and pathology such as emotional availability to the child, parenting confidence and investment in parenting (Woodman, 2015).

Stress is dependent on how individuals perceive their situation and whether coping strategies are used to manage stress but it is shown that caregivers of children with disabilities experience greater stress compared to caregivers with children with no disabilities (Lopez, 2008). In this situation, parents have less time available for their careers, hobbies. Disabled child will always need help from their parents and the role of the parents is to protect them from any challenges (physical, social or emotional), as a result of which additional stressors are related and families may experience also divorce and serious illnesses (Woofson, 2004).

Parents need to use coping strategies, for changing hope and denial into realization; uncertainty to certainty; frustration and anger to confidence; powerlessness to possibilities of action (Graungaard, 2006). Families with effective communication and problem solving skills tend to deal better with stressful situations as this. Connecting to similar families and ability to cope with negative life events brings also some positive emotions (Riley C., 2015).

Parents need to start to collect information, learn new skills, control the health professional's actions and decisions, investigate alternative medicine possibilities, training possibilities, seek for second opinion. Emotionally, it is important for the parents to: retain hope, create future images, ignore the seriousness of the condition, seek for social support, concentrate on the child possibilities, evaluate beliefs, identify positive aspects (Graungaard, 2006).

Over all, parents want to keep on dealing with situation that were before they had to raise disabled child. They want to keep their personal identity, physical and emotional well-being, feeling skilled and informed, they want to find the balance between caring and parenting, maintaining family life, positive adjustment of siblings, practical and financial resources and experiences as a service user (Beresford, 2007).

6.1.2 Siblings and financial situation

It is shown that siblings in these kind of families' experience less attention and have greater responsibilities at home and fewer friends. It is extremely important for the parents to find enough time to spend also with them, to listen them and make them heard (Riley C., 2015). These families, besides having an emotional breakdown, may be more often unstable, forego their fertility intentions, are more frequently in bad health or have lower wellbeing in general. But at the same time, they appreciate important and nice things in their life more and these positive emotions help them to cope with day-to-day life (Di Giulio, 2014).

Moreover, these families who have child with disabilities have been reported to have significantly lower income than parents of children without delays and disabilities (Lopez, 2008). Financial support to family with disabled child needs to be extended as the costs for raising such child is three times more compared to non-disabled child (Di Giulio, 2014). Disabled child in family is an economic risk as the treatment, resources, taking care of the child and developing him take times more resources than raising a normal child (TPIK, 2012). The well-being of the family is quite dependent on the country and government where the family lives.

6.2 Legal rights of disabled children

As described earlier, the changes a family needs to deal with when raising a disabled child, it is important to point out also the legislation that shows clearly how equal are the rights to information, access to services and benefits for these special children as it is for any normal and healthy child. What makes it all complicated is that the information a family with disabled child needs to deal with is new, complex, acceptance of the information is hard due to emotional feelings and the information is widely spread between organizations and institutions the family needs to deal with without any previous experience in this field.

Republic of Estonia Child Protection Act (Parliament., 1993) states the following with some of the paragraphs about child, including disabled child, rights:

- ✓ The Republic of Estonia Child Protection Act provides for the internationally recognized rights, freedoms and duties of the child and protection thereof in the Republic of Estonia.
- ✓ Child protection is based on the principle that the best interests of the child shall be a primary consideration at all times and in all cases.
- ✓ Child protection is provided through state and local government bodies and non-governmental organizations.
- ✓ Every child has an inherent right to life, health, development, work and well-being.
- ✓ The child has an equal right to receive assistance and care and to develop, regardless of his or her sex or ethnic origin, regardless of whether the child lives in a two parent family or single parent family, whether the child is adopted or under custody, whether the child is born in wedlock or out of wedlock, or whether the child is healthy, ill or disabled.
- ✓ The disabled child shall have opportunities for education, development and self-realization equal to those of able children.
- ✓ The disabled child has the right to special care in accordance with the child’s specific needs. The child and his or her caregiver shall have access to multifaceted social, medical and spiritual assistance.

The Constitution of the Republic of Estonia says also that: Families with a large number of children as well as people with disabilities enjoy special care of the national government and of local authorities (Parliament, 1992b).

The Convention on the Rights of the Child by United Nations Human Rights, Article 23 states that, States Parties recognize that a disabled child should enjoy a full and decent life; the child has right to special care and ensure the extension of it that is appropriate to the child’s condition; assistance shall be provided free of charge, whenever possible and taking into consideration the financial resources of the family shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development (OHCHR, 1992).

This all means that a child with special needs has equal rights for living a normal life as any other healthy child but it must be kept in mind that a child with any special need, needs extra care and treatments, more effort for the family to develop this child and also more resources.

6.3 Early intervention of disability and interruption

Early perception and intervention is very important in the life of disabled child. The goal is to reach the family who needs help as early as possible. Access to services, the speed receiving it and finances, interdisciplinary and diversity are the keywords, no matter where the family lives, city or countryside, or what the financial situation of the family. Accessibility is the keyword here and then closeness, financial availability. The services should be for free or for reasonable price. When being interdisciplinary, it helps with information exchange and management between the team members. Service variability, involving different services from different service providers, combining them and managing it better so that a parent should not talk about the child situation all over again (TPIK, 2012).

Discovering development problems, the first years are the most critical. The doctors who check the child at birth, family doctor and other medical staff members examine the child 14 times until the child is three years old. Regular inspection helps to discover development disorders and if needed, the doctors can provide help and support together with social workers and specialized doctors (Rääk, 2014).

It is important to start to treat the child as soon as possible but at the moment, in Estonia it can be done only after the decision of disability and this decision and evaluation can take up to one year. The later the child gets help, the more the state pays for the treatment. For some child there is even no need for rehabilitation plan and when separating these two systems, the state can save resources (Rääk, 2014). Besides this, the situation of the family should not be forgotten. When fast and relevant treatment is provided, the future of the child and family may be better.

Early noticing and interruption is well described and explained in “Early noticing and interruption analysis report (Soriano, 2005), where also the legislation has brought out. Early noticing of the child and family needs and need for support has major influence on the child life and future and the same for the family (Soriano, 2005).

6.4 Access to information

Information assists the process of adjusting emotionally to child’s disabilities to enable parents to access services and benefits, improve management of their child’s behaviors. Having access to the necessary information help parents to plan and feel more in control. Need for information is connected to enhancing management of the child as people with experience can help, help parents to cope emotionally as information helps parents to accept the child’s difficulties and adjust expectations and to be able to access benefits and services to know what is available and to enable them to choose what was most appropriate for their child (Pain, 1999).

Families with disabled members have pointed out obstacles that come up and are related to health care experiences, including poor coordination among health care service providers, difficulties with insurance, finances, transportation and facilities, short duration of visits with physicians, inadequate information provision. Also, transportations for persons with mobility problems was a major concern (de Vries McClintock, 2016). It is found that the obstacles exist even more for children and young people with disabilities as they are dependent on their parents. Parents are responsible of the coordination the care needed by children. It can be even more complicated if the family is living in rural areas and not urban, as the access to health and support services has even bigger barriers (Walker, 2016).

Access to care can be also connected to socioeconomic status as lack of insurance brings delays in receiving care or they may be unable to obtain care. Access barriers are also (as mentioned before) cost, transportation, lack of available services, lack of competence by the health care provider, lack of health care insurance coverage. Once the social barriers are removed, then parents can cope better with the situation, otherwise there is also threats such as higher level of psychological stress, negative feelings toward parenting, less satisfaction with their marriage, financial and physical burden. With no adequate support, families with disabled child may not be able to provide optimal support to their child (Walker, 2016).

The approach to disabled child and the family is fragmented. Child is evaluated by different offices, the child may have several action plans (treatment plan, rehabilitation plan, case plan, individual development and study plan). For each plan there is a lot of resource used, also time and energy of the child and parent. The parent actually does not know to whom to turn to for help. There is no certain office or person to turn to who would advise and help to find necessary services. Cooperation between social workers and child protection is limited due to huge work load and incompetence of disability specific knowledge (Rääk, 2014).

6.5 Disabled children and access to services

The following part will give overview of some statistics and surveys to describe better the current situation meaning that access to information about services and benefits is not to easy. The case studies will describe in more detail the process of some necessary services for parents of disabled child. Interviews conducted will give insight to different parties to get to know their viewpoints of the current situation and how would they see the situation to be developed. Sociotechnical systems are involved to show trough agent-oriented models the interactions between the services, actors and how the functional and emotional goals are divided and presented.

In 2011, in Estonia, there were around 6300 families with disabled child (0-17 years old) and around 7300 children. 28% from these families had just one parent and 18% of families are where none of the parent works. The families and disabilities of children are different but what unites them all is usually higher need for help (services, support, any other type of help). Childs who have deep need for help, their family is usually in a very difficult economic situation. One of priorities of Estonia is demographic growth and positive birth rate as at the moment the growth is negative and the population is ageing (MSA, 2011).

6.5.1 Statistics of disabled children

According to WHO and World Bank “World Report on Disability”, in 2011, 15% of world population has disabilities, this means 1 billion people out of 7 billion are disabled. In Estonia, in 2012 there were 130 000 citizens with disability and this is around 10% of the population. These people are mostly old and retired, 59% of all are more than 63 years old, 35% are in working age and around 6% are between 0-17 years old children (around 8 000). In Tallinn the percentage (from the population) is 5.7% (24 000 people) and 6% (1 600) of them are children (TPIK., 2012). Another source brings out even higher numbers. In 2013, there was 9983 diagnosed disable child’s (0-16 years old) (Rääk, 2014).

Advanced (medical) technology combined with improvements in preborn babies (neonatal) care have increased the survival rates of preborn infants and infants born with severe birth defects. Babies born like this are at greater risk for all developmental problems and need a lot of extra care, rehabilitation, therapies and treatments. As babies born prematurely survive, then the statistics also show that there are more and more families raising children with disabilities. Medicine brings them alive but parents and the family need to keep them alive. For example, in 2010, 500 000 infants were born preterm and number of children with disabilities living at home has doubled since 1960 in United States of America (Riley C., 2015). Medical technology also helps to keep many disabled children alive longer as they get special treatment, medicines and with the information technology possibilities, information about for example rare diseases can be exchanged fast between doctors to make quick decisions in the treatment plans.

6.5.2 Access to services for disabled child in Estonia

In 2009, the Ministry of Social Affairs conducted a survey among families with disabled child. The results of the survey show that many parents are not satisfied with the way services to their child is provided or how accessible is the information about the services and benefits. 66% of parents feel that they would need more support in advice and information about social support services and benefits. 97% of parents agreed that they should be better informed about possibilities (MSA, 2009).

It is important for the disabled child to have access to medical care as fast as possible and as much as needed. These services cost additional money to the family and therefore 63% of the respondents would like to get additional financial support from the state to finance the treatments. 34% would like to receive directly the service itself instead of money (MSA, 2009).

Receiving any social service, around half of all the parents have experienced variety of obstacles. Mostly what causes the lack of satisfaction is that the service is provided too far from home (54%), then that the service delivery, bureaucracy is complicated (62%), line to access the service is too long (57%) and that parents were not aware of possible services (48%). One third of parents have experienced problems when receiving support, most commonly the obstacle is the complicated process (MSA, 2009).

The most used service is physiotherapy (30%) and secondly, rehabilitation plan tutorial service (40%), speech therapist service (33%) and psychologist (29%).

Disabled child in the family influences the life of all family members. It affects the most spending time together with the whole family. Families very often would just like to take a rest (60%) or take time for their hobbies (55%). In every third family, one of the parent’s changed radically the working conditions to take care of the disabled child. 43% of families had not turned anywhere with their questions about taking care of disabled child, getting support with babysitting and taking care. Around 50% of parents turn to their family doctor or family member, only 10% parents turn to social workers to ask advice and help (MSA, 2009).

A plan exists for a bonded model to reorganize the existing system (for child education, healthcare, rehabilitation and social services) and to optimize the current services system to avoid doubling, reduce bureaucracy, provide for each child individual and personal access to services. One step towards the model is to have reliable statistics behind the plans. Statistics that reflect the need of the target group (Rääk, 2014). The information about special need to evaluate child development, noticing special needs, plan for intervention, information for services and service providers, information about where to turn to for help is collected and made easily accessible (Rääk, 2014).

In the plan it is suggested that local area rehabilitation centers will be created for making the model work and a case manager will be designated, who coordinates the support services for the child and family. The role of this person is to help the family and parents to be more parents instead of coordinating the disability services organization and planning. Rehabilitation services are provided on mobile way. With the help of this working model, special needs of a child will be noticed and interrupted early considering the fact that the number of disabled children is increasing every year, the support services will be provided coordinately (information is available) and quality, and they consider the needs of child and families. Resources are used wise and activities are not doubled (Rääk, 2014).

6.5.2.1 Satisfaction with e-services

According to survey by EMOR (Emor, 2014), Estonia's rate of Internet users among citizens aged 16-74 is 77% in 2014 and it is growing considering the aggressive spread of Internet mobile and smart phone users. Higher rate of service users via Internet is due to larger possibilities of e-services as people are more aware of the e-services and new e-services available through Internet. Over the years, citizens are more aware and are using more the websites of local government and other public organizations – the most visited websites by 61% of people. The portal www.eesti.ee is known by 82% of Internet users. The satisfaction level with e-services in average is 4.5 (out of 5.0). People are mostly satisfied with the e-prescription (4.8) but less satisfied with patient portals (3.9).

Citizens who were not satisfied with some e-services pointed out the problems of user-friendliness – the e-service is complicated to use (61%), the tutorials and customer support are inadequate (43%), using the e-service takes too much time, the service does not provide sufficient possibilities (32%). People expect that the e-service would function as promised and also that it works on different devices. Security was mentioned to play important part in using e-services.

The survey shows that the awareness of e-services has not raised during the years 2012 to 2014. 2/3 of citizens know and use e-services. People are searching for information more from information portals (67%) by themselves, then ask advice from friends (45%) and websites (40%). A list of services provided by public administrative websites would be useful in finding and using e-services provided by those organizations (73% of respondents agreed).

People use public administration websites mostly for finding information (55%) and secondly, for using e-services (46%, in 2012 it was 23%). Most of these users agree that using e-services, helps them save time (87%), has helped to save money (73%) and has reduced bureaucracy (73%).

When using the e-services through www.eesti.ee, then applying for support or compensation, the satisfaction level is lower than for several other services (4.3 out of 5.0, the same in 2012).

The awareness of state and local government provided e-services has not changed from 2012 to 2014. 25% of respondents think they are quite aware, only 8% replied that they are very aware of the provided services. This makes 33% in total and the rating is only 3.2 out of 5.0 (Emor, 2014).

More people use e-services in social and health care fields (82% in 2014, compared to 72% in 2012) (Emor, 2014).

6.5.3 Outcomes of eHealth services for families with disabled children

The value in health care is measured by the outcomes achieved and not by the volume of services delivered. Sometimes there is a need to spend more on some services to reduce cost and reduce the need for others and improving one outcome dimension can benefit others (for example, more timely treatment can improve recovery) (Porter, 2010). This is especially important to keep in mind for all stakeholders when children are involved as through them, the whole family system is involved an affected, depending on the support systems in a better or worse way. Health related issues are complex and depend on many particles that need to match together.

eHealth should not only fix the relationships of patients, doctors and insurances but also to help to ensure better quality to the current health care system, efficient provision of current and new services. It is also important to inform the public about projects and processes (Saluse, 2010).

Some of the possible efficiency factors that came out from using the eHealth system in Estonia are described by Saluse (Saluse, 2010):

- ✓ For the patient: better access to treatment and medical information, less and shorter hospital stays, higher satisfaction, less visits to doctor, receiving treatment faster, smaller hospital cost, less cost for visiting doctor.
- ✓ For the health care service provider: accessing all necessary data, better planning of resources, better time management, less and shorter hospital days, less and shorter visits, smaller expenses for the hospital, saving time, shorter visits, shorter waiting time.
- ✓ For the society: better planning of resources, less hospital treatment, better chance to take part of surveys, less prescriptions, less sickness benefits, better planning of health care programs, more years lived healthy, more taxes paid, faster return to work.

Threats that may arise when using the health care information systems consider the service provider, society and the patient in the fields as: if there is enough security and trust to collect and use the sensitive data, if there is access to IT equipment and if people involved are ready to use them, the closer contact between patient and the doctor will fade, patients understand the health data wrong, cyber-attacks and accessibility to IT by the patients (Saluse, 2010).

7 Current situation findings

The following paragraphs will describe three case studies that are described trough processes descriptions and with what parents of disabled child may experience some day. It is shown how information about these services does not arrive to the parent, how the application process is long and resources consuming and how different are the websites and processes that the parent needs to get to know besides everyday life obstacles that the family is in due to the child disability. After that, results of interviews by different stakeholders in health care system are presented to show the situation overview of the existing system, and ideas and plans for new system. Eleven persons were interviews and some ideas are brought out – what are the things interviewees are not satisfied with what they think should be done differently, what are the ideas of developing new and perhaps more complex, and why not even proactive service for the family who have a disabled child.

