

University of Groningen

Participation of adults with visual and severe or profound intellectual disabilities

Hanzen, Gineke

DOI:
[10.33612/diss.134517652](https://doi.org/10.33612/diss.134517652)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2020

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Hanzen, G. (2020). *Participation of adults with visual and severe or profound intellectual disabilities*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen.
<https://doi.org/10.33612/diss.134517652>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

preference

autonomy

hobby nature

tablet work

abilities

participate

job

social

sport



involve

support

vacation

friends

wis

activ

attent

self-management

communication

interest

vicinity

movements

interaction

surprises

belong

possibilities

experience

inclusion

General introduction

Introduction

Over the last decade, the participation of people, including adults with visual and severe or profound intellectual disabilities (VSPID) has been increasingly emphasized. According to the definition formulated by Schalock et al. (2010), individuals with VSPID, whose intelligence quotients (IQs) fall within a range of 20–34, are considered to have severe intellectual disabilities (IDs) while those with IQs of below 20 are deemed to have profound IDs. These limitations in intellectual function further constrain these individuals' adaptive behaviours that relate to their social, conceptual, decision-making, and practical skills (Schalock et al., 2010). Individuals with severe or profound IDs often have motor and/or sensory impairments along with various medical problems, such as obstipation, epilepsy, and challenging behaviours (Nakken & Vlaskamp, 2007; Poppes, Van der Putten, & Vlaskamp, 2010; Van Timmeren, Van der Putten, Van Schroyen, Lantman-de Valk, Van der Schans, & Waninge, 2016). The prevalence of blindness or visual impairments in individuals with severe or profound IDs is as high as 92% (Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). A visual impairment is defined by the World Health Organization (WHO) as visual acuity < 6/18, while blindness is defined as a visual acuity < 3/60 and/or a visual field < 10 degrees around the point of fixation (ICD-10, 2016). Compensation mechanisms do not function in the case of adults with VSPID; they can neither compensate for their ID using their eyesight, nor can they compensate for vision loss through the employment of their cognitive capabilities. Consequently, visual and intellectual disabilities are mutually reinforcing (Kiestra, 2005), thereby compounding the limitations experienced by these individuals in their daily activities, for example, in communication, initiatives, and living skills (Evenhuis, Sjoukes, Koot, & Kooijman, 2009). Because of their limitations, adults with VSPID are dependent on others in almost all areas of their lives (Nakken & Vlaskamp, 2007).

In the Netherlands, the number of adults with VSPID ranges between 10,000 and 15,000, accounting for approximately 0.05–0.08% of the Dutch population (Limburg, 2007). Despite a general trend of deinstitutionalization that has been evident over the past 40 years in various Western countries (Chowdhury & Benson, 2011; Mansell & Beadle-Brown, 2010; Tøssebro et al., 2012), in the Netherlands, not all adults with VSPID currently live outside the institutions; they live in both residential facilities and in group homes within the society (Woittiez, Putman, Eggink, & Ras, 2014). The introduction of the citizenship paradigm (Van Gennep, 1997) in the 1990s prompted a process of deinstitutionalization in the Netherlands. Consequently, in the past 25 years, individuals with IDs have moved to ordinary neighbourhoods (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). In addition, some residential facilities have changed into neighbourhoods in which people with and without IDs live side by side, called “reversed integration” (Venema, Otten, & Vlaskamp, 2016).

In recent years, perceptions of society relating to the participation of citizens have evidently shifted. The emphasis now is on promoting citizens' participation within society to the greatest extent possible. According to the United Nations Convention on the Rights of People with Disabilities, which has been effective in the Netherlands since July 14, 2016 (Nederlandse overheid, n.d.), disabled individuals, irrespective of the extent of their disabilities, have the right to participate fully within society and in community life (United Nations, 2006). This changed perception and the associated policy relating to participation and inclusion, which also extends to adults with VSPID, has far-reaching consequences for persons involved with individuals with VSPID, and at all levels in society. At the societal level, new demands are being made, because they have to open up to people with disabilities (Scior et al., 2020).

