YOUNGCARE

RELIEF FOR YOUNGER PEOPLE IN NEED OF CARE AND THEIR INFORMAL CARERS

National report:

An Overview of the Situation of Informal Caregivers and Younger Adults in Need of Care in the Netherlands

Co-funded by the European Union

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ABOUT THIS PUBLICATION

This report summarizes the national overview of informal care services and caregivers of individuals aged 18 to 65, outlines the needs and challenges encountered by the YoungCare target group, and provides practical support along with examples of good practices. Erasmus+ project **YoungCare: Relief for Younger People in Need of Care and their Informal Carers** (Grant agreement: 2022-1-DE02-KA220-ADU-000086558). **PROJECT WEBSITE:** https://youngcare.eu/

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Abbreviations and Acronyms

IVA	*Inkomensvoorziening Volledig Arbeidsongeschikten* (Income provision for the Fully Occupationally disabled Act)
MS	Multiple Sclerosis
Pgb	*Persoonsgebonden budget* (Personalised budget)
WGA	*Werkhervatting Gedeeltelijk Arbeidsgeschikten* (Labour resumption for Partially Occupationally abled Act)
Wgbh/cz	*Wet gelijke behandeling handicap of chronische ziekte* (Equal Treatment Act of the Disabled and Chronically Ill)
WIA	*Wet werk en Inkomen naar Arbeidsvermogen* (Work and Income according to Labour Capacity Act)
Wlz	*Wet langdurige zorg* (Long-term Care Act)
Wmo	*Wet maatschappelijke ondersteuning* (Social Support Act)
Zvw	*Zorgverzekeringswet* (Health Insurance Act)

1. Aims of the national report

The project "YoungCare - Relief for younger people in need of care and their informal carers" aims at improving the situation of younger people in need of care. This is a group of younger adults up to the age of 65 who have become dependent on care as a result of a drastic event such as an accident or serious illness and can no longer manage their everyday lives without help. In most cases, these people are neglected in care services and have problems receiving care tailored to their needs. In most cases, therefore, they are cared for at home. The partner organisations from Germany, Italy, Lithuania, the Netherlands and Portugal want to draw attention to the sometimes precarious situation of young adults in need of care and the people who care for them.

The national report is supposed to be an important part in assembling a European compendium. The compendium is meant to provide a scientifically based but practice-oriented and easily accessible overview of the situation of younger people in need of care and their informal carers. It is aimed primarily at these informal carers and people in need of care who are confronted with disease and care for the first time or who feel the need to improve their situation. It is part of Work Package 2 of the YoungCare project, which is intending to collect evidence on the perspectives of the target group, creating an extended knowledge base and developing solution strategies. The results of this work package are also meant to contribute to the development of the digital learning opportunities and for the development of the publicity strategy in the following work packages. In order to accomplish the task of the European compendium being the main output of this Work Package the national reports from all the partner-countries (Germany, Portugal, Italy, Lithuania and the Netherlands) are an important piece of input and information.

Although the main aim is to be a fundamental piece towards completing the European compendium the publication of the national reports also gives an overview of the situation of YoungCare in each of the countries represented by a partner organisation. It is important because it sheds a light on the daily struggles and hurdles young people in need of care and their informal carers have to face locally. Also, the political, public and scientific discussion will be elaborated. Particularly because of the scarcity of data and information, it is important to use the national reports to provide an insight into the everyday lives of young people in need of care and their informal caregivers.

2. Methodology

Before describing the methods applied to achieve the above-mentioned aims, it is important to specify the target groups summarized as “younger adults in need of care”. The main criterion for the differentiation is the question if need for care has already existed since birth or was acquired in the course of life (between 18 and 65 years of age).

We intentionally use the term "younger adults" for the project to describe the age group that can neither be described as children and young people nor as senior citizens. This is done with the knowledge that this age group encompasses a large age variation.

The distinction between the need of care since birth and a later acquisition seems to make sense in the context of the YoungCare project's objective to develop a practical educational tool. The thesis is that the first group (from birth) is already introduced into the social and care system through the offers in the child and youth sector. Even if problems arise with the transition to adulthood and care services (presumably) deteriorate, this group has experience with the issues of care and the social system. In the second group, there is a need to acquire this knowledge in an extreme situation.

People in need of care are defined as those persons who are dependent on help in managing their daily lives. All people who informally help other people to cope with their everyday life are defined as carers.

The following methods were applied during the finalisation of this National Report:

2.1 Desk Research

The partners conducted the desk research in their countries with a special focus on the national situation and focussed on the following topics:

- Facts and figures on care services, care needs, types of illnesses and types of care provided
- Scientific work on the topic
- Political and practical debates on the topic
- Obstacles and difficulties for the YoungCare target group in the provision of care and services
- Suitable offers and good practice offers for the YoungCare target group
- Suitable practical support for those affected and their carers (first aid)

2.2 Interviews

In each country, interviews with an open structure were conducted. They were conducted primarily with informal carers but if possible, depending on the individual situation of the persons concerned, persons in need of care were also interviewed. A short amount of the interviews was conducted with experts to improve the understanding of the overall situation.

In the Netherlands, the citizen interviews included six individuals with care needs and four caregivers, two of which are both caregiver and care receiver. Furthermore, three interviews were conducted with experts in the social domain, one of which has care needs and two provide informal care for their child. For the (young) adults, the age at which care needs arose varied between 29 and 65. Based on one of the interviews, there will be a short portrait of a caregiver and activist, which can be found in chapter 3.5.

3. Results

3.1 Overview of the national situation

Care needs are highly personal and are not so easily defined or categorised. Care needs arise from illnesses, injuries, or conditions that have led to disorders, impairments, and/or participation problems. However, not every person with a similar health state experiences the same needs. There are several factors involved that determine whether or not a person is in need of care; **personal factors**, determined by someone's own capacity and lifestyle, and **external factors**, determined by the environment and the way our society is adapted to fit a person's needs (Breedveld et al., 2013). In literature, there are different terms and definitions used to describe specific health states and care needs, like 'impairment', 'disability', and 'handicap'. Because these terms can be stigmatising, it is important to clarify what is meant by this:

An impairment is defined as "*any loss or abnormality of psychological, physiological or anatomical structure or function*."

A disability is "*any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being."*

A handicap means "*a disadvantage for a given individual that limits or prevents the fulfilment of a role that is* [considered] *normal."* (Carter, 2018)

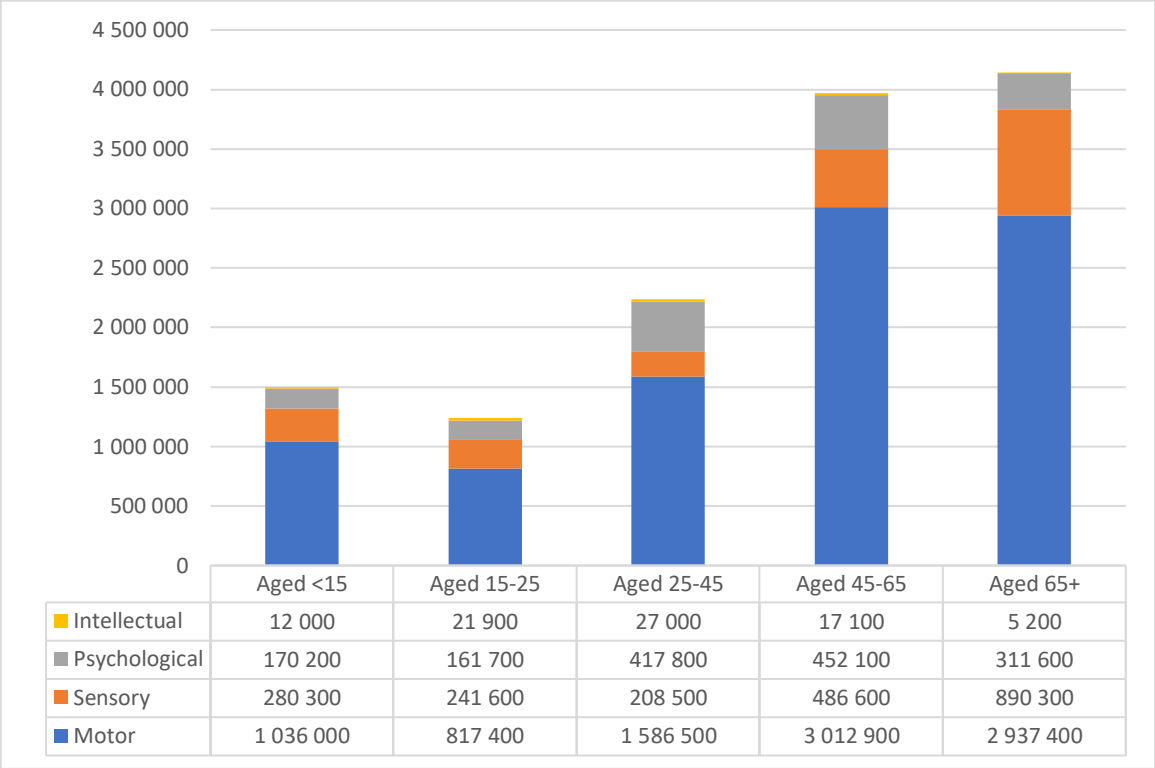
Individuals that are impaired do not necessarily have a disability, and people who are disabled don't have to be or feel handicapped in their everyday lives. In addition, people who are disabled do not always need formal or informal care, and people who give or receive care may not be registered as such. All these factors make it difficult to find accurate statistical information.