7.1 Case studies introduction

Three case studies are described that may come up with raising a disabled child. These case studies are based on the situation that a family with disabled child can have experience in Tallinn and in Estonia. Each local government does its own rules, budget and possibilities when giving out benefits and services and for the same kind of benefit, the support given may also vary. Not all local governments provide the same benefits and services. At the moment there is missing a unified system and for example local governments are independent in managing their budgets.

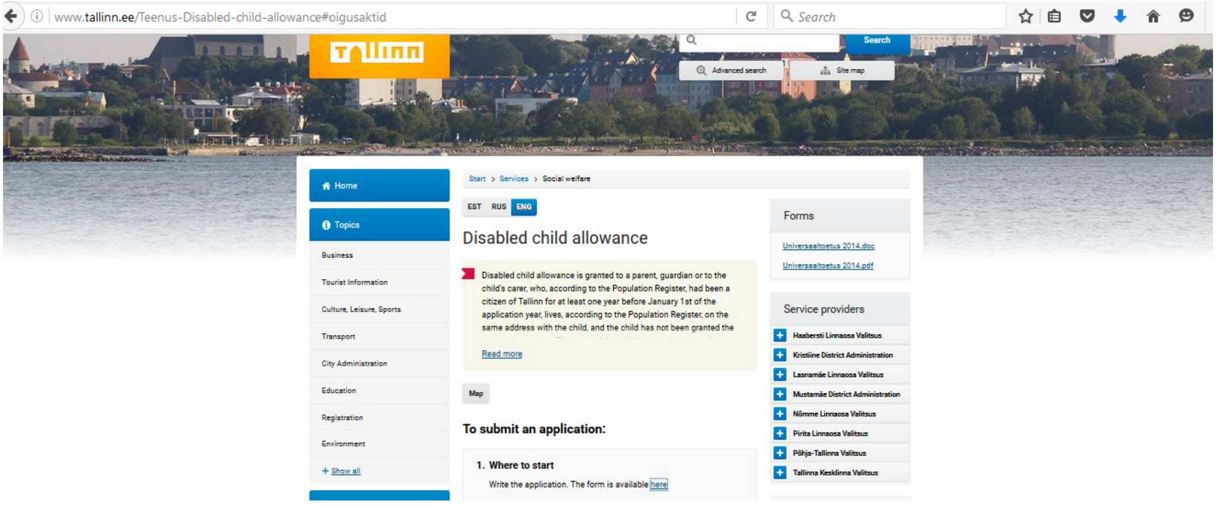
The fields of support given by local governments are also different, as well as the complexity of application procedures. Information is usually presented on the web-pages of local governments and then the family can either submit the application online or on printed version. The webpage of www.tallinn.ee has now for example self-service portal to manage the application of allowances easier. Other local governments in Estonia use webpage for sharing information and possibility to download forms and communicate with the state by email or by visiting the office or by calling.

These case studies are just a part of all the different services, benefits and allowances the family with disabled child needs or can get to support the development of the child and also family well-being. The case studies show the complexity of the system and how information can be found and searched from, from many different websites and portals. The case studies present also the unclear overview of all the possibilities the family can have. The doctors and especially the social workers are also involved in the whole process, but it is shown that lack of interest and motivation due to probably high work load does not let them to help the family as much as the family would need.

7.1.1 Case study One as-is – application process description for yearly allowance for a disabled child in Tallinn

The allowance has been paid in the city of Tallinn since the year 2008. Today it is possible to apply for it via www.tallinn.ee self-service portal or via www.eesti.ee, and also by visiting local city governance office. The application itself is easy to submit online as the data into the application is collected from information systems and the parent needs to check prefilled form, make the necessary changes and submit the application. The condition is that the parent or person responsible of the child has been Tallinn citizen for at least one year before applying.

The picture of the webpage of www.tallinn.ee in English for applying for the yearly support is shown on Figure 1.



Disabled child allowance

Disabled child allowance is granted to a parent, guardian or to the child's carer, who, according to the Population Register, had been a citizen of Tallinn for at least one year before January 1st of the application year, lives, according to the Population Register, on the same address with the child, and the child has not been granted the

Read more

To submit an application:

1. Where to start

Write the application. The form is available here

Figure 1. Webpage and self-service portal of www.tallinn.ee to apply for yearly allowance for a disabled child

For other type of benefits and the application procedures, the webpage gives information about them but then again, leads to some responsible person working in the local government, with whom the parent needs to contact for application details – to call or to go to meet in the office. The webpage only shares information about it.

To show the application process better, it is modelled on Bizagi Business Process Modeler by as-is situation. Figure 2 is showing how here, at the moment, two sides are involved, the parent and the local government officer. The parent initiates the process by applying for the allowance from the local government self-service portal. The application is received by the officer and the data is checked. In case there is something that needs complementing, the officer asks parent to do it. Otherwise, if all is correct, after certain time, parent receives the support money on the bank account. Next year, parent needs to initiate the process again.

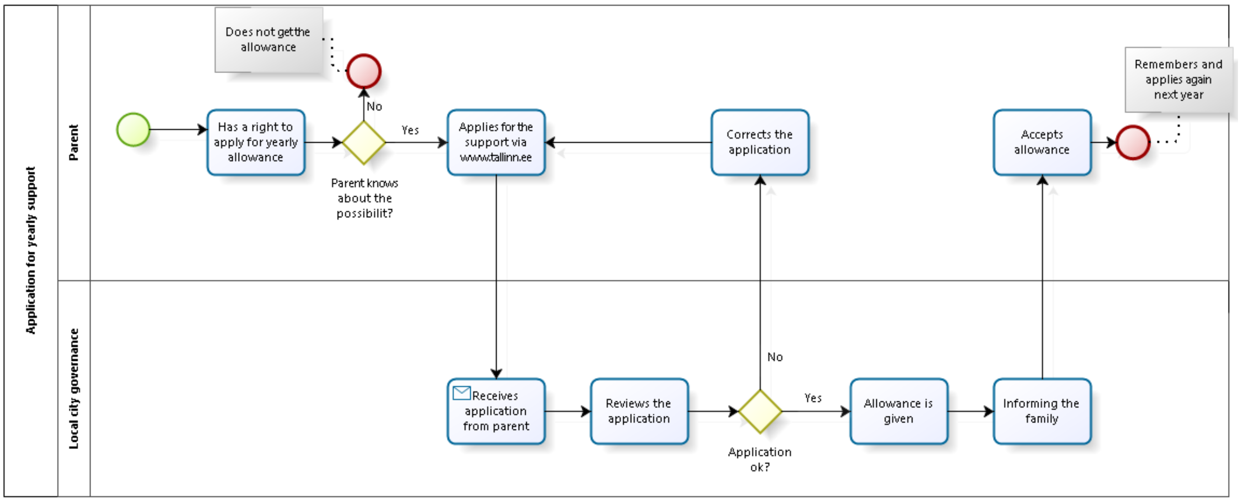


Figure 2. Applying for yearly allowance from local city governance process as-is for a disabled child in Tallinn

Information about this specific allowance possibility is available on www.tallinn.ee webpage and then a few news that search engine can find, but this news is static on different webpages and from 2008. In Tallinn, this service concerns around 1000 child and families every year.

7.1.2 Case study Two as-is – application process for special nutrition or food support for a disabled child

Applying for special nutrition or food support for a child with severe disability is at the moment not regulated as the application process and chance to receive this support takes long time, includes filling in several documents, sending and bringing the paper documents and the criteria for received the support is not too clear. The support is, if it is, usually given for short period of time after what the family has the right to re-apply. The decision if the child needs special food and nutrition is decided by the doctor who suggests it to the child. This special food can be bought from a few medical companies.

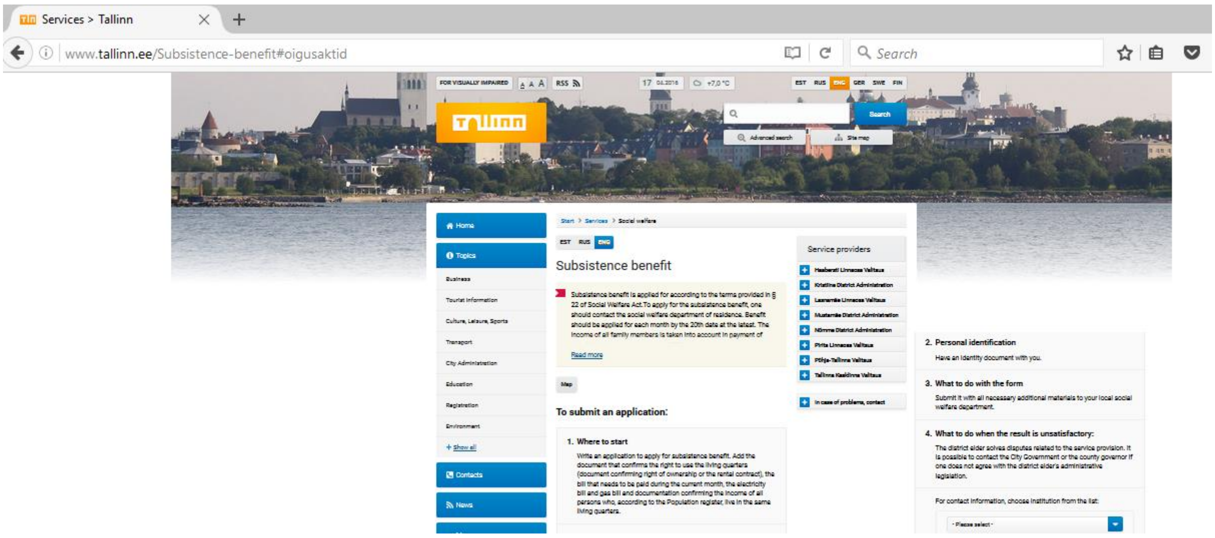
Active search for information to apply for support starts once the family faces situation that the child needs to start to eat special nutrition solutions to cover necessary nutrients and energy level. These are important factors of growing and developing for some disabled children, especially for those who have problems with metabolism. Today there are several very special baby-foods developed that cover the need for nutrients, but unfortunately, as they are not used massively and are produced under very strict conditions, the price of these foods is many times higher than “normal” milk powder of food parents cook at home for their healthy children.

The average amount of food a one-year old “special” child should eat is around 700ml per day and this means 6 bottles of 125ml special milk. One bottle of this milk costs 1,54 euros and per day this is around nine euros. For one month, the expense is around 270 euros. Some disabled children use g-tube and syringes with a special pump for eating. These systems cost around 4,65 euros per day and 140 euros per month. In addition, renting the pump, 20 euros per month. In total, for the family, this is around 430 euros extra outgo every month.

There are at the moment three known possibilities to apply for support to buy special food for baby or to apply for partial support to cover the expenses made.

The first place to turn to is the local city district (in Tallinn case) or local government. For this, in Tallinn, an application has to be filled on paper to show all the income resources and family budget details. The allowance is very much connected to the family income and the average income per person. Any bank transfer arriving on the account is income and will be considered, no matter if it is regular or one-time arrival. Also the property family members own, real estate, cars, land, and so on. It may depend on the city district as well, how high is the possibility for the allowance as some city districts have more people with higher needs than others. Figure 3 is showing the webpage and self-service portal of Tallinn City Governance from where information about this service can be found and from where the application form can be downloaded. In addition, contact information of social workers can be found from these pages.

The total support a family may receive in Tallinn is 358 euros per year. For the application, medical description and the need for the special food needs to be described and proved by the doctor of the child. For this, the doctor needs to take time to write a comment or fill in a form. In best cases, this can be done by email, otherwise the parent needs to go to visit the doctor at least two times during the application – first to go to ask for the document and then to go to pick it up.



Subsistence benefit

Subsistence benefit is applied for according to the terms provided in § 22 of Social Welfare Act.To apply for the subsistence benefit, one should contact the social welfare department of residence. Benefit should be applied for each month by the 20th date at the latest. The income of all family members is taken into account in payment of

To submit an application:

1. Where to start

Write an application to apply for subsistence benefit. Add the document that confirms the right to use the living quarters (document confirming right of ownership or the rental contract), the bill that needs to be paid during the current month, the electricity bill and gas bill and documentation confirming the income of all persons who, according to the Population register, live in the same living quarters.

2. Personal identification

Have an identity document with you.

3. What to do with the form

Submit it with all necessary additional materials to your local social welfare department.

4. What to do when the result is unsatisfactory:

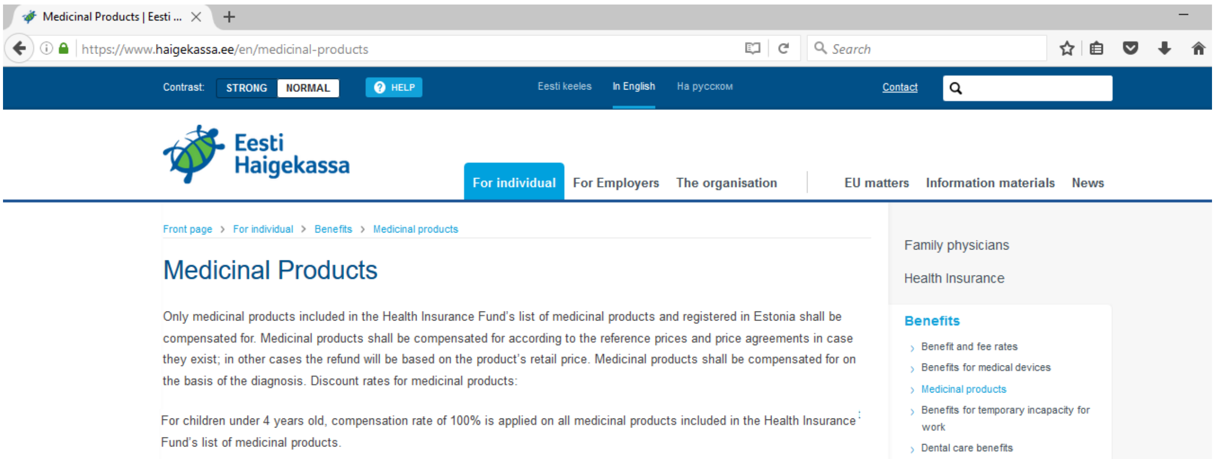
The district elder solves disputes related to the service provision. It is possible to contact the City Government or the county governor if one does not agree with the district elder's administrative legislation.

For contact information, choose institution from the list:

Figure 3. Webpage and self-service portal of www.tallinn.ee to get information about allowance for application process for special nutrition or food for a disabled child.

The parent, once all the necessary documents are collected, submits by sending the documents by email or bringing to the office, the application and then receives feedback from the social worker about the process. Additional documents may be needed and in the end, family will get to know if they receive part of 358 euros yearly support or not.

Another source to apply support for special food is from Health Insurance Board. They have some information on their webpage (the webpage image is shown on Figure 4) about medicinal products benefit and additional information can be asked via email or visiting the office. When asking additional information, instructions are given by email how to proceed with applying benefit for special food for disabled child. A free format application has to be written and additional document from the child doctor has to be asked. For this again, the parent needs to contact the doctor to ask for special certificate to prove the need of the child either by email or by visiting the doctor's office. These documents should be sent back to Health Insurance Board. A committee will make a decision. Usually for children, the support is 100% of the special food cost that is necessary for medical reasons. If needed, additional documents need to be presented.



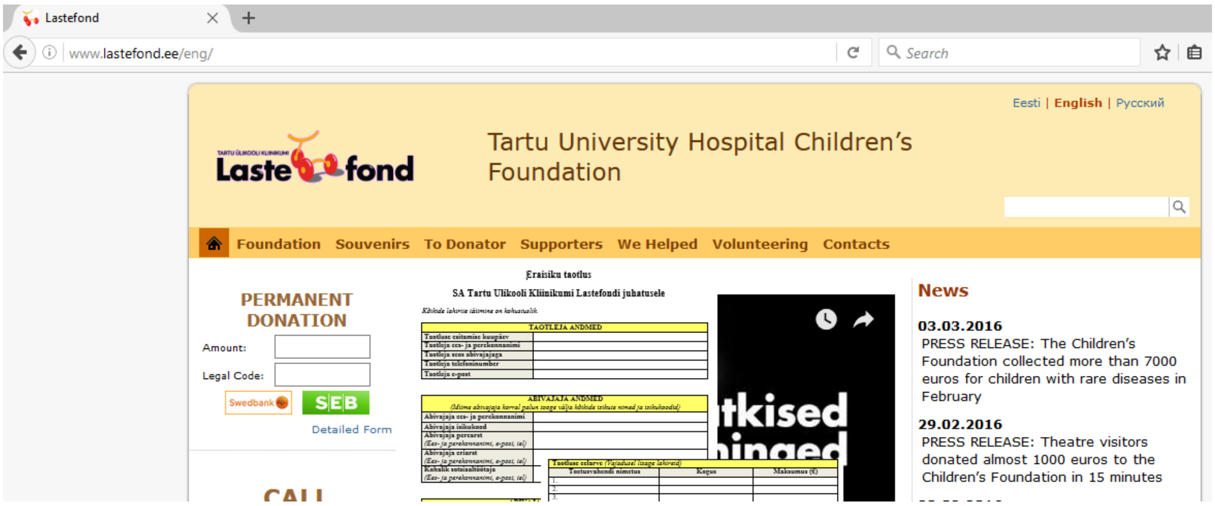
Medicinal Products

Only medicinal products included in the Health Insurance Fund's list of medicinal products and registered in Estonia shall be compensated for. Medicinal products shall be compensated for according to the reference prices and price agreements in case they exist; in other cases the refund will be based on the product's retail price. Medicinal products shall be compensated for on the basis of the diagnosis. Discount rates for medicinal products:

For children under 4 years old, compensation rate of 100% is applied on all medicinal products included in the Health Insurance Fund's list of medicinal products.