To achieve this vision of the participation and inclusion of adults with VSPID, policy-makers should propagate inclusiveness and provide necessary resources. Simultaneously, local communities, including these adults' neighbours, also have an important role to play in the realization of this goal (Overmars-Marx, Pepping, & Thomése, 2018; Van Alphen, Dijkster, Bos, Van den Borne, & Curfs, 2011). Moreover, this changed policy has consequences for the individuals with VSPID themselves, their family members, and others involved in supporting them (Shelley et al., 2018). Influenced by the aforementioned citizenship paradigm, the role of the families of individuals living in residential care facilities and their involvement in the lives of these individuals have been strengthened in recent decades (Schuurman, 2014). For example, they may visit their family members, represent their interests, or attend events with these individuals outside of the residential facility (Axelsson & Wilder, 2014).

Within the residential facilities, adults with VSPID are facilitated by direct support professionals and by other healthcare professionals, such as healthcare psychologists, physiotherapists, speech therapists, and those with expertise in the field of blindness and visual impairments. The families, along with the support professionals in residential facilities, have to work together to support the individuals living in these facilities (Bigby & Fyffe, 2012; Grey, Griffith, Totsika, & Hastings, 2015; Jansen, Van der Putten, & Vlaskamp, 2017). As a result of the paradigm shift towards participation, residential facilities and their healthcare professionals are now faced with new requirements. Accordingly, they must reorient the methods and approaches they use to support persons with disabilities towards increasing their participation (in society), even if these individuals have severe or profound IDs (Bigby & Wiesel, 2015; Schippers, Bakker, & Peters, 2018; Venema, Otten, & Vlaskamp, 2016).

In general, participation is considered to be important for all people (United Nations, 2006). Additionally, the findings of studies conducted on individuals with IDs indicate that participation contributes to improved life quality (Cobigo et al., 2016; Schalock et al., 2010; Schippers et al., 2018). The reported positive effects of the participation of individuals with IDs cover different areas that include, for example, more choice-making opportunities, more independence, more friends, more meaningful activities, and more participation within community life (Mansell & Beadle-Brown, 2010; Taylor-Roberts, Strohmaier, Jones, & Baker, 2019). However, in research only partially revealed the assumed effects of participation, reported above, with regard to individuals with more severe IDs because these effects are associated with better adaptive skills (Kozma, Mansell, & Beadle-Brown, 2009). Studies have shown that compared with individuals who do not have these disabilities, those with severe or profound IDs are much less likely to engage in participation (Axelsson & Wilder, 2014; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Kamstra, Van der Putten, & Vlaskamp, 2015; Nijs, Penne, Vlaskamp, & Maes, 2016). The likelihood of participation is also low for individuals with visual impairments (Alma et al., 2011; Elsman, Van Rens, & Van Nispen, 2016; Salminen & Karhula, 2014). In addition, to achieve participation, adults with severe or profound IDs are highly dependent on persons in their environment because of the severity of their disabilities (Nakken & Vlaskamp, 2007). They are also affected by other environmental factors, such as the attitudes of staff members (Bigby et al., 2009; McConkey, & Collins, 2010; Talman, Gustafsson, Stier, & Wilder, 2017), family support (Axelsson & Wilder, 2014; Kamstra et al., 2015), and the availability of necessary facilities or resources (Maxwell, Alves, & Granlund, 2012). For adults with VSPID, we assume that participation may contribute to their lives in various areas. Nonetheless because of the significant risk of low participation of individuals with visual disabilities or severe/profound IDs, and the uncertainty associated with their dependence on their environments, the participation of adults with VSPID is expected to be suboptimal. However, data on the current participation levels of this group are lacking.

Although participation is assumed to be important for adults with VSPID, an additional problem is that the exact meaning of the concept of participation in relation to adults with VSPID remains unclear. Various authors have noted that there is still no scientific consensus on the concept of participation in general (e.g., Bigby, Anderson, & Cameron, 2018). Consequently, the definition and operationalization of the concept of participation varies within different models, such as the theoretical model of ID developed by the American Association on Intellectual and Developmental Disabilities (Luckasson et al., 2002) and the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) as well as within various studies (Chang, Coster, & Helfrich, 2013; Coster & Khetani, 2008; Maxwell et al., 2012). Furthermore, it appears that different definitions of the

concept of participation are used for different target groups. For example, definitions and modes of operationalizing the term for children and adults differ (Chien & Rodger, 2011; Rainey, Van Nispen, Van der Zee, & Van Rens, 2014). In sum, the concept appears to be multidimensional and requires further clarification (Adair, Ullenhag, Keen, Granlund, & Imms, 2015; Bigby et al., 2018). Because of the lack of definitional clarity and of a consensus regarding the mode of operationalization of participation for adults with VSPID, it is difficult for persons who support these adults to enhance the participation of this target group in practice. Therefore, research that yields a clear definition and concrete operationalization of the concept of participation is important for fostering clarity, thereby increasing the likelihood of improving the participation of this target group, which could, in turn, contribute to their quality of life.

