Sociaal en Cultureel Planbureau

An international comparison of care for people with intellectual disabilities

An exploration

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Preface

Demand for care and support by people with an intellectual disability has been growing for many years. The SCP report 'Cost considerations. Unravelling the growth in the costs of intellectual disability care' (*Lasten onder de loep*) (2013) showed that this demand increased particularly sharply between 2007 and 2011, especially among people with a mild or borderline intellectual disability (IQ between 50 and 85). More recent figures also show an increase in demand for the most intensive forms of care by people with intellectual disabilities. No national figures have been published in the Netherlands since 2015 on the number of people with intellectual disabilities who receive ambulant care and support.

The SCP report 'A better understanding of care' (*Zorg beter begrepen*) (2014) showed that factors such as the increasing complexity of society have played an important role in the increased demand for care. It is important to close the gaps in knowledge in this field.

The societal developments which have driven up demand for care for people with intellectual disabilities do not appear to be unique to the Netherlands. The central question addressed in this report is therefore whether other countries have also seen a sharp increase in demand for care for people with intellectual disabilities (ID care), and if so, whether this can be related to societal developments.

The provision of care and support in the Netherlands has been partially decentralised and privatised since the introduction of the Social Support Act 2015 (Wmo 2015), and the implementation of the Participation Act (Participatiewet) is intended to promote a more inclusive society. Therefore, for this study regions were selected which differ from the Netherlands in the degree of decentralisation (Flanders) privatisation (England) and inclusion (Ontario). To be able to answer the research question, SCP drew on statistics, scientific literature and policy documents, supplemented by the insights of experts in the various countries/regions who are active in the field of care for people with intellectual disabilities.

The study shows that people in Flanders, England and Ontario with an IQ between 70 and 85 either have no access to publicly funded ID care or find it less easy to access such care than in the Netherlands. However, the limited access for this group has not reduced the demand for care and support by people with intellectual disabilities in these regions.

The interviewed experts in the countries/regions studied believe that, as in the Netherlands, the growth in demand for ID care is due among other things to digitalisation, the fact that there are fewer suitable jobs for this group and that education for this group too often fails to lead to work. In this report we describe how these insights contribute to the knowledge agenda for an inclusive society.

This report could not have been written without help from others. SCP is particularly grateful to the experts who were willing to share their insights. The reading committee also made valuable comments on the draft texts. In particular, I should like to thank the external members for their critical and constructive contribution: Han Huizinga from the Dutch Association for the Care of People with Disabilities (VGN), Professor Monique Kremers (WRR/UvA) and Professor Xavier Moonen (Koraalgroep, UvA, Zuyd University of Applied Sciences).

Professor Kim Putters
Director, SCP

Management summary

Motivation

People with intellectual disabilities (ID) by definition have a cognitive disability and a disability in adaptive functioning, both having started before adulthood. They are often unable to independently run a household, manage their finances, take part in the employment process or participate in leisure activities; they need help with these activities. Demand for care and support for people with intellectual disabilities (ID care) has been growing rapidly in the Netherlands in recent decades, especially among people with mild intellectual disabilities (IQ of 50-69) and borderline intellectual disabilities (IQ of 70-85 and problems with adaptive functioning; admitted to ID care in the Netherlands) (Ras et al. 2013). This growth is striking given the absence of any broad demographic or other evident growth-generating process. Instead, an increasingly complex society is posited to be the main cause of the growth and this growth has been facilitated by the care system, (Woittiez et al. 2014a). In this report we investigate how the demand for care and support for people with mild and borderline intellectual disabilities has developed in other countries and what explanations can be given for these developments. This exploratory study seeks to add to the debate on policy aimed at people with ID and on how appropriate care can best be organised for this group. Given its exploratory nature, this study provides relevant insights but makes no determination as to the relative importance of one explanation over another; nor does it claim to be exhaustive in scope.

We selected Flanders, England and Ontario for the comparison with the Dutch situation because they differ from the Netherlands with respect to the degree of decentralisation of care (Flanders), the privatisation of care and support (England) and the intended degree of inclusiveness of society (Ontario). This study is based on the (scientific) literature and policy documents, as well as interviews with a number of experts in the field in the three regions and the Netherlands. Gathering the appropriate information proved to be difficult because statistical data on this subject are scarce. Nevertheless, we provide as complete a picture as possible, based on the available statistical data, and assessments by a variety of experts among which leading authorities on quantitative information in each region on the other. In addition to providing answers to the research questions, the interviews yield supplementary material that we did not intend to collect, but which provides valuable clues for considering the way in which care and support is organised in the Netherlands. We present our findings on the development of demand and its causes and considerations briefly below. For a more extensive summary see Summary and Conclusion; for more detailed information on a specific region, see the corresponding chapter.

Growth in demand for care and support

In each of the regions studied, we found indications that the demand for care and support by people with intellectual disabilities had grown. In the Netherlands, demand for care and support grew by 6% per annum between 2007 and 2011, and more recent figures show an annual growth rate of 7% for the most intensive forms of residential care between 2012 and 2016. The growth in demand in Flanders is also relatively well documented (around 6% annually between 2009 and 2015). In Ontario, demand has also grown, but the information is fragmented (the growth in demand for residential care was 8% per year between 2009 and 2015). In England, the **demand** for care and support is unknown; the **use** of care and support has grown slightly (community social services shows annual growth of 1.6% and residential care a year-on-year decrease of 0.9% between 2005/2006 and 2013/2014). Although interviewees in England expressed the view that the need for care and support has grown substantially, austerity measures meant that the use of care did not show concomitant growth.

The interviewees suggested several explanations for the growth in demand for care and support. Some explanations are similar, such as the complexity of society, while others differ between regions. Most experts suggest the disappearance of low-skilled jobs and digitalisation posing difficulties for people with ID as possible explanations, although at the same time digitalisation is also mentioned as a possible solution. More and earlier diagnoses are also pushing up demand in most regions, according to the experts. Some interviewed experts in England feel that the education system increases the need for care and support due to the poor match with the world of work and the high (theoretical) standards demanded by schools; an observation we also found to be applicable for the Netherlands. By contrast, the experts in Flanders and Ontario believe that the education system may curtail the growth in demand for care and support thanks to vocational training and inclusive education. According to the interviewees from the Netherlands and Flanders, the availability of supply, the financial incentives it produces and the substitution of informal care by formal care all play a role, but these factors were not mentioned by the interviewees from England and Ontario. In Ontario, the inclusiveness of society was suggested by the interviewees as the most important cause of the increasing demand. Interviewees in the Netherlands were the only ones to suggest the growth in demand by people with borderline intellectual disabilities as an important reason for the increase. In the other regions studied, this group are generally excluded from ID care as such, though may receive care through 'non-ID' care and support systems, for example if problems in the autistic spectrum are also present.

Considerations regarding care and support for people with ID in the Netherlands

The supplementary material in the interviews led to reflections on the care and support for people with intellectual disabilities in the Netherlands, and possibly in other countries as well. The discussions that appear to be central in the debates in the other regions lead to six themes that are relevant for the Dutch situation.

Deinstitutionalisation is an important issue in the Netherlands, especially following recent policy changes (Wmo 2015 and WLZ) aimed at ensuring that care and support are provided in the recipient's home as far as possible. According to the Ontarian interviewees, *deinstitutionalisation* carries risks: for instance loss of specialist experience with care and support for people with an intellectual disability, problems with crisis situations and possibly placement of people with ID in unsuitable housing settings, such as hospitals.

One of the fundamental ideas behind the recent Dutch policy reforms (Dutch Participation Act and Wmo2015) is the drive for a more inclusive society. According to the Ontarian interviewees, enabling people with intellectual disabilities to *participate fully in society requires* more support in home care, mental health services and employment services, as well as a culture of acceptance within society.

In each of the regions studied, including the Netherlands, the use of 'personal budgets' is increasing. Interviewees in all four regions cite some *risks of personal budgets* for people with ID or their networks. A personal budget makes persons with ID and their networks responsible for gauging their need for external support. Making this judgement may be beyond their competence. It may also be tempting for persons with ID to use the personal budget for things other than care and support (for example a new TV or smartphone).

Since 2015, youth ID services in the Netherlands have been separated from adult services to a greater extent than previously, while the other regions studied already have long experience with this distinction. According to the Ontarian and English interviewees, this distinction creates problems in *the transition from youth to adult care and support*. These interviewees also highlighted the risk that young people with ID could end up without any support at all, bringing the risk of all manner of problems, potentially pushing them into other sectors, such as health or psychiatric care or the criminal justice system.

As in other countries, *the financial tenability of the care system* in the Netherlands is under discussion. The transition towards the provision of care and support under the Social Support Act 2015 (Wmo2015) has been accompanied by budget cuts. Curtailed budgets for care and support could lead to undesirable situations for people with ID, such as waiting lists and unmet needs, as is evident in the three foreign regions included in our study. According to the interviewees, curbing budgets imposes constraints on the use of health and social care services but does not solve the problems experienced by people with ID. In the three foreign regions studied, people are increasingly having to rely on informal help. However, people with borderline or mild intellectual disabilities often have a 'weak' network which makes it hard for them to secure appropriate support.

Limiting budgets often implies that people with relatively low care needs – among them people with borderline ID – do not receive care and support. But people with borderline ID are often vulnerable; they have difficulty understanding certain situations, and are relatively often poor, unemployed or homeless. Furthermore, they may have problems with alcohol or drug abuse and with their behaviour and/or mental health. There are indications (albeit no firm evidence as yet) that providing them with guidance early in life, when their problems are still relatively minor and new behaviour can be learned relatively easily, may help prevent significant problems later on. However, the large number of people with borderline ID means that additional budgets are needed. In order to make a sound assessment of whether preventive guidance is a sensible way of spending public resources, it is necessary to know how and to what extent adequate preventive care and support can prevent significant problems from arising later, such as unemployment, drug or alcohol abuse or criminal behaviour.

Summary and conclusion

Netherlands not unique in growing demand for care and support

S.1 Motivation for this study

People with intellectual disabilities (ID) are often unable to independently run a household, manage their finances, take part in the employment process or participate in leisure activities. They need help with these activities, because having an intellectual disability implies a cognitive disability and a disability in adaptive functioning, beginning before adulthood. Demand for care and support for people with intellectual disabilities (ID care) has been growing rapidly in the Netherlands in recent decades, by approximately 6% annually. This increase has been especially notable among people with mild intellectual disabilities (IQ 50 - 69) and borderline intellectual disabilities (IQ between 70 and 85 *and* problems in adaptive functioning, which are included in ID care in the Netherlands) (Ras et al. 2013). This growth is remarkable. Unlike in sectors such as elderly care, for example, there is no broad demographic or other evident growth-generating process present. An increasingly complex society, facilitated by the care system, has been suggested as the main cause of this growth in demand for care and support (Woittiez et al. 2014a). In this report we address the following questions:

1. *How has demand for care and support for people with mild and borderline intellectual disabilities developed in other countries?*
2. *What explanations can be given for these developments?*

We focus in this report on demand for care and support, defined as the number of people who are eligible for publicly financed care and support within their regional system. The most relevant pieces of legislation in the Netherlands in this regard are the Long-term Care Act (Wet langdurige zorg - Wlz), which assigns responsibility for care provision to central government, and the Social Support Act (Wmo; Wet maatschappelijke ondersteuning), under which local authorities carry responsibility. The Wlz covers the most intensive forms of care and support, generally provided in a residential (institutional) setting. The Wmo covers less intensive care and support, provided in the recipient's home setting. The costs of providing ID care account for a quarter of total spending on publicly financed care in the Netherlands (CBS 2014).
Particular attention is devoted in this exploratory study to persons with mild (IQ of 50-69) and borderline intellectual disabilities (IQ 70-85 *and* problems in adaptive functioning) since the growth in demand for care and support in the Netherlands has manifested itself most strongly in these groups. In addition to the situation in the Netherlands, we investigated the situation in the regions[1] Flanders, England and Ontario. This study is based on the (scientific) literature and policy documents on supporting persons with intellectual

disabilities, as well as interviews with experts in the field in the four regions studied.
As well as providing answers to the research questions, the interviews yielded supplementary material that we were not intending to collect, but which provide useful insights in the ongoing discussions in the regions and the dilemmas involved in the care for people with ID. This provides valuable clues for considering the way care and support are organised in the Netherlands, and these are also presented in this report.
This study aims to add to the debate about policy aimed at people with ID and how appropriate care can best be organised for this group. Comparing the Dutch situation[2] with the situation in other regions provides insights from outside our own Dutch framework, and sheds light on the different beliefs and values in relation to caring for people with ID in different countries. As far as we are aware, such a comparison has not been made before.

S.2 Selection of regions and method

S.2.1 Selection of regions

This study aims to offer insights into the development in demand for care and support in various regions. For the comparison we select regions that differ from the Netherlands with regard to the degree of decentralisation and privatisation of care and support and the inclusiveness of society. We do this because the Netherlands has recently partly decentralised the provision of care and support through the implementation of the Social Support Act (Wmo2015), and is aiming to create a more inclusive society through the introduction of the Participation Act and the Wmo2015. In *England* (UK), local authorities are responsible for arranging social care services for people with intellectual disabilities, in the same way that support is provided under the Wmo2015 in the Netherlands. The provision of services in England is mainly in the hands of the private and voluntary sector. Care and support services in England are dominated by the marketisation model. This differs from the situation in the Netherlands for personal care, for example, though the Netherlands is moving towards private provision of household help. *Flanders* (Belgium) is similar to the Netherlands in some respects but differs in others. As in the Netherlands, the focus in Flanders is shifting from residential care to care provided in the recipient's home or in the community, i.e.it is deinstitutionalisating. However, the funding of and access to care is still centralised in Flanders, which is different from the Netherlands. Deinstitutionalisation is much further advanced in *Ontario (Canada)* than in the Netherlands and most other

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[1] Since there were significant differences within countries, we investigated parts of countries, which we refer to as 'regions'. More information on these regions and why they were chosen may be found in Section 0.2.

[2] No recent data are available on the numbers of people with an intellectual disability seeking or receiving care and support. Since the introduction of the Long Term Care Act (Wlz) and the Social Support Act (Wmo) in the Netherlands in 2015, only demand for intensive care and support (provided under the Wlz) by people with an intellectual disability is registered at national level. Demand for community care provided under the Wmo is not registered nationally. The expert views used for the Netherlands also date from before 2015.

countries. There are virtually no (large) residential institutions for people with intellectual disabilities remaining in Ontario today. Inclusion is the guiding principle in the organisation of care and support, and people with intellectual disabilities receive support from their families, friends and community-based agencies. Ontario claims itself to be an inclusive society.

S.2.2 Method

We focus on demand because it can be seen as a proxy for the need for care and support. We define demand for care and support as the number of people who are eligible for publicly financed care and support within their regional system. This means that the target group in each region may differ. Eligibility decisions are based on needs assessments.
A needs assessment of a person's care needs may lead to either a positive or negative assessment. In the event of a negative assessment, the care need does not lead to demand for publicly financed care and support and the care need is either met by informal carers or remains unmet. A positive assessment leads to demand for publicly financed care and support. Demand can be met by the provision of publicly funded care and support ('use of care'). If there is not enough supply to provide help to all those with a demand for care and support, this will result in unmet needs and/or waiting lists.
Some regions use the term 'care', while others refer to 'support'. Throughout this report we use the term 'care and support', to include all kinds of services to support people with intellectual disabilities.[3] Figures on the development of demand for care and support (research question 1) are drawn from national statistics in the selected regions.If information on the **demand** for care is unavailable we look at data on **use** of care and support and **waiting lists**, since together these give an indication of demand. Use of care and support is affected to a greater extent than demand by the system and budgets within a region.[4] Budgets for ID care and support were also explored in this study.

To determine the causes of the observed developments (research question 2), national and international literature and policy documents were analysed. The description of the care system in each region is indicative and is limited to highlighting the legislation and regulations that are most relevant for people with intellectual disabilities. We supplement the information gathered from the literature and policy documents with information from interviews conducted with a number experts in the field in the different regions studied. Some of these experts are engaged in research on this topic, or publish advisory reports. Others are involved in shaping care policy or in care allocation, providing care or protecting the interests of care recipients. We interviewed six experts for England, twelve for Flanders

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[3] The term 'developmental disabilities' is used in Ontario and adopted in Chapter 5; this is somewhat broader than intellectual disabilities. In England, the term 'learning disabilities' is used. In this chapter we use the term 'intellectual disabilities' forall regions.

[4] Demand may be affected by the system through the assessment process and eligibility constraints. The use of care is not only dependent on the assessment process and eligibility constraints, but also to the available budgets to actually provide care and support.

and seven for Ontario[5]. All these experts are committed to people with intellectual disabilities. We selected potential interviewees by first approaching the most influential persons in the field, based on the existing literature and policy documents. We then used the snowball method by asking these potential interviewees to suggest names of people they felt should definitely be included in this research. We also used our personal networks to find appropriate interviewees. See Appendix A for a list of interviewees.

S.2.3 Exploratory study

This study is exploratory in nature. It provides relevant insights, but makes no determination as to the relative importance of one explanation over another, nor does it claim to be exhaustive in scope. Gathering the appropriate information proved to be difficult for a number of reasons, not least the fact that statistical data on this subject are scarce. Nevertheless, we provide as complete a picture as possible, based on the available statistical data and indications provided by leading authorities on quantitative information in each region. While we acknowledge that a full description of the care system in each region is necessary to fully understand the development of the demand for care and support in the various regions, we limit the description to highlighting the legislation and regulations that are most relevant for people with intellectual disabilities. Finally, international comparisons are notoriously difficult due to the numerous differences between countries on many, partly unmeasured, aspects. However, such comparisons do provide worthwhile insights from outside our own Dutch framework.

S.3 Characteristics of care and support systems in different regions

A person’s demand for care and support is the result of their personal capacity and the context in which they function (Thompson et al. 2009). Thus demand for support depends on not just on a person’s intellectual disabilities but also on the expectations that society in each of the regions places on people with intellectual disabilities, as expressed for example through the inclusiveness of society and the help offered through the prevailing care system. These aspects are therefore described below.

S.3.1 Paradigms

Inclusion is a policy aim in each region that we investigated. In the Netherlands, care for people with ID is based on the maxim of enabling people to function as independently as possible with the highest quality of life possible. The policy in Flanders is aimed at fostering autonomy, participation and full integration of disabled persons in society. Central to English policy is social inclusion in the widest sense, addressing issues such as

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[5] For Ontario it proved to be very difficult to contact experts to be interviewed. Therefore, we used various methods for the interviews with Ontarian experts: one expert has filled in a written list of questions, one was interviewed by telephone and with 5 others we had an extended conversation on the subject on a conference.

housing, education, general health and employment, and introducing concepts such as advocacy, person-centred planning, choice and control. Ontario strives to remove barriers that limit the ability of Ontarians to participate in life in the communities: living in an institution is considered undesirable.

S.3.2 Intellectual disabilities defined

Internationally, there are three leading sources of definitions of intellectual disability: the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the American Association on Intellectual and Developmental Disabilities (AAIDD) and the World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF). See e.g., Harris and Greenspan (2016) for an extensive overview. All these definitions have three main elements in common that are perceived to be necessary for ID to exist: a cognitive disability, a disability in adaptive functioning and onset of the disability before adulthood. Cognitive functioning refers to reasoning, problem-solving, planning, judgment, learning and practical understanding and is measured using an Intelligence Quotient (IQ) test.

An IQ test score of below 70 indicates a limitation in cognitive functioning. More specifically, an IQ of 50-69 indicates a mild intellectual disability, and an IQ below 50 a severe intellectual disability. People with an IQ of between 70 and 85 *and* with problems in adaptive functioning are classified as having a borderline intellectual disability.[6]
Deficits in adaptive functioning refer to not being able to independently run a household, manage one's own finances, take part in the education or employment process or participate in leisure activities, or having problems with communication. Adaptive functioning is determined by scores for conceptual, social and practical skills (Buntinx et al. 2010; Schalock et al. 2010).

In theory, the DSM-5 definition is used in the Netherlands, implying that access to formal care and support is restricted to people with an IQ of around 70/75. In practice, people with an IQ between 70 and 85 and problems in adaptive functioning are also eligible for access to care and support for people with intellectual disabilities (CIZ 2017; NJI 2017; Staatscourant 2017). The rationale behind this is that these people with borderline intellectual disabilities mostly face the same kind of problems as people with an IQ between 50 and 69 (Snell et al. 2009; Woittiez et al. 2014a), and offering the same kind of support could therefore be effective. In most other countries, people with borderline ID are not regarded as having intellectual disabilities and are not eligible for ID care and support.[7] In Flanders and Ontario, people with borderline ID and other disorders such as an autistic spectrum

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[6] It should be borne in mind that the IQ that emerges from the intelligence test is not completely fixed since it also depends on the emotional state of the subject during the test, the surroundings, time schedule and (native) language in which it is administered, as well as the test type (Nisbett et al. 2012).

[7] However, they may receive support through the education system or other sectors less specifically aimed at helping people with ID.

disorder, may receive care through the ‘non-ID’ care and support system.[8] In England, people with borderline ID and even people with mild ID seldom have access to care and support due to the austerity measures taken in the care system.

A summary of the similarities and differences in the paradigm, definition of ID and access for people with borderline intellectual disabilities between the regions can be found in Table S.1. More information on the paradigms and definitions may be found in Section 1 of Chapters 2-5 on the four regions.

Table S.1
Similarities and differences in paradigms, definitions of ID and access for people with borderline ID between the four regions

	Netherlands	England	Flanders	Ontario
paradigm	live as independently as possible with the highest possible quality of life	social inclusion in the widest sense	autonomy, participation and full integration in society	communities are strong, inclusive and sustained by the economic and civic contributions of all Ontarians
definition	DSM-5 IQ < 85 and disability in adaptive functioning	WHO-ICF IQ < 70 and disability in adaptive functioning	AAIDD IQ < 70 and disability in adaptive functioning	AAIDD IQ < 70 and disability in adaptive functioning
access for people with borderline ID to ID care and support	explicit access to formal care and support under Wlz and implicit access to formal care and support through Wmo	no access	may enter care system via other diagnosis, such as autism	may enter care system via other diagnosis, such as autism

Source: Chapters 2-5 of this report

S.3.3 Main features of care and support systems

It is to be expected that the demand for care and support by people with intellectual disabilities depends upon the care system (Thompson et al. 2009). Therefore, we highlight the features of the care and educational systems that are most relevant for people with intellectual disabilities (see Chapters 2-5 of this report). In each region there are various laws and arrangements that are relevant for people with intellectual disabilities, administered by various government ministries (see Appendix B for an overview).

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[8] The literature shows a substantial concurrence of autism and intellectual disability (Bourke 2016, Howlin 2002, Postorino 2015, Harris & Greenspan 2016).

However, the types of care and support provided are fairly similar, ranging from personal care and mentoring in the home setting to care in a residential setting. The most relevant differences and similarities are described here (see also Table S.2).

Table S.2
Main aspects of care systems related to ID in the four regions

	Netherlands	England	Flanders	Ontario
decentralisation[a)]	+ (care at home) - (residential)	+	-	+
residential care[b]	+	+	+	-
different regulation for adults and youth	+	+	+/-	+
inclusiveness of employment[c]	-	-	-	-
inclusiveness of education[d]	-	-	?	+

+ Aspect is present.
- Aspect is not present.
? No information.
a Responsibility lies with the communities rather than central government.
b High percentage of ID care provided in a residential setting; 49% of Dutch ID care was provided in residential facilities in 2011. The figure for Flanders is 24%, the same as in England (also 24%), in Ontario the share is close to 0.
c The employment rate of people in receipt of disability benefit under the Invalidity Provision (Early Disabled Persons) Act (Wajong) with or without ID in the Netherlands is 22%, the employment rate of people with ID who are known to social services in England is 6%, In Flanders, of those claiming to have limitations in performing daily activities (ID or other problems), 37% have a job; the employment rate among people with ID in Ontario is 22%.
d In the Netherlands 20% of children with ID are in mainstream schools (2009). In England, 28% of children with special educational needs are in mainstream schools, in Ontario. In 2002, around 55% of 5-14 year-old students with disabilities were in regular classes. The figure in Flanders is unknown, but 4.35% of children in primary and secondary education are in special schools. In the Netherlands this percentage was 4.4% in 2014/2015.

Source: Chapters 2-5 of this report

The organisation of care for people with ID in Flanders is entirely centralised, while in the Netherlands this holds only for the most intensive forms of care (mostly residential) care provided through the Wlz, but not for care given at home (from the Wmo2015). Social care services in England and Ontario are fully decentralised. The needs assessments are also organised along these lines.
Ontario has closed all its large residential institutions, while in England care is more often provided at home than in institutions. In the Netherlands and Flanders a process of deinstitutionalisation is still ongoing.
Different laws apply for children and adults in all the regions studied. Children in Flanders need to contact the Youth Welfare Agency's Intersectoral Access Portal in order to gain

access to care and support. This is different from the admission process for adults. Apart from the admission process, ID care and support are organised by the same organisation (VAPH) as for adults. In England, young people up to 25 years with disabilities or with special educational needs can receive care and support based on the Children and Families Act 2014. In Ontario, various programmes administered by different government ministries are available for children with ID. The application process starts all over again when they reach adulthood.

The inclusiveness of society as measured by the inclusiveness of employment (people with ID working in a regular job) and education (children in ID attending regular schools) shows Ontario to be very inclusive. This holds especially for education, with almost all children attending regular schools. In England, 28% of children with special educational needs are in mainstream schools. In the Netherlands 20% of children with mild intellectual disabilities attend mainstream primary schools. The percentages in Flanders are unknown. All regions score low on inclusive employment, with employment rates among people with ID of 22% (Ontario), 22% (the Netherlands) and 37% (Flanders). The figure in England is 6%. It should be borne in mind that these figures relate to different groups of people in each region, but they nonetheless give an impression of the degree of inclusiveness.

S.4 Growth in ID care and its causes

To investigate the development in demand for ID care and support (first research question), we first look at the development in the prevalence of people with intellectual disabilities, since this could be a driver of the trend in demand.

S.4.1 Prevalences uncertain

As far as we are aware, there are no official records of the number of people with intellectual disabilities in any country. Registration would be costly and cumbersome for many people involved. Prevalence is hard to estimate since ID is partly based on adaptive functioning, which is difficult to measure. Estimates of how many people have intellectual disabilities do exist, but vary a great deal in all countries and are uncertain (see e.g. Roeleveld et al. 1997; Leonard & Wen 2002; Maulik et al. 2011).

According to rough estimations by The Netherlands Institute for Social Research (SCP), the prevalence of people in the Netherlands with an IQ below 70 was about 0.85% in 2013. A similar estimated prevalence is found in Ontario. The estimated prevalence of ID below IQ 70 in England and Flanders is higher than in the Netherlands, at 2-2.5%. These prevalence figures all lie within the range of prevalence estimates given in the literature review by McKenzie et al. (2016). Prevalences can differ between regions because average parental age, socioeconomic status and sex ratios can influence the prevalence and incidence of intellectual disabilities (McKenzie et al. 2016). The prevalence of people with borderline intellectual disabilities (IQ between 70 and 85 and problems in adaptive functioning) is estimated at around 8% in the Netherlands, but there is much uncertainty regarding this estimate. The prevalence of borderline ID in other regions is unknown.

S.4.2 Increased demand for ID care and support

Statistical information on demand for care and support is scarce. Where the demand is not known, we resort to use of care and waiting lists as a proxy for demand. However, this information is also fragmented. It seems that in the Netherlands, as well as in England and Ontario, where care and support are decentralised, information on demand and use of care has become less readily available.[9] See Table S.3 at the end of this section for an overview of the available information on changes in demand, use of care and support and waiting list in the four regions.

Apart from the Netherlands, none of the data from the regions allowed us to separate the demand for (or use of) care and support by people with mild or borderline ID from that of people with severe ID.

The Netherlands

Roughly 0.9% of the Dutch population[10] had a demand for care and support from the ID care system in 2011 (Ras et al. 2013). Between 2007 and 2011, the demand for care and support grew rapidly (6% per annum), especially among people with mild (7% p.a.) and borderline intellectual disabilities (15%). Demand by people with severe intellectual disabilities grew only slightly (0.9%) (Ras et al. 2013). More recently, the more intensive forms of residential ID care grew by 7% per year between 2012 and 2016. No recent figures are available for non-residential care (provided under the Wmo2015).

Like demand for care and support, the use of care and care expenditure also increased by 6% per year between 2007 and 2011 (Ras et al. 2013; Van der Kwartel 2013). More recent information on total expenditure or total use of care is unavailable.

England

For England, no data are available on the development in demand for care and support, and nor are data on the total number of users of care and support. To indicate how many people need care and support we rely on data on the use per type of social care service. Use of residential care by adults decreased slightly (-0.9% annually), while use of community-based social services increased slightly (1.6% annually) between 2005/2006 and 2013/2014. *Use* of care and support in England thus grew slowly, because more people receive social care services than residential care. Between 2005/2006 and 2013/2014, overall spending on social services for working-age adults with intellectual disabilities more than kept pace with inflation (Hatton et al. 2016), rising by 1.9% annually; this also indicates that the need and demand for care and support increased, albeit to only a slight extent. However, the interviewees stated that the available English data do not offer a

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[9] For instance, in the Netherlands detailed information is available until 2014. In 2015 the system was decentralised, leading to fragmentation and loss of information on non-residential demand for and use of care and support.

[10] This is higher than the prevalence of IQ < 70 referred to in Section 0.4.1, since people with borderline ID may also have access to ID care and comprised 22% of applicants in 2011.

complete picture: the increase in the need and demand for care and support is much higher than suggested by the increase in use of care. Due to austerity measures the number of people receiving social care services is much smaller than the number who need care – a finding that is confirmed by Fernandez et al. (2013) and which appears to be reflected in the increase in 'first assessments': between 2005/2006 and 2013/2014 the number of people assessed by local authorities for the first time ('first assessments') grew by 7.7% per year. Although it is unknown how many of them were assessed as eligible for care and support and thus classified as having a demand for care and support, it is highly likely that the growth in first assessments reflects growth in the need for social care services. Thus, combining the experts' views with the different pieces of information it is plausible to assume that the need for care and support in England has grown.

Flanders

In Flanders, the growth in the macrobudget for clients of the Flemish Agency for People with a Disability, VAPH (Vlaams Agentschap voor Personen met een Handicap) receiving support or care in kind or cash averaged 2% per annum between 2009 and 2015. These were mainly people with ID, but also people with other disabilities. The number of adults receiving support or care grew from 36,000 in 2009 to 48,100 in 2015, an average increase of 5% per annum. The waiting lists grew faster (11% per year on average), but were fairly stable from 2013 to 2015 (VAPH 2016b). When we add up use and waiting lists as a proxy for demand, this produces annual growth rates of about 6%.
From 2008 to 2011, total expenditure by VAPH grew by 8% per annum for ambulant support and 3% for residential support (not shown in table); between 2013 and 2016 the annual increase was 3%. All this suggests growth in the demand for care which is comparable to that in the Netherlands.

Ontario

Waiting lists for residential grew by 11% per year (2009-2013). Waiting lists for funding via the Passport programme (arranging personal budgets) grew by 40%[11] annually (2012-2016) and the number of Passport users is also growing rapidly. The budget for developmental services and support has doubled in Ontario in recent years, and use of care and support has also increased. Adding use of care and support and waiting lists results in annual growth of 55% in demand for the Passport programme between 2012 and December 2015 and a 4,4% yearly increase in demand for residential services between 2009/2010 and 2013/2014. All this indicates that demand for care and support by people with ID is also growing rapidly in Ontario.

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[11] This growth rate is very high but it needs to be borne in mind that the growth was measured over a small number of years, and shortly after the introduction of the programme.

Table S.3

Indication of increase in demand for care and support for people with intellectual disabilities in the four regions (annual increase in %)

	Netherlands	England	Flanders	Ontario
demand[a]	6[b]		6[e]	55[f] (passport) 4.4[g] (residential)
use	6 [b] 7[c] (residential)	1.6[d] (community); -0.9[d] (residential)	5 (adults)[e]	0.3[g] (residential)
waiting lists			11[e]	11[g] (residential) 40[f] (passport)
budget	7[b]	1.9[d]	2[e]	4.3[i]

a Possibly including some people with borderline intellectual disabilities.
b Period:2007-2011.
c Period: 2012-2016.
d Period: 2005/2006-2013/2014.
e Period: 2009-2015.
f Period: 2012-2016; the program started in 2012.
g Period:2009/2010-2013/2014.
i Period:2012-2016.