In the following subchapters an overview is given of the prevalence of impairments and disabilities in the Netherlands. Because these statistics were taken from different sources, in different years, using different methodologies and definitions, the data can vary. Furthermore, there are several different scales as how to measure and categorise disabilities, like GALI, OESO, ADL, and IADL, leading to various categorisations of impairments and diseases and overlap within these categories. **These issues further highlight the complex nature and generalising attempt of datafying individuals with care needs.**

3.1.1 Statistics on the prevalence of impairments by age and gender

In 2019, **10.513.900** Dutch people were reported to have a **chronic or long-term impairment**; 61.3% of the total population. In the age group of 15 to 65 years, 6.229.100 of people have an impairment, which is 55.8% of the total population in this age group. Most people with an impairment (89%) have a motor impairment. Second most common is a sensory impairment (20%). Figure 1 shows the division per condition and age. Motor,

sensory, and psychological impairments occur more often in women, while intellectual disability is more prevalent in men (van Zeijl et al., 2022).



	Aged <15	Aged 15-25	Aged 25-45	Aged 45-65	Aged 65+
Intellectual	12 000	21 900	27 000	17 100	5 200
Psychological	170 200	161 700	417 800	452 100	311 600
Sensory	280 300	241 600	208 500	486 600	890 300
Motor	1 036 000	817 400	1 586 500	3 012 900	2 937 400

Figure 1. The prevalence of chronic or long-term impairments in the Netherlands in 2019 (CBS 2022).

These figures include all long-term and chronic conditions that are in some way impairing and therefore illustrate how common it is for people to have some form of impairment (close to two-thirds of the population). However, these numbers say nothing about the care needs of people. In the next subchapters an overview is given of different disabilities and disorders and their prevalence in the Netherlands to give a better insight of where the care needs are and how they may differ.

Physical disabilities and care needs

Physical disabilities can be divided into three main categories:

Motor impairments *are physical impairments as a result of non-terminal disorders in the nervous system and/or the bones, muscles, joints, or connective tissue, in which improvement is not possible* (Verschuren; Driessen; Meijer, 2016). In total, **14.6%** of Dutch individuals have a motor impairment (as recorded in 2021). This percentage increases with age; in the age group of 18-65, 19.1% of Dutch individuals have a motor impairment, the majority of which are women (12.6%). For people aged 65+ the total percentage rises

to 76.9%, of which 49.3% are women (VZinfo, 2023). In 2020, 28.835 people with a motor impairment received long-term care support (CBS, 2022).

Sensory impairments *include visual or auditory impairments and severe difficulties with language or speech (that are not the result of communication problems or an intellectual disability)* (Verschuren; Driessen; Meijer, 2016). In 2021, **5.6%** of Dutch people had an **auditory impairment** and **6.9%** had a **visual impairment**. In the age group of 18 to 65, 9.5% of individuals had a hearing impairment, and 13.2% a visual impairment. Auditory impairments are slightly more prevalent among men and visual impairments slightly more among women (VZinfo, 2023). In 2020, 3240 people with a sensory impairment received long-term care support (CBS, 2022).

Somatic disorders *are diseases or conditions that can potentially be cured or improved through medical treatment, for example cancer, epilepsy, rheumatism, and kidney failure* (Verschuren; Driessen; Meijer, 2016). When a somatic disorder cannot be completely cured it is called a chronic somatic disorder. Examples of this are diabetes, arthrosis, and chronic pains. About **10 million** people suffered from a chronic somatic disorder in 2020 (VZinfo, 2022). In 2020, 57.845 people with a somatic disorder received long-term care support (CBS, 2022).

Mental disabilities and care needs

Mental disabilities can be divided into five main categories (RIVM, 2017):

Congenital brain disorders *occur within the first year of life and include abnormalities in the central nervous system and neurological conditions leading to severe intellectual disability.* In 2016, **100.300** Dutch citizens were registered with a congenital brain disorder (RIVM, 2017). The Dutch Social and Cultural Planning bureau (SCP) estimated there to be 440.000 people with some form of intellectual disability in the Netherlands (meaning an IQ < 70) in 2018, of which 70.000 people have a severe intellectual disability (with an IQ < 50). Another 2,3 million citizens are estimated to have an IQ between 70 and 85. Officially, this group of people is not intellectually disabled, but approximately 730.000 individuals have care needs due to social self-sufficiency problems (VZinfo, 2023). In 2020, 115.575 people with an intellectual disability received long-term care support (CBS, 2022). Even though intellectual disabilities are congenital, care needs are likely to change throughout a person's life.

Non-congenital brain damage *or an* **acquired brain injury** *(ABI) is when damage to the brain has occurred at a later age. An ABI changes the neuronal activity in the brain, which may result in a wide variety of symptoms and care needs. The cause of an ABI can either be traumatic (e.g. a hit to the head) or non-traumatic (e.g. a brain tumour, a stroke, or lack of oxygen due to heart failure)* (HandicapNL, 2023). In the Netherlands, there are **645.900** people that experience restrictions due to non-congenital brain damage. Every year, around 130.000 people are affected by ABI and survive, of which 40.000 will retain significant disabilities (RIVM, 2017; Hersenz, 2023). This group of people is especially

relevant to the YoungCare project, since an ABI can occur at any age and will drastically change the lives of the affected individuals and their carers.

Psychological disorders, *among which autism spectrum disorders, personality disorders, substance use disorders, anxiety, and depression, are also often referred to as mental or psychiatric disorders.* Care needs vary greatly. In 2022, nearly **3,3 million** Dutch adults had a psychological disorder; **26%** of the total adult population. 48% of citizens in the age of 18-75 years has had a psychological disorder at some point in their lives. Mood disorders and anxiety are the most common (with over 25%) and are more prevalent among women, followed by substance use disorders (17%), which occur more among men. In total 51.8% of adult women has had a psychological disorder, compared to 44.9% of adult men. Mood disorders, anxiety and substance use disorders are most common in younger adults, between the age of 18-24 and decrease steadily in older individuals. No age correlation is found for congenital disorders, like autism and ADHD. 14% of adults with a psychological disorder make use of general healthcare (like the GP, social work, or the company physician), and 9% use mental healthcare offers (like a psychologist or psychiatric treatment) (Ten Have et al., 2022).

Chronic brain disease, *i.e. brain damage through a neurodegenerative disease, are progressive conditions in which nerve cells or connections between nerve cells die off. The effects can be physical and/or cognitive, but always become more severe over time.* The speed of deterioration varies per person, and the age at which the first symptoms appear vary depending on the disease and the individual. Therefore, care needs also vary from person to person. Alzheimer, for instance, will most likely occur after the age of 65, Parkinson most often develops between 45 and 60 years of age, and MS typically first appears between age 20 and 50 (Hersenstichting, 2017). In 2016, **1.337.800** Dutch citizens (almost 8%) were known to have a chronic brain disease (RIVM, 2017).

Sleep disorders, *such as insomnia, restless leg syndrome or apnoea, involve problems that disturb someone's normal sleep pattern and can result in an impairment of functioning during the day*. In 2019, **545.500** individuals were recorded at the GP's office with a sleep disorder. Sleep disorders occur 1.5 times more often in women. Although sleep disorders do not have to be chronic, there can still be care needs that affect the lives of the afflicted and their carers, such as increased help in the household, with work and finances, and with managing symptoms. In addition, sleep disorders increase the risk of developing dementia and depression (Hersenstichting, 2023).

Multiple impairments and care needs

Multiple impairments *can be congenital, caused by e.g. a brain disorder or lack of oxygen during birth, or non-congenital, caused by a disease or accident* (Máxima MC, 2023). Individuals with multiple impairments suffer from a combination of cognitive, physical and/or functional restrictions. Any of these restrictions can come in varying degrees of severity. In the Netherlands, there are estimated to be **10.000** individuals with severe multiple impairments of which 9.000 receive care and board (Heliomare, 2023).

3.1.2 Statistics on informal carers and care receivers

In 2019 there were around **5 million** *mantelzorgers* (informal caregivers) in the Netherlands. 830.000 of those caregivers gave care that is considered both long-term (more than 3 months) and intensive (more than 8 hours per week), but only a quarter of the *mantelzorgers* consider themselves as such. 460.000 informal caregivers feel severely overwhelmed (MantelzorgNL, 2022).

Figure 2 shows the age and gender of informal carers in the Netherlands, as well as their relation to the care receivers. Most *mantelzorgers* are female, aged 65+, and most care is given to parents (in law). This is likely due to rising care needs with age. Not surprisingly, the number of caregivers also rise with age, since older individuals are more likely to need to give care to their ageing parents and/or partner (the rise in the youngest age group, 16-34, is likely because this age group covers a 19-year timespan instead of 9).

