

ANED 2018-19

Task 1.2

Living independently and being included in the community

Country: Luxembourg

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PART A – Factual information and statistical data

1 Current situation and direction of travel

A major challenge concerning Luxembourg is the lack of data or the insufficient availability of data on some of the concerning issues. The international, European, and national compilations of data on independent living and related issues indicate sometimes "blanks" for Luxembourg or merely estimations in the corresponding tables. In addition, the figures do not allow direct evidence to be derived on the situation of people with disabilities, as no disability-related internal differentiation is made. For example, the OECD data collections¹ on institutionalised and independent living are not broken down by disability: Thus, indicators like number of beds in nursing and residential care facilities; long time care recipients in institutions or at home can only be used as indirect estimates for independent living of people with disabilities.

The beginning of de-institutionalization policy in Luxembourg is associated with the so-called Häfner report (1993)² about psychiatry in Luxembourg. Following his report, the national central psychiatric hospital started a de-institutionalization process, which still continues to date particularly in the context of persons with intellectual disabilities. In 2005 the Rössler Report³ concludes that 0,25 places per 1,000 inhabitants offered in Luxembourg do not comply with WHO guidelines, which assume a minimum of 0,3 – 0,5 places per 1,000 inhabitants for long-term care of the chronically ill alone.⁴

Neither Häfner's nor Rössler's Report published precise data on independent living structures for persons with (mental) disabilities.⁵

Warnier and De Keyser (2007, 375)⁶ already stated in their report on de-institutionalisation and community living in Luxembourg that there is no national data

¹ OECD 2019 (OECD.stat Homepage) The footnote to the WHO data contains the following entry: *Luxembourg. Source: Fichiers de la sécurité sociale. Data prepared by General Inspectorate of Social Security (IGSS). Coverage: Data only cover long-term care insurance recipients. - Preliminary results for 2016. - Data refer to numbers as of 31st December every year. No brake down by disability.*
https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

² Rössler, W., Salize, H.J., Häfner, H. (1993). *Bestandsaufnahme der psychiatrischen Versorgung in Luxembourg -Zusammenfassung und Schlußfolgerungen, Empfehlungen zur Weiterentwicklung der psychiatrischen Versorgung.* Mannheim: Zentralinstitut für Seelische Gesundheit.

³ Rössler W. (2005) *Psychiatry Luxembourg.* Luxembourg: *Ministère de la Santé publique.*
<http://www.sante.public.lu/publications/systeme-sante/politique-nationale-sante/rapport-rossler-psychiatrie-luxembourg-planungsstudie-2005-bestandeserhebung/rapport-rossler-psychiatrie-luxembourg-planungsstudie-2005-bestandeserhebung.pdf>. Website no longer available. See following footnote:

⁴ Rapport Rössler «*Psychiatrie Luxembourg Planungsstudie 2005: Bestandsaufnahme und Empfehlungen*» <http://sante.public.lu/fr/publications/r/rapport-rossler-psychiatrie-lux-planungsstudie-2005-bestandsaufnahme/index.html>.

⁵ Limbach-Reich, Arthur (2012). *Luxembourg Desk Report Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities.*
<https://www.humanconsultancy.com/projects/fundamental-rights-of-persons-with-intellectual-disabilities-and-persons-with-mental-health-problems>.

⁶ Warnier, C. & De Keyser, H. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study Country Report Luxembourg* In: Beadle-Brown, J. & Kozma, A. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European*

on the number of people with disabilities in Luxembourg. While there were 410 beds (*lits/places conventionnés*) in 1995,⁷ Beadle-Brown and Kozma reported a total of 704 institutionalised places for people with disabilities in Luxembourg in 2006. Of those places 410 are in institutions with less than 30 inhabitants and 294 in institutions with more than 30 inhabitants. Furthermore, the authors break down the data according to the following aspects:

Figure 1: institutionalised places for people with disabilities in Luxembourg (2006)

| | Places total | Male | Female | Children | Adults | Age unspecified |
|--------|--------------|------|--------|----------|--------|-----------------|
| Number | 704 | 395 | 309 | 48 | 655 | 1 |

Source: Carole Warnier & Hilde De Keyser (2007, 364)⁸

In addition to this data, the Report on Fundamental Rights (FRA-Report) on independent living in 2017⁹ indicates that in Luxembourg, the number of persons living in residential institutions rose from 701 in 2010 to 785 in 2016. In this Report it was pointed out that in Luxembourg in contrast to the great majority of all other European countries the percentage of persons with disabilities who agree or strongly agree with the statement: '*I feel I am free to decide how to live my life*' (84 %) is higher than that of persons without disabilities (82 %). The high approval rate may well be due to the fact that, (as a result of the data generation),¹⁰ only persons living in a household were included in the sample, which means that no statement can be made about persons living in institutions.

The national ANED report in 2009¹¹ deplores the absence of clear statements in favour of independent living for disabled persons in legal documents in Luxembourg and states that there is not much pressure from self-advocate groups or users' organisations to implement independent living, neither are there centres for independent living. However, the general tendency already noted in this report was that in Luxembourg there has been a constant movement away from big segregated institutions to smaller residential homes during the last 35 years. The above mentioned

Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 360-377.

https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Country_Reports.pdf.

⁷ *Ministre aux Handicapés et aux Accidentés de la Vie (1997). Evaluation de la situation des personnes handicapées au Luxembourg. Plan d'action en faveur des personnes handicapées. Luxembourg: MHAV.*

⁸ Warnier, C. & De Keyser, H. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study Country Report Luxembourg* In: Beadle-Brown, J. & Kozma, A. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 360-377.* https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Country_Reports.pdf.

⁹ European Union Agency for Fundamental Rights. (2017) *From institutions to community living - Part III: outcomes for persons with disabilities.* <https://fra.europa.eu/en/publication/2017/independent-living-outcomes> based on data compiled by the Ministry of Family and the Integration, Annual report 2016 (*Rapport d'activité 2016*); and Annual report 2010 (*Rapport d'activité 2010*), p. 76. <https://mfamigr.gouvernement.lu/fr/publications.html>.

¹⁰ EQLS 2012 Methodology <https://www.eurofound.europa.eu/de/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2012/eqls-2012-methodology>.

¹¹ ANED country report on the implementation of policies supporting independent living for disabled people. 2009 <https://www.disability-europe.net/downloads/460-lu-7-aned-2009-request-07-task-5-report-on-independent-living-approved-final-in-layout-to-ec>.

ANED report (2009) highlights three developmental steps in the implementation of Independent living:

- 1) In the beginning there have been efforts to close the huge psychiatric and religious institutions for persons with a disability.
- 2) Subsequently, small residential 'family like' groups were created, permitting a more participative way of living.
- 3) Finally, efforts were made to give people more opportunities to have private housing (to rent or buy their own housing / apartment), including specialised support services.

The national long-term care insurance¹² provides domestic assistance in day-to-day activities. The national act about employment for persons with disabilities¹³ improved the financial basis for independent living of people with disabilities.

The ANED Synthesis Report in 2009, amended in 2010¹⁴ states that only a few summary statements could be made on Luxembourg because the national final report was not available in time.

The first National Action Plan (2012)¹⁵ sets out the challenge of enabling people with disabilities in Luxembourg to decide: how, where and with whom they want to live, and this with the greatest possible autonomy, self-determination and responsibility in developing alternative housing options. Therefore, adequate offers of support and care in various forms in smaller housing units are called for.

As indicated in the FRA report (2012),¹⁶ steady progress towards independent living can be observed, especially for people with cognitive impairments, but major challenges remain. In particular, no general personal care budget system has yet been established in Luxembourg¹⁷ and the high cost of rents and real estate makes it difficult to implement an independent living system.

¹² Regulation of the long-time care assurance (*Assurance dépendance*) 1998. <https://www.secu.lu/assurance-dependance/>.

¹³ *Loi relative aux personnes handicapées - service de travailleur handicapé/ salarié handicapé* <http://legilux.public.lu/eli/etat/leg/loi/2003/09/12/n1/jo>.

¹⁴ Townsley, Ruth, Ward, Linda, Abbott, David and Williams, Val (2009). *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report of the Norah Fry Research Centre University of Bristol*. (November 2009, amended January 2010). <https://www.disability-europe.net/downloads/284-aned-task-5-independent-living-synthesis-report-14-01-10>.

¹⁵ Ministry of Family Affairs Integration and the Greater Region (2012) First action plan to implement the CRPD in Luxembourg (*Aktionsplan der Luxemburger Regierung zur Umsetzung der UNO-Behindertenrechtskonvention*) <https://mfamigr.gouvernement.lu/dam-assets/le-ministere/attribution/personnes-handicapées/plan-d-action-du-gouvernement-luxembourgeois-en-faveur-des-personnes-handicapees.pdf>.

¹⁶ Luxembourg Desk Report Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities 2012 <https://www.humanconsultancy.com/downloads/342-luxembourg-desk-report-fundamental-rights-situation-of-persons-with-mental-health-problems-and-persons-with-intellectual-disabilities>.

¹⁷ There is a lumpsum system for some impairments, e.g. blindness. *Loi du 1er avril 1971 portant création d'une allocation spéciale pour aveugles*. <http://legilux.public.lu/eli/etat/leg/loi/1971/04/01/n1/jo>.

The initial report of Luxembourg on implementing the CRPD¹⁸ in 2014 emphasizes the big shift towards decentralizing psychiatric care, that has taken place in Luxembourg since 1994. From 1994 onwards, persons with disabilities living in psychiatric hospitals have been transferred either to special institutions for persons with disabilities or, where possible, to sheltered accommodation. The mental health reform in Luxembourg, which gained renewed momentum in 2005, has been summarized as follows: “*de-institutionalization, de-centralization, de-stigmatisation and prevention.*”

The first state report (2014) provides the following figures concerning disability and long-time care in 2011:

Figure 2: Persons with and without disabilities receiving benefits by the national long-time care assurance.

| Population | Benefits from long term care insurance (LTC) | LTC % | LTC with disabilities | LTC % with disabilities | Within the total of LTC with disabilities (N=3995) | |
|--------------|--|--------|-----------------------|-------------------------|--|--------------------|
| | | | | | | |
| | 12,327 | | 3,995 | 32,41% | | |
| Women | 8,037 | 65.20% | 2,153 | 26,79% | 53,89% | |
| Men | 4,290 | 34.80% | 1,842 | 42,94% | 46,11% | |
| Age <65 | | | 1,847 | 14,98% | 811 women = 43,91% | 1,036 men = 56,09% |
| Children <19 | | | 594 | 4,82% | 226 girls = 38,47% | 368 boys = 61,95% |

Source: first state report 2014

In 2011 a total of 3,995 disabled people (32,41%) benefited from long-term care insurance, among these disabled beneficiaries are 594 children under 19 years of age (226 girls and 368 boys) and 1,847 adult beneficiaries (811 women and 1,036 men) under 65 years of age.

The first shadow report (2016)¹⁹ deplores that to some extent, there is still a “*parallel world*” for persons with disabilities, mostly State funded or co-funded. The shadow report claims that, many persons with disabilities still live with their parents, because there are no better options for them. The shadow report recognises, however, that no

¹⁸ Initial country report on implementing the CRPD (*Mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées - Premier rapport périodique du Grand-Duché de Luxembourg* (2014). https://mfamigr.gouvernement.lu/content/dam/gouv_mfamigr/le-ministère/attributions/personnes-handicapées/premier-rapport-periodique-de-mise-en-œuvre-de-la-convention-onu.pdf.