Source: Chapters 2-5 of this report

Conclusion on development of demand

The statistical data, interview data, scientific literature and policy documents all point in the same direction. Although the data have limitations, we find that in the Netherlands, Flanders and Ontario the demand for care and support for people with intellectual disabilities has grown significantly. There are also indications of an increase in the need for care and support in England, though not as marked as in the other regions; the reason for this is that the demand for care and support is unknown. Our indications of a growing need for social care services in England are based on an increase in the use of care, budgets, the number of first assessments and the interviews with experts.

S.4.3 Causes of growth in demand for care and support

The possible explanations for the development in demand for care and support by people with mild and borderline intellectual disabilities (research question 2) are broadly similar between the regions (see Chapters 2-5), though there are also marked differences.[12]

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[12] It must be borne in mind that most of theexperts in Ontario had not thought beforehand about the question of whether society has become more complex and the impact this might have on demand for care by people with ID. In England, almost all experts believe that social change has played only a minor role in the current use of care and support. Nevertheless, they do feel that social change affects the need for care and support of people with learning disabilities.

See Table S.4 at the end of this section for an overview of the factors suggested by the interviewees as causing the growth in the regions studied.

Factors related to the care system

The access for people with borderline intellectual disabilities (IQ between 70 and 85 and problems in adaptive functioning) is an important factor in the growing demand for care and support in the Netherlands. However, since people with borderline intellectual disabilities are generally not eligible for care and support in the other regions studied, their growing need for help is not a driver of the growing demand for care and support in those regions. In England, even people with mild intellectual disabilities have difficulty gaining access to English social care services due to budget constraints.

According to the experts in the Netherlands, Flanders and Ontario, the increased demand is driven by more and earlier diagnoses. The advantage of early diagnosis is the ability to offer (light forms of) help at an early stage in order to prevent problems getting out of hand later on. The interviewees also suggested that the care systems in the Netherlands and Flanders allowed for the growth in demand, and may have enhanced it through financial incentives and the creation of new forms of more appropriate care.

In the Netherlands, the notion that people with borderline or mild intellectual disabilities often have a ‘weak’ network and are therefore forced to turn to the care system has been put forward as a driver for growing demand for (publicly funded) care and support. This tendency towards replacing informal care with formal care has also been put forward in Flanders. The experts pointed out this was related to a decrease in informal care due to more women participating on the labour market for more hours, an increase in the number of single-parent families and very old parents not being able to take care of their older child with ID.

In Ontario, inclusion is seen as a major driver of the growing demand for care and support. The Ontarian experts all suggested that the inclusiveness of society was the most important cause of the increasing demand. Inclusion means participation in all aspects of life, and this places heavy societal demands on people with ID. This may result in a mismatch between their needs and those societal demands, translating into growing demand for support.

Factors related to an increasingly complex society

According to the experts, demand for care and support has grown because there are fewer jobs available for people with ID, possibly due to the economic crisis (England,[13] Ontario) and because simple and routine work has disappeared or has become more difficult to carry out (the Netherlands, Flanders). A Flemish expert also felt that people with mild or borderline intellectual disabilities do not have the opportunity to work because they are often less productive than employees without intellectual disabilities.

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[13] This relates to the growth in need for care since the demand is unknown.

A further suggestion by the interviewees is that the education system has become too large in scale, less structured (the Netherlands) and more academic (the Netherlands, England[14]), making it difficult for people with (mild) intellectual disabilities to manage without care and support. In contrast to what we found for the Netherlands, the experts pointed out that in Flanders there still are schools where pupils with a mild or borderline disability can learn practical job skills, but added that after they have finished school it is almost impossible for these pupils to find a regular job. The Ontarian experts did not suggest the complexity in education as one of the causes of the growth in demand, though they did emphasise the inclusiveness of education and the need for educational support.

The experts in all regions pointed out that digitalisation makes daily life more difficult because of the increased need to use computers or smartphones, creating a barrier for people with ID. As a result, their need for care and support increases. On the other hand, digitalisation can make tasks easier, for example through the use of apps.

As in the Netherlands, daily life in England is becoming increasingly complex and the needs of people with intellectual disabilities are growing as a result. The impact of the austerity measures has been so great that the interviewees had to think hard about the possible influence of social change on the use of care and support. Almost all of them believe that social change has played only a minor role in the current use of care and support and that the austerity measures are a major reason why fewer and fewer people with intellectual disabilities in England are receiving help.

Demographic factors, such as premature birth, low birth weight, higher age of mothers and higher life expectancy of persons with ID have all been suggested as causes of the growth in demand for care and support in the Netherlands and Flanders. However, these factors seem to have played only a minor role in the Netherlands, because the numbers involved are small. We were unable to find any quantification in Flanders.

Conclusion

Based on the experts' opinions, we conclude that the explanation for the increase in demand for care and support by people with mild or borderline ID is multifaceted.

In general the explanations are similar across the regions, but differ on some aspects. In all the regions studied for which we have data on demand for care and support, the interviewees suggested that the growth in demand for care and support was due to the disappearance of simple jobs and increasing digitalisation. In the Netherlands, unlike in the other regions studied, the access of people with borderline intellectual disabilities is an important factor in the growing demand for care and support. In some – but not all – regions, more and earlier diagnoses, the substitution of informal by formal care and the complexity of the education system are suggested as factors driving the growth in demand. Since we have no complete data on the demand for social care services in England, it was harder for the interviewees to pinpoint the role of social change in the need for care and support. Although they do believe that a more complex society has affected

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[14] This relates to the growth in need for care since the demand is unknown.

the need for care and support, they argue that austerity measures mean the rise in use for care and support has been outstripped by the growth in the need.

Table S.4
Causes of growth in demand for care and support for people with intellectual disabilities as suggested by the interviewees in the four regions

	Netherlands	England	Flanders	Ontario
care system				
access borderline	+	-	-	-
more/earlier diagnoses	+		+	+
supply creating demand	+		+	
less informal care	+		+	
complex society				
fewer simple jobs	+	+	+	+
education complex	+	+	-	
digitalisation	+	+	+	+
inclusion	+			+
risk factors				
demography	+/-		+	

+/- suggested as a cause of growth (+ positive; - negative effect).

Empty cell: not suggested as a cause of growth.

Source: Chapters 2-5 of this report

S.5 Insights regarding care for people with ID

The supplementary material in the interviews led to reflections on the care and support for people with intellectual disabilities in the Netherlands, and possibly also in other countries. It can provide useful insights for professionals and policymakers in the ongoing discussions and the dilemmas involved in the care for people with ID. The themes that appear to be central in the debates in the other regions result in six themes that are relevant for (at least) the Dutch situation.

S.5.1 Risks of deinstitutionalisation: are loss of experience and need for crisis placements

With the recent introduction of the Wmo 2015, the Netherlands is deinstitutionalising since it is aimed at providing care and support at home where possible. With respect to deinstitutionalisation, we can learn from experiences in other regions in which this process is more advanced. The Ontarian experience of closing down institutions shows that expertise, such as that of doctors specialised in dealing with people with ID, is likely to be lost. This is in line with findings for the Netherlands, where local authorities and care providers point out that they have insufficient knowledge about people with psychiatric disorders and/or intellectual disabilities (Feiten et al. 2017, Van der Ham et al. 2018, Mee 2017). The Ontarian experience suggests that deinstitutionalisation should not be undertaken without introducing alternative forms of support. Experience has for example shown that adequate provision is needed for people with intellectual disabilities in crisis situations. In Ontario, the lack of such provision sometimes results in admission to expensive psychiatric wards, hospitals or long-term care homes that are unsuited to the individual's needs. They also require support at home. It is suggested that lack of this support hampers inclusion. The closing of institutions has also increased demand for housing that is suitable for people with ID; if that is not available, people with ID have to live with their families.

S.5.2 Inclusion is not automatically achieved by living in the community

The goal of t a more inclusive society is one of the fundamental ideas behind the recent Dutch policy reforms (Participation Act and Wmo2015). It is driven by the assumption that inclusion enhances quality of life. However, as experience in Ontario has shown, people with intellectual disabilities are not automatically included simply by living in the community. Inclusion involves high societal demands: interviewees in Ontario cited increased demand for support workers, home care services, mental health services, and employment services which may be linked to increased participation in the community for people with ID who are no longer institutionalised or living in isolated group homes.

Employment is an important condition for inclusion in society. However, evidence in all four regions shows that finding and staying in work is not easy for people with ID. According to the interviewees, employers' attitudes and beliefs about the capabilities and limitations of people with intellectual disabilities throw up a barrier in this regard. Job coaches could ensure that people with ID are placed in appropriate employment and that support procedures are in place. The Flemish and English interviewees felt that apprenticeships could work well.

For inclusion to function well, a change in mind-set is required concerning what people with intellectual disabilities can achieve, not only among employers, but also in the general population (Blamires 2015; Melling 2015). Life in school, but also life in general, could become a little less complicated for people with intellectual disabilities if the broader pedagogical goal of accepting differences or behaving kindly towards vulnerable people were included as part of the school curriculum (Beckett 2015). A culture of acceptance increases the involvement of people with intellectual disabilities, as Hall (2016) shows for the US. If inclusion of people with intellectual disabilities starts in childhood, as is nowadays the case in Ontario, it will be easier for them to participate as fully as possible as adults because people without ID will be more used to people with ID. This will not have an effect from day one, but will take time. Nevertheless, in addition to promoting inclusion, one Ontarian expert argues that a way must be found to keep people with ID in contact with their peers. In England, ‘safe havens’ have been introduced. These might be a café or a particular shop where people are friendly towards people with ID, or a football club that supports them. At times of need people, with intellectual disabilities can go to these locations and there will be somebody who can help them. According to the interviewees, these safe places do appear to make society more inclusive.

S.5.3 Personal budgets may be too difficult to manage

In each of the regions studied, including the Netherlands, the use of personal budgets is increasing. A personal budget favours a more client-driven system and allows clients more freedom to purchase the care they need. It also enables members of informal networks to provide support. This type of help is offered in one form or another in each of the regions in this study. However, Flemish, English and Ontarian interviewees doubt whether all people with ID or their networks are capable of managing their resources adequately, and feel that this may be beyond their competence. A voucher system is suggested in Flanders as a viable alternative to personal budgets. In England, the bureaucracy associated with personal budgets was cited as a drawback.

S.5.4 The gap between youth and adult services can lead to loss of support

Youth services differ from adult services in all four regions studied. Support from youth services ends at a certain age, and adult services have to be applied for anew. In Ontario, young people with intellectual disabilities have to apply for a new assessment after school age, and according to the interviewees it is their own responsibility to do this. Not all of them will apply, and even if they do apply they may not be considered eligible for adult services. This means they may well end up without support (especially if they have mild or borderline ID), potentially leading to all kinds of problems, such as families in crisis situations, homelessness or even becoming embroiled in the criminal justice system.
This problem concerning the gap between youth and adult services is also recognised in the Netherlands, and is the subject of research (Feijten et al. 2017; Pommer & Boelhouwer 2017). In this respect, Mee signals a shortage of suitable living arrangements for youngsters with mild intellectual disabilities or autism (Mee 2017). For young people needing permanent, 24-hour care and support, there need not be a gap between youth and adult services because they are eligible for care and support under the Wlz both as a child and as an adult.

S.5.5 Curtailing budgets will constrain use but not solve the problems

In the Netherlands, as in other countries, the financial tenability of the care system is under discussion. The transition towards the Wmo2015 has been accompanied by budget cuts in the Netherlands (CPB 2013; NJI 2017). In Ontario and Flanders, curtailed budgets lead to long waiting lists and waiting times of sometimes several years. Interviewees argue that too few specialist services are available (Flanders), and this may be an obstacle to inclusion (Ontario). According to the interviewees in England, austerity measures have led to poor assessments and inadequate support. In all regions people (increasingly) have to rely on informal help. However, care and support given by the informal network is sometimes less adequate in enabling people with intellectual disabilities to play a part in society and live as independently as possible, because of protective behaviour, as suggested by one interviewee. Moreover, people with borderline or mild intellectual disabilities often have a 'weak' network which has difficulty providing appropriate support. This could be borne in mind when reflecting on the recent Dutch reforms that were accompanied with curtailed budgets[15] and a shift towards support provided by people from the recipient's social setting.

S.5.6 Admitting people with borderline ID to the ID care system could prevent problems later on

Due to budget constraints, care and support in Ontario and England is mostly provided to people with the most severe forms of ID; this is less often the case in the Netherlands and Flanders. With respect to the curtailing of budgets, interviewees in Flanders raised the question of whether people with low care needs (including people with mild or borderline ID) should receive support, or whether it should go only to people with the most pressing needs. Although precise numbers are not available, there are many people with borderline ID (see e.g. Woittiez et al. 2014b). And while the expenditure per person may be low for this group, their large number means that budgets must be substantial in order to provide care and support to each of them. Another drawback of admitting people with borderline intellectual disabilities to ID care and support is that the label of having mild or borderline ID may be stigmatising, thus hampering inclusion and lowering their self-esteem.

At the same time, it is widely recognised that people with mild or borderline ID are vulnerable because they have difficulty understanding situations, are often poor, unemployed or homeless Furthermore, they may have problems with alcohol or drug abuse as well as with their behaviour and/or mental health (Bexkens 2013; Peltopuro et al. 2014). In the Netherlands, this is one of the reasons that they are included in the ID care system. With respect to the admission of people with borderline ID to ID care, the Netherlands differs from the other regions studied in this report. In those regions, the impairments of people with borderline ID are either not recognised or are judged to be not severe enough to qualify for ID care and support. There are indications (albeit no strong proven evidence as yet) that providing guidance early in life when problems are relatively minor and new behaviour can be learned relatively easily, helps prevent significant behavioural problems later on (Ham et al. 2018, Broekhuizen & Jakobs 2010). Due to lack of appropriate support, people with borderline or mild ID may end up in other, more expensive, types of care such as psychiatric or forensic care, or be homeless. To make a proper appraisal on whether preventive guidance is a sound way of spending public

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[15] 75% of the budget for non-residential care and support previously funded centrally through the Exceptional Medical Expenses Act (AWBZ) has been transferred to local authorities (see e.g. Movisie 2016).

resources, it is necessary to know how and to what extent adequate preventive care and support can prevent significant problems arising in later life, such as unemployment, drug or alcohol abuse or criminal behaviour.

S.6 Gaps in knowledge

The United Nations Convention on the Rights of Persons with Disabilities was ratified in the Netherlands in 2016. The aim of the Convention is to improve the position of people with disabilities, including intellectual disabilities. Among other things the Convention states that they should have the same rights as every other citizen to live independently, go to school, use public transport or have a job. Central government is responsible for facilitating this. To be able to comply fully with the Convention, knowledge of the situation of people with intellectual disabilities and the care and support they receive is essential. Our study provided us with insights into a number of gaps in our knowledge concerning the care received by people with mild intellectual disabilities, and their well-being. We have grouped the gaps in knowledge into four themes: care and support, prevention, inclusion and well-being.

a Care and support

Related to the findings of our study, there is a need for knowledge on *how many people with intellectual disabilities receive care and support in the Netherlands*. Since the introduction of the new Social Support Act in 2015 (Wmo 2015), this information is no longer available. It is important to gain an insight into this, because people with intellectual disabilities need a different approach from people who do not have these disabilities.

The introduction of the Wmo 2015 shifted the emphasis to the provision of care by the social networks of people with health impairments (including people with mild intellectual disabilities). Although little is known about the informal networks of people with mild intellectual disabilities, there are indications that those networks are often small and vulnerable (Woittiez et al. 2014a). It may be that this makes members of this group extra vulnerable. It is important to know *what kind of informal networks people with mild intellectual disabilities have* in order to gain an impression of *the extent to which the members of those networks are capable of offering help to people with mild intellectual disabilities when needed*.

b Prevention

Based on the maxim that prevention is better than cure, it is important to gain an insight into *the effect of early support for people with mild intellectual disabilities in preventing unemployment, homelessness, indebtedness and criminal behaviour, and in which groups this works and in which it does not*.

The number of people with mild intellectual disabilities is greater than the number with severe intellectual disabilities. If providing support means that fewer people with mild intellectual disabilities become unemployed, homeless, get into debt or come into contact with the criminal justice system, the benefits may outweigh the costs. It is therefore important from a societal as well as an financial perspective to have an *understanding of the costs and benefits of providing support to people with mild intellectual disabilities*.

c Inclusion

In considering the provision of early support, it is important not to lose sight of the fact that a diagnosis of intellectual disabilities can have a stigmatising effect, which does nothing to make achieving inclusion easier. Inclusion is in any event not a simple matter, because genuine inclusion requires the acceptance of being different. Studies in several countries substantiate this (Woittiez et al. 2014b; Blamires 2015; Melling 2015; Hall 2016). An understanding of *what is needed to achieve acceptance* will contribute to the achievement of inclusion.

An important step towards inclusion is full participation in the labour market. Work can help people feel valued and recognised. Yet while many employers state their willingness to take on and retain people with an employment disability, this does not happen often in practice. Gaining an insight into *the conditions which are important to employers to actually recruit people with intellectual disabilities* will contribute to inclusion.

Inclusion is not restricted to full participation in the labour market; it also extends to full participation in other areas of society, as stated in the United Nations Convention on the Rights of Persons with Disabiilities. Our report suggests that technological developments make that participation more difficult for people with intellectual disabilities. On the other hand, technology also offers opportunities to make inclusion easier to achieve, for example apps which assist with speech or travel or which offer help when needed. Technology can provide support for people with behavioural problems, or measure stress. In general, knowledge is needed about *which technology can help promote better functioning and what requirements that technology must meet*.

d Well-being

As well as charting the effects of providing early support, it is necessary to look at *where the best place is to make the diagnosis: at school, in community teams or by the general practitioner?* As a corollary to this, it is essential to acknowledge the negative (and probably unavoidable) connotations of being diagnosed with an intellectual disability.

Recognising that someone has an intellectual disability is for example important in helping them resolve debt problems. In practice, applying for help with debts proves to be too complex for this group, and they are therefore unable to submit the right documents without help. Problems such as these also play a role in helping them find work, preventing school dropout or criminal behaviour. We are therefore keen to know *how many people with intellectual disabilities in the Netherlands encounter socioeconomic disadvantage and to what extent there is overlap between these two factors*.

The biggest gap in our knowledge about people with intellectual disabilities is that we do not know how they are faring in society. Does the care they receive have the desired effect? Does it genuinely enable them to play a full part in society? And what about the people who do not receive care and support? Do they not receive that care and support because they are managing perfectly well, or is it the case that some people who are not receiving care and support are not doing very well but are not on the care radar? To obtains answers to these questions, we want to know *how well people with a mild or other intellectual disability participate in society*. As a first step in providing an answer to this question, SCP is currently engaged in a study of the prevalence of mild intellectual disabilities among non-participants in the labour market and among schoolchildren with learning difficulties.

1 Demand for care and support for people with mild or borderline intellectual disabilities

1.1 Growing demand for care and support in an increasingly complex Dutch society

Demand for care and support for people with intellectual disabilities has been growing rapidly in the Netherlands in recent years, by approximately 6% annually.[16] This growth is more rapid than might be expected on the basis of demographic trends (Ras et al. 2010; Woittiez et al. 2012). The growth in demand has been especially marked (15% per year) among people with borderline intellectual disabilities (IQ between 70 and 85) and to a lesser extent (7% annual growth) among people with mild intellectual disabilities (IQ of 50-69) (Ras et al. 2013). An earlier SCP study found that risk factors for intellectual disability (premature birth, low birth weight, greater age of mothers) offer only a very partial explanation for the substantial growth in demand for care and support by people with intellectual disabilities. The main drivers of the rapid growth are the increasing complexity of society (digitalisation, changing nature of simple jobs, etc.) and an extensive care system that has made this growth possible (Woittiez et al. 2014a). If the challenges of a more complex society are universal (as Snell et al. (2009) and Fernell & Ek (2010) suggest), demand for care and support for people with intellectual disabilities is also expected to grow in other countries. In this report we examine whether this is indeed the case.

In what sense is society becoming more and more complex? In the Netherlands this manifests itself in various ways. For example, finding and keeping a job is more complex than in the past. Employment that is suitable for people with mild or borderline intellectual disabilities is usually simple and routine; however, a lot of this type of work, such as simple jobs in the docks, at garages or in the cleaning industry, has disappeared or become more difficult to carry out. Although today's society does still have simple and routine employment, it increasingly has to be carried out independently and efficiently, even in sectors such as the cleaning industry. Consequently, it is less suitable for people with mild or borderline intellectual disabilities. Also, activities of daily living such as travelling by public transport (using a public transport smartcard) and arranging banking affairs (including online) have become more complex. The increasing complexity of society is also

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[16] Between 2007 and 2014 the number of clients with a demand for intellectual disability care in the Netherlands grew by 5-6% per year (Ras et al. 2010),(CIZ 2014b). More recent information on the numbers of clients with a demand for ID care and support are not available. Since the introduction of the Long Term Care Act (Wlz) and the Social Support Act (Wmo), only the nationwide demand for most intensive forms of care and supervision (which falls under the Wlz) is registered. Between 2012 and 2016 the number of people with an intellectual disability with a demand for more intensive forms of Wlz-funded-care grew by 7% per year (Rebel 2017). Community care provided under the Wmo is not registered at national level.

evident at school; the Dutch education system today is larger in scale and less structured, and the link with the world of work has weakened. School dropout and lack of appropriate employment takes away the structure that people with mild or borderline intellectual disabilities need. A complex and demanding society intensifies the demand for care and support. The Dutch care system allows for this growing demand for formal care and support, and more and more people with intellectual disabilities with an IQ between 50 and 85 and problems in adaptive functioning demand – and receive – care and support.

1.2 Growing demand for care and support in other countries as well?

In their article on people with intellectual disabilities with higher IQs (slightly above 70-75), Snell et al. (2009) suggest that these people face several challenges in life. One major challenge is coping in an increasingly complex, information-based and technologically demanding society. Fernell and Ek also warn that a large minority of people with borderline intellectual disabilities have problems in coping in today's society. They posit that negative consequences are likely to ensue from the combination of the invisibility of the disability and the high level of intellectual functioning demanded by today's society (Fernell and Ek 2010). The invisibility stems from the fact that most people with intellectual disabilities and higher IQs are physically indistinguishable from the general population because no specific physical features are associated with intellectual disabilities at higher IQs (Snell et al. 2009). Williams et al. (2015) suggest that even people without cognitive limitations face challenges in an increasingly complex world. They argue that as a consequence more and more people are less well equipped to deal with aspects such as the demands of technology or the minutiae of financial services.
In the Netherlands, the increasingly complex society has resulted in growing demand for care and support for people with intellectual disabilities (with higher IQs). Assuming that an increasingly complex, information-based and technologically demanding society is a universal phenomenon, it is interesting to investigate whether the demand for care and support for people with mild or borderline intellectual disabilities in other Western countries has also grown. With this in mind, the Dutch Ministry of Health, Welfare and Sport asked the Netherlands Institute for Social Research (SCP) to find answers to two research questions. The first is as follows:

1 How has the demand for care and support for people with borderline and mild intellectual disabilities developed in other countries?

We compare the development of demand for care and support by people with mild or borderline intellectual disabilities in the Netherlands with that in England, Flanders and Ontario. Special attention is given to people with mild and borderline intellectual disabilities, since it is in these groups that the growth in the Netherlands has manifested itself. We selected regions which differ with respect to the responsibility for providing care (local authorities or central government) (Flanders), the influence of the free market

process on the care and support system (England) and the inclusiveness of society (Ontario). More information on the selection of regions can be found in Section 1.5.
The added value of comparing the Dutch situation with that in other countries is the possibility to gain insights from outside our own Dutch context. As far as we are aware, international comparisons of the growth in demand for care and support for people with borderline and mild intellectual disabilities are rare.
Providing an insight into the development of demand for care and support in other countries is one thing; the next intriguing question is then to examine the drivers of this development. 'An increasingly complex, information-based and technologically demanding society' (Snell et al. 2009) may influence the demand for care and support elsewhere as it has in the Netherlands. Furthermore, people with borderline intellectual disabilities are viewed in the Netherlands as people with intellectual disabilities (Schalock et al. 2010; CIZ 2014c, 2017) and therefore have access to care and support for people with intellectual disabilities. The Dutch care system has thus created scope for additional growth in the demand for care and support. Other countries may have stricter criteria for accessing care for people with intellectual disabilities and higher IQs, as research seems to indicate (Woittiez et al. 2014a, Buntinx et al. 2010). By exploring the drivers of the development in the demand for care and support in the other countries, we are able to answer the second research question:

2 Which possible explanations can be given for this development?

Our study is intended to be an exploration rather than an extensive description of differences between countries. Nevertheless, experiences from other regions, as found in the literature, policy documents and in experts' opinions provides important insights with respect to the Dutch way of arranging care and support for people with mild or borderline intellectual disabilities.
With the causes of the growth in the Netherlands in mind, we investigate whether the complexity of society, the organisation of care in general and access to care and support in particular, and the inclusiveness of society, also play a role in other countries.

1.3 Intellectual disabilities defined

Internationally, there are three leading definitions of intellectual disabilities. One is reported in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5); the other two are found in the American Association on Intellectual and Developmental Disabilities (AAIDD) and the World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF). All the definitions have three main elements in common, namely a cognitive disability, a disability in adaptive functioning and the condition that the disability started before adulthood (for an extensive overview of the similarities and differences between the definitions see e.g. Harris & Greenspan (2016)).

The definition used in Dutch policy is the international definition in the DSM-5. It includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. Deficits in intellectual functioning refer to reasoning, problem-solving, planning, judgment, learning and practical understanding (Buntinx et al. 2010; Schalock et al. 2010). One way to measure intellectual functioning is through an Intelligence Quotient (IQ) test, although it must be borne in mind that the IQ that results from the intelligence test is not completely fixed, since it also depends on the subject's emotions at the moment and the surroundings in which the test is administered (Nisbett et al. 2012). Generally, an IQ test score of around 70 indicates an impairment in intellectual functioning[17]. Deficits in adaptive functioning refer to not being able to independently run a household, manage one's own finances, take part in the education or employment process or participate in leisure activities, or having problems in communication. Adaptive functioning is determined by scores on conceptual, social and practical skills (Buntinx et al. 2010; Schalock et al. 2010).

Classifying an intellectual disability according to the DSM-5-definition implies that, in theory, the Dutch government employs an IQ threshold of around 70/75 for access to formal care and support. That is the theory; in practice people with an IQ between 70 and 85 with problems in adaptive functioning also have access to social care and support (CIZ 2017; NJI 2017; Staatscourant 2017). The rationale behind this is that people with an IQ between 70 and 85 accompanied by problems with adaptive functioning face the same kind of problems as people with an IQ between 50 and 69 (Snell et al. 2009; Woittiez et al. 2014a). We refer to the group with an IQ between 70 and 85 accompanied by problems with adaptive functioning as people with borderline intellectual disabilities. Those with an IQ of between 50 and 69 are classified as having mild intellectual disabilities, while people with an IQ below 50 are classified as having severe intellectual disabilities.

The definition used in the Netherlands (CIZ 2014a, 2017) thus differs from most international standards in the sense that in most other countries people with an IQ between 70 and 85 and problems with adaptive functioning are not regarded as having intellectual disabilities (Harris & Greenspan 2016).

There are pros and cons to providing access for a broad group of people with intellectual disabilities (including those with the higher IQs) to formal care and support. A broad 'definition' of intellectual disability could be stigmatising, and furthermore it might be the case that the resources available for care and support for people with intellectual disabilities are shared among a much larger group, which could be disadvantageous for people with IQs lower than 70. A positive aspect of using a broad 'definition' is that people with borderline intellectual disabilities, who face the same kind of problems as people with mild intellectual disabilities, could be helped with the same kind of support as people with

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[17] This is two standard deviations or more below the population mean.

a mild intellectual disability (Woittiez et al. 2012). This help could then be effective and efficient. Snell et al. (2009) also posit that an intellectual disability occurs along an IQ continuum, and that similar problems in functioning are shared between people with mild intellectual disabilities and people with borderline intellectual disabilities.

In determining whether someone has intellectual disabilities, the interaction of the individual and their 'environment' is very important. To put it differently: 'no man is an island', according to the 17th-century theologian John Donne (as cited in Jokinen 2006) and Thompson et al. (2009)), and thus disability is experienced differently in different contexts (McKenzie (2013)). Within the framework of this report, this means that disability may be experienced differently in different countries. The ability to cope depends on the precise activity or situation with which an individual is faced (Williams et al. 2015).

Apart from the intellectual disability, behavioural problems, mental health problems, autism and alcohol and drug abuse are quite often also present in the group with mild and borderline intellectual disabilities. In addition, socioeconomic problems regularly co-exist with mild intellectual disabilities, such as poverty, debts, unemployment, homelessness, relatively frequent hospitalisation, loneliness and vulnerability Snell et al. (2009), Pommer & Boelhouwer (2017). These are not only related to the person themselves, but also to the environment in which they function. Their overrepresentation in the criminal justice system seems plausible but is difficult to prove due to a lack of reliable data (Holland et al. 2002; Kaal 2016; Correctional Services Canada (2014)). In the Netherlands, the prevalence of people with mild and borderline ID based on diagnostics is found to be 10% in regular detention and between 15% and 25% in specific detention units, such as forensic psychiatric wards (Kaal 2016). Holland et al. (2002) posit that although people with ID might be overrepresented in the justice system, the overrepresentation is strikingly low given the intellectual and psychosocial disadvantages they experience.

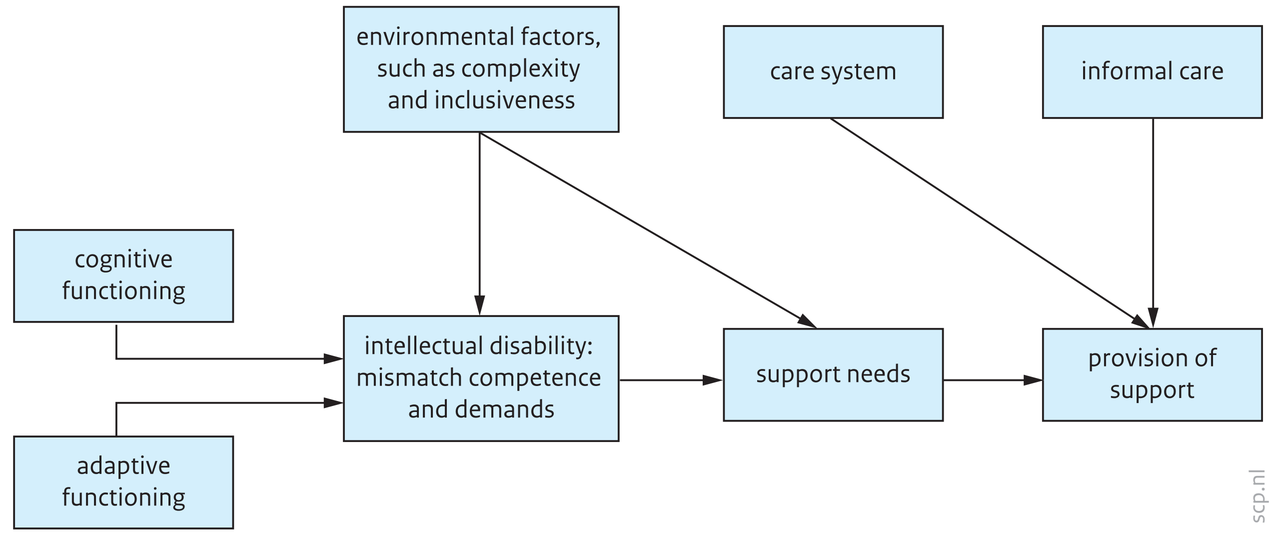
1.4 Demand for care and support in a complex society

Since the definition of an intellectual disability is not just based on someone's cognitive impairments, but also depends on the society in which they live, it is to be expected that the demand for support by people with intellectual disabilities also depends upon their environment. In this section we describe a theoretical model (Thompson et al. 2009) which describes the factors affecting the demand for support. One of the underpinnings in the support model as described by Thompson et al. (2009) is the appreciation of the circumstances and environment within which behaviour occurs. This is consistent with Andersen's theoretical model in which the influence of individual characteristics on care need cannot be separated from the environment in which someone lives (Andersen & Newman 1973; Andersen 1995; Babitsch et al. 2012). That environment is for example defined by the prevailing opinions on disability and inclusion. In this report we follow this theoretical concept of the environment being an important factor for care need. We do so because the interplay of dealing with a complex society and care-related factors has been a leading cause of the growth in demand for care and support in the Netherlands (Woittiez et al. 2014a). Building on this idea, we see a person's demand for support as a result of personal capacity and the context in which they function. Or, as Thompson et al. (2009) put it: 'Support needs are the result of a mismatch between personal competency and environmental demands'.