Figure 4. Webpage of Health Insurance Fund information page about medicinial products support

The last known option to apply for benefit to buy special food for disabled child with rare disease is Tartu University Hospital Children's Foundation that is based on charity and that helps children who need additional help for funding food, therapies, travels to other countries for meeting specialist, medical equipment and child care. An application form can be found on the webpage (the picture of the webpage and the application form is shown on the Figure 5) and a comment from social worker and child doctor is needed to complement the application. Also, basic calculations for the monthly need and description of the child state, family situation and data is required. The application is digitally signed and sent by email. If needed, additional comments are asked and made. In the end, committee will make a decision and the parents are informed about it. In case of positive decision, the family can start to order necessary food and the invoice will be sent directly to the fund to be paid. The support is usually given for certain period of time but if necessary, it may be prolonged.



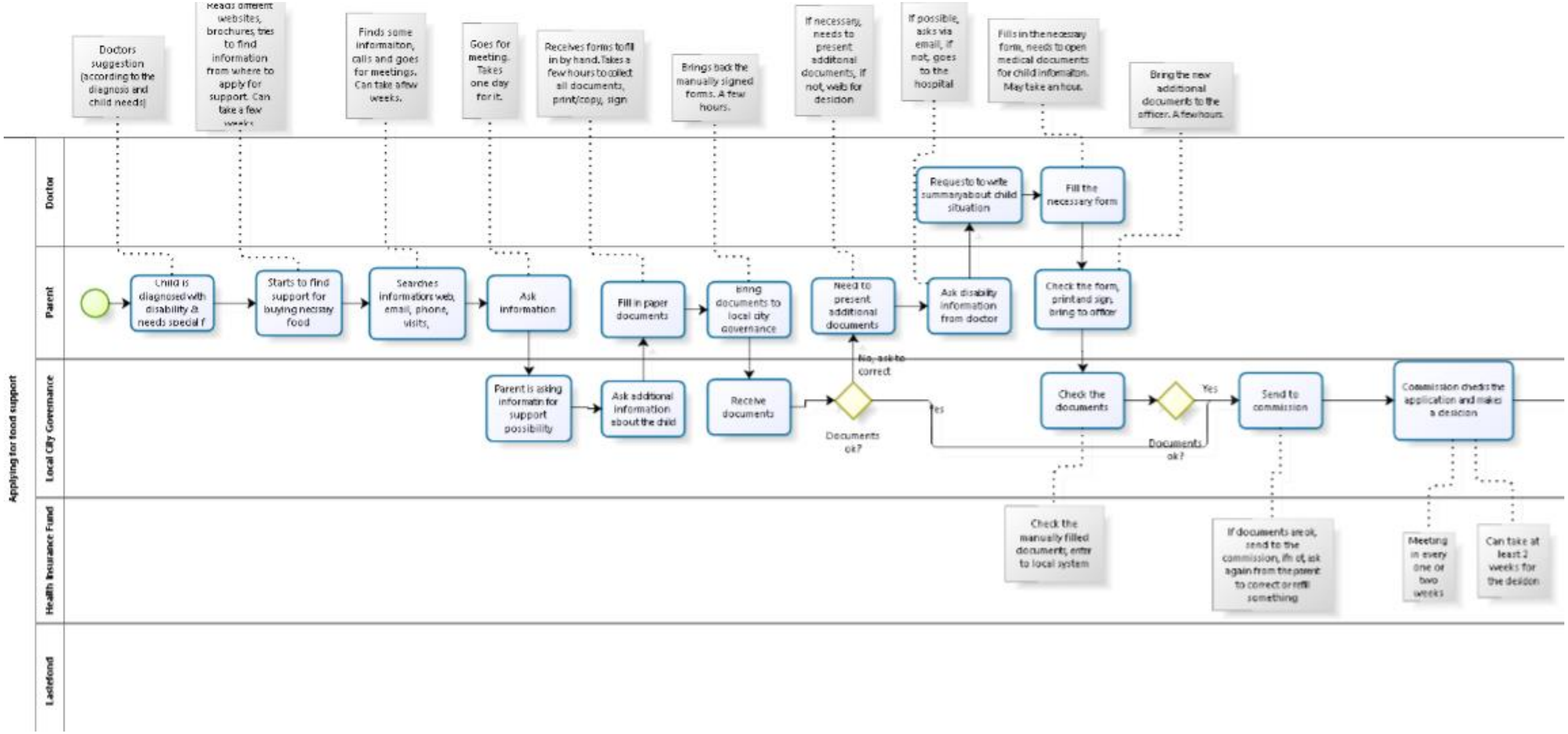
03.03.2016
PRESS RELEASE: The Children's Foundation collected more than 7000 euros for children with rare diseases in February

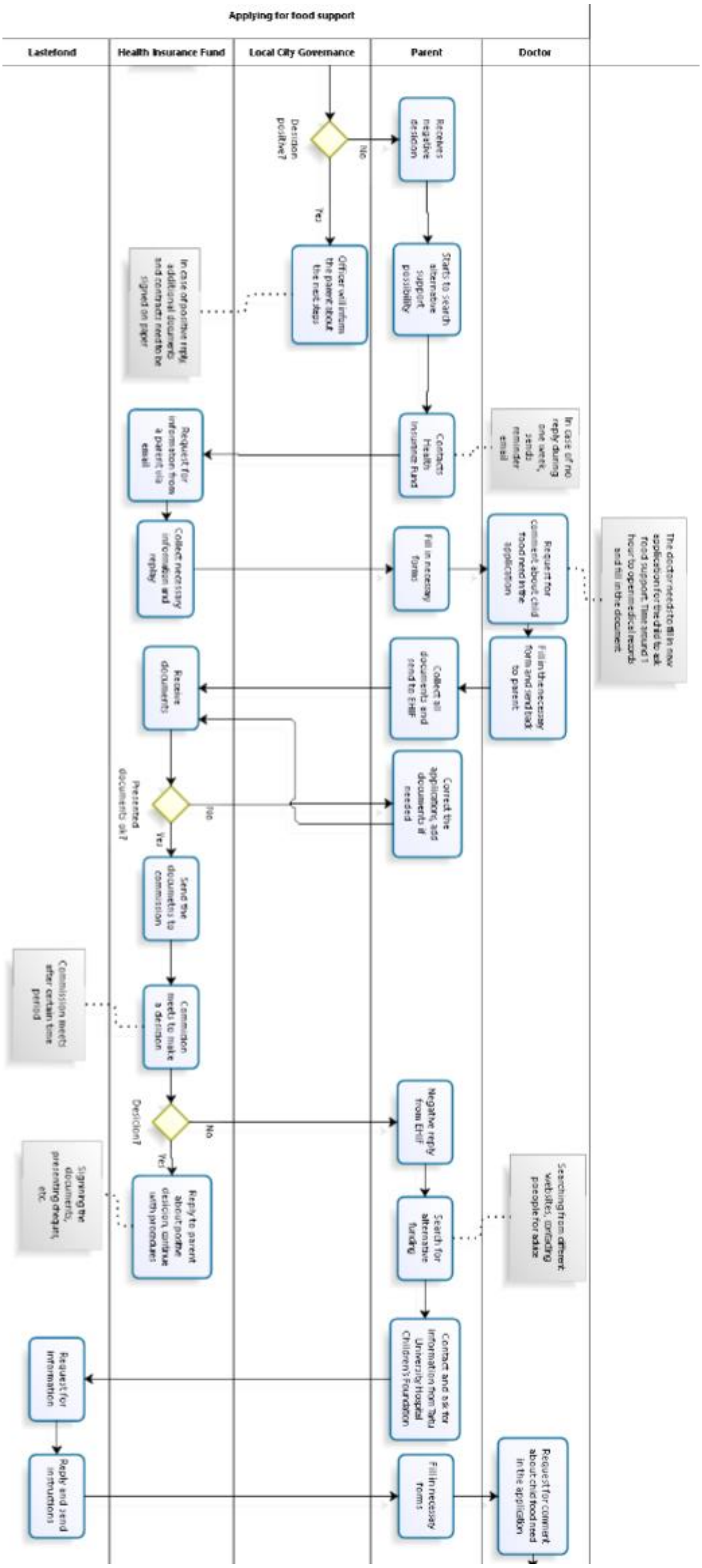
29.02.2016
PRESS RELEASE: Theatre visitors donated almost 1000 euros to the Children's Foundation in 15 minutes

Figure 5. Webpage and application form of Tartu University Hospital Children's Foundation about and for applying for support

In general, the first obstacle with applying for one of these possibilities is how to access this information. Information about these possibilities is not proactively delivered to parent. The parent is free to search for information via Internet or asking from medical staff and local city governance social worker. In all cases, documents need to be filled from scratch – starting with the name of the applicant, name of the child, contacts, medical situation description and so on. The files or applications are not prefilled Also, a special comment and even a comment on a separate paper as a certificate must be written by the doctor to prove the health situation of the child and the need for special food.

To describe the process of application, a Bizagi Business Modeler figure is created on Figure 6 to visualize the current situation and system better. The three described options are presented on the figure to show the path of application process together with explanations for a parent of a disabled child. As the figure is capacious, it is divided into three parts and should be imagined as one sequence of actions for the parent.


Applying for food support
Lastefond
Health Insurance Fund
Local City Governance
Parent
Doctor
Child is diagnosed with disability & needs special f
Starts to find support for buying necssary food
Searches informations web, email, phone, visits,
Ask information
Parent is asking informatin for support possibility
Ask additional information about the child
Fill in paper documents
Bring documents to local city governance
Receive documents
Documents ok?
No, ask to correct
Yes
Need to present additional documents
Ask disability information from doctor
Request to write summary about child situation
Fill the necessary form
Check the form, print and sign, bring to officer
Check the documents
Documents ok?
Yes
Send to commission
Commission checks the application and makes a decision
Doctors suggestion (according to the diagnosis and child needs)
Reads different websites, brochures, tries to find information from where to apply for support. Can take a few weeks
Finds some informaiton, calls and goes for meetings. Can take a few weeks.
Goes for meeting. Takes one day for it.
Receives forms to fill in by hand. Takes a few hours to collect all documents, print/copy, sign
Brings back the manually signed forms. A few hours.
If necessary, needs to present additonal documents, if not, waits for decision
If possible, asks via email, if not, goes to the hospital
Fills in the necessary form, needs to open medical documents for child informaiton. May take an hour.
Bring the new additional documents to the officer. A few hours.
Check the manually filled documents, enter to local system
If documents are ok, send to the commission, if not, ask again from the parent to correct or refill something
Meeting in every one or two weeks
Can take at least 2 weeks for the desicion


Applying for food support
Lastefond
Health Insurance Fund
Local City Governance
Parent
Doctor
Decision positive?
No
Yes
Receives negative decision
Starts to search alternative support possibility
Officer will inform the parent about the next steps
In case of positive reply additional documents and contracts need to be signed on paper
Contacts Health Insurance Fund
In case of no reply during one week, sends reminder email
Request for information from a parent via email
Collect necessary information and reply
Fill in necessary forms
Request for comment about child food need in the application
The doctor needs to fill in new application for the child to ask food support. Time around 1 hour to open medical records and fill in the document
Fill in the necessary form and send back to parent
Collect all documents and send to EHIF
Receive documents
Presented documents ok?
No
Yes
Correct the applications, add documents if needed
Send the documents to commission
Commission meets to make a decision
Commission meets after certain time period
Decision?
No
Yes
Negative reply from EHIF
Reply to parent about positive decision, continue with procedures
Signing the documents, presenting cheques, etc.
Search for alternative funding
Searching from different websites, contacting people for advice
Contact and ask for information from Tartu University Hospital Children's Foundation
Request for information
Reply and send instructions
Fill in necessary forms
Request for comment about child food need in the application

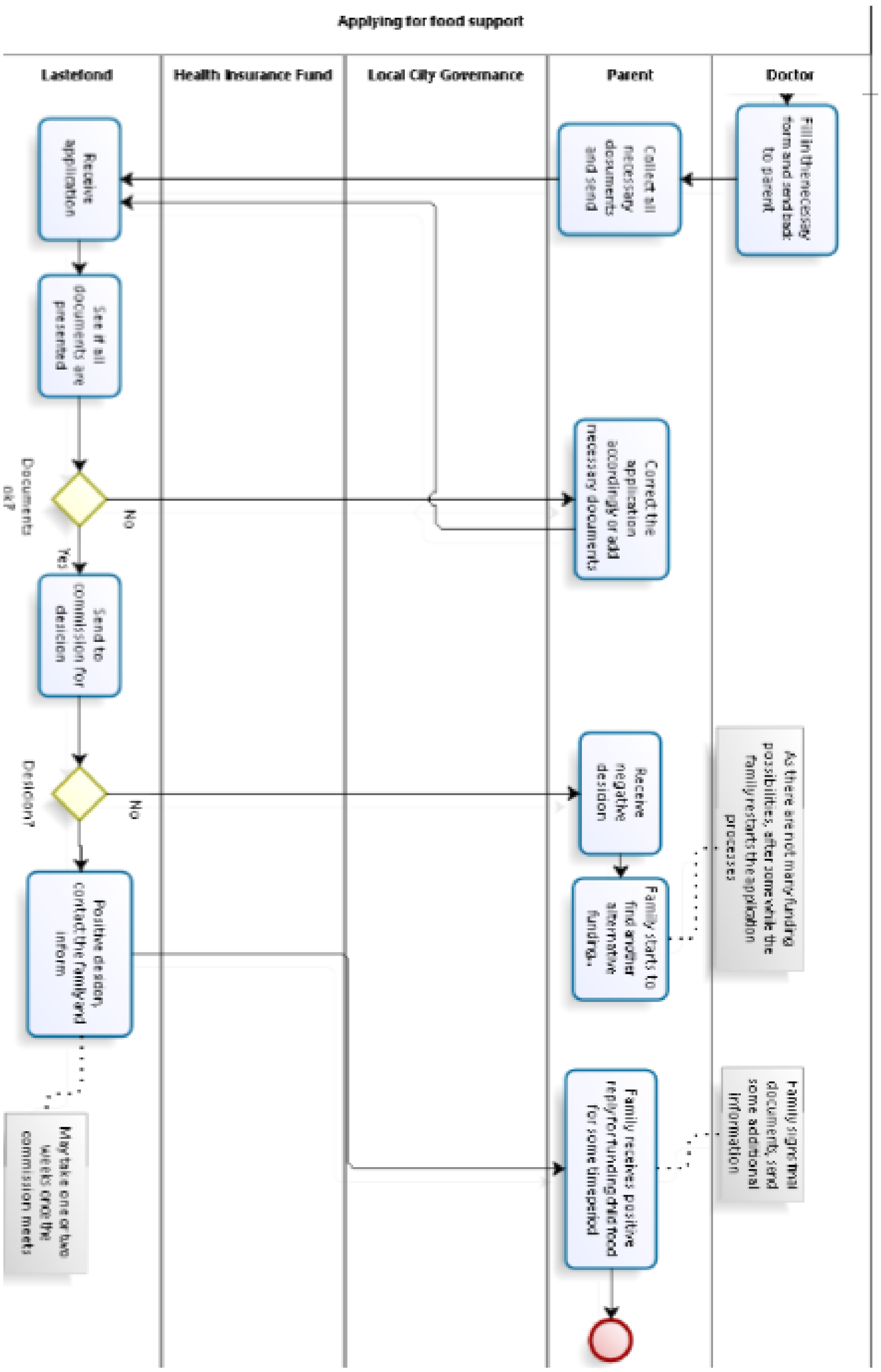


Figure 6. Applying for food support from different sources as-is

In this way of looking for information, finding information and in the end application, a lot of time and resources are wasted. First the time to get to know about the possibility, then to get to know more information about it, to get to know the application process and to find the forms, fill in or print and fill in the forms. Ask comment or document from the doctor and a certificate. Collect all the documents and send or bring on the spot. The doctor spends valuable time on writing another medical comment about this child. The doctor needs to open medical records, either open and save a file or start a new one, sign digitally or print out sign and stamp, scan and send by email back to the parent. The parent needs to organize visiting the offices, to take time to get to know the application process and also, accept negative replies as not every application gets funded. But at the same time, the child needs to eat, get other treatments and the rest of the family-system needs to keep running.

7.1.3 Case study Three as-is – application process for a daycare for a disabled child

At some age it becomes important that a child, even with disability or severe disability needs to go to kindergarten. In this institution, there are professionals working who have studied to develop the child, to help the child manage better in the world and it is also a useful "tool" for the parents to go back to work. The financial support to a parent who gets allowance for raising the child at home ends when the child is around 18 months old. There are many institutions in Estonia and Tallinn, and it is also stated in the laws that any child has right for education, including kindergarten.

Disabled child, especially severely disabled, needs additional care compared to healthy child and in some cases, the child needs also special daycare (kindergarten) where the staff is able to take care, develop and if needed, feed the child via g-tube. There are governmental institutions in Tallinn dealing with these issues but in some cases, information about them does not arrive to the family at the right time, if at all.

