

Supported Autonomy

for people with disabilities

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MINISTRY OF
SOCIAL AFFAIRS AND HEALTH



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1. Introduction

1.1 Project brief

People with disabilities struggle in a society designed only for non-disabled people, and the current disability service system is, in many ways, limiting them further.

The central task is to identify deficiencies within current disability services that could benefit from more flexibility, novel modes of support, as well as cost and resource effective solutions.

This policy change process should strengthen the social participation and equality of persons with disabilities. This requires connecting relevant stakeholders for collaborative purposes and calls for planning a process that enables disabled persons to express their individual needs and co-define different models of support together with service providers, such as municipalities, and disability service producers. (DfG Personal Budgeting - Project brief, 2021)

1.2 Our take on the brief

As we took on this brief and started researching and mapping out the current system, we felt the need to redefine the brief and focus on the pressing issues. We found some fundamental issues in the current disability service system, such as a lack of communication between stakeholders, which we believe must be addressed in order for a future personal budgeting model to be successful.



Image 1

2. Research methods

2.1 Round table

In the second week of the project we had an opportunity to meet with representatives of the commissioning organisations, THL and Kela and other ' stakeholders from Aalto and the city of Espoo in a virtual roundtable. Over a Microsoft Teams call, together with the two other groups working on the same brief, we facilitated an open discussion guided by our questions with the aim to better understand the given brief and what results are expected and valuable for the clients.

2.2 Desk research

We started our project with desk research which helped us understand the current system of services and benefits for people with disabilities. From our secondary research, we acquired a comprehensive view of the social security system in Finland including the benefits and allowances offered by Kela and municipalities. Furthermore, we studied the earlier personal budgeting pilots conducted both in Finland and abroad. We also followed THL's intraweb to follow the process of the Personal Budgeting project. Finally, we gained perspective of how people experience the current disability services (See Appendix).

2.3 Interviews

We joined forces with the two other student groups working on the same brief to recruit and interview all the stakeholder groups. We conducted seven semi structured interviews guided by an interview script with carefully selected questions. Through the interviews we obtained a deeper understanding of the current system and its challenges, information about the current personal budgeting pilots, as well as the perspectives and personal experiences of end-users.

Kela • customer support specialists • customer support specialists	12th March 2021
Service provider • Service provider & personal caretaker for a family member	16th March
Disability association • communication responsible & person with disability	17th March 2021
Municipality • Head of Disability Services • Senior social worker • Social worker	17th March 2021
Person with a disability	19th March 2021
Personal caretakers • Mother of a person with severe disability • Sister of a person with severe disability	19th March 2021
THL • Personal budgeting model project manager	1st April 2021

