ANED 2018-19 **Task 1.2**

Living independently and being included in the community

Country: Netherlands

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Contents

PART A – Factual information and statistical data

1 Current situation and direction of travel

1.1 Numbers and proportions of disabled children and adults residing in institutional care or community-based settings

1.1.1 Current figures

The number of children and adults residing in institutional care or community-based setting can be deduced out of the number of people who are formerly declared to be entitled to residential care. There is a very accurate account of the number of people declared (at their own request) eligible for residential care.[1] Not all children and adults who have the eligibility status actually reside in institution. Care providers may provide care within someone's own home. People who are eligible may also opt for a direct payment and organise their care in their own home with that payment. At the same time, people who have direct payment, may use that payment to buy their place in a residential care institution.

The total number of children in residential care based on youth care act (paid for by municipalities) in 2017[2] was 46,185 children. This group includes children in foster homes (when custody of their parents is taken away) children who committed crimes, children who show severe behavioural problems) and children with disabilities who need support. If children in foster homes, children with behavioural issues and children who committed crime are taken out, a group of 10,355 remain of children who receive long term residential care remain, likely due to disabilities.

Another group of around[3] 3,200 children in 2018 (3,500 in 2016) are eligible for long term care and they actually live in residential settings.

The number of adults entitled to residential care was 295,115 (year 2017).[4] Of these 95,100 were between 18-65 years of age. The number of 95,100 can be broken down to 4,430 people with mental health disorders; 6,535 with physical disabilities and 84,135 people with intellectual disabilities or a combination of physical and intellectual disabilities. It should be noted that people with mental health disorders can be living long term in psychiatric hospitals or residential homes for people with psychiatric disorders. These psychiatric hospitals and homes are (for the first three years for every patient) financed based on Health Care Act[5] as opposed to Long term Care Act.[6]

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1 Statistics Netherlands (CBS) https://www.cbs.nl/en-gb/about-us/organisation provides these figures and feeds into international data sources such as OECD 2018, Long-Term Care Resources and Utilisation: Beds in nursing and residential care facilities / Long-term care recipients - https://stats.oecd.org/Index.aspx?QueryId=30142.

2 *Jongeren met jeugdzorgcombinaties in natura; kenmerken, regio*, 2015-2017 https://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=82965ned&D1=a&D2=0,3-6&D3=0&D4=l&HDR=G3,G2,G1&STB=T&VW=T.

3 Estimation by a spokesperson of the association of care providers for people with disabilities VGN.

4 Statistics Netherlands CBS: *Gebruik bijdrageplichtige Wlz-zorg; leveringsvorm, zzp, regio* https://mlzstatline.cbs.nl/Statweb/publication/?DM=SLNL&PA=40055NED&D1=0&D2=0&D3=0,10-12&D4=a&D5=0-2,13,44&D6=0&D7=l&HDR=G5,G1,G2,G3,T,G6&STB=G4&VW=T.

5 *Zorgverzekeringswet* 2005 https://wetten.overheid.nl/BWBR0018450/2019-01-01.

6 *Wet Langdurige Zorg* 2014 https://wetten.overheid.nl/BWBR0035917/2019-01-01.

People living there in the first three years are not within the number of people eligible for long term care.

Adults who are eligible for long Term Care may opt for a “care package at home”. Of the total of 295,115 people receiving long term Care 14,190 people (4.8 %) opted for a care package at home. Another group of 22,985 people (7.7 %) opt for a direct payment with which they can organise either care in their own home or pay for a place in a residential home.

According to the Ministry of Health, Welfare and Sport about a quarter of people with an intellectual disability (to be distinguished from the elderly eligible for long term care) not the elderly) eligible for long term care opt to stay out of a residential home and one in five people with an intellectual disability opt for a direct payment.[7]

The number of people with intellectual disabilities in the Netherlands has been estimated at 142,000 in the year 2013, measured as people with an IQ below 70. This represents 0,85 % of total population. Of that total of 142,000 an estimated number of 68,000 had an IQ below 50.[8]

The association of care providers VGN states[9] that residential care is provided for a total of 87,650 people (adults and children) with disabilities, of which 75,750 have an intellectual disability, 2,400 have a sensory disability and 9,500 a physical disability.

Legislation for long term care makes it possible for people with disabilities to choose direct payment or to ask a care provider to provide care at home. Care providers are completely free to decide how they organise long term residential care: either in large residential settings (with usually groups of people clustered together with an individual bedroom, in group homes (of around 10 to 30 people living together) or in small group homes or individual homes. There is no inventory of? living conditions known.