It is not known precisely how the participation of adults with VSPID should be defined and operationalized. Consequently, their current participation levels are not known. While the participation of adults with VSPID is expected to be suboptimal, the precise extent and the specific areas of this suboptimal participation have not yet been ascertained. Additionally, it is not known how the expected suboptimal participation of adults with VSPID could be improved. Although possible factors that could influence participation, such as the attitudes of direct support professionals and other environmental factors, are known (Bigby et al, 2009; Maxwell et al., 2012), a number of questions arise. Notably, how could the participation of adults with VSPID be improved or increased? Further, what types of interventions would be effective for improving participation?

In sum, participation is considered important for people with IDs in general as well as specifically for adults with VSPID. However, many aspects of the participation of adults with VSPID remain unclear. The aim of this study was to gain insights into the participation of adults with VSPID and to explore ways of improving their participation through the development and testing of a new intervention. This thesis addresses the following research questions:

1. How should participation for adults with VSPID be defined and operationalized by concerned stakeholders?
2. To what extent do adults with VSPID participate, according to the, by concerned stakeholders, operationalized concept of participation for adults with VSPID?
3. What are the effects of a newly developed intervention on the participation of adults with VSPID?

Outline of the thesis

In light of the general objectives of this thesis, the following chapters provide insights into the participation of adults with VSPID and explore ways of improving their participation. Chapter 2 presents a definition of the participation of adults with VSPID and clarifies the operationalization of participation of these individuals based on the findings of a study conducted to elicit the opinions of family members, professionals, and others with expertise relating to this target group. Chapter 3 subsequently presents the findings of research, premised on the above definition and operationalization of the target group's participation, on the current participation of adults with VSPID. This study was based on an assessment of individual support plans of adults with VSPID.

In light of the above findings, Chapter 4 describes the development of a new intervention, 'Care for Participation+' (CFP+), aimed at improving the participation of adults with VSPID, as operationalized by the concerned stakeholders. The chapter also presents the results of a process evaluation of this new intervention within a residential care facility for persons with VSPID in the Netherlands.

Chapter 5 presents the effects of the new CFP+ intervention on direct support professionals' attitudes towards the participation of adults with VSPID. The CFP+ intervention was tested in a pilot non-randomized controlled trial with three parallel intervention arms at two residential care facilities for persons with VSPID in the Netherlands.

Chapter 6 discusses the effects of CFP+ on the participation of adults with VSPID in terms of life quality, and active involvement in daily life activities. This discussion is based on the findings of the same above-mentioned pilot non-randomized controlled trial conducted at the two residential care facilities for persons with VSPID. Given the small sizes of the groups of research participants, qualitative methods were applied in addition to quantitative methods to gain deeper insights into the results.

Lastly, Chapter 7 presents a general discussion on the outcomes of the previous chapters in relation to the general aims of this thesis. Theoretical as well as methodological reflections are offered in this chapter, which concludes with some thoughts on future research and policy directions relating to the subject of this thesis.