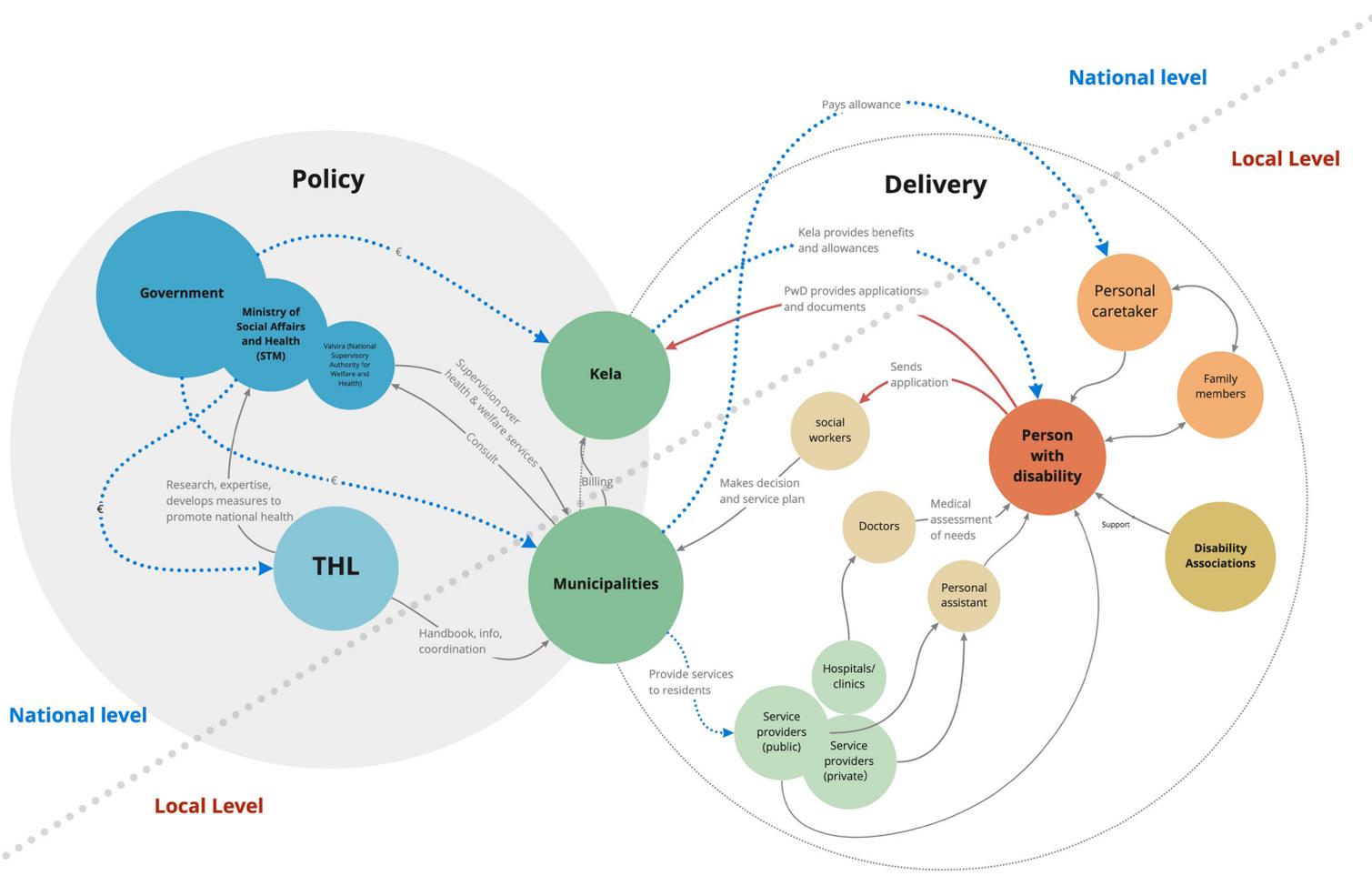
2.4 System Map

System mapping proved to be one of the most useful tools we utilized in this course. Through our desk research, roundtable discussion and various interviews with stakeholders we started to understand the relationships between stakeholder groups and organisations. The system map served as a dynamic image of our understanding of the system, evolving as our comprehension of the system developed. The map is divided into a national and local level using a diagonal line. The two grey circles indicate policy and delivery sectors of the system, and all the stakeholders are situated accordingly within the map.

2.5 Analysis

After finishing the research phase, we went through all the materials gathered from the interviews and desk research. We decided to use Affinity Diagramming to help us start the analysis process. Affinity Diagramming is a method that helps the user to cluster large bodies of qualitative information (Dam & Siang, 2021).

In practise, we began the process by placing one piece of information per one post-it note in Miro, an online whiteboard. We grouped notes together based on a shared nominator and after a while, themes and relationships started to slowly emerge in our data. Next, we picked out the insights from the data and formed an Insight Map. Finally, we identified seven key insights within five core themes.



3. Key insights

We crystallized the data gathered on the disability service system into seven key insights that were related to the themes of communication, application, social workers, caretakers, and the future of the disability service system.

3.1 Communication

People with disabilities suffer from the siloed system, which makes the relevant information hard to find. The information is scattered on different websites, organisations and people. From our interviews, we noticed that few people have a coherent understanding of the system, and even their interpretations of it vary.

[After getting the diagnosis], no one from the municipality told us anything, we had to search for information ourselves.

- Family member of a person with a disability

3.2 Application

People with disabilities are exhausted by the complicated application process, which they need to do regularly even if their life situation isn't changing. They also experience lack of assistance with applying.