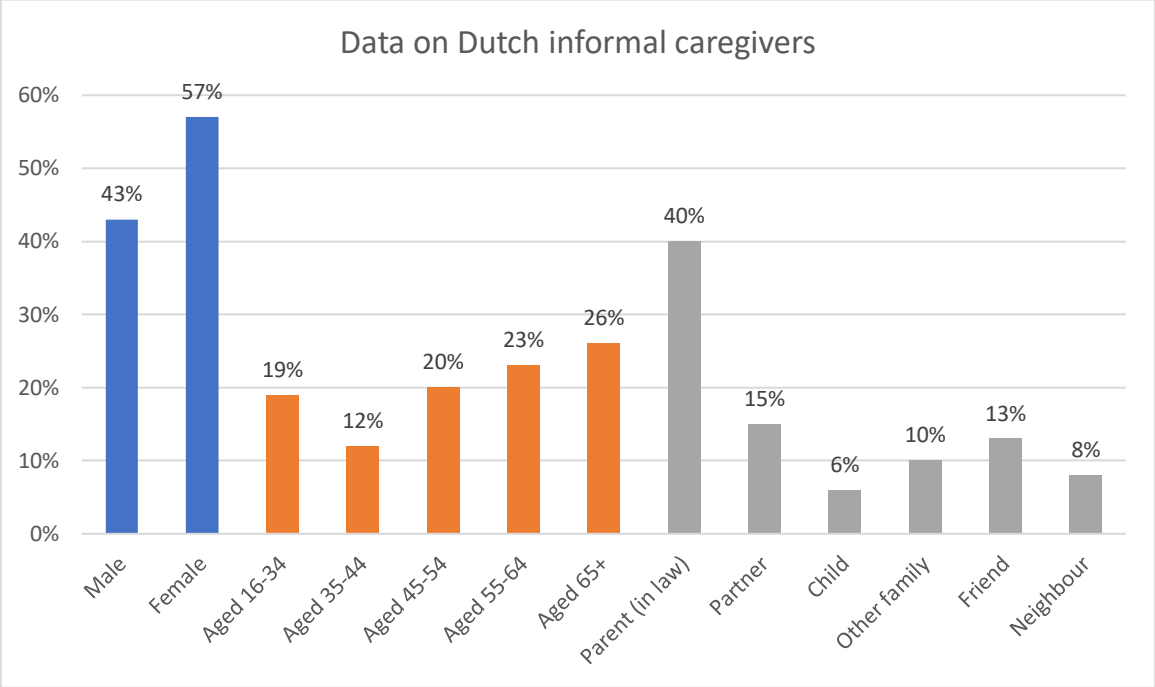


Figure 2. Percentage of Dutch informal caregivers by gender and age and the relation of the care receiver in 2019 (SCP; CBS, 2020; IZG, 2019).

Only 29% of informal caregivers use any kind of caregiving support (figure 3). Most of this support consists of information and advice, while both material and financial support were indicated to be needed, but not received by many (SCP; CBS, 2020; IZG, 2019). Since 2015, caregiving support is arranged and financed by municipalities. Due to budget cuts, it has proven difficult for cities to adhere to the set expectations in this area. In addition, knowledge is lacking about available caregiving support measures, especially among caregivers with a non-western migration background and those who are severely

overwhelmed. It is therefore necessary to improve communication and actively reach out to these disadvantaged groups (de Boer et al., 2020).

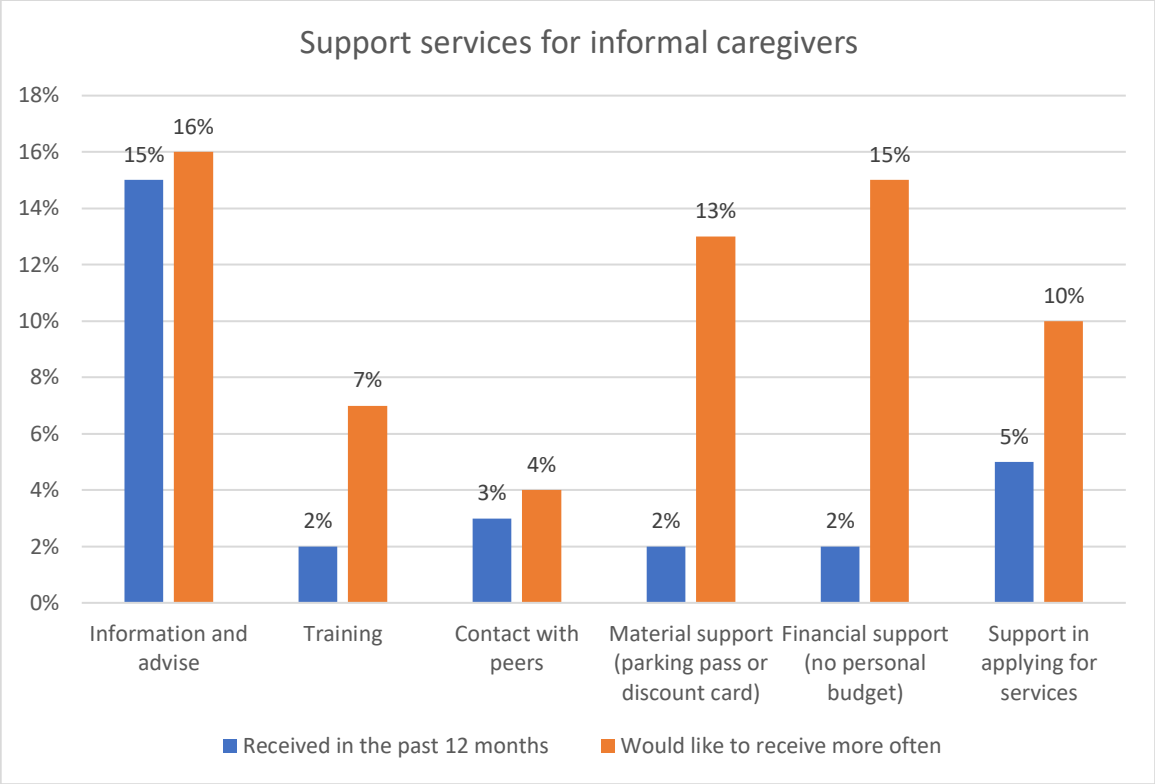


Figure 3. Support services for informal carers that were used in the past year and those that carers would like to receive more often (SCP & CBS 2020: IZG2019).

The exact number of Dutch citizens that receive informal care is difficult to assess. According to data from the Dutch Central Bureau of Statistics (CBS, 2023a; CBS, 2023b), **1.238.785** people (over 7% of the population) received funding from the Social Support Act (Wmo, see chapter 3.2) in 2022. These are (mostly) adults with care needs living at home. In addition, **342.095** people (1.95% of the population) received funding from the Long-term Car Act (Wlz) in 2021. These are adults with care needs, living either in institutions or at home. These numbers give an estimation of individuals with care needs, but not necessarily people that receive informal care. Also, individuals who do not receive funding are not included in these figures. Compared to the number of individuals with an impairment (see chapter 3.1.1), about 15% receive funding.

Figure 4 gives an overview of the age, gender, and type of care of Dutch informal care receivers. Most care receivers are female, which is mainly due to the longer average life span of women and increased care needs at a higher age. Most care that is given consists of companionship and emotional support, followed by transport, assistance with doctor's visits, and household chores. Women tend to help more in making arrangements, visiting

medical professionals, and providing personal care, while men help more with administration and transport (SCP; CBS, 2020; IZG, 2019; de Boer et al., 2020).