Once the family knows about this kind of service possibility, application process starts. The representative of the school gives documents to fill and sign on paper or by email to the parent. Again, the parent needs to fill in all the documents starting from the names, id-codes, medical situation description and so on. Once the documents are digitally signed, sent by email and received by another institution, the application process has started.

A meeting is set to meet an adviser by governmental institution and who asks specific questions about the child and family needs, if needed, also additional documents are required, including medical situation description by the child doctor. Child is suggested to be taken to the meeting, so that the adviser can also see and meet the child. Once all the documents are collected, a commission will meet and the parent together with the child and advisor will reply to questions asked and will then wait for the decision and reply by the committee if the child will get a place in the special kindergarten. For the final decision of the committee, parent together with the child visits the office at agreed time. The commission does the decision on the spot and the documents about the decision are sent to the parent either by post or digitally signed and by email. The parent then applies for the kindergarten spot by contacting the kindergarten and attaches the decision of the committee proving that the child has a right for a place in this daycare.

The application process is also described in more detail and visual way on Figure 7. As the figure originally is capacious, it is divided into two parts and these parts should be imagined as sequential process.

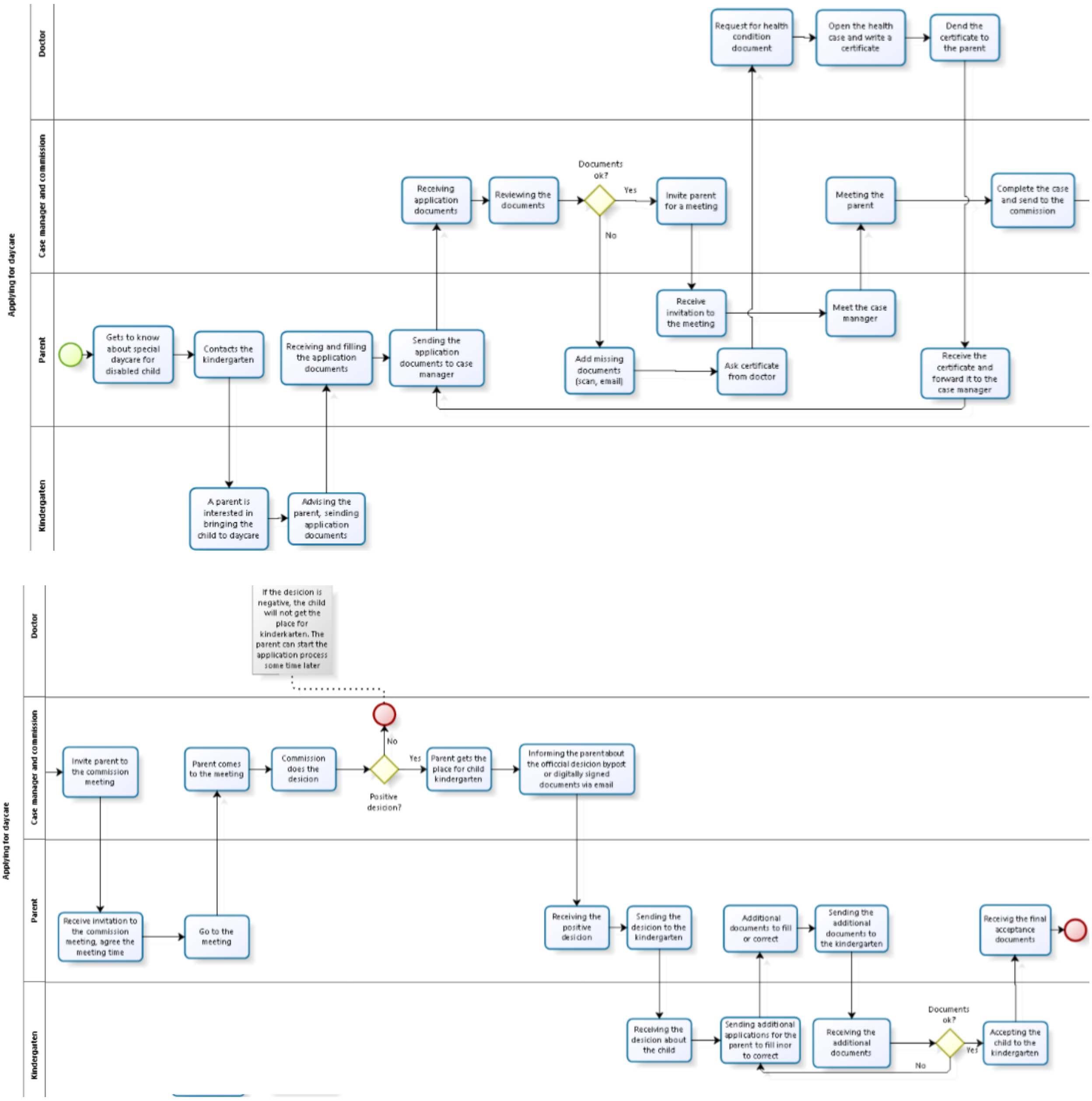


Figure 7. Applying for kindergarten place for disabled child as-is

This application process consumes many resources. First of all, time spend all single steps and overall the whole application time is long. To receive documents from the doctor, to fill in and send the documents, the commission meets after every certain week and so on. Many documents are filled, printed, scanned and sent, probably also inserted manually into some information system that is not connected to other information system. The family needs to visit the doctor for getting the certificate and the office for the commission also twice and keep track over the documents presented, missing and the following steps after the decision be the commission to have all the documentation correct for the kindergarten.

7.1.4 Conclusion of case studies

These three case studies show, how the system of applications and information presentation is not as good and smooth as it can be. First the parent needs to find information about the service, then to contact the service provider, ask for additional information, fill in different documents, ask additional documents from doctor and so on. Although, all this information exists already in different information systems and databases is not used well and the information systems do not communicate with each other. The information is also presented on different organizations webpages that parent needs to find, learn to use and start to use. Some webpages and some organizations have self-service portals but many still work with downloadable forms that are either possible to fill in using computer but often these forms need to be printed. This results in losing resources – financial and time, especially considering that a parent with disabled child is not doing these things as a hobby but due to the need, the emotional level of these application processes is difficult and does not help the family as much as it could.

7.2 Interviews introduction

Interviews were conducted during April 2016 to get feedback and opinion about the current situation of informing parents who have disabled children – how the necessary information about possibilities for disabled children arrives to families, how satisfied families are with it, is there something missing, what is the opinion about doctors’ side, how much are they involved with the social questions and also, what does the state think and what are he plans. How could the system become better for all the parties? The questions asked are presented in appendices of this thesis.

The answers are divided into groups and answers by the interviewees are given. In total, eleven people from different parties were interviewed. Information about the interviewees is presented on Table 3.

Table 3 Names and information about interviewees

Interviewee	Occupation	Interview location	Time and duration
Külli Urb (KU)	Parent of disabled child, volunteer in the field of disabled people, author of handbooks about and for disabled people and children	Tallinn City's Board of Disabled People, Endla 59, Tallinn	07.04.2016, 47 minutes

Margit Krjukov (MK)	Parent of disabled child, project manager in Eliise Puhkusepesa	Tallinn Children's Hospital, Tervise 28, Tallinn	12.04.2016 and 13.04.2016, 39 minutes
Liis Toome (LT)	Doctor and Head of Department of Neonatal and Infant Medicine in Tallinn Children's Hospital	Tallinn Children's Hospital, Tervise 28, Tallinn	06.04.2016, 65 minutes
Karin Agrov (KA)	Social worker in Tallinn Children's Hospital	Tallinn Children's Hospital, Tervise 28, Tallinn	06.04.2016, 65 minutes
Birgit Kaasik	Clinical speech therapist in Tallinn Children's Hospital	Tallinn Children's Hospital, Tervise 28, Tallinn	06.04.2016, 22 minutes
Riin Luts	Clinical child psychologist in Tallinn Children's Hospital	Tallinn Children's Hospital, Tervise 28, Tallinn	06.04.2016, 22 minutes
Kairit Joost (KJ)	Medical geneticist in Unified Centre of Laboratories Genetics Centre in Tartu University Clinic	Unified Centre of Laboratories Genetics Centre, Hariduse 6, Tallinn	07.04.2016, 46 minutes
Jürgen Kask (JK)	Advisor in Estonian National Social Insurance Board	Estonian National Social Insurance Board, Endla 8, Tallinn	07.04.2016, 31 minutes
Gerli Aavik (GA)	Chief Specialist in Sector of Social Policy in Ministry of Social Affairs	Ministry of Social Affairs, Gonsiori 29, Tallinn	12.04.2016, 40 minutes
Gabriela Rooso (GR)	Chief Specialist in Department of Children and Families in Ministry of Social Affairs	Ministry of Social Affairs, Gonsiori 29, Tallinn	12.04.2016, 40 minutes
Janek Rozov (JR)	Head of Department in Department of Information Society Services Development	Ministry of Economic Affairs and Communications Harju 11, Tallinn	18.04.2016 26 minutes

7.2.1 Access to information – knowing about the benefit and services

Currently one of the problems in this area is that information does not arrive to the parent on time, too late or not at all. Parents are informed about child diagnosis and need for information in the hospital or in any case, by the doctor of the child. In the opinion of medical staff, the questions that come up after the diagnosis and about social topics, are related more to social workers and local governance. Parents at the same time still continue to ask their questions from doctors as a doctor is the closest person they think who can help the family and the disabled child.

During the interviews it came out also very clearly that accessing relevant information about benefits, allowances and services is a problem and should be changed.

When KU got to know her child's disability, she had no previous contact with disabled people and there was not enough information for her to start her new life. It was a big confusion at the beginning although she had studied Special Education in the university, she was still in a completely new situation. It was helpful that she had friends in Finland who advised her about what she may face in the future. She is very skilled by now about disability topics in Estonia as she is active in this social sphere but still there are things she thinks should be organized differently.

KU is explaining how she received information at the beginning and how she accesses information now:

> *"I found one woman in Estonia and found the support group – from her I got to know many things, she explained to me a lot. Also emotional support. It was a big confusion. It is important to think also about older child's and to manage also yourself. It was a big challenge. Currently the information arrives to me through information days as I am very involved also in the whole system. I take care of the whole network. I know more than usual parent."*
>
> *"www.tallinn.ee responsible people from city governance say they have all online but once there is new service available, the information does not arrive to me. Should I go all the time and search for something new? Usually I even do not know the name of the service. Russian speaking people are in even worse situation."*
>
> *"A person who is in the puzzle, the person cannot manage that well. Even the social workers rely on the brochure we have made ("*Abiks puudega inimesele*"). And what they, social workers, point out is that they (parents) should look on* www.tallinn.ee *webpage but*

> *people say they cannot find all the necessary information from there. Having a special child is a new situation for the family, it's not a passion or hobby that you know even the vocabulary. You need to study all from the beginning. The parent even does not know the concept. Arriving to the information is very problematic. There is new information coming every day that we were not aware of. You can search specifically, then you can find the information you need. You just do not think about all and there is too much information."*

From the hospital, in case the diagnose is given shortly after the birth or in case the child has been in the hospital, then the doctor, as a medical worker, usually gives out medical information. LT from Children's Hospital describes the process:

> *"Mostly the disability is given during the first year of life. The role of the doctor, as a rule, is that she gives diagnosis. Then, there will be disability given. We are guided by the diagnosis and we give the information to our social worker who helps the parent. But still the parent needs to start the application process for the documentation and official disability. We, the doctors, explain also to the parent, what is the problem of the child, what is the diagnosis and information about this. The doctor sends case history to www.digilugu.ee and the information is available there for the disability documentation."*

Often parents need to turn back to doctors from time to time to ask for child's medical condition certificates or to fill in some documents for the parent so that the parent can ask for certain services or benefits. For this the doctor, first needs to open the medical history files of the child and start another document or certificate for the parent. This is extra work for the doctors, as LT describes:

> *"Parents do contact us a lot. There was a case recently with special food application. It took me half a working day to find and fill in the form, if I consider all the steps. When the parent asks additional certificates and questions, then it is social problem, the doctor should not deal with it. The doctor should not know about this. It is hard to follow the social system and I cannot always give advice, it all changes all the time. At the moment, the situation disturbs our work, what we do, to fill in additional documents. For example, when a child goes to kindergarten, this is social problem, the doctor should not write anything additional. It is not medical; it is social problem. In the Children's Hospital, the doctors have a chance to turn to our social worker for replying questions. The doctor gives opinion and decides, what the child needs on medical side but the additional counseling is for someone else to do, for example to the social worker. It should be explained to the parent, what are the laws and rights. And still some parents need more help than others."*

KA shares her experience as a social worker in the hospital about obstacles and brings out critical aspect of information and the information translated for example into Russian language considering the scope of disabled children who live in non-Estonian families:

> *"Parents do not make difference, who is the service provider, what comes from Health Insurance Fund and what from Social Insurance Board. These assignment letters have been very confusing and there is always a lot of explanation. In each county the situation is different and the possibilities are also different. We are not aware of all the information in the hospital about the possibilities to the parent and we sent the parents often to local city governance to social worker who is there. Also, the language is a big problem. Russian speaking families are in big trouble as they have no access to information if it is not translated"*

KJ is critical about the current information system for the medical worker and what parents ask from the medical workers as they are not supposed to advice on social topics:

> *"I do not know to whom these systems comfortable are as the digital system for the doctors is not working well. Besides this, parents do come to ask additional information. I reply that the system is so complicated that I don't understand and cannot help them so much. The system is so complicated and I ask them to turn to Social Insurance Board. It disturbs my work a lot. It is not what I should do as a doctor. The medical worker and doctor should not even know so detailed information about the services or what comes after the diagnosis besides medical questions. For issuing proofs and certificates, for this I have a special form on my computer desktop to change the information text and it is for preparing for patents presenting for different schools and offices."*

GR from the Ministry of Social Affairs confirms the complexity of the current system for parents and admit the foggy situation:

> *"The current situation is yes not good and it is complicated to the parent. A parent needs to send application to different places and even to one office, several applications are needed. It is not clear system, especially considering the difficult system for the parent, to search necessary information is not a good solution to the parent now."*

The state sees also problems in the existing system as the division of finances and disability is equal to everyone, no matter the real need as some children need more services than others:

> *"All the resources that the state has are at the moment divided between everybody equally, no matter the need. But the plan is to re-divide all so that the ones who need get more and who do not need, do not get just because they can get although they do not need."*

MK shares her experience what she had with her daughter and still has when she is giving advice to parents who have just heard about their child disability and need to start the process:

> *"For us, we applied for disability as it was suggested, to get some financial support. It was really difficult to run from one office to another, I did not get good approach to my questions and also my family doctor did not know much what to do with disabled child and where to turn to. From the hospital we did not get any support. There was no information at all.*
>
> *We did not actually use the rehabilitation plan but we had it still as it was necessary to have it. I did not know that there was any difference between rehabilitation and Health Insurance Fund. The plan was not understandable at all. When you get to know the disability, then it is hard to understand. Especially the table in the end. It was not explained the plan. Also, I did not know about benefits. I started to go to local governance to ask questions.*
>
> *Now when I council the parents, then I can admit, I say, it is still complicated situation for me. Now there are more social media groups where a lot of information is shared. But of course, if I had more information before, we would have used more possibilities, for example for swimming and physiotherapy. Parents who are shy, they do not get information at all. Even today actually I am not aware of all the services. Our doctor has shared information and I get information also from other parents.*
>
> *There were many things I was not aware of. About advisors, it is more important to talk to some parent who is in similar situation and it is a lot easier than to talk to friends who do not have child with disability.*
>
> *At the moment I go to Internet to search for information. I google. The Ministry of Social Affairs webpage is quite complicated. You need to search a lot."*

7.2.2 Speed of receiving the service or benefit

Once the child is born and diagnosed with disability, the speed of receiving certain services and also benefits to help the family to raise this child are crucial as in some cases, starting the treatment and rehabilitation may play important part of helping the child to develop better and to have better future. It is also important in the aspect of the whole family, so that the stress of managing the situation would be smaller to avoid other drawbacks between relationships, other siblings suffering, losing economic stability and social position.

In KU opinion, these children and their parents should be informed as soon as possible. Here we face the personal information protection case, then she says it is not forbidden by law to inform the parent about possibilities:

> *"There still should be someone dealing with these children to inform city governance that a disabled child is born or is diagnosed and help should be provided. It is not forbidden to bring information package to home to this family but the hospital does not give information to welfare. I have experience from Finland when we were in the hospital and the doctor also invited experience advisor to the meeting and I had a good chance to talk to this person. We talked a lot, she showed me pictures and although this meeting was emotionally hard, it gave me insight what may happen in the future and I was prepared better and it was a very useful experience for me. What I mean is that information exchange between organizations is allowed. But it is extra work for example for the hospital. Now they try to give many duties for family doctor that they would do visits at home and that family doctors should become the first link. For the child it is really important that the services should arrive to the child as soon as possible, urgently. Every parent has experience with if I only had heard before."*

In the opinion of LT, it also depends on the parent, how interested they are to get to know more information in their situation:

> *"Sometimes it all also depends on the activity of the parent. Some parents who are not that active and educated, they arrive to do the rehabilitation plan later and then yes it may be that the child does not get the needed service."*

7.2.3 Suggestions to new system

In KU opinion, the local government social worker should be the closest person to the family when there are any questions about the child's disability, either about getting information or accessing services and any benefits. This person should know what is the situation of the family and is the most important contact.