UN-CRPD concluding observations on the initial report of Luxembourg (CRPD/C/LUX/1) https://webcache.googleusercontent.com/search?q=cache:Hnp_yXmX-0IJ:https://tbinternet.ohchr.org/Treaties/CRPD/Shared%2520Documents/LUX/CRPD_C_LUX_CO_1_28811_E.docx+&cd=1&hl=de&ct=clnk&gl=de&client=safari.

¹⁹ Alternative Report on Implementation of the United Nations Convention on the Rights of Persons with Disabilities Luxembourg 2016. https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fLUX%2f26160&Lang=en.

reliable data are available on this topic and refers to interview data (“*There was no data available, but about a third of adults with disabilities interviewed for this report lived with their parents or parent*”, p. 29).

The Committee on the Rights of Persons with Disabilities (2017)²⁰ expresses in their Concluding observations on the initial report of Luxembourg concerns about:

- (a) The reform of the long-time care assurance act, which continue to curtail the right to independent living by setting limits and controls on persons with disabilities;
- (b) The lack of an action plan for the deinstitutionalization of persons with disabilities with a specific timeline and appropriate funding;
- (c) The absence of a clear strategy to promote and ensure the transition to full independent living for all persons with disabilities within the community, including with support of a personal assistant, and that future plans and construction projects still contain elements that limit the rights of persons with disabilities under article 19.

The national working group currently preparing the second national action plan (2018-2019)²¹ identifies as current priorities: the implementation of personal assistance, the introduction of a general personal budget, and the creation of new housing structures that allow and encourage more autonomy and self-determination (independent living).

As a result of earlier disability related legislation, there is still today a budget for people who are completely blind, people with spina bifida and people with communication difficulties due to severe hearing problems, dysarthria and those who have undergone laryngectomy who receive a lump sum cash benefit once the diagnosis is made by a specialist doctor approved by the assessment and referral team of the national care assurance.²² People with other disabilities have not yet been granted access to this benefit.

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

It is difficult to extract accurate figures on the situation of people with disabilities in independent housing, as there is no comprehensive definition of disability at national

²⁰ UN-CRPD Committee on the Rights of Persons with Disabilities (2017). Concluding observations on the initial report of Luxembourg (CRPD/C/LUX/1) https://webcache.googleusercontent.com/search?q=cache:Hnp_yXmX-0IJ:https://tbinternet.ohchr.org/Treaties/CRPD/Shared%2520Documents/LUX/CRPD_C_LUX_CO_1_28811_E.docx+&cd=1&hl=de&ct=clnk&gl=de&client=safari.

²¹ Ministry of Family, Integration and the Grand Region 2018 Working group on the development of the new National Action Plan for the implementation of the UN Convention on the Rights of Persons with Disabilities. (*Ministère de la Famille, de l'Intégration et à la Grande-Région 2018 sur l'élaboration du nouveau Plan d'action national de mise en œuvre de la convention de l'ONU relative aux droits des personnes handicapées*). https://mfamigr.gouvernement.lu/fr/actualites.gouvernement%2Bfr%2Bactualites%2Btoutes_actuelles%2Bcommuniqués%2B2018%2B07-juillet%2B03-reunion-personnes-handicapees.html.

²² First national Report implementing the CRPD Luxembourg (2015, Point 194) <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/201/47/PDF/G1520147.pdf?OpenElement>.

level.²³ An initial approximation permits the collection of the data compiled by the National Care Service, which provides resources for both home care and institutionalised care. However, the number of people with disabilities is not congruent with the number of benefit recipients, as temporary and age-related benefits are also included. On the other hand, the figures do not include persons who have a disability but have not claimed benefits or are not entitled to benefits (who are not insured for long-term care).

1.1.1 Current figures

A first indicator to be mentioned here refers to the national number of beds in care facilities. The OECD²⁴ distinguishes between two indicators: The national number of beds in nursing and residential care facilities per 1,000 inhabitants and the national number of beds in nursing and residential care facilities per 1,000 inhabitants aged 65 or older. (See Appendix Figure 3)

Both time series indicate that from 2014 (no data are available for the year 2013) no proportional increase of beds in institutions can be observed, which suggests that living independently in the community generally has increased (given a rising population of persons with disabilities). The extent to which people with disabilities in particular are affected here cannot be determined.

A second indicator to be mentioned deals with the number of people in institutionalised long-term care facilities: *'Men and women receiving formal (paid) long-term care (LTC) in institutions (other than hospitals) or at home'*.²⁵

As the data show (see Appendix, Figure 4), the number of people receiving care at home is higher than the number of people receiving care in an institution and this applies to both sexes. The OECD report contains data for 2013, but there are no more recent data than 2016 and there is no break down by disability.

²³ Limbach-Reich, A. (2013). *Inklusion im Widerstreit theoretischer und praxeologischer Konzepte*. Kongress der Internationalen Gesellschaft für erzieherische Hilfen; (Fédération Internationale des Communautés Educatives; International Federation of Educative Communities. FICE). Bern: Switzerland 07 - 12 October 2013. <http://www.fice-congress2013.ch/programm/abstracts/inklusion-im-nationalen-widerstreit-theoretischer-und-praxeologischer-konze/> Reference: *La Constitution du Grand-Duché de Luxembourg Chapitre II. – Des libertés publiques et des droits fondamentaux (Intitulé ainsi modifié par la révision du 02 juin 1999.) Article 11, (Révision du 29 mars 2007) Art. 11 Egalité devant la loi.* <http://www.legilux.public.lu/leg/textescoordonnes/recueils/Constitution/Constitution.pdf>.

²⁴ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability. https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

²⁵ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability. https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

In 2016, the number of people receiving care at home amounted at 9,182 persons (3,869 men and 5,313 women) and the number of people receiving care in institutions amounted to 4,560 (1,130 men and 4,330 women).

Broken down by age group the data (for year 2016) *on long-term care recipients in institutions or at home show that the need for long-term care increases with age and affects women more than men in old age.*²⁶ Independent living seems to be more feasible for older men than for women. While men in older age tend to receive care at home, women tend to receive care in an institutionalised context. This difference may, however, be entirely due to the higher life expectancy of women. (See Appendix, figure 5).

The reports “*From institutions to community living - Part I: commitments and structures*” and part II “*From institutions to community living - Part II: funding and budgeting*” prepared by the European Agency for Fundamental Rights (FRA) only addresses Luxembourg in a few places and does not provide systematically empirical data.²⁷

Luxembourg is also not 1 of the 10 member States of the “*Funds Watch Group of the European Structural and Investment Funds (ESIF)*” on community living in Europe to support independent and community living for persons with disabilities, children and older persons.²⁸

The following table shows the most recent data published by the national social security insurance.²⁹

Figure 6: Number of beneficiaries by age group and care performance (2016)

| Age group | 2016 | | | |
|-----------|---------------|----------------------------------|--------|-----------------|
| | Domestic care | Institutional care ³⁰ | All | Domestic care % |
| 0-19 | 968 | 0 | 968 | 100 |
| 20-39 | 573 | 4 | 577 | 99,3 |
| 40-59 | 1,177 | 57 | 1,234 | 95,4 |
| 60-69 | 1,057 | 201 | 1,258 | 84,0 |
| 70-79 | 1,769 | 653 | 2,422 | 73,0 |
| 80-89 | 2,858 | 2,394 | 5,252 | 54,4 |
| >=90 | 780 | 1,251 | 2,031 | 38,4 |
| All | 9,182 | 4,560 | 13,742 | 66,8 |

²⁶ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

²⁷ FRA (2017- 2018) From institutions to community living - Part I: commitments and structures <https://fra.europa.eu/en/publication/2017/independent-living-structures> And from institutions to community living - Part II: funding and budgeting <https://fra.europa.eu/en/publication/2017/independent-living-funding>.

²⁸ Community Living for Europe: Structural Funds Watch <https://communitylivingforeurope.org>.

²⁹ Rapport Général sur la Sécurité Social au Grand-Duché de Luxembourg 2016.

http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf.

³⁰ Including persons living collective households, such as old people's homes and nursing homes.

Source: Social insurance (Securité social 2017)³¹

Comparing institutional care and home care are compiled in last column by the author. As the data show, domestic care decreases with age. This suggests that independent living seems increasingly difficult in old age and may be as well more difficult for people with disabilities. According to this social security data compilation, one third (33.2%) of all persons (all age groups) who receive assistance through the insurance live independently in 2016. This represents an increase of 0.8% compared to the first country report (2014), which reported a proportion of 32.4% based on data end of 2011. However, most of these data do not include persons with cognitive impairments, since there are usually hardly any claims for support from the long-term care insurance. Therefore, the “de facto” percentage of people with disabilities living in institutions might be higher than two thirds.

The Ministry of Family Affairs³² publishes annual figures on persons with disabilities who wish to use their specific housing structures and ask for accompanying services. The Ministry's annual statistical data is usually broken down into three different housing structures for people with disabilities: 1) fully institutionalised structures (living in the institution), 2) semi-autonomous (living in an apartment or housing group in close association with an institution) and 3) autonomous structures (including support services). However, the boundaries are sometimes blurred and the same provider covers each of the three possible housing structures, so that a classification is not always explicit. Unlike in Figure 6 above, residents in old people's and nursing homes for the elderly with and without disabilities are not included here.

The capacity of accommodation services for people with disabilities is 874 beds, including 822 fixed beds and 52 temporary beds (fully institutionalised). At the end of 2017, a total of 797 places were occupied in the various accommodation facilities.

With semiautonomous structures, a total of 56 places were available in 2017 and 45 were occupied at the end of the year. The number of people with disabilities who are availing of autonomous housing services has been calculated at 274 for 2017. Among them were 143 men and 131 women with disabilities. This does not record persons with disabilities who live in the community without demand for any support or advice.

1.1.2 Trend since 2013

Looking at the data delivered by the OECD³³ the number of beds in nursing and residential care facilities per 1,000 inhabitants and per 1,000 inhabitants aged 65 or older indicate hardly any significant development in the observation period (2013 to

³¹ *Rapport Général sur la Sécurité Social au Grand-Duché de Luxembourg 2016.*

http://www.mss.public.lu/publications/rapport_general/rg2016/rg_2016.pdf;

http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf.

³² *Ministère de la Famille, de l'Intégration et à la Grande Région - Rapport d'activité 2017.*

<https://gouvernement.lu/dam-assets/fr/publications/rapport-activite/minist-famille-integration-grande-region/2017-rapport-activite-famille/2017-rapport-activite-famille.pdf>.

³³ OECD (2019) Data prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

2017). No data are available for 2013, so that data from 2014 were used. More recent data are not available (see Appendix, Figure 7). As Figure 7 shows, despite an increase in the absolute number of inpatient beds, the number of beds per 1,000 inhabitants and the number of beds per 1,000 inhabitants aged 60 and older declined during the observation period. Overall, however, the variations are very small and range around 5 % of the 2014 reference value. This may suggest that some more people are living at home and not in institutions. In Figure 7 (and following figures), the Y-axis is strongly stretched, to illustrate the barely apparent development.