1.1.2 Trend since 2013

The number of persons with an intellectual disability requesting long term care[10] (including residential care) has grown from 63,000 to 147,000 in the period 1998-2003, according to the Netherlands Institute for Social Research SCP.[11] That represents a

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7 Noted in *the report Volwaardig Leven* by Ministry of Health, Welfare and Sport, page 56. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/09/30/programma-volwaardig-leven/Programma+Volwaardig+leven.pdf.

8 Based on research by SCP the Netherlands Institute for Social Research and noted on the webpage: *Prevalentie van verstandelijke beperking Gezondheidszorginfo*. https://www.volksgezondheidenzorg.info/onderwerp/verstandelijke-beperking/cijfers-context/huidige-situatie#!node-prevalentie-van-verstandelijke-beperking and in the report *Volwaardig Leven*, page 56. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/09/30/programma-volwaardig-leven/Programma+Volwaardig+leven.pdf.

9 Webpage VGN, association of care providers: https://www.vgn.nl/feitenencijfers.

10 Financed on the Long-Term Care Act, then called *AWBZ* (General Act Exceptional Care Costs).

11 SCP-publicatie 2010/4, *Steeds meer verstandelijk gehandicapten? Ontwikkelingen in vraag en gebruik van zorg voor verstandelijk gehandicapten* 1998-2008, Michiel Ras, Isolde Woittiez, Hetty van Kempen, Klarita Sadiraj, Den Haag, Sociaal en Cultureel Planbureau, maart 2010, ISBN 978 90 377 0468 6,

yearly growth of 9 % each year while the population growth was 0,5 % per year. Requests for specifically residential care grew in that period with 5 % each year. The number of people with an intellectual disability requesting long term care has been stabilized after this period. According to the SCP about half of people with intellectual disabilities requests residential care.

The research institute notes that although people with an intellectual disability have a longer life expectancy than before, their proportional part in general population stays the same. The increasing demand for long term care is attributed to wider eligibility criteria for especially people with minor intellectual disabilities combined with growing complexity in society causing more young people to ask for assistance in coping with these demands.

A major reform of long-term care was implemented from 2015. The aim was to provide more personalised care of higher quality, to have fewer people (elderly people and people with a disability) living in institutions, to enhance social cohesion (such that people within social networks would provide each other more informal care and support), and to reduce the growth of cost experienced in recent years.[12] The means to reach these aims were to shift responsibility of providing all long-term care for children and all non-residential care for adults to municipalities with a tighter budget and to introduce stricter eligibility criteria for long term residential care (only for people with intellectual disabilities and dementia in need of constant surveillance). Since this reform, the number of people receiving long term care decreased from 324,585 to 320,030 (2015-2017) and the number of people within this group requesting direct payment grew from 28,400 to 34,060.[13]

The divide between residential care (financed and regulated by the Long-Term Care Act) and non-residential care financed and regulated by the Social Support Act,[14] is not always as clear as the terms suggest. People eligible for long term care receive for the majority care in residential institutions. Residential institutions provide care in larger residential institutions but also in group homes in the communities and in individual homes (either owned by the care provider or owned by or rented by the receiver of care. People eligible for long term care may opt for direct payment as well and organise their own care in their own home. At the same time, municipalities (responsible for Social Support) may finance group homes, thus providing an institutionalised form of support.

Part of the reform in 2015 was also the transfer of responsibility for youth care from national care insurers and provincial governing level to municipalities. The number of children placed in institutions or foster homes declined somewhat in 2015, increases

https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2010/Steeds_meer_verstandelijk_gehandicapten.

12 Country report Netherlands on the European semester, https://www.disability-europe.net/downloads/889-task-eu2020-year-3.

13 Statistics Netherlands CBS: *Gebruik bijdrageplichtige Wlz-zorg; leveringsvorm, zzp, regio* https://mlzstatline.cbs.nl/Statweb/publication/?DM=SLNL&PA=40055NED&D1=0&D2=0&D3=0,10-12&D4=a&D5=0-2,13,44&D6=0&D7=0,l&HDR=G5,G1,G2,G3,T,G6&STB=G4&VW=T.

