Appendix

Developing and applying a conceptual framework to translate and embed '*the curriculum*' into an existing e-health application

Tom Oostewechel

Master Thesis Industrial Design Engineering

UNIVERSITY OF TWENTE.

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Tom Oostewechel

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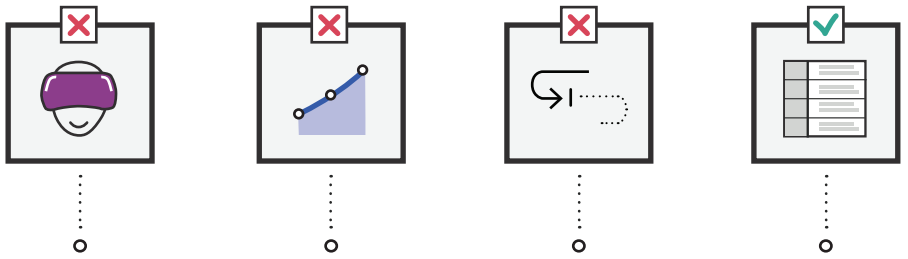
Appendix A
Selecting a final research direction

The objective of the initiation phase was twofold: elaborate which topic could deliver the most value to Jouw Omgeving on the one hand while investigating if the topic was comprehensive enough for a graduation project on the other. The topics were researched in an iterative manner by briefly examining the rationale behind these topics and their corresponding opportunities, limitations and probable boundaries.



Virtual reality

In which way can we integrate virtual reality in our platform?

Data

Should we expand our services on data collection and visualization?

Implementation

Could we improve our current implementation process?

Curriculum

Can Jouw Omgeving Integerate the curriculum in their platform?

Topic 1: Virtual reality

Currently, healthcare organisations acknowledge virtual reality as a valid application for delivering treatments. Many researchers, companies, and healthcare organisations are exploring and evaluating areas where virtual reality can add value over traditional assessment and intervention approaches. Jouw Omgeving wants to anticipate on this development through investigating the possibilities for integrating virtual reality in their platform so they could enhance and diversify their services.

The rise of virtual reality in healthcare

The first applications of virtual reality for health care slowly began to emerge in the ‘90s. Since its introduction, the promise of the technology has always been high (Shapiro & McDonald, 1992). Initially, hospitals used virtual reality primarily for visualising complex data and educating key personnel, such as surgeons (Satava, 1994). Hereafter, the application of virtual reality gradually extended to other areas in the medical field such as mental health therapy, motor skills enhancement, rehabilitation, the treatment of post-traumatic stress syndrome and eating disorders (Riva, Dakanalis & Mantanovi, 2015). Despite the fact researchers and companies were given the opportunity to immerse themselves in complex virtual environments, the adoption was still slow. This slow adoption rate was partly due to the lack of usability of the technology and the high initial costs of the equipment. Firstly, it was difficult or almost impossible to use the technology without having to request the assistance of a trained technician. Also, the equipment and

the development of three-dimensional environments was still costly and time-consuming. The gap between the possibilities offered by and the actual application of virtual reality in daily practice was often too big (Riva & Wiederhold, 2015). However, this situation is changing rapidly by the recent introduction of various low-cost devices (e.g. Oculus Rift, Samsung Gear VR, Google Cardboard). These devices show promise for significant market uptake at an affordable cost. Furthermore, the continued shift from desktop to mobile devices contributes to a faster adoption of virtual reality. Using mobile devices for virtual reality has a lot of potential for both developer and user. Mobile devices are more user-friendly, better accessible, affordable and equipped with a lot of sensors that can measure relevant user data. Overall, the technique for virtual reality is quickly maturing and on the verge of a broad adoption by healthcare organisations.

The use case of virtual reality in healthcare

In general, the healthcare sector concentrates on two specific areas of virtual reality, as a simulation tool for physicians and surgeons and secondly, as an interaction tool for the (behavioural) therapists (Srivastava, Das & Chaudhury, 2014). Due to the flexibility of virtual reality, the applications are extensive, ranging from diagnosis, treatment, and rehabilitation to the design of operations rooms.

- **Simulation tool**
  One of the main aims of researchers and companies is to strive towards virtual reality environments that are indistinguishable from situations in the real world. In other words, the design and interpretation of virtual objects that can affect human senses should be identical to their natural counterpart (Riva & Wiederhold, 2015). For instance, an engaging virtual reality system for the education and training of surgeons should provide realistic body parts that interact with external devices as close as possible to real life situations.
- **Interaction-tool**
  The other area focusses on creating new human-computer interaction types. In this case, healthcare professionals make the shift from utilising paper-based protocols and interventions to generated 3D computer environments for treating their patient. Within this environment, the patient has the opportunity of learning, in a highly-enriched fashion, to manage a problematical situation related to their illness. On the other hand, the virtual reality environment provides the healthcare professionals with a high level of control over the course of the treatment (Girini, Gagnoli, Vigna & Riva, 2008).

The challenges of virtual reality in healthcare

Despite the recent technological advancements and development of low-cost devices, virtual reality technology is still in its infancy. In general, the more complex and costly a technology is, the less likely the user is to accept it (Riva & Wiederhold, 2015). This statement also applies to the healthcare sector. However, a significant additional condition is that the technology and related treatment forms should be widely accepted as evidence-based practices. An evidence-based practice involves integrating individual clinical expertise with the best available external evidence from systematic research, combined with the preferences, wishes, and expectations of the client. Simply put, if

certain (virtual reality) treatments or interventions are not evidence-based, healthcare organisations are much less likely to adopt it into daily practice. While there already exist many (paper-based) evidence-based protocols for the treatment of various conditions, it remains difficult to convert these protocols directly into a virtual reality based treatment. This conversion causes new obstacles ranging from technical complexity (e.g. the development of affordable, high-quality hardware), practical challenges (e.g. establishing practice and safety parameters) to user specific problems (e.g. lending virtual reality equipment to users).

Motivation

Jouw Omgeving collaborates with several organisations that are increasingly interested in deploying virtual reality as an interaction-tool for the treatment of specific conditions. Most of those organisations already have, to some extent, access to the equipment (mostly to an Oculus Rift) and have been moderately experimenting with virtual reality treatments. Nevertheless, there are still some underlying, more fundamental challenges than specified above, present in practice. Currently, these limit the adoption and use of virtual reality in healthcare organisations. At this moment, there is no framework present that defines the application and use of virtual reality in various treatment scenarios. Most of the healthcare organisations already have access to virtual reality-based treatments, but these are often very generic and mostly not evidence-based. For example, a development partner of Jouw Omgeving offers 360-degree movies to support the treatment of anxiety disorders. However, the therapist cannot tailor the video's (in real-time) to the specific needs of the client due to their static nature and lack of interactivity. The more fundamental problem is the absence of an 'inventory phase' in which researchers and healthcare professionals concur on the most relevant parameters for each condition or disease. Simply put, a patient with a fear of spiders could be afraid of the colour (parameter x) of the spider while the other might be frightened by the number of legs (parameter y) of a spider. The collection and arrangement of those parameters are decisive for designing virtual reality treatments that have the potential to be effective, interactive and, in real-time adaptable to the individual needs of the clients. Subsequently, there must be determined which technology (both hardware and software) are best suited to represent those parameters. After the design of the underlying framework, the more practical and user specific challenges should be addressed ranging from drafting practice and safety guidelines to the establishment of logistic criteria.

Conclusion

Virtual reality is quickly maturing, and the equipment is cheaper to acquire and better accessible due to the continued shift from desktop to mobile devices. Moreover, Jouw Omgeving collaborates with several healthcare providers that are increasingly interested in deploying virtual reality through the platform of Jouw Omgeving as an interaction-tool for the treatment of specific conditions. Most of those organisations already have, to some extent, access to the equipment and have been moderately experimenting with virtual reality based treatments. Nevertheless, there are still some fundamental challenges with the use of virtual reality in healthcare practice. A major obstacle is that it remains difficult to convert evidence-based protocols directly into virtual reality based treatments since this conversion creates a whole range of new barriers. At this point, the fundamental

problem is the lack of an underlying framework that indicates what parameters are most relevant for each condition or disease and subsequently, in which way these parameters should be used in the design of virtual reality treatments. Besides, researchers and healthcare professionals should concur on which hardware and software are best suited to represent those parameters. Finally, there are various practical (e.g. quality of hardware) and safety barriers (e.g. unattended treatment) that need to be tackled. While the mentioned challenges are extensive enough to be addressed in a possible graduation project, it was concluded that pursuing virtual reality does not fit well within the context of Jouw Omgeving. The bottom line is that virtual reality has currently too many downsides that make it not financially or strategically attractive for Jouw Omgeving to pursue this direction at this point.

Topic 2: Data collection and visualisation

Currently, technology continues to evolve, and the data creation is growing exponentially, where 90% of the data in the world has been created only during the last two years. Healthcare organisations face new challenges regarding data collection and visualisation where having access to data is not enough since healthcare data is complex and voluminous. To fully leverage data to improve a patient health, healthcare organisations must be able to integrate and align data from different sources so they can create insights that can directly impact and improve the quality of human lives. At this moment, Jouw Omgeving is already analysing the online behaviour through their platform by applying various analytical tools. Mainly, Jouw Omgeving wants to identify if they need to expand their services on data collection and visualisation.

Data in healthcare

Historically, the healthcare sector has always generated vast amounts of data. Essentially, thorough record keeping, compliance and regulatory requirements, and the complexity of patient care all attributed to this high data generation (Raghupathi, 2010). Now, healthcare organisations still record many types of data in paper archives but are digitising patient records in an ever-increasing rate. Furthermore, they are increasingly monitoring patient related data through connected medical equipment, smartphone applications, and home automation.

The challenges of data in healthcare

The rapid digitalisation and collection of patient related data also bring new challenges. Research indicates that big data is growing faster than healthcare organisations can consume (Hansen et al., 2014). Besides, 80% of this data is still unstructured, which means it is not contained in a database or some other data structure (specific format for organising and storing data). However, most of this data is regarded as clinically relevant. One of the fundamental challenges of data collection is to leverage this ‘big data’ to gain a better understanding of, for example, the patient’s needs, the course of the treatment and the effectiveness of treatment or medicine. However, this complex process requires very specialistic knowledge. Furthermore, after the data is collected and structured, the data must be visualised and presented in such a way that the users are motivated to make the right decisions to improve their health independently.

Motivation

Jouw Omgeving can contemplate on two possible objectives with data collection and visualisation. On the one hand, they could utilise data to improve the user experience of their platform while on the other, they could provide healthcare organisations with valuable insights into the progress of treatment, which eventually could empower them to improve their care services. However, due to the fact Jouw Omgeving operates in the healthcare landscape, there are strict privacy and confidentiality restrictions which ensure that tracking of individual users, for example with Google Analytics, is prohibited. These limitations make it troublesome to collect data that could be used to optimise the functionality and user experience of the platform. Furthermore, Jouw Omgeving analyses, through their platform, the specific online behaviour of clients and professionals of associated healthcare organisations by applying various analytical tools. In contrast to, e.g. Google Analytics, these tools do not store data beyond the secure certified servers of Jouw Omgeving, and therefore, this form of data collection is permitted. Simply put, these tools retrieve data from the platform and subsequently, visualise this data in a web portal that is accessible for affiliated healthcare organisations. The analytical tools monitor, among other things, the following daily components: the number of active users, the amount of chat and messages sent, awards created and handed out, and completed action points. Currently, healthcare organisations utilise this data, for example, to create actionable management information.

Conclusion

Historically, the healthcare sector has always generated vast amounts of data but are currently digitising patient records in an ever-increasing rate. Potentially, if this data is structured, interpreted and presented in the right way, it holds the promise of supporting a broad range of medical and healthcare functions. However, 80% of this data is still unstructured while healthcare professionals regard most of this data as clinically relevant. One of the fundamental challenges of data collection is to leverage this data to gain a better understanding of the patient's needs, the course of the treatment and the effectiveness of treatment or medicine. However, this complex process requires very specialistic knowledge. Besides, the visualisation of the data should motivate users to make the right decisions which improve their health independently of a healthcare professional. Currently, it is debatable whether the platform, in its current structure, can gather enough relevant data and subsequently, present it to healthcare organisations and clients in such a way that could incite activities which could improve, for example, the current treatment. Primarily, the main concern is the limitation in tracking users, which eventually is causing fewer opportunities for both improving the user experience of the platform as providing valuable insights into the progress of treatment. Therefore, the conclusion is that it is currently not worthwhile for Jouw Omgeving to offer additional services for data collection and visualisation.

Topic 3: Implementation

Nowadays, it is apparent that e-health technology has, despite the present issues and challenges, a lot of potential for substantially reducing cost and improving the efficacy of healthcare. Nevertheless, e-health technologies often face adoption problems. Overall,

there are many reasons for the difficulties encountered with the implementation of e-health ranging from fragmented literature, poor communication between stakeholders to sceptical healthcare professionals (Ross, Stevenson, Lau, & Murray, 2016). Now, Jouw Omgeving is struggling, to some extent, with these widespread difficulties and wants to explore in which way they could improve and optimise their implementation method.