Compared to 2013 the proportion of female and male recipients of long-term care in institution increases. However, the proportion of men receiving home care in the period covered by the study also rises. The only decrease emerged in the proportion of women receiving home care. Overall, however, there are no major changes (range less than 10 %). All data considered together, indicate that the increase of places in institutions is bigger than the increase of care at home during the period under study³⁴ (See Appendix, Figure 8).

The stronger increase in institutionalised care compared to care at home suggests that independent living has not yet been implemented in many cases and that probably even an increasing proportion of people with disabilities live in institutions.³⁵ Overall, however, the changes remain at a rather low level and only become visible due to the high spread of the Y-axis in the figure (see Appendix, Figure 9).

There have also been hardly any changes over the observation period in the data on long-term care insurance with regard to the various age groups of persons requesting appropriate support measures for independent living. The relative share of applications in the institutionalised context compared to applications from persons living independently in the municipality hardly changed during the observation period.

The development of data on *number of beneficiaries independent living per age group* between 2013 and 2016³⁶ show that the housing situation remained the same during the period examined (2013-2016). No data were available for 2017 at the time this report was compiled.

³⁴ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

³⁵ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

³⁶ *Rapport Général sur la Sécurité Sociale au Grand-Duché de Luxembourg 2016*
http://www.mss.public.lu/publications/rapport_general/rg2016/rg_2016.pdf;
http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf.

Based on data from the Ministry of Family Affairs,³⁷ it can be seen that the proportion of people with disabilities living in institutions has declined during the observation period. However, a simultaneous increase in independent living cannot be shown on the basis of the data.

These data (based on the statistics of the national long-term care assurance) show that almost three-quarters of all persons with disabilities continue to live in institutions in Luxembourg. But the actual number of people with disabilities who live autonomously is likely to be seriously underestimated by the available figures, because people who do not ask for counselling or support have not been included. No data are available for 2014. More recent data were not available when the report was compiled.

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

Measures that support independent living are mainly financed by the national long-term care insurance.

1.2.1 Current figures

A comparison of the expenses from the current annual report (2017) of the national care insurance (data basis 2015) shows that the benefits for stationary measures exceed the benefits for domestic measures.³⁸ The yearly national care insurance reports present reimbursements broken down by place of care and age (see Appendix, Figure 11).

Figure 12: reimbursements broken down by age group and place of action in million Euro

| Age group | 2015 Budget care Insurance (in million Euro) | | | |
|-----------|--|--------------------|-------|-----------------|
| | Domestic care | Institutional care | All | Domestic care % |
| 0-19 | 11,4 | 1,7 | 13,1 | 87,0 |
| 20-39 | 11,5 | 9,5 | 21,0 | 54,8 |
| 40-59 | 18,6 | 21,1 | 39,7 | 46,9 |
| 60-69 | 22,2 | 19,5 | 41,7 | 53,2 |
| 70-79 | 46,3 | 40,9 | 87,2 | 53,1 |
| 80-89 | 82,5 | 149,1 | 231,6 | 35,6 |
| >=90 | 27,9 | 327,5 | 113,5 | 24,6 |
| All | 220,5 | 4,560 | 548,0 | 40,2 |

Source: compilation by the author based on data of the national care insurance³⁹

³⁷ Ministry of Family affairs -MFI (2017) <https://gouvernement.lu/dam-assets/fr/publications/rapport-activite/minist-famille-integration-grande-region/2017-rapport-activite-famille/2017-rapport-activite-famille.pdf>.

³⁸ Ministry of social affairs (2017) http://www.mss.public.lu/publications/rapport_general/index.html.

³⁹ *Rapport Général sur la Sécurité Social au Grand-Duché de Luxembourg* (2016) http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf.

With regard to nursing services, the same report states the distribution of financing between home care and inpatient care in 2016 as follows: home care (*prestations à domicile*) EUR 211 million versus stationary care (*prestation en milieu stationnaire*) EUR 308.4 million.

As the preceding tables show, financial support for home care predominates in the early and middle stages of life, while financing institutional measures predominates in old age.

1.2.2 Trend since 2013

Figure 13: Budget developments 2013-2016 in millions of Euro

| Year | 2013 | 2014 | 2015 | 2016 | Trends since 2013 |
|-----------------------------|-------|-------|-------|-------|-------------------|
| Home care (million €) | 208.5 | 218.6 | 215.1 | 211.0 | + 1.2 % |
| Stationary care (million €) | 299.6 | 321.5 | 326.9 | 308.4 | + 2.9 % |

Source: rapport social security 2017, p. 132⁴⁰

As the table illustrates, the budget for stationary services grew more strongly than the budget for domestic services during the observation period (2013-2016).

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

The ministerial programme of action to improve the living conditions of people with disabilities (*Plan d'action en faveur des personnes handicapées 1997*)⁴¹ for the first time covered all existing regulations and pointed out the need for action.

The establishment of long-term care insurance with a performance-related billing orientation in 1999 required a detailed recording of the need for support and the expenses made available. The focus here was on ensuring financing in line with demand. In 2001, the law on the accessibility of public buildings and infrastructures laid the foundation for the expansion of accessibility in Luxembourg.

In 2003 followed the act on disabled worker (*travailleur handicapé*) and in 2011 Luxembourg ratifies the CRPD.

The legal measures in favour of disabled people in Luxembourg are assigned to different ministries depending on the subject area. The Ministry for Family, Integration and the Greater Region is responsible for coordinating the various measures and, if necessary, initiating new ones. In general, disability policy is based on the interaction of different actors in Luxembourg.

⁴⁰ *Securité social 2017* http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf p.132.

⁴¹ *Ministère aux Handicapés et aux Accidentés de la Vie (1997). Evaluation de la situation des personnes handicapées au Luxembourg. Plan d'action en faveur des personnes handicapées.* Luxembourg: MHAV. http://www.info-handicap.lu/index2.php?option=com_docman&task=doc_view&gid=36&Itemid=26 site no longer available source Limbach-Reich (2011).

- The State organises certain areas itself, such as specialised education for pupils with disabilities.⁴²
- The State concludes contracts / conventions with providers of services (workshops and housing facilities) and bears the costs relating thereto.
- Disability associations receive state or municipal subsidies
- Self-help groups do lobby work and take on tasks in the field of sensitisation and public relations, thus influencing politics.

“In Luxembourg, cooperation between public authorities and associations (asbl foundation) for the disabled is generally intended to take place by mutual agreement and without public dissent.” (Sagramola, Silvio 2009, 241)⁴³

2.1 In which document(s) are government commitments and plans concerning support for independent living in the community set out?⁴⁴

Luxembourg society has a long tradition of the institutional view of well-being and care,⁴⁵ so that before the adoption of the UN Convention on Human Rights for Persons with Disabilities in 2011 there were hardly any clear statements in the legal documents in favour of independent living for people with disabilities, except for a brief declaration of intent in the Disability Action Plan⁴⁶ published by the former Ministry concerned. (*Plan d’action en faveur des personnes handicapées*, 1997, p.15).⁴⁷

⁴² In 2018, the structures of the special education system (*éducation différenciée*) were replaced by a system of national competence centres designed towards better inclusion of pupils with special needs. <http://www.men.public.lu/fr/actualites/articles/communiqués-conference-presse/2018/06/26-centres-competences/index.html>.

⁴³ Sagramola, S. (2009). *Behindertenpolitik*. In: H. Willems, G. Rotink, D. Ferring, J. Schoos, M. Majerus, N. Ewen, M.A. Rodesch-Hengesch, C. Schmit (Ed.), *Handbuch der sozialen und erzieherischen Arbeit in Luxemburg. Manuel de l'intervention sociale et éducative au Grand-Duché de Luxembourg* (unter Mitarbeit von C. Reuter, M. Schneider, K. Brandhorst). Luxembourg: Éditions Saint-Paul, 341-342.

⁴⁴ The sources mentioned by the Consortium here are hardly suitable: [DOTCOM deinstitutionalisation](#) contains more summarising data and less political declarations of intent [Community Living for Europe: Structural Funds Watch country profiles](#) includes no entry for Luxembourg [Opening up communities, closing down institutions – report by Community Living for Europe: Structural Funds Watch \(2017\)](#). No entry for Luxembourg. [EU Agency for Fundamental Rights – from institutions to community based living section 1 – commitments and structures](#) based on data of year 2011 statements rather than actual expressions of intent.

⁴⁵ Haas, C.; Gaitsch, R.; Limbach-Reich, A. & Peters, U. (2009). *Professionalisierung sozialer Hilfeleistungen in Luxemburg: Entwicklungslinien und Zukunftsperspektiven der Ausbildung Sozialer Arbeit in Luxemburg*. In H. Willems, G. Rotink, D. Ferring, J. Schoos, M. Majerus, N. Ewen, M.A. Rodesch-Hengesch, C. Schmit (Ed.), *Handbuch der sozialen und erzieherischen Arbeit in Luxemburg. Manuel de l'intervention sociale et éducative au Grand-Duché de Luxembourg* (unter Mitarbeit von C. Reuter, M. Schneider, K. Brandhorst). Luxembourg: Éditions Saint-Paul, 411-423.

⁴⁶ Sagramola, Silvio (2009). *Behindertenpolitik*. In: H. Willems, G. Rotink, D. Ferring, J. Schoos, M. Majerus, N. Ewen, M.A. Rodesch-Hengesch, C. Schmit (Ed.), *Handbuch der sozialen und erzieherischen Arbeit in Luxemburg. Manuel de l'intervention sociale et éducative au Grand-Duché de Luxembourg* (unter Mitarbeit von C. Reuter, M. Schneider, K. Brandhorst). Luxembourg: Éditions Saint-Paul, 341-342.

⁴⁷ Ministère aux Handicapés et aux Accidentés de la Vie (1997). *Evaluation de la situation des personnes handicapées au Luxembourg. Plan d’action en faveur des personnes handicapées*. Luxembourg: MHAV. http://www.info-handicap.lu/index2.php?option=com_docman&task=doc_view&gid=36&Itemid=26, website is no longer available: source Limbach-Reich, A. (2011).

Current statements of will are mostly manifested in the form of financing takeovers or subsidies as well as in the provision of corresponding structures, without an abstractly formulated conceptual directive being prescribed for them.

The national compulsory long term care insurance (*assurance dépendance*, 1998)⁴⁸ specifies as main purpose to provide benefits in kind, assistance and care as well as technical aids and housing adaptations and distinguishes between two scenarios: Payment of services in a stationary environment (*Prise en charge des prestations en milieu stationnaire*) and Coverage of services in the case of home support (*Prise en charge des prestations en cas de maintien à domicile*) without committing to a preference for the last mentioned - *independent living*.

The basic income guarantee (RMG renamed and substantially reformed in 2018 to REVIS - *Revenu d'inclusion sociale* income for social inclusion)⁴⁹ and basic income guarantee for persons with disabilities unable to work (*revenu pour personne gravement handicapée - RPGH*)⁵⁰ both don't emphasize independent living as a priority of the legislation.⁵¹

One of the first governmental documents which tackles independent living is the above-mentioned ministerial programme of action to improve the living conditions of people with disabilities (*Plan d'action en faveur des personnes handicapées* 1997). Under the heading "*Intégration sociale et vie autonome*", (social inclusion and independent living) the report stated that in 1995/96, round about 70 % of people with disabilities lived in institutions, however these structures have changed enormously in terms of the quality of life offered. Luxembourg policy promotes a better quality of life for the disabled person through greater autonomy and independence and thus increased participation of the disabled person in the activities of his or her daily life. The report recommends the following measures to relieve the burden on families in the context of a disability and to help them to live a normal and independent life:

- to extend daytime placement measures for persons with severe disabilities;
- to extend the offer of occupational activities for any adult person unable to provide paid work;
- to extend the offer of leisure activities outside school hours for any child in home care;
- to provide a sufficient number of temporary or emergency beds in the various regions of the country;
- to create home support and assistance services that take into account the needs of people with disabilities.