14 Social Support Act 2015 https://wetten.overheid.nl/BWBR0035362/2018-11-17.

by 15 (institutions) and 25 % in foster homes. The number of placements in foster families stayed the same.[15]

1.2 Overall spending on institutional care versus services for support for living independently and being included in the community, including information about proportion/amount of funding provided from EU funds

1.2.1 Current figures

Residential institutions or community-based group homes are usually financed based on the Long-Term Care act.[16] In 2017 total expenditure on long term care was 20 billion (of which 12 billion to elderly people in homes and 8 billion for people with mostly an intellectual disability), reported by the Ministry of Health, Welfare and Sport.[17]

According to Netherlands Institute for Social Research the total expenditure on residential long-term care was 16,6 billion in 2017 and on social support, including youth care, in the community by municipalities for people with a disability 7,8 billion in 2017.[18]

1.2.2 Trend since 2013

According to the Netherlands Institute for Social Research the expenditure for long-term care increased by 3.3 % between 2010-2012, decreased with -1.1 % in the period 2012-2014 and increased by 0.6 % in the period 2014-2017.[19] Expenditure for long-term care (health and social care combined) in the Netherlands is the highest within EU and the OECD.[20]

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15 *Actieprogramma Zorg voor de Jeugd*, Ministry of Health, Welfare and Sport, April 2018. https://www.rijksoverheid.nl/documenten/rapporten/2018/04/01/actieprogramma-zorg-voor-de-jeugd.

16 See for the specific eligibility criteria: *Beleidsregels indicatiestelling Wet langdurige zorg (Wlz)* 2018 (translates as: Policy rules assessment Long Term Care Act 2018) , page 7: https://www.ciz.nl/images/pdf/beleidsregels/Beleidsregels_indicatiestelling_Wlz_2018.pdf. Or the Country report Netherlands on disability assessment https://www.disability-europe.net/downloads/921-country-report-on-disability-assessment-netherlands.

17 The report *Volwaardig Leven* by Ministry of Health, Welfare and Sport, page 56. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/09/30/programma-volwaardig-leven/Programma+Volwaardig+leven.pdf.

18 Evaluation report on reforming Long-Term Care by SCP the Netherlands Institute for Social Research: *Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg*, (changing care and support for people with a disability, national evaluation of the reform long term care June 2018. https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking.

19 Evaluation report on reforming Long-Term Care by SCP the Netherlands Institute for Social Research: *Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg*, (changing care and support for people with a disability, national evaluation of the reform long-term care June 2018. https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking.

20 OECD 2018, Long-Term Care Resources and Utilisation: Beds in nursing and residential care facilities / Long-term care recipients - https://stats.oecd.org/Index.aspx?QueryId=30142.

There is a shift visible between cost for expenditure on residential long-term care to social support provided for by municipalities. According to the evaluation report by the Netherlands Institute for Social Research: the total expenditure on residential long-term care decreased from 18,9 billion in 2012 to 16,6 billion in 2017 whereas expenditure on social support by municipalities for people with a disability grew from 5,1 billion in 2012 and 7,8 billion in 2017.[21]

2 Government commitments on living independently and being included in the community including the transition from institutional care to community-based living

2.1 In which document(s) are government commitments and plans concerning support for independent living in the community set out?

Plan for implementing the CRPD: 'Programma VN-verdrag Onbeperkt meedoen!'[22] (June 2016).

Plan for improving quality of care and standard of living for people with severe disabilities and complex needs 'Programma Volwaardig leven', by the Ministry of Health, Welfare and Sport[23] (September 2018).

Plan to improve opportunities to live independently: 'programma Langer Thuis' (June 2018).[24]

Action plan for youth care: Actie programma zorg voor de jeugd.[25]

The National Reform programme 2018 has no mention of independent living or residential care and support. Disability is briefly mentioned in the National Reform Program in relation to social inclusion of people who are vulnerable on the labour market.

A substantive reform of long-term care and social support has been laid down in legislation and letters to Parliament known as "Hervorming Langdurige Zorg". This package of legislation serves as the basis for Government commitment since 2015 to

[21] Evaluation report on reforming long Term Care by SCP the Netherlands Institute for Social Research*: Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg*, (changing care and support for people with a disability, national evaluation of the reform long term care June 2018. https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking.

[22] Programma VN-verdrag *Onbeperkt meedoen*, Ministry Health, Welfare and Sport. June 2016. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/06/01/programma-vn-verdrag-onbeperkt-meedoen/programma-vn-verdrag-onbeperkt-meedoen.pdf.

[23] Programma *Volwaardig leven* (could be translated as Dignified Life), September 2018. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/kamerstukken/2018/09/30/kamerbrief-over-programma-volwaardig-leven/kamerbrief-over-programma-volwaardig-leven.pdf.

[24] Programma *Langer Thuis*, by the Ministry of Health, Welfare and Sport, June 2018, letter to Parliament: https://www.rijksoverheid.nl/documenten/kamerstukken/2018/06/18/kamerbrief-over-programma-langer-thuis.