KU suggest as well the social worker (or case manager, or any other designated person) to be the contact point for receiving important information about the possibilities:

> *"People should be made aware of trough city governance. Social worker should have the information and should give it to the family. Personal approach should be the solution. All*

> *package should be "delivered" by this person to the family. No matter if it is state service or local governance service. The problem is also that the person cannot accept too much information at the same time. There should be good logics behind the system – what comes first, primary. Information comes vertically and horizontally. It should be linked to new information automatically. What makes all difficult is that things change very rapidly (laws, possibilities etc.). Dynamically changes all the time. Children are always connected to rehabilitation plan. There should be connection with all fields – a doctor etc. I also forget what is written there, so it would be good that I could have possibility to check my situation. There should be offers for services what the child may need. All should be connected, holistic. Now all is separated."*

KU thinks that now is a good timing for new developments:

> *"Now it is the right time for this system. Now people would use and can have access to the services. But still today people go around with paper documents. It is still unbelievable. Would be good if it is all in one place, connected, all layers. It would be a good focus group to test this kind of system. People really do not know about the services; only a few percentage of people really use the services. The way until the service is complicated."*

LT would like to point out the disability decision and levels as at the moment the system is that there are three levels of disability, but the system of division and giving the disability to a child is not clear:

> *"The disability and the benefits in general should be based on need."*

LT also suggest online and automated system for the parents. She compares it to paying electricity bills where the used amount is automatically counted, invoice is sent through the bank and according to the contract, money is taken from the bank account automatically:

> *"Like I pay my electricity – I do not have to do anything for it. If the doctor has made the decision and filled the files, then for the kindergarten for example, the doctor should not do anything extra. The page should be easy and understandable. It cannot be overloaded and not too much text. It often also depends on the parent ability to understand."*

Automatic reminders in addition to digital signing would be useful for the new system as KA points out:

> *"For the rehabilitation plan, there is still manual signing. There is also no reminder after three years for the parent to renew the plan. A complete and complex service would be*

> *really helpful. Otherwise we do not know everything and we cannot help the parent as much as needed"*

BK is critical about the current rehabilitation plan and suggests that the plan should also be combined according to the specific case and information about the child and the need:

> *"It is the job of ministries to manage the possibilities what the child needs. During the time, the need may change. It all depends on the situation and sometimes it is not clear. Some parents even do not want to accept the disability. Rehabilitation plan does not work also well as it does not show the real need and use of service. It is a big waste of money. We would of course use this system. Also the rehabilitation plan should come automatically out from the new system."*

RL gives her ideas for changing the current system of sharing and providing information to the parent. In her opinion the information at the moment is fragmented and suggests a collection of information on one page:

> *"The information for the parent is spread around. It is fragmented and splintered. A place to connect these possibilities, state ones, would be good. It would be of course good if there is a system for it. Also possibility of support person contacts. Some families who need help, they do not know to ask due to the confidentiality although there maybe is money in the local city governance budget. Even if the possibilities at least are collected together would be good and useful."*

KJ suggest as well a contact person and patient centered approach:

> *"Would be good If there is a person to whom the parent can turn to or a website from where to get information. With this system, there is need for personal touch. For example, the speed ticket is sent really fast even during weekends and it is personal. Patient centered approach is important. At the moment there is approach that officer centered. It is important that information is accessible and that people reach it. At the moment it needs high IQ to reach the services.*
>
> *It would for sure make my work easier as it scares me how many services there are that I am not aware of. And yes, it all takes time to do these additional things. It is not hard or difficult, but takes time.*
>
> *Besides that, it will make my work easier but most important, it would also make the life of parents also easier. Sometimes people come and talk because they just want to talk and*

> *together we find some solution. It is important to help the family as we see often how the family breaks and parents' divorce."*

About medical information and restrictions in sharing it, KJ suggest:

> *"Genetic information is also very sensitive and it should be kept in mind. Perhaps the parent itself can release information to other officers (the person can choose how much to show)."*

MK points out an idea that contacts of medical companies would be useful to be on the new system so that parents can contact them directly for buying or getting devices and necessary tools, medicals or other things:

> *"One place with good and easy text would be useful, all should be explained, what to do, what are the next steps, why is it important. The need for rehabilitation plan and how to use it.*
>
> *The pharmacies give consultation, perhaps the contacts of medical companies could be useful on the webpage. From where to order what."*

7.2.4 State plans for new system

KU is sceptic about state plans:

> *"Until now there is nothing heard about the plans for* new system. *There is nothing known about ministry plans. Also they want to hide behind data protection when planning something new."*

JK about plans of new services and solutions, also proactive services:

> *"Yes, there are plans, for several years there are many ideas and plans going around. The web will be new and we will start to measure service usage more, how information is read, received, used and to see the customer behavior, how the need develops and how people use it. How well the channel is used and if it is used. SKAIS will be new SKA with new website and self-service portal. Communication with service providers and users will be more precise. The plans are based on the state plans and Social Insurance Board plans. Parents of disabled child will be involved in the development. The parents will be contacted and there is a working group working on it."*

GR explains the idea of the new system in development:

> *"Today, some benefits are given from local governance, the state and then different administrations. The main support should come from local governance, there should be a*

> *case manager, who manages all. Information to this person comes from parent or some medical institution, they will turn to case manager in local governance, to inform about the family. The case manager will invite together a commission to decide what the child needs.*
>
> *Depending on the cost of child's special need, this new system should cover the expenses. All the necessary benefits will be included there. The most difficult children, they will get more funding from the state budget. For the parent, that there is one certain office where to turn to. Evaluation instrument will be created and according to this, the plan will be made to see the child as individual and evaluate, what is the need.*
>
> *Today's division will be changed completely. Rehabilitation plan will be changed and there will not be this plan. If here is deeper need for the child, additional evaluation will be done and then the officer will come to visit the family. The doctor should be member of the committee and the doctor should inform the case manager about any changes.*
>
> *Local governance and state budget will be combined. Most of resources is on state level. We would like to change it that the local governance will evaluate the child. The family should not go on state level at all.*
>
> *Families who actually do not need additional financing will not get it and families who need more financing, will get more."*

To questions about the e-service for the parent, GR replied:

> *"We do not know what kind of IT solutions here will be. We have two models and in the summer the management will decide, with which model to continue.*
>
> *The plan (as e-service) should be visible somehow to the parent. The parent should see, how big is the budget, how much is used and how much is left."*
>
> *"The data will arrive on the plan for the parent. When we take the child case, then the cases are so different. There won't be state services, the child will get the money and receive as much services as the child needs. Case manager will involve necessary people, including the doctor and then the package will be put together and then the child gets all he needs. It should be visible from home by logging in."*

GA complements the case manager need over the online tool:

> *"The case manager role is important, online tool alone does not help. The experts can suggest, what the parent needs and knows to suggest."*

The new system will use the already collected data and the information and numbers should be also visible to the parent as GA explains:

> *"Today's information systems are old, once SKAIS2 is ready, it can be connected to STAR and eHealth information system and then the data can be used better. First the databases need to be ready. The existing data needs to start to move and to be used. The information the state needs should be asked once. Here the question of private information comes out as the health data is sensitive (GR complements that "it should be asked from the parent, if the parent shares data"). But for sure the numbers should be visible for the parent, how many services the child should get and how much is left."*

To the question, who will be the owner of the new system, GA replied:

> *"This needs to be agreed between Ministry of Social Affairs and Ministry of Education. The state center, will it be under Ministry of Social Affairs or Ministry of Education."*

JR says there are regulations in work for the important next step about service owners and proactive service:

> *"We are doing at the moment a regulation where we write down for the first time on state level, what is a proactive service. This is in the legal area that gives us the mandate to push the service owners to provide better services. First still, the services need to have owners, the next step then is to list the services. When a service is not in the catalogue, the question is, why it is not there as all services need to appear in the list of services. Then the next systems can be done, either complex services or added services. based on the user actions towards the state, the profile is presented about the user. Based on this, services can be offered. This needs of course that the service users are active and the service providers are thinking and not only following the law, it is important also to think about the created value. The system is of course complicated as it is divided between different institutions, local governments and the state."*

JR explains the current system and politics:

> *"Today providing public service is based on volunteer will. It you do not want a service, it is not provided to you as actually, there are people who do not want a service, for example, they do not want to admit their child disability. There needs to be some type of classificatory in between, before the state can proactively provide the service. The general politics is also this that there is not enough money for everyone and the systems are based on who asks, will get. Here is the trick with proactive service and free will.*

> *But for the developed and changed system, it should be seen, what part of the work is possible to automate with an intelligent information system. The answer should come from the service owner if there is a need for a person, case manager, and why the part of this person cannot be automated, what is the extra value this person brings to the system, especially in the part of sharing information.*
>
> *There are so many stakeholders, this makes it complicated. To do a new information system, then probably you will fail. You should see, where today there is most of information gathered and working, to add extra functionality to there. To see what is missing there and to put the focus there.*
>
> *To do one new, what is the meaning but the focus should be to add functionality to something that already exists."*

7.2.5 Time plan for the development of state-planned new system

GR explains how the plan for the new system will be:

> *"The time plan is so that by summer the plan has to be ready, also the financial plan. Next year, in 2017, we would like to pilot in some county to test it. In general, nothing big will happen before 2020 as all existing will be destroyed and new system will be done. All legislation, evaluation systems, trainings for the case managers – it all takes time. Everything that is involved to the levels of disability, if the levels are removed, then many things change. IT-solutions will be discussed after the vision is set."*

JK confirms the state plan about the Social Insurance Board new information systems:

> *"In the beginning of 2017, SKAIS2 and web need to work and these are the base of all future developments."*

8 Towards proactive service

Plans and goals exist in the field of health care in the world, Europe and local, Estonian level. Health care systems are big and complex, so many different stakeholders are involved and huge amount of information and data that is constantly collected. Now it is the turning point to develop this kind of information systems and software that starts to connect the databases and that starts to analyze this data to help the medical workers, social workers and also patients use the data in the best possible way for treatment and also for prevention of health concerns.

Sociotechnical systems are a key to better use of collected and created information. These systems will become a useful tool for many people's everyday life.

Parents who have disabled child growing in the family are in this situation most probably for the first time in their life and it is usually not a questions if they want to continue or not. It is a life situation that they need to cope and continue. The family needs to re-evaluate their life, learn to manage with the new complicated situation financially, emotionally and socially. This takes many resources and to keep the family united and to help them to maintain "normal family life" any helpful service in this situation is valuable, no matter if it is good information about some service, benefit or allowance or a service provide to the child or family proactively. It is the goal of the state to take care for its citizens and children with equal rights, even if they have severe disability and providing useful tools for them to deal with it is important. Therefore, the analyses case studies of some situations with just a minor amount of services a child and parent need, and conducted interviews with stakeholders show that big changes should be done to better use the data.

There are several guidelines and handbooks, also in Estonian and released by the Ministry of Economic Affairs and Communications that give directions to design and create or recreate public services. Changes are also made in the legal system to map better the state of public service and proactive service. There are also action plans for health care services in Estonia and in the world that are goals to achieve and to help the medical staff and the people. Considering all this, an idea of creating a useful integrated proactive e-service for parent with disabled child has developed. It is explained in more detail via sociotechnical system and agent-oriented modeling way in the next paragraphs. But before, the previously described case studies are redesigned and results of the interviews are analyzed keeping in mind the idea of a proactive e-service.

8.1 Case studies discussion

8.1.1 Case study One to-be – application process description for yearly allowance for a disabled child in Tallinn

The problem today for the parent with this allowance is that the parent of disabled child may not know about this allowance as the parent is not notified about it automatically or proactively by the city although the city governance has the data about the child and the family. Information about this service is up on some portals and some news can be found about it, but in reality, the information does not arrive to the parent once the parent does not look for this specific information by himself. Usually, a parent who has newly diagnosed child, does not know about this kind of possibilities. When asking about the existence of this service from interviewed doctors, they were also not aware of this service.

For the parent, no matter if it is the first time to apply for it or it is another time for sending the application, a notification about it should arrive to the parent. In www.tallinn.ee self-service portal it is possible to "order" notifications in interested field, but the same issue arises also here – the parent may not know about the service or the possibilities of the self-service portal.

A proactive e-service here would be useful that would remind the parent (after checking from information systems the newest information about child disability) every year that this allowance is possible and would suggest applying for the benefit.

For the first case study, a to-be model has been created and presented on Figure 8. This model takes into consideration the collected data about the support that it exists and the conditions of application and "getting it". One the child is diagnosed and the corresponding remark is made in the medical history of the child, the parent receives automatically a notification about the possibility to get the support. The parent simply needs to choose, if he wants the support or not and if he accepts to take the support, the money is transferred on the bank account of the parent. The information about the family situation and if the family is allowed to receive this support as it may vary according to the location, residence permit of both parents, or any other condition. The parent does not have to know these details and the parent does not have to search for information or even fill in any documents, the parent also does not have to go to different webpages of different organizations, all should arrive on one complete information portal that is clear and easily understandable for any level of service user.

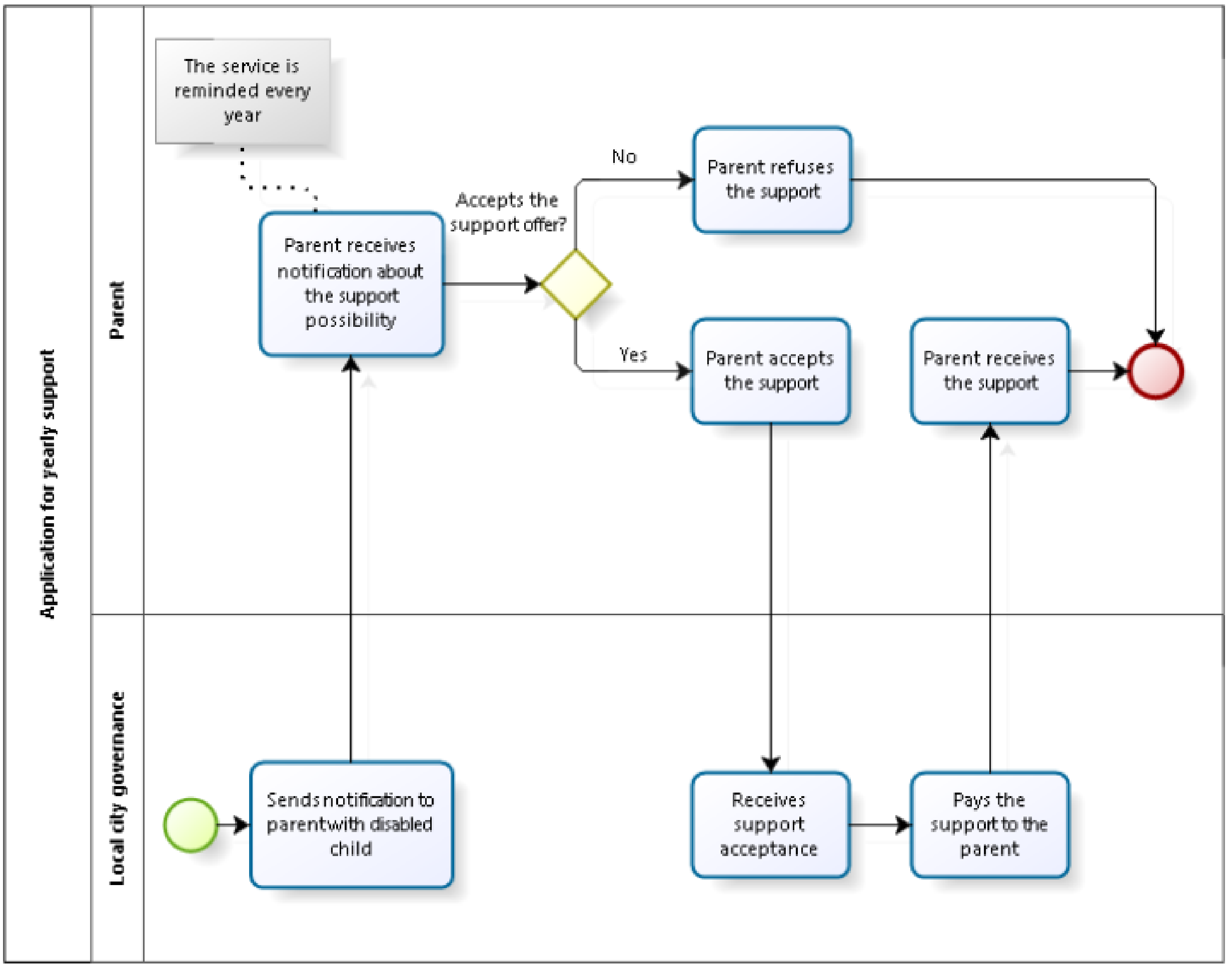


Figure 8. Applying for yearly support from local city governance to-be

At first, after the diagnosis and the disability decision, the parent may need to confirm or allow state and local governance systems to analyze and propose the services as there may be parents who do not accept the child disability situation or they do not live in Estonia or they do not need any service concerning the child.