The support model is also consistent with the socio-ecological model in which it is assumed that a person's functioning depends on person-specific and setting-specific factors as well as the match between individuals and their environment. Human Performance Technology (HPT) theorists also assume that human functioning is the product of interactions between a person's behaviour and his or her environment (Gilbert 1978; Thompson et al. 2009)). In the HPT model created by Wile (1996), human performance is assumed to be influenced by organisational systems, incentives, cognitive supports, tools, physical environment, skills/knowledge, and inherent ability.
In our theoretical model, the provision of support is determined by an interplay of the support needs, informal care and the care system in which the access to and types of care are specified. For the Netherlands and the three other regions in our comparison, we present a brief description of both the care and support system for adults and children as well as the education system for children with intellectual disabilities. The support may vary from personal care to nursing care, mentoring and treatment delivered as ambulant support and to residential or crisis support.

In short, in this report we see that a person's demand for support is the result of their personal capacity and the context in which they function. This conceptual framework recognises the role played by the social environment as well as the prevailing care system (see Figure 1.1).

Figure 1.1
Supports model



Source: Thompson 2009, SCP treatment

1.5 Care and support for people with intellectual disabilities in England, Flanders and Ontario

As the foregoing has made clear, whether and to what extent people with intellectual disabilities have a demand for support depends in large part on the environment, and thus the country or region in which they live. Since regions may differ in their attitudes towards people with intellectual disabilities and in the organisation of care and support for them, the demand for support by people with intellectual disabilities may also differ between regions. This makes an international comparison useful in better understanding the development in demand in the Netherlands. We chose regions which differ from the Netherlands in various aspects.

England is included in our study since it organises its care and support system in a way that has recently been adopted in the Netherlands (see also Chapter 3).[18] Social care services are decentralised: in England local authorities are responsible for arranging the funding and provision of social care services for people with intellectual disabilities. In contrast with the Netherlands, the provision of services in England is mainly in the hands of the private and voluntary sector. England is deinstitutionalising the care and support for people with intellectual disabilities.
In the federal state of Belgium, *Flanders* organises care and support for people with intellectual disabilities in similar ways to the Netherlands in several respects (see Chapter 4).[19] Like the Netherlands, Flanders is deinstitutionalising the care and support for

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[18] Since the organisation of care and support in the UK differs between regions, we have opted for one specific region, namely England.

people with intellectual disabilities. There are also differences between the two countries/regions. Funding is centralised in Flanders, but much less so in the Netherlands since the introduction of the new Social Support Act in 2015 (Wmo2015). In Flanders, formal responsibility for care and support lies with the government and the recipient's family. The Netherlands is beginning to move from a country in which responsibility lies completely with the government towards being a country in which responsibility is shared with the family.

We also included Ontario, a province of another country (Canada) (see Chapter 5). Ontario has virtually no residential institutions for people with intellectual disabilities. Children and adults with intellectual disabilities are included in Ontario's communities. They receive support from their families, friends and community-based agencies.

1.6 Method: statistics, interviews and literature

We focus on demand because it can be seen as a proxy for the need for care and support. We define the publicly financed demand for care and support as the number of people who are eligible for care and support within their regional system. This means that the target group in each region may differ. Eligibility decisions are based on needs assessments.

A needs assessment of a person's care needs may lead to either a positive or negative assessment. In the event of a negative assessment the care need does not lead to demand for publicly financed care and support and the care need is either met by informal carers or remains unmet. A positive assessment leads to demand for publicly financed care and support. This demand can be met by the provision of publicly funded care and support; we term this 'use of care'. If there is not enough supply to provide help to those with a demand for care and support, this will lead to unmet needs and/or waiting lists.

We investigated the development of the demand for care and support (research question 1) by looking at national statistics and literature. If information on the **demand** for care was unavailable we looked at data on **use** of care and support and **waiting lists**, since together they give an indication of demand. Use of care is affected by the system and budgets in a region to a greater extent than demand.[20] To obtain as complete a picture as possible we also looked at data on needs assessments and budgets.

To ascertain which causes might have influenced the observed developments (research question 2), findings from the national and international literature and policy documents on the subject of the demand for care and support by people with borderline or other intellectual disabilities were studied. To this we added information from interviews

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[19] Since the organisation of care and support in Belgium differs between regions, we have opted for one specific region, namely Flanders.

[20] Demand may also be affected by the system through the assessment process and eligibility constraints. In addition to the assessment process and eligibility constraints, use of care also depends on the budgets available to actually provide care and support.

conducted with experts in the field in the three regions. We interviewed a variety of people. Some experts are engaged in research on the topic or publish advisory reports. Others are involved in shaping care policy, supervising care institutions or care allocation, providing care or looking after (the interests of) care recipients. A list of interviewed experts may be found in Appendix A. We selected potential interviewees by first addressing the most influential persons in the field, based on the existing literature and policy documents.

We then used the snowball method, by asking these potential interviewees to suggest names of people they felt should definitely be included in this research. We also used our personal networks to find appropriate interviewees. We were able to interview six experts for England, twelve for Flanders, and seven for Ontario. All these experts are committed to people with intellectual disabilities. For Ontario, it proved to be very difficult to interview experts face-to-face. We therefore used various methods for the interviews: one expert completed a written questionnaire, one was interviewed by telephone and with five others we held a conservation on the subject for about an hour during a conference. Appendix C contains the questionnaire that was used as a guide in the interviews.

In addition to providing answers to the research questions, the interviews yield supplementary material that we did not intend to collect, but which provide useful clues for considering the way care and support is organised in the Netherlands. Besides giving answers to the research questions, each chapter on a specific region also reports these considerations.

In the Netherlands, care and support for people with intellectual disabilities fall under the responsibility of the Ministry of Health, Welfare and Sport. In our selected regions this care and support might fall under several government ministries; whether or not this is the case forms part of our research. Some countries use the term ‘care’, while others refer to ‘support’. Throughout this report we use the term ‘care and support’, to include all kinds of services to support people with intellectual disabilities.

1.7 List of abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
HPT	Human Performance Technology; WHO-ICF: World Health Organization International Classification of Functioning, Disability and Health
ID	intellectual disability
Wlz	Wet Langdurige Zorg / Long Term Care Act
Wmo	Wet maatschappelijke ondersteuning / Social Support Act

2 The Netherlands: Growing demand for care and support as a result of a more complex society

> *All kinds of social problems mean the group with an IQ between 50 and 85*
> *have lost their way... The sector has now developed to keep pace with this trend:*
> *there is now a wide range of ambulant help for people*
> *with mild intellectual disabilities.*
> (Source: one of the interviewed experts in the Netherlands)

In this chapter we discuss the growth in demand for care and support in the Netherlands and its causes in more detail than in the previous chapter. Demand for care and support for people with intellectual disabilities has been growing rapidly in the Netherlands in recent years. The growth in demand has been especially marked (15% per year between 1998 and 2011) among people with borderline intellectual disabilities (IQ between 70 and 85). Demand also grew among people with mild intellectual disabilities (IQ of 50-69), though to a lesser extent (7% per year) (Ras et al. 2013). Woittiez et al. 2014a cite digitalisation, fewer simple jobs, less practical education, more diversity in supply, more and earlier diagnoses as drivers of the rapid growth in demand for care and support. The growth seems to have continued in more recent years; between 2012 and 2016 the number of people with intellectual disabilities who have an assessment for more intensive forms of residential care provided under the Long Term Care Act-care grew by 7% per year (Rebel 2017). From 2015 onwards – the year of introduction of the Wmo2015 – the total number of people with ID demanding or using ambulant care and support is unknown.
The purpose of this chapter is to provide input for the comparison of the growth in demand for care and support in the Netherlands and its causes with that in other regions. To that end we present a summary of the findings of Woittiez et al. 2014a[21]. We extend this summary with an update of the latest policy changes and figures.

2.1 Vision and definition of people with intellectual disabilities

“The Netherlands healthy and well”; this is the motto of the Ministry of Health, Welfare and Sport (VWS). The ambition of the Ministry of VWS is to keep everyone healthy as long as possible. The Ministry also seeks to support people with a physical or mental limitation and promote social participation (VWS 2017). According to the VWS Policy Agenda (VWS 2017), the main question when dealing with care is ‘what do you need?’. For people with intellectual disabilities (ID) the question becomes: ‘what do you need to function as independently as possible with the highest possible quality of life?’. Since 2015 care has

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[21] The quotes in this chapter are based on the interviews that were held for the research reported in Woittiez et al. 2014a.

been organised in such a way that an individual approach is possible: care in or close to the recipient's home where possible, further away where necessary.

Definition of intellectual disabilities

The Netherlands adopts the international definition set out in DSM-5 (CIZ 2017). According to this definition, the intellectual disability must have started before the age of 18 and concerns disabilities in cognitive functioning as well as in adaptive functioning such that the person concerned cannot function independently in daily life. Those with an IQ between 50 and 69 are classified as having mild intellectual disabilities, while people with an IQ below 50 have severe intellectual disabilities. In addition to the DSM-5 definition, people with an IQ between 70 and 85 combined with problems with adaptive functioning are also regarded as having intellectual disabilities, referred to as borderline intellectual disabilities.

According to the Dutch Care Needs Assessment Centre (CIZ), a person is eligible for access to ID care and support ('grondslag' intellectual disability) if he or she has an IQ below 70 and if the disabilities in adaptive functioning are such that permanent support is needed. If he or she has an IQ between 70 and 85 and if serious disabilities in adaptive functioning are present and intensive support is needed, that person also has access to disability care.

The definition used in practice in the Netherlands thus differs from most international standards in the sense that in most other countries people with an IQ between 70 and 85 and with problems with adaptive functioning are not regarded as having intellectual disabilities (Moonen 2015; Moonen 2017). On the other hand, the Dutch definition used in practice takes into account the problems associated with functioning adequately in society. As such it matches the supports model in which intellectual disabilities are defined on the basis of the mismatch between competence and functioning in the environment.

2.2 Care and (financial) support for people with intellectual disabilities

There are a number of laws regulating the entitlement to care and (financial) support for people with intellectual disabilities in the Netherlands. Different laws apply for adults and young people, and various government ministries are involved. The majority of care and support for both adults and young people is under the aegis of the Ministry of Health, Welfare and Sport (VWS). Financial arrangements for adults are come under the Ministry of Social Affairs and Employment, while some parts of care and (financial) support related to education are the responsibility of the Ministry of Education, Culture and Science.

2.2.1 Care and support for adults with intellectual disabilities

The Long-term Care Act (Wlz)

Since January 2015 the Long-term Care Act (Wet langdurige zorg - Wlz) has covered the most intensive forms of care and supervision. This comes under the responsibility of VWS. To receive care, a person must be assessed as having a care need by the Care Needs Assessment Centre (Centrum indicatiestelling zorg - CIZ). The most important condition for eligibility is the need for 24- hour care and support close by. An IQ-test is also obligatory. The care may incorporate several care functions or types of care, such as personal care, nursing care, support, treatment and/or residence. The type of care incorporated in the assessment depends on the nature of the applicant's disability, but also on what their social network can offer by way of care and support.[22]
Until January 2015, care and support for people with intellectual disabilities was regulated through the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten - AWBZ). Applications for help were mainly submitted through a Care Needs Assessment Centre. Since January 2015, only the most intensive elements of the care and support provided through the AWBZ fall under The Long-term Care Act; some elements fall under the Social Support Act (Wmo), and others under the Care Insurance Act (Zvw), see below.

Social Support Act (Wmo)

Most less intensive care and support provided in the home setting, falls under the responsibility of municipalities/local authorities and is covered under the *Social Support Act* (Wmo; Wet maatschappelijke ondersteuning). This law applies to all people living independently in need of support due to a physical, intellectual or mental disability. Examples of the support provided are household help, individual or groups support, appliances and sheltered living. The support may be provided in kind or through a personal budget. An IQ-test is not obligatory for eligibility for Wmo-funded support[23] and eligibility may differ between municipalities, which are required to conduct an assessment ('onderzoek') to enable them to estimate the support need adequately. This assessment includes a conversation between a support worker and the potential client, as well as collection of supplementary information from the general practitioner, support professional or other practitioners.[24]

Care Insurance Act (Zvw)

From January 2015, personal and nursing care has been provided under the Care Insurance Act (Zvw). This care is financed by the recipient's health care insurance. It covers help with activities such as getting up and showering, treatment or administering medication. Applications for help are arranged via a home care institution or nurse.

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[22] For a more detailed description of the Wlz, see e.g. Gijzel et al. 2017.

[23] Since there is no distinction between different groups of clients.

[24] For a more extensive description of the Wmo see e.g. Ham et al. (2018).

2.2.2 Care and support for children and young people with intellectual disabilities

Youth Act

In the Netherlands, care and support for children and young aged up to 18 with intellectual disabilities has been provided under the *Youth Act* (Jeugdwet) since January 2015. The Youth Act assigns responsibility to municipalities/local authorities.[25] Parents are responsible for their children, and only if parents and their social networks fall short and the care and support is not deemed to be 'usual care' (*gebruikelijke zorg* in Dutch), can publicly funded care and support be provided. Examples of the support provided include individual or group support, treatment, short stay residence and sheltered accommodation. It can be provided in kind or through a personal budget. Access to care provided under the Youth Act is determined by an assessment made at local level by district teams (*wijkteams*).[26] If it is clear that the intellectual disability means that children will need lifelong care and support, access to care provided through the Wlz is possible.

Appropriate Education Act

The aim of the *Appropriate Education Act* (*Wet Passend Onderwijs*), in force from August 2014, is that every child attends a regular school that must provide education suited to his/her talents and capabilities. For children who need extra assistance, schools adapt their teaching to the individual child's development. All schools have a 'duty of care' to offer an appropriate place to children who need extra assistance. This implies that every child will in principle attend a mainstream school, or if that is not possible, a special school.[27]
In the Netherlands, 20% of the children with intellectual disabilities were in mainstream primary schools in 2009[28]. More recent figures are not available but since the introduction of the *Appropriate Education Act* more children have attended regular schools.

2.2.3 Financial help and labour market support for people with intellectual disabilities

Participation Act

Since January 2015 the *Participation Act* (*Participatiewet*) has applied for people who need assistance to get a job due to a physical, mental or intellectual impairment. The goal is to help them work in a mainstream job if possible and if that is impossible to pay them a living wage. If necessary, sheltered employment must be offered. The Act also applies for young people with insufficient employment capacity to earn a living independently. The Participation Act assigns responsibility to municipalities/local authorities and falls within

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[25] Until January 2015 children with intellectual disability who needed care and support applied for support from the AWBZ via a Care Needs Assessment Centre just like adults did or via a Bureau for Youth Care (Bureau Jeugdzorg in Dutch).

[26] For a more extensive description of the Youth Act see for example Pommer and Boelhouwer (2017).

[27] For a more extensive description of the Participation Act see for example Pommer and Boelhouwer (2017).

[28] This percentage is found in Smits (2010). More recent numbers were not found.

the remit of the Ministry of Social Affairs. The Participation Act replaced the *Sheltered Employment Act* (WSW; Wet Sociale Werkvoorziening), *Work and Social Assistance Act* (WWB; Wet werk en Bijstand) and partly the *Invalidity Provision (Early Disabled Persons) Act* (Wajong; Wet arbeidsongeschiktheidsvoorziening jonggehandicapten). Until January 2015 sheltered employment was provided under the WSW. It was intended for people with a physical, mental or intellectual disability who could not work in normal circumstances. Until January 2015 the Wajong applied for people who already had an impairment before the age of 18 which meant that they would never be able to work, or only partly. They received benefit.[29] In 2006, 31% of people with ID receiving a Wajong benefit were in work (Jehoel-Gijsbers 2010; Versantvoort & Van Echtelt 2016). More recent figures do not allow us to differentiate between people with and without ID. The share of people receiving a Wajong benefit declined from 26% in 2008 to 22% in 2014 (Versantvoort & Van Echtelt 2016).

Equal Treatment of Disabled and Chronically Ill People Act

The principle of *the Equal Treatment (Disabled and Chronically Ill People) Act* (*Wet Gelijke Behandeling*), in force since 2003, is that disabled and chronically ill people must be able to participate fully in society. This means they must be able to play their role in society with or without support, in a way that they themselves consider meaningful. It applies to housing, education, labour, social relations and leisure time. The UN Convention on the Rights of Persons with Disabilities was ratified in the Netherlands in 2016.

2.3 Figures on growth in demand for care and support

Number of people with intellectual disabilities

It is unclear how many people have intellectual disabilities in the Netherlands. According to calculations by SCP, in 2013 there were around 142,000 people in the Netherlands with an IQ below 70 (Woittiez et al. 2014b). 68,000 of them had severe intellectual disabilities, meaning a prevalence of 4.1‰, 74,000 had mild intellectual disabilities (a prevalence of 4.4‰) according to rough estimates. There are approximately 2.2 million people in the Netherlands with an IQ of between 70 and 85. Based on the scarce information available, SCP estimates that the number of people with borderline intellectual disabilities (IQ between 70 and 85 and accompanying problems in adaptive functioning) may be around 1.4 million.

Growth in demand for care and support

Roughly 166,000 people in the Netherlands with intellectual disabilities applied for care and support in 2011[30], around 0.9% of total Dutch population. Of this total of 166,000, roughly 67,000 had severe intellectual disabilities, over 72,000 had mild intellectual

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[29] For a more detailed description of the Appropriate Education Act see e.g. Pommer and Boelhouwer (2017).

[30] The IQ distribution could only be estimated for 2011 and some earlier years.

disabilities and just under 37,000 had borderline intellectual disabilities (Ras et al. 2013). The expenditure on the most intensive care falling under the Wlz amounted to around 6 billion euros in 2016, 0.8% of Dutch GDP. The number of people with disabilities (including non-ID) receiving care and support financed through the AWBZ and excluding personal budgets was 81,000 in 2014.

Between 2007 and 2011, demand for care and support by people with borderline intellectual disabilities grew especially rapidly (15% annually). The number of applicants with mild intellectual disabilities rose by 7% and the number of applicants with severe intellectual disabilities grew by 0.9% (Ras et al. 2013). Earlier studies by SCP show that there was also strong growth in demand for care and support for people with intellectual disabilities in the period 1998-2008 (Ras et al. 2010). Between 2012 and 2016 the number of people with intellectual disabilities with an assessed need for the most intensive forms of care provided through the Long Term Care Act grew by 7% per year (Rebel 2017).

Information on demand for ambulant care and support (provided under the Wmo) by people with intellectual disabilities is not available because it is not known what type of disability a Wmo-client has.

Like demand for care and support, use of care and expenditure on care increased by 6% per year between 2007 and 2011 (Van der Kwartel 2013; Ras et al. 2013). It is not possible to present more recent information on total expenditures and use of care.

We have no information on the total number of people with intellectual disabilities on waiting lists, including people waiting for Wmo-care and support. The number of people with a disability (ID or non-ID) waiting for Wlz-care was just over 3,500[31] in October 2017 (Zorginstituut Nederland 2018). This is around 5% of the 75,000 people with ID receiving Wlz-care in 2016.

2.4 Expert views on factors causing growth in demand for care and support[32]

2.4.1 Factors related to a complex society

Societal developments seem to have played an important role, especially in the growth in demand for care and support among people with mild and borderline intellectual disabilities. In today's more complex world, it is increasingly difficult for these people to function adequately without support.

Employment

One of the reasons for this greater difficulty is the change in the content of employment that is suitable for this group of people with intellectual disabilities. They have to rely on work activities that are simple and routine. However, today most of this work has to be

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[31] The total number of people actively waiting for ID care for longer than six weeks, with or without care and support, and of people not actively waiting for ID care, with or without care and support, asat 1 October 2017 (33+59+804+2791=3687).

[32] Citations in this section have been reported previously in Dutch in Woittiez et al. 2014a.

carried out increasingly independently and efficiently, making it more and more unsuitable for people with intellectual disabilities. In addition, many simple jobs have disappeared.

> *Before the introduction of flexible employment, we had a woman working in our department with an intellectual disability. She worked there for at least fifteen years. It was never a problem until the new system came in. Her job was to manage the birthday collection box, go round the department with a card if someone was ill, but that's not possible any more, because we no longer have fixed work stations. She also used to water the plants, but the introduction of the clean desk policy means they've all gone. She used to make photocopies, but that's also disappeared with the introduction of the paperless office. It's all gone now, and there's no work for her now.*

Education

A more complex society not only manifests itself on the labour market, but also in the classroom. Today's education system is larger in scale and less structured, and the link with the world of work has weakened.

> *The increases in scale have led the education system to develop in a certain direction, which means this group of vulnerable young people especially have been left behind. Schools have become too big: a regional training centre has around 1,500 students. A school like that is no good for young people with a mild intellectual disability who often already have lots of problems at home and who are not encouraged by those in their home setting to do their best.*

School dropout, although significantly reduced in recent years (TK 2016/2017), and lack of appropriate employment takes away the structure that people with borderline intellectual disabilities need. They are consequently forced to rely on the care system.

Daily life

Even everyday life activities, such as travelling by public transport (using a public transport smartcard) or arranging banking affairs, (e.g. online) are more complicated.

> *Everything has become more complicated. Organising your banking affairs and arranging household help, for example. It was simpler in the past. Even something as simple as travelling on public transport has become complicated. In the past, with the old 'strip tickets', you could see how many strips you still had left. But you can't do that with the new public transport smartcard; you only get to see the balance on your card when checking in and out, but only for a very short time. A great many things today are arranged via the Internet and there are also more and more online shops.*

Life is also becoming more complicated because we have to make all kinds of choices, for example about which energy supplier we want to use and what kind of insurance we wish to purchase. It is also hard to judge which mail is serious and which is advertising.

Inclusion

The demand for care and support is also intensified by the internationally widespread view (United Nations 2006) that people with intellectual disabilities should play as full a part in society as possible. Playing a full part in society means they should have the same daytime activities (school or work) as people without intellectual disabilities, and live their lives as independently as possible. If they have difficulty in doing so, they need care and support. It is not self-evident that care and support can be provided by the social network, since people with mild or borderline intellectual disabilities often have a weak network. In that case, publicly financed care and support is required.

2.4.2 Care system-related factors

Access open to people with an IQ equal to or higher than 70

Half the annual 6% growth in demand for care and support is attributable to the increase in the number of people with borderline intellectual disabilities. Slightly less than half of the yearly increase of 6% is due to a rise in the number of people with mild intellectual disabilities (Woittiez et al. 2014a). In other words, a new type of client has emerged requiring care and support.

> *All kinds of social problems mean they have lost their way. A completely different help system needs to be developed for them from the institutionalised care of the past. The sector has developed in line with these trends. There's now also a wide range of ambulant care available for people with a mild intellectual disability.*

Among the issues that people with borderline intellectual disabilities often have to deal with are behavioural problems (Peltopuro et al. 2014; Greenspan 2017). As a result, there seems to be an overrepresentation of people with mild and borderline ID in the justice system, although the numbers vary considerably (Holland et al. 2002). The overrepresentation in the Netherlands is cited in Wegwijzer jeugd en veiligheid; Kaal (2016) (see also Chapter 1). Kaal presents the following figures, but casts doubt on their reliability. Based on diagnostics using an IQ-test, the prevalence of people with mild intellectual disabilities in regular detention is 10%, in special units 15-20% and in forensic psychiatric institutions 20-25%. Based on a screening instrument such as SCIL, the prevalence is higher still, for example 30-45% in regular detention (Kaal 2016). These prevalences are much higher than the estimated 4.4‰ in the population as a whole. Also the interviewees recognise the problem.

> *Young people with a mild intellectual disability come into contact with the justice system because they fall in with the wrong friends...They are asked by the other youngsters to do the rotten jobs... standing lookout. And of course they are the first to be caught, because they are slower, take longer to understand what's happening.*

Another interviewee put it as follows:

> *The problems facing people with mild intellectual disabilities are considerable. Criminality, trauma, complete disassociation, inability to form relationships with others, lack of trust in other people. These latter aspects, trusting other people and forming relationships, is precisely what people with an intellectual disability need to learn at the earliest possible stage. They need one person with whom they can form a bond, who supports them at times when they need it, but who also leaves them alone when they are able to manage by themselves.*

Earlier diagnosis

Driven by the idea that detecting intellectual disabilities early in life is beneficial, people are being assessed at younger ages and more people are being diagnosed. The advantage of an early diagnosis is the ability to offer (light forms of) help at an early stage in order to prevent problems getting out of hand later on (Hoekman 2015). The disadvantage is the stigma that the person concerned acquires at a young age. Furthermore, a diagnosis of intellectual disabilities creates a tendency to look at problems instead of someone's capabilities, prompting people to seek (publicly funded) care and support.

> *There are a number of factors behind the much earlier diagnosis. It produces what I call 'sickness profit', extra resources that can be used when someone is given a particular label. If a child is a bit difficult, the school has to pay for the extra attention and support needed to ensure that the child functions adequately from its own regular funding. If that same child is diagnosed as having an intellectual disability, the school can obtain additional funding. The school 'profits' from this, in other words. In order to receive a bit of extra funding, a child currently has to have a label, and that's wrong to my way of thinking, but how you change a system like that I don't know.*

Supply-created demand

Another factor which plays a role in the growth in demand is the sharp rise in availability of care and support. The residential capacity in the Netherlands increased by 6% per annum between 2005 and 2013 (Van Staalduinen et al. 2014). New care providers have entered the 'care market' and have instigated new forms of care and support, such as care farms and various parent initiatives. The existing care providers have followed the example of these new care providers. It is likely that the (new and extra) supply has created demand: latent demand might have been made manifest by the more varied range of care and support available.

> *Every [private] Institution could offer support if there was a function-specific assessment. This created a reservoir of possibilities. Institutions could now also offer combinations of care. For clients, this meant that they no longer had to spend their days with their family or friends, but could also access* AWBZ*-funded placements.*

No overflow?

Calculations suggest that the growing demand for care and support for people with intellectual disabilities does not appear to be due to an 'overflow' from other sectors[33]. By overflow we mean that clients in other sectors of the health care system apply for ID care. They might do this because access to care has become more difficult in other sectors of the health care system or because they think that the care and support in the ID-sector is more suitable. For this assumption to hold, we would expect the growth in the intellectual disability sector to be accompanied by a decline in demand in other sectors, such as mental health care and youth care. That is not the case, however: other sectors have also experienced strong growth in demand; demand for youth mental health services, for example, grew by 10.3% per year between 2001 and 2011. Overflow from these other sectors thus seems unlikely to be the main cause of the growth in demand for care and support for people with intellectual disabilities. There could also be overflow from other sectors such as the Wmo or even the criminal justice system, but we have no information on this. Moreover, from the point of view of quality of care, it is less important to know from which sector care and support is delivered, as long as the care and support is appropriate and sufficient.

Lack of financial incentives

What may have contributed to the growth in demand for care and support is the lack of financial and other incentives to constrain that demand at that time (before 2011). Applicants for care and support did not have a financial incentive because there were virtually no co-payments[34]. Assessors, care administration offices and care providers also had no incentive because the right to care was laid down in law (AWBZ) and the cost of care was always reimbursed.

> *In my view, no one benefits from putting a brake on the demand for care, except the government from the macro-perspective of rising care costs. At micro-level, everyone has an interest in simply delivering the care that is required. That applies for both the patient and the caregiver, as well as for all the other people involved.*

Substitution from informal to formal care

People with borderline or mild intellectual disabilities often have a 'weak' social network. They are forced to turn to the care system, leading to growing demand for (publicly funded) care and support. In addition, many people feel it is the government's task to provide care and support.

> *At present, people don't automatically think of organising the care in the recipient's own circle, but immediately go in search of professional care. That's also because there is an*

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[33] Rebel 2017 agrees that the figures offer no evidence of overflow, but states that this was mentioned by experts.

[34] The financial incentive is only one of the instruments which may induce people to apply for less care.

> *entitlement, so someone who needs care is quickly inclined to think, 'why shouldn't I enforce that entitlement?'*

According to another interviewee the knowledge about the possibilities for receiving care has led to growth in demand as long as the clients have the feeling that they will benefit from formal care.

> *As there is more familiarity with applying for all kinds of care (provisions), people increasingly tend to do so. If people hear from each other what is possible, because they are reasonably well organised, they become even better organised, and that makes it easier for them to obtain care.*

2.4.3 Other factors

Demographic factors seem to have played only a minor role in the growing demand for care and support. The numbers involved in risk factors, such as premature birth, low birth weight and higher age of mothers, are small, as is the higher life expectancy. These factors offer only a very partial explanation for the substantial growth (Woittiez et al. 2014a).

2.5 Summary

According to the international consensus (United Nations 2006), people with intellectual disabilities should play as full a part in society as possible. This means they should have the same daytime activities (school or work) as people without intellectual disabilities, and live their lives as independently as possible. On top of this, there is increasing social pressure on people to perform 'adequately'. But more and more people with intellectual disabilities are failing to function well in today's more complex Dutch society. If they have difficulty in functioning well, they tend not to seek support from those close to them (informal support), but from professionals. This tendency is reinforced by the incentives and lack of restrictions in the care system, and by the increased availability of care and support.
The interplay of social and care-related factors, rather than an increase in the risk factors for intellectual disability, has led to growing demand for care and support in the Netherlands.
It is not possible to say precisely how much the many causes of the growth in care and support have contributed to the increase in demand for care and support, because the necessary data are not available. Only the increase in the number of applicants with borderline or mild intellectual disabilities and the growth in the availability of care services can be quantified.

As mentioned earlier, some themes emerged in the interviews that may be useful for considerations with respect to the way care is organised in the Netherlands. For instance, it was mentioned that people with ID are very vulnerable, and may end up in a criminal environment. They may be easily caught, and end up in jail. There are indeed indications that people with (borderline) ID are overrepresented in prisons. Trusting relationships with

others may prevent this type of problems, but they need help to establish such relationships.
Earlier diagnosis may prevent escalation of problems, but may have increased demand (for less intensive care and support), but it also has a downside according to the interviewees, in that it may lead to a stigma at a young age, hampering further development. In addition a diagnosis of intellectual disabilities creates a tendency to look at problems instead of someone's capabilities, prompting people to seek (publicly funded) care and support.

2.6 List of abbreviations

AWBZ	Algemene Wet Bijzondere Ziektekosten / Exceptional Medical Expenses Act
CIZ	Centrum Indicatiestelling Zorg/ Care Needs Assessment Centre
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
ID	intellectual disability
VWS	Ministerie van Volksgezondheid, welzijn en Sport / Ministry of Health, Welfare and Sport
Wajong	Wet arbeidsongeschiktheidsvoorziening jonggehandicapten / Disable Invalidity Provision (Early Disabled Persons) Act.
Wlz	Wet Langdurige Zorg / Long Term Care Act
Wmo	Wet maatschappelijke ondersteuning / Social Support Act
WSW	Wet Sociale Werkvoorziening / Sheltered Employment Act
WWB	Wet werk en Bijstand / Work and Social Assistance Act
	Zvw: Zorgverzekeringswet / Care Insurance Act

3 England: rising numbers of people in need but levelling numbers of care and support users[35]

> *What we are witnessing now is the strange contradiction*
> *that people are more aware of (learning) disability than they have ever been,*
> *but the number of people receiving care and support diminishes.*
> (Source: one of the interviewed experts in England)

To compare Dutch care and support for people with intellectual disabilities, England – the largest country in the United Kingdom – is a good case. It organises and finances its care and support system in a different manner from the Netherlands. Care and support services in England are dominated by the model of marketisation.[36] Since the 1980s, the provision of care and support services in England has shifted from public to private agencies (Boyle 2011). Furthermore, there has been a shift in provision from health services to social care services (Boyle 2011). Local authorities are responsible for arranging (the funding of) social care services for people with intellectual disabilities. England seems to be a forerunner of the Dutch system. In 2015, municipalities in the Netherlands were made responsible for providing a substantial part of the care and support for people with intellectual disabilities. It is therefore interesting to examine how the number of people receiving care and support in this group has developed in England.