Motivation
Implementing an e-health technology has a large impact on the primary care processes and business operations in general. Hence, Jouw Omgeving has implementation experts who are actively involved in the implementation of the platform in healthcare organisations. To support the complex process, they developed a method which offers guidance to organisations in the implementation process. The method is based on the normalisation process model (NPM) which is a sociological model explaining why some new technologies become fully embedded in practice, and others do not (Murray, May & Mair, 2010). Furthermore, Jouw Omgeving supplemented the method with extensive knowledge and experience, which was built up over the years during the deployment of the platform to several healthcare organisations. The method enables healthcare organisations to make an initial scan of their business and on which scale they are ready to start an implementation process. The scan is repeated multiple times throughout the implementation phase to monitor the process and to determine if goals were reached or need adjustment.

Conclusion
Overall, implementation is a complex process with a lot of interdependencies and widespread difficulties. However, it became evident that Jouw Omgeving is already putting a lot of effort in the implementation process. They developed their implementation tool and have experienced implementation managers that guide the implementation process in healthcare organisations. In conclusion, there were no concrete opportunities present within this direction that provide sufficient cause to start a new project.

☑ Topic 4: Curriculum

The Quality of Life Centre is a company that supplies coherent products and services to all key stakeholders in the healthcare sector in the Netherlands. They position themselves as expertise and resource centre in the knowledge landscape of persons with complex intensive support needs (CISN). CISN is a generic term for all in the Netherlands existing subgroups within the disabled care and specifically emphasizes on questions of people instead of their limitations or disabilities. The Quality of Life Centre identified an existing fragmentation in the field of care and education for people with CISN. They regard the current curricula as incomplete since they are not capable of transcending domains and are not integrally applicable. Most of these curricula are not sufficient for the parents and children with CISN (from now on referred to as end users). These end users and close relatives get astray in the healthcare landscape and do not receive care and education tailored to their needs. Besides, professionals have no prescriptive advisory and work system that could be applied integrally and is capable of transcending domains (not related to legislation, type of care or living environment).

Currently, the Quality of Life Centre has partly solved the described problem. They combined the current care and educational curricula into one coherent curriculum that is both integrally applicable and capable of transcending domains. Furthermore, the Quality of Life Centre based their curriculum on a knowledge framework, which serves as a basis for all their products and services. This framework revolves around the Capability Approach (Nussbaum, 2011) and the derived intervention 'Floreren' (Beernink, 2015), the Quality of Life Concepts (Schalock et al., 2002), the International ICF framework (WHO, 2001), and principles of the UN Treaty (WHO, 2001). A central pillar of the curriculum development was the evidence-based methodological framework of Vlaskamp (Vlaskamp, 1993). This method describes a roadmap that enables parents and professionals to offer support tailored to the needs and wishes of persons with profound and multiple disabilities. The Quality of Life Centre applied this roadmap as the foundation for their curriculum and supplemented it with additional (sub)steps and filled it with (existing) knowledge products and services. Presently, these products and services are mainly deployed solitary and used in the care and educational practice whether appropriate or not. Therefore, the Quality of Life Centre organized and classified those products and services through utilizing the systematic steps embedded in the Vlaskamp method. This process further detailed the curriculum and intents to make the Vlaskamp program more user-friendly and better accessible to the end user and professionals from the care and educational field. It should provide them a founded prescriptive advisory and work system. However, in its present form, the Quality of Life Centre cannot provide the curriculum in an efficient and widespread manner to the end users and professionals. Presently, there is a lack of a digital infrastructure and accompanying software. According to the Quality of Life Centre, the curriculum needs to be converted into a convenient 'online version.' This transformation process requires additional product as well as process development to ensure that the vision and intended purpose of the curriculum are secured.

Proposition for collaboration between Jouw Omgeving and Quality of Life Centre
During the initiation phase, it became evident that Jouw Omgeving has the right resources and knowledge, such as an existing online platform and the technical know-how to facilitate the problem of the Quality of Life Centre. Ordinarily, in a typical client – contractor relationship, the Quality of Life Centre will compile a set of requirements and collaborative conditions and will pay Jouw Omgeving for the services that are needed to develop an online version of the curriculum. However, considering the recent developments in the healthcare landscape and the observed problem of Jouw Omgeving, this project plan proposes to make Jouw Omgeving co-owner of the problem of the Quality of Life Centre and vice-versa. Both parties operate in the same healthcare landscape and are both equally subjective to the developments that are taking place. They should move along and adequately adjust their services to those recent developments. These adjustments enable organisations to respond actively to new developments rather than reactive, and may eventually yield key advantages over competitors. More specifically, both parties operate in the disability sector, where the Quality of Life Centre has the universal and specialistic knowledge and services, while Jouw Omgeving has the appropriate online platform and the intention to become the market leader e-health in the entire disability sector. Hence, it is evident that both parties can strengthen each other through collaboration. On the one hand, the curriculum can potentially contribute

to the observed problem of Jouw Omgeving. The curriculum is equally relevant to a person, regardless of the complexity of the support questions. Theoretically speaking, the current assumption is that the curriculum could provide the necessary knowledge foundation for Jouw Omgeving of working towards a universal platform. Furthermore, the curriculum primarily focuses on people with CISN, which means it can contribute to a market expansion for Jouw Omgeving. Meanwhile, Jouw Omgeving can contribute to the need of the Quality of Life Centre since they have an existing digital infrastructure and the technical knowledge needed to translate the curriculum into a suitable online variant. Through cooperating on an equal basis, both parties can create circumstances in which they could reach significant synergy advantages. Consequently, both companies will feel equally responsible for execution and results of this project. Through providing preliminary insight into these synergy benefits, it should be easier to reach consensus on the allocation of the roles and responsibilities throughout the project and more importantly, ensure continuity after the completion of this project. Table A.1 depicts an overview of the comparison of both companies on multiple areas.

Area	Quality of Life Centre	Jouw Omgeving
Supply channel	All key stakeholders in the healthcare sector in the Netherlands	All key stakeholders in the healthcare sector in the Netherlands
Market position	An expertise and resource centre in the knowledge landscape of persons with CISN	Market leader in e-health for youth care and persons with a mild mental disability
Short term goal	Disclose the curriculum in an efficient manner that fits the current technology driven society	Achieve a leading position for supplying e-health to the entire disability sector
Long term goal	Become market leader regarding a standardised curriculum for health and education for the entire disability sector	Systematically work towards a platform that is suitable to use as a personal health environment (PHR)
Method	Applies a process-orientated method, where it attempts to work as closely as possible with different stakeholders	Applies a process-orientated method, where it attempts to work as closely as possible with different stakeholders
Expertise	Extensive knowledge on the care an education of persons with CISN, training, supporting children, advice	Visual design, user interface, design, technical realisation, and training and implementation of e-health in practice

Table A.1 Comparison of both companies on multiple business areas

Appendix B
The implications of CISN for a person

In their daily lives, persons with CISN are very 'care intensive' for persons in their direct environment. Compared to 'normal' peers, they have additional support questions and are permanently and often non-stop (24/7) dependent on the help of others. In all situations, there is a disorder and/or mental disorder present which varies from mild to very severe. Thus, the support questions of these persons also span and range over different areas such as nursing, physical care, medical treatment, regular treatment, therapy, permanent supervision, communication support, daily life activities, learning, behavioural interventions, continual stimulation, and individual as well as group support (Expertisecentrum EMB, 2017). The nature and gradation of support questions eventually determine the intensity and complexity of care. Hence, the target group CISN is comprised of persons who form a heterogeneous population. Heterogeneity implies that individuals with CISN all have different characteristics and are therefore difficult to define unambiguously. The Quality of Life Centre uses the term CISN as a generic term for existing subgroups within the disabled care and specifically emphasises on questions of people instead of their limitations or disabilities.

What immediately strikes persons with CISN is that their limitations are profound and unquestionable. Consequently, their limitations are thus much more exposed than their possibilities. Besides severe cognitive and physical limitations, there are often additional motorial limitations that impede persons with CISN to walk independently or without the help of tools (Hiemstra, Vlaskamp, & Wiersma, 2007). Usually, there are also critical limitations in their sense of perception which indicate that the processing of sensory information in the brain is severely disturbed. Hence, they often cannot hear or see correctly, where the extent to which they can process information is problematic to map. In addition to limited eyesight and hearing, some persons with CISN have problems with their sense of touch and are therefore hypersensitive or even less sensitive for physical contact. Along with a lack of sight and hearing, the taste, sense of balance, posture and movement, smell, and taste could be absent or might not function correctly.

Communication on a different level

People with CISN often do not possess an active or passive understanding of a language (speech, gestures or use of symbols). Mostly, they communicate through body language and use different movements that alter in frequency, intensity, and direction. They make sounds with a changing intonation, pace, pitch and they show physiological responses such as variations in the tempo of respiration, muscle tension or pupil dilation. Even the most basal facial expressions such as raising eyebrows or making eye contact are a means of communication. It is evident that persons with CISN have communication possibilities, but the signals are often so subtle that they require a lot of observational ability to even recognize those signals in the first place and subsequently, act accordingly. Hence, for many persons it is hard to participate in group activities since they might not perceive what others are doing or they do not grasp the right social skills needed for group interaction such as 'waiting till it's your turn'. This highly influences the way in which these persons function in social situations.

Health and behaviour

Overall, persons with CISN are very vulnerable and have a substantially increased risk of health problems. Diagnosis and treatment are difficult since a person cannot verbally express and indicate what is wrong with him or her. There is often a question of epilepsy, constipation, and reflux. Sleep problems are also very common. Often, they have trouble with falling asleep, problems in staying asleep, and even following another sleep rhythm and thus sleep at times when there are day time activities. Many persons with CISN have problems with eating due to swallowing problems. Consequently, respiratory tract infections often occur. With the advancement in age, even more, health problems might come to the surface or develop. For example, there is a change that due to growth, abnormalities occur in the skeleton or that existing problems grow in intensity. Besides the physical limitations, there are often various behavioural problems such as self-inflicted injuries, stereotyping (e.g. making the same movements, screaming), and finally, retracted behaviour.

Small differences, major implications

Within the heterogeneous group, all the previous mentioned disabilities and disorders might vary in severity and occur in different combinations from person to person. Most of the time, the severe disabilities were caused by brain damage due to a chromosomal aberration, infection, metabolic disorder or complication before, during or after birth. It frequently occurs that the cause is not known. Thus, persons with CISN differ from each other in physical condition, motorial skills, and visual and communicative possibilities. Some of them are indeed able to point out things, grab objects or even say a few basic words. Thus, they can make clear what they want, while others are not able to communicate at all. Some people can move independently, while other persons depend on caregivers to move. Other people have a short attention span regarding things in their immediate environment which makes it difficult to establish contact or learn new things. Some can see over a distance of a few meters so they can see who enters or leaves a room while others are dependent on their other senses and stimuli such as smell or the sound of a voice.

Furthermore, one person might indicate that he has pain and thus ask for comforting while the other is not able to do this and might retract himself. Another important attribute is time since the behaviour from certain persons might change as they age, and even lose opportunities that they previously had. These differences might seem small and irrelevant at first but often have significant consequences for direct interaction. Another characteristic is the lack of compensating possibilities. People with CISN experience limitations that extend over all areas of human functioning and their support needs, therefore, differ greatly per individual. Generally, they don't have a strong area that they can use for compensating a deficit on other fields.

Almost completely dependent

Simply put, persons with CISN are all very different. However, a common feature is that their limitations almost always result in an excessive 24-hour dependence on the support system of a person with CISN (Maes et al., 2011). Obviously, persons with CISN have the right to the best possible development, but they are not able to independently discover

the world and obtain experiences. To this end, they need relationships with others such as their family and associated professionals. These relations can make their world understandable and secure on the one hand while keeping it also exciting and challenging enough on the other. This process asks for much commitment from all those involved, and the vitality, well-being, and happiness of persons with CISN are therefore mainly determined by the attitude and dedication of those involved.

Social network

In general, persons with CISN that are living at home or in an institution often have a (very) small social network. This social system primarily consists of members of the family, grandparents, and the professional network that is formed by the family. Generally, they don't have their connections and are not able to enter individually into one. Besides, a family member with CISN heavily influences the whole dynamic within a family. The intensity of care has a tremendous impact on the life of the members of a family since their daily tasks and activities mainly revolve around addressing the care needs of the person with CISN. Other, also important family duties and activities, are often organised around the care needs, postponed, or even neglected. As a result, parents experience little freedom and flexibility due to the intensive care tasks they perform every day and are often physical, practical and emotionally burdened. Contact and social activities are taking place less frequently and spontaneous. Consequently, the social network around the family decreases over the years. Besides, when a person with CISN gets older, the intensity and gravity of the support need gradually increase. Certain care tasks become so precise, complicated or liable that these cannot be carried out by caregivers in the direct network. These difficulties force the parents to rely on professionals to continue the care at home.

Conclusion

In their daily lives, persons with CISN are very 'care intensive' for persons in their direct environment. Compared to 'normal' peers, they have additional support questions and are permanently and often non-stop (24/7) dependent on the help of others. They often do not possess an active or passive understanding of a language (speech, gestures or use of symbols). Overall, persons with CISN are very vulnerable and have a substantially increased risk of health problems and with the advancement in age, even more, health problems might come to the surface or develop. Within the heterogeneous group, disabilities and disorders might vary in severity and occur in different combinations from person to person.