⁴⁸ *Assurance dépendance* 1998. <https://www.secu.lu/assurance-dependance/>.

⁴⁹ REVIS Loi du 28 juillet 2018 relative au revenu d'inclusion sociale. [https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServingServletImpl?path=C494183FC4B3B0B336289854BC485032D127AEE1A536C19A87CFB52B635B24060FACFF3028C5AB038F480B470730E697\\$C438EB2AB11CDE7D4AE6DF1EA2866DDD](https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServingServletImpl?path=C494183FC4B3B0B336289854BC485032D127AEE1A536C19A87CFB52B635B24060FACFF3028C5AB038F480B470730E697$C438EB2AB11CDE7D4AE6DF1EA2866DDD).

⁵⁰ Loi du 12 septembre 2003 relative aux personnes handicapées https://www.fns.lu/fileadmin/file/fns/legislation/RPGH/RPGH_LOI.pdf#pageMode=bookmarks.

⁵¹ ANED DOTCOM Luxembourg https://www.disability-europe.net/dotcom/?l%5B%5D=23&t%5B%5D=23&t%5B%5D=24&t%5B%5D=25&t%5B%5D=26&t%5B%5D=27&t%5B%5D=28&t%5B%5D=29&t%5B%5D=30&view_type=mat rix.

With regard to the accommodation of the person with a disability in ordinary housing, various measures are provided by the government to enable the person with disabilities to lead a relatively independent life.

Thus, the Ministry of Housing⁵² grants financial assistance (allowance for accommodating the needs of people with physical disabilities) to people with disabilities. This aid is intended to finance certain special housing facilities which are necessary, inter alia, for wheelchair users.

In the framework of deinstitutionalisation in the field of mental illness, the Report of Louazel & Lair (2013)⁵³ emphasise that the ministry of health (Ministère de la Santé) finances four outpatient services, each including consultation services with psychiatrists, psychologists, occupational therapists, social workers, nurses and/or educators and a day centre (with therapeutic activities) for persons with psychological and psychiatric disorders. Each service has a residential facility, with a total of 220 beds for the whole country.

The national Action plan on the UNCRPD (2012) mentions some aspects of independent living. For example, Inclusion requires infrastructures that respect the principle of "design for all". The aim is to make accessibility a standard in all areas of life in the long term. The area of application of the "Accessibility" Act should also be extended to the private sector. In addition, the legal scope of application will be extended to residential construction. Accessibility standards should apply primarily to new buildings and, as far as possible, to the existing building environment. In principle, no exceptions may be made for new buildings.

With regard to independent living, the first national action plan emphasises the important role of long-term care insurance in day-to-day assistance for people with disabilities and support services, e.g. in the field of personal counselling and support, in semi-autonomous settings. This is followed by an equally indefinite declaration of intent aimed at ensuring that everyone receives the necessary assistance and support to realise his or her personal life plan. Barriers should be removed as early as possible.

In addition, the action plan highlights the imperative to enable people with disabilities to decide how, where and with whom they would like to live, with the greatest possible autonomy, self-determination and personal responsibility, alternative housing options must be developed. Adequate offers of support and care in various forms in smaller housing units are needed. However, the report does not comment on what will be the role of the state or what will be the public policy and what the government is willing to perform here. Also, the first national implementation report states that the Ministry of Family Affairs has chosen to persevere on the path of inclusion and to ensure that

⁵² Ministère du Logement(2018) <https://logement.public.lu/dam-assets/documents/publications/aides-logement/amenagement-speciaux/amenagements-sp-DE.pdf>.

⁵³ Louazel, Véronique et Lair, Marie-Lise (2013). *Grand-duché de Luxembourg: Réforme de la psychiatrie et politique de santé mentale: les résultats intermédiaires de l'état des lieux 2011-2012 sur l'avancement de la réforme de la psychiatrie au Luxembourg, les filières de prise en charge et le futur de la politique de santé mentale. -- (Study on interim results of the 2011-2012 inventory on the progress of the reform of psychiatry in Luxembourg, the care sectors and the future of mental health policy).* <http://www.copas.lu/wp-content/uploads/reforme-psychiatrie-politique-sante-mentale-2013.pdf>.

people with disabilities are not excluded from a process that affects them closely. A second National Action Plan is currently under development at time of writing.⁵⁴

The formulations of the national objectives in the context of Independent living usually do not go beyond general objectives without mentioning defined timetables or criteria for the achievement of objectives. The self-help group “*Nëmme mat Eis*”⁵⁵ criticises that measures discussed before, such as individualised assistance, were not included and that the wording of many of the measures and objectives was kept rather vague. For example, it was unclear what a “*continuous*” period would mean for the commitment.

The first country report (2014)⁵⁶ confirms that Luxembourg government supports the objective of independent living in the community of people with disabilities through the support and assistance services introduced (point 188). In addition to traditional (institutional) accommodation structures and with a view to promoting the greatest possible autonomy for people with disabilities, the Ministry of Family Affairs supports the development of structures that offer assistance and support in autonomous and semi-autonomous environments (point 197).

The Report on the reform of psychiatry and mental health policy in Luxembourg (2013) (*Réforme de la psychiatrie et politique de santé mentale*)⁵⁷ emphasises under proposal no.5 that the national strategy should focus on three main areas: promoting mental health, preventing mental disorders and accompany the patient as much as possible in his or her living environment. In view of the current situation, the focus should be on health care services at home or in the community and on the stability of living spaces, depending on the concept of “Housing First” in order to promote the patient's stability in his or her living environment and quality of life, which is: at home, with family and friends, children, at work and in leisure. The offer of home care should be sufficiently flexible, more or less intensive, multidisciplinary, global according to needs, to prevent the risk of disorders and relapses. The resources deployed in the different sectors and regions must be globally rethought on the basis of a national master plan: population

⁵⁴ Ministry of Family, Integration and the Grand Region 2018 Working group on the development of the new National Action Plan for the implementation of the UN Convention on the Rights of Persons with Disabilities. (*Ministère de la Famille, de l'Intégration et à la Grande-Région 2018 sur l'élaboration du nouveau Plan d'action national de mise en œuvre de la convention de l'ONU relative aux droits des personnes handicapées*).
https://mfamigr.gouvernement.lu/fr/actualites.gouvernement%2Bfr%2Bactualites%2Btoutes_actualites%2Bcommuniqués%2B2018%2B07-juillet%2B03-reunion-personnes-handicapees.

⁵⁵ Home page Nemme mat eis
<http://www.nemmemateis.lu/online/www/content/32/542/DEU/index.html>.

⁵⁶ Initial country report implementing the CRPD (Mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées - Premier rapport périodique du Grand-Duché de Luxembourg (2014)
https://mfamigr.gouvernement.lu/content/dam/gouv_mfamigr/le-ministère/attributions/personnes-handicapées/premier-rapport-periodique-de-mise-en-œuvre-de-la-convention-onu.pdf.

⁵⁷ Louazel, Véronique et Lair, Marie-Lise (2013). Grand-duché de Luxembourg: Réforme de la psychiatrie et politique de santé mentale: les résultats intermédiaires de l'état des lieux 2011-2012 sur l'avancement de la réforme de la psychiatrie au Luxembourg, les filières de prise en charge et le futur de la politique de santé mentale. -- (Study on interim results of the 2011-2012 inventory on the progress of the reform of psychiatry in Luxembourg, the care sectors and the future of mental health policy). <http://www.copas.lu/wp-content/uploads/reforme-psychiatrie-politique-sante-mentale-2013.pdf>.

and needs covered, number of beds, number of accommodation places, missions covered, etc. in agreement with the established strategic objectives (FRA-Report 2017).⁵⁸

The coalition agreement of the new government (2018),⁵⁹ does not speak directly about independent living, but some statements of intent are likely to have an impact on independent living. (see Appendix. Extracts from the 2018 coalition agreement). The coalition agreement indicates no data about completion dates for the development of alternative accommodations and services.

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

There is no government declaration dedicated solely to independent living. Only the first national UNCRPD implementation plan (2012)⁶⁰ can be used as an essential reference source, which identifies assessments, declarations of objectives, allocations of responsibilities and time horizons for implementation. However, the situation analyses, and target formulations are kept in a very non-binding and very general form, so that hardly any concrete information can be derived here, which also applies to the assigned measures. Particularly on de-institutionalisation and independent living, neither figures nor deadlines are given in recent declarations.

The following overview emphasises some of the points related to independent living in the national action plan 2012:

- The aim is to raise awareness of the situation and needs of disabled people. Sufficient awareness of all those involved, in all sections of society, e.g. through national campaigns, should lead in the long term to an inclusive society in which people with disabilities can exercise their rights on an equal footing with all others. These include the introduction of a competence centre for easy language and the recognition of sign language. For these two topics, deadlines refer to the year 2012 and 2013 in achievement of the goals.
- With regard to accessibility, the aim is to ensure comprehensive accessibility as a basis for self-determination and participation of people with disabilities. This includes equal barrier-free access to all means of information and communication.

⁵⁸ FRA (2017 and 2018) From institutions to community living - Part I: commitments and structures <https://fra.europa.eu/en/publication/2017/independent-living-structures>. And From institutions to community living - Part II: funding and budgeting <https://fra.europa.eu/en/publication/2017/independent-living-funding>.

⁵⁹ Coalition accord 2018 <https://gouvernement.lu/de/publications/accord-coalition/2018-2023.html>.

⁶⁰ Ministry of Family Affairs Integration and the Greater Region (2012) *First action plan to implement the CRPD in Luxembourg* (Aktionsplan der Luxemburger Regierung zur Umsetzung der UNO-Behindertenrechtskonvention) <https://mfamigr.gouvernement.lu/dam-assets/le-ministère/attributions/personnes-handicapées/plan-d-action-du-gouvernement-luxembourgeois-en-faveur-des-personnes-handicapees.pdf>.

- Alarm signals of any kind should be made accessible to people with hearing impairments (e.g. by light signals, messages by SMS, FM transmitters or GPS indicating ambulances in the immediate vicinity). The target date for this is 2012.
- People with disabilities should be able to maintain their income independently of social support or employment measures. Training and transition to the world of work should be tailored to each person's personal strengths and goals. Competent bodies should advise and support the persons concerned so that they can lead a self-determined life. Measures to this regard are intended for 2012 and ongoing.
- The aim is to promote the mobility of people with disabilities through ensuring accessibility. It should be taken for granted that people in towns and villages can circulate barrier-free and, if possible, without an accompanying person. Accessibility should be actively promoted, and new barriers to mobility must be prevented.
- Inclusion must not be limited to a specific area. Inclusion must be understood as a project for society as a whole. Inclusion requires infrastructures that respect the principle of "design for all". The aim is to make accessibility a standard in all areas of life in the long run. An adaptation of the relevant Accessibility Act is planned for 2012-2014.
- The three different measures provided by Luxembourg law on the protection of adults with severe disabilities ("*Incapables majeurs*") merge into a single measure, the assistance. This assistance is designed in different ways according to the individual's needs and enables solutions to be tailored to the individual. There is a strict priority of assistance over care, and the proportionality of legal interventions is guaranteed by regular monitoring. Corresponding legislative changes are planned for 2012-2015.
- The concerns of people with disabilities are taken into account in all policy areas. Everyone receives the assistance he or she needs to realise his or her personal life plan. Barriers should be removed as early as possible. The measures provided for in this target are intended to apply between 2012 to 2015.
- Health services for people with disabilities should be regularly evaluated and adapted to their needs. (2012-2014)
- There is no information available about milestones such as a defined number of people who are expected to leave existing institutional care facilities by a target date.