The greatest challenge of the current system is having to constantly apply for everything. You don't get anything without demanding it.

- Mother of a person with a disability

3.3 Social worker

Municipality social workers carry significant responsibility over the lives of people with disabilities while not having enough resources to provide high quality service. The client is dependent on the social workers' guidance with the services. However, they have limited time and financial resources, and therefore cannot provide the needed assistance.

Few people want to work for social services for a long time. Apparently the work is so difficult that no-one wants to stay in the job.

- Disability association employee

3.4 Caretaker

Clients are entirely dependent on caretakers' availability, which This means that their autonomy over their own lives is severely limited.

We have to arrange our lives on the carer's terms.

- Family member of a person with a disability

3.5 Future system

People with disabilities have different needs and therefore the new disability service model should be a one-fit solution. Instead, it should be a combination of the old and new system or radically more flexible than the current one.

There should always be a possibility to go back to the old [disability service] model.

- Association employee

The purpose of Personal Budgeting is important and should be communicated clearly. Many clients worry that the new model aims at cutting costs of disability services, not increasing their freedom of choice.

Not many people participated in the PB pilot. It's so difficult to get the services in the first place that they don't want to risk them.

- Personal caretaker

With the help of Personal Budgeting, the needs of disabled people could be better met with less costs due to more efficient use of resources. For example, the clients would not need to take a taxi to a daytime activity they don't enjoy, but instead spend it elsewhere.

Personal budgeting could be a cost-efficient way to provide services [...] and might avoid environmentally unsustainable services.

- Municipality social worker

4. Key problem areas

Based on the key insights, we formulated three main issues that we aim to solve with our proposal:

Social workers are under-funded and lack resources, leaving them with no time to provide individual support for end-users.

People with disabilities need more support and assistance with applying for benefits and services.

Information about disability services is hard to find and understand.

5. Leverage points

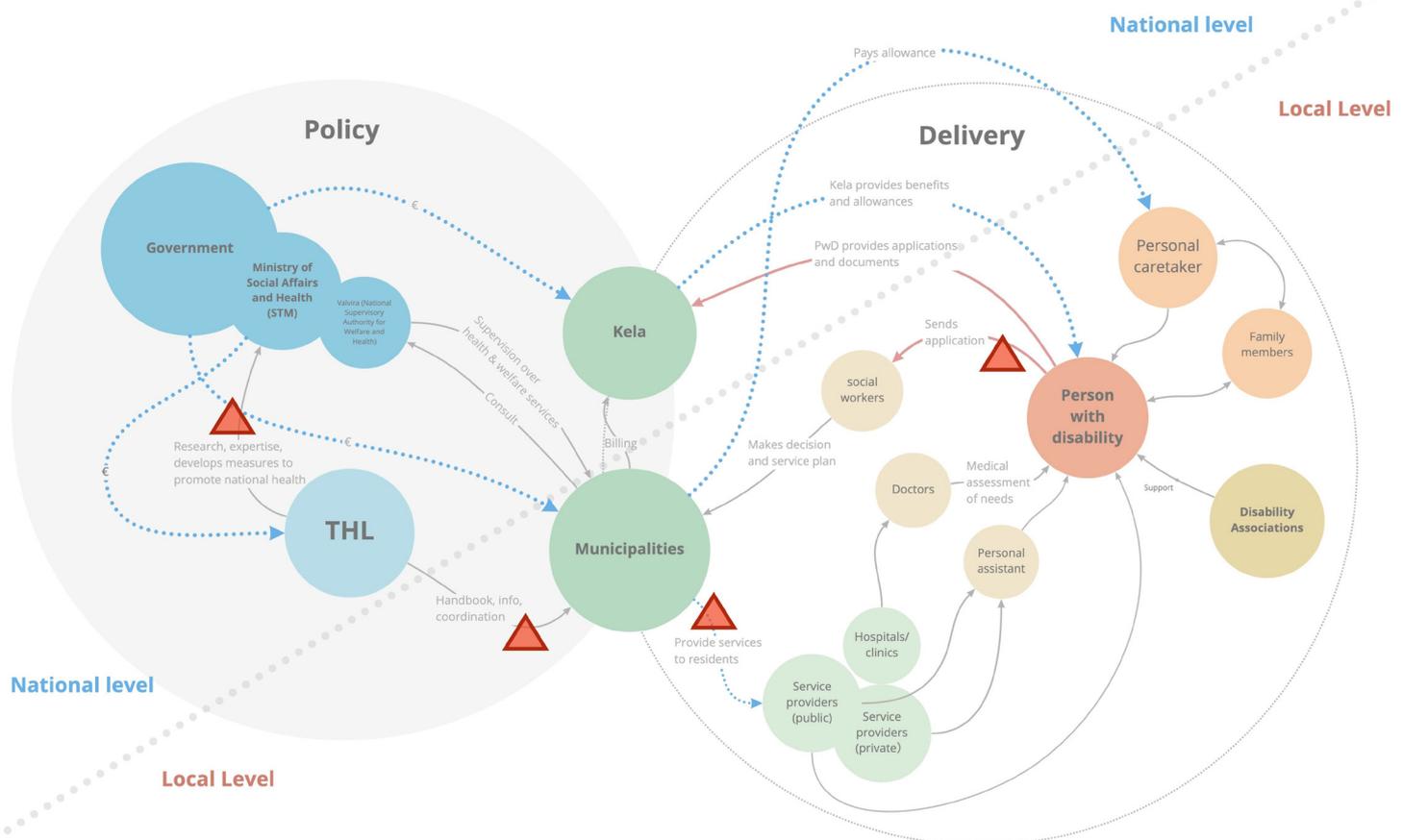
After identifying the key problem areas, our next step was to identify leverage points in the system. These are places where an intervention or solution can create change in the whole system. (Meadows, 1999) In our research we found that municipalities play a key role in disability services, as they are the places where legislation, subsidies, applications and provisions for disability services are processed and synthesized into services delivered to the end-users.