Hence, they differ from each other in physical condition, motorial skills, and visual and communicative possibilities but their limitations almost always result in an excessive 24-hour dependence on the support of others. Due to their limitations, their social system primarily consists out of members of the family and their professional network. Often, they don't have their connections and are not able to enter individually into one. Finally, a family member with CISN heavily influences the whole dynamic within a family. The intensity of care has a tremendous impact on the life of the members of a family since their daily tasks and activities mainly revolve around addressing the care needs of the person with CISN. Consequently, the social network around the family decreases over the years.

Appendix C
Business Environment Analysis

This appendix presents the results of an elaborate analysis of the Dutch healthcare landscape, which is the environment both the Quality of Life Centre and Jouw Omgeving operate in. The objective of the analysis was to uncover the changes that are happening in the field that might influence and affect the topic described in this research project. The business environment is described alongside three topics: key trends, market forces, and industry forces.

Key trends
(Technology, regulatory, societal, cultural, and socioeconomic trends)

- **Rising life expectancy due to prevention and improved healthcare**
  Since 1950, the average life expectancy increased by nearly eleven years, to eighty-one years in 2014. According to recent scenarios, the life expectancy will continue to rise, but less steeply than over the last decades (Hoeymans et al., 2014).
- **People are developing chronic diseases at an earlier age**
  This growth is partly attributable to the ageing population but also to the improvements made to medicine and diagnostics. Diseases that were once untreatable became treatable, and besides, an early detection of a chronic illness implies that people will live longer with their disease. As with the life expectancy, the prevalence rate of chronic illnesses is expected to increase.
- **Rising healthcare expenditures**
  Between 1973 and 2014 healthcare expenditures grew from 8,7% to 14,2% of GDP (CBS, 2017), where the highest cost was for the categories cardiovascular disease, other mental disorders and intellectual disabilities. The expenditures are expected to rise, but at which rate remains difficult to predict.
- **Legislation and initiatives shift towards autonomy and freedom of choice**
  Individuals with health problems are more engaged in managing their own care and reinforced with technological and e-health resources resulting in more personally tailored care, more self-management and self-reliance. It is expected that future generations will prefer and demand more shared decision-making (Hoeymans et al., 2014).
- **A stronger voice for the individual, more empowerment**
  The patients right act gives patients, clients and their representatives a stronger voice in their treatment (De Vries & Kossen, 2015)
- **Decentralisation: 'bringing care closer to the people'**
  The transfer of functions and responsibilities from the central government to the local authorities. In doing so, the government assumes that local authorities can offer more targeted care and better meet the individual needs against lower cost and with less bureaucracy (Rijksoverheid, 2013).
- **Laws encourage reliance on social network**
  Before relying on publicly provided care, citizens should arrange care within their own personal networks (parents, friends or relatives).

- **Changing relation individual – healthcare provider**
  Delivery of care will be increasingly independent of the time and place. Private individuals will gain access to opportunities for performing self-diagnosis and self-treatment where healthcare providers will probably shift their focus to complex diagnostics and joint decision-making, in which personal considerations are decisive (RVZ, 2015).
- **New technological developments**
  Fast rise of new e-health resources, that enable self-management, such as applications for smartphones and wearables, health platforms, and personalized health records. Future technological developments such as artificial intelligence, sensors and robotics will allow decision-support, self-diagnosis and self-treatment (RVZ, 2015).
- **The demand for care will increase in which there will be regional differences**
  People are growing older which will result in an increase in the demand of care. Besides, due to demographic differences, young people living in the cities will need other types of care than elderly that live in the province.

Market forces
(Market issues, market segments, needs & demands, revenue attractiveness)

- **Imbalance between actors**
  There is a market imbalance between the three actors in the healthcare landscape: individuals experience huge information asymmetry compared to health providers and purchasers and therefore, lack resources to manage the risk of illness properly.
- **Few early adopter's resulting in slow adoption**
  In the healthcare market, there are barely any paying consumers and thus, few early adopters. The largest part of the market is determined and controlled by financing health insurers (Dohmen, 2013)
- **Payment structure penalizes new ways of working**
  Generally, healthcare purchaser's work with annual contracts which discourage healthcare providers to invest in innovative processes since they have no long-term security in earning back their investments (RVZ, 2017).
- **Fragmented market**
  The healthcare market has multiple sub-markets (sectors) which differentiates itself by sector-bound characteristics. Effectively, there is no single healthcare market but all sub-areas that interfere with each other. However, they all have their distinct dynamics and financial frameworks. (Dohmen, 2013).
- **Highly regulated market**
  The collective payment of healthcare results in strong regulation which is defined by norms, standards, and guidelines which obstruct and delay new ways of working (RVZ, 2017).
- **Primary focus on process improvement**
  Annual contracts between healthcare purchasers and healthcare providers discourages them to invest in innovative processes since the return on investment is highly uncertain.

Industry forces
(Competitors, substitute products, services, stakeholders, suppliers, value chain actors)

- **An plethora of stakeholders**
  The healthcare sector has a plethora of stakeholders that each have an own agenda with often conflicting and competing interests. The incumbent stakeholders have many resources and power to influence public policy and opinions (Herzlinger, 2006). Ideally, innovators should be capable of recognizing the complex interests of the different stakeholders.
- **Lack of funding and investors**
  Funding innovations in healthcare brings multiple financial challenges for investors. Beforehand, it is often not clear who will pay for the eventual product or service. Besides, the healthcare sector has complex, regulations, payment structures and reimbursements, which deter investors.
- **Accountability for the innovator**
  Healthcare purchasers often make (technology) innovators accountable for their innovation. They require that the innovator meets the demand of the payer, for instance, by proving cost-effectiveness, long-term safety, and safety requirements. However, without funding these demands are not easy to meet.
- **Provider shortages**
  Patients have to wait longer and longer for (specialistic) care or treatments due to a shortage of personnel.

Appendix D
The four core acts

The Healthcare Insurance Act (2006)
Focus - Providing curative care with an emphasis on serving to cure or heal.
Context - All private individuals that work or live in the Netherlands are required by this law to insure themselves for medical expenses (Healthcare Insurance Act, 2006). They can buy insurance policies from health insurance companies. This policy gives them access to basic entitlements such as general practitioner care and much of specialized medical care, medicines, and mental care. Furthermore, they might choose to purchase supplementary insurance, for example, physiotherapy or maternity care.
Dutch abbreviation: *'ZVW – Zorgverzekeringswet'*

The Long-Term Care Act (2015)
Focus - Government of high level care and intensive forms of support
Context - Covers private individuals who require 24/7 care and supervision, for example, due to a (severe) mental or physical disability. The act ensures that they are entitled to either home-based or institutional care (The Long-Term Care Act, 2015). This act is primarily designed for individuals who are not able or no longer capable to look after themselves, mostly because they have a disability or are old.
Dutch abbreviation: *'WLZ – Wet Langdurige Zorg'*

The Social Support Act (2015)
Focus - Support private individuals to live at home for as long as possible
Context - The act states that local authorities (often municipalities) are responsible for supporting people who are not self-reliant (Social Support Act, 2015). The act ensures that private individuals can be self-reliant and productive members of society for as long as possible. Local authorities must ensure that individuals receive the appropriate care that they need, for instance help with housekeeping.
Dutch abbreviation: *'WMO – Wet Maatschappelijke Ondersteuning'*

The Healthcare Insurance Act (2006)
Focus - Government of all health services for young people in the Netherlands
Context - The act states that local municipalities are responsible for decreasing the number of children in specialized care, increasing preventive and early intervention support, and the promotion of utilizing the social network of the private individual (Dutch Youth Care System, 2015).
Dutch abbreviation: *'Jeugdwet'*

Appendix E
Literature study

This appendix presents the results of an elaborate literature study of e-health applications. The objective was to identify failure factors of e-health and successful concepts for e-health development. Subsequently, failure factors were classified into one of the four groups and coupled to the identified successful concepts (Appendix F).

Class	Failure factor	Source	Concept (Appendix F)
System	Standardisation of products and processes limits exploration of new ways of working and small-scale customisation	RVS (2017	[-]
System	Annual contracts discourage healthcare providers to invest in innovation processes since they have no long-term security in earning back their investments	RVS (2017	Bypass by transferring ownership of the e-health application from healthcare provider to the individual
System	Innovations inherently provide a potential saving elsewhere in the care chain resulting in that the investor is not necessarily the one that collects the reimbursements	RVS (2017; Ossenbaard et al. (2017)	Social Return On Investment (SROI); Cost Effectiveness Study; Business modeling
System	Savings and budget cuts are realized through (small) yearly decreases in budgets of healthcare providers which stimulates them to focus on incremental improvement rather than innovation	RVS (2017	Bypass by transferring ownership of the e-health application from healthcare provider to the individual
System	Payment structure penalizes healthcare providers for successful e-health applications where it leads to high investments and lower revenue, which eventually results in a decrease of budget	RVS (2017; Schippers & van Rijn (2014)	Bypass by transferring ownership of the e-health application from healthcare provider to the individual

Class	Failure factor	Source	Concept (Appendix F)
System	The collective payment of healthcare results in strong regulation defined by norms, standards, and guidelines which obstruct and delay new ways of working	RVS (2017; Van Limburg et al. (2011); Van Gemert-Pijnen et al. (2011)	[-]
System	A lack of early adopters within the healthcare sector	RVS (2017	[-]
Development	An unawareness of complex stakeholder relationships with interdependencies between technology, people and sociocultural environment	Van Gemert-Pijnen et al. (2011); Van Limburg et al. (2015)	System thinking, Stakeholder identification, Stakeholder network
Development	A lack of adaptability to adjust the e-health application to better fit the local context.	Ross et al. (2016)	End user participation
Development	A lack of interoperability and open API's results in high cost due to extensive system adjustments. There is an inability of new systems to exchange information with systems already in place	RVS (2017); Ross et al. (2016); Schippers & Van Rijn (2014)	[-]
Development	A lack of end-user and stakeholder engagement in the development	Ross et al. (2016); Van Gemert-Pijnen et al. (2011)	Value Proposition Design, Customer Segmentation
Development	A lack of cooperation between healthcare providers, health insurance companies and ICT providers results in the development of solitary solutions that often serve the same goal	Schippers & Van Rijn (2014)	Establish partnerships, involve patient associations

Class	Failure factor	Source	Concept (Appendix F)
Development	The high cost of e-health systems associated with development, implementation, ongoing cost and cost related to a loss of revenue.	Ross et al. (2016); Van Limburg et al. (2011)	Cost-effectiveness study, Business modelling
Development	A lack of evidence about the distinct effects of e-health technologies on health and healthcare	Ross et al. (2016); Van Gemert-Pijnen et al. (2011)	[-]
Development	The fragmented use of classification leads to a biased comparison, non-standardised evaluation and an overall lack of scientific evidence on efficiency and quality	Ossenbaard et al. (2017); Akkersdijk et al. (2016)	Formal evaluation, Summative evaluation
Organisational	E-health applications do not fit well within work practices of end users or the daily clinical work	Ross et al. (2016)	Workflow analysis
Organisational	E-health applications disrupt existing workflow and established professional roles	Ross et al. (2016)	[-]
Organisational	A lack of leadership engagement and involvement of implementation champions	Ross et al. (2016)	[-]
Organisational	Organisation readiness for the implementation of e-health applications	Ross et al. (2016)	[-]
Individual	Uncertainty among the involved actors about the expected benefits and impact of e-health applications hinders choosing	Ossenbaard et al. (2017); Van Limburg et al. (2011)	[-]
Individual	Low e-health literacy	Ross et al. (2016)	[-]

Appendix F
Successful concepts

This appendix presents an overview of different concepts (frameworks, approaches, methods, tools) mentioned in literature and are assumed to be capable of overcoming one or more failure factors.