[25] Actieprogramma *Zorg voor de Jeugd*, Ministry of Health, Welfare and Sport, April 2018. https://www.rijksoverheid.nl/documenten/rapporten/2018/04/01/actieprogramma-zorg-voor-de-jeugd.

reduce costs of residential care. The final evaluation report by the Netherlands Institute for Social Research: *Veranderde zorg en ondersteuning voor mensen met een beperking,* may serve as a summary of the reform package.[26]

The Netherlands are not been subject to research by the Structural Funds Watch, nor recently by the Fundamental Rights Agency.

2.2 What are the aims and objectives of relevant strategies, including relevant targets and milestones? Are they linked to ESIF?

Implementationplan: '*Programma VN-verdrag Onbeperkt meedoen!*' (2016).[27] The plan focuses on seven themes: building and living, work, education, transport, participation and accessibility, care and support and national Government as an employer. When it concerns the theme building and living, the aim is to improve accessibility of buildings and to provide 'enough' houses and group homes for people with disabilities. Within the theme care and support the aim is to guarantee 'good quality' of care and support as this is considered an important condition to participate in society. There is no explicit aim of deinstitutionalisation and no quantifiable targets in any of the themes.

Plan for improving quality of care and standard of living for people with severe disabilities and complex needs '*Programma Volwaardig leven'* (2018), by the Ministry of Health, Welfare and Sport.[28] The aim is threefold; to improve quality of (residential) care for people with more severe disabilities, by making it more person centred and to enable people in residential care to gain more control over their lives; to provide 'enough' and at least 100 more residential places for people with complex needs and to provide at least 425 family members of people with severe disabilities support in organizing adequate care and support within the bureaucratic eligibility system. The aim is not to deinstitutionalize.

Plan to improve opportunities to live independently: 'Programma Langer Thuis' (June 2018).[29] This programme is specifically aimed at elderly people who are in need of care and support. The aim is to enable elderly people to live independently during a longer period. National Government has the aim to reduce costs for long term care[30]

[26] SCP the Netherlands Institute for Social Research: *Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg*, (changing care and support for people with a disability, national evaluation of the reform long term care June 2018. https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking.

[27] Programma *VN-verdrag Onbeperkt meedoen*, Ministry Health, Welfare and Sport. June 2016. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/06/01/programma-vn-verdrag-onbeperkt-meedoen/programma-vn-verdrag-onbeperkt-meedoen.pdf.

[28] Programma *Volwaardig leven* (could be translated as Dignified Life), September 2018. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/kamerstukken/2018/09/30/kamerbrief-over-programma-volwaardig-leven/kamerbrief-over-programma-volwaardig-leven.pdf.

[29] Programma *Langer Thuis*, by the Ministry of Health, Welfare and Sport, June 2018, letter to Parliament: https://www.rijksoverheid.nl/documenten/kamerstukken/2018/06/18/kamerbrief-over-programma-langer-thuis.

[30] The programme Reforming long term care as of 2015. See paragraph 2.1.

and implicitly aims to have a lower percentage of elderly people living in residential care. No quantifiable target is set.

Action plan for youth care: *Actie programma zorg voor de jeugd* (2018)[31] aims to improve quality of youth care, to improve access to youth care, to support children in need of youth care in an environment that resembles 'home' as much as possible and to end separation in closed residential settings for children.

2.3 Please summarise the planned approach and the actions to be taken in relevant strategies

The planned approach in the CRPD Implementation plan (*Onbeperkt Meedoen*) is to coordinate actions by local municipalities, NGOs, DPOs, organisations of employers and trade unions. These parties are stimulated to write a guideline on accessible building; to stimulate municipalities and housing corporations to plan innovative social housing projects in which renters can also be provided with care; to consider stricter accessibility criteria for new buildings and to stimulate municipalities to make an inventory of existing barriers in the built environment.

Concerning the themes participation and improving accessibility, the chosen approach is the same: municipalities, DPO's at national and local level, employer organisations and trade unions are stimulated to come up with actions to improve participation for people with disabilities. There are no quantifiable targets set for these themes. Concerning improving participation on the labour market (125,000 reserved jobs for people with disabilities) and in transport, quantifiable targets were set in legislation dating back before ratifying the CRPD in 2016.[32]

The approach in the plan for improving quality of care and standard of living for people with severe disabilities and complex needs *'Programma Volwaardig Leven'*, is to discuss with the association of DPO's and association of care providers existing problems concerning quality of care; possible lack of budgets; incidentally higher budgets for adults and children with severe disabilities to live independently,[33] ways to improve person centred approaches within residential care settings and to provide ways to support family members who organize care for their loved ones and who find themselves lost in the bureaucratic eligibility system. Special focus is being given to problems for young children with disabilities who may not be entitled to long term care but who also may be refused for social support or housing adaptations and who experience difficulty in being accepted in school (special or regular) because schools say they have no budget to provide care for them. Regular meetings will be organized to discuss progress, coordinated by the Ministry of Health, Welfare and Sport with

[31] *Actieprogramma Zorg voor de Jeugd,* Ministry of Health, Welfare and Sport, April 2018. https://www.rijksoverheid.nl/documenten/rapporten/2018/04/01/actieprogramma-zorg-voor-de-jeugd.