References

- Adair, B., Ullenhag, A., Keen, D., Granlund, M., & Imms, C. (2015). The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Developmental Medicine & Child Neurology*, doi: 10.1111/dmcn.12809.
- Alma, M. A., van der Mei, S. F., Melis-Dankers, B. J., van Tilburg, T. G., Groothoff, J. W., & Suurmeijer, T. P. (2011). Participation of the elderly after vision loss. *Disability and Rehabilitation*, 33(1), 63-73. DOI :10.3109/09638288.2010.488711
- Alphen, van, L. M., Dijkjer, A. J. M., Bos, A. E. R., Borne, van den, B. H. W., & Curfs, L. M. G. (2011). Explaining not-in-my-backyard responses to different social groups: The role of group characteristics and emotions. *Social Psychological and Personality Science*, 2(3), 245-252.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders. 5th edition*. VA, US: American Psychiatric Association.
- Axelsson, A. K., & Wilder, J. (2014). Frequency of occurrence and child presence in family activities: a quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. *International Journal of Developmental Disabilities*, 1, 13-25.
- Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 363-376.
- Bigby, C. & Fyffe, C. (2012). Services and families working together to support adults with intellectual disability. Proceedings of the six roundtable on intellectual disability policy. Bundoora, VIC Australia: La Trobe University.
- Bigby, C., & Wiesel, I. (2015). Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 28, 307–318.
- Bigby, C., Anderson, S., & Cameron, N. (2018). Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 31(2), 165-180. DOI: 10.1111/jar.12390.
- Chang, F. H., Coster, W. J., Helfrich, C. A. (2013). Community participation measures for people with disabilities: a systematic review of content from ICF perspective. *Archives of Physical Medicine and Rehabilitation*, 94, 771-781.
- Chien, C., & Rodger, S. (2011). Applying a new participation definition with pediatric populations: Issues and challenges. *Archives of Physical Medicine and Rehabilitation*, 92, 2096.
- Chowdhury, M. & Benson, B. A. (2011). Deinstitutionalization and Quality of Life of individuals with intellectual disability: A Review review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities*, 8(11), 256–265. DOI: 10.1111/j.1741-1130.2011.00325.x
- Cobigo, V., Brown, R., Lachapelle, Y., Lysaght, R., Martin, L., Ouellette-Kunz, H.,...Fulford, C. (2016). Social inclusion: a proposed framework to inform policy and service outcomes evaluation. *Inclusion*, 4(4), 226-238.
- Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30, 639-648.
- Elsman, E. B. M., Van Rens, G. H. M. B., & Van Nispen, R. M. A. (2016). Impact of visual impairment on the lives of young adults in the Netherlands: a concept-mapping approach. *Disability and Rehabilitation*, 39(26), 2607-2618. doi:10.1080/09638288.2016.1236408.
- Evenhuis, H. M., Sjoukes, L., Koot, H. M., & Kooijman, A. C. (2009). Does visual impairment lead to additional disability in adults with intellectual disabilities? *Journal of Intellectual Disability Research*, 53, 19-28.
- Gennep, van, A. Th. G. (1997). Paradigmaverschuiving in de visie op zorg voor mensen met een verstandelijke handicap. *Tijdschrift voor Orthopedagogiek*, 36, 189-201.

- Grey, J.M., Griffith, G.M., Totsika, V., & Hastings, R.P. (2015). Families' experiences of seeking out-of-home accommodation for their adult child with an intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 12(1), 47–57.
- ICD-10, Version:2016. <http://apps.who.int/classifications/icd10/browse/2016/en#/H54>. Accessed 30 July 2018.
- Jansen, S.L.G., van der Putten, A.A.J., & Vlaskamp, C. (2017). Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: A multiple case study. *Journal of Intellectual Disabilities*, 21(1), 53–67.
- Kamstra, A., van der Putten, A.A.J., & Vlaskamp, C. (2015). The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28, 249–256.
- Kiestra, T. (2005). *De unieke handicap, referentiemodel voor meervoudige beperkingen*. Vries: De Brink.
- Kozma, A., Mansell, J. & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Association on Intellectual and Developmental Disabilities*, 114(3), 193–222.
- Limburg, H., (2007). *Epidemiologie van visuele beperkingen en een demografische verkenning: Een studie in opdracht van Stichting InZicht*. Health Information Services, Grootebroek.
- Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Reeve, A., Schalock, R. L., Snell, M., Spitalnik, D. M., Spreat, S., & Tasse, M. J. (2002). *Mental Retardation: Definition, Classification, and Systems of Support*. Washington, DC: American Association on Mental Retardation. ISBN 0-940898-81-0.
- Mansell, J. & Beadle-Brown, J. (2010). Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Intellectual Disability Research*, 54(2), 104–112.
- Maxwell, G., Alves, I., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY: findings from a systematic literature review. *Developmental Neurorehabilitation*, 15, 63–78.
- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54, part 8, 691–700.
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disability*, 4, 83–89.
- Nederlandse overheid. (n.d.). Convention on the rights of persons with disabilities. Retrieved January 19, 2018, from <http://wetten.overheid.nl/BWBV0004045/2016-07-14>
- Nijs, S., Penne, A., Vlaskamp, C. & Maes, B. (2016). Peer interactions among children with profound intellectual and multiple disabilities during group activities. *Journal of Applied Research in Intellectual Disabilities*, 29, 366–377.
- Overmars-Marx, T., Thomése, F., Verdonshot, M., & Meininger, H. (2014). Advancing social inclusion in the neighborhood for people with an intellectual disability: An exploration of the literature. *Disability & Society*, 29, 255–274.
- Overmars-Marx, T., Pepping, B., & Thomése, F. (2018). Living apart (or) together—neighbours' views and experiences on their relationships with neighbours with and without intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31, 1008–1020.
- Poppes, P., Putten, A.A.J. van der, & Vlaskamp, C. (2010). Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, 31, 1269–1275.
- Rainey, L., van Nispen, R., van der Zee, C., & van Rens, G. (2014). Measurement properties of questionnaires assessing participation in children and adolescents with a disability: a systematic review. *Quality of Life Research*, 10, 2793–2808.