Concept	Goals	Source
Business modeling	To explore early opportunities for an e-health application, to make the development process stakeholder focused and value driven, to provide evidence of cost-saving	Van Limburg et al. (2011), Osterwalder et al. (2010)
Customer Segmentation	To divide the target market into segments, to identify the most valuable groups, to determine the end user groups of an e-health application	Van Velzen et al. (2013), Hague & Harrison (2017)
Descriptive Value Web (DVW)	To reveal the stakeholders that are involved in the development or use of an e-health application	Kumar (2013)
End user participation	To improve usability, to increase adaptability, to reduce complexity, to uncover needs and wishes	Ross et al. (2016), Dohmen (2012), Van Limburg et al. (2011)
Formal evaluation	To inform system development, to evaluate impact, to monitor and measure the Consumer Quality Index (CQI)	Pagliari (2007)
Human centered approach	Approach that starts with the people you're designing for and ends with new solutions that are tailor made to suit their needs	Van Gemert-Pijnen et al. (2011)
Prescriptive Value Web (PVW)	To show how value will flow in a network structure if new nodes or links are introduced or existing nodes or links are modified	Kumar (2013)
Prototype Design	To fail early and inexpensively, evaluate and gather more accurate requirements, resolve conflicts between designers and developers, uncover the technical challenges of a new design, attract financing more easily	National Instruments (2014)

Concept	Goals	Source
Requirement specification	To improve usability, to prevent inclusion of superfluous features, to prevent spending of money	Van Velsen et al. (2013)
Scenario's	To facilitate the discussion about the e-health application, to present conceptual models, to provide multi-angle viewpoints (political, social, clinical, and behavioural)	Van Gemert-Pijnen et al. (2011)
Schooling	To increase staff acceptance of e-health applications, to challenge negative attitudes	Ross et al. (2016)
Stakeholder identification	Aims at creating a list of stakeholders that need to be involved in the design of the e-health application	Van Velsen et al. (2013)
Stakeholder network	To map the involved stakeholders, to understand the relations between them, to grasp how value is exchanged and flows between stakeholders	Van Gemert-Pijnen et al. (2011)
Stakeholder participation	To retrieve value needs of involved stakeholders which guide the design of the technology as well as the success of implementation	Van Gemert-Pijnen et al. (2011), Van Limburg et al. (2011), Dohmen (2012), Ross et al. (2016)
System thinking	Approach that offers a set of analytical tools to improve the capability of identifying and understanding systems, predicting their behaviours, and devising modifications to them to produce the desired effects	Arnold & Wade (2015)
Value Proposition Design (VPD)	To reveal value drivers of an e-health application, to determine the benefits end users can expect from an e-health application	Osterwalder et al. (2014)
Workflow analysis	To provide insight into the specific collection of tasks, to reveal resources and information objects that are present in an organisation and determine how they relate to an e-health application	Ross et al. (2016)

Appendix G
A comprehensive list of ‘pains’ and ‘gains’

This appendix presents the results of an elaborate analysis of the available documentation and insights of the Quality of Life Centre, including the results of an extensive international project Enablin+ (2014 – 2017). By analysing this documentation and through multiple consultation sessions with the Quality of Life Centre, a comprehensive list with ‘pains’ (●) and ‘gains’ (●) was compiled.

Topic	Statement	Label	Source
Knowledge	Professionals are often unable to properly apply knowledge products	●	Project Enablin+ (2017)
Knowledge	Knowledge is available in a fragmented manner (internet, books, organisations)	●	Project Enablin+ (2017)
Knowledge	The quality and reliability of knowledge products can hardly be controlled	●	Quality of Life Centre (2017)
Knowledge	Insufficient information about existing tools and knowledge products	●	Project Enablin+ (2017), Quality of Life Centre (2017)
Knowledge	There is no insight and overview of the necessary facilities for education, rehabilitation and treatment in the region	●	Quality of Life Centre (2017)
Knowledge	Local networks insufficiently share knowledge with each other	●	Project Enablin+ (2017)
Knowledge	Existing knowledge regarding my child’s support questions is poorly accessible and difficult to apply	●	Quality of Life Centre (2017)
Knowledge	There is no common terminology framework available for the target group CISN	●	Quality of Life Centre (2017)
Knowledge	Available knowledge products are applied solitary and ‘ad hoc’	●	Quality of Life Centre (2017)
Knowledge	The transfer of knowledge over CISN through vocational training is minimal	●	Quality of Life Centre (2017)
Knowledge	My experience is insufficiently included in the choices that are made for my child	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Knowledge	Involved persons communicate in the same language and work in unison	●	Quality of Life Centre (2017)
Knowledge	Provide better information and advice on knowledge for the target group CISN	●	Quality of Life Centre (2017)
Knowledge	Communicate in the same language with the different stakeholders that are involved	●	'POZ' (2017)
Knowledge	An (regional) overview of facilities that are suitable for my child	●	'POZ' (2017), Quality of Life Centre (2017)
Knowledge	Get insight in which knowledge products are already investigated for the target group	●	Quality of Life Centre (2017)
Knowledge	Targeted and efficient application of knowledge products	●	Quality of Life Centre (2017)
Knowledge	Understanding the context and application of knowledge products (situational awareness)	●	Quality of Life Centre (2017)
Knowledge	Knowledge products are rated with a quality mark	●	Quality of Life Centre (2017)
Care and education	Daily programs within organisations are not tailored to the needs of my child	●	Quality of Life Centre (2017)
Care and education	The offered help for my child and our family is often incidental and not preventive	●	Quality of Life Centre (2017)
Care and education	We as parents are surrendered to the current services for my child	●	Quality of Life Centre (2017)
Care and education	These children learn fragmentarily and that requires expert guidance	●	Quality of Life Centre (2017)
Care and education	Students achieve inadequate outcomes during learning activities	●	Quality of Life Centre (2017)
Care and education	Fragmented collaboration between care and education	●	Quality of Life Centre (2017)
Care and education	There is insufficient and fragmented imaging and diagnostic available for my child	●	Quality of Life Centre (2017)
Care and education	Fragmented 'imaging' and care services for the target group CISN	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Care and education	The indication statement for the support of my child is often not complete	●	Quality of Life Centre (2017)
Care and education	The facilities of these children do not increase as the child grows older and the care needs increase	●	'POZ' (2017)
Care and education	Sink into the current 'care swamp' (rules, laws, system)	●	Quality of Life Centre (2017)
Care and education	Practical help is often too far away, incidental, or not available	●	Quality of Life Centre (2017)
Care and education	The offered help is often incidental and problem driven	●	Quality of Life Centre (2017)
Care and education	The daily program for my child is not significant for him or her	●	Quality of Life Centre (2017)
Care and education	The staff in 'living groups' have not been adequately trained to be able to deal with the support questions of my child	●	'POZ' (2017), Quality of Life Centre (2017)
Care and education	Too little empathy among professionals for my child and his or her situation	●	Quality of Life Centre (2017)
Care and education	The values that are of importance to my child are insufficiently incorporated in his or her life	●	Quality of Life Centre (2017)
Care and education	Insufficient coherence in the care and educational offer for persons with CISN	●	Quality of Life Centre (2017)
Care and education	No comprehensive edcuation offering for the target group	●	Quality of Life Centre (2017)
Care and education	The topics that are studied are isolated and not applied in other situations	●	Quality of Life Centre (2017)
Care and education	Development oriented offering in education is not self-evident	●	'POZ' (2017), Quality of Life Centre (2017)
Care and education	The learned topics do not adequately integrate into the child's daily life	●	Quality of Life Centre (2017)
Care and education	Offer care that matches the specific questions of my child	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Care and education	Offer care that matches the specific questions of my child and family	●	Quality of Life Centre (2017)
Care and education	Offer tailored care and structural solution within the 'WLZ'	●	Pamflet 2CU (2017)
Care and education	Contribute to assistance focused on prevention	●	Quality of Life Centre (2017)
Care and education	Integral support plan for the child which is managed by the parents instead of organisations	●	Quality of Life Centre (2017)
Care and education	A balanced individual (24/7) day- and week program for my child	●	Quality of Life Centre (2017)
Care and education	A meaningful daily schedule for my child	●	Quality of Life Centre (2017)
Care and education	Better cooperation between healthcare organisations	●	Quality of Life Centre (2017)
Care and education	An integral care and educational arrangement for my child	●	Quality of Life Centre (2017)
Care and education	Learning can take place in every environment and doesn't stop after school time	●	Quality of Life Centre (2017)
Care and education	There are possibilities for individual, dynamic customisation	●	Quality of Life Centre (2017)
Care and education	Education is tailored to the care and educational questions of my child	●	Quality of Life Centre (2017)
Care and education	The lifestyle of my child should be put central, just like in a normal life	●	Quality of Life Centre (2017)
Care and education	In an institution my child is regarded as an individual beside group member	●	Quality of Life Centre (2017)
Care and education	In an institution my child is regarded as an individual beside group member	●	Quality of Life Centre (2017)
Logistics	We as parents do not have support during the multiple logistical issues (what should we do, and when?)	●	Quality of Life Centre (2017)
Logistics	No unambiguous reference framework care and education for the target group (each organisation has it own care program)	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Logistics	The groups in 'living forms' are too large and the number of supervisors too little to provide individual attention and support	●	Quality of Life Centre (2017)
Logistics	There is a lack of appropriate and qualitative 'guest spots' for my child (nothing for 18+)	●	'POZ' (2017)
Logistics	The waiting lists for receiving help, support, and care are often too long	●	'POZ' (2017)
Logistics	There is no night supervision / night service available at the residence	●	'POZ' (2017)
Logistics	The care question for my child must be repeatedly proven	●	'POZ' (2017)
Logistics	Parents have ownership over the dossier and should coordinate all care	●	'POZ' (2017)
Logistics	Transfer care is not arranged after hospitalisation, referred to 'meerzorg' procedure	●	'POZ' (2017)
Logistics	A lack of qualitative and appropriate living facilities for my child	●	'POZ' (2017)
Logistics	Organisational structure hinders an efficient individual support of my child	●	'POZ' (2017)
Logistics	Not enough support from politics for addressing problems and providing solutions regarding the target group CISN	●	Pamflet 2CU (2017)
Logistics	Residents that are living in 'living forms' only come outside when parents or family are visiting	●	Pamflet 2CU (2017)
Logistics	No insight and overview of what my child wants, can and does at school, or in a living group	●	Quality of Life Centre (2017)
Logistics	We as parents are on their own and don't feel supported by others	●	Quality of Life Centre (2017)
Logistics	Found poli's in which medical, paramedical, and behavioral knowledge is bundelded, developed, and people with CISN are treated	●	Pamflet (2017)
Logistics	Anticipate on new milestones in the life of my child through providing advice or reassessment	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Logistics	Decrease the bureaucratic process and put more trust in parents	●	Pamflet (2017)
Logistics	Parents want to have insight in waiting times and want to decrease these, if possible	●	Pamflet (2017)
Logistics	Structural and concrete collaboration between informal and formal network	●	Quality of Life Centre (2017)
Logistics	Relieve parents as much as possible in incidental procedural matters	●	Quality of Life Centre (2017)
Logistics	Professionals should be educated more emphatically	●	'POZ' (2017)
Logistics	Personalised small scale care opportunities for my child	●	'POZ' (2017)
Logistics	Involve 'experience experts' such as parents in the design of day-week programs	●	'POZ' (2017)
Logistics	Practice manager who carries out the following roles as a generalist: family coach, confidant, support, and lifestyle coach	●	Quality of Life Centre (2017)
Logistics	Advisor who carries out the following roles as a generalist: diagnostics and imaging, allocation of care and education, design of individual care and learning path of the child	●	Quality of Life Centre (2017)
Politics and laws	Due to the different laws, my child's questions are approached in a fragmented manner	●	Quality of Life Centre (2017)
Politics and laws	Budgets are allocated to each domain (care, education) and for an individual child	●	Quality of Life Centre (2017)
Politics and laws	The system is too rigid with many rules which hinders the structural solving of problems	●	Pamflet 2CU (2017)
Politics and laws	Problems with the allocation of 'PGB' money for school and hospitalisation	●	'POZ' (2017)
Politics and laws	Employees of institutions do not understand the target group CISN well enough	●	'POZ' (2017)
Politics and laws	More investments targeted at well balanced day-week programs	●	Pamflet (2017)
Politics and laws	An indication that is substantiated and financed from one central 'place'	●	Pamflet (2017)

Topic	Statement	Label	Source
Politics and laws	Indication statement is based on a 24/7 arrangement and covers all lifestyle domains	●	Quality of Life Centre (2017)
Politics and laws	Provide structural solutions within the long-term healthcare act ('WLZ')	●	Quality of Life Centre (2017)
Politics and laws	Financing for care and education should be combined into one source	●	Quality of Life Centre (2017)
Politics and laws	Solutions that are carried, controlled and facilitated by politics	●	Quality of Life Centre (2017) Pamflet 2CU (2017)
Politics and laws	Identify and acknowledge the group CISN in all its complexity and their lifelong very complex disability	●	Pamflet 2CU (2017)
Politics and laws	Tailor the system towards the individual instead of the other way around	●	Quality of Life Centre (2017)
Politics and laws	Special status for target groups which facilitates the design of a customised profile	●	Quality of Life Centre (2017)
Politics and laws	Government should support innovative open processes instead of closed systems	●	Quality of Life Centre (2017)
Politics and laws	There should be room for experiments where the different laws are combined into one	●	Quality of Life Centre (2017)
Family life	The values that are of importance to my child are insufficiently incorporated into his or her life	●	Quality of Life Centre (2017)
Family life	Too little support for the family, despite the heavy care burden	●	Pamflet 2CU (2017)
Family life	A big separation between my child's formal and informal network	●	Quality of Life Centre (2017)
Family life	More attention for the question of how we as family can deal with life together	●	Quality of Life Centre (2017)
Family life	Coordinated support (social, emotional, business) for my child and our family	●	Quality of Life Centre (2017)
Family life	Professionals (system world) connect with the family (living world) and not vice versa	●	Quality of Life Centre (2017)

Topic	Statement	Label	Source
Family life	Less care tasks, more relaxation to feel like a 'normal' parent	●	Quality of Life Centre (2017)
Family life	Protect and expand the social network of the child	●	Quality of Life Centre (2017)
Family life	Keep my child at home for as long as possible	●	Quality of Life Centre (2017)
Good life	That my child is seen as a human being and is thus more than his or her diagnosis or behaviour	●	Quality of Life Centre (2017)
Good life	Focus on both the ordinary life and special support for my child	●	Quality of Life Centre (2017)
Good life	More control and participation opportunities for my child	●	Quality of Life Centre (2017)
Good life	The lifestyle of my child should be put central, just like in a normal life	●	Quality of Life Centre (2017)
Good life	My child is seen as child instead of as a client	●	Quality of Life Centre (2017)

Appendix H
Value proposition canvas: three customer profiles

This appendix presents the customer profiles of the three end user groups as based on the framework of Osterwalder et al. (2014). Jobs were not described in this research, pains are negative experiences that arise before, during and after trying to get a job done, and gains describe the outcomes and benefits the end users want to achieve.