This is why we believe that the highest leverage points (marked as red triangles) are located between the municipalities and other key stakeholders (Kela, social workers, service providers and THL). Changes on the legislative level can also have significant systemic impacts. Since THL informs the Ministry, which creates the legislation

regarding disability services, we added a leverage point between them as well.

The leverage point we decided to focus on was between the municipality and the end-user, and especially on communication and the role of social workers. This also required us to look at who informs social workers/municipalities, and how.

We used the Policy Lab design interventions taxonomy to think about the types of design interventions that would be suitable in targeting these leverage points (Cooper, 2021). We found this tool to work as a helpful prompt to start thinking beyond the usual set of design tactics. The most relevant intervention types to our proposal are advising, informing, setting standards, educating, and providing.



6. Design drivers

Our design drivers will act as guiding principles for our design process, which we can also use as criteria to measure the quality of our ideas. Our 4 drivers are:

Accessibility

Make the information about services easily discoverable & understandable, and application processes easier

Autonomy

Increase freedom and control for people with disabilities over their own lives

Shared understanding

Improved communication and transparency among stakeholders

Enable people with disabilities to become active members of society

7. Co-design workshops

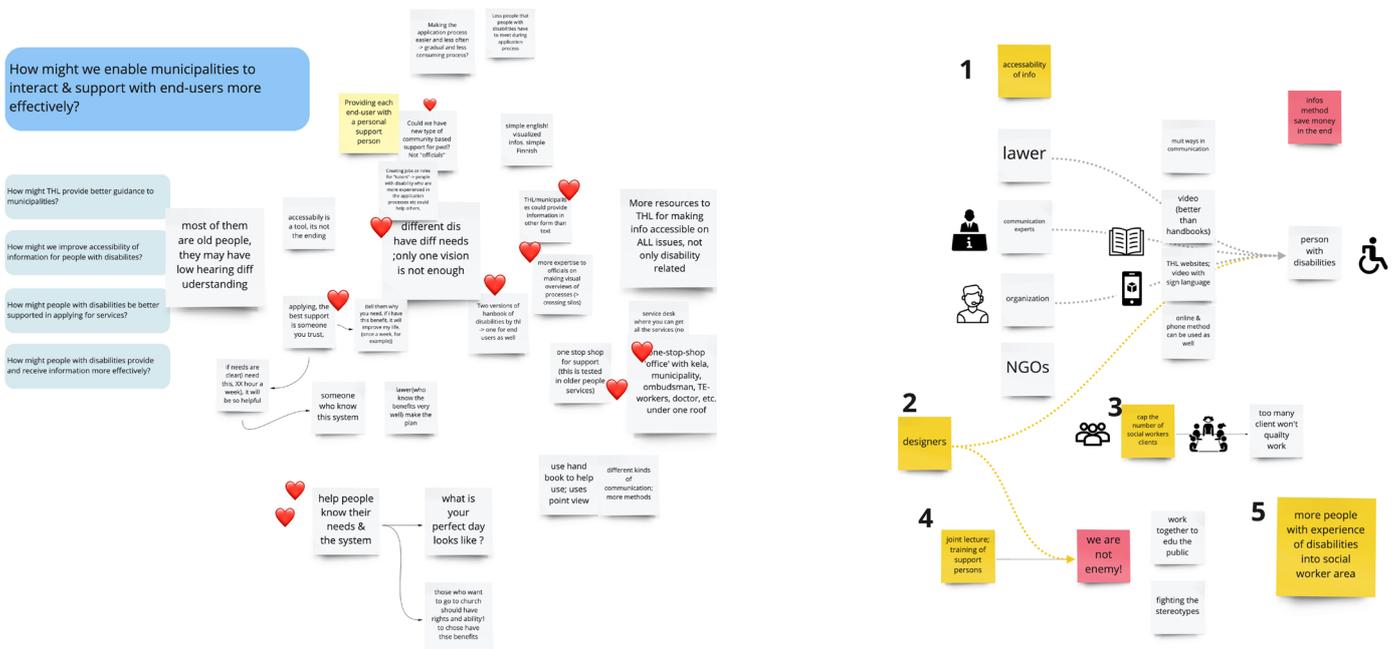
At a very early stage in the project, we knew we wanted to conduct co-design workshops because through this method we can bring together different stakeholders and hear their opinions and ideas to ensure our solution serves them.

We started with an ideation workshop that involved one THL employee and one end-user, with the aim to generate a large quantity of ideas. Many interesting and valuable ideas emerged from the workshop. After the workshop, we chose three preliminary proposals to proceed to the next stage, which were: info package, support person, increasing the value of social workers, creating

a unified website, and creating public service centers which bring all services under one roof.

However, we want to make sure these proposals will really meet the needs of different stakeholders, so we organized an evaluation workshop. Another THL employee and a municipal employee were invited to evaluate the five proposals. They emphasized the need to consider funding issues and who would be responsible for delivering each part of the proposal. Based on their suggestions, we chose two ideas to develop further: info-pack and support person.

Brainstorm



Screenshot of ideation session on Miro

Second part of the ideation workshop where participants chose their favourite idea to develop further

8. Proposal: Supported Autonomy

Our final proposal consists of two parts that aim to ensure people with disabilities are well-informed about their rights to disability services, in order to enable them to better take control of their lives.

8.1 Info-Pack

The first part of the proposal is the info-pack. It will solve the problem of information being hard to find and understand by bringing the information about disability services into one place

in various accessible formats. As was described earlier, information about disability services is scattered and usually communicated in a difficult and formal language. So, instead of end-users having to look for the information themselves in a vulnerable life situation, the information would be brought to them in the form of an info-pack.

The info-pack is a modular product that can be easily personalized to each user. It consists of three types of content: national, local and personal content.