[32] See for the specific targets in public transport: DOTCOM: the Disability Online Tool of the Commission. https://www.disability-europe.net/dotcom?l%5B%5D=25&t%5B%5D=19&t%5B%5D=38&t%5B%5D=39&t%5B%5D=40&t%5B%5D=41&view_type=list. See for the specific targets in employment of people with disabilities: https://www.disability-europe.net/dotcom?l%5B%5D=25&t%5B%5D=38&t%5B%5D=39&t%5B%5D=40&t%5B%5D=41&view_type=list.

[33] *Meerzorgregeling, Programma Volwaardig Leven*.

DPO's, the association of care providers and organizations who support people with disabilities in eligibility processes.

The approach in the plan to improve opportunities to live independently for a longer period: '*Programma Langer Thuis'* is to stimulate regular meetings between municipalities (responsible for providing social support and care at home), care providers, care insurers, stimulate e-health projects, stimulate coordination of respite care, stimulate deployment of specialists in elderly care with general practitioners, stimulate municipalities to build more houses according to wishes of elderly people, to build more clustered housing projects for elderly people, to come up with at least ten innovative projects that combine housing with care. An intervention team and a 'community of practice 'will be formed to stimulate executing of this policy. Indicators (such as the percentage of people who state their house is suited for their needs) are being used to monitor progress.

The approach in the Action plan for youth care is to develop and use interventions to help children while staying with their parents; to develop an action plan to recruit more foster parents, to develop innovative small group homes where care would resemble family life and to decrease the number of placements in closed settings (no specific target is set). Regarding the aim to end all separations, the strategy[34] is to count how many times children in youth care are being separated, to use this count to set realistic targets for ending separations, to halve the number of separations in the first action year, top introduce a registry for all measures which limit freedom of youth in residential settings and to prepare legislation with the aim to prohibits all separations of youth in residential settings.

2.4 What budgetary commitments are made to support these strategies, both for domestic and EU funds?

There is no budgetary commitment for the implementation plan CRPD. For the program *Volwaardig Leven* (improving quality of care) 98 million euro has been committed in 2019 to raise maximum budgets for residential care (and direct payments) and another 75 million euro for transport to day care activities for people with disabilities in long term care. For the program *Langer Thuis* (live independently for a longer period) 340 million is reserved for the period 2018-2021. For the action plan Youth care 108 million euro is being reserved for the specific parts in the action plan that would transform the care (such as the ending off separations and the campaign to find more foster parents.

2.5 What is the (official) involvement of persons with disabilities and/or their representative organisations in the development of the strategies and plans

At national level the association of disabled people organisations *Iederin*[35] is formally involved. At local level, municipalities consult with local advisory boards for social policies and possibly with local DPO's.

[34] Page 30 *Actieprogramma Zorg voor de Jeugd*, Ministry of Health, Welfare and Sport, April 2018. https://www.rijksoverheid.nl/documenten/rapporten/2018/04/01/actieprogramma-zorg-voor-de-jeugd.

[35] Federation of associations of people with disabilities or chronic illnesses *Iederin* https://iederin.nl/.

3 Implementation and monitoring

3.1 Summary of relevant calls for proposals

There are no calls for proposals concerning the transition for institutional care to community-based living, none by national, regional or local government, nor by the managing authorities for ESIF.

3.2 Summary of relevant projects funded

There are no relevant projects.

3.3 Overview of other relevant measures since 2013

A substantive reform of long term care and social support has been laid down in legislation and letters to Parliament known as *"Hervorming Langdurige Zorg"*.[36] This package of legislation serves as the basis for Government commitment since 2015 to reduce costs of residential care and to have municipalities to provide support at home in order to enable – especially the elderly – to live independently as long as possible. There are no national guidelines issued to direct care providers for long term care or social support how to support people to live independently.

Average care budgets based on the Long-Term Care Act are based on the assumption of people living in groups and sharing care workers and spending day care activities within groups.[37] This assumption and budgets based on that assumption leads most care providers to offer care within group living arrangements.