Customer profile
Parents

Jobs	Pains	Gains
☒	• Surrendered to the current offering for my child • Sink into the current 'care swamp' (rules, laws, system) • We parents are on their own • There is insufficient and fragmented imaging and diagnostics available of my child • We as parents do not have support during the multiple logistical issues (what should we do, and when?) • Daily programs within organisations are not tailored to the needs of my child • The offered help for my child and our family is often incidental and not preventive • A big separation between my child's informal and formal network • The care question or my child must be repeatedly proven	• A balanced individual day- and week program • Focus on both the ordinary life and special support for my child • Involved persons communicate in the same language and work in unison • There are possibilities for individual, dynamic customisation • More control and participation opportunities for my child • An integral lifestyle plan for my child • Learning can take place in every environment and doesn't stop after school time • Professionals (system world) connect with the family (living world) and not vice versa • Coordinated support (social, emotional, business) for my child and our family

☒	• The values that are of importance to my child are insufficiently incorporated in his or her life • My experience is insufficiently included in the choices that are made for my child • The daily program for my child is not significant for him or her • The indication statement for the support of my child is or was incomplete and inconsistent • No insight and overview of what my child wants, can and does at school, or in a living group	• That my child is seen as human being and is thus more than his or her diagnosis or behaviour • My child receives an integral 24/7 care and education package including care, counselling, and treatment • More attention for the question of how we as family can deal with life together

Customer profile
Advice professionals

Jobs	Pains	Gains
☒	• The system is too rigid with too many rules which hinders the structural solving of problems • The support, care and learning questions of persons with CISN are approached in a fragmented manner due to different laws • Employees of organisations (municipalities, indication agency) often do not know and understand the target group CISN well enough	• Indication statement that is based on a 24-hour arrangement which covers all living areas • Well balanced day-week programs (balance between nursing and care on the one hand and treatment, development, activation and individual attention on the other) • Decrease the bureaucratic process and put more trust in parents

	• No unambiguous reference framework care and education for the target group CISN • Too little support for the family, despite the heavy are burden • No comprehensive education offering for the target group • Insufficient coherence in the care and education offer for the target group CISN • These children learn fragmentarily and this requires expert guidance • Students achieve inadequate outcomes during learning activities • Development oriented offering in education is not self-evident • The facilities for these children do not increase as the child grows older and the care needs increase • Fragmented collaboration between care and education	• A balanced individual day- and week program • Focus on both the ordinary life and special support for my child • Involved persons communicate in the same language and work in unison • There are possibilities for individual, dynamic customisation • More control and participation opportunities for my child • An integral lifestyle plan for my child • Learning can take place in every environment and doesn't stop after school time • Professionals (system world) connect with the family (living world) and not vice versa • Coordinated support (social, emotional, business) for my child and our family

Customer profile
Work professionals

Jobs	Pains	Gains
	• No time for individual attention for a person during work time • The passion for work is increasingly disappearing to the background	• More possibilities to work from a collaborative perspective • More insight in the support questions of the perspective of all those involved

	• Parents and others are hard to deal with • The care questions of persons are becoming increasingly complex • We have to work on too much goals at the same time • There is no qualitative day-week program for a person • There is too little attention for development oriented offering of a child • In our work, we have to deal with a lot of persons and disciplines • The digital dossier often does not fit to the applied approach in practice (method) • There is often no (traceable) history of the child available • There is a lot of individual documentation and lacks consistency	• Parents are equal partner of professionals • I want to execute my work as carefully and efficiently as possible • More clarity about the expectation of a child • More support during work • Facilitates communication • Facilitates possibilities to 'follow the customer' • Insight in what is custom made care means for a person • Brings all the different interests together on an equal level

Appendix I
Prioritise ‘pains’ and ‘gains’ with questionnaires

This appendix presents the results of the questionnaire that was held under the three end user groups: parents, professionals advice, and professionals work.

Parents | Professionals - Advice | Professionals - Work

Statement (‘pains’)	Weighted average*	Total
Surrendered to the current offering for my child	4.56	n = 18
Sink into the current ‘care swamp’ (rules, laws, system, etc.)	4.44	n = 18
We parents are on our own and feel ‘abandoned’	4.06	n = 18
There is insufficient and fragmented imaging and diagnostic available of my child	3.78	n = 18
We parents do not have support during logistical issues (what, how and when?)	3.78	n = 18
Daily programs within organisations are not tailored to the needs of my child	3.76	n = 17
The offered help for my child and our family is often incidental and not preventive	3.61	n = 18
A big separation between my child’s informal and formal network	3.61	n = 18
The values that are of importance to my child are insufficiently incorporated in his or her life	3.61	n = 18
The care question for my child must be repeatedly proven	3.56	n = 18
My experience is insufficiently included in the choices that are made for my child	3.17	n = 18
The daily program for my child is not significant for him or her	3.00	n = 18
The indication statement for the support of my child is or was incomplete and inconsistent	2.94	n = 18
No overview of what my child wants, can and does at school, or in a living group	2.94	n = 18

* (1 = unimportant to 5 = very important)

Parents	Professionals - Advice	Professionals - Work

Statement ('gains')	Weighted average*	Total
That my child is seen as human being and is more than his or her diagnosis or behaviour	4.88	n = 16
Involved persons communicate in the same language and work in unison	4.59	n = 17
Professionals (system world) connect with the family (living world) and not vice versa	4.59	n = 17
Focus on both the ordinary life and special support for my child	4.53	n = 17
A balanced individual day- and week program for my child	4.47	n = 17
There are possibilities for individual, dynamic customisation	4.47	n = 17
Learning can take place in every environment and doesn't stop after school time	4.35	n = 17
My child receives an integral 24/7 package including care, counselling, and treatment	4.35	n = 17
More attention for the question of how we as family can deal with life together.	4.31	n = 16
More control and participation opportunities for my child	4.25	n = 16
An integral lifestyle plan for my child (and family)	4.13	n = 16
Coordinated support (social, emotional, business) for my child and our family	3.94	n = 17

* (1 = not a priority to 5 = essential)

Parents | **Professionals - Advice** | Professionals - Work

Statement ('pains')	Weighted average*	Total
Too little support for the family, despite the heavy care burden	4.17	n = 12
The system is too rigid with too many rules which hinders the structural solving of problems	4.08	n = 12
Employees of organisations (municipalities, indication agency) often do not know and understand the 'target group CISN' well enough	4.00	n = 12
The support, care and learning questions of persons with CISN are approached in a fragmented manner due to the different laws.	3.83	n = 12
These children learn fragmentarily and this requires expert guidance	3.83	n = 12
The facilities for these children do not increase as the child grows older and the care needs increase	3.75	n = 12
Development oriented offering in education is not self-evident	3.67	n = 12
Insufficient coherence in the care and education offer for the target group	3.50	n = 12
No unambiguous reference framework care and education for the target group (each organisation has its own care programs risking tunnel vision)	3.42	n = 12
Fragmented collaboration between care and education	3.42	n = 12
Students achieve inadequate outcomes during learning activities	3.25	n = 12
No comprehensive education offering for the target group	3.25	n = 12

* (1 = unimportant to 5 = very important)

Parents | **Professionals - Advice** | Professionals - Work

Statement ('gains')	Weighted average*	Total
Well balanced day-week programs (balance between nursing and care on the one hand and treatment, development, activation and individual attention on the other)	4.27	n = 11
Tailor the system towards the individual instead of the other way around	4.27	n = 11
Protect and expand the social network of the child	4.10	n = 10
Indication statement is based on a 24-hour arrangement which covers all living areas	4.09	n = 11
Identify and acknowledge the group CISN in all its complexity and their lifelong very complex disability	4.09	n = 11
Decreases the bureaucratic process and put more trust in parents	3.91	n = 11
Offer care that matches the specific question of the child and family	3.91	n = 11
Offer tailor made care and structural solution at this level	3.82	n = 11
Advisor who carries out the following roles as a generalist: diagnostics and imaging, allocation of care and education, design of individual care and learning path of the child	3.55	n = 11

* (1 = not a priority to 5 = essential)

Parents | Professionals - Advice | **Professionals - Work**

Statement ('pains')	Weighted average*	Total
No time for individual attention for a person during work time	3.43	n = 8
The care questions of persons are becoming increasingly complex	3.29	n = 8
In our work, we have to deal with a lot of persons and disciplines	3.14	n = 8
There is often no (traceable) history of the child available	3.00	n = 8
We have to work on too much goals at the same time	3.00	n = 8
The digital dossier often does not fit to the applied approach in practice (method)	2.86	n = 8
There is too little attention for development oriented offering of a child	2.86	n = 8
There is a lot of individual documentation and it lacks consistency	2.71	n = 8
There is no qualitative day-week program for a person	2.57	n = 8
Parents and others are hard to deal with during our work activities	1.86	n = 8
The passion for work is increasingly disappearing to the background	1.86	n = 8

* (1 = unimportant to 5 = very important)

Parents | Professionals - Advice | **Professionals - Work**

Statement ('gains')	Weighted average*	Total
I want to execute my work as carefully and efficiently as possible	4.71	n = 8
More possibilities to work from a collaborative perspective	4.57	n = 8
Insight in what custom made care means for a person	4.43	n = 8
Bring all the different interests together on an equal level	4.17	n = 8
Parents are regarded as equal partners of professionals	4.14	n = 8
More insight in the support questions of the perspective of all those involved	4.14	n = 8
Facilitate better communication between involved persons	4.14	n = 8
Facilitates possibilities to 'follow the customer'	4.00	n = 8
Provides more clarity about the expectations of all those involved	3.71	n = 8
More support during the execution of our work	3.14	n = 8

* (1 = not a priority to 5 = essential)

Appendix J
Value proposition canvas: the three value maps

This appendix presents the value maps of the three end user groups. The value map consists of three parts. Products and services describe a list of what a company offers, the pain relievers describe how exactly the products and services alleviates specific end user's pains, and gain creators describe how the products and services create end user gains.

Value map
Parents

Product	Pain relievers	Gain creators
Curriculum	• Experience expert will get an equivalent position • Equal partnership between formal and informal network • Provides space for the childs' story including the values that are of interest to him or her • Guides the users towards a more meaningful offering for care and education • Advises for individual day-week programs • Provides an overview of what a child wants, can and does • Makes insightful who needs what and at which moment • Provides logistical support in one place • Makes the (structural) care and educational question comprehensible • Navigates on a dynamic, individual and custom made care package	• Provides a standardised process with a clear language usage • Offers a 'road map' which coordinates the support process • The parents and family remain owner of the process and professionals add in and out • Provides the opportunity to zoom in on the capacity and burden of the family • Offers cross domain, 24/7 opportunities • Focus on the ordinary life, with special support where needed • Advises for an appropriate care and educational package • Provides insight into the individuals daily and weekly program • Provides a holistic and integral approach

Curriculum	• Advises for preventive, structural and solution-orientated help • Advises for an indication statement • An integral and timely carried out imaging and diagnostics • Get insight into the possibilities and get influence in the decision process	• Focuses on the execution of individual customisation • Built in attention to self-management and participation • Built-in attention for the ordinary life and special support

Value map
Advice professionals

Product	**Pain relievers**	**Gain creators**
Curriculum	• Exert influence based on the added information • All information revolving the imaging phase is collected in one place • Advises in the image phase and for an appropriate care and educational arrangement • Clear reference image for care and education for the target group • Maps the support questions of the family • Provides a comprehensive offering for education • Enhanced cooperation based on the choices of a child • Brings coherence in the offered advice	• Assumes a 24-hour arrangement • Focusses on the design, organisation, and execution of balanced day-week programs • Maps information that is collected around an individual and makes it insightful • Gives the individual a central place in the process • Maps the social network of the child and the family in one overview • Makes the specific care and education questions of the child and family insightful • Possibilities to arrange care based on individual preferences

	• Provides a clearer picture of the learning question, how to answer it, and the means to do that • Determine the type of care based on the questions • Anticipate on important milestones of what might be needed in the future • Offers cohesion in the educational offering	• Minimises procedural issues through providing a comprehensive overview of the current situation • Offers the opportunity to bring out advice with the help of predefined templates

Value map
Work professionals

Product	Pain relievers	Gain creators
Curriculum	• Facilitates a more efficient planning, execution and evaluation of work • Brings all perspectives together, which enhances the mutual understanding • It focuses on the essentials of work • It makes the complexity insightful and advises for solutions • It limits the amount of goals that have to be achieved in a certain period of time • Advises and focuses on an (individual) qualitative day-week program • Offers inspiration and opportunities for development oriented services (learning lines)	• All involved will get an equal role • That you do what is required, but not more than is necessary • Provides insight into the roles and appointments of all those involved • Work system that provides direction to the activities • Makes the support questions of the person and others involved insightful, before and during the 'care path' • Makes interdisciplinary collaboration possible • All information is available in one central place • Contributes to the organisation and execution of individual customisation

	• Organises the collaboration between all those involved • No longer dependent on organisational characteristics but assumes customer preferences • In the dossier, a traceable history is recorded • Relevant information from different reports is merged into one integral lifestyle plan	• The built in systematic follows the customer • Facilitates collaborations based on available information

Appendix K
Workflow Analysis - Curriculum

This appendix presents the results of the workflow analysis. This section provides an elaborate overview of the processes, user stories, and information objects.