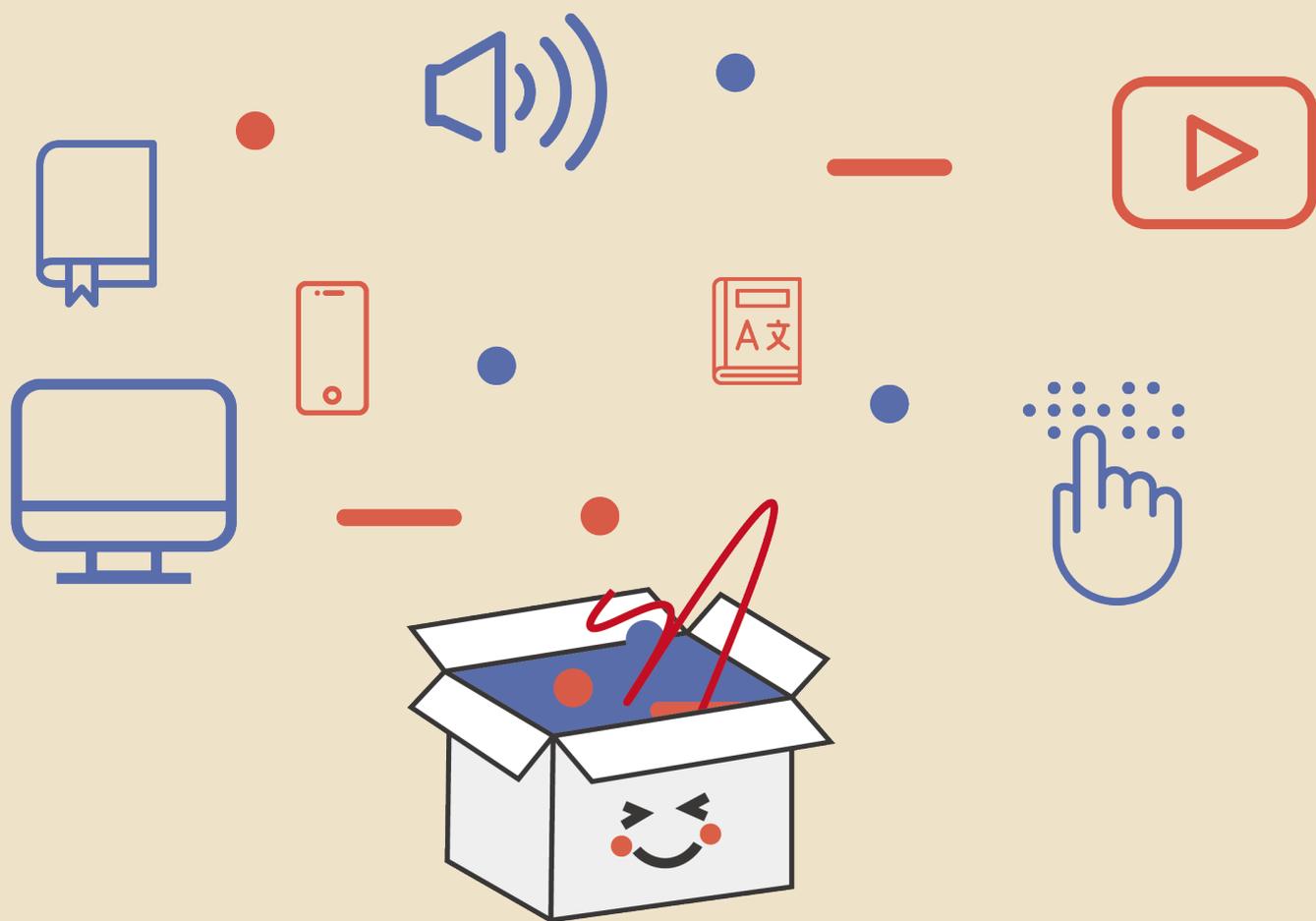


The process of creating the info-pack, which THL will oversee, will force various stakeholders to come to a consensus on how the disability service system is understood and communicated.

The info-pack comes in various different formats (for example: video, audio, digital or paper pamphlet, plain language, etc.) so the end-user can choose to receive the information in the format they find most accessible. The info-pack will be put together and provided

by the municipality after a person gets a diagnosis of a disability, or when there is a change in a disabled person's situation. A digital tool will automatically generate the info-pack according to details provided about the end-user.

This means that end-users will not have to search for the info themselves from various sources that may be unreliable, conflicting, or not applicable to their situation. Instead, end-users would receive a readily curated info-pack from their social workers.