The direct payment system has been established in long term care for people with disabilities in the Netherlands for around 25 years. Until a few years ago direct payments used to be the main instrument that people with an intensive need for support could use to organise their care in their own home. Direct payments equal the costs of residential care budgets.

Part of the reform program was a new financial instrument to allow care providers to provide support to people with an intensive need for support in their own home. Criteria of an existing regulation have been widened in 2018 to provide considerably higher care budgets for people with high needs for support for whom forced group living is not considered a good option.[38]

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[36] See paragraph 2.1.

[37] Eligibility criteria for Long Term Care considered until 2018 the severity of (intellectual and behavioural problems) to determine the numbers of hours of care to be allocated per client in residential care thus implicitly determining the number of people who are supposed to share care workers in order to have 24 hours per day availability of care workers within the group. See for criteria: *Regeling Langdurige Zorg*. https://wetten.overheid.nl/BWBR0036014/2019-02-20.

[38] The regulation is known as '*Meerzorgregeling'*. The Ministry of Health, Welfare and Sport developed together with a private initiative an action plan on how to use this regulation to set up independent living for people with a severe disability and behaviour that would make group living considered impossible. See for the action plan: Action plan residential care at home: https://www.opaz.info/instellingsplek-aan-huis.

The financial system and regulations make it thus possible for care providers and for people with disabilities to use care budgets to provide care in one's own home. Legislation and regulation also give care providers freedom to organise residential setting. Rules on quality of residential housing (including minimum norms for square meters per individual bedroom), were abolished in 2010.

There is no recent research on de-institutionalisation in the Netherlands. The association of care providers VGN did not mention reports on projects on capacity building or training and development programs for independent living. For the elderly, in need of support, there are initiatives for innovative projects by care providers in cooperation with housing cooperation's[39] as part of the programme *Langer Thuis* (for elderly people), see paragraph 2.1.

3.4 Monitoring mechanisms and approaches

3.4.1 Monitoring mechanism(s)

There is no monitoring mechanism on independent living or on the transition of institutionalised care to community-based support as there is no action plan with targets set. The programs mentioned in paragraph 2.1 partly aim for more elderly people to receive support in their own home and to make care more person centred for people with severe disabilities. These programs have no quantifiable target. The program for elderly people mentions indicators. These indicators are not very precise nor specifically aimed at independent living. An example is the indicator: percentage of elderly people who express satisfaction with their living arrangements.

3.4.2 Measurement and data collection

The National Human Rights Institute monitors implementation of the CRPD including article 19 of the CRPD, the right to independent living by collecting statistical data.[40] Indicators used are the number or percentage of people with disabilities owning their own house; who can choose their house; who can choose the people to share housing accommodation; who have adaptations in their house, who have applied for and received adaptations in their house, who have adequate income or benefit to live independently, who have access to public buildings and provisions (such as sport clubs) in their neighbourhood, who are accepted as client to buy insurances.

4 Impact and outcomes

4.1 Progress against explicit targets and milestones

The National Human Rights Institute states in its monitoring report[41] on implementing article 19 of the CRPD, that the most important principle of article 19 is the respect for personal autonomy, including the right to determine where to live and with whom to live and an important part of article 19 is the aim to provide support not in residential

[39] See for example: www.aedes.nl/dossiers/wonen-en-zorg.html.
[40] *Report Inzicht in inclusie* by National Institute of Human Rights, September 2018: https://www.mensenrechten.nl/nl/node/2281.
[41] See paragraph 3.4.2.

settings but in one's own environment. The Human Rights Institute concludes in its monitoring report that on both aspect no progress has been made in the Netherlands between 2012 and 2016. The National Human Rights institute found that 41 % of people with a moderate intellectual disability were not allowed to choose their living arrangement both in 2012 and in 2016.

4.2 What is replacing institutional care?

4.2.1 At the point that persons with disabilities are being moved out of institutional care facilities, what types of accommodation and support are they being moved into?

Financing system and regulations leave much discretionary freedom to providers of residential care to organise housing options for people with disabilities dependent on their care. The financial budgets assume group living but there are possibilities to finance small living arrangements or even independent living. See also paragraph 3.3. This freedom for care providers leads to a large variety of options offered by care providers in residential care.[42] Two[43] out of 31 larger care providers[44] for people with disabilities have been known for their policy to close down all residential buildings and transferring all clients to small community-based group homes or to individual homes. One of these care providers, Arduin, decided December 2018 to relocate all clients back to clustered group living due to financial problems. The Ministry of Health, Welfare and Sport allocated in January 2019 EUR 20 million to this care provider to help finance what can be considered re-institutionalisation.[45]

4.2.2 What services, supports and measures are being developed and instituted to build long term support for the right to live independently and to be included in the community?