Registration | Intake | Imaging | Advice | Execution

Proces	User story	Information object(s)
Het aanmelden voor een intakegesprek	Als medewerker van het Quality of Life Centre stuur ik een uitnodigingsmail naar de zorgvrager, zodat deze geïnformeerd en voorbereid naar de intake komt	Uitnodgingsmail • Details gesprek • Contactgegevens • Doel gesprek • 'Link' vragenlijst
Het ontvangen van zelfmanagement informatie	Als 'intaker' wil ik voor het intakegesprek inzicht hebben in het (huidige) zorgproces van de zorgvrager, zodat ik mij goed kan voorbereiden op het gesprek	Zelfmanagementinformatie • Ingevulde vragenlijst
Het aanmaken van een nieuw account in Jouw Omgeving voor de zorgvrager	Als 'intaker' wil ik voor het intakegesprek toegang hebben tot een account, zodat er tijdens de intake gelijk gegevens van de zorgvrager geregistreerd kunnen worden	Accountgegevens • Inloggegevens
Beoordelen van de aanmelding	Als 'intaker' moet ik bepalen of en hoe de gevraagde zorg geleverd kan worden, zodat een eenduidige beslissing genomen kan worden over het vervolgtraject	Zelfmanagementinformatie • Ingevulde vragenlijst

Registration | **Intake** | Imaging | Advice | Execution

Proces	User story	Information object(s)
Het invullen van het intakeformulier	Als 'intaker wil ik diverse gegevens registreren met betrekking tot de kenmerken, conditie en beperkingen van een zorgvrager en wil ik door middel van gerichte vragen informatie verzamelen, zodat de hulpvragen, levensgewoonten, voorgeschiedenis, leefstijl, knelpunten en wensen inzichtelijk worden	Intakeformulier • NAW gegevens • Sociale omgeving • Hulpvragen van betrokken partijen • Problemen van persoon / gezin • Leefstijl huidige en gewenste situatie • Randvoorwaarden

Het afnemen van een (nul)meting	Als 'intaker wil ik bij de start van elk nieuw zorgtraject een (nul)meting afnemen en vervolgens op standaard momenten, zodat de effecten van het gebruik van het curriculum objectief geanalyseerd en gevalideerd kunnen worden	(Nul)meting • Gestandaardiseerde vragenlijsten
Het in kaart brengen van de financiën	Als 'intaker wil ik financieringsbronnen inventariseren en een overzicht maken van beschikbare financieringsvormen, zodat er een begroting kan worden opgesteld voor de zorgvrager en kan worden bepaald of de ondersteuning al dan niet kan worden verleend	Financieel plaatje • Financiële foto nu • Financiële foto benodigd
Het invullen en ondertekenen van een toestemmingsformulier	Als 'adviseur' wil ik (schriftelijke) toestemming van de zorgvrager of diens wettelijk vertegenwoordiger, zodat ik gegevens kan opvragen, verwerken, gebruiken en opslaan	Toestemmingsformulier • Gegevensgebruik • Gebruiksonderzoek • Foto en film • Opvragen dossiers

Proces	**User story**	**Information object(s)**
Het opvragen en analyseren van het huidige dossier van een persoon	Als 'onafhankelijk adviseur' wil ik opgevraagde dossierstukken analyseren, zodat de historie van de zorgvrager en zijn en/of haar leefomgeving wordt meegenomen in het leven en de ondersteuning daarbinnen	Dossieranalyse • Samenvatting
Het houden van gesprekken met de verschillende betrokkenen rondom een persoon	Als 'onafhankelijk adviseur' wil ik gesprekken voeren met verschillende betrokkenen, zodat er consensus kan worden verkregen vanuit verschillende perspectieven en gekomen kan worden tot gewenste keuzes	Gespreksverslag • Aanwezig • Gesprekconclusies • Tevredenheid gesprek
Het observeren van de persoon in zijn (leef/leer) omgeving	Als 'onafhankelijk adviseur' wil ik verschillende observaties van de persoon uitvoeren, zodat vanuit het perspectief van een onafhankelijk adviseur een beeld kan worden verkregen van het kind in verschillende situaties	Media • Foto • Video

Het registreren van medicatie van de zorgvrager	Als (werk)professionals en ouder wil ik de medicatie van het kind registreren, zodat iedereen een totaaloverzicht heeft	Medicatielijst
Het analyseren van persoonlijke profielen	Als 'onafhankelijk adviseur' wil ik persoonlijke profielen analyseren, zodat ik de verschillende deelvragen kan ontrafelen en beantwoorden en bepaalde functioneringsgebieden in kaart heb (specialistisch)	Persoonlijke profielen • Quality of Life • Gezondheid • Functioneren (ICF)
Het registreren van de (gestelde) diagnose van een persoon	Als 'onafhankelijk adviseur' wil ik de diagnose registreren, zodat ik over de hier aan gerelateerde vervolgstappen voor het dagelijks leven en de in te zetten hulp kan adviseren	Diagnose • Medisch • Psychologisch
Het in kaart brengen van het informele en formele netwerk van de zorgvrager	Als (werk)professionals en/of ouder wil ik een netwerkcirkel invullen, zodat ik weet welke personen en instanties er allemaal betrokken zijn (geweest) bij de persoon	Netwerkcirkel
Het schrijven van een holistisch persoonsbeeld	Als 'onafhankelijk adviseur' wil ik een holistisch persoonsbeeld opstellen en vastleggen, zodat ik het totale functioneren van het kind in beeld kan brengen (generalistisch)	Holistisch persoonsbeeld
Het in kaart brengen van het huidige 24/7 arrangement	Als 'adviseur' leg ik het huidige zorg en onderwijs arrangement vast, zodat er inzichtelijk wordt wat de verdeling is van het gewone gezinsleven van een persoon en de speciale ondersteuning die daarbij nodig is	Huidig 24/7 arrangement • Voorkeuren • Bevindingen • Leefstijldomeinen • Domeinen speciale ondersteuning

Registration | Intake | Imaging | **Advice** | Execution

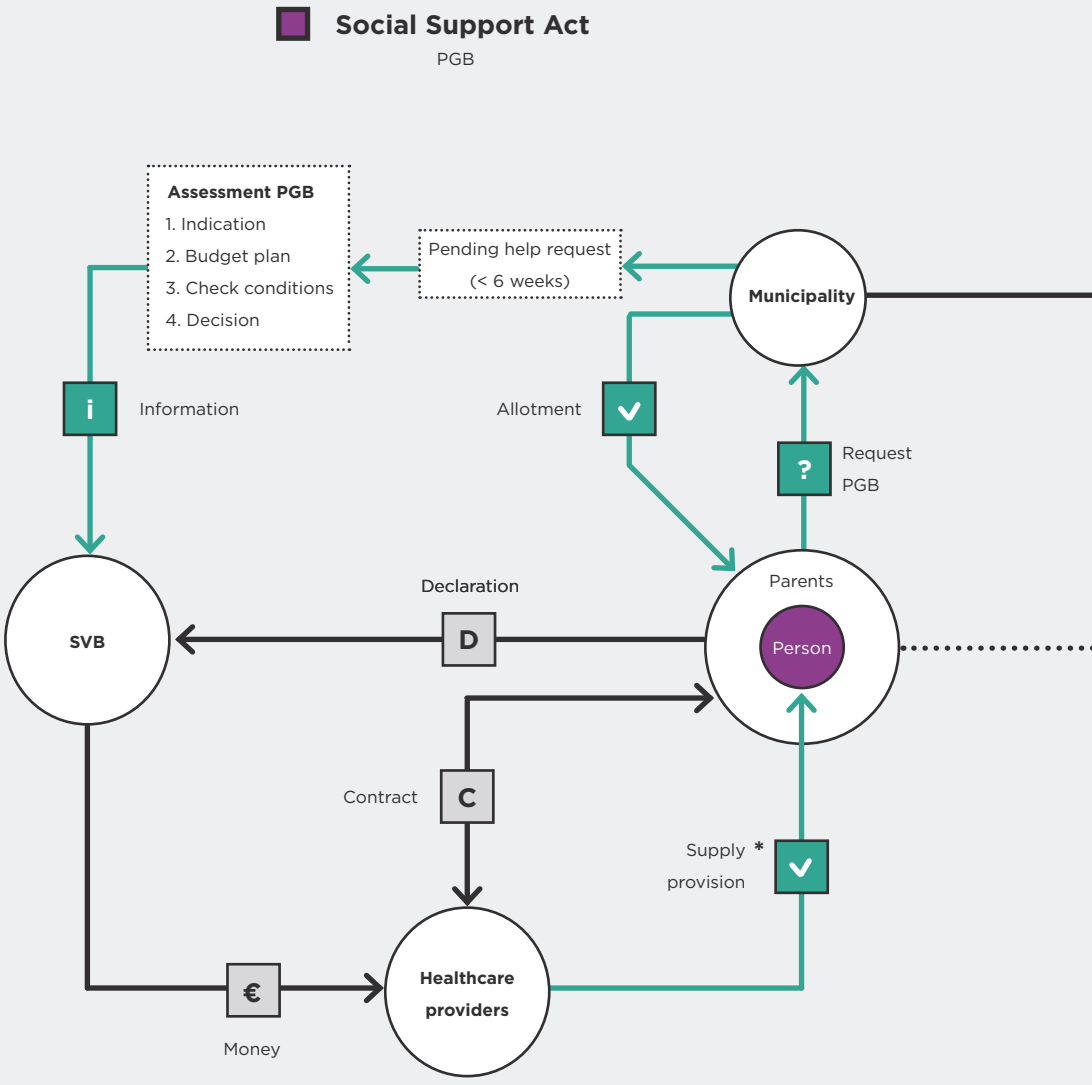
Proces	User story	Information object(s)
Het in kaart brengen van het gewenste 24/7 arrangement	Als 'onafhankelijk adviseur' leg ik op basis van de resultaten van het huidige 24/7 arrangement, een gewenst 24/7 arrangement vast, zodat er gefundeerde keuzes gemaakt kunnen worden voor een passend dag weekprogramma	Gewenst 24/7 arrangement • Wensen • Leefstijldomeinen • Advies aan uren • Domeinen speciale ondersteuning
Adviesrapport opstellen	Op basis van de resultaten van de beeldvorming van de persoon wordt door de onafhankelijk adviseur (indicatie) advies uitgebracht over de invulling van een passende route en programma voor de in kaart gebrachte situatie	Adviezen rapport • Diagnostiek • Verdere beeldvorming • Passend gewenst 24/7 arrangement • Prioritering doelen • Passend concreet dag-week programma • Aanzet leefstijlplan

Registration | Intake | Imaging | Advice | **Execution**

Proces	User story	Information object(s)
Het opstellen van lange en korte termijn doelen	Als uitvoerend professional en ouder wil ik op basis van het advies doelen kunnen stellen voor de zorgvrager, zodat er gericht en methodisch gewerkt wordt aan het realiseren van mooi leven van de persoon	Gewenst 24/7 arrangement • Wensen • Leefstijldomeinen • Advies aan uren • Domeinen speciale ondersteuning
Het invullen van een 'mooi leven' leefstijlplan	Als uitvoerend professional en ouder wil ik op basis van het advies een leefstijlplan kunnen invullen en bijhouden voor de persoon, zodat een passend dag-week programma kan worden ontworpen, gefaciliteerd en gerealiseerd	'Mooi leven' leefstijlplan • Wensen • Leefstijldomeinen • Advies aan uren • Domeinen speciale ondersteuning
Het aanmaken van een activiteitenlijst	Als professional en ouder wil ik op basis van het advies activiteiten kunnen aanmaken, zodat deze tijdens het opstellen van het dag-weekprogramma ingepland kunnen worden	Activiteitenlijst • Activiteiten • Beschrijving