In England, people with cognitive impairments are classified as having a 'learning disability', and this term is also used in policy documentation. English academic literature mainly uses the term 'intellectual disabilities'. For the sake of consistency, we use one label throughout this chapter: 'learning disabilities', but in the summarising chapter we will use the term 'intellectual disabilities' so as to be consistent with the chapters on the other countries.

To investigate the number of people with learning disabilities with a demand for care and support in England, and the development in that demand over time, we have to rely on data recording the *use* of care and support. This is because England does not collect data on the *demand* for care and support. This different method of data registration makes it harder to compare the English case with the Dutch situation. Nevertheless, we will attempt to identify as accurately as possible the similarities and differences between the Netherlands and England in the development of the number of people with learning disabilities who have a demand for and use care and support.

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[35] This chapter has been written by Lisa Putman and Isolde Woittiez.

[36] The welfare services in England have the same model.

3.1 Vision and definition of people with learning disabilities

At the start of the new millennium, people with learning disabilities became a cause for concern in English policy. Under the Conservative government of the 1980s, people with learning disabilities and the services that support them had not been a priority. That changed when the 'New Labour' government came to power in 1997 (Whitehead et al. 2008). With the publication of the White Paper[37] *Valuing People* (Department of Health 2001) persons with learning disabilities became a policy priority. Central to *Valuing People* is social inclusion in the widest sense.

> *All people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens.* (Department of Health 2001)

The White Paper addressed issues such as housing, education, general health and employment, and introduced concepts such as advocacy, person-centred planning, choice and control. *Valuing People* became policy in 2001. Although considerable progress had been made by 2004, there appeared to be a wide gap between the rhetoric and reality. For a few people life got a lot better, for some it got a little better, but for most there was little change (Whitehead et al. 2008). Almost no change had been made as regards employment (Whitehead et al. 2008). To extend and refresh *Valuing People*, a new three-year delivery programme was agreed, *Valuing People Now* (Department of Health 2009b). The priorities remained – rights, independent living, control and inclusion[38] –, but *Valuing People Now* had a wide-ranging performance framework, stronger links between the implementation team and the social care delivery chain, and strong ministerial support in order to bring about cross-government support (Whitehead et al. 2008). In addition to the priorities in *Valuing People Now,* an extra White Paper was introduced to improve the labour market position of people with learning disabilities, *Valuing Employment Now* (Department of Health 2009a). In 2009 the British government also ratified the United Nations Convention on the Rights of Persons with Disabilities. When the coalition government led by David Cameron came to

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[37] Besides acts of law and government strategies, the government publishes White Papers to provide information or proposals on how to resolve particular issues.

[38] The first guiding principle 'rights' means that people with learning disabilities and their families have the same human rights as everyone else. The second priority, 'independent living' is about (1) greater choice and control over the support people with learning disabilities need in their daily lives; (2) greater access to housing, education, employment, leisure and transport opportunities and (3) participation in family and community life. The aim of the third guiding principle 'control' is to offer people with learning disabilities the information and support to make informed decisions about their own lives. Finally, the fourth priority, 'inclusion' signifies the ability to participate in all aspects of community – to work, learn, get about, meet people, be part of social networks and access goods and services – and to have the support to do so (Department of Health 2009a).

power in 2010, *Valuing People Now* continued as government policy (Blamires 2015; Melling 2015).

According to the White Papers, a person with intellectual impairments has a significantly reduced ability to understand new or complex information and/or to learn new skills; in general this person has a low intelligence quotient (IQ) (below 70). To label impairments as learning disabilities, the impairments must have started before adulthood and must have a lasting effect on development. Someone with a low intelligence quotient quite often also has problems with social functioning and communication skills: a reduced ability to cope independently. To be labelled as having learning disabilities, someone with a low intelligence quotient also needs to have this impaired social functioning (Department of Health 2001). In its policy documentation, England follows the international definition(s) of intellectual disabilities; its definition is broadly consistent with the WHO International Classification of Disease (ICD-10; www.bristol.ac.uk). England resembles the Netherlands to a large extent but differs in one respect: in the Netherlands, people with an IQ between 70 and 85, whose functioning is referred to as borderline (Snell et al. 2009), are also entitled to publicly funded care and support when they have problems in social functioning. In England they are not eligible for statutory social care and support (Department of Health 2011).

3.2 Care and (financial) support for people with learning disabilities

Since people with learning disabilities have difficulties in coping independently, in most cases they need help. Depending on the severity of the learning disability, the type of help varies. It might be care and support to help them function properly in school, get in and out of bed, go to work, see friends or be part of the community. Help might also involve emotional support at times of difficulty and stress (Department of Health 2015).

In England, people with learning disabilities can apply for all these different kinds of help. Local authorities are responsible for the care and support services, also known as social care services. They are the planners, commissioners and monitors of services contracted out to non-statutory providers in the private and voluntary sector.[39] Responsibility for the health care services in England, provided through the National Health Service (NHS), lies with the Department of Health (see Appendix D for a more detailed description of the NHS).[40] From the inception of the NHS in 1948, health care and social care services have

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[39] This mode of delivery started during the 1980s. Until that time local authorities were monopoly providers of care. With the National Health Service and Community Care Act of 1990 the Conservative government introduced an 'internal market' through a split between the 'purchasing role' (i.e. local authorities) and the 'providing role' (i.e. care providers (in the private and voluntary sector)): a mixed economy of care (McLaughlin 2009; Boyle 2011).

[40] The NHS provides primary, secondary and tertiary (or top clinical) care. The NHS is largely free at the point of use. The National Health Service and Community Care Act of 1990 not only created a mixed econmony of care for the social care services (see previous footnote), but also for the health care services delivered through the NHS.

been separated. Like the Netherlands, England has different legislation to provide social care services for children/ young people and adults with learning disabilities.
To compensate for the (extra) costs that come with having learning disabilities, people can receive benefits. Due to their learning disabilities some of them are unable to work, and need financial support. In the rest of this section we briefly describe the English legislation that regulates the different kinds of help for adults and children.

3.2.1 Care and support for adults with learning disabilities

The publicly funded care and support services for adults in England have recently undergone the most significant reform in 60 years: the introduction of the Care Act 2014. This Act fundamentally reframes the statutory duties of local authorities. Their tasks have changed from arranging services for specific client groups to promoting people's wellbeing. To ensure people's wellbeing, i.e. to enable them to have more control over their own lives and to help them remain independent (for longer), local authorities have to assess the needs of people who may require social care and have to arrange (the funding of) services for those who meet the eligibility criteria. The latter means that local authorities have to help out by guaranteeing that people receive the information and advice they need to make good decisions, and by ensuring that people can choose from a range of care and support services.
The Care Act 2014 introduced the right to an assessment for anyone in need of support, including carers and self-funders. When people's needs meet the national eligibility criteria,[41] local authorities have a duty to commission or provide help; this could be residential care or non-residential services. When local authorities decide that non-residential care is the most appropriate for a client, they first have to offer the client a personal budget instead of services to meet the assessed needs: the so-called 'personalised care and support'.[42] Clients do have to be assessed as willing and able to manage a personal budget. They can spend the budget as they see fit (with the responsibility of accounting), may receive a direct payment, or can tell the local authority how they would like to spend it. Furthermore, the budget can also be given to a separate organisation (for example a user-controlled trust) that will spend the money on care as the budget-holder wishes: the Individual Service Funds.[43]

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[41] People are eligible for social care services if they meet all of the three following criteria. (1) Needs should arise from or be related to a physical or mental impairment or illness. (2) These needs render them unable to achieve two or more outcomes from a specified list of ten outcomes, for example including maintaining personal hygiene or keeping their home sufficiently clean and safe. (3) Not being able to achieve the outcomes impacts the person's wellbeing. For more details on the national eligibility criteria, see www.nhs.uk (2018).

[42] The Care Act 2014 places personalisation on a statutory footing for the first time, providing those who are eligible with a legal entitlement to a personal budget.

[43] In practice there are wide variations across local authorities in how they do things, including many which impose quite severe restrictions on how people can use their 'personal budget'.

Based on the assessment, care providers formulate a 'care plan', in which care providers state the number of hours of support. Their ideas on what clients need could exceed the budget they have been assessed for, for example because care organisations have explicit ideas on what is best for clients or because care providers want to have professionalised social care staff with up-to-date expertise. Clients can decide to pay the extra costs or search for another care provider which adheres to the budget determined in the assessment.

To finance social care services, contributions are raised from both public and private parties. The public expenditure is the task of local government bodies (local authorities or councils).[44] Local authorities have considerable autonomy to decide on the allocation of funds. Care and support users contribute mainly through out-of-pocket expenses. Local authorities are free to decide whether and how much they charge non-residential care users (e.g. home care, meals-on-wheels); although almost all do charge (Boyle 2011).

3.2.2 Care and support for children with learning disabilities

As a responsibility of the Department for Education and the Department of Health, children and young people aged up to 25 years with disabilities or with special educational needs (SEN) can receive care and support based on the Children and Families Act 2014. Local authorities set out the education, health and social care provisions that are available for disabled children and young people with special educational needs at their schools and colleges. These provisions aim to help children and young people prepare for adulthood. One of the policy intentions of the change in legislation in 2014 is that the education for children with special needs focuses more on life after school than previously. For children and young people with more complex special educational needs for whom the school or college's provisions are not adequate, there are Education Health and Care (EHC) plans (www.gov.uk; Department of Education 2013). EHC plans are issued only after an EHC needs assessment. Based on this assessment process, local authorities decide whether or not there will be an EHC plan. If they decide to issue a plan they have to produce a draft for the parents or young person to consider, and they are asked to name the type of school/college they want e.g. mainstream or special school. Local authorities have a legal duty to ensure that the educational provision specified in the EHC plan is delivered. The local health care provider has a duty to arrange the health care provision specified in the EHC plan.

In 2015, 28% of children with special educational needs associated with learning disabilities were being educated in mainstream schools. The percentages are lower for children with severe or children with profound and multiple learning disabilities, at 21% and 19%, respectively (Hatton et al. 2016). By contrast, children with moderate learning disabilities

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[44] They receive their budgets from central government as part of the annual settlements The size of the grants has historically been calculated using information on population and social structure set against local income from council tax and business rates. Each local authority receives a basic amount per client, supplemented by an extra sum that takes into account local factors (mainly deprivation and local area costs) that affect service costs (Chinn et al. 2016).

mainly attend mainstream education, although the number of children with moderate learning disabilities attending primary school dropped by 2% annually between 2009 and 2015, to around 46% (Hatton et al. 2016).

3.2.3 Financial help and labour market support for people with learning disabilities

People with (learning) disabilities in England receive financial help. This may take the form of direct financial support,[45] but may also be in the form of policies on arranging employment or making employers aware of the job needs of people with learning disabilities. The Department of Work and Pensions is mainly responsible for both kinds of financial help.

To help with the extra costs caused by long-term ill health or disability there is a *Disability Living Allowance* (DLA) for children (up to 16 years) and a DLA for adults (16-64 years). Both allowances are tax-free benefits. The DLA for adults is being gradually replaced by the Personal Independence Payment (PIP). The Attendance Allowance is a tax-free benefit for people aged 65 years or over with a disability and a need for care and support.

The *Employment and Support Allowance* (ESA)[46] offers financial support to disabled people in England who cannot work, or if they are able to work they are offered personalised help. Depending on the severity of the disability, people are either placed in a work-related activity group or a support group. People receiving ESA in the work-related activity group have 'limited capability for work' because of their poor health, but are (eventually) able to work. They are required to participate in pre-employment coaching in order to improve their skills and to help set job goals. People with ESA in the support group have an illness or disability that severely limits what they can do. They are therefore not required to prepare for work. The level of the allowances is set centrally and differs between the two groups. The support group receives higher allowances.

Employment often provides the social structure people with learning disabilities need. However, most people with learning disabilities do not work;[47] in 2014/2015 their employment rate was 6%[48]. In assisting people with learning disabilities to get a job, the government today mainly relies on preventing employers from discriminating against them. The Equality Act (2010) protects people with learning disabilities from discrimination

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[45] Carers can also receive financial help: the Carer's Allowance (www.gov.uk). This benefit offers carers a sum of money to look after someone with substantial care needs. Carers can also apply for a Carer's Credit which they can use to prevent gaps in their National Insurance record due to caring responsibilities.

[46] ESA replaced three older benefits: Incapacity Benefit, Income Support paid because of an illness or disability, and Severe Disablement Allowance.

[47] Social workers could also help in looking for a job. In some cases care providers have several houses for supported living in a village and run a village shop. If they are able, clients help to manage the shop so that they build up day-to-day (work) routine and gain work experience.

[48] It is the rate for working age adults with intellectual disabilities in all forms of work, including paid/self-employment and voluntary (unpaid) employment known to councils with adult social service responsibilities.

in the workplace and in wider society.[49] Together with the United Nations Convention on the Rights of Persons with Disabilities, the Equality Act 2010 aims to help enforce, protect and promote the rights of disabled persons. Another way to help people with learning disabilities to get a job is to implement specific employment policies for this group of people. Since the 1990s significant progress has been made in the development of this kind of policy (Blamires 2015). An important policy document on employment for people with learning disabilities is *Valuing Employment Now* (Department of Health 2009a). It aims to improve the labour market position of this group of people by introducing and emphasising the importance of cross-government working; employment is not just the responsibility of the Department of Work and Pensions, but also of the Department of Health and the Department of Education.

3.3 Figures on growth in demand for care and support

It is hard to know how many people have learning disabilities. Government departments in England do not collect data on the presence of learning disabilities in the population, and learning disabilities are not recorded in the ten-yearly census of the UK population (Hatton et al. 2014; 13). Therefore, there is no definitive record of the number of people with learning disabilities. However, there are estimates.

Number of people with learning disabilities

The easiest way to estimate the number of people with learning disabilities is by using registration data on use of care and support. Data on the registration of people who use social care services only count the people who receive care and support, whereas there are also people with learning disabilities who (need care and support but) do not receive help. They have to be taken into account in the estimates as well. This makes it particularly difficult to obtain precise information on the number of people with learning disabilities in the population.

Hatton et al. (2016) estimated that in 2014/2015 2.5% of children in England had learning disabilities.[50] This estimate is somewhat higher than the results of meta-analyses of existing epidemiological research (Hatton et al. 2016). In 2014/2015, around 70,000 children in England were identified as having learning disabilities. Between 2009/2010 and 2014/2015, the number of children in England with learning disabilities reduced by 6.5%. This was driven by a reduction in the number of children identified with mild learning disabilities (24% over the period), tempered by modest increases in the number of children

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[49] According to the Equality Act, someone is disabled when (s)he has a physical or mental impairment that has 'substantial' and 'long-term' negative effects on the ability to do normal daily activities. By 'substantial' the Act means more than minor or trivial; that is for example if someone needs much longer to complete a daily task like getting dressed. 'Long term' denotes 12 months or more.

[50] The estimate is based on data from the Department of Education on the special educational needs of all children in maintained schools and non-maintained special schools (i.e. about 97% of English children of statutory school age) in 2013/2014 and 2014/2015 (Hatton et al. 2016).

identified with severe learning disabilities (15% over the period) and profound and multiple learning disabilities (15% over the period) (Hatton et al. 2016; for a definition of the degree of intellectual disabilities see Chapter 1).

For the adult population, Hatton et al. (2016) estimated that 2.16% of English people aged 18 and over have learning disabilities. Of these approximately 930,000 estimated English adults with learning disabilities, only 23% are identified on GP registers (Hatton et al. 2016). Since 2006/2007 GPs have been asked to keep a register of people in their practice whom they know to have learning disabilities (Hatton et al. 2016). The remaining 77% of adults with learning disabilities have been referred to as the 'hidden majority', who remain invisible in data collections.

Number of people with learning disabilities receiving care and support grows slightly

The number of working-age adults with learning disabilities who are known to councils increased slowly from 136,000 in 2009/2010 to just under 142,000 in 2013/2014.[51, 52] 'Known to councils' does not mean that people are eligible for social care services and thus that they use these services. It simply means that people have had an assessment. To be eligible to receive social services, people first need to have an assessment. This may lead to either a positive or negative evaluation. In the event of a positive assessment, people are entitled to social care services. When someone's assessment is negative, (s)he is not eligible for social care services; the need for care is either met by informal help or remains unmet.

Between 2005/2006 and 2013/2014 the number of first assessments – people who are new to local authorities – grew rapidly (7.7% per year).[53] Unfortunately, the evaluation of the assessments is not registered, and we therefore do not know to what extent the growth in the number of first assessments leads to increased demand for social care services.

As regards the registered data, to gain a better idea of the demand for care we have to rely on the number of people receiving social care services. The number of adults with learning disabilities using some form of community (i.e. non-residential) social services increased steadily by 1.6% per year from 2005/2006 to 2013/2014. In terms of specific community social services, day services are the type of help used by the largest number of adults with

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[51] Data are available for 2014/2015. However, it is hard to compare the statistics for 2013/2014 and 2014/2015 because of changes in the data collection system for social care. A number of wide-ranging changes were introduced in 2014/15 such as the approach to designating individuals' main reasons for receiving support and a different approach to estimating the total number of people for whom services could be relevant (Hatton et al. 2016).

[52] Unfortunately, the recording of data on the number of people with learning disabilities known to local authorities only started in 2009/2010.

[53] Besides information on the number of first assessments data are also collected on the number of working-age adults with reviewed assessments. It is not clear whether the sum of the number of first and reviewed assessments offers a complete picture of the need or demand for social care services in a particular year because it is not clear whether all existing working-age adults had a reviewed assessment. Furthermore, for a complete picture of the need or demand for social care services we would need information on the evaluation of the assessment (i.e. positive or negative) which we do not have.

learning disabilities, though the number of people using this kind of service declined steadily by 2.0% per year. Other services with large numbers of users with learning disabilities are home care services (with a yearly increase of 6.2%) and professional support. Professional support is a service included as part of a care plan. The professional provides therapy, support or professional input (e.g. from social workers, occupational therapists or counsellors). From 2005/2006 to 2008/2009 there was a yearly increase in the number of people receiving professional support of 4.7%, while in the period 2008/2009 to 2013/2014 the number of people with learning disabilities receiving this kind of support fell sharply by 13.7% per year (Hatton et al. 2016).

Besides community social services, local authorities also provide residential care, although most working-age adults with learning disabilities receiving long-term support from the council live with family or friends (Hatton et al. 2016). The number of people receiving residential care is much smaller than the number receiving non-residential social care services; 24% of people receiving any type of council-funded care and support in 2013/2014 receive residential care.[54] Additionally, the data on council-funded residential support for adults with learning disabilities aged 18+ show a steady decline in the numbers of adults with learning disabilities living in both residential care and nursing care (-0.9%). The steady decrease in the larger number of adults with learning disabilities aged 18 to 64 years in both residential and nursing care (-1.0% annually) is partially offset by the increase in the smaller number of adults aged 65 years or over living in residential and nursing care (4.0% annually).

As regards total gross expenditure, in 2013/2014 local authorities spent 5.38 billion pounds on social care provisions for working-age adults with learning disabilities; 0.40% of the Gross Value Added for England in 2013[55]. Between 2005/2006 to 2013/2014 overall social services spending more than kept pace with inflation (Hatton et al. 2016), growing by 1.9% annually.

To summarise the findings, the number of children in England identified as having learning disabilities and receiving help dropped, while the number of adults with learning disabilities receiving community social care services increased slightly (1.6% annually between 2005/2006 and 2013/2014). This contrasts with the situation in the Netherlands, where *demand* for and *use* of care and support has increased more rapidly among people with learning disabilities in recent years. However, there are signs in England that the need

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[54] These are not 'unique' persons. To calculate the share of residential care, we divide the number of people receiving residential care by the total number of people receiving care. To calculate this total number we added together the number of people receiving residential care and those receiving non-residential community services. We might make a calculation error because in any given year people can receive both residential and non-residential care. We do not know how many people receive both types of care in a given year.

[55] In 2013 the Gross Value Added – the value of the economy due to the production of goods and services – amounted 1,331 billion pounds at current prices (www.ons.gov.uk/economy/grossvalueaddedgva 2017). Unfortunately, no data are available for England on GDP; this information is only reported for the United Kingdom as a whole.

or demand for care and support may be stronger than the use of care suggests: the number of first assessments grew more rapidly (7.7% annually between 2005/2006-2013/2014). The main reason for the rising demand in the Netherlands is an increasingly complex society facilitated by the organisation of care and support, offering people with an IQ between 70 and 85 (and with accompanying problems in adaptive behaviour) access to social services as well (Woittiez et al. 2014a). As the growth in the number of people with learning disabilities in England receiving care and support has not kept pace with that in the Netherlands, can we assume that society in England is less complex, that the organisation of care and support in England applies stricter access criteria, or are there other reasons for this development in the use of care and support by people with learning disabilities?

3.4 Expert views on factors causing changes in the use of care and support

Research on the numbers of people with learning disabilities and their (demand for and) use of care and support in England is scarce. That holds even more so for the drivers of the changes in use of care and support. In exploring potential reasons for the development in use of care and support for people with learning disabilities in England, we have to rely on interviews with experts in the field, including scientists, social care providers and local policymakers. The face-to-face interviews with the experts took place in March 2016. We first asked them whether they had observed any changes in the number of people with learning disabilities and whether there have been any changes in the number of people receiving publicly funded help. We also asked whether any such changes are related to the organisation of care and support or whether other factors are responsible.

3.4.1 Care system-related factors

In contrast to what the data on the number of people with learning disabilities receiving social care services show, almost all experts referred to a decline in use of care and support by people with learning disabilities. This is a puzzling finding. We believe that their view is related to the austerity measures taken by the governments that were elected in 2010 and 2015, which led to a series of cutbacks in social care services. According to Fernandez et al. (2013), ‘the scale of reductions in spending and provision are almost certainly without precedent in the history of adult social care.’ Those most affected in terms of coverage (the number of people receiving care) are older people, people with physical disabilities and people with mental health problems. People aged 18-64 years with learning disabilities have been least affected by the cutbacks in social care provisions; in fact, over the period 2005/2006 to 2012/2013 there was a small increase in the number of social care users (Fernandez et al. 2013). However, after controlling for the influence of socioeconomic indicators of *social care need*, Fernandez et al. (2013) found that in 2012/2013 there were fewer users with learning disabilities of social care and support services than in 2005/2006. In other words, they found that despite the estimates of growing numbers of eligible applicants with learning disabilities (Emerson & Hatton 2011), there were fewer of these users of social care and support services. We believe this is why interviewees – based on their own daily routine – reported that the number of people with learning disabilities receiving social care services has declined even though figures show that their number has increased slightly. This prompted one of the interviewees to proclaim:

> *What we are witnessing now is the strange contradiction that people are more aware of learning disability than they have ever been, but the number of people receiving care and support diminishes.*

According to the experts fundamental for the development of the use of social care service of people with learning disabilities is the way in which help in England for children and young people as well as for adults is financed. The experts are not advocates of the current system; they all criticise it. To summarise briefly what we will describe in more detail in the following sections: as a result of the austerity measures, assessment of needs is poor and access to care inadequate, especially for children and adults with mild (and borderline) learning disabilities. They do not receive the care and support they need to enable them cope well (independently). In addition, the austerity measures have had an adverse effect on self-advocacy groups. As well as suggesting drivers for the development in the use of care and support, the interviews yield insights into the dilemmas involved in the care for people with learning disabilities.

Management of financial resources

Whether people who need care and support actually receive it depends among other things on the available budget for care and support. The experts agreed that the care and support system has become more austere in recent years. Underlying the austerity measures is the concept of Big Society: the government doing less and the community stepping up and doing more. The experts argued that in order for communities to work together better they have to be supported by a strong state; communities and the state have to cooperate to solve multidimensional problems. Instead of cooperating, however, the government has simply withdrawn.

Besides criticism of the austerity measures, the interviewed experts have doubts about the way in which the available budgets are spent.

> *There is a huge amount of public money being wasted.*

According to some experts, too much money is spent on treatment units offering forensic care to people in crisis:

> *That is not efficient because problems seem to first have to get out of hand before they are solved. Furthermore, in most cases patients do not receive any real treatment in these hospitals. They just stay there and in many cases for too long.*

This idea is based on the conclusion of a review published following the closure of Winterbourne View Hospital; a private hospital for people with learning disabilities in crisis situations. The hospital had to close overnight because of abuse and cruelty by the staff.

> *It became government policy to no longer tolerate that people were being placed in inappropriate care settings. But they still are. These complex people could be looked after in ordinary housing in the community provided with what they needed and sufficient staff.*

The experts believe that the lack of change in the treatment of people with learning disabilities is the result of a ‘cost-shunting issue’.

> *People in social care services are paid for by the local authorities, people in assessment and treatment units are paid for by the Health Service Commissioners, and people in a forensic inpatient service are paid for by the* NHS *England. Once people receive a particular kind of help there is no advantage in financial terms to transfer them to other (more adequate) kinds of care and/or support.*

The experts also question the current practice of the personalisation of social care and support. With the introduction of the Care Act 2014, the personalisation of care took the form of a legal entitlement to a personal budget.[56] Since the mid-1990s, people assessed as being eligible for social care and support have had the option of taking a direct payment to purchase the support they need.[57] The central idea of the reform of the care system in the 1990s was that people’s needs should form the basis of a personal package of care. According to some experts, the personalisation of care and support in the form of personal budgets is a morally and ethically good idea. Personal budgets give people the freedom to choose how and when they receive care and support. Personal budgets enable informal networks to provide support. That could be parents who help their intellectually disabled child, but also a classmate who supports his or her peer with learning disabilities to get on the bus to school. However, personal budgets are not a good option for everyone who needs care and support, according to some interviewees. ‘For some people with learning disabilities it is too complicated. Some of them make a mess of it.’ According to some of the interviewees another negative aspect of the personal budgets is the bureaucracy.

> *Though personal budgets sound like direct payment for most people with learning disabilities it is council managed. They don’t know how much it is and they don’t have control on how it is spent.*

The austerity measures did not apply only to social care and support services, but also to other welfare services, such as welfare support and benefits (Hamnett 2013; Hastings et al. 2015).

> *Everything is pushed out into the market. In England private organisations are paid to support people with learning disabilities receiving Employment and Support Allowance into*

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[56] Although the initial plan was that all social care users should receive personal budgets, criticism from the Association of Directors of Adult Social Services forced the Minister for Care and Support to amend this to 70%.

[57] There is a difference between direct payments and individual budgets. Direct payments concern money from a local authority social care budget while individual budgets combine resources from different funding streams to which an individual is entitled (Carr & Robbins 2009).

> *work. These employment providers have an incentive for cherry picking. They put most effort into supporting people with learning disabilities who do not need that much effort. That is because they get paid for the results. The provider can't take the risk of taking on people who are further away from being 'work ready' as they are paid by the results and if the provider doesn't get paid, they risk bankruptcy.*

One expert gave an example of the problems people with learning disabilities are now facing.

> *I know of a lady who needed a car to go to work but who was, due to the budget cuts to mobility benefits, no longer entitled to a car. It meant she couldn't go to her work anymore. She lost her job. She went from somebody who worked to somebody struggling for benefits.*

People who stay in the mainstream welfare system have to look for work on three days a week, otherwise they are sanctioned. Sanctioning is quite common, according to the experts.

> *People who are sanctioned often disappear from the benefit system. That has been really bad. In England there are two narratives about people with borderline learning disabilities. One is that they don't have a problem. They are just lazy and 'beg for money'. The other is that people with borderline learning disabilities do have a problem for which they need help. They are vulnerable.*

Poor assessments and inadequate access for adults with mild and borderline learning disabilities

Fair Access to Care Services (FACS) guidelines were introduced in 2003 as a means of providing local authorities with a common framework for determining individuals' eligibility for social care services and with the aim of reducing the variation in eligibility to social care and support across England. McInnis et al. (2011) showed that in the northwest of England, despite the FACS guidelines, there were still differences in eligibility criteria across areas. By creating a single, consistent route to establishing entitlement to publicly funded care and support, the Care Act 2014 aims to make the way people receive help more consistent across England. Whether the Act is succeeding in this aim is uncertain.

The Commission for Social Care Inspection (2008) stated that in meeting people's needs (i.e. 'cutting the cake fairly') the key issue is not the criteria used to assess people's eligibility for publicly funded care and support, but the amount of resources allocated: 'the size of the cake'. The interviewed experts endorse this view as we saw in the previous section: 'the cake is not large enough to cut it fairly'. As a result, access to care and support is problematic, especially for people with mild or borderline learning disabilities, as the experts state. The social care budget comes partly from central government and partly from Council Tax.

> *It is very much up to the local authorities how they spend the available money. It is no longer ring-fenced. There is hardly any central standard setting, central criteria, for working out*

> *how much the budget should be. It is left to the council to sort out. Some are upfront and transparent. Many are not. They are very secretive about budgets.*

The eligibility criteria tend to be set locally. The care and support offered varies from one local authority to another, depending on the local authority culture. In some cases or areas people who should receive a service do not; there is randomness in access to social care services. Assessment is however difficult, for both the assessor and the assessee.

> *Social workers try to distance themselves from the assessment by saying: fill in this form, I will put it into the computer and this will tell you how much you are entitled to. Social workers feel the pressure* [from the system] *to reject people who need support.*

Someone with mild intellectual difficulties may still be able to perform some activities independently but in general needs help to cope well. Interviewees mentioned that some organisations try to work around the strict conditions of the assessment by focusing on the additional problems of people with learning disabilities. To offer the person the required help, these organisations stress the other problems that someone with mild learning disabilities might have. With two different kinds of disability, the chances of receiving care and support are much higher. From the point of view of the assessee, too, the assessment process is tricky. The focus is too much on what people with learning disabilities are still able to do.

> *For example, during the assessment process people have been asked whether they watch a particular programme on TV. And if so, if they watched it entirely, say the programme lasted half an hour, when both questions are answered affirmative the conclusion of the assessment will be that this person is able to concentrate well.*

Experts felt that this is a misrepresentation of the situation. It is not so simple to determine less severe learning disabilities.

All experts stated that it is hard for people with mild learning disabilities to obtain the support they need. *They receive support but only if they got other very difficult issues.* For people with borderline learning disabilities it is even more difficult.

> *Who is officially recognised as a person with learning disabilities? People with borderline are not. They are hardly in social care. They are kind of invisible. In England they are completely outside the realm of learning disability.*

Another expert stated:

> *people with borderline learning disabilities are more vulnerable to cuts in support than people with profound learning disabilities. The latter do receive some care and support and sometimes they have strong advocates in their families who help out in case of trouble. People with borderline learning disabilities mostly receive care and support from their social network. Often they live in less affluent neighbourhoods and these informal helpers are often in need of help themselves.*

In some cases people with borderline learning disabilities do receive publicly funded care and support, but according to some experts this only occurs if ‘something else happened’: they are ill, homeless or they have broken the law.

> *People with borderline learning disabilities are moving from social system clients to criminals. They don’t know where they fit in. They can’t pass the driving test, so they drive without a driving licence. They get in with the wrong kind of crowd. A lot of it is not a major crime, but it is illegal; it is against the law. Some of them act out of poor impulse control. Others just don’t understand the law. And they are not bright enough to not get caught.*

In order to prevent people with borderline learning disabilities from committing criminal acts, care and support are needed.