There is no additional information, apart from the programs mentioned in paragraph 2.1 and 3.3 on specific services, measure and supports.

4.3 Satisfaction levels among persons with disabilities

The evaluation report by the Netherlands institute for social research SCP[46] on long term care reform (aimed at reducing cost for residential care by reducing the number

[42] Country study Netherlands on the right to independent living of persons with disabilities: Summary overview of types and characteristics of institutions and community-based services for persons with disabilities available across the EU. Fundamental Rights Agency, November 2017. https://fra.europa.eu/sites/default/files/fra_uploads/netherlands-services-mapping-independent-living-nl.docx.

[43] Care provider Arduin https://arduin.nl/ and Esdege Reigersdaal https://www.esdege-reigersdaal.nl/.

[44] Members of the association VGN: https://www.vgn.nl/feitenencijfers.

[45] Letter to Parliament by the minister of Health, Welfare and Sport on the financial problems at care provider Arduin. https://www.tweedekamer.nl/downloads/document?id=94e96d39-b643-4430-b565-be0f640ba0dc&title=Continu%C3%AFteit%20van%20gehandicaptenzorg%20in%20Zeeland.pdf.

[46] *Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg*, (changing care and support for people with a disability, national evaluation of the reform long-term care), June 2018.

of people in residential care), notes that people with disabilities are dissatisfied when they apply for care but are denied or when they feel compelled to refrain from requesting support because of difficult application procedures or because of obligatory contributions). The researchers could not establish if the level of dissatisfaction was more or less after the reform of legislation.

The programme *Volwaardig Leven* (see paragraph 2.1) aims at providing more person-centred care for adults and children with more intensive support needs. Reports describe that dissatisfaction with quality of care[47] and the hardship of having to navigate eligibility assessments system was the reason to design the program. The Netherlands Institute for Social Research notes in a report on users of social support[48] that 20 % of people dependent on social support felt very lonely in 2017 (compared to 16 % I 20-15). Most of the people who lost support between 2015 and 2017 due to the reform of the care and support system, indicate in this report that they could not find alternative support within their social network. The researchers asked users of social support if they felt satisfied with their quality of life. Users of any form of social support rate the quality of their life on average lower then people who do not apply to social support. There were minor differences measured between 2015 and 2017.

https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking.

47 Described among other in a report on incidents with poor quality and financial abuse in residential care by the parents association Klokkenluiders VG and four other DPOs: https://www.tweedekamer.nl/downloads/document?id=d2e4248e-963c-418b-8f46-082a9c765578&title=Eindrapportage%3A%20Vroegtijdige%20signalering%20van%20mogelijke%20zorgfraude.pdf.

48 *Overall rapportage sociaal domein 2017*, by SCP December 2018. https://www.scp.nl/dsresource?objectid=479a5ed9-efc9-4ccc-a05d-de399f575b84&type=org.

PART B – Critique and evaluation

5 Observations and recommendations of official bodies

5.1 Observations by the UN Committee on the Rights of Persons with Disabilities on Article 19

The Netherlands have not been reviewed by the UN Committee on the Rights of Persons with Disabilities on Article 19.

5.2 Recent observations by other official European and international bodies

There are no observations by European and international bodies. The latest report on residential care and community living by the Fundamental Rights agency on the situation in the Netherlands dates from 2011.[49]

5.3 Observations and recommendations by national human rights bodies

The National Human Rights Institute monitors the right to independent living, based on statistical indicators. Their monitoring report shows no progress between 2012 and 2016. See paragraph 4.1 The Institute notes this lack of progress in its official report on implementing the CRPD. The Institute recommends national Government to ensure more affordable housing will be made available for people who want to leave residential institutions and to encourage municipalities to increase awareness of independent client support amongst persons with disabilities.

5.4 Observations and recommendations by national or regional/devolved Parliaments and assemblies

There are no observations nor recommendations on the right to independent living by national Parliament.

6 Views and perspectives of civil society including DPOs

6.1 UNCRPD civil society shadow and alternative reports

No shadow report is yet available in the Netherlands.

6.2 ‘Grey literature’ at the national level

There is no literature available concerning the transition from institutional care to community-based living. The transition is not subject of political discourse nor of research.

[49] Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities: desk report The Netherlands. Fundamental Rights Agency 2011. Authors: Anna van der Zwan, José Smits.