The Country factsheet of Luxembourg on the European Structural and Investment Funds⁶¹ states, that Luxembourg has been allocated EUR 140 million from ESI Funds

⁶¹ The European Regional Development Fund (ERDF), the European Social Fund (ESF), and the European Agricultural Fund for Rural Development (EAFRD) Luxembourg
https://ec.europa.eu/regional_policy/en/information/publications/factsheets/2016/european-structural-and-investment-funds-country-factsheet-luxembourg.

over the period 2014-2020. With a national contribution of EUR 316 million, Luxembourg has a total budget of EUR 456 million to be invested in various areas, from protecting the environment to creating greater economic diversification for jobs and growth as well as supporting social cohesion. There are no identifiable links between independent living and EDF programs.

On the level of “Partnership Agreement with the European Commission”⁶² there are three points that may be connected with independent living:

- tackling unemployment, in particular youth unemployment, by raising the qualifications and skills of the youth and job seekers with an immigration background and focusing on a better match between offer and demand in the labour market;
- reducing poverty through improved access to services and support to the social economy, including the integration of vulnerable minorities;
- enhancing equal access to lifelong learning to all age categories, in order, among others, to keep older worker longer in the work force;

But looking at the expected outcomes there are only two targets that may correspond in a very far manner to Independent living (tertiary or equivalent education to be completed by 66 % of 30-34 years, up from 52,5 % in 2013, and employment rate for the population aged 20-64: 73 % (71,1 % in 2013)).⁶³

In a very recent statement about a draft act on accessibility the government confirms:

*“In Luxembourg, the inclusion of people with disabilities in social life and the guarantee of a life as independent as possible are priorities of social policy. In practice, this means guaranteeing that people with disabilities can exercise and fully enjoy their rights and freedoms, through the implementation of specific measures, in particular by making places open to the public, public roads and collective housing accessible to all.”*⁶⁴

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

The central approach here is that of inclusion, which is expressed both as a method and as a goal. The first national action plan proclaimed (2012,1): *“The overall objective is inclusion. An integrative system aspires to an insertion of “problematic cases”. On the other hand, an inclusive system does not keep anyone out, but accepts each as he is. However, such a system only makes sense if our environment is previously adapted to the needs of each person.”*⁶⁵

⁶² Partnership agreement with Luxembourg - 2014-20.

https://ec.europa.eu/info/publications/partnership-agreement-luxembourg-2014-20_en.

⁶³ Summary of the Partnership Agreement for Luxembourg 2014-2020 Overall information

⁶⁴ Statement on the draft law on accessibility (2019)

[https://www.chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=A2A75CF85C09915B9999B68B3E9441BADA922DC0FB061F241D67517B95AF096FB02DF2939A997DA367C102671C2ADA80\\$DD2EF981C2F13DF214417E56D84FCCF6](https://www.chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=A2A75CF85C09915B9999B68B3E9441BADA922DC0FB061F241D67517B95AF096FB02DF2939A997DA367C102671C2ADA80$DD2EF981C2F13DF214417E56D84FCCF6).

⁶⁵ Bilingual statement in the First national action plan, p.1: *«L’objectif général visé est l’inclusion. Un système intégratif aspire à une insertion des «cas problématiques». En revanche, un système*

The concept of universal design (“*conception universelle*”) is regarded as an essential approach in this respect. Finally, sensitization and awareness rising programs are seen as an essential approach to reach the targeted inclusive society. With regard to universal designs, it was decided to create a national competence centre,⁶⁶ which would coordinate the measures and be available to advise on private construction projects. The timeframe was given as "consecutive".

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

For independent living or traditional housing projects for people with disabilities, no data are available on EU funded projects in Luxembourg.⁶⁷ So far, and also at present, the governmental payments refer to the costs resulting in the associated sector (*secteur conventionné*). (See Part A, chapter 1).

Figure 14: domestic budgetary commitments to support independent living

| Budgetary commitments in millions EUR in 2015 | Budget care Insurance |
|---|-----------------------|
| | Domestic care |
| Euro | 220,5 |

Source: national care insurance⁶⁸

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

In the preparation of the first national action plan, the government organised five working group meetings with the participation of people with disabilities and representatives of disability groups. However, people with disabilities and groups of representatives afterwards showed themselves to be dissatisfied with their participation in the plans drawn up and stayed away from a final press conference.⁶⁹

In 2018 new working groups on the next action plan have been established under participation of person with disabilities.

inclusif ne tient personne à l'écart, mais accepte chacun comme il est. Un tel système n'a toutefois de sens que si notre environnement est préalablement adapté aux besoins de chaque personne. Une société inclusive, qui équivaut d'ailleurs à une augmentation du potentiel économique et social, présente donc des avantages pour tout le monde.» / Das übergeordnete Ziel heißt Inklusion. Ein integratives System strebt die Eingliederung von „Problemfällen“ an. Ein inklusives System hingegen grenzt gar nicht erst aus, sondern nimmt jeden an wie er ist. Ein inklusives System macht nur Sinn, wenn diesem eine Anpassung unserer Umwelt und unseres Umfeldes vorausgeht. Inklusion bedeutet einen Zugewinn von sozialen und wirtschaftlichen Potentialen: dies gilt es zu vermitteln.

<https://mfamigr.gouvernement.lu/dam-assets/le-ministère/attributions/personnes-handicapées/plan-d-action-du-gouvernement-luxembourgeois-en-faveur-des-personnes-handicapees.pdf>.

⁶⁶ Centre de compétence national pour l'accessibilité des bâtiments (CCNAB)

<http://www.adaph.lu/j3/>.

⁶⁷ None of the following documents tackles Luxembourg EU Agency for Fundamental Rights – from institutions to community-based living Part II - funding and budgeting; Community Living for Europe: Structural Funds Watch country profiles; Opening up communities, closing down institutions – report by Community Living for Europe: Structural Funds Watch (2017).

⁶⁸ Assurance dépendance 1998. <https://www.secu.lu/assurance-dependance/>.

⁶⁹ Nëmme mat Eis pressinformation

<http://www.youtube.com/watch?v=6S8n8vQQgk&feature=share>.

3 Implementation and monitoring

The national advisory and counselling office (INFO-HANDICAP) on disability deplors that there is no organisation in Luxembourg that promotes independent living.⁷⁰

No corresponding calls for proposals to implement the independent living concept in Luxembourg could be identified.⁷¹ (No relevant funding calls for proposals concerning the transition from institutional care to community-based living by national, regional or local government and/or managing authorities under ESIF, since 2013, concerning the transition from institutional care to community-based living.)

The ESF⁷² lists 20 projects funded in Luxembourg but none of these projects covers the transition from institutional care to community-based living. One project may be linked to independent living “the Autism Ambulance Project”, funded with a total of EUR 499,900,00 (ESF share 50 %: EUR 249,950,00); Duration 01/01/2013 - 31/12/2015.

The ambulatory intervention service project focuses on support in open settings and the development of social skills for people with pervasive developmental disorders (autism spectrum disorder), and more specifically Asperger's syndrome. The vast majority of other projects are in the field of labour market and employment.

3.1 Summary of relevant calls for proposals

No relevant information available.

3.2 Summary of relevant projects funded

No relevant information available.

3.3 Overview of other relevant measures since 2013

There were no legislative measures such as caps in the size of residential facilities, or introduction the right to personal assistance in Luxembourg. The development of personal assistance schemes is under discussion but still there is no individualised budget system in Luxembourg; Sector capacity building has mainly been based in inclusion of individuals with disabilities in mainstream structures; Training and development programmes focussed on labour market and employment (COSPH);⁷³

⁷⁰ Info Handicap (n/a, p.6) Behindertengerechtes Wohnen = Selbstbestimmtes Wohnen? Logement adapté = Logement autodéterminé? «In Luxembourg gibt es leider noch keine Organisation die sich für selbstbestimmtes Leben einsetzt.»

<http://www.info-handicap.lu/index.php/de-DE/dokumente/test/537-top-thema-logement/file>.

⁷¹ ESIP https://ec.europa.eu/eip/ageing/actiongroup/index/c2_en and https://ec.europa.eu/eip/ageing/actiongroup/index/b3_en.

⁷² FSE

http://www.fonds-europeens.public.lu/fr/projets-cofinances/index.php?~=do&from=search&r%5B0%5D=f%2Fcategory%2Ffse&r%5B1%5D=f%2Ftype%2Finclusion+sociale+et+pauvrete&res_length=10&q=%23all&s=score&b=10#main.

⁷³ COSP-HR (Centre d'évaluation et d'orientation socio-professionnelle pour les demandeurs d'emploi ayant le statut du salarié handicapé et/ou du reclassement externe) Advisery office for persons with disabilities or reduced working capacity. <http://www.fonds->

Research or campaigns to improve public attitudes exist but particularly issuing to the inclusion of persons with disabilities in the context of independent living couldn't be found; also no improvements could be observed in data collection.

3.4 Monitoring mechanisms and approaches

In Luxembourg, there has not been established a dedicated independent mechanism to monitor the transition from institutional care to community-based living.

Monitoring transition from institutional care to community-based living is not included in the yearly activity reports of the concerned ministries.

There is no relevant information available on the involvement of persons with disabilities and their representative organisations in monitoring mechanisms and approaches of independent living.

3.4.1 Monitoring mechanism(s)

The first shadow report (2016) points to a fundamental and structural problem concerning monitoring transition processes and independent living of persons with disabilities in Luxembourg: The facilities and services (*asbl*, *foundation*, private or public organisations) need state approval (“*agrément*”). a licence and in case of State funding or co-funding certain additional requirements have to be met. But, once licence and funding are approved there is no further monitoring through independent bodies. The State (the various ministries) checks on finances, administration and hygiene matters. Most facilities and services have their own, internal department charged with monitoring professional conduct and human rights violations. Hence, complaints can be brought to the attention of the police. Since 2012, the Ministry for Family and Integration has been making efforts to improve the situation, in cooperation with DPOs. Some of the most urgent problems, such as lack of staff and the absence of participative advisory boards have begun to be addressed.

The act on services in favour of persons with disabilities (2009)⁷⁴ stipulates in Article 3 the different types of services, including home assistance service and accommodation service.

Home assistance service (“*Service d’assistance à domicile*”) includes any service that provides care and/or material and psychological assistance to individuals in a family setting in a situation of disability and to their families. The purpose is to promote home support and ensure that it is taken in charge of end-of-life situations adapted to the individual needs and expectations of the people concerned.

europeens.public.lu/fr/projets-cofinances/fse/2014-2020/1042/index.html see also FSE: <http://www.fonds-europeens.public.lu/fr/projets-cofinances/fse/2014-2020/1042/index.html>.