> *Care and support definitely help. Sometimes people will not accept help. It is difficult to force care and support on people. Assessments should focus more on emotional needs, particularly in the transition from childhood to adulthood. In social care services children with mild learning disabilities get ‘lost’ once they are adults. Thousands of people have disappeared through the system. We don’t know where they go. From some we do know: they end up in the justice system. With more care and support we could get the emotional needs right and then we would have less casualties.*

Some interviewees stated that in policy debates the term ‘borderline learning disability’ is open for discussion.

> *About 20 – 30 years ago, people with borderline learning disabilities, as well as people with mild learning disabilities, were more likely to get care and support. In order to reduce expenditures, there is a sharpening of the definition what (borderline) learning disability is. The eligibility for social services changed. It is getting tighter.*

The ideas of the experts correspond with the findings of Roulstone (2015). He posits that disability is what a state deems it to be. It expands or shrinks the disability category in response to fiscal crises or rapid social change. Decisions as to who deserves protection change depending on broader social sentiment. The malleable nature of the category has been used to widen or narrow the category of who counts as disabled.

From including to excluding children via inadequate support

The interviewees mentioned that the austerity measures have also had an impact on the care and support for children with (borderline) learning disabilities.

> *For children who are identified as having special educational needs there used to be extra money (from outside school (= school action or action plus)). The government claimed that the system* [before 2014] *wasn’t working very well. The statements* [the predecessor of the education, health and care plan] *became the gold standard. The government made it quite clear: most of the children with statements don’t need support; only the most vulnerable. What England will face now is a cohort of children without the label learning disability which they previously would have had. There will be more exclusion. Some schools*

> *do not take children with special educational needs because they ‘mess up’ their figures. That is in contradiction with inclusion.*

The experts acknowledge that it is hard to claim that the eligibility to care and support has been reduced since the introduction of the Children and Families Act 2014.‘There is no central database that registers the actual education, health and care plans. We can’t say anything about changes over time.’ Collecting data is crucial for the delivery of equitable and effective service supports (McConkey & Craig 2015).

From self-advocacy groups to advocacy groups and eventually to no groups at all?

Besides their influence on access to services, the cut in budgets also affected the support for self-advocacy groups. Under the Blair administration, self-advocacy groups received funding and became professionalised. Now the money goes, the professionals go. That is a real shame.

At the root of the financial support for self-advocacy groups was the desire of parents for the involvement of social care professionals. Their attitude towards the system changed. Parents used to be adverse to the system but now have higher expectations of professional care.

> *There are indications that people with learning disabilities live longer than, say, 15 years ago. So parents are really worried who takes care of their children when they die. Sometimes brothers or sisters could take care of their sibling with learning disabilities but they may not be living nearby anymore or may not feel they are in the position to take over for long. It is where social services step in.*

The self-support groups were also beneficial for people with learning disabilities. These groups made them more independent in the sense that they experienced less bureaucracy and more support (not going to a day centre but performing ordinary activities but still with one-to-one support). Before the publication of the White Paper *Valuing People*, there were many well-functioning self-advocacy groups. As self-advocacy groups became more formalised, had to observe safety rules, and attached more importance to keeping staff in jobs because of professionalisation, advocacy became the model rather than self-advocacy. According to one of the experts:

> *It is not just that there is less money but there is also the question what is that money funding. I think that it is funding advocacy instead of self-advocacy.*

3.4.2 Factors related to a complex society

One of the major drivers of the development in demand for care and support in the Netherlands is social change. Due to digitalisation, daily life in the Netherlands has become more complicated. Life in Dutch schools for children with borderline or other learning disabilities is more difficult because of an increasingly academic and competitive curriculum. Finally, it is becoming harder for Dutch people with learning disabilities to find and keep a job in a more competitive labour market. All these aspects have contributed to growth in Dutch demand for care and support. We wonder whether social change is also a driver of developments in the use of care and support in England. The first thing that came to the interviewees' minds in explaining the current development in the use of care and support are the austerity measures. Their impact is so great that the interviewees had to think hard about the possible influence of social change. Almost all of them believe that 'social change has played a minor role in the current use of care and support'. Nevertheless, the experts do think that social change affects the lives of people with learning disabilities. Social change has made daily life more complex, along with life in school and at the workplace. As a consequence, the experts expect the need for help on the part of people with learning disabilities to increase. In the following subsections we describe the interviewees' views on social change and its impact on the need for care of people with learning disabilities, and not its impact on rising levels of use of social care services.

Daily life

According to the experts, there is a range of activities of daily life aspects in England that are more difficult for people with learning disabilities to perform than previously. The connectedness through social media has excluded people with learning disabilities (see also Chadwick et al. 2013), who may not have online access.

> *People with learning disabilities are hardly connected for economic reasons. Furthermore they are less likely to have internet at home and the (internet) systems that are there in terms of paying bills are not routinely made accessible to them. People in care systems or people living with families are quite restricted in how they can use internet. They were excluded from it, it was not talked about at schools.*

As a result, according to one expert society is becoming less personal for many people with learning disabilities. What makes daily life more complicated for people with learning disabilities is that England is moving to an online welfare system. For reasons of efficiency, contact with people with borderline or mild learning disabilities will henceforth be exclusively online. On the other hand, some experts think that new technology could help improve people's daily lives and a more digital society could be more inclusive and accessible. There is a move in England towards people being contacted more online (see also Waight & Oldreive 2016).

In today's society, people with borderline and mild learning disabilities are more vulnerable. This is a point on which all experts agree.

> *As compared to the general population people with mild and borderline learning disabilities experience more poverty, economic hardship, unemployment, poor health and less connectedness to neighbourhoods.*

To feel safe they try to find places where they feel comfortable and unthreatened.

> *These* [so called] *safe havens are a café or a particular shop where people are friendly, or a football club that supports them. In case of need people with learning disabilities can go to these places and there will be somebody who can help them.*

According to the interviewees these safe places appear to make society more inclusive – although the experts stress that not everyone has a safe haven, nor does every community. Inclusiveness is still a work in progress.

School

The interviewees stated that life in school has become more complicated. Since children with mild and borderline learning disabilities often attend a mainstream primary school, the interviewees believe it is even more difficult for them because the curriculum is increasingly academic and competitive. Expectations are that life in schools will not become less complicated following the establishment of 'academies'. These schools are independent and state-funded; they receive their funding directly from central government, rather than through a local authority. Although the day-to-day running of the school is in the hands of the head teacher or principal, he or she is overseen by individual charitable bodies called academy trusts, and may be part of an academy chain. The government hopes these academies will drive up standards by putting more power in the hands of head teachers on issues such as pay, length of the school day and term times. Moreover, the curriculum appears to be becoming more concentrated on 'hard' subjects such as maths and languages, and schools seem to be becoming more competitive.

> *One of our key problems is that education, and work, are set up for a narrow sense of achievement. We have narrowed the definition of education: we are obsessed by becoming as good as Finland in education, which means narrowing of the curriculum. Moreover it results, in shifting kinds of students you want in the schools and the ones you don't.*

In general, and particularly in residential schools – in which children are present 24/7 for 52 weeks a year – children with learning disabilities do not learn the skills needed to perform well in adulthood. Young people with learning disabilities in particular need to develop self-help skills and self-regulation. According to one of the interviewees, staff in these schools instead sometimes learn to adapt in order to keep the peace.

> *They come along to me: 19 year-olds who are ready to put your lights out. For some of them their behaviour has been problematic since they were young. They have had little help to learn them to behave better.*

What would help, according to the interviewed experts, is to put children's needs at the centre of the support offered.

> *These could be related to issues schools in general need to solve – extra help to be able to read, calculate, etc.– but also to more emotional and behaviour problems.*

Putting children's need at the centre of the support offered also means, according to another expert, taking into account what children with learning disabilities would want to do.

> *Although there is a transition program from age 14 onwards where preparation for adulthood and thus work should be an important part we have culturally very low aspirations for people with learning disabilities.*

For children with borderline learning disabilities life in school is more complex because, as stated by one of the interviewees, there are hardly any vocational schools in England.

> *It is important to learn how to do a job while being in the job itself. Pupils in their final year should go on internships –a partnership between school and an employer. In these cases pupils still attend school but also work. Between 65% and 75% of these pupils move into employment. It is a pity that we don't invest (enough) in these successful strategies and that we don't have them across the country.*

Beckett (2015) shows that non-disabled children think less positively about their disabled peers. Life in school, but also life in general, could be made a little less complicated for people with learning disabilities if the broader pedagogical goal of accepting differences or behaving kindly towards vulnerable people were part of the school curriculum.

> *A more positive view on disabled people would help because people with borderline and mild learning disabilities do not feel comfortable in today's competitive society.*

Workplace

Of the people with learning disabilities who are known to local authorities in 2013/2014 only 7% had a (small) job (Hatton et al. 2016).

The interviewed experts reported that in a more competitive labour market it has become more difficult to find a job in general, and more so for people with borderline and mild learning disabilities.

> *The recession made it really difficult for disabled people generally. It certainly did for people with mild learning disabilities who used to work in factories: sweeping the floor, etc. These jobs have all gone. There are no other jobs available for them. Therefore people with mild learning disabilities get stuck at home or they get stuck with a very limited life. They may have some support and may have some activities. In terms of job satisfaction or life satisfaction, it is much reduced. Sheltered workshops used to be another way to employ people with learning disabilities. In these workshops they would produce craft things and packaging. Machines took over these activities, they do all the packaging now.*

Another expert mentioned that jobs for people with borderline and mild learning disabilities have disappeared not because the type of jobs suitable for these people have themselves disappeared, but because these work activities have to be performed within a different type of contract.

> *In general people with learning disabilities have a part time job. The conditions of these part time jobs are not good. There is a long term shift away from permanent full time work to precarious jobs with zero hours contracts. Instead of people with learning disabilities, more and more new graduates, who normally would look for full time jobs applied for these precarious part time jobs during the crisis.*

Even without this displacement, however, the type of contract is not attractive for people with learning disabilities. It acts as a barrier to moving into employment and makes it even harder to run a household.

> *People with precarious jobs have a hard time to manage their lives. That is not only due to the insecure labour market conditions. People with low income jobs in most cases receive housing benefits. Because of the irregular number of hours work per week for people in precarious jobs the entitlement to housing benefits varies as well. Thus accepting a precarious job may not improve the living conditions due to a loss in welfare support.*

Some experts think that in theory there are plenty of jobs that people with learning disabilities can do. 'NHS and employers started an initiative to try to employ more people with learning disabilities. They can work in labs or as porters. There is quite a large range of jobs that people can do.' In practice, it is difficult for people with learning disabilities to perform well in ordinary jobs. It is important to make things easier for them: easy to read, more accessible, more training. The expert concerned was aware that, although there seem to be enough activities that people with learning disabilities could perform: 'it is very difficult to put all the required elements for success together in a reliable job'.
Employers too have a responsibility to increase the employment rate of people with learning disabilities. 'They have to enforce and disseminate the values of inclusion and diversity.' The *Disability Confident* programme introduced by central government offers employers guidance and resources in employing disabled people (www.gov.uk). It aims to halve the disability employment gap – the difference between the employment rates of disabled and non-disabled people (House of Commons 2017). One of the initiatives to reduce the gap is apprenticeships (www.gov.uk 2016). The experts have good experiences with apprenticeships.

> *Employers get someone to do the job. The employees work alongside the person with learning disabilities as a team. That brings benefits of itself. Unfortunately not each council embraces it. It depends on local authorities whether they are willing to bring the programme into practice.*

Improving the (labour market) position of people with learning disabilities requires more than (some) effort on the part of employers, central government and local authorities. What is needed to include and value people with learning disabilities (in the workforce) is a change in mindsets about what people with learning disabilities can achieve, not only on the part of employers, but also in the general population (Blamires 2015; Melling 2015). A culture of acceptance increases the involvement of people with learning disabilities, as Hall (2016) shows for the us.

3.5 Summary

In the Netherlands, demand for care and support for people with intellectual disabilities has grown rapidly in recent years – more rapidly than might be expected on the basis of demographic trends. An increasingly complex society and a care system that has allowed for this growth have driven the demand for care and support for people with learning disabilities. To put the Dutch situation in perspective, England offers a good case. In England, local authorities are responsible for arranging social care services for people with learning disabilities. England thus seems to be a forerunner for the Netherlands, where municipalities became responsible for providing a substantial part of care and support for people with learning disabilities in 2015. A problem in the comparison of the Dutch and English case is that England does not record detailed information on the *demand* for care and support, but only on the use of social care services. England does indeed turn out to be an interesting case. In contrast to the Netherlands, England has not experienced a rapidly growing use of care and support for people with learning disabilities. The number of children identified as having learning disabilities and thus receiving help fell by 6.5% between 2009/2010 and 2014/2015. The number of adults with learning disabilities receiving community social care services increased only slightly (1.6% annually between 2005/2006 and 2013/2014), while council-funded residential support for adults with learning disabilities aged 18 and over showed a steady decline (-0.9%). However, based on the development in the number of first assessments – people who are new to local authorities – there appears to have been an increase in the need for care and support. The number of first assessments grew rapidly between 2005/2006-2013/2014 (+7.7% per year), although not everyone assessed is eligible for social care services.

The impression of a growing need for help resulting from the development in the number of first assessments is confirmed by the interviewed experts. They state that the limited increase in the use of social care services among adults with learning disabilities is not a consequence of a reduced need for care and support. As in the Netherlands, daily life in England is becoming increasingly complex. Relationships are moving more and more online. The connectedness through social media excludes some people with learning disabilities because they do not all have online access. As English welfare services shift to an online delivery system, daily life for people with learning disabilities is becoming even more complicated. For children and young people with learning disabilities, life at school has also become more complicated. The curriculum in mainstream schools has become more academic and there are hardly any vocational schools. As in the Netherlands, therefore, the needs of people with learning disabilities in England are growing as society becomes more and more complex. This begs the question of why people in England do not receive the care and support they need.

Most experts believe that the austerity measures are an important reason why not all people with learning disabilities in England who need help receive care and support (a finding supported by Fernandez et al. (2013)). Due to scarce resources, social workers feel under pressure to reject people who need support. In particular, children and adults with mild learning disabilities do not obtain the care and support they need to cope well independently. People with borderline learning disabilities have an even harder time obtaining help. In England they are not eligible for social care services. And although in some cases they do receive social care services, this is mainly the case when they are homeless or have become involved in criminal activities. Not all experts believe that there is insufficient money going to the learning disability sector; some interviewees believe care and support budget could be spent more efficiently. They believe that there is a huge amount of public money being wasted. Too much money is spent on treatment units offering forensic care for people in crisis. Experts feel this is inefficient because it seems as if problems first have to get out of hand before they are solved.

To summarise, the development in use of care and support by people with learning disabilities in England can best be described as follows. The present century got off to a very promising start for people with learning disabilities in England. With the introduction of the White Paper 'Valuing People' (2001), they and the services that support them became a policy priority. This was followed by the ratification of the UN Convention on the Rights of Persons with Disabilities in 2009, reflecting the government's aim of creating a society in which intellectually disabled people can play a full role. Over time the need for care and support also grew due to society becoming more and more complex. However, despite all this extra attention for and awareness of learning disabilities in English society, austerity measures hinder people from receiving the care and support they need. That is a strange contradiction, as one of the experts stated.

3.6 List of abbreviations

DLA	Disability Living Allowance
EHC	Education Health and Care plan
ESA	Employment and Support Allowance
FACS	Fair Access to Care Services
IQ	Intelligence Quotient
NHS	National Health Service

4 Flanders: changing system to combat waiting lists[58]

> *For years we have been seeing a constant increase in*
> *both the support given and the number of people applying for it.*
> [Source: one of the interviewed experts in Flanders]

In this chapter we investigate Flanders, the Dutch-speaking northern region of Belgium. Belgium is a federal state, and Flanders is one of its three Communities. Care and support for people with intellectual disabilities (ID) in Flanders to some extent resembles the situation in the Netherlands. The system uses centrally set admission criteria and provides care and support. Until recently, this provision was mainly in kind. System changes in 2016 moved towards providing personal budgets to people with ID and, as an additional option, facilitating admission to a directly accessible but limited form of help.
The fact that the system of care and support for people with ID in Flanders resembles that in the Netherlands makes it an interesting region to compare.

4.1 Vision and definition of people with intellectual disabilities

Paradigm change

A paradigm shift has taken place in Belgium, from a medical and protecting perspective to a model that strives for autonomy, participation and full integration of disabled persons in society. This holds generally for all types of disabilities (not just ID). To understand the recent system changes in the organisation of care and support, it is important to be aware of their background. The UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) was rapidly ratified by many countries. Belgium signed up in 2009, seven years before the Netherlands. Van Hove and De Beco (2016) report that progress has been made in implementing the Convention, but that 'Belgium still has a lot of work to do to reorganise and reconvert the historically developed 'special/parallel/segregated systems'. Another important factor is the existence of long waiting lists despite investments over many years. The number of applicants for support for (all) disabled people has continued growing for years.

To combat waiting lists and implement the principles of the UN Convention, the plan *Perspectief 2020* (Vandeurzen 2010) was written, and adopted by the Flemish government. The plan accepts enduring demand growth and presents two main objectives. First, disabled persons with the greatest support need should all be receiving help in 2020, either via support in kind or via a budget that allows them to buy the support they need themselves. Second, support should be demand-driven in 2020; clients should be well informed and should be living in an inclusive society. A consequence of the plan is that

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[58] This chapter was written by Michiel Ras and Isolde Woittiez.

more generic welfare institutions and society as a whole have a task in this regard (VAPH, 2014).

Government vision on support specifically for people with ID

The Flemish government, represented by the Flemish Agency for People with a Disability (Vlaams Agentschap voor Personen met een Handicap; VAPH) presents care and support for disabled persons as a shared responsibility. Five concentric circles are used to visualise the principle. With the disabled person in the centre, the circles represent an ordering of different possible sources of support, starting with basic self-help and ending with specialist ID care and support. The sources can be used simultaneously and independently of each other. However, when support is insufficient, the ordering is crucial. Support in a 'higher' circle should not be used if sufficient support is available via 'lower' circles. In considering the optimum mixed circle support, no caregivers in any circle should be overburdened. Higher-circle support may be used to prevent lower-circle support from becoming exhausted (VAPH 2014).

Figure 4.1
Concentric circles (in Flemish)

Circle 1: Self-support: care and support arranged by the person themselves
Circle 2: Usual support: daily care and support given by family members living together
Circle 3: Care and support by family, friends and acquaintances not living together
Circle 4: Professional care and support for all citizens: general welfare (Centra Algemeen Welzijnswerk; CAW), family care (*gezinszorg*), cleaning services (*poetshulp*), child care and others.
Circle 5: Professional care and support specifically directed at people with ID (financed by the VAPH)

Source: VAPH (2018)

Who is intellectually disabled?

The VAPH uses the international definition of ID of the American Association on Intellectual and Developmental Disabilities (AAIDD) (VAPH, 2016a). However, the focus is on the need for support rather than being too rigidly on IQ scores. An IQ assessment is used, but the starting point is the VAPH definition of disability (of any kind) as laid down by decree

(Vlaamse Codex 2004): any long-term and significant participation problem experienced by a person and attributable to a combination of functional disorders of a mental, psychic, physical or sensory nature, limitations in the performance of activities, and personal and external factors.

The problem must have started before the age of 65, thus excluding general elderly care. Note that the environment ('external factors') plays a significant role in the definition. As such, the definition used in Flanders differs from the AAIDD in that it takes participation as a central concept.
The cut-off IQ score is set at 70 within the confidence interval of the test used. The confidence interval can amount to several points, depending on the test. This means that in specific cases people with an IQ slightly higher than 70 can also receive ID care.
There is also another argument as to why IQ is not used in a strict sense, according to two experts. Specific circumstances during the test must be taken into account. For example, IQ scores may increase following the use of Ritalin, or decrease during a period of extreme fatigue. The organisation of the test itself (e.g. splitting the test into several smaller parts) may also have an influence. If a person also has psychological problems or an autistic spectrum disorder, care is taken to assess the primary disorder (ID or non-ID) correctly.
Above age 65, care and support are only given to persons who applied before reaching this age. There is a clear difference with the Netherlands here, where scores up to 85, in combination with problems in adaptive functioning, are regarded as sufficiently low to warrant provision of ID care. In Flanders, people with borderline ID only (IQ 70-85, with problems in adaptive functioning) have no direct access to VAPH care and support. However, if they have other problems as well, such as an autistic spectrum disorder, the 'non-ID' disorder will be the guiding factor in their admission to support.
According to one expert, borderline ID often is not recognised as such. Many people with borderline ID may be unemployed because of problems not directly associated with low IQ. Furthermore, they wish to avoid the stigma of being seen as 'retarded', because they do not see themselves in that way – in contrast to people with recognised ID who are used to receiving support.
Another expert posited that a sizeable proportion of people with financial problems belong to the borderline ID group. A third expert noted that the informal network may play a dominant role here: a good, stable network may keep a person out of problems; a network of 'bad guys' may lead to all kinds of problems as the person concerned is not strong enough to resist. This also (and perhaps especially) holds for parents in relation to a child with weak capabilities, as well as for partners.
One expert mentioned a problem with continuity of care, especially when people reach adulthood. It regularly occurs that they return to the support services after they have committed a crime:

> *For some people who don't find it easy to ask for help, committing an offence can be a ticket to receiving that help. In Flanders, this is referred to as a 'crime premium'.*

We do not know how often this happens and whether it is deliberate, but according to one expert people with severe behavioural disorders are treated with priority in this situation. On the other hand, this is not specific to Flanders: it is an internationally well-known fact that people with borderline ID are overrepresented in jail (Holland et al. 2002). Since 2017, the government in Flanders has made available additional resources to facilitate the transition to adulthood (VAPH 2017a).

There is also a link with deprivation and poverty:

> *Sadly, people with a disability are more likely to live in single-parent families, in deprived neighbourhoods and in disadvantaged situations. Van Gennep (1983) long ago introduced the term 'deprivation cycle' for this. We are now seeing it return in full force.*

4.2 Care and (financial) support for people with intellectual disabilities

In Flanders, decrees form the legal basis for support for people with ID. A 2004 decree regulated the foundation of the Flemish Agency for People with a Disability (VAPH) (Vlaamse Codex 2004). The VAPH became operational in 2006 (its predecessor being the Vlaams Fonds, dating from 1990[59]). The mission of the VAPH is to enhance integration and participation of disabled persons, with a view to their inclusion in society.
Income replacement benefits are organised at federal (Belgian) level. In 2014 a new decree regulated the change to a system based on personal budgets (Vlaamse Codex 2014a).

4.2.1 Care and support for adults with intellectual disabilities

The VAPH is also the central organisation providing care and support for people with disabilities. It 'aims to promote participation, integration and equal opportunities for the disabled in all areas of social life. Our ultimate goal is to help these people lead a better and more independent life.'
All experts agree that there is a limited role for the decentral sphere, although it has to be borne in mind that the shift towards an inclusive society will inevitably demand a contribution from municipalities and local welfare organisations. Key organisations in this context are the municipal welfare organisations OCMW (*Openbaar Centrum voor Maatschappelijk Welzijn*) and CAW (*Centra voor Algemeen welzijnswerk*) which among other things provide psychosocial support. There may be local differences due to municipality-specific arrangements for caregiving, though these arrangements are reportedly modest. This is a difference compared with the Netherlands, where most of the non-residential ID care and support is now provided at local level. In the past, care and support were mainly provided in kind, with a relatively high proportion of residential support.

More inclusiveness has recently been mentioned as an aim of Flemish policy (Vlaamse Codex 2014a). However, at the end of 2015, the share of adult residential care and support

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[59] In full: Vlaams Fonds voor de Sociale Integratie van Personen met een Handicap.

(as a percentage of all help provided in kind) was still 24% (VAPH, 2016b), including people with non-ID disabilities[60]. According to Ras et al. (2013), 54% of Dutch people with a demand for ID care and support were seeking residential care and support, two-thirds of these being intensive care forms. These data imply that Flanders has less institutional care than the Netherlands, but several experts doubt whether this can be verified, or do not recognise this.

Personal budget

Until recently, a small proportion (about 6%) of help provided by the VAPH took the form of a 'Personal assistance budget' (PAB - *Persoonlijke assistentiebudget*). A decree was passed (Vlaamse Codex 2014a) introducing budgets to replace support in kind for adults, in line with the paradigm shift (towards autonomy). Since 2016, budget financing is available on a much larger scale. This new system[61] is demand-led. Clients receive a personal budget that is designed to be appropriate to their support need. They are free to decide how to spend the budget.

The system consists of two parts. The first part is the 'basic support budget' (BOB – *basisondersteuningsbudget*), which is designed for people with a recognised disability and limited need for support (Vlaamse Overheid, 2017). During the transition process, a BOB is first assigned to people who have been on waiting lists for a long time. The BOB consists of a monthly payment of 300 euros and is paid not by the VAPH but by the Flemish Social Protection Agency (*Vlaamse Sociale Bescherming*) (Vlaamse Codex 2017).[62] The idea behind the BOB is that people with low support needs use it for their own network or for payments for directly accessible support. No checks are carried out on how the money is actually spent.

The second part is the 'Personal budget' (PVB – *Persoonsvolgend Budget*), a personalised annual sum which can be used by people with a disability to purchase care and support from within their own network, from volunteers, individual companions, professional carers and VAPH-accredited care providers. The Personal budget is for adults who require intensive or frequent disability-specific support as a result of their disability (VAPH 2017b).

PVBs have been available since April 2016.[63] The budget is intended to purchase care and support only; living costs (renting accommodation; food, etc.) are dealt with separately. This means that the aspects related to 'living' are organised in the same way as for all Flemish people. Until now, in many cases care and support has been given in all-in form, i.e. including the 'living' aspects. For new clients, and gradually for 'old' clients as well, the

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[60] Separate information on ID is not available.

[61] "Persoonsvolgende Financiering" (PVF; system of personal budgets). Applicable to all kinds of disabilities.

[62] A list of prerequisites to obtain this budget is given on Sociale bescherming (2017).

[63] One is allowed to use a part of the PVB in the same way as the BOB, without check on actual spending.

shift towards separate funding of care and living may make way for care and support which is separate from living expenses.

Access to care

Adults need to apply for care and support via the VAPH itself[64]. However, since 2013 persons with an occasional need for assistance may apply for limited 'directly accessible support' (RTH – *Rechtstreeks toegankelijke hulp*) (Vlaamse Codex 2013). RTH gives an entitlement to 61 night stays or 91 units of day care per year, for example. RTH is concerned with care and support, in contrast to BOB which offers a fixed amount of money. Both forms of support can be used at the same time. There is no application procedure for RTH; being actually or assumed to be disabled suffices. In the latter case it is the VAPH or the provider which has to 'suppose' the existence of a disability (no formal test needed). Recipients must be younger than 65[65] and must not be using support via the VAPH. They may contact a provider of directly accessible support. Co-payments must generally be paid for each form of RTH.

The introduction of RTH in fact adds support for an additional, lighter need level. It is restricted in volume, but more easily accessible, although two experts mentioned that having to wait for support is not unusual. Less severe cases will also be directed towards general welfare organisations. This is a change, not only for clients but also for providers.

In general, multidisciplinary support is important for ID people. The VAPH recognises the role of multidisciplinary teams during the admission process. In 2016 all kinds of VAPH services for adults were restructured into Flexible supply for adults[66]. In 2017, these flexible supply types are no longer directly paid for by the VAPH, but by clients using their personal budgets.

Waiting lists

For each province within Flanders, a regional priority committee[67] decides on priority. This prioritisation is then used to determine who receives care and support (or the budget to arrange it) and who has to wait (Vlaamse Codex 2016), taking into account special regulations for emergency situations and procedures, and continuity of support. The result was first called the 'waiting list' and later the 'central record of support demand'. The committee works as independently as possible. The waiting list includes not only people

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[64] In The Netherlands the 'VAPH-work' is done by several organisations. The CIZ is responsible for the application process for residential care, but does not arrange residential care. Residential care is arranged by the 'Zorgkantoor' and supplied by care providers. In The Netherlands the municipalities are responsible for assessments and supply of ambulant care and support.

[65] Being recognised as having a need is also sufficient, or continuation of RTH that started before the age of 65.

[66] Flexibel aanbod meerderjarigen (FAM).

[67] Regionale Prioriteitencommissie (RPC); comparable with the 'Zorgkantoor' in the Netherlands.

not currently receiving care or support, but also people in receipt of ‘next-best’ support (about 50%, VAPH 2016b).
Three urgency categories are used to determine how critical a person’s need for support is. A predetermined allocation system is used to distribute the macro-budget across these three categories, taking into account special situations and RTH support. This concerns the more severe cases, who are receiving help from the VAPH (Vlaamse Codex 2016).

4.2.2 Care and support for children with intellectual disabilities

The same definition of ID is used for children. However, they are required to contact the Youth Welfare Agency's Intersectoral Access Portal (Intersectorale Toegangspoort, ITP) for care and support. This portal was set up to organise admission via a multidisciplinary Gateway, to avoid fragmentation of different types of support. Apart from the admission process, ID care and support is still organised by the VAPH. One expert agreed that in the old system the IQ of a child might be decisive in determining which sector would provide help: lower or higher than 70. Nowadays this it is intended to be more flexible.
Children with severe ID generally become known to the VAPH at relatively young age. Children with mild ID become known later because their disability is not identified until later, for example at age 6 or older. One expert mentioned that children with mild ID mostly are assessed in secondary education. Multifunctional centres (MFC – *Multifunctionele centra*) were set up in 2016 to serve children, after four years of experiments. They are still paid for by the VAPH, but the system will change with the introduction of budgets for children. RTH is also accessible for children.

The education system is changing from a system with many special schools to an inclusive organisation. The ‘M-decree’ (Vlaamse Codex 2014b), where ‘M’ stands for ‘measures’, is aimed at including more children in mainstream schools, with additional resources from the shrinking special schools. In Flanders, 4.35% of children in primary and secondary education are in special schools (M-decreet 2015). The figure in the Netherlands is 4.4% in 2014/2015 (StatLine 2018a; StatLine 2018b).

The Pupil Support Centres [68] actively monitor children from an early age, and advise on the best school and support for children, which may include a Personal assistance budget (PAB). This represents quite a change for the ‘old special school’ children and for ‘regular school’ children, and also places demands on their teachers. Borderline ID children (IQ 70-85) mainly attended regular schools in the past (and will continue to do so). Admission criteria to special schools were made stricter in 2015; for example, in the old education type ‘moderate or severe ID’, an IQ criterion of 60 was introduced.

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[68] CLB (Centrum voor leerlingenbegeleiding).

The Flemish Government wishes to reduce early school dropout. Despite this the dropout rate in special secondary schools was as high as 18.4% in 2012/2013 (Van Hove & De Beco, 2016).
Boarding schools are quite common in Flanders. In 2014/2015 just over 10,000 children attended such schools in Flanders (0.90% of all children). In Flanders, a boarding school is less expensive for parents than caring for their child themselves. One expert regards this as perverse, although it could be argued that the absence of financial barriers to boarding schools may be beneficial to the child.

4.2.3 Financial help and labour market support for people with intellectual disabilities

Support on the jobs market

The Flemish Ministry of Employment and Social Economy strives for equal opportunities and diversity in the labour force[69]. Equal opportunities extend to persons with a disability, women, older persons and people with a migration background, and not just to people with ID. A special organisation set up by the Ministry (Disability and Work; Steunpunt handicap en arbeid, 2017) supports advisers in their work with people with a disability.

Regular jobs seem to be possible for only a small proportion of people with ID. Van Hove and De Beco (2016) report that in Belgium, of those claiming to have limitations in performing daily activities (ID or other problems), only 37% have a job. In general, sheltered employment or employer subsidies are needed.

Job market support is mainly organised via the Flemish Service for Employment and Vocational Training[70]. For support on the jobs market, the IQ cut-off score is not 70 (as for care and general support) but 85 (thus including the borderline ID group). This special job support[71] can take several forms, ranging from adjustments in job content and transport to sheltered work placements.
Employers may also receive a five-year subsidy if an employee has an employment disability that affects his or her functioning (productivity loss of 20% or more). This five-year period may be extended. This 'support premium'[72] applies for people with an IQ below 70. A higher premium is possible for people with an IQ lower than 50/55.