There is a critical report[50] by professor of applied science G.H.P. van der helm Hogeschool Leiden on residential youth care on the quality of youth care, including the negative effects of decentralizing all youth care to municipalities and the use of the medical model for interventions for children in need. The report describes a general lack of knowledge of the importance of helping children in need of youth care within their trusted social environment; family and school and describes remedies. One remedy is, apart from finding more foster parents and invest in their knowledge and skills to invest in small foster homes, where family life is resembled.

6.3 Pan-European and international civil society organisations

[non known.]

7 Academic research

There is no recent research known concerning the transition from institutional care to community-based living. Research concentrates on the evaluation of the reform of long-term care. Deinstitutionalisation is not subject of political discourse nor of research.

[50] G.H.P. van der Helm. *Hoop op het gewone leven voor kinderen die het niet getroffen hebben een 'plekje' voor Alicia*. March 2018. https://www.hsleiden.nl/residentiele-jeugdzorg/publicaties/publicaties.

PART C – Key points

8 Positive developments, including promising practice examples

There is no known oversight of promising practices in the transition from institutional care to community-based living. Anecdotal evidence is known of the closing down of residential care for all clients of care provider Esdege Reigersdaal.[51] Residential care has been substituted by (mostly clustered) independent houses. A negative practice is shown by care provider Arduin. Deinstitutionalisation is being reversed due to financial problems with financial aid by the Ministry of Health, Welfare and Sport. See paragraph 4.2.1.

9 Negative developments, including examples of poor practice

In general, there is no awareness among policymakers, care providers and DPO's about the imperative of article 19 CRPD; the right to live independently and the need to transition from institutional are to community-based support. So far only the National Institute for Human Rights describes clearly that the right to live independently and to make autonomous choices should lead to transition of residential care into community-based support systems.

Although the reform of long-term care was induced by the high costs of residential care in the Netherlands and the, in international comparison, high proportion of people living in residential care, there has never been the aim to transition all residential care to community-based support. The transform of long-term care has not led to significant lower proportion of people with disabilities living in residential care, nor to significant lower costs.

The system of financing and organizing long term care allows for direct payment and for incidentally higher care budgets. Care providers have the option to offer full care and support at individual's homes. However, few care providers make use of these possibilities in a systematic way and Government nor care insurers urge to change this. The vast majority of people eligible for long term care are offered places in group homes, with shared living rooms and the necessity to accept shared care workers without a free choice.

A negative practice is shown by care provider Arduin. This care provider has been one of the few care providers known for the past 20 years to de-institutionalise. Arduin decided in December 2018 to relocate all clients back to clustered group living due to financial problems. The Ministry of Health, Welfare and Sport allocated in January 2019 20 million euro to this care provider to help finance what can be considered re-institutionalisation.[52]

[51] Based on an interview with the CEO of Reigersdaal.

[52] Letter to Parliament by the Minister of Health, Welfare and Sport on the financial problems at care provider Arduin. https://www.tweedekamer.nl/downloads/document?id=94e96d39-b643-4430-b565-be0f640ba0dc&title=Continu%C3%AFteit%20van%20gehandicaptenzorg%20in%20Zeeland.pdf.

10 Recommendations

A recommendation is to raise awareness amongst all stakeholders, national government, policymakers, care providers and DPOs on the imperative of article 19. It is vital that, for this awareness raising program, the general comment on article 19 is used in order to prevent an interpretation that deinstitutionalization is just about replacing institutional buildings by individual housing or group homes.

Although it is clear that the vast majority of people eligible for long term care are offered places in group homes, with shared living rooms and the necessity to accept shared care workers without a free choice; the system also allows for direct payment and for incidentally higher care budgets. Care providers can theoretically offer a wide range of options, varying from shared bedrooms to independent apartments.

A recommendation is to make an inventory of all the options that are actually been offered or realised, and to make an inventory of actual living conditions of people with disabilities and the realisation of their right to live independently, to make autonomous choices and to live within the community. The inventory could identify both good and bad practises.

Based on such an inventory Dutch government could be given compelling instructions on goals for the transition of residential care to community-based support.
Dutch government in its turn could impose more strict guidelines on care providers to actively transition institutional care into community-based support and thus reduce their freedom to keep on organising residential institutions.

Care and support for people with disabilities is organized and financed based on three particular acts (Long Term Care Act, Social Support Act and he Health Care insurance Act, involving three major parties (municipalities, long term care insures and insurers for basic health care) with three separate financial flows of budgets. The transition from residential to community-based support could profit if these three acts could merge into one and if all available budgets could be put to work more flexible.

The action plan on Youth care aims, apart from ending all separations in residential youth care, to increase the number of foster parents and the number of small foster homes. A recommendation is to decide not only to end separations but to end all residential institutions for the youth and to replace residential care by foster parents and small foster homes according to a time schedule.