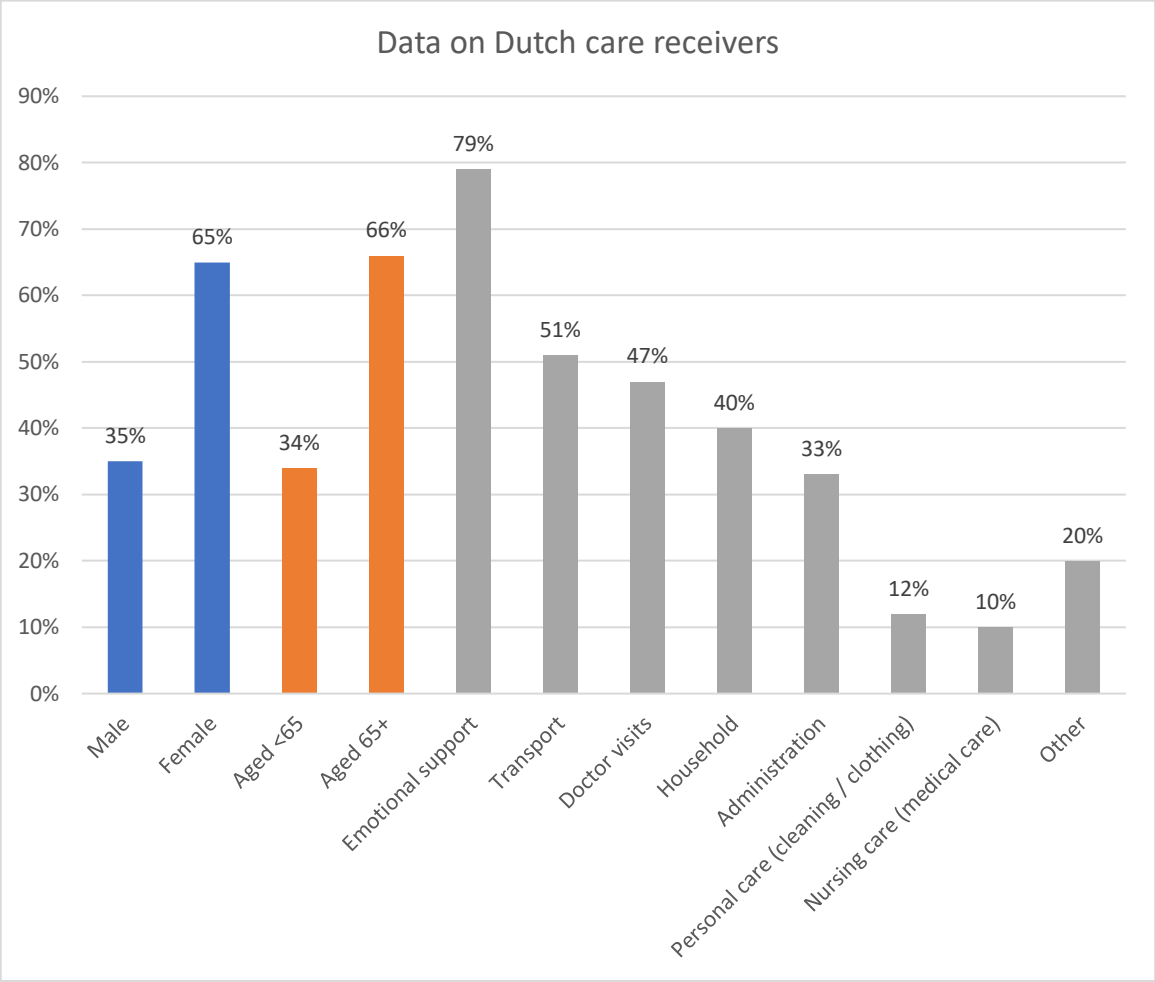


Figure 4. Gender, age and type of support of Dutch citizens with care needs (SCP & CBS 2020: IZG2019; de Boer et al. 2020).

Most care is given to individuals with physical impairments (see figure 5). This is not surprising, since physical impairments are the most prevalent in the Netherlands (see §3.1.1). The percentage of care given to individuals with psychological (e.g. depression or anxiety) and psycho-social (e.g. loneliness or addiction) problems has increased significantly since 2014. This may be due to a lower mental wellbeing and/or a decline in available professional help. Informal carers of individuals with psychological problems have a greater risk to get overwhelmed (de Boer et al., 2020).

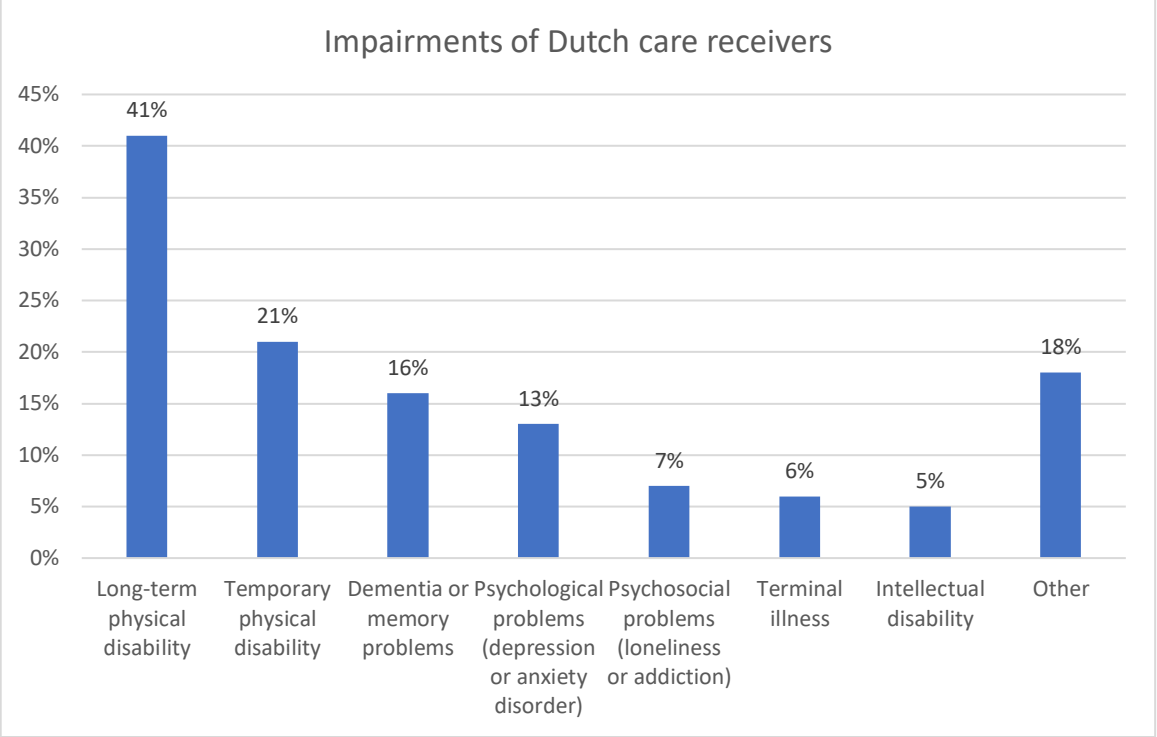


Figure 5. Reasons for care needs of Dutch citizens (SCP; CBS, 2020; IZG, 2019).

3.2 Overview of the political, public and scientific discussion regarding younger care

3.2.1 Dutch laws and regulations on disabilities and care needs

Individuals with a disability or chronic illness have the right to be equally included in society, as stated in the Equal Treatment Act of the Disabled and Chronically Ill (Wgbh/cz), established in 2003. According to the Wgbh/cz it is forbidden to discriminate between individuals with and without impairment in housing, education, employment, and public transport. Since 2016, this also includes goods, services and assistance dogs, and in 2017 a standard for general accessibility was added. This latter standard states that schools, work environments, and businesses should be accessible to all people, unless the improvement of accessibility is considered disproportionately burdensome due to e.g. financial or time constraints (Rijksoverheid, 2023a).

Available financial support for care and means

Everyone that lives or works in the Netherlands has an equal right to basic healthcare, as is stated in the Dutch **Health Insurance Act** (Zvw) dating from 2006. The Zvw describes which healthcare treatments, services and products must be made available to people by the various private health insurance companies and health providers. This so-called 'basic care' is financed by tax- and insurance premium payments. Citizens are required to take out health insurance but are free to choose their own healthcare insurer and any additional coverage (Zorginstituut Nederland, 2023a). The basic healthcare plan covers

district nursing care, consisting of personal care at home, at work, or in daytime care that is needed due to an illness or impairment (Zorginstituut Nederland, 2023b).

Apart from the Zvw, there are three other major laws arranging healthcare in the Netherlands: the Long-term Care Act (Wlz), the Social Support Act (Wmo), and the Youth Act, all of which have been in effect in its current state since 2015. As the names suggest, these laws arrange care and financing for people in need of fulltime long-term care, domestic or social support, or help with physical, mental or behavioural problems in children (VWS, 2016).

The **Social Support Act** (*Wet maatschappelijke ondersteuning* – Wmo) dictates that people should be supported to live their lives at home for as long as possible. This support is financed and arranged by the municipality and includes means and subsidies, for e.g. changes in the house, special transport, and daytime care. In some cases, an own-risk contribution is required. Individuals can also request a personal budget (*Persoonsgebonden budget* – pgb), which varies depending on the needs of the care receiver. With a pgb people can arrange their own care and support from providers of their choice. This allows disabled individuals and their caregivers for more control over their lives, but also adds more administration, arrangements, and planning (Rijksoverheid, 2023b).

Individuals that need intensive and constant care or supervision receive support via the **Long-term Care Act** (*Wet langdurige zorg* – Wlz). Wlz-care is financed and arranged through healthcare offices. This includes care in care institutions, but if possible can also be arranged at home. Also via the Wlz people can choose to have care arranged for them (*in natura*) or arrange it themselves through a personal budget (VWS, 2016).

Care and support for minors (<18 years) is arranged through the **Youth Act** (*Jeugdwet*) and includes help for families and children with behavioural problems, psychological care needs and intellectual disabilities, as well closed youth care, youth protection, and forensic care. The municipality is responsible for the implementation of the Youth Act (VWS 2016). When a child turns 18 their care arrangements are transferred to the Wmo or Wlz. In some cases, support from the Youth Act can be extended for a maximum of five years, if care cannot be arranged through different laws or if a treatment is ongoing (VWS, 2023a).