8.2 Support Person

The second part of our solution addresses the issue of people with disabilities needing more support with understanding their needs, applying for services and understanding how the system works. Currently, social workers do not have time to provide this level of support.

Our proposed solution is that everyone with a disability diagnosis will have the right to a support person. People with disabilities can directly contact their support person with any questions or concerns they may have, big or small. The support person helps the end-user with practicalities, like understanding what services they need and how to apply for them.

End-users receive the contact details of their assigned support person alongside their info-pack, but they also have the option to opt-out from this service if they do not want a support person. The support person contacts the assigned person with a disability soon after they have received the info-pack to go through the content together. The support people can be contacted via low-threshold channels, i.e. whatsapp, at any time.

Anyone can apply for the support person training, but priority is given to people with disabilities, who already have experience about the disability service system. Support persons receive training from multiple stakeholders, like the municipality, disability associations, THL and Kela, as well as basic training in counselling.



Image 2

8.3 Impact

The info-pack brings many benefits to several stakeholder groups. The benefits are the most immediate for the end-user, as information is power. By being better informed and supported, people with disabilities will have more autonomy over their lives, ultimately enabling them to become more active members of society as they are no longer burdened by navigating a complex system alone.

The info-pack will also benefit governmental organizations. For THL it provides an effective, standardized tool for communicating about disability services for municipalities and end-users. Municipalities will benefit from more content and active citizens and inclusive societies. This can potentially result in fewer people moving away and more taxpayers. The info package will also mean fewer resources needed for customer service, and the need to spend time and effort on communications and advising people will decrease.

As with the info-pack, the biggest beneficiaries of the support person are people with disabilities. With more personalized help, people with disabilities will have a better understanding of the system and their needs, they will also have someone to go for advice who has only her interest in mind. They will gain more confidence in the system, and become less and less reliant on the support person, which means they will have more autonomy, freedom and control over their own lives.

The support person brings multiple advantages to caretakers and social workers, alleviating their workload. Social workers will be able to do their jobs more effectively when they are not burdened with having to provide personalized support to each individual.

The caretaker won't be burdened with helping their client with bureaucratic tasks which they are not experts in, and can instead spend more time helping their client do things they enjoy.

Environmental impact

Although our primary focus was on social sustainability, our proposal has indirect positive effects on environmental sustainability as well. Our proposal will lead to more people getting the right benefits and services at the right time. As resources are used more efficiently, unnecessary emissions and wasted resources are decreased.

8.4 Additional recommendations

From our research we identified additional changes that need to be done to reach the level of support people with disabilities need to have more autonomy.

1. We strongly recommend capping the number of customers per social worker.
2. We recommend creating more centralized information channels, by creating a unified website for all information, and moving towards centralized 'one-stop-shop' service centers, which bring all services under one roof, i.e. Kela, social services, TE employment services, etc.

9. Next Steps

Our suggestions for how to bring this proposal to life:

The Ministry of Social Affairs and Health will form a task force in charge of creating the info pack and curriculum for training the support person, which will consist of representatives from THL, Kela, municipalities, disability associations, and an ombudsman.

The task force then creates the first iteration of the info pack and support person training curriculum,

and runs a small scale pilot for a selected group of people with disabilities. Feedback received from this first pilot can be used to inform further iterations and development of the info-pack and support person. The second iteration can be tested with a larger pilot in a selected region. By the third iteration most of the flaws should be eliminated and the info pack and support person program can be launched on a nationwide level.