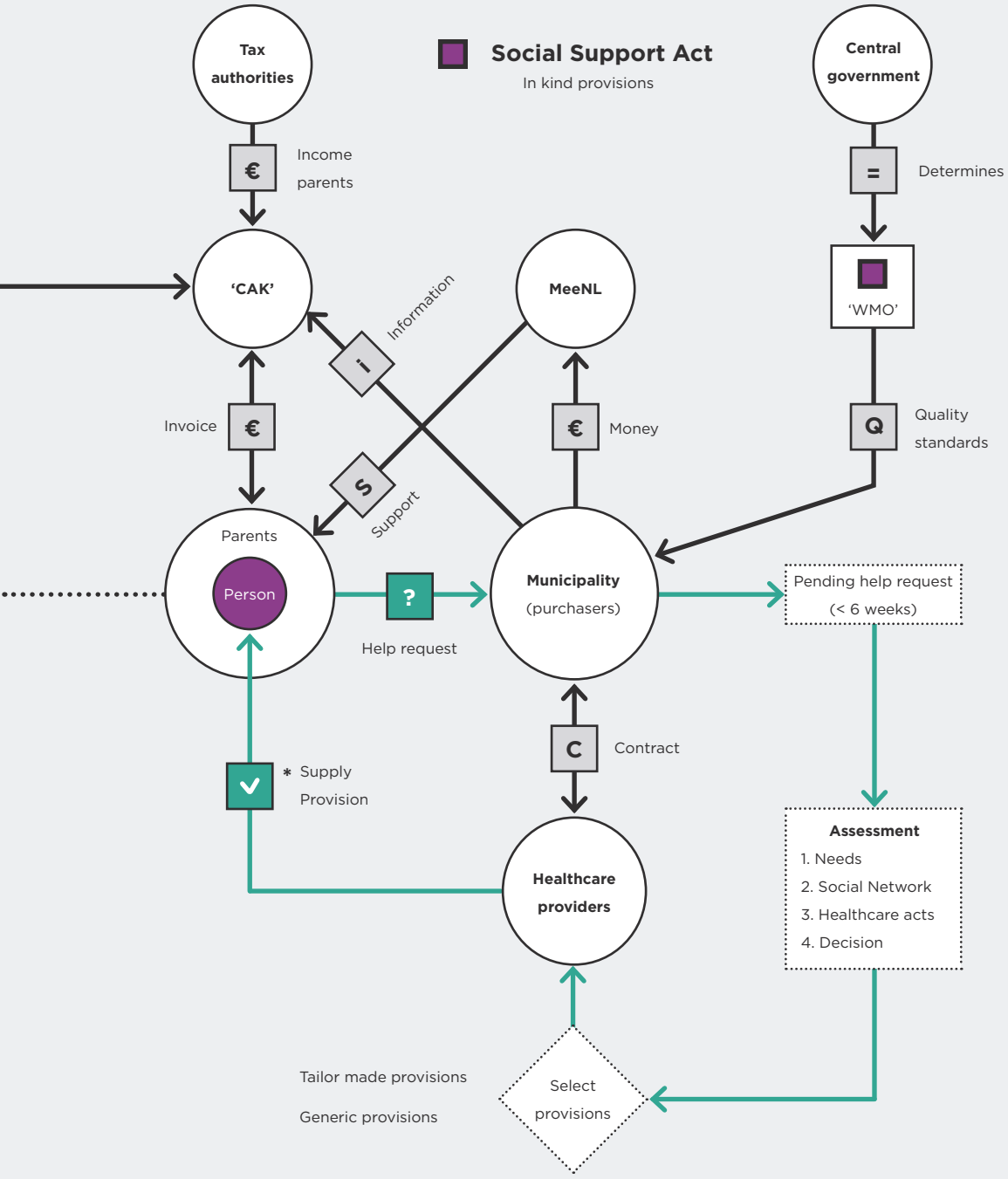
Het vaststellen van het gewenste dag-weekprogramma	Als uitvoerend professional en ouder wil ik activiteiten inplannen die passen bij het advies, zodat ik een betekenisvol en passend dag-weekprogramma kan samenstellen	Dag-weekprogramma
Het rapporteren op activiteiten	Als uitvoerend professional en ouder wil ik kunnen rapporteren op activiteiten, zodat voor iedereen inzichtelijk wordt hoe deze zijn verlopen	Rapportage
Het beoordelen van activiteiten binnen het dag-weekprogramma	Als uitvoerend professional en ouder wil ik activiteiten kunnen beoordelen, zodat voor iedereen inzichtelijk wordt hoe deze zijn verlopen	Evaluatie activiteit
Het evalueren van de gestelde korte en lange termijn doelen	Als uitvoerend professional en ouder wil ik de gestelde doelen kunnen evalueren, zodat duidelijk wordt of deze zijn behaald of niet	Evaluatie doelen

Appendix L
Stakeholder networks



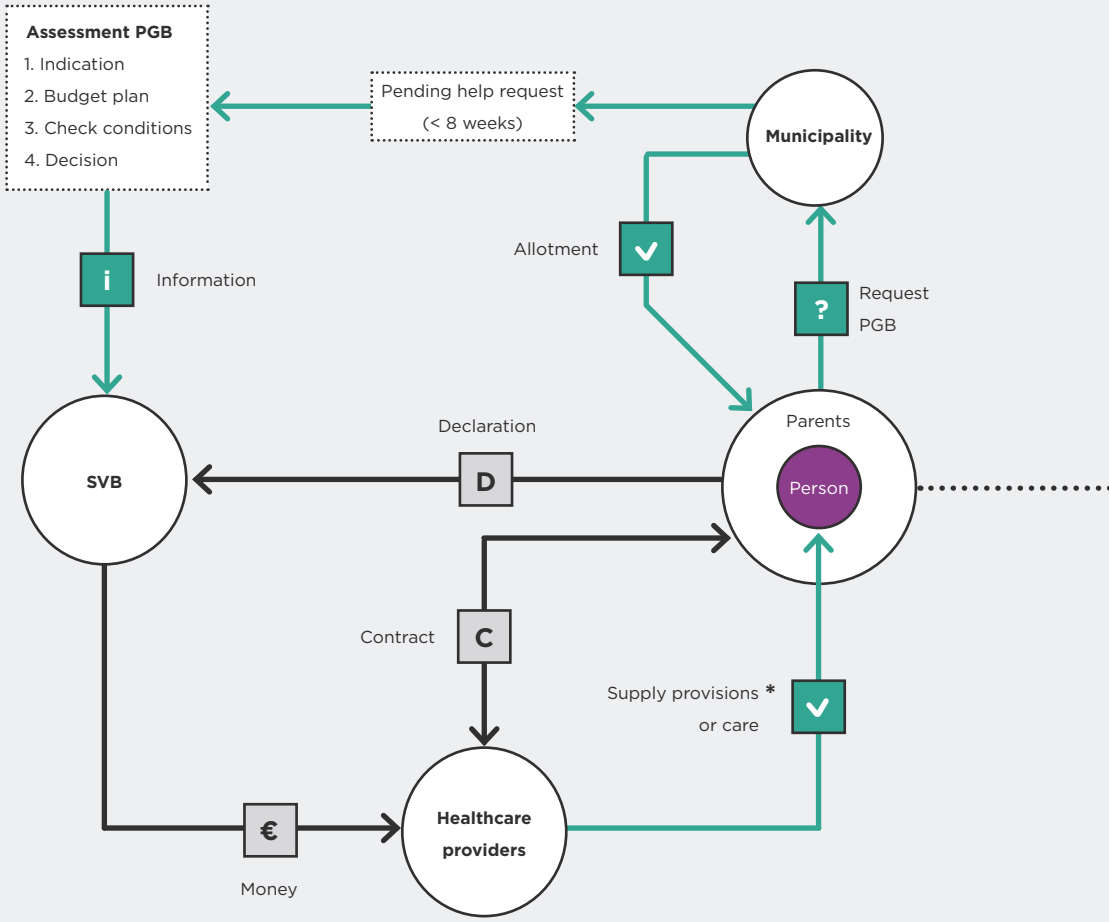
* **Provisions under the Social Support Act**

Individual guidance	Provisions for transport
Help in household	Tailor made and generic provisions
Short stay (protected living)	Home modifications


Social Support Act
In kind provisions
Tax authorities
Income parents
Central government
Determines
'CAK'
MeeNL
'WMO'
Information
Invoice
Money
Quality standards
Support
Parents
Person
Municipality (purchasers)
Pending help request (< 6 weeks)
Help request
Contract
* Supply Provision
Assessment
1. Needs
2. Social Network
3. Healthcare acts
4. Decision
Healthcare providers
Tailor made provisions
Generic provisions
Select provisions

Youth Care Act

PGB

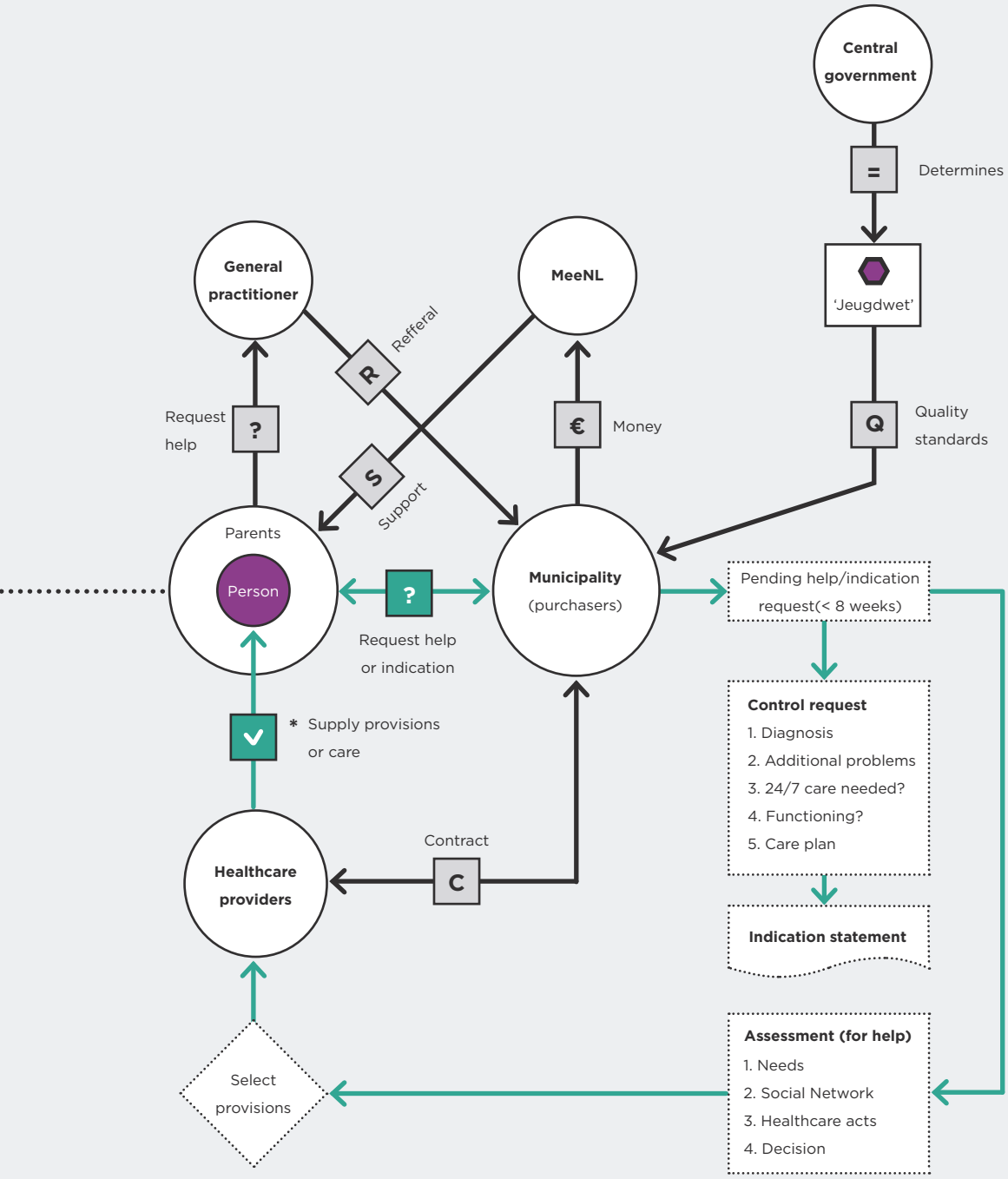


* **Provisions and care under the Youth Care Act**

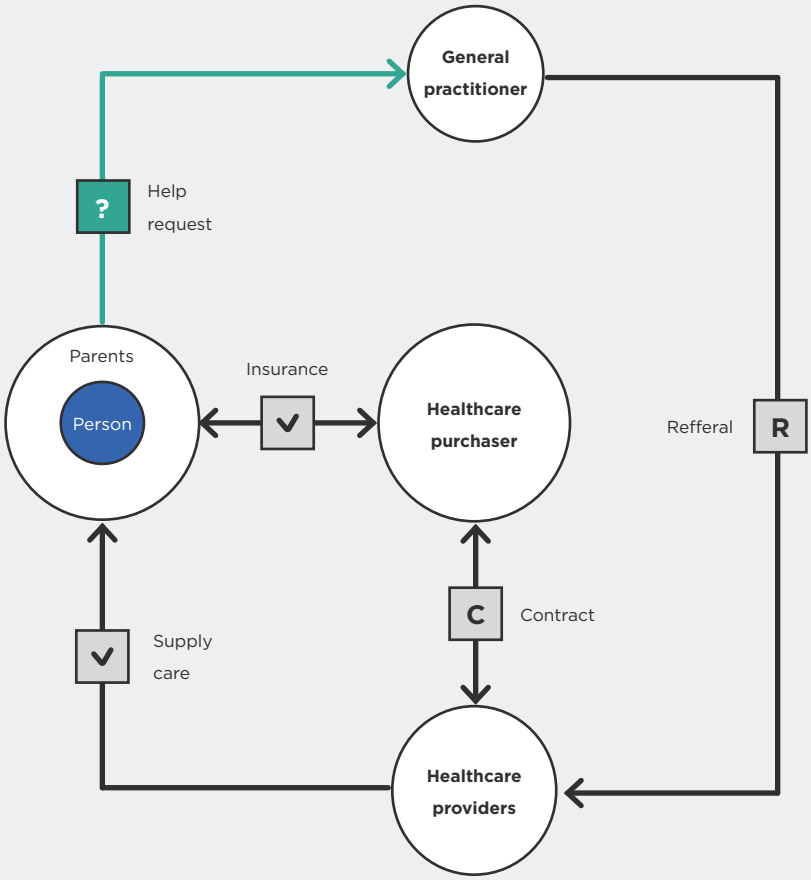
Individual/group guidance
Short stay (protected living)
Personal care
Growth and parenting support

Youth Care Act

In kind provisions



Health Insurance Act



Appendix M
Design document requirements

This appendix presents the results of requirement specification. This document embodies the minimal set of requirements that are required for the curriculum to function in practice.