Informal caregivers can receive subsidies via an additional coverage package in their health insurance for e.g. respite care and care courses, and they can get travel costs reimbursed via tax returns or their municipality (VWS, last access June 2023b). In addition, informal carers have the right to take care leave from work. Each year informal carers are entitled to twice the number of hours they work per week for 70% of their salary. Long-term care leave can be taken for six times the number of hours someone works per week every year, but payment is not required (Rijksoverheid, 2023c).

Despite these regulations, the unemployment rates among *mantelzorgers* in the Netherlands is very high. In 2016, only 26.5% of caregivers between the age of 16 and 67

(the Dutch retirement age) have a paid job of more than 12 hours per week. Among *mantelzorgers* that give intensive care (≥8 hours a week) this percentage is even lower: 21%. Informal caregivers that combine intensive care with work indicate to have a lower quality of life and experience more time pressure. 27% of informal caregivers indicate they are unable to properly combine care with work (SCP, 2019).

Available education options for children and young adults

For disabled **children** under the age of 18 there are two education options. If both desired and feasible, a child can follow mainstream education, potentially with personalised support. Children that need intensive educational support can join a special education school, designed to better fit their needs (OWS, 2023).

For **young adults** who want to follow a professional education only mainstream education is available. The Wgbh/cz dictates that schools are required to accommodate individuals with an impairment if reasonably possible. The mainstream education system with personalised adaptations is beneficial for students with physical disabilities but has proven to be problematic for individuals with psychological disorders, like autism. The current problem-based learning methodology is based on self-sufficiency and responsibility, which does not work well for this group of young adults, who require more structure. Additionally, due to budget cuts and a shortage of teachers, there is less time available for individual students (van Lierop; Cremer, 2005).

Available support measures for employment and unemployment benefits

There are several available financial support measures for individuals whose disability prevents them to work or to work fulltime. The **Wajong** allowance is for individuals who became work disabled before their 18th birthday or during their studies before their 30th birthday. With the Wajong, someone receives a maximum of 75% of the minimum wage (€1995,- per month in 2023; 75% being €1496,25). If the total income of the family is below the social minimum (€1934,45 for a joint income in 2023), additional benefits are possible (Rijksoverheid, 2023d).

The **WIA** is for individuals who became work disabled while employed and as a result can only make up to 65% of their previous salary. The WIA can be divided into the WGA and the IVA. The **IVA** is for individuals who are occupationally disabled and can only make 20% or less of their previous salaries. The **WGA** is for individuals who are occupationally disabled and can only make between 35% and 80% of their salaries, or individuals who are temporarily disabled with an 80% or less work capacity. People with a WIA can only receive a maximum of 75% their previous wage, and people with a 35% decreased work capacity do not receive additional income support (unless the total income of the family is less than the social minimum) (Rijksoverheid, 2023e; Rijksoverheid, 2023f).

In order to give individuals with an occupational disability the chance to have a regular job, the Dutch government has set up the so-called '***banenafspraak***´ (job deal), as part of the Participation Act from 2015. The goal of this deal is to have created 125.000 extra jobs (100.000 in corporate organisations and 25.000 government positions) at the beginning

of 2026. Organisations receive a bonus per employee hired via the job deal, which varies depending on the number of hours the employee works, and a quota can be applied to companies with more than 25 employees. So-called '*regionale werkbedrijven'* (regional work companies) - collaborations of municipalities, the Employees Insurance Agency (UWV), employers, unions, and schools from one region - make arrangements to help individuals with an occupational disability to find work (Rijksoverheid, 2023g; Rijksoverheid 2023h).

The goal of the Participation Act is to create an inclusive job market, but an analysis from 2021 showed that the process is stagnating and prospects for the future are worrisome. Municipalities are responsible for supporting individuals with an occupational disability to find work, but they are free to make their own political and policy-related considerations. Recent world affairs, such as the covid-19 pandemic and the war in Ukraine, have led to financial constraints and disparities between regions (Cedris, 2021). Although the situation has improved after the end of the pandemic, adults with an occupational disability are still very disadvantaged on the job market. Research on the employment rates of disabled individuals at the end of 2021 indicates that only 50.2% of employable individuals that became impaired at a younger age were employed. For individuals that became partially occupationally disabled at a later age the employment percentage is 49.1% (Berendsen et al., 2022). In total there are about 1,1 million disabled individuals in the Netherlands who are able to work, of which more than 450.000 do not have a job. In addition, 54% of the people that do have a job experiences obstructions in their work, of which 10% experiences significant obstructions. The main problems that are listed are:

- having to work below their educational and psychological level;
- getting paid below minimum wage;
- not receiving compensation for provisions, and
- discrimination at work (Ieder(in) 2021).

The regulations for people with a (partial) occupational disability are complex, leading to people needing to switch arrangements and individuals that are not included at all. A study on the effectiveness of the *banenafspraak* indicates that a large group of people cannot apply for this deal (figure 6). The rules exclude individuals with the same or similar disabilities based solely on e.g. the age they became impaired (<18 or >18). To avoid not adhering to the quota, employers hire impaired individuals that are registered as part of the job deal, excluding all others. The side effect of this exclusion is that job opportunities for people with a disability that do not qualify for the *banenafspraak* are heavily decreased. This applies to more than 800.000 Dutch citizens. The authors state that in order to create a true inclusive job market, a drastic change in policy is required, where rules and regulations are broadened to accommodate all disadvantaged people in society. In addition, a more complete oversight is needed of the situation of individuals with an occupational disability and the effectiveness of the current system (Ieder(in) 2021).

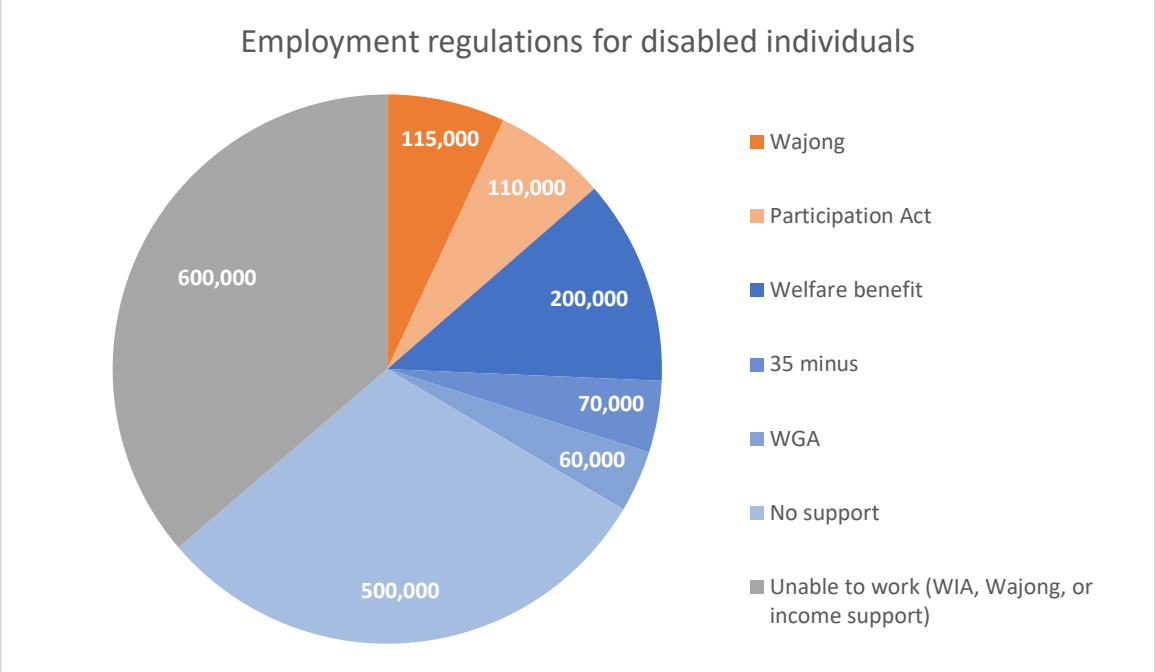


Figure 6. The different financial regulations for individuals with an occupational disability. The orange sections are the people included in the job deal, the blue sections are not included, and the grey section involves individuals (mostly) unable to work (adapted from Ieder(in) 2021).

3.2.2 Social participation and discrimination

Disparities can also be found for the inclusion of disabled individuals in sports and leisure. The percentage of individuals with an impairment that participates in sport at least once a week is 21.1% with a physical impairment, 35% with a mental impairment, 21.4% with a visual impairment, and 24.2% with a auditory impairment. On average, only a quarter of impaired individuals participates in sports. For the general population this is 60.1% (Kenniscentrum sport & bewegen, 2023).

Also on a social level people with an impairment are reported to be excluded, stereotyped, stigmatised or discriminated against, but statistics on how many people deal with ableism on a regular basis are lacking. Questionnaires on discrimination are not adapted or made available for people with intellectual disabilities, but according to studies this group has the most negative public image (Fitzpatrick, et al., 2022).

A study on ableism in the workplace has shown that a majority of people assume that hiring a disabled person will cost time and energy and this is seen as a negative addition. Interviews with employees working with disabled individuals, however, have expressed highly positive opinions, where the cooperation between differently-abled people has improved the working atmosphere and increased the overall willingness to help others in their tasks (Driessen Groep, 2023).