⁷⁴ Additional text to the Regulation on agreements of service providers in favor of persons with disabilities - 2009 (*Texte coordonné du 4 mars 2009 du règlement grand-ducal modifié du 23 avril 2004 concernant l’agrément gouvernemental à accorder aux gestionnaires de services pour personnes handicapées*) <http://www.fedas.lu/wp-content/uploads/2016/10/AGREMENT-services-pour-personnes-en-situation-de-handicap.pdf>.

Accommodation service (“*Service d’hébergement*”) includes any service that offers multidisciplinary accommodation and/or professional support to more than three people with disabilities. The purpose is to provide professional supervision to the person in a situation of disability in accordance with a global and coherent approach by providing assistance and care within the meaning of the law of dependency insurance and socio-pedagogical support and a management of end-of-life situations adapted to their individual needs and expectations.

Officials shall be responsible for monitoring the application of the Act. They may be assisted in their duties by officials of the Ministry of Family Affairs, as well as by experts. During a visit, the officer or officers in charge of the surveillance mission shall identify themselves by means of a legitimization card bearing the signature of the competent minister. Visits to the services shall be carried out at least once every three years. The manager may request an extension of this time limit if, for reasons beyond his control and for reasons beyond his control will, it cannot comply within the time limit set.

After the compliance period has expired, the competent minister may, subject to the provisions of Article 4 of the Act, revoke the approval of the manager.

Article 4 of the act stipulates that the manager of a service for people with disabilities, is required to guarantee users a multidisciplinary professional framework aimed at the quality of life of the person with disabilities and making it possible to satisfy the principles of autonomy, normalization and full participation. He must prove the conformity of his individual solution with the general guidelines laid down in this Regulation.

The legal regulations lay down certain minimum standards with relation to the qualifications of the staff, the maximum number of users, differentiated according to the degree of autonomy and the architectural conditions of the building.

3.4.2 Measurement and data collection

No relevant information available.

4 Impact and outcomes

4.1 Progress against explicit targets and milestones

The de-institutionalisation measures demanded in the psychiatric report (2005-2009)⁷⁵ should have been implemented by 2012. In a press conference, the Luxembourg Government (2013)⁷⁶ stated that the goals had been achieved, but sees an ongoing need for action, especially in the area of independent living, without giving precise

⁷⁵ Rössner, Wulf (2009). Psychiatrie Luxemburg Stand der Umsetzung der Empfehlungen der Planungsstudie 2005. <https://gouvernement.lu/dam-assets/fr/actualites/articles/2009/04-avril/20-bartolomeo-psychiatrie/Lux-PC.pdf>.

⁷⁶ Le Gouvernement du GdL 2013 Communiqué de presse : Réforme de la Psychiatrie et politique de santé mentale Date : Jeudi 26 Septembre 2013 https://gouvernement.lu/dam-assets/fr/actualites/articles/2013/09-septembre/26_reforme-psychiatrie/Communique_de_presse_-_R_orme_de_la_psychiatrie_et_politique_de_sant_mentale.pdf.

figures. The first national report on implementing the CRPD mentions also the big shift that has taken place concerning decentralisation in Luxembourg. A compilation on progress against explicit targets and milestones can be found in the appendix (“milestones, concerning the psychiatric reform and decentralisation in Luxembourg, mentioned in the first national report, points 143 - 146):⁷⁷

Concerning the implementation of article 19 “*living independently and being included in the community*” the first national report refers to some important achievements which concern both the housing situation and measures of independent living. (See Appendix, Implementation of article 19 “*living independently and being included in the community*”).⁷⁸

4.2 What is replacing institutional care?

The national institutions for people with disabilities began years ago to provide semi-autonomous and autonomous living structures with advisory services (see chapter 1).

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?

Already the ANED Report 2009⁷⁹ on independent living indicates three types of accommodation and support (depending on the kind and severity of a given disability). These types of accommodation and support still persist to date.

- 1) To respond to the needs of disabled people with profound (intellectual) disability and associated disabilities or illnesses (poly-handicap), autistic spectrum disorders, challenging behaviour or severe mental health problems, service provision is systematically organized by specialized providers. However, it should give a framework of individualised support for the resident, involving him or her as much as possible in the personal development project and assuring quality of life. These residential homes have a certain number of residents (20 to 35 persons) always subdivided into smaller living units of about 10 people. Most attention will be on organisational aspects and group functioning rather than on individual independent community living. The main purpose is to give specific attention to the special-needs residents may have, providing clear guidance and provide special technical aids, by specially qualified staff etc.
- 2) People with a milder disability, who need a low but constant level of support in everyday life, while allowing a “normal” social and individual sequence of day home and leisure (individual & group) activities, private space, etc. These groups will be small residential groups of eight disabled people with a basic support staff (educators, social workers or care staff depending on the disability needs) based

⁷⁷ Initial report of Luxembourg implementing CRPD (2014).

https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FLUX%2F1&Lang=en.

⁷⁸ First national Report implementing the CRPD Luxembourg (2015) <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/201/47/PDF/G1520147.pdf?OpenElement>.

⁷⁹ Luxembourg ANED country report on the implementation of policies supporting independent living for disabled people. 2009 <https://www.disability-europe.net/downloads/460-lu-7-aned-2009-request-07-task-5-report-on-independent-living-approved-final-in-layout-to-ec>.

in a “normal” house in a “normal” social living environment (community based). The residents will be very much involved in the organisation of all activities, individual needs will be considered, etc. The ideal situation is to give a minimum of support and protection, allowing a maximum of individual planning and social contact to develop.

- 3) The majority of service providers offer support to disabled people who want to live independently. These individual support services are developed on the basis of an Individual Project Plan, where the disabled person is the major actor and will be designed together with her/him taking account of the competences, wishes, but also the economic and realistic environment of the person. This support will need a preparation phase, to build up the relationship between the disabled person and the support staff. After this, the disabled person, will normally live in his/her own flat, with only a targeted presence of support staff. The disabled person is active in everyday life, but he/she does not hire, control or direct the staff that support him. This provision still will be managed by a service provider.
- 4) It should further be added that the benefits of long-term care insurance can make it easier to stay in one's own home, particularly for person with mental health disorder, the association *Hëllef Dobaussen*⁸⁰ committed to the model of social psychiatry aims at the care of people with mental disorders living in the community. Their services include open encounters, listening, help, support and care adapted to your specific situation, always respecting your personal values and choices.

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?

INFOHANDICAP should be mentioned here as the umbrella institution that offers counselling and advice for person with disabilities and their relatives. The national care insurance covers questions about funding, care, and housing adaptations. Regional social services can take over social work measures and are available to people with disabilities and their relatives. Furthermore, disability specific counselling and competence centres are available.

4.3 Satisfaction levels among persons with disabilities

It was not feasible to identify usable data on the housing situation of people with disabilities beyond the information provided by the FRA Report 2017 that highlights a high approval rate (84 %) of persons with disabilities who agree or strongly agree with the statement: *'I feel I am free to decide how to live my life'*. The high approval rate may well be due to the fact that only persons living in a household were included in the sample. (see Section 1).

⁸⁰ *Leben bei LIEWEN DOBAUSSEN* <http://www.liewen-dobaussen.lu/de/links.html>.

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 Committee observes on article 19 “*Living independently and being included in the community*” and expresses the following concerns.⁸¹

(a) Laws in place, including the reform to Act 7014 of 8 July 2016, which continue to curtail the right to independent living by setting limits and controls on persons with disabilities;⁸² (b) The lack of an action plan for the deinstitutionalization of persons with disabilities with a specific timeline and appropriate funding; (c) The absence of a clear strategy to promote and ensure the transition to full independent living for all persons with disabilities within the community, including with support of a personal assistant, and that future plans and construction projects still contain elements that limit the rights of persons with disabilities under article 19.

The Committee recommends that the State party should take into account the General Comment No. 5 on article 19 of the Committee (2017) and: (a) Adopt the necessary legal and other measures, including repealing Reform Act 7014 and relevant disability insurance systems, replacing them by legislation promoting the right to independent living and being included in the community and providing for, among others, personal assistance, and clarifying the responsibilities and resource allocations of central and local authorities; (b) Develop and implement an effective deinstitutionalisation plan, with a clear timeframe and benchmarks, involving persons with disabilities through their representative organisations in all stages; (c) Adopt the necessary measures to ensure that persons with disabilities have a legal entitlement to a sufficient personal budget for independent living, which takes into account the additional costs related to disability, and at the same time, redirect resources from institutionalization to community-based services increasing the availability of personal assistance.

5.2 Recent observations by other official European and international bodies

No information found.

5.3 Observations and recommendations by national human rights bodies

The Commission Consultative des Droits de l'Homme (CCDH)⁸³ states that:

⁸¹ CRPD/C/LUX/Q/1 (2017) <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsvP%2BdTiDrgtVugxAW%2B69tiKIXBXKwMnQXT%2Fmo%2FEyFUOnby%2FrpQIV67BUhoNbCdpCAc7SIOMvANsJafd2PwWE94Ei7KuLj0ghi2PXCwnuevVb>.

⁸² The draft law has now entered into force as Loi du 29 août 2017 portant modification du Code de la sécurité sociale with a certain caps of benefits (*forfaits maximales*). <http://legilux.public.lu/eli/etat/leg/loi/2017/08/29/a778/jo>.

⁸³ CCDH 2019 Commission Consultative des Droits de l'Homme (CCDH) National Human Rights Observatory Luxembourg <https://ccdh.public.lu/fr/avis.html>.

Many people still cannot afford independent living, and new, affordable forms of housing must therefore be developed.

Despite barrier-free infrastructures and services, many people with disabilities are still dependent on help and assistance.

In this context, the question for CCDH arises whether it would not be appropriate to consider the establishment of an independent focal point that would act as a mechanism to promote and protect the rights and interests of people with disabilities (in the public and private sectors) who would receive complaints, have legal standing and monitor the implementation of the UN-CRPD, on the one hand, and monitor its implementation, on the other hand, with the possibility of informing the government about aspects for which existing legislation is inadequate. An additional task for this focal point would be the external monitoring of the institution for the disabled, in particular those houses where people are dependent.⁸⁴

The benefits of long-term care insurance are a very important aspect in deciding whether a person with a disability can live a self-determined life or not. In determining the benefits that can be claimed, however, the so-called institutional support is still preferred. The limited availability of personalised aids and the limited possibilities for converting benefits in kind into cash benefits severely restrict the possibilities for a self-determined lifestyle.⁸⁵

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

No information found.

6 Views and perspectives of civil society including DPOs

The organisation “Trisomie 21 Lëtzebuerg”⁸⁶ points out the problem of living and working conditions of people with Down’s Syndrome in Luxembourg. *There are a few housing offers too, especially in the area of autonomous living. The situation on the housing market or in specialised care and housing facilities is not much better (than the situation on the labour market). There are simply several hundred places missing.*⁸⁷

⁸⁴ CCDH 2018 Reflexionsdokument Rechte von Menschen mit Behinderungen Institutionenlandschaft im Bereich der Rechte von Menschen mit Behinderungen (Human rights observatory statement on Rights of Persons with disabilities in institutions and care facilities <https://ccdih.public.lu/dam-assets/fr/avis/2018/6-institutionenlandschaft-menschen-mit-behinderung.pdf>).