Income support

The Directorate-General for Persons with a Disability (Directie-generaal Personen met een handicap), an arm of the Belgian federal government, provides three types of allowances to disabled persons. The Income replacement allowance[73] is intended to compensate

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[69] EAD (Evenredige Arbeidsdeelname en Diversiteitsbeleid).

[70] VDAB (Vlaamse Dienst voor Arbeidsbemiddeling en Beroepsopleiding).

[71] BTOM (Bijzondere TewerkstellingsOndersteunende Maatregel).

[72] VOP (Vlaamse ondersteuningspremie).

disabled persons (younger than 65 years) if they have limited capacity to work. The second and third types of benefit are designed to compensate for costs incurred by disabled persons in integrating into society. They are the Integration allowance[74] for persons younger than 65, and an Allowance for older persons[75]. The allowances are intended as residuary benefit, after means -testing and testing for the presence of other types of benefits (unemployment, pension, etc.).

4.3 Figures on growth in demand for care and support

Number of people with intellectual disabilities

As in other countries, the number of people with ID in Flanders is not known. Simply using information on demand for or use of care and support generally yields excessively low results. Another problem is that clients often receive support for a certain period, after which they are able to manage without it for a while (according to one expert). Clients have become much more diverse.

The prevalence of people with an IQ between 70 and 85 is 13.2% based on the normal distribution of IQ. The borderline ID group is much smaller, however, because it is defined as people experiencing IQ-related problems. Unfortunately, no information is available on the prevalence of these problems. Raeymaekers and Molleman (2014) estimated the number of people with mild ID, possibly including some people with borderline ID. Their estimate was based on information on 14 year-old children obtained from national education statistics for the period 1982-1998.[76] Using educational information to estimate the population prevalence is a risky assumption[77], but it is the most accurate information available. An overall prevalence percentage of 2.5% was found. This is higher than the Dutch figure for people with an IQ lower than 70 (0.85%), but lower than the Dutch rough estimate of people with borderline ID (8%). This would mean that more than 126,000 persons in the Flemish population aged 0-64 years have mild ID or possibly borderline ID.[78]

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[73] IVT (Inkomensvervangende tegemoetkoming).

[74] IT (Integratietegemoetkoming).

[75] THAB (Tegemoetkoming voor hulp aan bejaarden).

[76] The number of children who were in special schools (buitengewoon onderwijs type 1) is used as a proxy for the number of children with mild ID, although in some cases (socially weak background; non-natives) this is likely to be an overestimation. On the other hand, the mild ID children referred to another special school type (for combinations of disabilities) are not included here, which will lead to an underestimation.

[77] Prevalence may vary with age. The age pattern of demand by people with mild ID in the Netherlands shows a peak at the age of 14 to 19 years (Figure 5.3 in Woittiez et al. 2012). It is unclear whether this pattern reflects prevalence differences. At a younger age, the ID may be unnoticed. At the age of 14, mild ID may have become most visible, or hamper school work most. At a higher age, people may have found their place in society without needing care or support any longer. Cohort differences may also play a role.

Increasing Flemish Budget

Total expenditure by the VAPH amounted to 1.53 billion euros in 2016 (Jaarverslag VAPH 2016c), equivalent to 0.6% of GDP[79]. During the period 2010-2019, an additional total of 475 million euros was spent in relation to the objectives to combat waiting lists (see Paradigm change in *Perspectief* 2020; Vandeurzen 2010; VAPH 2017c). Between 2013 and 2016, total expenditure grew by 9%. Three experts mentioned the financial limitations of the government, and two of them felt that budgets were probably increasing at a slower rate than the number of applicants.

Increasing demand for and use of care and support

The number of clients of the VAPH [80] who receive support or care (in kind or in cash) grew from 70,100 ultimo 2009 to 78,400 at the end of 2012, an average increase of 4% per annum (VAPH 2014). The number of adults receiving support or care rose from 36,000 in 2009 to 48,100 in 2015, an average increase of 5% per annum (VAPH 2016b). The number of disabled persons with a need for support as expected to grow further by 3% per annum based on increasing life expectancy, changing perception of disabilities, better provision and medical progress (better diagnosis and better survival in the event of premature birth and accidents; VAPH 2014). Raeymaekers and Molleman (2014) estimated that of the 126,000 persons with mild or borderline ID, 15,200 applied for care or support from the VAPH and 3,100-7,300 actually received care or support in 2013. This means that 0.06%-0.14% of 0-64 year-olds receive specialist care or support from the VAPH, a much smaller figure than in the Netherlands.[81] However, it has to be borne in mind that in Flanders more general organisations such as the OCMW and CAW referred to earlier also offer support to people with mild and borderline ID. Unfortunately, no data are available on this.

One expert stated that support at home and ambulant support have been growing for more than 20 years. This diversification was reinforced by the introduction of personal budgets in 2015. The number of people applying for a personal budget is increasing rapidly in relative terms (8% per annum on average). The relative increase in the waiting list was even more rapid (11% on average), but waiting lists remained fairly stable from 2013 to 2015 (VAPH 2016b). If we add use and waiting list data together and interpret the sum as total demand, an annual growth percentage of 6% (2009-2015) emerges.[82]

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[78] Extrapolating this information to persons aged 65 years and older would produce a total of 156,000, but this is an overestimation as people with mild ID have a below-average life expectancy.

[79] GDP was 241 billion euro in 2015 (the most recent year for which data are available) (Nationale Bank van België 2018).

[80] Only a small fraction of clients have other disabilities, according to some experts.

[81] In the Netherlands, this percentage is estimated at 0.53%, based on the (estimated) use/demand proportion in Woittiez et al. (2012) and an estimated number of non-elderly people with mild or borderline ID taken from Ras et al. (2013).

Use of directly accessible help (RTH) has also been growing recently. Among adults, use of non-directly accessible support remained unchanged between 2014 and 2015 (VAPH 2016b). This will increase the role of local organisations. One expert stated that demand for RTH exceeds acknowledged supply.

The number of disabled persons aged 21-64 years (including non-ID persons) claiming income support in Belgium rose steadily from 70,900 in 2009 to 111,100 in 2014 (FOD Sociale Zekerheid, 2015). Expenditure on these benefits accordingly rose to 1,910 million euros in 2014.

4.4 Expert views on factors causing growth in demand for care and support

The experts we interviewed confirmed that the demand for care by people with an intellectual disability has risen quite strongly for several years in succession.

> *We have been seeing a steady increase in both the support that is provided and the number of people asking for support. The waiting lists here in Belgium are rising rapidly and still not everybody is being helped. In reality, only people with a very urgent demand for care are eligible for support.*

The experts also noted a large increase in the number of people needing a small amount of support, e.g. once a week.

The Flemish document *Perspectief 2020* (2010)[83] in which the Minister of Welfare, Health and Family's vision is presented, sets out a list of causes of the growth in the demand for care by people with intellectual disabilities. According to this document, the number of people and their support need have grown for the following reasons:

- prevalence
  - demography: rising birth rate and rapidly increasing life expectancy
  - improved perinatal survival of disabled people
- society
  - shrinking social networks
  - more need for work-replacement activities
- care and support system
  - policy changes in other parts of the health care sector
  - better supply (more suited to personal needs).

These factors are partly in line with the causes of the growth we found for the Netherlands (Woittiez et al. (2014a)). Notable differences compared with the Netherlands are the

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[82] In 2015, about 23% of this sum related to people on the waiting list. The share of people on the waiting list who already receive another type of care or support stood at 12% of total demand.

[83] This is based on (VAPH 2014).

omission of more complex daily life and education. Demographic factors such as the birth rate and the perceived increasing effect of perinatal survival are mentioned as causes for the growth in Flanders, without quantification. The effect of these factors appeared to be small in the Netherlands.

In several interviews we asked Flemish experts which factors might be responsible for the development in demand for care and support. The experts generally mentioned the same kinds of causes as their Dutch counterparts (Woittiez et al. 2014a). In the following sections we present the insights offered by the experts on the causes. We have drawn a distinction between factors related to the care system, the complexity of society and demographic factors.

4.4.1 Care system-related factors

The experts mentioned several factors related to the care system as causes for the growth in Flanders. As in the Netherlands, more and earlier diagnoses, supply creating demand, 'overflow' from other sectors and less informal care were mentioned; most of these are also cited in the government plan published by the Minister of Health, Welfare and Family, Jo Vandeurzen (2010).

More and earlier diagnoses

According to the experts, the increase in diagnoses is one of the causes of the growth in the number of people with mild intellectual disabilities in Flanders. Providers of support are more attentive to this group. The experts mentioned not only more diagnoses, but also earlier diagnoses:

> *I think they are detected sooner today, because there is greater sensitivity to what is going wrong both on the part of schools and among parents. Our child and family nurses who monitor each child also detect problems more quickly. Special education today provides a ticket to further care. It didn't exist in the past.*

A few experts observed that people with intellectual disabilities are developing a demand for care and support at younger ages than in the past. The number of people with intellectual disabilities with a demand for formal care has grown because in the past they used to stay at home, whereas today this can no longer be taken for granted.

> *The demand for formal care has increased considerably because in the past people tended to be looked after at home more. A few decades ago when I was working, they were people aged between around 35 or 40 up to around 60, 65 or 70. Today, young adults are applying for care because they have come from a residential facility and their parents no longer feel able to look after them. When their children come out of a residential facility, parents are inclined to try to make the transition to another residential form immediately. They don't look for a very intensive form of residential care, but one that is more inclusive. So a great many of these young people are on the waiting lists who weren't on the lists in the past.*

Access for people with borderline intellectual disabilities

The picture that emerges from the literature and the interviews is that access to ID care in Flanders has traditionally been, and mostly still is restricted to people with an IQ below 70. This differs from the situation in the Netherlands, where we have seen an increase in access both by people with borderline ID and people with mild ID (Woittiez et al. 2014a).
On the other hand, access by people with autism has changed in recent years in Flanders.

> *People with autism are now genuinely recognised as a target group; that wasn't the case in the past. They used to be grouped together with people with intellectual disabilities, but now they form a separate category.*

It could therefore be the case that people with borderline ID in Flanders do receive care, but on the basis of other diagnoses. The literature shows that a substantial percentage of children with an autistic spectrum disorder also have an intellectual disability; percentages of more than 50% are mentioned frequently, though there is wide variation (Bourke, 2016, Howlin, 2002, Postorino, 2015).

Supply creating demand

The more attractive the supply and the better the supply fits demand, the more people will demand care and support. To a greater extent than in the past, adequate supply is available for people with ID living independently or with family. In the last decades of the last century, only residential services existed (Claes et al. 2017).
Today, the supply (at least for adults) is more flexible, with care and support for a few days or hours per week for people with ID living with relatives or independently.

> *Parents and other caregivers were looking for this because it gave them the odd Wednesday afternoon or weekend off. That's possible now.*

However, the experts think that residential care still plays a major role.

> *A transition has been under way since the 1990s, involving a shift in emphasis towards ambulant care. But a great deal of money still goes on residential care.*

As mentioned earlier, the share of (all VAPH) residential care and support (as a percentage of all help provided in kind) was still 24% among adults at the end of 2015 (VAPH, 2016b). Based on the age profile of the residents, the natural outflow out of residential care and support will probably remain low.[84]
Accessing ambulant care and support has become easier since the introduction of personal budget financing. Several forms of care and support can be purchased, not just a place in a care facility, and this is considered an improvement. One possible drawback mentioned is that the demand often increases when a new type of care and support is introduced. As an

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[84] Most clients in residential care and support are aged between 41 and 60 years. Only 16% are older than 60. With the rising life expectancy of disabled people, low outflow is expected (VAPH 2014).

example, the introduction of supported living by the VAPH was mentioned in one of the interviews.

The experts expect a future increase in demand for personal budgets because it has become possible to pay informal carers.

> *I do think that people are turning to the government more often for support, especially financial support. The Assistance budget allows the partner to act as a paid informal carer. In the past, it was the parents who provided the necessary care for their child, and they did so for no financial reward. They considered themselves to be the best caregivers.*

because today's system means you can also fund yourself with an Assistance budget, this could be a reason for the increased demand.

The effects are uncertain as yet since the Personal budget was only introduced in 2016.[85] For the Netherlands only a small part of the growth in demand for care and support by people with ID could be attributed to the personal budget system (Woittiez et al. 2014a).

Waiting lists

Although the supply has increased and become more suitable, supply alone is not enough since there are sizeable waiting lists. One expert said that the waiting times for some people have been up to eight years in the past. The citizen's rights organisation GRIP claims that the real waiting time for PAB may be much longer, but is not being reported due to administrative restrictions (GRIP, 2016). Waiting times seem to be longer than in the Netherlands, where the 'Treek-norm' standard is six weeks for daycare and 13 weeks for residential care.

One expert mentioned the difficulties involved in providing appropriate care with an insufficient budget. To distribute care

> *really means to distribute poverty and scarcity. All the cases are of course serious. When is something so serious that it stands out from the rest? Someone can acquire a higher priority if they have a well-written case file. These are some of the difficulties of the system.*

De Coster (2014) also warns that the support guarantee set out in *Perspectief 2020* has to be seen in the light of the finite macro-budget. Furthermore, this research suggests that more than half the people with a disability (of any kind) in Flanders do not receive or even demand specialist care or support, which seems to be in line with Raeymaekers and Molleman (2014).

The experts put the waiting lists into perspective a little by commenting that the waiting list not only includes people not currently in receipt of care or support, but also persons receiving 'next-best' support. Indeed, about half of all people on the waiting list in 2015 were receiving another type of care or support (VAPH 2016b). The experts also mentioned a

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[85] The PAB has existed since 2000, but no data are available to analyse this effect.

perverse incentive of putting someone on the waiting list: the more people are on a waiting list, the more supply was allowed to expand.

> *So if people weren't encouraged to have themselves registered, those types of provisions weren't extended. Whereas a great many people on those waiting lists were in fact already receiving some form of support, but not the support they actually wanted.*

Under the new budget system, this incentive should no longer exist, because people will be waiting for a budget, not for a particular form of supply.

Substitution of informal care by formal care

Another cause of the growth referred to is the tendency to replace care tasks which used to be performed by informal networks by formal care. In Flanders, several causes have been mentioned for the decrease in informal care (Vanderleyden & Moons 2015), for example that more women are participating on the labour market for more hours, leaving them with less time to provide care. The increase in the number of single-parent families and the increased age at which women are having children were also mentioned.

> *In the past, when people's networks were stronger, less formal care was provided. In those days, elderly parents only asked for care for their son or daughter for when they would no longer be there.*

This remark shows the tendency towards people providing less informal help. Formal help sometimes helps people with intellectual disabilities more than informal help to play as full a part in society as possible and to live as independently as possible. An expert uses the example of a client to illustrate this:

> *He actually spent his whole life living with his mother, and it's only just over a year ago that he came here and a whole world opened up for him.*

In terms of the concentric circles, therefore, lower circles may prove less effective. According to the *Visie 2050* document (Vlaamse regering 2016) individualisation will demand more material, social and cultural capital from citizens. Social cohesion is reported to be high, but 10% of adults have little contact with family or friends. Informal care is expected to be less available in the future than today. In Flanders, the government vision is that care and support for disabled persons is a shared responsibility, starting from basic self-help and help from the informal network. If that is not enough, formal ID care and support can be provided (VAPH 2014). This concept of concentric circles has not yet been realised, according to two experts; a lot of support is still given by professionals.

> *The idea is to build up the amount of volunteering. That's essentially what those concentric circles come down to, but I don't think we're there yet. I think people are still inclined to look for professional help in the first instance.*

Another expert felt that the circles are already being used to explore the possibilities within the network, possibly reducing costs of formal care and support.

System of personal budgets: pros and cons

The transition to a more client-led system means giving more freedom to clients, but this may come at a cost. Several experts stated that the system of personal budgets has been promoted by disabled people themselves for some time, but mostly by people with a physical disability, and typically not by people with ID. The question may be asked as to whether people with ID or their networks are always capable of managing their resources adequately. Another expert mentioned that many people with ID have a parent or a professional to manage their money, but this is not obligatory. This can avoid financial distress, but may also be too much interference. A voucher system has been mentioned as an alternative.

One expert made the more specific critical comment that this system makes people with ID and their networks responsible for judging their need for support from outside their own circle. This may be beyond their competence, thus questioning the optimality of the system and the support guarantee set out in *Perspectief 2020*. Two experts feared that it will be tempting for persons with ID to use the BOB for things other than care and support (e.g. to buy a TV or smartphone); there are no built-in checks on how the money is used. On the other hand, another expert argued that the old system also had many flaws. Support was given in kind by providers, and it was not uncommon for excessive amounts and excessively different types of support to be provided.

Dealing with limited budgets

The experts also discussed the distribution principle: should as many people as possible receive support, or should only the people with the most severe needs get help? The new BOB and RTH systems give a relatively small amount of support to a relatively large number of people. Among the advantages cited are the facts that highly qualified personnel will no longer be providing ‘simple’ support such as helping with shopping, and RTH effectively lowers the threshold for people who only require a small amount of help. But two experts also cited a disadvantage: RTH may replace the old waiting list, thus obscuring people’s real needs. It thus removes some of the transparency of the old system. One expert expressed the fear that waiting lists will grow because of the attractiveness of personal budgets (relative to the old-style support in kind). Another expert felt that this applied mainly to the frequently given – and smaller – BOB.

Whether the financial capacity of the government is sufficient remains to be seen. Or, as one expert puts it:

> *It’s a time of austerity, and there’s not much our Minister can do about that. You do sense that the transition is driven in part by an austerity drive. We are now in a transitional phase, of course. A system of personal financing and personal budgets has been chosen; these systems were initially launched by people with a physical disability.*

It remains to be seen whether cost reductions will result.

Overflow

Overflow from mental health care has been mentioned as a cause of the growth in the demand for care for people with intellectual disabilities in Flanders, as in the Netherlands (Woittiez et al. 2014a). However, this was a long time ago in both countries and no longer appears to play a role.

> *25 years ago there was an operation in Belgium in which people with intellectual disabilities living in psychiatric care facilities were transferred to residential facilities for people with physical disabilities; and there was literally a mass influx.*

Overflow may no longer be an issue, but it does still influence the allocation between sectors:

> *That doesn't mean that there aren't still lots of people with ID living in psychiatric facilities. They had a lower priority on the waiting lists because they were already receiving care.*

4.4.2 Factors related to a complex society

The Flemish experts recognised the complexity of society that was cited by their Dutch counterparts, although less prominently than in the Netherlands. The Flemish experts pointed out that society has become more complex in daily life, at school and on the labour market. On the other hand, technological developments may increase self-reliance.

More complex daily life

According to the experts, the causes of more complex daily life are mainly digitalisation, the high pace of life and high societal expectations.

- Digitalisation

According to the experts, digitalisation is less advanced in Flanders than in the Netherlands, but the same trend towards more digitalisation is evident. The experts pointed out that digitalisation makes it more difficult for some people to find their way in society because the number of physical counters (e.g. for banking, energy services, etc.) has reduced and with it the amount of personal contact. Instead, computers (smartphones; Internet) have to be used to arrange things, which forms a barrier for people with mild and borderline ID. As a result, there are more and more people unable to manage day-to-day financial and administrative activities.

> *Where in the past you could just go to the counter in the bank to make a transfer, you now have to do everything on a computer. People with mild or borderline intellectual disabilities, who are actually running their households very well, are suddenly completely left behind by innovations like that.*

The same type of problems are encountered when an official document is needed. The appointment with the municipal official has to be made via a computer. One expert cited moving home as an example.

> *Suppose you are moving house; what are all the things that have to be taken care of? For people with an intellectual disability, there's a whole complex barrage of information and things they have to do. In the past, you just went to the Electrabel counter and said: 'I live here, I'm moving to there on such and such a date'. Now that all has to be done on the computer.*

Telephoning a provider, bank or municipality, for example, has also become difficult:

> *You're given a menu with up to seven options and you have to remember what each option means. And then you also have to press a hash key. You have to be patient for that, and our clients don't have too much patience. They want to be able to just ring up and speak to someone.*

On the other hand, digitalisation can make *certain* tasks easier, for example through the use of apps. The experts mentioned speech technology, adapted software which makes it easier to use computers and technology that helps people move around. Speech-based devices are used to help people's mobility. One expert gave the following example of a route planner:

> *The device just talks. You enter an address and the device says turn left here and there. It's a good example of how technology can help.*

Technology may help to organise more and better 'remote care' (Visie 2050 (Vlaamse regering 2016)). One of the initiatives in relation to digitalisation is BlueAssist. This offers support to people for whom it is difficult to ask questions of fellow citizens using a smartphone, for example (BlueAssist, 2017). Answers to questions such as, 'Is this the train to...?' or 'Is this the right place to apply for...?' are pre-installed in the apps.

- Higher pace of life and more temptations

The higher pace of life also makes society more difficult for people with ID. One expert explained it as follows:

> *When you go to the supermarket, you have to put your shopping on the conveyor belt quickly and you have to put it back in your trolley even more quickly. The people in the queue behind you are impatient.*

Another aspect of the more complex daily life are the increased temptations to which we are all exposed to and which we have to resist to avoid getting into trouble.

> *That's a common problem. You're sent an allegedly free set of books, for example, or someone in the street tries to persuade you to take out a subscription. People then enter into contracts; it can cost them a lot of money. You can apply for credit cards everywhere. That's why a number of our clients are placed under guardianship.*

- Higher societal expectations

The experts pointed out that society expects more and more from all its citizens, with and without disabilities. Some people are unable to meet those expectations. One interviewee with intellectual disabilities put it as follows:

> *demands more and more of people, of everyone: employees, employers. In the past, people were more content and helped each other more; now, people are more concerned with exploiting others. People were friendlier, kinder in the past.*

To make society less complex, it would help if certain aspects could be made simpler:

> *I would be happy to go to school, but slowed-down courses aren't available everywhere. I could then follow a computer course, for example.*

Educated for an occupation but no jobs

One of the issues mentioned for the Netherlands in Woittiez et al. (2014a) with respect to education is that education types which train students for a particular occupation have become less common. This seems not to be the case in Flanders.

> *Vocational education is still fairly heavily focused on practical learning. You really learn a trade. The students learn bricklaying or joinery, for example.*

Unlike what we found for the Netherlands, the experts pointed out that in Flanders there still are schools where pupils with a mild or borderline disability learn a job, but added that after they leave school it is almost impossible for these students to find a regular job.

> *The biggest frustration for teachers in special education (education type 3, which in principle trains students for the jobs market) is that they are apparently training young people for the wrong occupations. They learn manual skills, follow vocational training, woodwork, metalworking, all those kinds of things. They do give the students a sense of self-worth and show that they can achieve something, but once they have qualified, they can't find work anywhere; they're completely sidelined. At best, they end up in sheltered employment.*

Labour market

The experts differed in their opinions on whether there are enough suitable jobs for people with mild or borderline intellectual disabilities. One expert expressed the view that, in principle, people with mild or borderline intellectual disabilities can perform several tasks in regular jobs but that they are not given the opportunity to work because they are often less productive than employees without an intellectual disability.

> *It's not just that many of those jobs no longer exist, but they are also being performed by other people who are more productive.*

Another expert felt that working in regular employment has become too complicated. Jobs in the cleaning industry, for example, demand more skills because today machines have to be used. Other jobs require possession of a driving licence, which is unattainable for someone with an intellectual (or borderline) disability. Many jobs are related to computers, and even user-friendly apps require the user to know how to use the app.

> *Simple jobs no longer exist. As a society, we are actually making people disabled because they can no longer keep up as they could in the past.*

This comment shows how an intellectual disability can vary depending on the time or context. The disability can be viewed as the mismatch between skills and demands, as shown in the support model described in Chapter 1.

On the other hand, some changes may proceed slowly. Another expert told us that in the past 20 years none of their clients had worked in 'simple' jobs, such as dock workers. Going further back in history, some 50 years ago, it is clear that some jobs have disappeared:

> *When I was at boarding school, you also had people who worked in the kitchen; I should think they are now in sheltered employment. Or working as volunteers in a soup kitchen or something. But in the past those people would have been taken care of by a convent, for example. They weren't always the nicest jobs, but they did mean you had work and a roof over your head, and someone who gave you a bit of attention. That's all disappeared because very different norms apply today.*

The expert here referred to safety regulations at work.

One expert was quite critical about the labour market effects of the income support system:

> *Some people are better off not working and just keeping their benefits. We do have incentive premiums, though: if you take on someone with a disability, part of the wage cost is subsidised. But I think that's only having moderate success.*

Another expert mentioned and appreciated an organisation where people with mild or moderate ID work in jobs such as gardening or helping at schools. The same caveat applies, however: no payment is possible, because benefits would then stop. It is difficult to find a system for work which 'works', without demotivating people, and which gives them the feeling that they are genuinely contributing. One expert said that people functioning at the educational level that is intended to lead to regular jobs were unable to cope and had taken jobs in the sheltered employment sector, which are in fact intended at a somewhat lower educational level. As a result of this process of crowding out, the latter group had ended up with no job at all. He also mentions the increased workload in sheltered employment places:

> *In the past, it was the bottom rung of the ladder. In those days, almost everyone could step in at that level. But it's no longer like that; today, it's all about performance. But that's really only achievable for the 'better' clients. You do have to have a reasonable work ethic; you have to turn up on time each morning, and you must be able to maintain the effort all day. You have to be able to keep up, and it's also often very monotonous work. You also have to be socially adaptable. Getting on with your colleagues isn't always easy.*

A similar problem is signalled in the Netherlands. A form of employment situated between day centre and sheltered employment place would be very welcome, according to one expert. In some situations, volunteering may be an option and small rewards may be offered for this.

4.4.3 Other factors

Apart from the complex society and the care system, the experts also mentioned other socioeconomic and demographic factors, such as longer life expectancy and higher prevalence, as possible causes of the growth in demand for care by people with borderline or other intellectual disabilities. Demographic factors which play a role in the growth of the number of people with intellectual disabilities can be found (without quantification) in the multi-year analysis 'Meerjarenanalyse' by VAPH (VAPH 2014). One expert summarised the situation as follows:

> *More people are surviving serious car accidents, there are far more non-congenital brain injuries, more premature births in which the babies survive.*

4.5 Summary

In this chapter we have analysed the development in demand for care and support for people with intellectual disabilities in Flanders, and looked for explanations. The development in demand for care and support is based on figures provided by the Flemish Agency for People with a Disability (VAPH), which is responsible for assessing the need for care and support of people with ID (and other disabilities). The number of clients of VAPH in Flanders who receive support (in kind or in cash) has grown by an average of 4% per annum. This is confirmed by the experts we interviewed. They pointed out that demand for care by people with intellectual disabilities has been rising quite steeply for several years in succession, resulting in waiting lists. The experts noted substantial growth in the number of people needing a small amount of support, e.g. once a week.
The explanations for the growth are based partly on the Flemish document *Perspectief 2020* (Vandeurzen 2010), published by the Ministry of Welfare, Health and Family, and partly on expert views. Most of the causes of the growth that we found are similar to those in the Netherlands (Woittiez et al. 2014a): shrinking social networks, greater need for work-replacement activities, policy changes in other parts of the health care sector (overflow), and better supply (more tailored to personal needs). Demography, i.e. a growing birth rate and rapidly rising life expectancy, were mentioned but without quantification.

The experts mentioned several factors related to the care system as causes of the growth in demand in Flanders, such as more and earlier diagnoses, supply creating demand, and less informal care; all of these are also cited in the policy document. Mild intellectual disability today receives more attention from providers of support, and this has also resulted in a situation where people with intellectual disabilities demand care and support at an earlier age than in the past. To a greater extent than in the past, adequate support is available for people with intellectual disabilities living independently or with family. Accessing this type of care and support has become easier since the introduction of personal budget financing, although the availability of personal budgets might be restricted by limited national budgets, according to one of the experts. Several forms of care and support can be purchased, and this is considered to be an improvement. Another cause put forward to explain the growth in demand is the tendency to replace care tasks which were previously performed by informal networks, with formal care. This might be due to more women participating on the labour market for more hours, leaving them with less time to provide care. The increasing number of single-parent families and the greater age at which women are having children are also mentioned (also in Woittiez et al. 2014a).

The Flemish experts placed less emphasis on the complexity of the society than their Dutch counterparts in Woittiez et al. (2014a). And where they did it as a cause, this mainly referred to digitalisation and the falling demand for low-skilled workers. It may be that digitalisation was mentioned less often as a cause of the growth in demand because, as some experts suggested, the digitalisation is less far advanced in Flanders than in the Netherlands, although the same trend towards increasing digitalisation is evident. Apart from the increased complexity due to the use of the Internet for accessing all kinds of services, the Flemish experts also acknowledged that digitalisation can make *certain* tasks easier, for example through the use of apps. Specific education for people with ID is well organised, and trains them for a particular occupation, but there are few jobs which match their resultant competences. The experts and the policy document mention that performing regular jobs has become too complicated for people with ID. Workers in the cleaning industry, for example, require higher skills today because machines have to be used. In addition, people with mild or borderline intellectual disabilities would be able to perform several tasks in regular jobs but are not given the opportunity to do so because they are often less productive than employees without intellectual disabilities.

Apart from the complexity of society and the care system, the experts also mentioned greater life expectancy and higher prevalence (more people surviving serious traffic accidents or premature birth) as possible causes of the growth in demand for care by people with a borderline or other intellectual disability. We have no data on this.
The picture that emerges for Flanders from the literature and the interviews is that access to ID care has traditionally been and still is restricted to people with an IQ of less than 70 (substantiated exceptions possible). This differs from the situation in the Netherlands, which has seen an increase in access by people with borderline ID. On the other hand, it might be the case that people in Flanders with an IQ above 70 receive care because of other diagnoses.

4.6 List of abbreviations

BOB	Basisondersteuningsbudget / Basic support budget
BTOM	Bijzondere TewerkstellingsOndersteunende Maatregel / Special job support
CAW	Centra Algemeen Welzijnswerk / general welfare
CLB	Centrum voor leerlingenbegeleiding / Pupil Support Centre
EAD	Evenredige Arbeidsdeelname en Diversiteitsbeleid / Equal opportunities and diversity in the labour force
FAM	Flexibel aanbod meerderjarigen / Flexible supply for adults
ID	intellectual disability
IT	Integratietegemoetkoming / Integration allowance
ITP	Intersectorale Toegangspoort / Youth Welfare Agency's Intersectoral Access Portal
IVT	Inkomensvervangende tegemoetkoming / Income replacement allowance
MFC	Multifunctionele centra / Multifunctional centers
OCMW	Openbaar Centrum voor Maatschappelijk Welzijn / Public Centre for Social Welfare
PAB	Persoonlijke assistentiebudgetten / Personal assistance budget
PVB	Persoonsvolgend Budget / Personal budget
PVF	Persoonsvolgende Financiering / System of personal budgets
RPC	Regionale Prioriteitencommissie / Regional priority committee
RTH	Rechtstreeks toegankelijke hulp / Directly accessible support
THAB	Tegemoetkoming voor hulp aan bejaarden / Allowance for older persons
VAPH	Vlaams Agentschap voor Personen met een Handicap / Flemish Agency for People with a Disability
VDAB	Vlaamse Dienst voor Arbeidsbemiddeling en Beroepsopleiding / Flemish Service for Employment and Vocational Training
VOP	Vlaamse ondersteuningspremie / Flemish support premium

5 Ontario, Canada: More inclusive society but long waiting lists[86, 87]

> *There is a growth in demand for support workers, in home care,*
> *mental health services, and employment services that may be linked to*
> *increased participation in community for people with ID*
> *who are no longer institutionalised or living in isolated group homes.*
> [Source: one of the interviewed experts in Ontario]

This chapter focuses on care and support for people with intellectual disabilities in Ontario. Ontario is a province of Canada, which accounts over one third of the Canadian population (Statistics Canada 2015). In 2007, Canada was among the first countries to sign the United Nations Convention on the Rights of Persons with Disabilities. Nowadays it is accepted in Ontario that people with developmental disabilities would be safer and better within their communities if they are embedded in trusting, caring relationships with others (Crawford 2008). The process of deinstitutionalisation, that has also started in other countries is already much more a daily reality in Ontario than elsewhere: the last three large residential institutions were closed in 2009 (see e.g. Brown & Radford 2015). In the Netherlands, the process of deinstitutionalisation is ongoing but residential care is still available for people with ID, except for those with the least severe problems. Ontario is therefore a valuable case for inclusion in this comparative study.