8.1.2 Case study Two to-be – application process for special nutrition or food support for a disabled child

For the second case study, to-be process is drawn and explained on the Figure 9. As it was seen previously on Figure 6 on the as-is process, the parent had to search for information from different organizations and their webpages, follow different application processes, fill in documents on paper and ask medical history descriptions from doctor. In the to-be process, this information from different organizations about food support possibility is collected previously and is updated. The system will receive notification once a child is diagnosed and the doctor has made a remark that this child needs special food. The system analyzes the family possible need for support to buy this food, depending on the family income, location, other siblings and the cost for the food and additional equipment such as pump and feeding tubes and syringes.

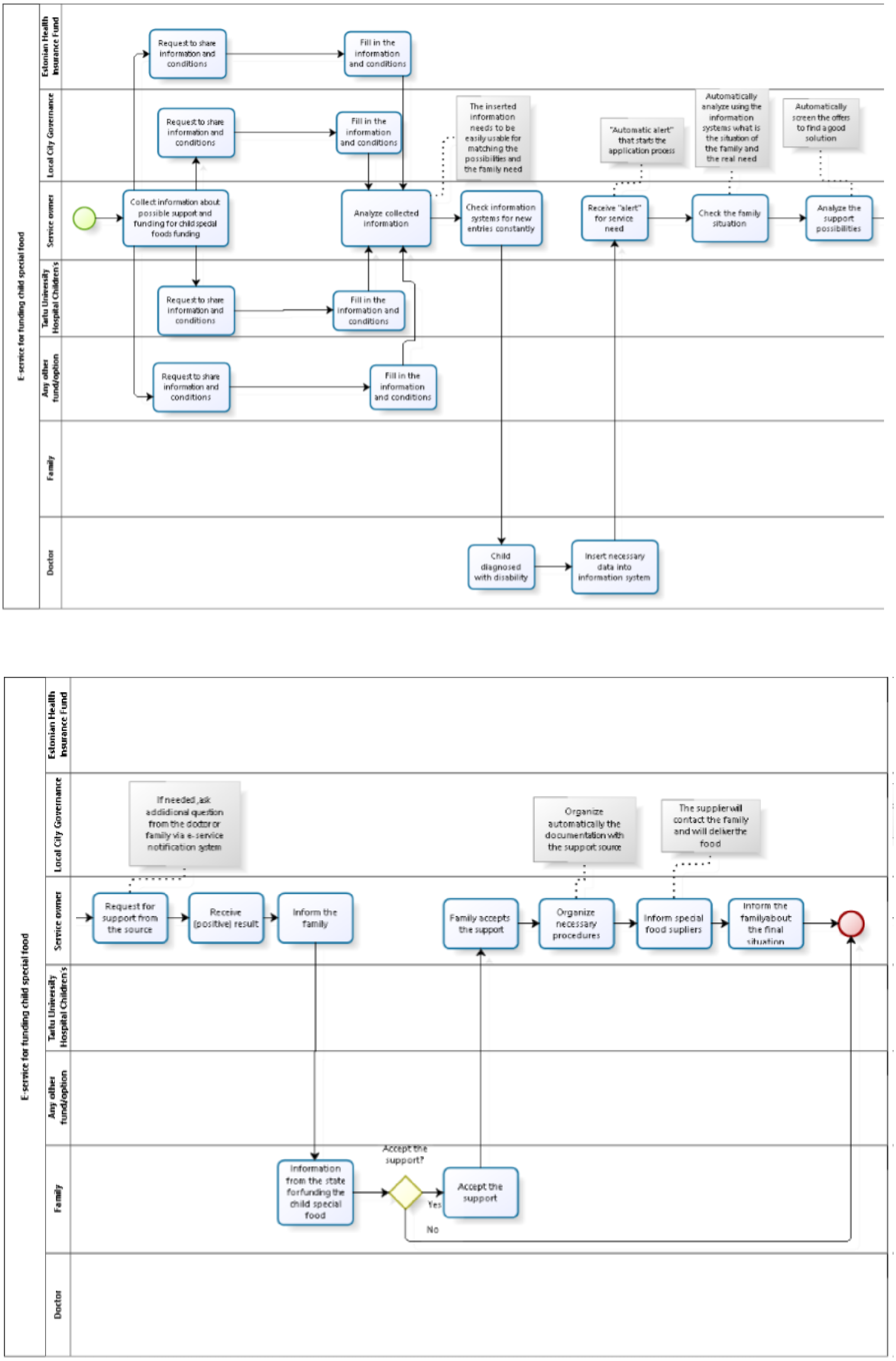


Figure 9. Applying for food support from different sources to-be

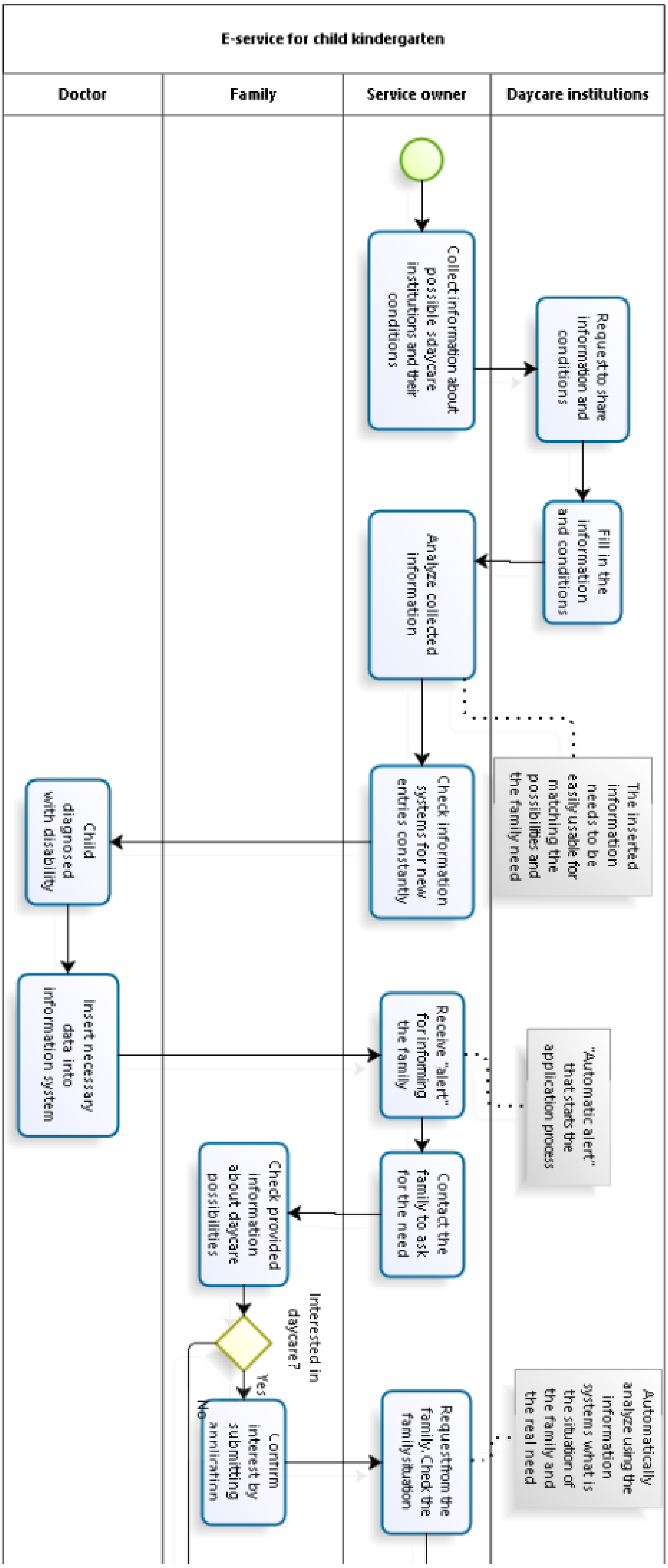
The family is then notified about the possibility to receive support for buying the food. The family can then accept or decline from the offer, if needed, some corrections or additions are made and after the confirmation, the system accepts the family's decision and acts accordingly. If needed, contacts the food supplier and organizes the food delivery to the family. Here, there is sociotechnical system behind the service as some human touch is needed but most of the information is collected and analyzed automatically by software.

An idea would be that these services are online, available for the family who fulfills the requirements and the service is provided proactively. All the necessary data is already inserted about the child medical condition and need for the food, the information should arrive automatically, using the information systems to the online environment from where the parent can submit the application. With this system, there is clear overview of the family and child need, possibilities for support and the process is easy to manage for the service owner and also to the parent. The parent has honest proposal by a proactive e-service for example trough the decision from the local government to cover the food expenses so that he family can maintain their living standard and to reduce any additional stress that comes together with being a parent to a disabled child who needs special food and treatments every day.

8.1.3 Case study Three as-is – application process for a daycare for a disabled child

When the time comes, family needs to start the application process to reserve a kindergarten place for their disabled child. As the process at the moment includes visiting the kindergarten, filling in documents for institution who decides if and to which special kindergarten the child could have a place, visiting this institution and meeting the case manager there and then meeting the commission and again, filling some papers, then this whole process could be designed a lot clearer and comfortable for the parent and also to the state or service owner who manages this process. Here again, the information systems and data collected can be analyzed and used better. At the point, the parent will have to decide if the proposed possibility is suitable. All the previous work is already done by the service owner with the help of software than analyzes the whole situation. The process is described in detail also on Figure 10 by Bizagi Process Modeler.

This process is should be flexible to accept necessary exceptions and additions, according to the system or family needs. By having a sociotechnical system as described, many resources will be saved – for example time, as all will be a lot faster, the human aspect will be removed when for example some people that need to take decision are on vacation or cannot issue necessary documents. Also, financially there will be savings, as the process is faster and clearer the child arrives to the institution faster, parent can go back to work faster, family life is healthier and the child, who is disabled, has a chance to get professional development on daily basis.


E-service for child kindergarten
Doctor
Family
Service owner
Daycare institutions
Collect information about possible sdaycare institutions and their conditions
Request to share information and conditions
Fill in the information and conditions
Analyze collected information
The inserted information needs to be easily usable for matching the possibilities and the family need
Check information systems for new entries constantly
Child diagnosed with disability
Insert necessary data into information system
Receive "alert" for informing the family
"Automatic alert" that starts the application process
Contact the family to ask for the need
Check provided information about daycare possibilities
Interested in daycare?
Yes
No
Confirm interest by submitting application
Request from the family. Check the family situation
Automatically analyze using the information systems what is the situation of the family and the real need

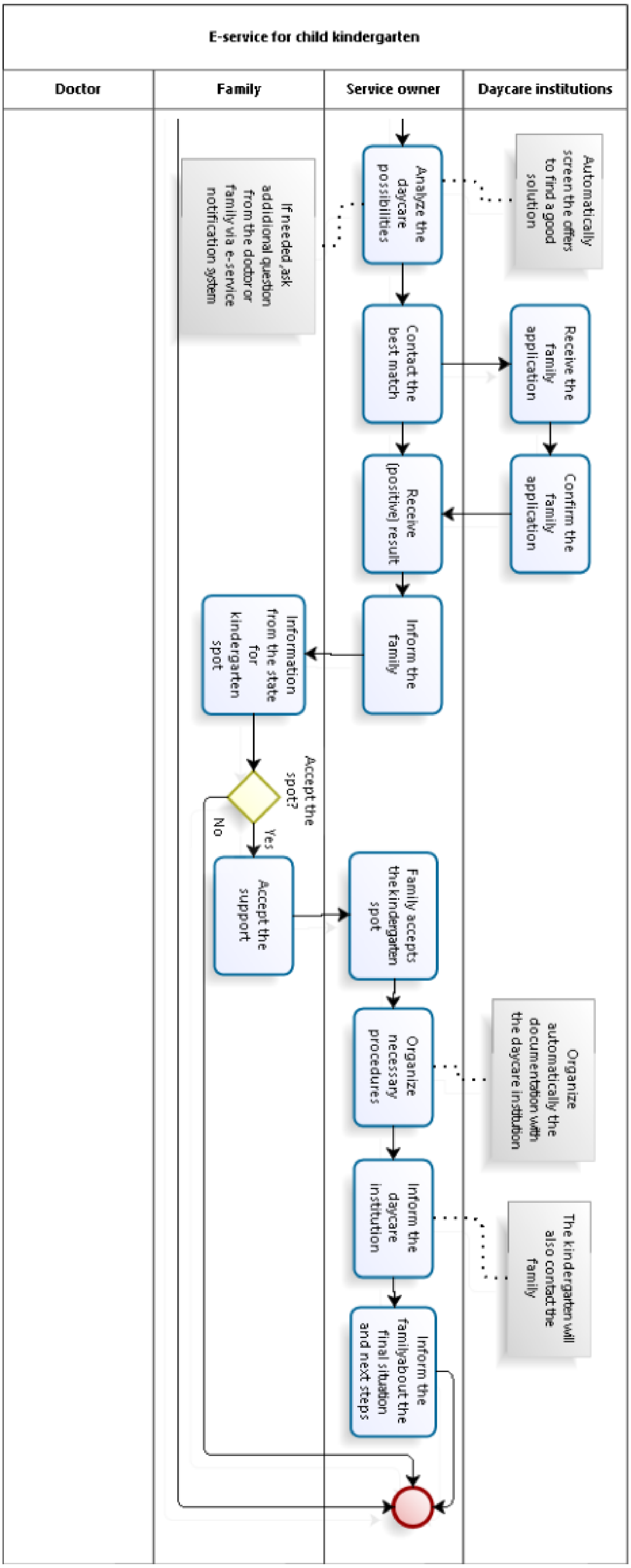


Figure 10. Applying for kindergarten spot for disabled child to-be

In ideal, the application process should again be online and provided to the family proactively as a service once the family shows interest in putting the child into daycare institution. Information about the child, child needs and family situation is already inserted in the databases of information systems. In this case, this information should be brought together into application form and the family should have the possibility to submit the application. Of course, meeting the advisor is necessary not to have the whole process online, but by this, information will move fast between parties and situation would be clearer for all of them. Resources will be saved and the situation, as much as it could be, is easier for the family.

8.2 Interviews discussion

Based on the interviews and replies by parents, it comes out clearly that the current system for parents of disabled children needs changing. Information is spread around organizations and webpages and even the social workers who are supported to help families in this situation, are not aware of all the possibilities and they can only guide the patent to another organization.

The interviewees and results by them show clearly that the medical workers are not satisfied with the current situation as the information flow is not smooth. Parents often turn to them to ask questions that are more from social field and not about medical condition of the child. Parents also need to ask medical descriptions of their child condition and this means extra work and time loss for the doctors as they need to open the medical history and fill in either some special form that they are not used to or to start a new document, save it, print it, sign and stamp it. For the parent, this takes also extra resources. The parents are also not so satisfied with the current system, as for most of parents, once they have disabled child, this is a completely new experience for them and they need to get to know all – the medical condition and possibilities for the child, social questions for additional supports and funding for special equipment, therapies, food and medicine. From the state side, the employees confirm also that the current situation is not as comfortable as it could be, but steps to improve this are taken and plans are in work.

The suggestion would be that there is one portal (proactive e-service environment) where necessary information about the child and the disability is collected, together with the possible services, benefits and allowances is presented. This portal would be personalized – according to the family situation, child disability and many other factors. All having the same goal – to provide better services for the child development and to make the life of parents easier to maintain. Additional information about the disability could be found there, contacts where to turn to if for example this disability has some associations by other similar families, if there are advisors who can help the parent, contacts of medical equipment companies and also kindergarten, school or therapies options. Most importantly, this portal should show, what are the services provided to this child no matter the service provider, and applications to apply for the service directly from the portal. And of course, also application possibilities for the benefits and allowances that are legally there for the child who has disability. All explained in simple, understandable language for all levels of users.

Through this, resources will be saved for the medical workers as the doctors have pointed out in their interviews that it disturbs their professional work if they need to deal with the family's social questions. The doctors do want to help but this is extra task for them and as they are usually occupied with medical treatment of many children, filling in some documents and advising parents with applying for benefits is not as it should be.

Parents usually do not make difference between who is the service provider and they do not know where to turn to for information and application. Some benefits remain unused that could be necessary for the child and also, this may result with development delays for the child and making the family situation even worse than it is due to negative emotional feelings of not understanding the system or getting to know about the services or benefits too late.

The state officers confirm that there are plans for new and better systems as the system at this level and condition does not satisfy any of the stakeholders. The state is planning to create a network of case managers who will start to manage all the necessary things a disabled child needs. This person will be the contact point for information and parent who needs information and what is behind the information – services and benefits. The system of giving financial support and other services will also be changed and will be based on the need of each child.

The idea of having a case manager should come together with a good and strong information system, on what the work of case manager should rely. Also the parent should have access to this information system, the portal, so check the condition of application, possible possibilities, and any additional information. Parents need to search for information often also during the time when it is not a regular working time for the case manager. Also, it should be thought, how much of the case managers work can be replaced by automation, so that the processes would be quick and would not depend on human touch. The case managers need training and they need to be aware of so many different cases that in this case, an information system that is able to collect, analyze and suggest options would work better and would be the main working tool for the case manager.