Studies have shown that the best way to abolish ableism is for people to meet and have positive qualitative interactions with disabled individuals. This method has shown to

reduce prejudices among both adults and children. The second-best way is for people to have indirect contact with disabled individuals through the media. Information and education are also important, but only work in combination with the first two methods. It is therefore important to create spaces in society where differently abled people can easily meet, and to increase positive representations of impaired individuals in the media (Fitzpatrick et al., 2022).

3.2.3 Scientific research

There is very little scientific research available on young adults with care needs, especially on adults between the ages of 18 and 65. Most scientific articles cover specific diseases and conditions and although there is a good amount of statistics on people with disabilities, no distinction is made between care needs from birth and care needs that have arose at a later age. Studies on informal care on the other hand, are much more abundant. Topics are varying, but mainly include mental load and quality of life for informal carers, and the work / care balance. This reflects both the current position many caregivers are in and the growing need for informal care in the future. Due to the ageing of Dutch society, informal care needs are expected to rise with 70% by 2040. With the rising retirement age many people will have to combine care responsibilities with work (RIVM, 2021). Mental load and work / care balance are therefore important topics.

3.3 Needs, challenges and solutions

To deepen the information, qualitative interviews were conducted in May 2023. In total eleven people were interviewed, including three experts who were caregiver or had care needs themselves (see Table 1). In the following paragraphs the results of the interviews will be discussed.

Table 1. List of the interviewees with an overview of their care situation, reason for care needs, current age of the care receivers, and age when care needs arose.

Interviewee	Care situation	Reason for care needs	Age (of care receiver)	Age, when need of care was diagnosed
1	Receives care from her family	Spinal Muscular Atrophy (type 2)	28	1½
2	Receives care from her husband	Multiple Sclerosis	56	40
3	Gives care to her husband	Stargardt disease (severe vision impairment)	52	39
4	Self-sufficient, but supported by his girlfriend	Stroke	59	48
5	Receives care from his family	Multiple Sclerosis (Primary Progressive)	47	29
6	Gave care to her husband, as well as her son (interviewee 5)	Husband: Dementia Son: MS (see above)	Husband: Diseased	Around 65

7 & 8	Husband and wife, give care to each other	Husband: Retinitis Pigmentosa Wife: Whiplash (2017), breast cancer (2019)	Husband: 57 Wife: 54	Husband: 30 Wife: 48
9 (expert)	Gives care to his daughter	Cortical dysplasia, restrictive cardiomyopathy, auto-immune disorder	23	Birth
10 (expert)	Gives care to her daughter	Intellectually disabled, epilepsy, possibly autism	21	3
11 (expert)	Self-sufficient, but supported by his family	Burn patient	48	40

3.3.1 From diagnosis to care: available support and lack thereof

Information and support for informal carers

Informal carers that take care of their spouse or child often indicate that they do not perceive themselves as informal carer, since taking care of your close family is part of everyday life, even when their care needs rise. Interviewee 8 explained that relationship matters in this; for instance, having to take care of an aunt would feel more like informal care. The transition to *mantelzorger* can therefore be very gradual for some. For others, the transition came very sudden which is overwhelming and can be difficult to accept. In both cases **support is lacking** and people have to discover many things by themselves. Especially for the informal carer, information and support are falling short.

The organisation of care

The way care is financed and organised differs from person to person and is mostly seen as difficult:

"*In the Netherlands much is possible in healthcare, but before you receive it everyone will have grey hair.*" (int. 6)

For instance, getting **support equipment**, like a new wheelchair, can be challenging. The company Medipoint arranges mobility and care equipment and maintenance. They are perceived as helpful by some, but waiting times can be long and some aspects are not organised well.

Interviewee 6 had received a **case manager** for her husband with dementia. The case manager gave advice and assisted her with arranging care, which was extremely helpful. For her son with MS, however, getting a case manager was not possible, since they are only available for older individuals, youth living alone, or people in an institution.

The **personalised budget** (pgb) is generally perceived as helpful, because you can arrange your own care professionals and therefore find someone that fits your needs. However, there is a chance that your application for a pgb is unfairly rejected. Accessibility is therefore not great. Furthermore, many things are complex and difficult to arrange with a pgb, because you have to do everything yourself.

3.3.2 Care between and within generations: different needs and challenges

Education

In the Netherlands special schooling is available for children that need intensive educational support (§3.2.1). However, **waiting lists and travel times to these school can be long**. Marcel Kolder (expert int. 9), activist and caregiver to his 23-year-old daughter, had to take the initiative to arrange special education in his city, because the government did not want to create a new school for children with disabilities in that area. Every morning a van with 180 handicapped children had to spend two hours in traffic to reach their school and two hours again on the way home; valuable time that was well needed for medical appointments and revalidation. Yet only after intense lobbying was the situation finally improved.

Transition to adulthood

The transition for young adults to 18 years is for many a significant problem. At this age *mantelzorgers* and care recipients need to switch to different regulations, care professionals, and hospital wards, and parents lose the legal authority over their child. Arrangements need to be made for school, work, daytime care, and housing, but for adults there is much less support available than for minors. These **complicated regulations** are restricting and make it more difficult for people to find the right help during a time that is already challenging for young care receivers.

Housing

Astrid van der Kooij (expert int. 10), *mantelzorger* to her 21-year-old daughter and researcher in the social domain, indicates that it is necessary for people to start arranging housing at an early stage, when the care-receiver is about 14 years old. This is due to **long waiting lists for adapted housing** in the Netherlands. Yet municipalities often do not want to invest in specialised housing in their city. Both Astrid and Marcel have to take own initiatives for future living arrangements for disabled youth. This leads to worries about the future and diverging opportunities between municipalities and individuals.

Dependance and the nature of relationships

Thomas Sanders (interviewee 5) describes in his interview that it was difficult for him to ask for help. After he was diagnosed with MS he wanted to keep control over his life and felt the drive to develop initiatives to fight the disease. As a result he founded MoveS, a foundation that organises events for people with MS, and he wrote a book about his experiences. In his book he describes how he went from surprise to denial, and then to anger and frustration. It took several years for him to accept that he needed a wheelchair (Sanders, 2021). Since MS is a degenerative disease, his growing dependence is still something he struggles with. Thomas's story is a good example of the Dutch mentality when it comes to asking and receiving care from family, friends or neighbours. The same issue is voiced by several other interviewees, who indicate that they want to keep as much control over their lives as possible. Also a study on care-dependent people in the Netherlands has shown that **Dutch individuals highly value their independence**

(Bredewold et al., 2019). They feel embarrassed to ask for help from their loved ones, because they want to protect the nature of their relationship and are afraid to overburden them. These norms are partly the result of the rise of the welfare state in the 1960s; when care moved from the family to care professionals, so did the meaning of autonomy and independence. At the end of the 20th century relying on the government for care was normalised. In order to shift (some of) this care back to someone's private network, people need time to adapt to this new idea of autonomy. Furthermore, the authors pose that informal care in Western countries is related to Mauss's theory of gift exchange, where relationships with less emotional connection, like friends or neighbours, are in greater extend based on reciprocity. So when a favour, like intensive informal care, cannot be reciprocated this leads to a sense of imbalance in the relationship and feelings of shame. This notion is further reflected by interviewee 2, who also suffers from MS. She indicated that one of the main challenges lies in making sure informal care does not negatively change the nature of your relationship. It is therefore necessary that social policy makers consider these cultural norms to avoid overburdening family relationships and guarantee the succesful implementation of informal care policies (Bredewold *et al.* 2019). At the same time, independence should be stimulated and facilitated.

3.3.3 The individual costs of care: limitations of the Dutch system

Non-suitable care

Current care and support offers are mostly regarded as insufficient. One of the main problems is the **lack of personalised care** in the Dutch healthcare system. Treatments are often too generalised, information is withheld, and consultations are inadequate. The lack of patient-focussed care is highlighted by the case of Titus Radstake (expert int. 11), strategic advisor 'patient perspective' at Erasmus MC and social entrepreneur. Titus suffered a burn-out due to his demanding job and ended up in a depression. This was treated by the GP with anti-depressants, which had severe side-effects. Titus became suicidal and set himself on fire, leading to severe 3rd degree burns and lifelong care needs. If care professionals would have listened to him and had responded better to his needs, the situation could have been avoided.

Also Astrid (ex. int. 10) experienced this generalising and insensitive treatment. She has a daughter with life-long care needs and often felt not heard by care professionals, who kept claiming nothing was wrong. It took doctors months to diagnose her daughter's febrile convulsions as epilepsy and only at age 3 was she officially considered intellectually disabled, despite numerous attempts to discuss her delayed development. Also other interviewees describe their experience with the healthcare system as non-communicative, slow or cold. One of the care receivers (int. 4) explained that after-care is very poorly organised in the Netherlands. After one-and-a-half years he found out he should have had a control appointment with a neurologist, but he was not notified. The initiative should have been with his GP, but he knew nothing about it. Information between care professionals and towards patients is clearly lacking.