In the national and regional literature and policy concerning Canada and Ontario, the terms 'developmental disabilities', 'intellectual disabilities' and 'developmental delay' are used, though there are differences between these concepts (Crawford 2009; Lunsky et al. 2013).[88] In this chapter the term 'developmental disabilities' is used, since this is the most commonly used term in Ontario. However, in the Summary section the term 'intellectual disabilities' is used to ensure alignment with the other chapters.

5.1 Vision on and definition of people with developmental disabilities

The vision of the Ontarian Ministry of Community and Social Services is that all communities are strong, inclusive and sustained by the economic and civic contributions of

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[86] This chapter was written by Evelien Eggink and Isolde Woittiez.

[87] This chapter is based on literature and websites in English. However, most government information is also available in French.

[88] For instance, developmental disabilities are defined more broadly than intellectual disabilities. Apart from intellectual disabilities, autistic spectrum disorders, Down syndrome and foetal alcohol spectrum disorders also come under the umbrella term developmental disabilities (Lunsky et al. 2013).

all Ontarians (Ontario Ministry of Community and Social Services 2013). The Ministry aims to remove barriers which limit the ability of Ontarians to participate in life. To that end the Ministry works with local communities agencies providing care and support, local governments, the non-profit sector and the business community. In this way the Ontarian government aims to provide support and services that help people with developmental disabilities live more independently and participate in their communities. Inclusion is a major driving force in policy in Ontario.

The definition of developmental disabilities used in Ontario is based on the definition of the American Association on Intellectual and Developmental Disabilities (AAIDD, see American Association on Intellectual and Developmental Disabilities 2013a). This definition is based on cognitive and adaptive functioning, but also includes activities of daily living (Ontario Ministry of Community and Social Services 2015b; Developmental Services Ontario 2016d; Dubé 2016a). Affected areas of life may be personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity (see e.g. Law Commission of Ontario 2009, 2012; Developmental Services Ontario 2016b). It very much resembles the DSM-5 definition used in the Netherlands (Harris & Greenspan 2016).

Both mild and severe developmental disabilities are acknowledged in Ontario. Borderline disabilities, one of the main subjects of this study, are usually not mentioned in the scientific and policy literature on Ontario. Experts state that people with borderline ID and autism appear in the support system via the diagnosis of autism rather than via their relatively low IQ. (Developmental Services Ontario 2016d). Elsewhere in the literature it is also stated that autism and intellectual disability are closely related (see e.g. Harris & Greenspan 2016), and the two are often mentioned together in Ontario (e.g. OPAAA 2016). This is not the case in the Netherlands, where autism is regarded as a mental health problem.

5.2 Care and (financial) support for people with developmental disabilities

All large residential institutions in Ontario have been closed, and care and support are now provided by community-based agencies. Nowadays most people with ID live with their family, while others live in small-scale residential facilities such as group homes or supported independent living setting, or live independently. Over the course of the de-institutionalisation process, the focus shifted from the notion of community living to a new vision of social inclusion (McCauley & Matheson 2016). People with disabilities are not included in society simply by living in the community (McCauley & Matheson 2016).
The Ontario Ministry of Community and Social Services provides funding and helps in the planning of new inclusive living environments where people with varying abilities can be connected to their families, friends, neighbours and community. This is part of the plan to create jobs, grow the economy and help people in their everyday lives (Ontario Ministry of

Community and Social Services 2016b). In the new situation, different types of care and support are needed. As the report of the Ombudsman of Ontario (Dubé 2016a) shows, not all needs are met and support is not organised properly in all cases. This section aims to provide an insight into the system of support for people with ID in Ontario, and the way this works in practice, and to compare it to the situation in the Netherlands.

Deinstitutionalization and inclusion in Ontario

There has been a significant movement in Ontario over the last 40 years towards the social inclusion of people with disabilities and recognizing their rights (Law Commission of Ontario 2009). Until the 1960s institutions were built to house people with intellectual disabilities, segregated from society (Brown & Radford 2015). The number of people living in institutions continued to grow until the mid-1970s, and by 1976 the 16 institutions in Ontario were providing residential care to more than 8,000 people with an intellectual disability (Ontario Ministry of Community and Social Services 2012).

Since then, Ontario has taken a major step away from a medicalised and institutional model towards inclusion of people with (intellectual) disabilities in their communities, through a process of deinstitutionalisation (closing large residential institutions). The focus shifted towards community services after the Ontario government launched its first long-term plan on this subject in 1977 (Dubé 2016a). The government started to look at different living arrangements within the facilities (smaller units) and programmes to help children and adults with a physical or intellectual disability live at home with their families (Ontario Ministry of Community and Social Services 2012).

Large institutions were closed down;this was done gradually, first by not admitting (new) children into the institutions, then by not admitting (new) adults, and finally by moving people back into the community. This was sometimes problematic: many of the residents had been there since early childhood; their family members were elderly or did not want to look after their relatives with disabilities (L'Arche Canada 2014). In March 2009 the last of Ontario's large institutions were closed and the residents moved into the community.

It is also reported that the transfer to the community and the subsequent adjustment were generally good and families indicated an overall satisfaction with the present placement and with the supports and services provided (Griffiths et al. 2015).

Care for people with developmental disabilities in Canada comes under social services or youth services rather than the health care sector. The system in Ontario is a complex one. Service delivery is mostly organised at the level of individual Canadian provinces or territories but the provinces are responsible for social services. Most provinces adopt a similar approach, since the provinces are autonomous but highly interdependent (Simeon & Papillon). There are various sources of funding in Ontario, and different services for adults and children.

In 2008 *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008* (SIPDDA) was passed. While most provisions in the Act are in force it is not yet fully operational since it is intended to come into force in several stages (Dubé 2016a). It replaced the 35 year-old *Developmental Services Act* which regulated services mainly for people living in institutions (Developmental Services Ontario 2016b). With the SIPDDA the government is seeking to improve services and support for adults with developmental disabilities and their families. It is also intended to lead to greater fairness and uniformity in eligibility for services and support (Dubé 2016a). The Act should give adults with developmental disabilities more control over their lives, by living independently with the right support (Ontario Ministry of Community and Social Services 2009; Law Commission of Ontario 2012). In addition, there are programmes for financial support and labour market support.

For children there are various other programmes, financed by the Ministry of Community and Social Services, the Ministry of Children and Youth Services and the Ministry of Education.

5.2.1 Care and support for adults with developmental disabilities

As in other countries such as the Netherlands, in Ontario there are various support programmes for adults with developmental disabilities.[89] It is a complex system (see Figure 5.1), or as (Dubé 2016a) puts it:

> *Today's developmental services system [...] is a matrix of diverse and individualised visions of hundreds of non-governmental agencies involved in this sector*

The Developmental Services Ontario Offices (DSOS) are the central access points for all adult developmental services and support funded by the Ministry. They are responsible for assessing whether individuals are eligible for services. The DSOS are non-profit-transfer payment organisations, which are required to comply with Ministry policy directives and regulated quality assurance measures. This means that applicants are assessed independently of providers of support, just like in the Netherlands. A psychological assessment is required for application for adult intellectual disability services and support to ascertain whether an individual meets the eligibility criteria. If an individual is considered eligible for services, a needs assessment is then carried out based on the Application for Developmental Services (ADSS) as well as the Supports Intensity Scale (Developmental Services Ontario 2016a).

The Ministry of Community and Social Services provides funding for services directly to service agencies. Under the SIPDDA the Ministry of Community and Social Services provides funding for the following types of services: residential services and supports; activities of daily living services and supports; community participation services and supports; caregiver

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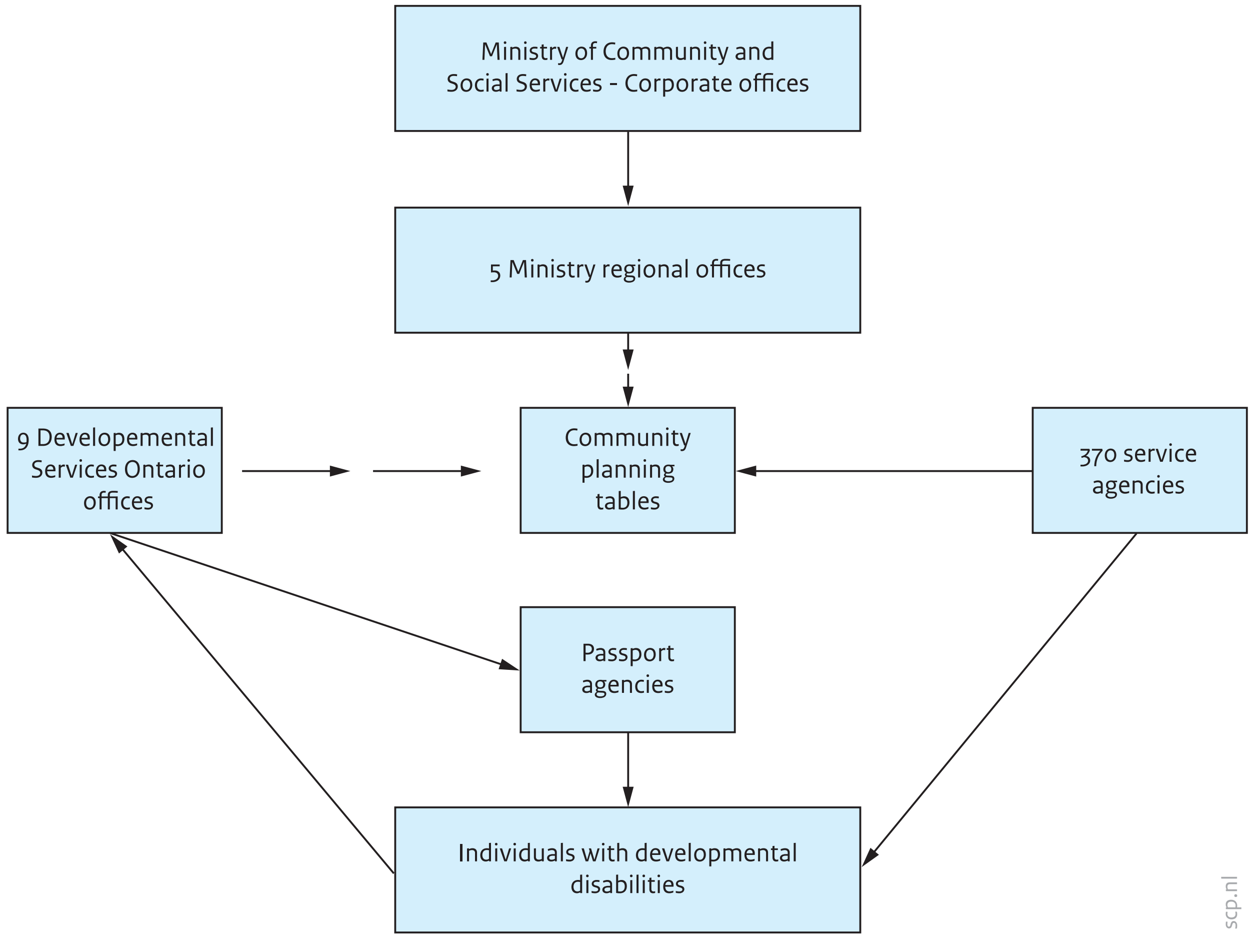
[89] The following description is mainly based on (Dubé 2016a).

respite services and supports; professional and specialist services; person-directed planning services and supports (Dubé 2016a).

Figure 5.1
Developmental Services System for Adults[a]



a A solid arrow indicates a direct relationship (application, funding, oversight or service provision); a broken arrow indicates a possible relationship, depending on the issue or relationship.

Source: (Dubé 2016a)

Service agencies must comply with regulatory requirements. Individuals may also receive direct funding to develop and purchase their own support arrangements (e.g. community participation services and supports, activities of daily living services and supports; caregiver respite services and supports; and person-directed planning services and supports). Priority for services is assigned through DSOs and local Community Planning Tables have responsibility. In general, individuals with urgent needs are rated at the highest priority. Following the priority rating, prioritised individuals are matched to available services and supports which are offered by various service agencies. Individual service agencies decide on the supports and services they offer. Figure 5.1 shows the complexity of the system. An individual with ID seeking support has to contact one of the Developmental Services Ontario offices in order to arrange an assessment. The Community Planning Tables, chaired by local service agencies, decide on the prioritisation of individuals who are found to be eligible for government -funded intellectual disability services (Dubé 2016a). The service agencies then offer services to the individuals concerned. Some adults may receive funding (from a 'Passport Agency', which implements the funding of the Passport programme; see below) and buy in the support they need themselves.

The criteria for developmental disabilities in Ontario include a low IQ (<70) (Select Committee on Developmental Services 2014).[90] Further, the Supports Intensity Scale (SIS) and the Application for Developmental Services (ADSS) are used to determine the supports needed. This instrument measures the support the individual needs in personal, work-related and social activities (American Association on Intellectual and Developmental Disabilities 2013b). This assessment should be performed by a psychologist.
The main services and supports for adults funded by the Ontario Ministry of Community and Social Services are as follows:

- Direct funding through the *Passport Program*
- *Community Participation Supports Program*
- *Person Directed Planning*
- *Adult Protective Service Worker Program*
- *Residential supports*
- *Specialised Clinical Services*

These programmes are described below.

The Passport Program

The Passport Program is aimed at adults with developmental disabilities. It helps people with intellectual disabilities to participate in their communities and offers funding for respite to their caregivers from their caregiving responsibilities. In practice the Passport Program provides funding for participating in community classes or recreational programmes, to develop work opportunities, volunteer, and daily life skills, or pay for a support worker. The funding may be used to purchase services from service providers such as community service providers, private service and support providers, but also (in some cases) neighbours, family members or friends (Developmental Services Ontario 2014). This is comparable to the personal budgets in the Netherlands. Passport is funded by the Ontario Ministry of Community and Social Services and administered by local Passport Agencies, while Developmental Services Ontario manages the application process (Ontario Ministry of Community and Social Services 2015a).

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[90] Problems with cognitive functioning can be established by a clinical determination made by a psychologist or a psychological associate.

The Passport Program

Community participation supports offer adults with a developmental disability opportunities to take part in community-based activities, such as social and recreational activities, faith-based or volunteering activities (Developmental Services Ontario 2016c). Agencies may offer support to individuals to develop skills in utilising community infrastructure (e.g. transportation, libraries), promoting inclusion as individuals transition from the education system, as well as planning to assist individuals in identifying life goals and finding and using services to meet those goals.

Caregiver respite services

Caregiver respite services are provided by a person other than the primary caregiver for the purpose of providing temporary relief to the primary caregiver (Developmental Services Ontario 2016c). Respite may be provided in the home of the adult with developmental disabilities or elsewhere, and may include short-term overnight stays (e.g. at a group home operated by a developmental services agency).

Person-directed planning

Person-directed planning helps a person with a developmental disability to find the tools and funding they need to realise their dreams and meet their goals (Developmental Services Ontario 2016c). It can help people to set goals and make choices for their future lives, find ways to participate in their communities and locate people who can help them achieve their goals.

Adult Protective Service Worker

The *Adult Protective Service Worker* (APSW) programme links adults with developmental disabilities who are living on their own and have limited social support to a professional (the *Adult Protective Service Worker*).[91] The goal of the programme is to help individuals live as independently, safely and securely as possible in the community (Ontario Ministry of Community and Social Services 2015a; Developmental Services Ontario 2016b). APSW helps them finding and maintaining supports, such as health care, counselling for emotional support, finding community-based social and housing services, and supporting them in legal and family matters.

Residential Support

Community agencies provide different *residential supports* that help people with developmental disabilities. These include supported living arrangements such as group homes, or specialised residences if they have additional needs, such as mental health services. In addition the *Host Family Program* offers residential support in a family-like setting, where adults with developmental disabilities live with families or others who

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[91] In some communities, Adult Protective Service Workers have different titles, such as Service Coordinator or Adult Support Worker (Developmental Services Ontario 2016b).

provide care, support and supervision in their own home (Ontario Ministry of Community and Social Services 2015a)

Specialised Clinical services

There are also *specialised clinical services* to help adults with developmental disabilities who have higher support and care needs. This includes people with a dual diagnosis who have developmental disabilities combined with mental and/or behavioural issues (Ontario Ministry of Community and Social Services 2015a).

5.2.2 Care and support for children with developmental disabilities

The services and supports for children are mostly aimed at providing support for both children and their families. The support for children with disabilities, including ID, may be organised by the Ministry of Community and Social Services, the Ministry of Children and Youth Services or the Ministry of Education.

Behavioural Management Program

The Behavioural Management Programs, funded by the Ministry of Community and Social Services, provide assessment and treatment services for children with developmental disabilities who also have behavioural issues. Services are provided through community hospitals and local community agencies (Ontario Ministry of Children and Youth Services 2016).

Infant Development Programs

The *Infant Development Programs* are designed to help children up to five years of age who have developmental disabilities or who are at risk of developmental delay (Ontario Ministry of Children and Youth Services 2016).

Special Services at Home Program

The *Special Services at Home Program* helps families who are caring for a child with an intellectual and/or physical disability (Ontario Ministry of Children and Youth Services 2016). The programme is funded and managed by the Ministry of Community and Social Services. It aims to provide funds to help the child learn new skills and abilities and provide respite support to the family. The amount of funding a family receives depends on the needs of the child, the network of the family, and the other support received by the family (Ontario Ministry of Children and Youth Services 2016). The programme resembles the Passport programme for adults and the personal budgets in the Netherlands.

Out-of-Home Respite

Families of children with multiple special needs can receive up to seven days of out-of-home respite per year, in their own home or elsewhere. The programme is aimed at children with multiple special needs because of a physical and/or intellectual disability, who live at home continually. The respite care is intended to relieve the family and prevent long-term residential placement (Ontario Ministry of Children and Youth Services 2016).

Education Act

In Ontario, children who have behavioural, communication, intellectual, physical or multiple disabilities may have educational needs that cannot be met through regular instructional and assessment practices (Ontario Ministry of Education 2016). The Education Act (1980) requires schools to offer students with such special needs, including students with developmental disabilities, education that will enable them to develop the knowledge and skills they need in order to participate in the community.[92] School boards must assess the identified student's strengths and needs that affect the student's ability to learn and demonstrate learning, and must write an Individual Education Plan (IEP) describing the special education programme and/or services required by the student concerned.

For students whose needs cannot be met entirely in the regular classroom, a range of placement options are available. These include placement in a regular class with assistance for the student or the teacher, or placement in a special education class, with or without integration with the students in regular classes. Placement in a regular class must explicitly be considered. The Ministry of Education supports special education in Ontario schools by regulation, providing experienced staff and funding. The majority of children with special educational needs attend regular schools.[93]

Provincial Transition Planning Framework

As in the Netherlands since the decentralisation on 2015, the support for children in Ontario differs from that for adults. When a child with developmental disabilities reaches adulthood, the availability of supports and services changes. At 18 years of age, access to the Special Services at Home supports ends and individuals may apply for Ontario Disability Support Program benefits as well as the supports funded by the Ministry of Community and Social Services. Individuals with developmental disabilities participating in daily school programming through the Ministry of Education up to the age of 21, from then on must rely on day programming that is funded privately or by the Ministry of Community and Social Services. Planning for the transition to adulthood is therefore important.

For this reason, the Ministries of Community and Social Services, Children and Youth Services and the Ministry of Education participate in the Provincial Transition Planning Framework. It aims to provide transition planning for every individual with developmental disabilities but does not guarantee an individual access to services and supports at age 18. The problems with and attention for a smooth transition to adulthood can also be seen in the Netherlands (see e.g. Pommer & Boelhouwer 2017).

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[92] This resembles the Appropriate Education Act in The Netherlands.

[93] In 2002 around 55% of 5-14 year-old students with disabilities were in regular classes, i.e. not in special education classes or schools (Kohen et al. 2007).

Other support for children with ID

In addition to the foregoing, more general support is available for children with developmental disabilities.[94] The *Assistance for Children with Severe Disabilities Program*, funded by the Ministry of Community and Social Services, provides financial support for low to moderate-income families to cover some of the extra costs of caring for a child living at home who has a severe disability (Ontario Ministry of Children and Youth Services 2016). The Child and Family Services Act is designed to protect children (Ontario Ministry of Children and Youth Services 2016). If a child needs support, for example if he or she suffers from a serious mental, emotional or intellectual condition and the parents cannot alleviate this, services can be provided under this Act. Services may include residential services and children's intellectual disability services, but also services such as legal services and adoption. In 2017 new legislation for children's services was approved to create a new Child, Youth and Family Services Act, 2017. This new Act, which is not yet in force, is similar to the existing Child and Family Services Act (Legislative Assembly of Ontario 2017). There is also aid for families with children or young people with developmental disabilities. Most services are delivered through community-based agencies. Services include respite care, specialised community supports and residential services.

5.2.3 Financial and labour market support for people with developmental disabilities

There are two programmes in Ontario that help people with ID to find a job, and give financial support: the *Ontario Disability Support Program* (ODSP) and *Ontario Works*. Where ODSP is meant for people who are unlikely to be economically independent, Ontario Works targets people who benefit most from employment support (Matthews 2004). There are also other sources of financial support for people with ID.

Ontario Disability Support Program

Ontario Disability Support Program (ODSP, 1997) aims at helping people with a disability, including people with developmental disabilities. It offers two types of support: financial and employment assistance to people with a disability unable to meet basic living expenses.[95] ODSP income support is available for adult Ontario residents who are in financial need and are (a family member of) a person with a disability. The disability must be substantial, continuous and result in restrictions to daily life, and it must be assessed by an approved professional.[96] Income support offers financial assistance to help with the

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[94] In the Netherlands there are tax exemptions and additional child allowances for families with children but no financial support dedicated to children with intellectual disabilities. In addition there are tax exemptions for high medical costs.

[95] In some cases both Ontario Works and ODSP can be used (Ontario Ministry of Community and Social Services 2015a).

[96] The definition of disability for eligibility for ODSP income support means that: the person has a substantial mental or physical impairment that is continuous or recurrent, and is expected to last one year or more; the impairment directly results in a substantial restriction in your ability to work, care for yourself, or take part in community life; the impairment, its duration and restrictions have been

costs of basic needs, like food, clothing and shelter. Income support also includes health and disability related benefits, like drug prescription and vision care, for clients and their eligible family member. The definition of disability for eligibility for ODSP income support requires that the person has a substantial physical or mental disability that is expected to last a year or more, and makes it hard to find or keep a job, care for yourself, or take part in community life (Ontario Ministry of Community and Social Services 2015a).[97] The eligibility for employment support is somewhat less strict than for financial assistance. Employment support includes services and supports to help clients with disabilities find and keep a job, and advance their careers (Ontario Ministry of Community and Social Services 2015a).

Ontario Works

Ontario Works is a programme funded by the Ministry of Community and Social Services which aims to help people who are in financial need (with or without disabilities). Like ODPS, it offers financial assistance covering the costs of basic needs such as food, clothing and shelter as well as health benefits, and employment assistance: help in finding, preparing for and keeping a job. The Ontario Works programme does not aim to cover living expenses and the financial assistance is given only temporarily. Where ODSP is meant for people who are unlikely to be economically independent, Ontario Works targets people who will benefit most from employment support (Matthews 2004). The employment rate of working-age adults with developmental disabilities was 22% in 2006 – less than a third of the rate for people without a disability (74%) (Crawford 2011; Bizier et al. 2015).

Financial support

There are other, more general sources of financial support for which people with developmental disabilities may be eligible, such as the Canada Pension Plan (CPP) Disability Benefits. This national plan provides disability benefits to people who have made enough contributions to the CPP and who have a prolonged and severe disability and are unable to work in any job on a regular basis. Benefits may also be available to their dependent children. In addition there is a Child Disability Benefit for families caring for a child with a severe or prolonged physical or mental disability (Developmental Services Ontario 2016b). People with ID use CPP more often than people with other types of disabilities, and this also holds for social assistance (Crawford 2009).

5.2.4 Other legislation

There are also laws governing recognition of the disadvantages of people with disabilities and aimed at removing the barriers to achieving full equality and participation (Law Commission of Ontario 2009). The *Ontario Human Rights Code* includes disability as a

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verified by an approved health care professional (Ontario Ministry of Community and Social Services 2015a).

[97] The impairment, its duration and restrictions must have been verified by an approved health care professional (Ontario Ministry of Community and Social Services 2015a).

protected ground, giving people with disabilities the right to equal treatment without discrimination. Both the *Ontarians with Disabilities* Act (ODA) and the *Accessibility for Ontarians with Disabilities Act* (AODA) are concerned with the systematic removal of physical, attitudinal, technological, informational or communications barriers for people with disabilities.

5.3 Figures on growth in demand for care and support

Number of people with developmental disabilities

There are no official records of the number of people with developmental disabilities in Ontario or Canada. Estimated prevalence rates may vary considerably, depending on the methods and assessment criteria used (Crawford 2009). Research from The Health Care Access Research and Developmental Disabilities (H-CARDD) Program finds a prevalence of 0.78% between 2009 and 2011 (Lunsky et al. 2013). Bradley et al. (2002) report a prevalence of 0.35% for mild ID and 0.36% for severe ID, leading to a similar though somewhat higher overall prevalence of ID for Ontario. A slightly lower estimate of around 0.6% of the population of Ontario having developmental disabilities is based on the PALS-survey[98] (see e.g. Statistics Canada 2008b; Crawford 2009; Statistics Canada 2013).

The prevalence of developmental disabilities among children (aged under 15) is found to be higher than for adults, at around 0.9% (Statistics Canada 2008a). This might be due to the inclusive educational system: children with ID are diagnosed at school and expectations are high. However, when children become adults, they have to reapply for care, and it is possible that as adults they may not be diagnosed as having developmental disabilities. They may also learn to deal with their disabilities, and in any event expectations are lower than at school. These factors may explain why they may leave the system altogether, resulting in a lower measured prevalence for adults. There is no quantitative information on possible changes in prevalence.

Growth in budgets

In 2008 and 2009 Ontario allocated over CAD 1.5 trillion or 0.27% of gross domestic product (GDP) to developmental disability services and supports (Ontario Ministry of Community and Social Services 2012; Statistics Canada 2016).[99] This includes residential supports in the community, community participation supports, respite care, Passport and the Special Services at Home programme. The total budget for intellectual disability services in 2012-2013 was CAD 1.69 billion, increasing to CAD 2 billion in 2016 with additional funding

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[98] The authors point out that this is probably an underestimate of the actual prevalence. This may be due to reluctance on the part of respondents to admit that they have ID, or respondents may not feel their activities are limited enough to answer the questions in the affirmative. Also, ID may simply go undetected.

[99] GDP = CAD 1.8 trillion (Statistics Canada 2016).

(Dubé 2016a). In order to provide supports and services, the intellectual disability services budget has doubled over the past 12 years, reaching CAD 2.1 billion per year in 2016-17 or 0.33% of GDP (Ontario Ministry of Community and Social Services 2016). Allowing for inflation produces a growth in the budget of 83% (4.3% per annum). Such a large budget increase indicates growing use of care and support, although changes in factors such as wage rates may muddy the waters somewhat here.

Growth in use of care and support

While records in the Netherlands show that demand for and use of care and support by people with ID is growing, there is limited information for Ontario on the extent of or growth in demand for support and care. Instead we look at the use of care and waiting lists. Records of total use of care and support by people with ID are unavailable for Ontario; there is only fragmented information. The reason for the lack of data is that, until 2014, the service agencies kept their own records and the Ontario Ministry of Community and Social Services did not have comprehensive information about individuals receiving intellectual disability services. Based on these data from individual agencies, it was calculated that over 33,000 adults (0.24% of the total Ontarian population) were receiving Ministry-funded intellectual disability services (Dubé 2016a, combined with population figures from Statisctics Canada 2015). About half of them were receiving residential services in the community, mostly supported group living residences (group homes) or supported individual living (Ontario Ministry of Community and Social Services 2012; Auditor General of Ontario 2014b; Dubé 2016a). Over 0.35% of the population receive income support from the ODSP (Ontario Ministry of Community and Social Services 2012). In the 2014/2015 school year over 178,500 students (1.2% of population) were identified by an IPRC as pupils with special needs, while a further 162,000 students (1.1%) were not formally identified but still received special education programmes and services (Ontario Ministry of Education 2016). It is not known how many of these students have ID. Between 2009/10 and 2013/14 the number of people receiving residential services grew marginally by 0.3% year-on-year, from 17,200 to 17,400 (Auditor General of Ontario 2014b). Between 2012, when the Passport programme started, and 2015 the number of individuals receiving Passport funding grew to 7,200 (Dubé 2016a). Thus, use of both residential and community support appears to have grown to a greater or lesser extent. In addition, since budgets increased by more than 80% in real terms, it can be assumed that use also increased or at least remained stable.[100]

Growth in waiting lists and demand

Apart from the care use records, information is available on waiting lists for specific types of care and support. Central registration of users and people on the waiting lists was introduced in 2012 (Developmental Services Consolidated Information System, DSICS).

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[100] Of course there may be other reasons for a budget increase, such as wage increases, or hiring more staff.

However, the database does not appear to be fully operational (Dubé 2016a). Based on this information, waiting lists for residential services are growing. The number of people receiving residential services grew only marginally. In 2009 the number of people on the waiting lists was 9,500, rising to over 14,000 (11% per annum) in 2013 (Auditor General of Ontario 2014b).

In 2012, when the Passport programme started, there were 3,700 individuals waiting for Passport supports. Between 2012 and 2016 7,200 more individuals received Passport funding and there were 14,400 individuals on the Passport waiting list (an increase of 289%, approx. 40% per annum). Adding together use and waiting lists results in 55% annual growth in demand for the Passport programme between 2012 and December 2015 and a 4.4% annual increase in demand for residential services between 2009/2010 and 2013/2014.

Since waiting lists are growing, as is the number of users, this indicates that the demand for care and support by people with ID is also growing in Ontario.

5.4 Expert views on factors causing growth in care and support

In the Netherlands, the increasing complexity of society was cited as a major cause of growing demand for care and support, and the incentives in the care system allowed for this growth (Woittiez et al. 2014a, and Chapter 2). The playing field in Ontario is different, with advanced deinstitutionalisation and a strong focus on inclusion. This means that other factors might be more prominent in driving up demand for care in Ontario than in the Netherlands. Although the experts presume that demand for care and support is growing, most do not have the full picture, probably due to the fragmented nature of the data. When asked to suggest causes of the growth, almost all interviewees mentioned the inclusiveness of Ontarian society (the system of support), and some also mentioned the complexity of society. Together with the causes of the growth, we present the drawbacks associated with the developments as these were pointed out by the interviewees.

5.4.1 Care system-related factors

Inclusion and more diagnoses were the most prominent growth-driving factors mentioned. As regards the system-related factors, all experts mentioned deinstitutionalisation, waiting lists and the problems associated with the transition from youth to adult care and support.

Moving towards more inclusion

The main cause of increasing demand mentioned by the experts was the inclusiveness of their society. Although the care for people with ID has been moved towards the community, the effects of this transition are not clear: simply moving people into non-residential settings is not enough to assure their inclusion in society. According to Thompson's support model, needs are the result of a mismatch between personal competency and environmental demands. Inclusion means participation in all aspects of life. Therefore more inclusion places high environmental demands on people with ID. This may result in a mismatch between their needs and the environmental demands and a growing demand for support. As one expert stated:

> *There is a growth in demand for support workers, in home care, mental health services, and employment services that may be linked to increased participation in community for people with ID who are no longer institutionalised or living in isolated group homes).*

The role of caregivers is also changing due to the move towards inclusion. Paid caregivers need to become community connectors, helping people with ID to (learn to) deal with community life, rather than simply being caregivers. This requires different skills and training (Brown et al. 2015).