⁸⁵ CCDH 2016 Empowerment meeting <https://ccdih.public.lu/dam-assets/fr/publications/Droits-des-personnes-handicapees/Empowerment-3-Brochure.pdf>.

⁸⁶ Trisomie 21 Letzebuerg (association on Down’s Syndrome Luxembourg) <http://www.trisomie21.lu>.

⁸⁷ Tageblatt Luxemburg 03 May 2018, p. 34) Trisomie 21 Lücken auf dem Wohnungs und Arbeitsmarkt.

6.1 UNCRPD civil society shadow and alternative reports

The authors of the first shadow report (2016)⁸⁸ conclude that to some extent, there is still a “parallel world” for persons with disabilities: Special schools, special training, “sheltered workshops”, specialised living facilities, mostly State funded or co-funded. In addition, the report notes in response to the first State report (indicating that only one third of persons with disabilities live in institutions), that, persons with intellectual or psychological disabilities are generally not included in this calculation. Social security and care insurance calculations are still based on a medical definition of disability. Focusing on Article 19 - Living independently and being included in the community the shadow report draws attention to the following points:

- The choice of housing is very limited. The State finances and co-finances living facilities where persons with disabilities sometimes live relatively “cut off” from the community and with little autonomy. There is a lack of procedures, structures and often a lack of political will for transitions to autonomous housing. Open housing and care structures, allowing for more autonomy, are still too rare and often too expensive, especially for persons with disabilities working in a ‘sheltered workshop’ and thus earning minimum wage. An adult person with disabilities working in a ‘sheltered workshop’ reported that they had to move back into their parents’ house because they couldn’t afford the monthly “rent and care package” with their salary. In fact, many persons with disabilities still live with their parents, because there are no better options for them. (There was no data available, but about a third of adults with disabilities interviewed for this report lived with their parents or parent.) Even though the persons in question were grateful for the parental support, life-autonomy often remained limited. There is a lack of accessible social housing. Rural areas need to be sufficiently covered too. Numerous problems exist concerning private housing: – Health insurance covers adjustments and accommodations of private homes (up to a certain amount). However, owners and landlords cannot be forced to allow adjustments. Adjustment clauses in lease contracts are not mandatory and remain rare. – In private residences with several apartments each owner can veto adjustments of common infrastructures such as entrances, – To this day there are no mandatory accessibility standards for the construction of new private buildings. A reform and extension of the 2001 Act on Accessibility of Public Buildings has been eagerly awaited for years (see article 9 - 3.7). Even with materially accessible housing problems can arise: In one case, two persons with disabilities wanted to live autonomously, as a couple, in a rental apartment. The employer of both persons, a State co-funded institution running “sheltered workshops”, contacted the owner of the apartment, to advise them against signing the lease contract.
- Focusing on living independently and guardianship the shadow report emphasises: For persons with disabilities under guardianship (especially full guardianship), all major decisions are taken by or with a guardian. The long-

⁸⁸ Shadow Report on Implementation of the United Nations Convention on the Rights of Persons with Disabilities Luxembourg 2016.
https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fLUX%2f26160&Lang=en.

awaited reform of guardianship legislation urgently needs to eliminate substitute decision-making and promote assisted decision-making.

- With a view to residential facilities the report indicates: (Only) few efforts have been made to de-institutionalize the areas of housing and living of persons with disabilities. In the absence of a generalized personal assistance system and the absence of an appropriate system of care at for persons with severe physical disabilities, it is not surprising that more than a third of persons with disabilities live in specialized facilities or nursing homes. Given the lack of appropriate programs and support services for living independently in the community, many interviewees viewed living in a specialized facility as their only option. These persons report having little autonomy as to how to live their life, or even, organize their day: Sleeping schedules, “feeding” schedules, choice of food, leisure activities, much is planned ahead with very little room for flexibility and personal preferences. Persons with disabilities, their relatives and persons working within such institutions suggested that this might also be linked to a lack of staff in many facilities.

To illustrate the situation, the report describes an authentic case from Luxembourg (see Appendix, shadow report).

On personalized care and personal assistance, the report deplors that unfortunately, too many persons with disabilities (who are not subjected under guardianship and / or do not live in nursing homes or other institutions) enjoy very little life-autonomy, especially persons with high support needs. At present, care and assistance acts need to be selected from a catalogue (from recognized care and assistance service providers) based on an assessment made by long-term care insurance (Assurance Dépendance). The allocated “budget” is established in minutes and hours due in services (maximum 56,5 hours per week). The legal maximum is insufficient in many cases. Persons with severe disabilities may need 24-hour support, assistance and care (168 hours per week). In some cases, it is not as much a question of living independently as of survival. In 2016, a project for a reform of the long-term care insurance system was presented. Many persons who will be affected by changes in the system fear a deterioration of the present situation. Legislation does not mention disability, nor the CRPD, and the reform does at present not plan to correct this. The reform will also replace the personalized assessments with 15 categories, which could lead to further depersonalization of services. The maximum amount of 56,5 hours per week is to remain the same.

On personalized budget and personal assistance, the report mentions, that persons with disabilities wanting to live independently and included in the community, often need assistance that goes beyond care. For years DPOs and individuals have suggested, or even insisted how beneficial an extension of “personal assistance” would be for the autonomy and quality of life of persons with disabilities. A personalized budget, that allows persons with disabilities which qualify for such assistance to choose and train their helper(s) or assistant(s) for various tasks of everyday life, could greatly promote living independently and inclusion in the community. A typical example shows the need for a personal assistance: If a person in a wheelchair wants to go out at night, careful planning and time are of the essence:

The last point raised in the report concerns transport services in Luxembourg. The special transport service (ADAPTO) only operates until 10pm (until midnight on Fridays and Saturdays). State-approved nursing and care networks only operate until 10 pm. If the person needs assistance to get into bed, everything needs to be thoroughly planned and work according to planned. As result of this lack of flexibility, nights are sometimes spent in the wheelchair, waiting for the employees of the care network to start their morning rounds.

Finally, the authors of the shadow report recommend to develop and implement an effective de-institutionalization and community-living-based strategy with clear time frames and benchmarks, in consultation with organisations of persons with disabilities, and to establish a framework providing for legal entitlement to personal assistance services to enable persons with disabilities to live independently in the community.

6.2 ‘Grey literature’ at the national level

Already, the national Caritas Report (2015)⁸⁹ pointed out that access to affordable housing is problematic in Luxembourg, particularly for people with a low income. They had to pay around 45 % of their revenue on housing, compared to 30 % for people with a higher income, considering that housing costs have increased between 2005 and 2014 from 23.5 % to 48.5 % according to different housing types. Amongst the beneficiaries of Caritas Luxembourg in 2014, 1,324 were receiving specific help regarding their housing problems, and 135 of them were children and youngsters in emergency or in long-term residential care settings. In the current report of 2017, the Caritas report⁹⁰ points to the persisting problem of the housing situation: Limited access to housing is putting a lot of young people at higher risk of poverty and social exclusion. Special statements on persons with disabilities are not provided. Even if no figures are provided, it can be assumed that people with disabilities in particular are also affected by the general lack of affordable housing in Luxembourg.

6.3 Pan-European and international civil society organisations

The pan European research project on compulsory admission and involuntary treatment of mentally ill patients – legislation and practice in EU-Member States⁹¹ in 2002 reveals structural deficits in both the legal and the sociosanitary areas, as well as a current practice that needs to be improved in Luxembourg: A major problem remains the absence of adequate structures for aggressive minors, who are therefore often placed in the CHNP. And there also is no institution other than the prison and the CHNP that is able to deal with mentally ill offenders.

⁸⁹ Caritas Cares Luxembourg Report (2015) <https://www.caritas.eu/wordpress/wp-content/uploads/2018/11/20171109-PU-Caritas-cares-youth-poverty-country-report-luxembourg.pdf>.

⁹⁰ Caritas Report (2017) <https://www.caritas.eu/wordpress/wp-content/uploads/2018/11/20171109-PU-Caritas-cares-youth-poverty-country-report-luxembourg.pdf>.

⁹¹ Compulsory Admission and Involuntary Treatment of Mentally Ill Patients – Legislation and Practice in EU-Member States Research Project - Grant Agreement No. SI2.254882 (2000CVF3-407) Mannheim, Germany, May 15, 2002 http://ec.europa.eu/health/ph_projects/2000/promotion/fp_promotion_2000_frep_08_en.pdf.

7 Academic research

Beadle-Brown's and Kozma's study⁹² on de-institutionalisation and community has been already mentioned in this report.

There is another research article on involuntary placement comparing European Countries written by Salize, H.J. and Harald Dressing, H. (published online 2018).⁹³ The authors concluded that total frequencies of admission and compulsory admission rates vary remarkably across the EU. Variation hints at the influence of differences in legal frameworks or procedures. Time series suggest an overall tendency towards more or less stable quotas in most member states. Placements have been more frequent in Luxembourg than in other European countries.

⁹² Beadle-Brown, Julie & Kozma, Agnes (2007). Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 360-377.

https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Country_Reports.pdf.

⁹³ Salize, H., & Dressing, H. (2018). Epidemiology of involuntary placement of mentally ill people across the European Union. *British Journal of Psychiatry*, 184(2), 163-168. doi:10.1192/bjp.184.2.163. <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/epidemiology-of-involuntary-placement-of-mentally-ill-people-across-the-european-union/3903619595BAD8A9FDEC6A49AACA7D4A>.

PART C – Key points

8 Positive developments, including promising practice examples

A positive note is that there has been a tendency to reduce the central psychiatric unit in Ettelbrück and that decentralised psychiatric care units have been created.⁹⁴

In typical inpatient facilities, group sizes have been reduced and family-like structures have been established.⁹⁵

Independent Living services have increased in number and can be found in the different communities.⁹⁶

The national long-term care insurance⁹⁷ covers to a defined extent care costs and costs associated with measures that can be assigned to barrier-free access and accessibility in the domestic context.

With "*Nemme mat Eis*",⁹⁸ a self-help initiative has been founded that advocates independent living from the perspective of those affected.

In its implementing provisions (*guide des normes d'accessibilités*),⁹⁹ added to the national accessibility law (2001)¹⁰⁰ it is clearly defined and precisely and in detail specified how accessibility must be implemented.

The Ministry of Family Affairs has published a brochure (year not specified) especially for the private housing sector which provides concrete examples of disability-friendly planning and design of private homes.¹⁰¹

9 Negative developments including examples of poor practice

There is no general definition of people with disabilities in Luxembourg, so their participation in specific social functions (living independently in the community) can only be inaccurately estimated.¹⁰²

⁹⁴ Psychiatrie Report Luxembourg (2013) *Réforme de la psychiatrie et politique de santé mentale* <http://www.copas.lu/wp-content/uploads/reforme-psychiatrie-politique-sante-mentale-2013.pdf>.

⁹⁵ See prior ANED reports (2009 and 2011).

⁹⁶ Réseau Psy, trente ans de sourires (*Luxemburger Wort* 21.05. 2018) <https://www.wort.lu/de/lokales/reseau-psy-trente-ans-de-sourires-5b02e6f8c1097cee25b89bb4>.

⁹⁷ Assurance Dépendance <http://www.mss.public.lu/dependance/>.

⁹⁸ Nemme mat Eis (Nothing about us without us) <http://www.nemmemateis.lu/online/www/func/news/DEU/index.html>.