Requirement #1	
User story	As parents, I want to invite professionals or family members so they can (temporarily) access (certain parts) of the online environment of my child.
Rationale	In its life, a child moves back and forth between multiple places such as day care, healthcare organisations, schools, etc. Therefore, the data generation and collection should take place at one central space and stay in ownership of the parents (or the Quality of Life Centre) because they are their legal representatives, have a full overview of the situation, and are constantly involved with their child
Value drivers	• Parents (and their family) have full ownership during the process and professionals add in/out (ranked 4.59) • Equal partnership between formal and informal network (ranked 3.61)
Information object	Not applicable
Priority score	4.10 (0 = low 5 = high)

Requirement #2	
User story	As a user, I can find all the necessary information regarding a person in one central and safe system through a simple interface.
Rationale	At this moment parents spend a lot of time (re)filling documents for their child, and professionals and other involved parties make decisions based on unavailable, incomplete or outdated information. When the most recent information about a child can be safely accessed, by all involved, from one central place, it facilitates collaborative decision making, and a holistic and integral approach
Value drivers	• Provide a holistic and integral approach (ranked 4.88) • Insight into the possibilities and gain influence in the decision process (ranked 4.56) • Provide logistical support in one place (ranked 3.78) • Parents (experience experts) get an equivalent position in the choices that are made for their child (ranked 3.17)
Information object	Not applicable
Priority score	4.40 (0 = low 5 = high)

Requirement #3	
User story	As user, I want to upload/register information that is collected by means of a physical conversation with the parents, child and family.
Rationale	By making the support questions of all involved insightful at the start, it becomes possible to understand what the involved persons need and what the implications will be in assembling a coherent offering.
Value drivers	• Makes insightful who needs what, and at which moment (rated 4.06) • Provide space for the persons story including the values that are of interest to him or her (rated 3.61) • Make the (structural) care and educational questions comprehensible (rated 3.56) • Provide insight in what a child wants, can and does (rated 2.94)
Information object	Intakeform
Priority score	3.74 (0 = low 5 = high)

Requirement #4	
User story	As intaker, I want the possibility to take a baseline measurement on predefined moments
Rationale	By taking questionnaires periodically, the effects of the use of the curriculum can be analysed objectively and validated over a longer period of time
Value drivers	Not applicable
Information object	(Baseline) measurement

Requirement #5	
User story	As intaker, I want to upload information regarding the funding sources of the parents
Rationale	By making the financial situation and the current budget insightful directly at the start, it can facilitate the decision whether or not the support can be granted by the Quality of Life Centre.
Value drivers	Not applicable
Information object	Financial situation

Requirement #6	
User story	As user, I want the possibility to digitally sign or approve specific documents in the dossier.
Rationale	By digitally signing documents, as little as delay as possible will occur between the intake and imaging phase.
Value drivers	Not applicable
Information object	Permission form

Requirement #7		
User story	As advisor, I want the possibility to upload the collected results of the dossier analysis	
Rationale	By analysing the current dossier, the history of the care recipient and his / her living environment is taken into account	
Value drivers	• Map information that is collected around an individual and make it insightful (4.09) • Anticipate on important milestones of what might be needed in the future (3.75)	
Information object	Not applicable (external files)	
Priority score	3.92	(0 = low 5 = high)

Requirement #8		
User story	As advisor, I want to register the conversations i have with the multiple persons that are involved	
Rationale	To reach consensus from different perspectives in order to make choices that are desired	
Value drivers	• Enhanced cooperation based on the choices for / of a child (rated 4.60) • Make the specific care and education questions of the child and family insightful (rated 3.61)	
Information object	Conversation form	
Priority score	4.10	(0 = low 5 = high)

Requirement #9	
User story	As user, i want the possibility to upload photo's and videos
Rationale	The collection of multimedia material has multiple functions: • By capturing different emotions of a child, other involved professionals will better know how they need to respond in a certain situation • By capturing different medical procedures, (untrained) professionals can faster learn how and what they need to do to offer the required care • An annual comparison between videos or photos can be made to track the often, small and subtle decline in the health of a child • Parents have more insight in what activities a child has done elsewhere (for example during day care)
Value drivers	• Equal partnership between formal and informal network (rated 3.61) • Provides insight in what a child want, can and does (rated 2.94)
Information object	Not applicable (external files)
Priority score	3.2 (0 = low 5 = high)

Requirement #10	
User story	As independent advisor, I want to upload (multiple) personal profiles
Rationale	Personal profiles are meant for people with a (complex) support question to untangle the multiple sub questions and to visualise certain areas of functioning, for example communication or alertness (specialistic). It gives an incentive towards the approach for stimulating well-being and the learning abilities of someone, for deploying help as well as to answer the current questions and to solve problems.
Value drivers	• Facilitates an integral and timely carried out imaging and diagnostics (rated 3.78) • All information revolving the imaging phase is collected in one place (rated 3.42)
Information object	Not applicable (external files)
Priority score	3.6 (0 = low 5 = high)

Requirement #11	
User story	As independent advisor, I want to register the medication of person
Rationale	The medication has a big influence on someone's well-being and also involves potential health risks. Providing the users with a list of all medication, more funded choices can be made regarding certain medicine.
Value drivers	• In the dossier, a traceable history is recorded (rated 4.00) • All information revolving the imaging phase is collected in one place (rated 3.42)
Information object	Diagnosis
Priority score	3.71 5 = high 0 = low

Requirement #12	
User story	As independent advisor, I want to register the diagnosis of person
Rationale	The diagnose serves as important starting point for determining the next steps where questions will be answered, help is deployed and problems are solved. The diagnosis helps to understand the overall health, the reasons behind a persons functioning and the behavior.
Value drivers	• Facilitates an integral and timely carried out imaging and diagnostics (rated 3.78) • All information revolving the imaging phase is collected in one place (rated 3.42)
Information object	Diagnosis
Priority score 5 = high 0 = low	3.60

Requirement #13	
User story	As independent advisor, I want to register the network of a person
Rationale	To get an idea of how many people are involved with the individual and his / her living situation. Besides, it is used to gauge the ratio between the informal and formal network. Ideally, this is in balance.
Value drivers	• Equal partnership between formal and informal network (rated 3.61) • Built in attention to self-management and participation (rated 4.25) • Maps the social network of the child and the family in one overview (rated 4.10) • Provides insight into the roles and appointments of all those involved in the care of a person (rated 3.14)
Information object	Network circle
Priority score	3.78 5 = high 0 = low

Requirement #14	
User story	As independent advisor, I want to register a (holistic) personal image based on previously collected information
Rationale	The personal image is meant for persons with a (complex) support question to query the sum of all questions and to visualise the overall functioning (generalistic). It provides direction for the approach to simulate the well-being and learning questions, for deploying help as well as to answer the current questions and to solve problems.
Value drivers	• Facilitates an integral and timely carried out imaging and diagnostics (rated 3.78) • Provides space for the childs story including the values that are of interest to him or her (rated 3.61) • Focuses on the ordinary life with special support where needed (rated 4.13) • Brings all perspectives together, which enhances the mutual understanding (rated 4.17)
Information object	Holistic personal image
Priority score	3.92 5 = high 0 = low

Requirement #15		
User story	As independent advisor, I want to upload a 24/7 arrangement	
Rationale	A (potential) 24/7 care and education arrangement is created to gain insight into the distribution of the normal (family) life of a person and the special support that is needed during this life. It also helps in making the right choices for a balanced program (balance between care and education, effort and relaxation, active and passive)	
Value drivers	• Offers cross domain 24/7 opportunities (rated 4.35) • Advises for an appropriate care and educational package (rated 4.35) • Assumes a 24-hour arrangement (rated 3.61) • Determine the type of care based on the questions (3.82)	
Information object	Not applicable (external files)	
Priority score	4.03	5 = high 0 = low

Requirement #16		
User story	As independent advisor, I want upload an advice report	
Rationale	Often various and complex questions are intertwined with each other. In addition, there is an emotional process and an ordinary family life. Besides, many people are involved in the situation and everyone often focuses (short-term) on their own part of the care. That's why it is important that someone with vision and expertise looks 'everywhere' and provides advice that fits as much as possible to the support, development and learning questions of a person.	
Value drivers	• Makes the structural care and educational questions comprehensible (rated 3.56) • Guides the user towards a more meaningful offering for care and education (rated 3.00) • Advises for preventive, structural and solution-orientated help (rated 3.91) • Brings coherence in the offered advice (3.91) • Anticipate on important milestones of what might be needed in the future (rated 4.09)	
Information object	Not applicable (external files)	
Priority score	3.70	5 = high 0 = low

Requirement #17	
User story	As user, i want to create short and long term goals
Rationale	While applying a (professional) intervention, of whatever nature, you have to know what you do, why and what results it has. This requires a goal-oriented and systematic working method. Based on this method one can work gradually towards a more desired situation. In doing so, it gives a grip on a complex situation.
Value drivers	• Provide a standardised process with clear language usage (rated 4.59) • Experience experts will get an equivalent position (rated 3.17) • Bring all perspectives together, which enhances mutual understanding (rated 4.57) • Limit the amount of goals that have to be achieved (3.00) • Make interdisciplinary collaboration possible (4.17)
Information object	Goals
Priority score	3.90 5 = high 0 = low

Requirement #18	
User story	As user, I want to register a lifestyle plan
Rationale	A plan makes it possible to follow the person as well as the things that are important in his or her life. By focusing on their lifestyle, one stays very close to the person in question. In the lifestyle of someone, the daily things of life are expressed. It is meaningful for one to have a certain lifestyle. It provides influence and direction but also meaning in ones life. By means of the plan, the lifestyle of an individual is constantly monitored and checked if it still matches the needs.
Value drivers	• Offer a 'road map' which coordinates the support process (rated 4.13) • Give the individual a central place in the process (rated 3.61) • Relevant information from different reports is merged into one integral lifestyle plan (2.71)
Information object	Lifestyleplan
Priority score	3.70 5 = high 0 = low

Requirement #19		
User story	As user, I want to fill out a day/week program (agenda)	
Rationale	In a day-week program, just like in an agenda, it is clear what someone is going to do. In the program a connection is sought with the questions and wishes of the person to find the necessary balance between effort and relaxation, activation and experience, etc. By implementing the day/week program into an agenda, it becomes very clear what you do, what is feasible and not, and how activities relate to each other. Besides, not the agendas of professionals are leading, but the agenda (daily life) of an individual.	
Value drivers	• Provides logistical support in one place (rated 4.31) • Navigates on the execution of individual dynamic custom made care (rated 4.47) • Work system that provides direction to the activities (rated 4.71) • Focus on the essentials of my work (4.43) • Well-balanced day-week programs for a child (4.27) • Provide an overview of what a child wants, can and does (2.94)	
Information object	Day/week program (agenda)	
Priority score	4.18	5 = high 0 = low

Requirement #20		
User story	As user, I want to report an activities inside the agenda	
Rationale	If you do activities, you also want to know if they deliver the results that were intended beforehand. It gives the involved persons insight but also inspiration and spirit to continue on the chosen path.	
Value drivers	• Map information around a individual and make it insightful (rated 4.00) • All information is available in one central place (rated 3.00) • A 'traceable' history is created of an individual (rated 4.00)	
Information object	Reportform	
Priority score	3.66	5 = high 0 = low

Requirement #21	
User story	As user, I want to evaluate a work goal
Rationale	Evaluating work goals is important because a statement is made about what has been achieved and in which specific way. It helps to understand what works, for whom, and under what circumstances. This understanding helps to contineously improve the day/week program of a child and ensures the treatment stays on track.
Value drivers	• Facilitates a more efficient planning, execution and evaluation of work (rated 4.71) • Make the complexity insightfull and advise for solutions (rated 3.29) • Facilitate collaboration based on available information (rated 4.14)
Information object	Evaluation
Priority score	4.04 5 = high 0 = low

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