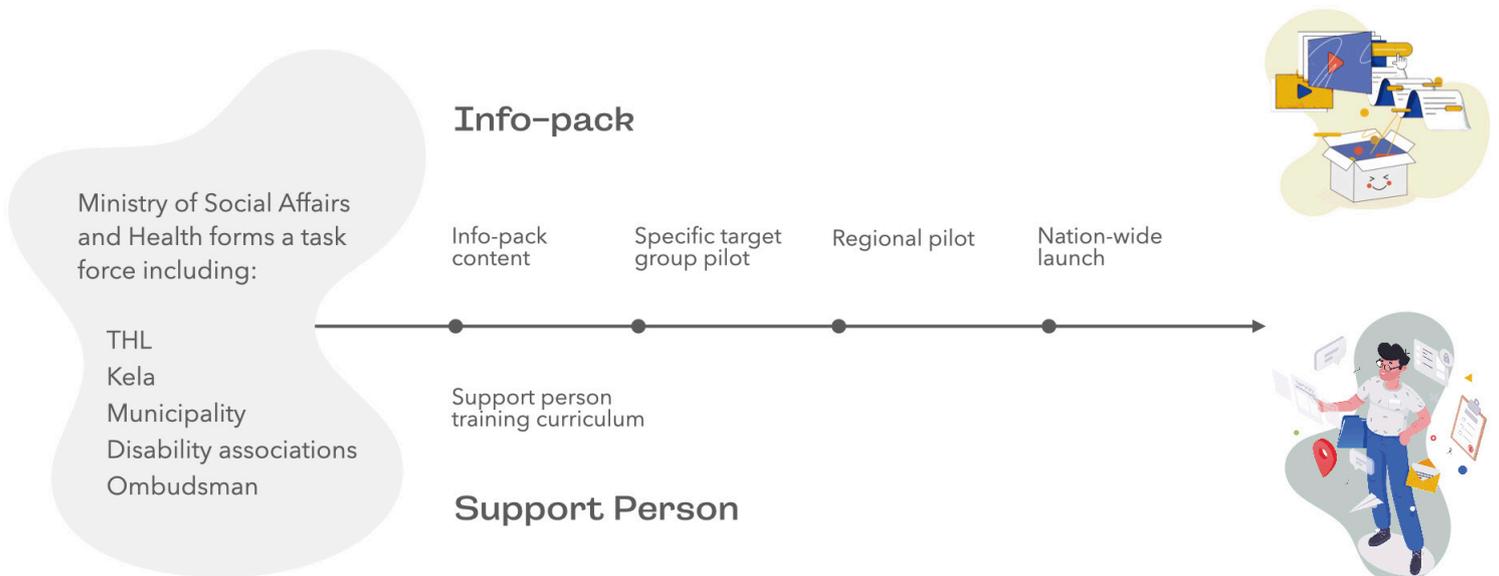


Image 3

10. Conclusions

Since learning how deeply flawed the system was, it was difficult to settle with just one solution. We were encouraged by our mentor to choose just the info-pack solution and focus on developing it further, but we felt that we would be letting down all the people we had interviewed by doing so, because the info-pack alone would be a surface level solution that would only treat the symptoms of the issues instead of tackling the cause behind them. This is why we chose a two-fold solution with the info-pack and support person and gave additional recommendations, even though it meant compromising the amount of detail we could deliver on the solution. Looking back, we should have narrowed down our focus earlier so that we would have had more time to polish the details of our solution.

Due to time constraints, this proposal remains on a relatively conceptual level, and would require more detailed consideration for it to be an implementable solution. However, it addresses the most pressing issues of the current disability service system at several leverage points.

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Appendix

Secondary research material:

- Characteristics of the social security system in Finland (brochure by the Ministry of Social Affairs and Health)
- Health and Rehabilitation: Reimbursements and allowances in case of illness, Rehabilitation and disability benefits (brochure by Kela)
- Guide for immigrants with disabilities and long-term illnesses (brochure/guide book by Hilma - the support centre for immigrants with disabilities.)
- Results of questionnaire for participants of HB project (Report by THL)
- Personal budgeting, project background material (by the Ministry of Social Affairs and Health)
- Pilot project on personal budgeting for persons with disabilities 2020-2021, Project guide (by the Ministry of Social Affairs and Health)
- "Like filling a lottery ticket with quite high stakes": a qualitative study exploring mothers' needs and perceptions of state- provided financial support for a child with a long-term illness in Finland (research article in BMC Public Health Journal)

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Images

1. Illustration of a wheelchair user. Adapted from Freepik by Marylong, n.d. https://www.freepik.es/vector-premium/mujer-joven-sostiene-cartel-marca-acceptacion-levanta-mano-signo-ok_10115795.htm. Copyright by Marylong
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