Many interviewees stress that Dutch care support is **very focussed on medical aspects** and does not incorporate enough assistance for aspects in everyday life, such as social participation, work, and activities, even though these are the elements that matter most in a person's life. One of the interviewees indicated that it is difficult to get a professional caregiver to come to your university or your work location, instead of to your home. Personal circumstances are often not taken into account. Also different cultural perspectives are not considered, which does not fit our current society.

In addition, the Dutch healthcare system is very **overcrowded**. This leads to long waiting lists for professional care and surgeries. Marcel (ex. int. 9), for instance, explained that he went to Belgium for his daughter's scoliosis surgery. This surgery needs to be done when a child reaches puberty, because this rapid growth spurt increases tension on the skeletal system. If the surgery is not done in time, it will lead to worsened physical problems. The waiting list in the Netherlands, however, was two years, while in Belgium Marcel's daughter could be helped within a few weeks. The Dutch situation could be improved with better policies and regulations; one of the surgeons Marcel talked to indicated that she could have operated all children on the waitlist if the hospital had bought in more surgeries. This story further indicates the non-patient centred focus of the Dutch healthcare system.

Also interviewee 4 felt the need to receive support from a foreign country. Due to a stroke, he no longer had full functionality of his right leg and arm. The revalidation centre had given him a splint and told him this was the best they could offer. After three years he found a better alternative in Germany; an adapted bandage that gives off electric pulses. In Germany this kind of support is covered by basic health insurance, but he had to finance it by himself.

The bureaucratic maze

The Dutch rules and regulations regarding care and means for disabled people are perceived as **incredibly complicated and convoluted**. To receive the appropriate support informal carers and individuals with care needs are required to navigate a complex bureaucratic labyrinth that takes up an incredible amount of their time and increases mental load. During the desk research has already been established that a large number of informal caregivers feel severely overwhelmed (see §3.1.1). From the interviews can be concluded that a considerable element in this is the way the Dutch system is organised. One of the care receivers (int. 2) describes the current system as a 'discouragement policy'. It was made extremely difficult for her to arrange household support in her municipality to the point that she sat crying in their office, because it was unclear what she was entitled to and what not. A good example of the complexity is the 'care and support landscape' that was made by an informal carer (see Annex I). The landscape includes all the different possibilities that people in need of care need to face when organising their care and support. Most of the involved institutions function independently from each other, meaning that everything has to be applied for separately and there is no oversight of what systems the recipients are involved in. Marcel describes

that they have to re-apply for benefits every single year, filing the exact same information on the condition of their child, which is permanent. The same argument was made by interviewee 1 with care needs from birth:

"*When you are known to people you would think that it should make things easier, but that was not the case. It takes so much time; you have to be on the phone continuously and you're being send from pillar to post.*"

This problem is not unknown and has been described in a monitor report by the Netherlands Institute for Human Rights. The report states that **the Dutch government does not adhere to the UN Convention on the Rights of Persons with Disabilities regarding access to support means**. Personal mobility (e.g. through wheelchairs, assistance dogs, and technologic devices such as hearing aids) is a basic right, but the current procedures are too complicated. Furthermore, there is a lack of customisation options, equipment cannot be transferred to other municipalities, and impaired individuals often suffer from financial problems. The Institute for Human Rights therefore recommends that disabled individuals should not have to continuously prove their own impairments and that there should be a central point where people can go to apply for support (College voor de Rechten van de Mens, 2021).

Financial shortcomings and employment

Financial shortcomings have been a recurring theme in the interviews. This is due to a combination of strict rules for applications, insufficient income support, and the inability to work fulltime or to find work at all. For informal carers it's often difficult to combine their career with providing care. Career development is for many not possible, leaving them stuck with **lower salaries**. Women that take care of a disabled child often choose to stop working completely to focus on the care, leading to a lower income for the family.

Self-employed individuals with no disability insurance cannot apply for benefits, which puts them in a tough financial position. These people are dependent on aid from foundations. Although foundations are described as very helpful, they should not have to replace care support from the government. There are plans to make disability insurance mandatory for self-employed individuals from 2027, but this insurance is very expensive and many are not able to afford it (NOS, 2023).

For individuals with an occupational disability **unemployment** is a significant problem. This has become apparent from the statistical data (see §3.2.1) and was stressed by Titus (ex. int. 11), who with helps people with disabilities to stay active in our society with his company *Van zorg naar inclusie*. Job opportunities and arrangements for occupationally disabled individuals are inadequate, especially for the ones that are not supported by the job deal. In addition, the **income support is insufficient**. Individuals that cannot make a full salary only receive up to 75% of their previous income, straining their financial means while also needing to spend more on medical care, support equipment, or home modifications, which often require an own-risk payment or are not subsidised at all.

Individuals that despite an occupational disability can still make up to 65% of their previous salaries do not receive income support at all.

Needs such as **home modifications are very costly**, but it is for the municipality to decide which adaptations are financed. Marcel (ex. int. 9) describes how his municipality did not want to subsidise a chair lift in his home, because their ground floor already covered the minimum accessibility standards. For Marcel it was understandably important that his daughter could reach all areas of the house, leaving him to finance the expensive chair lifts by himself. Many other families would not be able to afford such adaptations, creating inequalities based on income.

Inequality

Healthcare in the Netherlands is under pressure due to cutbacks and a lack of healthcare personnel. As a result, **the quality is deteriorating and the inequality between families with different incomes and educational backgrounds is increasing**. In practice, Astrid sees that many highly educated people with young adult children in need of care create their own housing facilities, because of a high demand and a lack of supply. For instance Marcel is arranging the construction of special informal care housing in his city (see housing). However, this is not an option for everyone, which further hinders the equality of opportunity between disabled individuals of different backgrounds. This notion is stressed by two of our expert interviewees (9 and 10).

Furthermore, people from a different cultural background have more difficulty arranging care and means, due to communication problems or discrimination.

3.3.4 Social participation

Loneliness

Astrid van der Kooij has done research on loneliness among disabled children and adults and underlined that loneliness forms a significant problem, especially **severe chronic loneliness**, which starts from a young age. This is not only caused by a lack of social contacts, friends, and/or a partner, but also due to a missing sense of purpose; "*Not mattering, not belonging.*" The extend to which loneliness can impact someone's health and happiness is significant. Regardless, knowledge on this topic is currently not utilised by institutes, and inclusion and participation are not stimulated sufficiently in our society, making it often impossible for disabled people to genuinely participate. Marcel confirms this problem. He indicates that his daughter, although socially active in many different ways, lacks meaningful friendships and is lonely as a result.

Inclusion and discrimination

Many interviewees feel that **the inclusion of disabled individuals in our society is not sufficient**. This is tied to the fact that support measures are mostly focussed on medical care and not on everyday life. Even though, in theory, education, housing, work, public places, and transport are available to all, in practice this is not the case, due to difficult

regulations, long waiting lists, poorly executed accessibility, discrimination, or financial constraints.

3.3.5 Obstructions for informal caregivers

The situation for informal caregivers is mostly described as **demanding and heavy**. Often the needs of the care recipient have priority, leaving little space for the needs of the *mantelzorger* or recognition of their important role. One of the care receivers indicated that, due to the increased responsibilities, there is a high chance the informal caregiver will get overwhelmed. Astrid (ex. int. 10) describes her role as informal caregiver as being "stuck" between giving care to your care-dependent child and guarding your own health; even though *mantelzorgers* know it is important to take good care of themselves to not burn out, this does not seem feasible with the current regulations. From the statistical analysis became clear that a large percentage of caregivers feel **extremely overwhelmed** (see §3.1.2). To counter the physical, mental, and financial pressure on our *mantelzorgers* support measures are needed, like respite care, work arrangements, and subsidies, but figures have shown that many informal carers do not know what is available to them or has trouble applying for it (see also §3.1.2).

3.3.6 Possible Solutions

According to Astrid (ex. int. 10), the Netherlands should be more open to inspiration and good practice examples. In Scandinavia, for instance, care is organised in a much better and accessible way. There is evidence that **regulations can be simpler and more effective**, but expertise in this area is lacking in the Netherlands. From the interviews it became apparent that the focus should be on self-suffiency and helping people to do things by themselves. It should therefore be both possible and affordable to **personalise means and support**, so that disabled individuals can participate in society and keep their independence as much as possible. According to Titus (ex. int. 11), **participation** is key for a succesfull reintegration. This includes being able to work, join in activities, and have a social life. Adapting support measures to better include these aspects will grealty improve quality of life and benefit both care receivers and society as a whole.

To tackle loneliness and decrease ableism, more inclusion is needed. There is a desire for **meeting places** for people with and without disabilities. Impaired individuals must be able to participate in sports and activities, so they can have a healthy lifestyle and a valuable social life. Parents of children with disabilities should be made more aware of the consequences of loneliness; making friends should move up the list as it is also important for learning social skills.