With this we face also with the obstacle of location and meeting place. In rural areas, the distances are long and it is not comfortable for any of the sides (the parent or the social worker) to go to meet the other. Also, the system of providing services (therapies, place for kindergarten or any other) or benefits would be clearer and transparent if the system is online and automated, automatically generated. An option to add special case conditions and exceptions should have a place there but instead of only human system, a case manager, in nowadays sociotechnical and developed world of information systems would be a big step back and would not satisfy especially the parent.

When developing a new system or attaching parts of it to some existing one should follow the proposed and analyzed model of designing a good public service, so that the new service would be accessible and even proactive from the state side, so that the family would not need to struggle to get to know about the service and then to get to know how to use the service. Also, it should fast to arrive to the family and it should not depend on how active is the parent socially. All children with disabilities are equal and need the services as fast as possible.

The idea of not creating a completely new system but to develop some existing system and by adding applications to it is a good development plan as it was explained in the work before, many newly developed IT projects, especially huge and complex ones as the health care systems are, may tend to fail. So completing and developing some already existing one would be a strong start.

At the moment, the state has plans for future plans to be fixed by summer of 2016 and the new systems running by 2020. Families with disabled children and medical workers and social workers should be involved in the development process as here, experience from current system and the deficit samples should be well analyzed.

To collect the design-ideas together for the integrated proactive service, describing the design of the new system of the e-service and developments is made using agent-oriented modeling. By describing scenarios, agents and models, using also the quality goals and functional goals, will give clearer understanding to all stakeholders.

8.3 Requirements' models for the future sociotechnical system

The systems we use in everyday life have become complex. These systems need to be responsive and secure to fulfill all the stated needs of users. In addition, the monograph (Sterling & Taveter, 2009) describes the attributes of modern environments that software should consider in order to be effective. These attributes are complexity, distributed nature, time-sensitivity, uncertainty, unpredictability, and open nature. In addition, to perform effectively and serve users well, the software needs to be adaptive, intelligent, efficient, purposeful and understandable (Sterling & Taveter, 2009). A question is how to design systems with such characteristics. Agent-oriented modeling (Sterling & Taveter, 2009) is an approach for designing sociotechnical systems consisting of people, devices and software components meeting the above-described characteristics.

Based on the interviews and case studies described an analyzed in chapter 7 the requirements for a sociotechnical system of the integrated proactive e-service for parents with disabled children are presented as models of the types suggested by agent-oriented modeling (Sterling & Taveter, 2009). In total, three goal models are represented, and the roles included by these models are described in more detail. An organization model and a domain model have been created and described to further explain the idea of the proactive e-service.

The idea for the e-service put forward by this Master's thesis has been described by agent-oriented modeling (Sterling & Taveter, 2009) because this method explicitly caters for representing quality goals and emotional goals along with functional goals for the sociotechnical system being designed. In the problem domain of designing e-services for parents with disabled children, quality goals and emotional goals are of enormous importance. Out of the types of models suggested by agent-oriented modeling (Sterling & Taveter, 2009), goal models, motivational scenario, role models and domain model have been created. These types of models are overviewed in sections 8.3.1-8.3.3.

8.3.1 Goal models

Goal models are used for representing the requirements for an integrated proactive disability service for parents with disabled children. The service provides the parents with the necessary information concerning their new life situation and helps them to find services required for the child as well as financial and other kinds of benefits that would help the family to manage better. The service analyses the information provided by the parents, healthcare professionals, civil servants and other stakeholders, and also "pushes" useful information and services to the parents. The service also keeps track of the medical situation of the child and updates it if necessary, and also analyses the user behavior to provide even better services for families with disabled children.

The quality goals for the disability service are:

- ✓ *Personalized;*
- ✓ *Proactive;*
- ✓ *Fast;*
- ✓ *Precise.*

The emotional goal is that the service should be *Helpful* for the family.

Roles taking part in the goal model are:

- ✓ *Parent*
- ✓ *Child*
- ✓ *Sibling*
- ✓ *Service Manager*
- ✓ *Feedback Manager*
- ✓ *Doctor*

Goal model on Figure 11 shows hierarchical relations between the functional goals and the roles required for achieving the goals. Parent, Child, and Sibling are the main stakeholder roles of the service. Other important stakeholder roles are Service Manager, Feedback Manager, and Doctor. The functional goal they achieve is proposing information and services for the family, so that the family could consume the information and services. The latter is represented as another functional goal. A Doctor regularly checks the condition of the Child and provides diagnosis, which is also modeled as a functional goal. The quality goals here are that the service is personalized for the family, proactive from the service provider side and also precise and fast. As an emotional goal, the service should be helpful for the family.

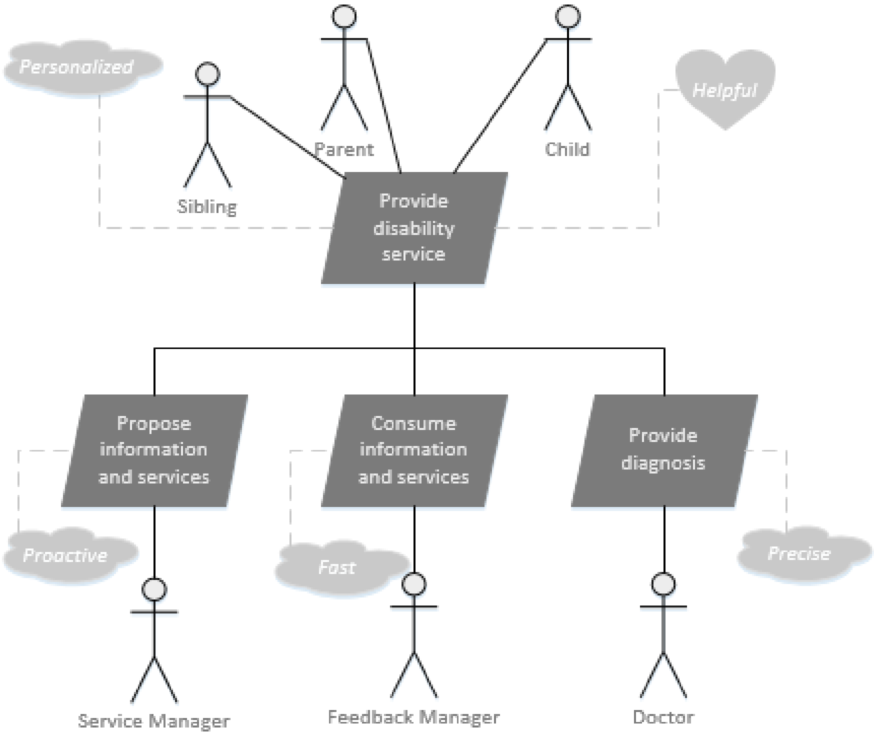


Figure 11. Goal model. Provide disability service

Figure 12 elaborates the goal of proposing information and the services represented in Figure 11. Accordingly, the Service Manager collects the necessary information that is needed to provide this service and proposes it proactively to the Parent. The information in general and information about the services is collected and analyzed in cooperation with Case Manager, the Doctor and Social

Worker. The Social Worker knows about the situation of the family (need for support, living conditions, income, expenses, etc.) and the Social Worker also knows, what can be the possible benefits and supports that the family may get from any state or city public (or why not even private) organization. The Doctor regularly checks the situation of the child and if needed, updates the medical information in the system. The Case Manager analyzes the needs of the family, developments and in conclusion, proposes relevant information and in cooperation with the Social Worker, proposes the necessary information and services to the family (taking into consideration the need of the Child due to the disability). The quality goals here are connected to proactivity by the Service Manager, personalized for the parent as the information and service using, also fast and precise, reliable and responsive from the system side to make the service easy and clear to use. The managers are working in parallel with information systems that have information collected and via software, analyzed accordingly. Some of the information will be provided to the family and Parent automatically but as the case of the Child can be complex, the existence of a human behind the system is also necessary, but of course, less in the case of just sharing information and it should be seen, how much it is possible to reduce the workload and part of human in the system in general and how much can be automated.

These kind of complicated systems are constantly in development and will never be completely ready. Therefore, analyzing the work and process of the system is constant and necessary additions and changes are needed as the problems or suggestions arise.

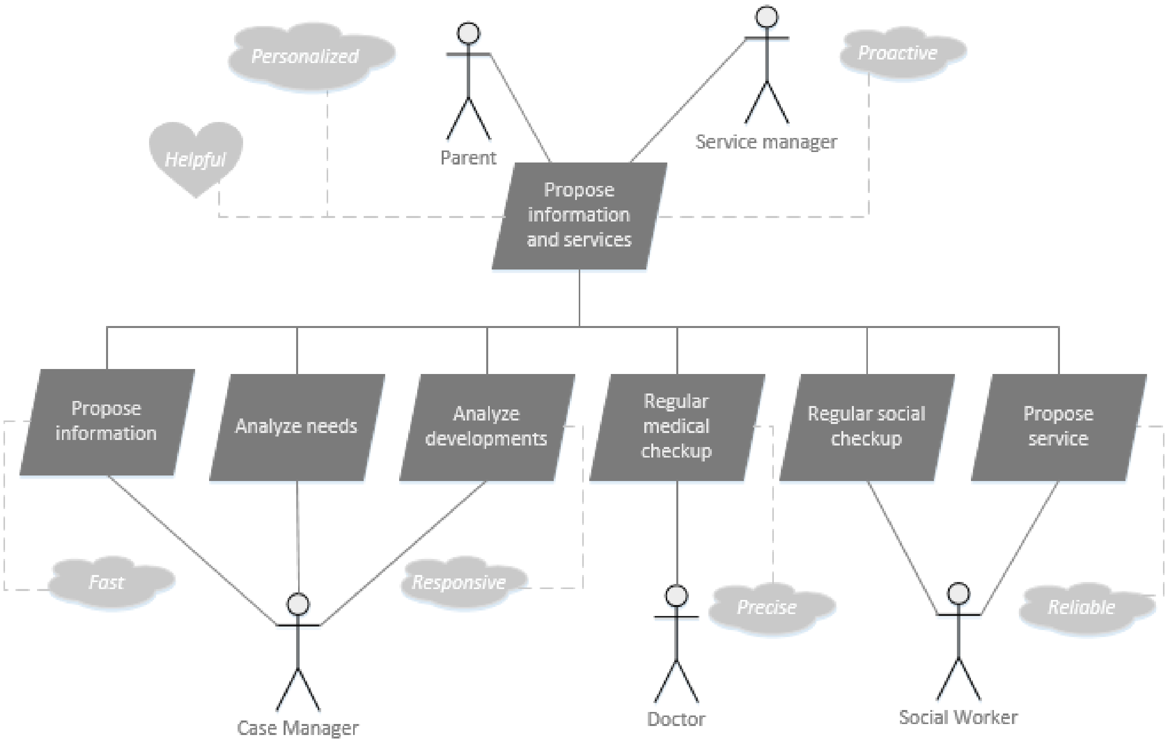


Figure 12. Sub-goal model. Propose information and service

Figure 13 elaborates the goal of proposing information and the services represented in Figure 11. In the goal model represented in Figure 13 the actual use of the service is analyzed in more detail to be able to improve the service (if there are services or information that is or is not necessary for the Parent, then this will be renewed), the Information Manager will know, how much and how some information and service was used and consumed and again, the social worker can update and propose needed services according to analyzed data. The service is personalized especially to the Parent and the Child in order to provide better access to necessary information and services to help the family cope better with the complicated situation. Through the information inserted by the managers and Social Worker and the information system analyze based on the information collected and stored in the databases, suggestions are made accordingly. Also here, as much as possible, the system should be automated and if needed, the managers, and human touch will be added as needed.

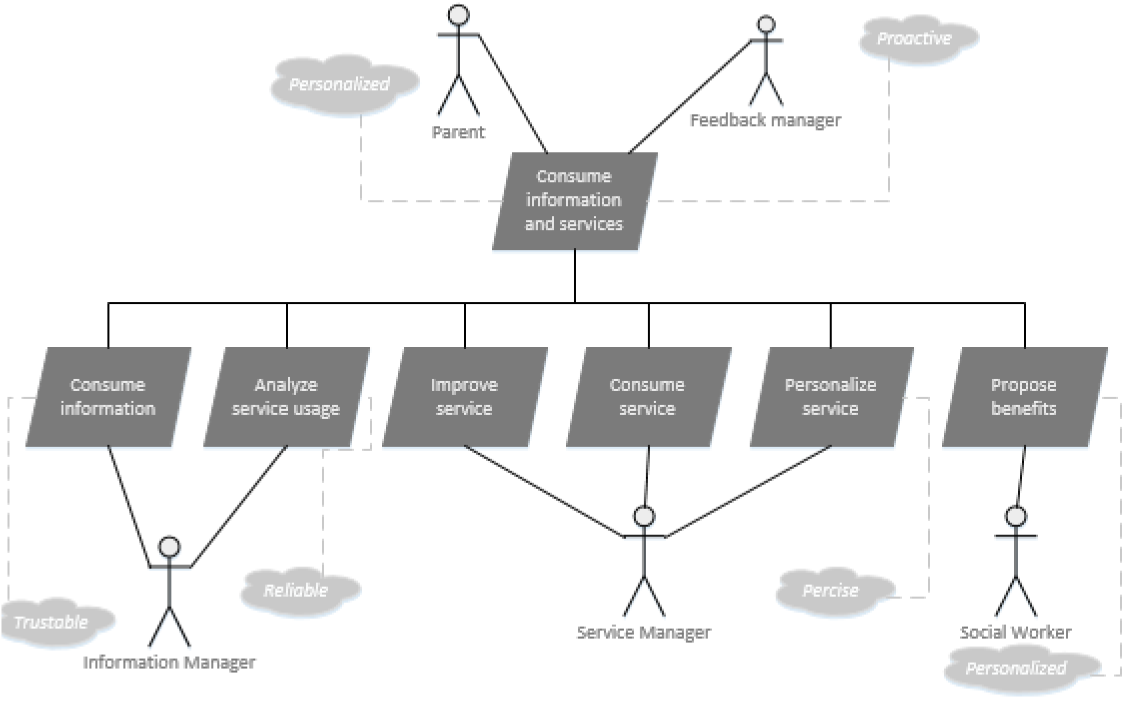


Figure 13. Sub-goal model. Consume information and service

8.3.2 The motivational scenario

The general scenario of providing this disability service to parent with disabled child is described in Table 4 more precisely. This table is a helpful part of the sociotechnical process description to understand the process of providing disability service better with scenario description and quality description.

Table 4. Motivational scenario of providing a disability service

Scenario name	Providing disability service
Scenario description	The owner of the service needs to provide a disability service to a parent who has disabled child. This involves following activities: (a) proposing information and services from the moment a child is diagnosed with a disability to help the parent manage the situation better since the beginning (to be aware of the situation and to have clear overview of the current situation, information and possibilities, including benefits and services necessary for the child and family) (b) using the information and services from the moment the child is diagnosed and all the documentation is complete for officially using the service and all the possible benefits that are analyzed considering the situation of the child and family. The information about the benefits is previously collected and regularly updated according to laws, projects and different decisions or possibilities. (c) providing diagnosis by the medical staff who regularly check the child’s health condition and makes necessary updates to the medical records according to what the following decisions are made for providing information and the benefits
Quality description	Providing the disability service should be proactive and useful for the parent to be able to take better care of the child (including being aware of the disability situation and possible financial benefits and services the child can use) and also through these described points, to take also better care of the whole family, partner and sibling to maintain as normal family life as possible in this situation

8.3.3 The role models

Roles express functions, expectations, and obligations of agents enacting them in the system of providing a disability service. A role model lists responsibilities of the role without saying anything about the order in which or under which conditions those responsibilities are to be exercised. The role model describes the role, lists responsibilities and also constrains. The role models of providing a disability system for Parent, Service Manager, Feedback Manager, Case Manager, Information Manager, Doctor, Social Worker are described.

8.3.3.1 The role of Parent

Table 5 is describing the role of a Parent with its responsibilities and constrains.

Table 5. The role of Parent

Role name	Parent
Description	The role of a Parent who needs information concerning child disability
Responsibilities	Log in to self-service/portal; read and get to know information; apply for benefits and services; give feedback if asked; insert necessary additional data if needed; fill the needs of the child trough using the service; behave reasonably
Constrains	Needs to use mobile device with Internet connection (needs some skills), needs to provide additional (personal) data

8.3.3.2 The role of Service Manager

Table 6 is describing the role of a Service Manager with its responsibilities and constrains.

Table 6. The role of Service Manager

Role name	Service Manager
Description	The role of a Service Manager who is responsible of the whole proactive e-service of disability. At least some part of the work is done automatically using technical solutions and software
Responsibilities	Collecting information about disabilities; possible benefits (no matter who is the benefit provider); analyzes collected information; including the data collected from the parent and the child about the disability and situation of the family; analyzes the use of the services and information by the family; collects data from medical workers and social workers to have up to date and latest versions and pieces of information
Constrains	Needs to deal with big amounts of sensitive medical data that needs to be analyzed. Needs Internet connection and devices to manage all, needs good staff and cooperation between organizations to develop interoperability working conditions

8.3.3.3 The role of Feedback Manager

Table 7 is describing the role of a Feedback Manager with its responsibilities and constrains.