- Salminen, A.L., & Karhula, M.E. (2014). Young persons with visual impairment: Challenges of participation. *Scandinavian journal of occupational therapy*, 21(4), 267-76.
- Schalock, R.L. et al. (Eds) (2010). *Intellectual disability: Definition, classification, and system of supports*. Washington: American Association on Intellectual and Developmental Disabilities.
- Schippers, A.P., Bakker, M. & Peters L. (2018). Van participatie naar sociale inclusie. *Nederlands Tijdschrift voor de Zorg aan mensen met een verstandelijke beperking*, 2, 106-117.
- Schuurman, M.I.M. (2014). Naar de samenleving. De transformatie van de inrichtingszorg voor mensen met verstandelijke beperkingen in Nederland, tussen 1989 en 2014. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen*, 1, 10-34.
- Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2020). Intellectual disability stigma and initiatives to challenge it and promote inclusion around the Globe. *Journal of Policy and Practice in Intellectual Disabilities*, doi: 10.1111/jppi.12330.
- Shelley, K., Donnelly, M., Hillman, A., Dew, A., Whitaker, L., Stancliffe, R.J., Knox, M., & Parmenter, T. (2018). How the personal support networks of people with intellectual disability promote participation and engagement. *Journal of Social Inclusion*, 9(1), 37-57.
- Splunder, J.van, Stilma, J.S., Bernsen, R.M., Evenhuis, H.M. (2006). Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study. *Eye (Lond)*, 20(9), 1004-1010.
- Talman, L., Gustafsson, C., Stier, J., & Wilder, J. (2017). Staffs' documentation of participation for adults with profound intellectual disability or profound intellectual and multiple disabilities. *Disability and Rehabilitation*, 1464-5165. DOI: 10.1080/09638288.2017.1340979.
- Taylor-Roberts, L., Strohmaier, S., Jones, F., & Baker, P. (2019). A systematic review of community participation measures for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32, 706-718.
- Timmeren, E.A. van, van der Putten, A.A.J., van Schroyen Lantman-de Valk, H.M.J., van der Schans, C.P., & Waning, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans. *Journal of Intellectual Disability Research*, 60, 1109-1118.
- Tøssebro, J., Bonfils, I.S., Teittinen, A., Tideman, M., Traustadottir, R., & Vesala, H.T. (2012). Normalization fifty years beyond. Current trends in the Nordic Countries. *Journal of Policy and Practice in Intellectual Disabilities*, 9(2), 134-146.
- UN General Assembly, Convention on the Rights of Persons with Disabilities, 2006, A/RES/61/106, Annex I.
- Venema, E., Otten, S., & Vlaskamp, C. (2016). The efforts of direct support professionals to facilitate inclusion: the role of psychological determinants and work setting. *Journal of Intellectual Disability Research*, 59(10), 970-979. doi: 10.1111/jir.12209.
- Venema, E., Otten, S., & Vlaskamp, C. (2016). Direct support professionals and reversed integration of people with intellectual disabilities: Impact of attitudes, perceived social norms, and meta-evaluations. *Journal of Policy and Practice in Intellectual Disabilities*, 13(1), 41-49. doi: 10.1111/jppi.12145.
- Woittiez, I., Putman, L., Eggink, E., & Ras, M. (2014). *Zorg Beter Begrepen: Verklaringen voor de groeiende vraag naar zorg voor mensen met een verstandelijke beperking*. Den Haag: Sociaal en Cultureel Planbureau. Accessed 8 February 2020, https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2014/Zorg_beter_begrepen
- World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems (ICD-10). 10th revision, Geneva, 2010.
- World Health Organization (WHO) (2001). *International Classification of Functioning, Disability and Health*. WHO, Geneva.