The experts mentioned the inclusiveness of society:

> *Changes in attitudes and increased participation for people with intellectual disability has led, I believe, to an increasingly inclusive society.*

Experts indicated that this inclusiveness holds particularly at school age. All children go to same school building, sometimes in separate classrooms.[101] Most of them live at home and attend a regular school. The parents plan what support is needed, and in general these supports are provided. The main advantage is that placement in regular classes may enhance inclusion, since children come into contact with children with ID at school and may accept it as being normal in later life, for instance if a work colleague has ID. A good example of this can be found in Brunswick:

> *In Brunswick the children really go to school together. Has been so for 30 years and the adults nowadays are used to differences between people.*

In a study of a small sample of children with severe ID, most were found to be moderately to highly socially included, and that inclusion was rated higher in inclusive settings than in segregated settings (Carvalho et al. 2014).

Nevertheless, the experts agreed that, for various reasons, the actual inclusion of people with ID could be improved. An important reason for this is that people still have to get used to inclusion since it is only fairly recently that the transition to inclusion was implemented; the last large residential facility in Ontario was only closed in 2009, and it may take a while yet for members of society to become familiar with people with developmental disabilities in the midst of their own community from an early age. On the downside, people with ID no longer meet their peers, i.e. people in a similar situation, who are important for all individuals throughout their lives. Therefore, in addition to promoting inclusion, a means needs to be found of keeping people with ID in contact with each other.

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[101] In the Netherlands there are still many children attending special schools, but there are movements towards inclusive education (for instance Appropriate Education Act).

Transition to adulthood

As in the Netherlands, youth services in Ontario differ from adult services, and this may lead to transitional problems. In the Netherlands this is the subject of research (e.g. Kinderombudsman 2015; Feijten et al. 2017; Pommer & Boelhouwer 2017). The interviewees in Ontario also raised this is a point of concern (e.g. Auditor General of Ontario 2014b). Some experts noted that young adults continue to live at home with their families once they complete school and wait to be prioritised for adult services.
One interviewee stated that

> *Ontario is an inclusive society, especially at school age, since all children go to same school building, though sometime in separate classrooms. However, after school age they have to find their way in the system over again. They must apply for new assessment which is not automatically done and some of them end up homeless. This transition is a big problem.*

There are many complaints from families in crisis, since services and supports for their family members living with autism and other developmental disabilities disappear on their 18th birthday (OPAAA 2016).

> *Many transitions to the adult system result in long waits for services and supports.*
> (according to one expert)

It may be partly due to this transition that the prevalence of ID in children is found to be higher than in adults. Some people may not apply for adult services. This may also be related to the fact that the government ministries responsible for supporting young people (Ontario Ministry of Education and Ministry of Children and Youth Services) use definitions of disabilities and eligibility criteria that are different from those used by the ministry responsible for adult support (Ministry of Community and Social Services).

Deinstitutionalisation

Related to inclusion is the deinstitutionalisation which has taken place in Ontario. Group homes are now the most common model of formal residential care for people with ID in Ontario. 'Institutions are closing and have fallen out of favour as a model. Generally people try to encourage smaller group living in community or supported independent living.' Eventually, living in a group home could lead to access to larger social networks, with people other than staff, family or others with ID, and more unpaid support (Crawford 2009).

However, deinstitutionalisation may also have drawbacks. For instance, closing down institutions led to the loss of a great deal of expertise, such as doctors specialised in dealing with people with ID. Emerson points out that the ability to support people with ID will become increasingly important as the demand for community living arrangements rises (Emerson 1999, cited in Crawford 2009). Until recently this was not recognised fully, according to one expert. Further, significant unmet need for suitable housing for people with ID is reported (Housing Study Group 2013; Ontario Ministry of Community and Social

Services 2016b), and there is a trend to provide housing and support in larger, segregated settings. This trend is in direct opposition to decades of effort to desegregate (Housing Study Group 2013).

As a result of the trend towards deinstitutionalisation, most people with developmental disabilities today live with their families, and ‘families are supposed to provide a major part of the support needed regardless of whether they are residing in the family home or in residential care’ (Werner et al. 2009; see also Bizier et al. 2015). The trend towards deinstitutionalisation has ‘often led to the family becoming the main source of support for family members with disabilities’. However care for family members with ID can be a burden and it is unclear whether families can continue supporting their family members with ID (Werner et al. 2009). In addition, adults with developmental disabilities frequently become frail earlier than the general population, resulting in higher care needs (McKenzie et al. 2016). Thus ageing may become a problem in the near future.

Another important aspect of deinstitutionalisation is that in crisis situations, (young) people with developmental disabilities may be placed in psychiatric wards, hospitals or long-term-care homes. These placements are expensive and unsuited to the individual’s needs (Auditor General of Ontario 2014a; Dubé 2016a). The Ombudsman of Ontario indicates that people with ID, in or after a crisis situation, spend long periods in nursing homes, hospitals or even jail, for lack of adequate placement options elsewhere. The Ombudsman refers to inappropriate hospitalisation, inappropriate admission to long-term care homes which are not designed for people with ID (Dubé 2016a).

Waiting lists

There is also room for improvement with respect to inclusion in the existence of waiting lists in Ontario. One expert mentioned that the adult services system has a fixed funding envelope. Demand currently exceeds the available funding and resources, leading to waiting lists. All experts also mentioned the long waiting lists, or more precisely the long time people with ID sometimes have to wait before adequate care and support is provided. Waiting lists are based on prioritisation of individuals, based on the extent and urgency of their needs (Dubé 2016a). People with the highest priority needs are not usually placed first (Auditor General of Ontario 2014a). The care and support available goes to the people with the most severe ID. However, they may not need (additional) support urgently. People with ID (or their families) believe there is a lack of community services, and this is echoed by the view that one expert shared with us:
Waiting lists are enormous, first to obtain an assessment, and then even longer to receive care.

This was a major obstacle to inclusion within communities of people with developmental disabilities (Ouellette-Kuntz & Burge 2007; Ouellette-Kuntz et al. 2010). This view is also found in the literature. ‘They have been waiting, and continue to wait, for supported residences. The wait can be years, or even decades' (Housing Study Group 2013). The Auditor General of Ontario (2014a) notes that there is no consistent process for accessing residential services for children, nor a consistent waiting list management process. As a result, the demand for children's residential services is not clear.

Personal budgets

There are community-based programmes which give budgets to people to organise their own care, such as the *Passport* programme (for adults) or the *Special services at Home* (for children). A criticism by one of the experts is that

> *that the money associated with family-based programs is paid directly to the family. They have to report on the way the money is spent, but this is seldom checked. In addition the question is whether the money can be handled adequately by parents, in particular when they have issues with developmental disabilities themselves. The money can also be transferred (directly or by the family) to community based services.*

More diagnoses of problems related to mild or borderline ID

- Borderline ID and autism

Associated with more inclusion, there is an increasing awareness that people with higher IQs (70-85) also need help and as a result more are diagnosed as needing help. However, one expert stated that they

> *don't have a lot of information with regard to borderline IQ or mild ID versus more severe disability. We don't have a mechanism for collecting severity of disability data reliably. And we often don't offer services to those with borderline IQ, from social services. So they 'show up' in health care. Doctors suspect they have intellectual disability issues but without confirmation. If their IQ is too high, often they can't qualify for needed services, so they are really marginalised.*

One expert explicitly stated that 'the increase in demand is mainly caused by people with autism, who often also are confronted with ID' (e.g. Harris & Greenspan 2016; OPAAA 2016). This might be a way in which people with borderline ID do receive some support, although this group are not eligible for ID-services. However, both this group and the group with a mild intellectual disability do not receive much attention to. As mentioned by one interviewee 'the care and support available goes to the most severe intelligence deficit'. In relation to the budget, one interviewee indicated that the Ontarian system works

> *budget wise because eligibility is mostly restricted to those with an IQ under 70. Moving this frontier to IQs under 85 would enlarge the target group so much that budgets would not suffice. However, it is possible that the costs for the group IQ 70-85 could be recouped in other sectors.*

The case of the Netherlands illustrates the budgetary consequences; the number of ID care users with mild and borderline ID users of care it is growing rapidly, while the size of the severe ID group is stable.

- Vulnerability of people with mild and borderline ID

There is a growing awareness that individuals with mild ID 'may be particularly vulnerable to addiction because their disabilities are either not recognised or are not severe enough to qualify for already scarce services and support' (H-CARDD 2015). Dubé (2016a) mentions that 'those with developmental disabilities are uniquely vulnerable and voiceless in the face of domestic assault and neglect'. The absence of adequate community-based support can result in vulnerable individuals, such as individuals with ID, becoming embroiled in the criminal justice system (Dubé 2016b). It is noted that adults with ID 'frequently experience diminished impulse control and aggression, making it challenging to find appropriate supportive housing in the community' (Dubé 2016a).

In addition, people with ID are amongst the most vulnerable citizens and highly susceptible to various forms of abuse and exploitation (Crawford 2008). Crawford (2008) states:

> *Often, people with developmental disabilities have difficulty understanding the seriousness of situations in which they may find themselves as victims or as alleged offenders. They often aim to please and thus they are easily led by those who would take advantage of them.*

Individuals with ID are also overrepresented in prison (Endicott 1991). There are indications that this group is growing (Dubé 2016a). Correctional Services Canada (2014) reports that

> *25% of the incoming men offenders had some level of cognitive deficit in 2006/2007. Legal concepts can be particularly mystifying for individuals with developmental disabilities and lack of understanding of key requirements can lead to recurring run-ins with the criminal justice system.* (Dubé 2016b)

There are cases where imprisonment is used as the safety net when adequate support was not available Dubé (2016a).

Some experts noted that this vulnerability may hold even more for the group with borderline ID (see e.g. Bexkens 2013; Peltopuro et al. 2014). This indicates that, although this group are not eligible for ID-services, they may nonetheless be in need of them. Or, as another expert phrased it:

> *We often don't offer services to those with borderline IQ, from social services. So they 'show up' in health care when health issues rise or when psychiatric problems arise or when families are getting old and parents die. Docs suspect they have intellectual disability issues but without confirmation. If their IQ is too high, often they can't qualify for needed services, so they are really marginalised.*

The accumulation of problems within households in Ontario, such as unemployment, criminal behaviour and shabby living conditions 'is a trend as well, but more and more people are recognising and focusing upon this issue'.

One interviewee indicated that ID-services or services from the mental health sector could also help individuals with borderline ID.

> *In particular, supporting this group may prevent other problems, such as criminal behaviour and prison. Prevention works! You deal with problems close to the heart. This may also prevent a lot of costs.*

There may be early indicators for criminal behaviour.

> *Impulse control issues and aggressive behaviours may escalate during life transitions or personal crisis points, but certain tendencies may be apparent long before an adult with intellectual disabilities comes into contact with justice officials.*

The Ontario Ombudsman advises: 'There should be capacity in the developmental services system for early identification of and support for individuals at risk of becoming involved in the criminal justice system.' (Dubé 2016a).

Thus, although the interviewees felt that prevention, and thus early diagnosis, would be a good thing, it may also mean that children are stigmatised as intellectually disabled at a young age and that ID students are forced to realise and accept that they are different.

5.4.2 Factors related to complex society

The main cause of growing demand in the Netherlands was found to be the increasingly complex society. Most experts in Ontario had not thought of the question of whether society has become more complex and the impact that might have on the growth in demand for care and support by people with ID. They noted it as an interesting thought, but it has not been studied in Canada. However, some of them thought it sounded plausible. Thinking about the issue, they mentioned some of the same types of factors as those which are making Dutch society more complex, such as digitalisation and loss of jobs.

Digitalisation in daily life

Some experts agreed with the notion that digitalisation makes daily life more complex for people with ID.

> *In particular the digitalised society one is important. We renew information online; we register births of children online. We book appointments online. We even get our bus fare on a card that we tap online, and we have to give credit card information to automatically refill our bus fare pass. What if you have no computer and no credit card?*

By contrast, others see no problems here, or even think that technological changes may have made life easier for people with ID. One expert added:

> *It just depends. Do you have someone to help you? Can you use a computer? Do you have a smart phone? Do you know how to ask for things to be done in an alternate way if you can't? So it is not straight forward. Technology can certainly help but we need support to use technology. And an expert states: I have not heard much about people with ID finding digital complex society difficult to manage. In my experience and the experience of my colleagues, most people I interact with see technological advances as beneficial and society as being much improved for people with ID compared to previous generations […]. While society may be more complex in some ways, I believe that it has also become more accessible.*

A parent notes for instance that life has not become more complicated for his son.

> *He can go to banking offices to do his banking affairs for example. He has been working almost all his life, doing easy jobs like storing things on shelves for a small wage. […] He receives 8 hours of support per week by a carer he himself pays.*

While the experts felt that technology may improve daily life, this does not reduce the need for support:

> *Modern technology such as Facebook, snapchat etc. while having pitfalls and risks, have been generally helpful in my experience, in connecting people with ID and promoting friendships. I think people with ID have always needed support and will continue to need support as society changes.*

Employment

One expert stated that the labour market is also becoming more and more inclusive. This is important, because as for other people a key means of achieving social inclusion for people with ID is to be productive (Lysaght et al. 2014). People with disabilities, and ID in particular, can also be valuable employees (IRIS 2014). This is being increasingly recognised by employers, governments and the public at large in Ontario (e.g. Burge et al. 2007).

However, finding employment is not easy for people with ID. Canadian Association for Community Living (2013) reports based on a survey that 25% of respondents report that the employment situation for people with ID has worsened. One expert said that *the main reason that society has become more complex is the crisis that caused jobs to disappear.* Employment rates for people with ID lag far behind those of people without disabilities or with different types of disabilities. The employment rate of working-age adults with developmental disabilities was 22% in 2006 – less than a third of the rate for people without a disability (74%) (Crawford 2011; Bizier et al. 2015) but much higher than in England (6% who are known to social services). One of the experts was hopeful since

> *there is an increasing participation of people with ID in society as community models change. People remain under-employed but this has been identified as a priority. Services have been trying to bridge this gap and the number of under-employed should decrease.*

On the other hand, employers were less likely than teachers, students and job coaches to agree with statements indicating positive attitudes and beliefs about individuals with developmental disabilities and that these students easily assimilate into the workplace (Bennett & Gallagher 2013). This finding leads to a caution for educators such as job coaches to ensure that placements are appropriate for their students and that support procedures are in place.

As regards the labour market, the interviewees suggested that there is room for improvement. People with disabilities, and ID in particular, believed that they had been refused employment because of their condition twice as often as people with other disabilities (Crawford 2009). The Canadian Association for Community Living (2013) states that the current system relies 'on an assumption of non-employment and reliance on workshops and day programs rather than inclusive, competitive employment. The current system is part of the problem. A new approach is needed'.

The government is now moving towards community-based integrated employment and trying to promote greater awareness and opportunities related to employment, but this may take several years (Ministry of Community and Social Services 2016).
Some of the most commonly reported job search barriers for people with developmental disabilities were inadequate training or experience, a lack of available local jobs, experiences of discrimination in the past, and a fear of losing additional supports (IRIS 2014).[102]

> *It is not surprising that employers are not inclined to hire a person with ID if there are many other, more productive, employees available* (according to one interviewee)
>
> *Employers may also not know how to deal with people with ID. In that case a quota for a minimum number of employees would be a good idea. A solution would be to pay the ODSP to the employer instead of the individuals with ID. Then, they could just work and receive a salary from the company, out of their own ODSP. In this way it would cost neither the employer nor the government additional money.*

However, from the perspective of the government, the idea of using the ODSP income and employment support programme to pay employers to hire people with ID is not seen as a good alternative. In their opinion, people with ID could be better working in regular jobs. They suggest that employers are willing to hire employees with ID if the employer's business needs are matched to the individual's needs and talents and if instruments such as job carving are used.

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[102] The PALS survey capturers the situation for quite severely disabled people and shows low employment rates. However, the 1991 Health and Activity Limitation Survey (HALS), which included a much higher proportion of people with mild intellectual disabilities, also showed quite low employment rates (IRIS 2014).

As in the Netherlands, the experts mentioned that, for people with ID, 'when working in a regular job, support on the job is required'. Two-thirds of employed people with developmental disabilities report that they require some kind of support in their work, job redesign or human support. This percentage is considerably higher than for people with other types of disabilities (Crawford 2009, 2011). The needs of those requiring (or receiving) some form of job support are often not met (Crawford 2009; Canadian Association for Community Living 2013). The use of the ODSP programme may help people with ID to secure employment. Lysaght et al. (2014) found that users of the programme reported the highest rates of engagement in paid employment. Not all people eligible for services actually use those services. This may be because of the difficulty of the application process. As Matthews (2004) states: 'Concerns were repeatedly expressed that the application process for ODSP is extremely cumbersome for people with intellectual or mental disabilities. It prevents eligible people from applying; they stay on OW (Ontario Works) when they belong on ODSP. I heard many concerns that lack of access to a family doctor limits a client's ability to apply for ODSP.'

The eligibility process was recently streamlined; adults with a developmental disability who have already been found to be eligible for some other types of services are now automatically considered eligible for ODSP income support (Ontario Ministry of Community and Social Services 2016a).

Education

The experts did not mention the complexity of education as one of the causes of the growth in demand for ID care and support, though they did stress the inclusiveness of education. Nevertheless, they commented on educational attainment still being challenging for people with ID in the more inclusive society. Many students with developmental disabilities (recently) attending school required educational support services, such as tutor assistance or extended test time. Not all these needs are met (Bizier et al. 2015). People with developmental disabilities are more likely than others to report difficulties with their educational careers, and many report that their choice of career has been affected (Crawford 2011). The literature also suggests that the separation of roles between the Ministry of Community and Social Services and the Ministry of Children and Youth Services regarding children's residential services is not clear. Confusion can arise over who is responsible for the overall delivery of children's residential services (Auditor General of Ontario 2014b).

5.5 Summary

Growing demand for care and support by people with ID

In this chapter we have examined how demand for care and support for people with developmental disabilities has developed in Ontario, and what explanations are put forward for this development. Some of the information on the developments in Ontario is based on regional data collected by the Ontario Ministry of Community and Social Services and Statistics Canada; other, fragmented information is supplied by various delivery offices. The quantitative information points to an increase in demand for care and support for people with developmental disabilities, and this is corroborated by the expert views. The total budget for intellectual disability services has doubled over the past 12 years (+83% allowing for inflation), waiting lists for residential services have grown by 47% within five years, and the number of individuals receiving and waiting for direct funding from the Passport support programme has also risen sharply.

Causes of growing demand

To find explanations for this development, we analysed both the scientific literature and policy documents, including the 'Ombudsman Report', and spoke with seven experts in the field.

When asked to state the causes of the growth in ID care and support, most experts mentioned the inclusiveness of society and greater recognition of people with mild ID. When asked, some mentioned the complexity of society, in particular more digitalisation and fewer jobs. However, this is not a subject of discussion in Ontario. The experts also mentioned waiting lists and problems associated with the transition from youth to adult care and support.

According to the experts, a major cause of increasing demand is the move towards inclusion in Ontario. They agree that Ontario is already a relatively inclusive society, especially for school-age children, and that it is moving towards more inclusion. More inclusiveness is associated with higher environmental demands and thus greater demand for support. On the other hand, one of the main positive aspects of inclusion is the access to larger social networks, with people other than staff, family or other people with ID, and an increased in unpaid support, alleviating the need for publicly funded support.

According to some experts, there is an increasing awareness that people with higher IQs also need help and as a result, diagnoses of developmental disabilities are increasing.

Digitalisation could make daily life more complex, but technological changes may also make life easier for people with ID. As elsewhere, the financial crisis led to the loss of (simple) jobs, hitting people with ID in particular. Despite this, the labour market too is becoming more and more inclusive in Ontario. This is important because, just as for other people, working is an important means of achieving social inclusion for people with ID. Although they have something to offer employers, employers might not be inclined to hire a person with ID if there are many other, more productive, employees available.

Ongoing discussion

Despite the positive opinions on inclusion, there is also criticism both from the experts and the (scientific and policy) literature. To summarise, the information in this chapter suggests that even though Ontario is labelled as an inclusive society, both by (Canadian and other) experts and the literature, this does not mean that there are no hurdles for people with ID to overcome in order to participate fully in society For example, according to the interviewees it was not fully recognised until recently that deinstitutionalisation required different types of support to be in place. Lack of community services is seen as a major obstacle to inclusion within communities. Closing down institutions led to the loss of a great deal of expertise, such as doctors specialised in dealing with people with ID. The trend towards deinstitutionalisation has in many cases led to the family becoming the main source of support, which may be very demanding. All the experts also mentioned the long time that people with ID sometimes have to wait before adequate care and support is provided.

While early diagnosis may prevent the use of intensive care and support later in life, the drawback is that children may be labelled as intellectually disabled at a young age, which can be stigmatising.

Both experts and policy documents mentioned the difficulties stemming from the support system for children being different from that for adults (transition). After school age, they must apply for new assessment, something which does not happen automatically. This may lead to loss of care and support. In some cases, those concerned may even end up homeless.

People with borderline ID are not eligible for ID-services, and both this group and those mild ID do not receive enough attention in the Ontarian system, according to the experts, whereas they may be particularly vulnerable. If adequate services are not provided, these people 'show up' in health or psychiatric care systems or may become embroiled in the criminal justice system, according to both experts and policy documents. People with ID constitute a small but growing proportion of suspects within the criminal justice system (Davis 2009).

On the other hand, if eligibility, which is currently restricted to those with an IQ below 70, were altered to include IQs below 85, this would enlarge the target group so much that the budgets would not be adequate – though it is possible that the costs incurred for the group with IQ 70-85 could be recouped in other sectors. The impact of easing the IQ restrictions would be similar to the Dutch situation, where a significant part of the growth in care use is due to people with relatively high IQs.

5.6 List of abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities
ADSS	Application for Developmental Services
AODA	Accessibility for Ontarians with Disabilities Act
APSW	Adult Protective Service Worker
CPP	Canada Pension Plan
DSICS	Developmental Services Consolidated Information System
DSOS	Developmental Services Ontario offices
H-CARDD	Health Care Access Research and Developmental Disabilities
ID	intellectual disability
ODA	Ontarians with Disabilities Act
ODSP	Ontario Disability Support Program
SIPDDA	The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008
SIS	Supports intensity scale

Appendix A List of experts

UK

- Patricia Frankish, director Pat Frankish Psychology and Psychotherapy Consultancy Ltd, Amara Care.
- Dan Goodley, professor at the University of Sheffield.
- Chris Hatton, professor at University of Lancaster.
- Pauline Heslop, professor of Intellectual Disabilities Research, Norah Fry Centre for Disability Studies, University of Bristol.
- Richard Parrott, commissioning manager, Communities Sheffield City Council Sheffield.
- Katherine Runswick, researcher Manchester Metropolitan University, Sheffield.

Flanders

- Ann Van den Abbeele, project manager for personal budgets PVF at the Flemish Agency for People with a Disability (VAPH).
- Sam Van Bastelaere, head of Legal Department VAPH.
- Wil Buntinx, researcher Maastricht University.[103]
- Sylvie Bijnens, client support worker Sherpa.
- Kris Ceyssens, (former) coordinator Assist.
- Steven Eerdekens, director Open Kans, Daycare Unit, Dienstencentrum Ter Engelen (Bree).
- Hakan Gultekin, experience expert.
- Marleen Gyssels, formerly Begeleid Wonen "ONDO" supported living department, Antwerp.
- Jos van Loon, researcher Remedial Education Unit Ghent / University College Ghent (Orthopedagogiek).[104]
- Catherine Molleman, director Study units / Team Policy VAPH.
- Hanna Steenwegen (VAPH), member of the Policy and organisation team.
- Stijn Vandevelde, researcher Remedial Education unit Ghent / University College Ghent (Orthopedagogiek).
- Heidi Vanlommel, teamcoach/supervisor, "ONDO" Antwerp.

Ontario

- Ivan Brown, professor at the University of Toronto.
- Heidi Diepstra, research associate at Surrey Place Centre and University of Toronto.
- Christine Hughes, manager, Policy Development and Coordination, Community Supports Policy Branch, Ministry of Community and Social Services

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[103] Provided information on both Flanders and The Netherlands.

[104] Provided information on both Flanders and The Netherlands.

- Barry Isaacs, Surrey Place Centre in Toronto, researcher and care provider.
- Yona Lunsky, director of the Health Care Access Research and Developmental Disabilities Program at the Centre for Addiction and Mental Health and Professor at the University of Toronto.
- Hélène Ouellette-Kuntz, professor in the Departments of Public Health Sciences and Psychiatry, (Division of Developmental Disabilities) at Queen's University.
- Meaghan Edwards, University of Calagary, Community Health Services Department.
- Bill Sullivan, family physician at St Michael’s Hospital and Surrey Place Centre in Toronto and Associate Professor at the University of Toronto.

Appendix B Table of laws and arrangements

B.1

Table of laws and arrangements related to ID care in the four regions[a]

	The Netherlands	England	Flanders	Ontario
care and support for …				
… adults	Wlz		VAPH	SIPDDA; Residential supports; Behavioural management program
	Social Support Act (Wet maatschappelijke ondersteuning (Wmo 2015))	Care Act 2014	VAPH	SIPDDA; – Adult protective service worker program – Community Participation Supports Program
	Zvw			Specialised clinical services
	Personal budget (Pgb)	Direct payment	PVF, RTH	Passport program
… young people	Youth Act (Jeugdwet)	Children and Family's Act 2014	PVF, RTH	– Infant development programs; – Special services at home program – Out-of-home-respite
	Appropriate Education Act	Children and Family's Act 2014	M-decreet	Education act
financial help	Participation Act (formerly Wajong) Local Assistance Scheme (Bijzondere Bijstand) formerly Act on Compensation for Chronically Ill and Disabled People (Wet tegemoetkoming chronisch zieken en gehandicapten)	Employment and Support Allowance Disability Living Allowance; Personal Independence Payments; Attendance Allowance;	VDAB VOP IVT IT THAB	Ontario Works ODSP Financial support

a See the relevant chapter on each region for an explanation of regulations and the abbreviations.

Source: Chapters 2-5

Appendix C Questionnaire

1 People in the Netherlands with mild and borderline intellectual disabilities (ID) find it difficult to function adequately without support in today's more complex society. We expect that this phenomenon might not be unique to the Netherlands. Do you recognise the notion that the society has become more difficult and that as a result more people with ID need support and care?

2 If so, how are the problems for these people with ID solved? In the Netherlands this has led to increase in the number of people with ID receiving care. In fact the demand for care has extended to include a new type of client with a higher IQ and more social problems. Have you experienced growth in demand for (specialised) health care, for social services, informal care or any other type of care?

3 If not, how do people with ID manage to participate in a more digitalised, faster and more complex society?

Definitions

4 Who is eligible for health care and who is eligible for social welfare? What definition of intellectual disability is used for assessments/referrals?

Numbers

5 How many people with mild ID (IQ 50-70) and borderline ID (IQ 70-85) are there in the UK?

6 How many people with mild ID (IQ 50-70) and borderline ID (IQ 70-85) receive or demand health care and social welfare in the UK?

Is support needed? Why, how and by whom?

7 Do people with ID manage to participate in society? By participation we mean working, going to school, living independently and so on. Is there enough 'simple' work suitable for them? Has the bar in education constantly been raised? Has traveling by public transport with a smartcard or performing online banking made life more difficult for people with ID? How much participation do they themselves and others want (how inclusive is society)?

8 What kind of health care, social welfare and other care is provided and by which institutions?

9 Do you see an accumulation of problems in the UK?

10 Are daycare and housing for people with ID covered by public care in the UK?

11 How do people with ID generally live in the UK? With parents or other family, or in institutions or otherwise?

12 Are there special apps for people with ID? Are they used to help them live independently?

13 Who is responsible for providing care: close relatives, the extended family or the government?

14 How big is the budget (as a percentage of GDP)? Have there been budget cuts? If so, what has been the impact of this?
15 Is the organisation of care decentralised?
16 Is there much privately funded care?
17 Is there much informal care?
18 What role do other sectors such as education play for people with ID?
19 Are there direct payments?

Changes in the recent period (2000-present)

20 Were there any changes in eligibility in the period 2000-2015? Were there any other reforms, e.g. restructuring of supply, a different organisational level (in the Netherlands there has been a process of decentralisation), changing paradigms, etc.
21 Has the number of people with mild and borderline ID been growing, decreasing or remained constant in your country?
22 If it has grown, can you suggest any factors that might play a role in that growth?
23 Do you think the growth is different for people with severe, moderate and mild ID?
24 How has the number (or prevalence) of people with mild ID (IQ 50-70) and borderline ID (IQ 70-85) with a demand for health care and social welfare changed in the UK?

Further research

25 Which articles should we definitely include in our research?
26 Which countries or best practices within a country are good examples with respect to care for people with borderline or mild ID?
27 Does the term ‘intellectual disability’ cover the same group and the same type of care in different countries?

Appendix D Health care services in England

Established in 1948, the National Health Service (NHS) provides primary, secondary and tertiary care to all those residing in England. From the beginning of the NHS in 1948, health care and social care have been separated.

The first point of contact for most people with general medical needs is primary care. It is delivered by a wide range of independent contractors, including general practitioners (GP's), dentists, pharmacists and optometrists, as well as NHS walk-in centres and the NHS 111 telephone service. NHS England is responsible for purchasing primary care services. There are four regional teams responsible for the commissioning of services in their areas. The primary care system plays a gatekeeping role in determining access to more specialised, often hospital-based, acute health care services. This secondary health care is provided by salaried specialist doctors (consultants), nurses, and other health care professionals (e.g. physiotherapists and radiologists) mainly working in hospitals. The health care services provided in hospitals are contracted by clinical commissioning groups (CCGs), who arrange urgent and emergency care and planned hospital care, but also rehabilitative care, most community health services and mental health services and learning disability services. Hospitals themselves are mostly managed by NHS trusts. Finally, a range of more specialised services, the tertiary health care, deal with the more complex or rare health conditions and are also mainly provided by NHS trusts. These trusts are usually also linked to medical schools or teaching hospitals.

To meet the demands of a constantly changing social, economic and political environment the NHS has had to evolve since its start in 1948. Over time it has experienced a steady expansion, like health care systems in other countries with a comparable economic status as England. Therefore, the NHS is in a state of constant transition and organisational flux. To a greater degree than elsewhere, funding and policy issues are clearly political in nature in England (Sturgeon 2013). A major managerial transformation began under the Thatcher government with the introduction of the 1990 National Health Service and Community Care Act. The basic idea was that funding should follow the patient. This meant that hospitals had to compete for resources. They could apply for self-governing status as NHS trusts, which would mean they were able to employ staff, own and dispose of assets, retain surpluses, and borrow money from both the government and the independent sector. The Act launched a framework for health services with greater competition and consumer power. The reforms of the early 1990s, led to a shift away from residential (or institutional) care to care provided in the community. Furthermore, the reforms led to a recognition of the importance of (informal) carers in health and social care policy. Today, residential (personal) care or nursing care is provided in residential care homes or nursing care homes; in the past there was considerable provision of care in NHS long-stay hospitals (Boyle 2011). Another extensive reorganisation of the structure of the NHS took place with the introduction of the Health and Social Care Act 2012, which removed the responsibility for the health of citizens from the Secretary of State for Health to the CCGs, run by the GPs and other clinicians, such as nurses and consultants.

Health services in England are largely free at the point of use and are mainly financed from public sources – primarily general taxation and national insurance contributions. Some services are either not covered by the NHS and patients must therefore pay themselves (direct payments), or are covered by the NHS but are subject to cost-sharing, usually in the form of co-payments. The relative share from each of these three financial sources has fluctuated over the years. Some care is funded privately through private medical insurances. Most of these insurances are offered to employees as part of their overall remuneration package. The central government sets the level of NHS funding in a given year through the Spending Review progress. With this process it estimates the amount of income the NHS will receive from the different financial sources. In case the national insurance contributions and/or the user charges are less than originally estimated, funds from general taxation are used to ensure the NHS receives the level of funding it was originally allocated.

Under the motto ‘Homes not hospitals’, care close to home is what the NHS aims to deliver for people with learning disabilities (as well as people with mental health problems; https://www.england.nhs.uk/learning-disabilities/care/) To prevent challenging behaviour and a potential stay in hospital as far as possible, community services have to be better equipped to offer adequate help to people with learning disabilities and/or autism.

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Werkprogramma

Het Sociaal en Cultureel Planbureau stelt jaarlijks zijn Werkprogramma vast. De tekst van het lopende programma is te vinden op de website van het SCP: www.scp.nl.