For informal caregivers it would be beneficial if there was more **contact between peers**. In practice, caregivers and/or care receivers often don't encounter each other, even though they could benefit from exchanging knowledge and experiences. Actively seeking each other out could achieve this, but the option should be better available. Astrid

emphasises the importance of forming a union, so that informal carers can make themselves heard. It would also help if there was a place to explain to others what it is like for people to be a caregiver. This could create more understanding in our society.

Two interviewees (3 and 6) indicated that both caregivers and care receivers need to learn to **ask for help**, to make choices, and to be able to say 'no'. At the same time, it should be possible to receive support, like respite care, when needed. This is still insufficiently available. A better system is needed that relieves the pressure on informal caregivers. Currently, support measures are arranged by municipalities, who have different policies and subsidies available. Since work or school may be in a different city, it is difficult to arrange professional care for all aspects of someone's life. Nationwide regulations would be preferable.

Lastly, good **communication** between caregiver and care receiver is incredibly important. Partners might need to relearn how to deal with each other, what the other person's needs are, and which everyday aspects they still can and want to do themselves. One interviewed caregiver (int. 6), for instance, explained that when someone is in a wheelchair it is important to tell them what you are going to do. If you need to enter the sidewalk backwards, telling the other you will turn around to do so, will give them a greater sense of control. Communication trainings might help with these matters.

3.4 Good practice examples

Foundation Calibris Advies. Calibris Advies is a social enterprise that connects the care and welfare sector with people that have trouble finding or keeping a job, such as individuals with an occupational disability, status holders, lateral entrants, and people living on benefits. Calibris organises on-the-job trainings and trajectories in adult education and helps care organisations with getting and retaining personnel and with the training and guidance of students. https://calibrisadvies.nl/

Foundation Klimmen tegen MS (MoveS) (Climbing against MS). MoveS organises walking and biking campaigns to collect money for research on Multiple Sclerosis. By combining sports with a good cause they hope to inspire people to move against MS. Their ultimate goal is to create a MS-free world. https://www.moves.ms/

Foundation MEE NL. MEE NL is a cooperative union of 20 MEE-organisations spread across the Netherlands. MEE NL provides knowledge and advice to municipalities and healthcare offices, and offers trainings to professionals and organisations in the area of treating and communicating with disabled individuals. Their vision is to create an inclusive society, where participation and quality of life are central. https://www.mee.nl/

Foundation Studeren en Werken op Maat (SWOM) (Customised Studying and Working). SWOM guides young professionals with an occupational disability in finding a fitting and fulfilling job. They provide tools and training, and offer the help of a life-coach who assists

with work, housing, and financial topics. They also help employers in arranging an inclusive workplace and offer advice on flexible scheduling, accessibility, training periods and leadership styles. https://studerenenwerkenopmaat.org/

Gehandicaptensport Nederland (Parasport Netherlands). An organisation that develops various projects and programmes for the development of parasport, such as giving educational trainings, setting up exercise offers for people with a sensory disability, and coordinating collaborations between healthcare, education, and sport.
https://www.gehandicaptensport.nl/

HandicapNL. An organisation that, with the use of donations, enables various projects and initiatives for handicapped individuals that are essential for their quality of life, but are not financed or arranged by the government or covered by healthcare insurance. Examples of projects are: help with revalidation at home, arranging buddies for disabled children and teens, and improving the inclusivity of festivals. www.handicap.nl

The HandicapNL website includes a section for news and blogs, among which with the story of Naomi, who explains the negative impact of the Dutch bureaucratic system: https://handicap.nl/blog/regelzucht/#

Kennisplein Gehandicaptensector (knowledge centre handicapped sector). Kennisplein Gehandicaptensector offers knowledge and experiences from care professionals, clients, and relatives through programmes, projects, meetings, social media, and their website. Their goal is to make information more accessible for everyone, in order to improve the quality of life and care in the handicapped sector.
https://www.kennispleingehandicaptensector.nl/

Regelhulp (arrangement help). Regelhulp is a government website that provides a guide for navigating help and support measures. They offer information and helpful links on various topics like education, housing, transport, work, and more.
https://www.regelhulp.nl/

On the same website you can find an explanation of the differences between the Wmo, Wlz, and District nursing care:
https://www.regelhulp.nl/onderwerpen/ondersteuning/wetten/verschillen

Schouder (shoulders). *Schouders* is a knowledge centre made by and for parents of disabled children. On their platform they share the knowledge and experience of parents and professionals about for instance available support measures, combining care with work, and finding time for your family and yourself. https://schouders.nl

Uitkomstgerichte zorg (outcome-oriented care). This program is a collaboration between the government and various branch organisations, aiming to improve the situation for patients and healthcare workers by not only looking at medical aspects, but also at the quality of life during and after treatment. By mapping out the outcomes of treatments

and properly discussing all decisions with the patient, care and support can be made more fitting and appropriate. https://www.uitkomstgerichtezorg.nl/

Van zorg naar inclusie (from care to inclusion). A social enterprise that helps people with a disability to remain active in society. Through collaborative projects, they are committed to ensure a positive transition of the healthcare sector and the labour market, and thereby contribute to the Sustainable Development Goals in the field of health and well-being, fair work and economic growth, and reducing inequality. https://vanzorgnaarinclusie.nl/

Visio. Visio is a Royal expert centre for blind and visually impaired individuals. They do research and offer information, advice, guidance, revalidation, education, and living arrangements. Visio is result-oriented and aims to provide personalised and fitting support, that incorporates someone's personal choices and quality of life. https://www.visio.org/

3.5 Portrait

Personal situation

Marcel Kolder describes himself as a changemaker and a *kanteldenker* (tipping thinker), the latter being a combination of his goal to change people's perspective regarding disabled care and his nightly repositioning task as an informal carer. Together with his wife he takes care of their 23-year-old daughter Mayim, who suffers from cortical dysplasia; a neurological disorder that leads to a range of conditions, such as a physical and intellectual disability, scoliosis, spasticity and epilepsy, or as Marcel likes to put it:

"The TomTom did not function during the creation of her cortex."

In addition, Mayim also has a heart condition called restrictive cardiomyopathy (stiff heart syndrome) and an auto-immune disorder, which were discovered at a later age. The care needs for Mayim are therefore extensive, and Marcel describes his life as an informal caregiver as extremely heavy. This intensified during the covid-pandemic, while his wife was recovering from cancer, and many of Mayim's regular daytime activities were no longer possible. Also Marcel's 26-year-old son has been affected by the challenging position of his sister. He visits home often, helps with Mayim's care needs, and chose to study applied psychology and sociology.

Mayim herself is a very cheerful and amiable person, who wants to take the best out of life. She has a job at a zoo, plays hockey, and paints art. Her biggest inspiration is Stephen Hawking, who, like Mayim and her family, focussed on his ability to create and the things that he could do, rather than the difficulties in life.

Professional background

Marcel is the owner of a communication bureau, focussed on change and innovation. After the government made plans to cut the personalised budget (pgb) in 2012, he also

became an outspoken activist for disabled care in the Netherlands. This is much needed, since care and support in the Netherlands is lacking on many fronts;

"You constantly have to stand up for your child, because she cannot do it herself."

Through the years Marcel has become an 'experience professional' and together with his daughter he has written an autobiography of Mayim's life to describe her perspective on the world and the difficulties she runs into (*MAYIM*, Kolder & Kolder 2021). As an expert on the topic, Marcel is invited to speak at conventions to stimulate change in the current situation. He is also a 'Parent Educator'; an initiative of the Free University of Amsterdam, where pedagogy and medical students meet with parents of disabled children to give them a better insight into their needs.

Restrictions

Marcel indicates that the Dutch system has no clear overview of what the situation is for people that receive intensive care at home. Support from professional carers and respite care are well needed, but very hard to come by. Mayim cannot turn herself around in bed, so she needs help with this about ten times per night to avoid bedsores. This takes an incredible toll on the lives of Marcel's family, but professional night care is costly and their personal budget is insufficient to arrange this for more than two nights per week. This lack of proper financing is also a large restriction in other areas. Marcel's family had to spend most of their savings on care and support for Mayim, and currently don't have money to go on holidays. For many others the situation is much worse. They might therefore be forced to put their child in an institution, which is a less than optimal solution. Marcel has no confidence in institutions, and also Mayim herself indicates to not want to live there, because of the secluded and restricted nature.

As an informal carer, Marcel explains it is hard to find time for yourself, to have a social life, and to build a career. He often sees burn-outs and divorces due to the pressure of informal care responsibilities, the psychological burden of which is extensive. This could be alleviated through proper professional support and adequate financing, but arranging help through the Dutch system can be incredibly complicated. Regulations around subsidies are often very strict, leaving no room for personalised needs. For Mayim, an electric wheelchair could be subsidised (which was not wanted), but a chair lift could not (which was actually needed).

"*What happens after I'm gone?"*

With the current state of the Dutch support system, Marcel and his family worry sometimes about the future. He took the initiative to start arranging the construction of informal care housing for Mayim, because the municipality refused to do so. Marcel stresses that there are many children, whose parents are less educated, well-spoken, and assertive. With his book and his actions, he hopes to raise awareness and help others in the same position.

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Annex 1 The Dutch care and support landscape