Table 7. The role of Feedback Manager

Role name	Feedback Manager
Description	The role of a Feedback Manager is to collect information about used data and services. As much as possible, this is all done automatically by using different information systems and databases by special software
Responsibilities	Collecting information about presented and used information and services to get to know what is possible analyzes the collected information; makes sure the information that is provided is relevant and up to date; if something needs to be changed according to the "customer behavior"; gives suggestions; completes the changes if necessary; keeps track also on the medical worker and social worker updates in the system
Constrains	Needs to deal with big amounts of sensitive medical data that needs to be analyzed precisely. Needs Internet connection and devices to manage all, needs good staff and cooperation between organizations to develop interoperability working conditions. There is also need for good analyzing capability by employees and well programmed programmes

8.3.3.4 The role of Case Manager

Table 8 is describing the role of a Case Manager with its responsibilities and constrains.

Table 8. The role of Case Manager

Role name	Case Manager
Description	The role of a Case Manager is to propose information, analyze needs and analyze developments. As much as possible, this is all done automatically by using different information systems and databases by special software
Responsibilities	Proposing information and services according to the analyzed data about the needs and developments analyzes the collected information for the need and developments; makes sure the information that is provided is relevant and up to date; if something needs to be changed according to the "customer behavior"; gives suggestions; completes the changes if necessary; keeps track also on the medical worker and social worker updates in the system

Constrains	Needs to deal with big amounts of sensitive medical data that is analyzed precisely. Needs Internet connection and devices to manage all, needs good staff and cooperation between organizations to develop interoperability working conditions. There is also need for good analyzing capability by employees and well programmed programmes

8.3.3.5 *The role of Information Manager*

Table 9 is describing the role of an Information Manager with its responsibilities and constrains.

Table 9. The role of Information Manager

Role name	Information Manager
Description	The role of an information manager is to manage the information about data and services concerning this e-service. As much as possible, this is all done automatically by using different information systems and databases by special software
Responsibilities	Collects information about presented and used information from different information systems (automatically); collects information about services from different information systems and from the social worker (automatically); analyzes collected information; checks if the information that is provided is relevant and up to date; checks if something needs to be changed according to the "customer behavior"; gives suggestions and completes the changes if necessary
Constrains	Needs to deal with big amounts of sensitive medical data that needs to be analyzed precisely. Needs Internet connection and devices to manage all, needs good staff and cooperation between organizations to develop interoperability working conditions. There is also need for good analyzing capability by employees and well programmed programmes

8.3.3.6 *The role of Doctor*

Table 10 is describing the role of a Doctor with its responsibilities and constrains.

Table 10. The role of Doctor

Role name	Doctor
Description	The role of a Doctor is to give a diagnosis (together with his team of medical workers) and update the medical information of the child
Responsibilities	Regularly keeping up to date medical information of the child; inserting any possible changes and needs about the child, so that the child can receive all the necessary benefits and supports for better rehabilitation and treatment and development
Constrains	Needs to learn to use the system and insert perhaps more information when starting to use the system. The information needs to be up to date according to the last visit of the child. Needs to use device and programme for inserting data

8.3.3.7 The role of Social Worker

Table 11 is describing the role of a Social Worker with its responsibilities and constrains.

Table 11. The role of Social Worker

Role name	Social Worker
Description	The role of a Social Worker is to keep information about the possible benefits and services updated and also keep track on the family situation for analyzing and providing better services
Responsibilities	Regularly keeping up to date social benefits and services information for the child; inserting any possible changes and needs about the child, so that the child can receive all the necessary benefits and supports for better rehabilitation and treatment; taking into consideration the medical information by the doctor and the analyzed data by other managers
Constrains	Needs to learn to use the system and insert perhaps more information when starting to use the system. The information needs to be up to date according to the last visit of the child. Needs to use device and programme for inserting data

8.3.4 Organizational model

Organizational model is described on Figure 14 represents visually the relations between different roles and to understand the whole system better. In the organization model, the reactions between the roles are described. Positions in organizations are described in terms of responsibilities and constraints. There can be control (delegate responsibilities), benevolence (self-interested) and peer (equal) relationships between roles.

In the organization, Child is peer (equal) to parent and the Parent is benevolent to the Service Manager (as he wants to use the service). In ideal, the service is provided to the Parent as proactive, but the Parent still needs to be interested in the service to be able to start to use it. Feedback Manager, Doctor and Social Worker are controlled by the Service Manager as the information they provide is necessary by the Service Manager and the Service Manager analyses the collected data to be able to provide this to the parent as a service. Information Manager is also equal to the Service Manager as it provides the necessary information and analyses it for providing better service.

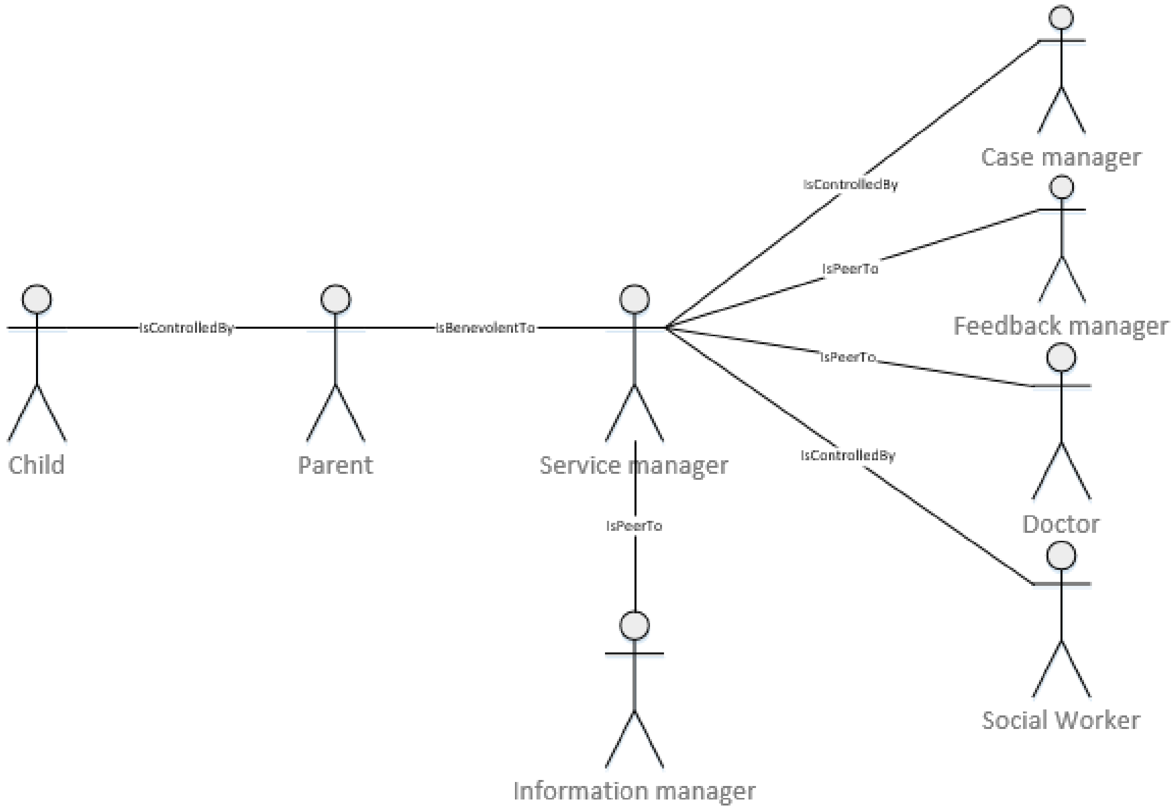


Figure 14. Organization model. Provide disability service

8.3.5 Domain model

Domain models represent the environments, the types of resources produced and stored by them, and the relationships between roles, environments, and resources in providing a disability service system. When a stakeholder models goals and roles for a system, he also has some idea of the environment(s) (that comes with particular knowledge) in which the agents of the system will be situated. The model of that knowledge is called a domain model (Sterling & Taveter, 2009). In the domain model presented on Figure 15, Parent and the Child have the role to provide information about health and family situation. The Social Worker and the Doctor will receive this information and share it to the system – with the Information Manager, who collects all the necessary information about the needs and also knows about the possibilities. According to this information, the Information Manager generates the service updates and improvements and most importantly, analyses the behavior and through this, provides necessary data to the Service Manager to give relevant information back to the parent and to Feedback Manager to analyze the information and to propose personalized services to the parent.

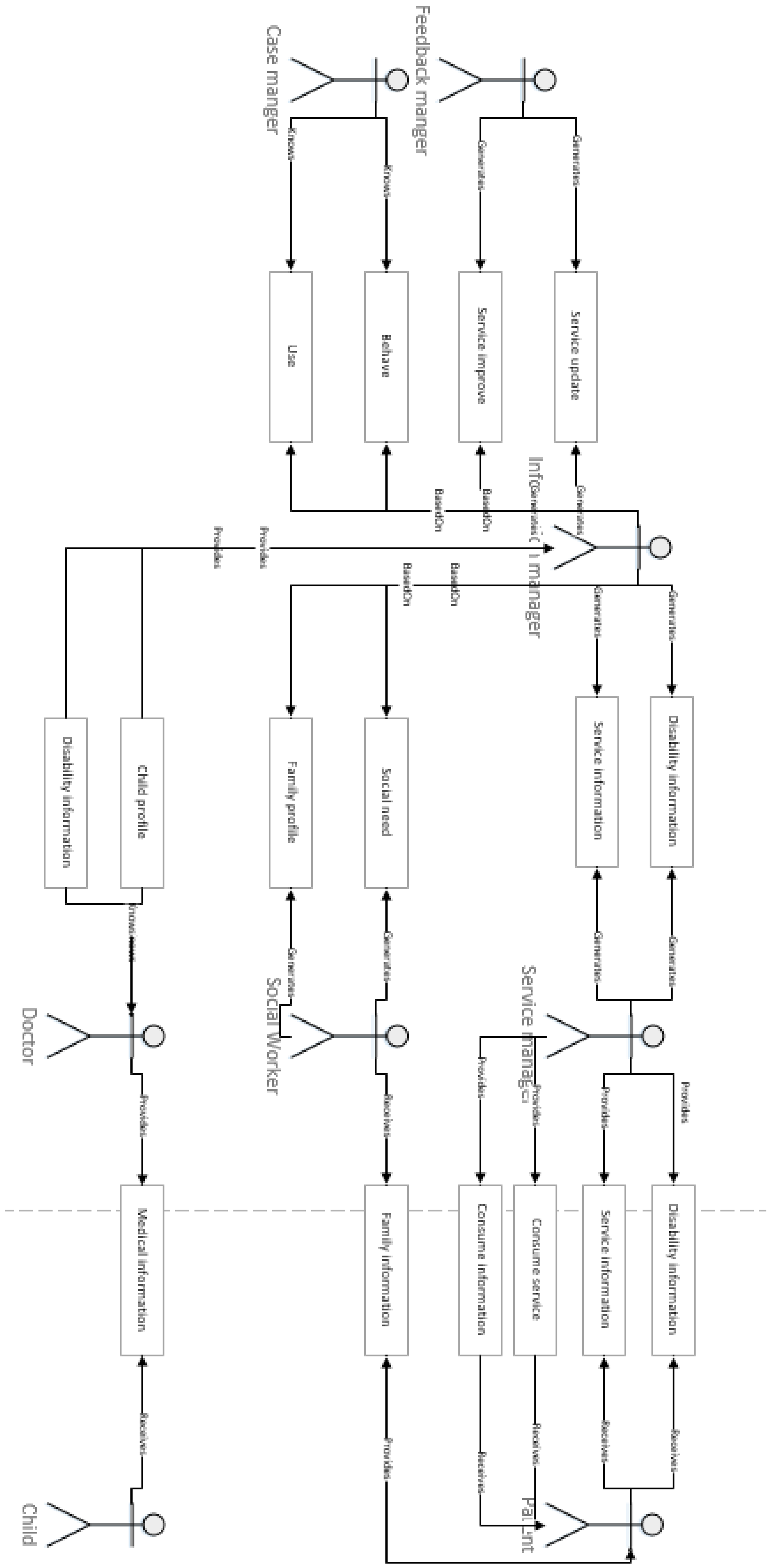


Figure 15. Domain model. Provide disability service

Conclusions

The literature review and theoretical background give overview of the health care system situation and plans in Estonia and broader, provide descriptions of good public services and also describe the situation of a family when a disabled child is born and what are the obstacles to face and what are the needs for services by the family.

The description and analysis of case studies and the conducted interviews show that the current situation for parents with disabled children in Estonia is not the best possible one in terms of receiving in a timely manner important and useful information about the services, benefits and allowances available for parents with disabled children. Application processes for the services, benefits, and allowances required are slow and paper-based, information collected about each case of a disabled child is not streamlined in information systems and registries, which results in wasting a lot of resources.

There is a need for change, which has been admitted and proposed by several stakeholders in the Estonian health care system. Prompted by that, a proposal based on the research question of how to design a proactive e-service for disabled child's parents, is made in the current thesis for an integrated proactive e-service for parents with disabled children. Such service, for example as a portal would analyze existing and new information about the family situation, and would accordingly propose relevant options for services, benefits and allowances, and would also provide any other useful information about, for example, advisors or support groups, that would enable to better manage the life of parents with disabled children.

Based on the case studies with process descriptions for as-is and to-be situations in particular current services for parents with disabled children and on the interviews conducted and analyzed, the requirements for a sociotechnical system of an integrated service for parents with disabled children are described by using the method of agent-oriented modeling.

Strong cooperation between stakeholders is needed for creating an integrated service put forward in this thesis. Such integrated service would help to save resources for the state, local government, medical workers, and the parents. The disabled children would receive the needed help by accessing the services and benefits in a shorter time and obtaining information about a wider selection of therapies, special food, medications, and educational institutions. The parents would be able to return to work to maintain the living standard of the family and to pay taxes. The medical staff could devote more time on medical issues rather than bureaucracy and together with the families, could spend resources on prevention instead of dealing with the consequences.

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Appendices

Questionnaire

These questions were initially planned for the interviews. Additional questions, that came up during the interview were asked spontaneously. Some questions presented here were sometimes not asked from some interviewees.

Questions to doctors, social and medical workers

- ✓ How the parent is informed about the child's disability?
- ✓ What kind of information and directions are given to the family?
- ✓ How much do you help the parent after this and do you know what help the parent needs?
- ✓ From whom this necessary information and help comes from (doctor, social worker)?
- ✓ What are the responsibilities of the doctor in this case?
- ✓ Do you think the parent knows what to do next and acts accordingly?
- ✓ What do you suggest to the parent? Do you think it is enough for the parent?
- ✓ How the parent understands the information you provide?
- ✓ If and how the parent, ask questions from you? Are the questions relevant or should someone else answer them? Then who?
- ✓ Does the parent contact you back several times? Does it disturb your work?
- ✓ Do you know how to help the parent? Do you think you help the parent enough?
- ✓ Is there something missing? What?
- ✓ Would an e-service to provide necessary information to the parent a useful tool after the parent knows about the child's disability?
- ✓ If and what kind of information could be shared via this portal?
- ✓ What kind of other information could be shared through this information portal?
- ✓ How would this tool be helpful for your work? Would it reduce your workload?
- ✓ How would this solution help the parent?

Questions to parents

- ✓ How did you get to know about your child's disability?
- ✓ Did you get useful information and information about the next steps to take? From whom?
- ✓ Was this information useful and helpful or enough?
- ✓ How do you evaluate access to information and the speed of accessing the information you needed at that point? Was it enough?
- ✓ Did you feel that you needed more information about what to do next? What was missing?

- ✓ From where did you find information about your child disability and the necessary steps to take about applying for disability and receiving the services?
- ✓ Were you in contact with the hospital or local government social worker?
- ✓ Did you receive enough information from them?
- ✓ Did you start to use proposed services? How long did it take to reach the rehabilitation services for your child?
- ✓ Did you get additional questions and did you search for answers? To whom did you turn to for the answers?
- ✓ Were there services or allowances and benefits you did not know about or got to know too late? Would it have changed something if you knew about them before? Can you name some?
- ✓ What would you do differently if you have the situation now after the whole experience? What would you do differently?
- ✓ How do you get to know about changes in allowances, benefits and services today?
- ✓ What could the state or local governance do differently? If yes, then what?
- ✓ What could be another solution for parents who have disabled child?
- ✓ If information about your child's disability and information about necessary benefits, services and allowances would arrive to you proactively – what would you think about it?
- ✓ Would this kind of service or portal helped you when you got to know you have disabled child?
- ✓ How would you imagine this service? What should be included in this service?

Questions to the officers

- ✓ Please describe the current situation of informing the parent about child's disability?
- ✓ Through which channels the parent is informed about necessary services, benefits and allowances?
- ✓ Do you think the information provided to the parent is enough to maintain everyday life with disabled child and taking care of the child or is there something missing?
- ✓ Are there any developments planned for these services and information channels? If yes, then please specify.
- ✓ What are the bottlenecks of the current system and what are the possible changes?
- ✓ Who will benefit from the renewed system and what is the benefit?
- ✓ Could the new system be proactive? How much do the plans rely on the state action plans?
- ✓ Are there any plans for united services and who would be the service owner?
- ✓ What is the timeline for the new system and what are the main milestones?