⁹⁹ Guide des Normes 2000 <https://mfamigr.gouvernement.lu/fr/publications/guide-manuel/minist-famille-integration-grande-region/guide-normes-accessibilite.html>.

¹⁰⁰ Act on Accessibility (Loi du 29 mars 2001 portant sur l'accessibilité des lieux ouverts au public) http://data.legilux.public.lu/file/eli-etat-leg-recueil-accessibilite_lieux_publics-20081224-fr-pdf.pdf.

¹⁰¹ Ministère de la Famille, de l'Intégration et à la Grande Région <https://mfamigr.gouvernement.lu/dam-assets/publications/brochure-livre/minist-famille-integration-grande-region/br-design-for-all/design-for-all-habitation-adaptable-accessibilite-durable-de.pdf>.

¹⁰² Limbach-Reich, A. (2013). Inklusion im Widerstreit theoretischer und praxeologischer Konzepte. Kongress der Internationalen Gesellschaft für erzieherische Hilfen; (Fédération Internationale des Communautés Educatives; International Federation of Educative Communities. FICE). Bern: Switzerland 07 - 12 October 2013. <http://www.fice-congress2013.ch/programm/abstracts/inklusion->

The reduction of group size may be a positive indicator of quality of life in institutions, but does not indicate an increase in independent living. Institutional care is still widespread in Luxembourg. The very high apartment and rent prices make it difficult for people with disabilities who do not have sufficient financial means to live in the community.

Disability is often seen as a person sitting in a wheelchair and measures are based on this paradigmatic model, so that especially for people with cognitive impairments and psychological problems no adequate support measures result.¹⁰³

There is no national disability coordinator in Luxembourg who could identify shortcomings and organise actions.¹⁰⁴

For people with disabilities under guardianship, the legal situation has not changed, although Luxembourg's legal practice has already been criticised since the first national Action Plan.¹⁰⁵

Except for the historically established grants for the visually impaired, for example, no individual assistance or care budget has been implemented in Luxembourg. People with disabilities in Luxembourg could not succeed in Luxembourg with the demand for an individualised and self-managed care budget.¹⁰⁶

The Accessibility Act has so far only applied to buildings open to the public and has not been sufficiently monitored. As a result, not all essential buildings (for example, the domestic university of the country) are barrier-free, as required by law.¹⁰⁷

Finding affordable housing in a community is particularly difficult for people with mental disabilities, which is also due to the generally very difficult housing market in Luxembourg.¹⁰⁸

10 Recommendations

A comprehensive definition of persons with disabilities should be introduced, which does not, as in the past, only refer to school performance deficits or restrictions on the

[im-nationalen-widerstreit-theoretischer-und-praxeologischer-konze/](#) Reference: *La Constitution du Grand-Duché de Luxembourg Chapitre II. – Des libertés publiques et des droits fondamentaux (Intitulé ainsi modifié par la révision du 2 juin 1999.)* Article 11, (Révision du 29 mars 2007) Art. 11 Egalité devant la loi
<http://www.legilux.public.lu/leg/textescoordonnes/recueils/Constitution/Constitution.pdf>.

¹⁰³ For example, there are elevators at the new campus of the University of Luxembourg in Esch, but there is no guidance system for the blind at all. Limbach-Reich, A. & Powell, J. J.W. (2016) *Studieren und Barrierefreiheit: Stolpersteine auf dem Weg zur Barrierefreiheit und wie sie aus dem Weg geräumt werden könnten. Forum für Politik, Gesellschaft und Kultur in Luxemburg*, 36, 6, 30-33.

¹⁰⁴ CET 2017 <http://cet.lu/wp-content/uploads/2017/07/Brochure.pdf>.

¹⁰⁵ This issue has been addressed in the current working group on the second national action plan.

¹⁰⁶ This point is also being discussed in the current working group on the second national action plan.

¹⁰⁷ Limbach-Reich, A. & Powell, J. J.W. (2016) *Studieren und Barrierefreiheit: Stolpersteine auf dem Weg zur Barrierefreiheit und wie sie aus dem Weg geräumt werden könnten. Forum für Politik, Gesellschaft und Kultur in Luxemburg*, 36, 6, 30-33.

¹⁰⁸ «Réseau Psy» : *30 Jahre Sozialpsychiatrie Tageblatt* 29. May 2018 <https://www.pressreader.com>.

ability to work or the need for long-term care (in old age), but considers the whole person independently of predetermined performance standards.

The abolition of the existing guardianship system and establishing of a more flexible and individualised system of protection in favour of persons with disabilities. The Ministry of Family Affairs (2012, 46) acknowledges that the legal situation at present is not in line with the ethos of the UN-CRPD. “*On reading the CRPD, it appears that the guardianship measure is irreconcilable with the concept of strict proportionality enshrined in Article 12 of the CRPD.*”¹⁰⁹ A support law tailored to the individual situation should be introduced, which in particular does not make participation in community life dependent on the decision of the guardian.

The introduction of a national disability commissioner who can take action in cases of maladministration and coordinate action. For several years now, people with disabilities and their respective organisations have been calling for the introduction of the post of a disabled person's representative, who can influence - on an equal footing with the ministerial administrations - the coherence in terms of time and content of measures relating to participation or inclusion.¹¹⁰ An inclusion and specific needs department should be responsible for defining existing requests in relation to disability and should be empowered to take legal action.

The legal requirements for the implementation of accessibility must be tightened up. The current law does not provide for systematic monitoring or sanctions for non-compliance. Institutions that do not adhere to the regulations should be set definite deadlines and sanctions should go as far as the withdrawal of the operating licence in the event of persistent non-compliance.¹¹¹ Particularly in higher education, the existing inadequate accessibility and complete suppression of student life must be overcome when discussing the inclusion of students with disabilities.

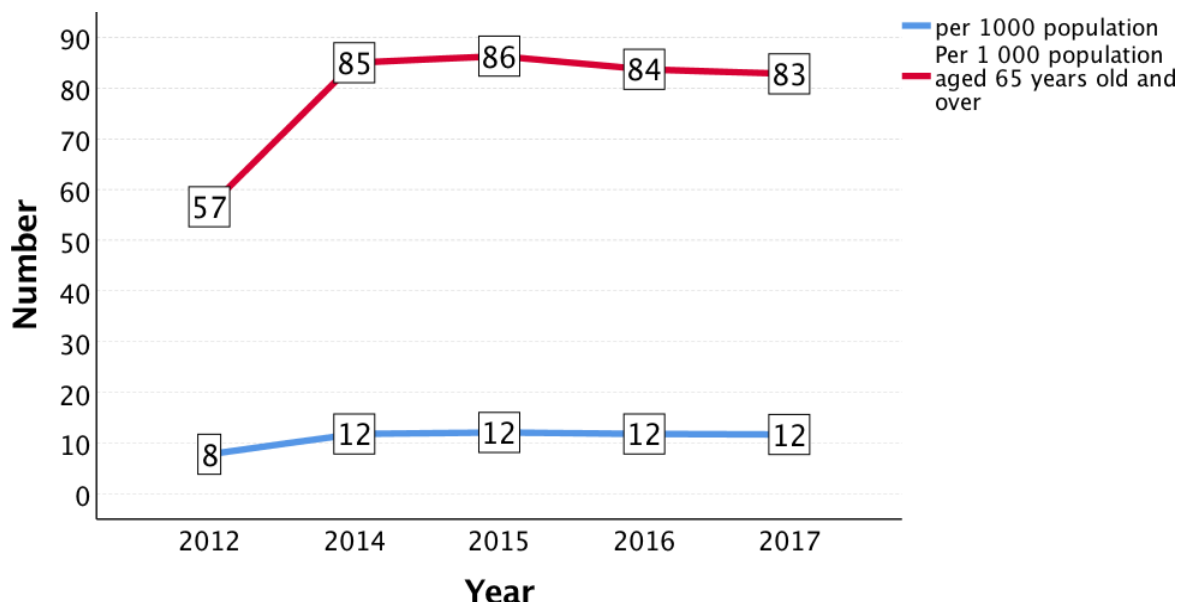
¹⁰⁹ Ministry of Family Affairs Integration and the Greater Region (2012). First action plan to implement the CRPD in Luxembourg (*Aktionsplan der Luxemburger Regierung zur Umsetzung der UNO-Behindertenrechtskonvention*), p. 46
<https://mfamigr.gouvernement.lu/dam-assets/le-ministère/attributions/personnes-handicapées/plan-d-action-du-gouvernement-luxembourgeois-en-faveur-des-personnes-handicapees.pdf>.

¹¹⁰ Centre for Equal Treatment (*CET Centre pour Égalité de traitement*) (2017).
<http://cet.lu/wp-content/uploads/2017/07/Brochure.pdf>.

¹¹¹ Limbach-Reich, A. (2015). Report for the Sustainability Group of the University of Luxembourg (*Barrierefreiheit und Bildung für Alle, Postulate integrativer Nachhaltigkeit, Raumplanung, Architektur, Infrastruktur und Lehre sowie Soziale Aspekte*). Luxembourg University of Luxembourg.

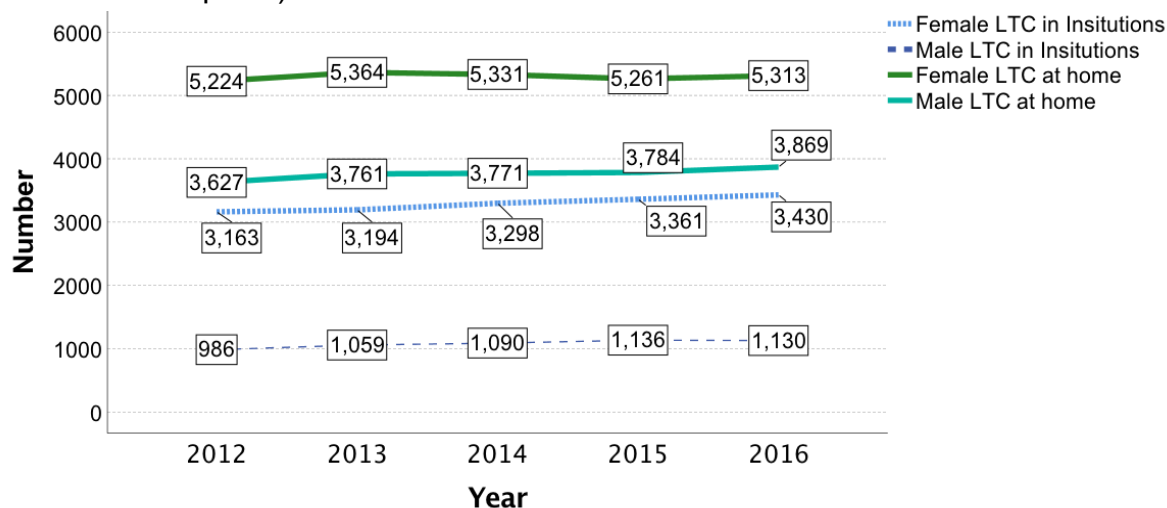
APPENDIX

Figure 3: National number of beds in nursing and residential care facilities per 1,000 inhabitants and per 1,000 inhabitants aged 65 or older



Source: Authors' own presentation based on OECD data¹¹²

Figure 4: Men and women receiving formal (paid) long-term care (LTC) in institutions (other than hospitals) or at home



Source: Authors' own presentation based on OECD data `long-term care recipients`¹¹³

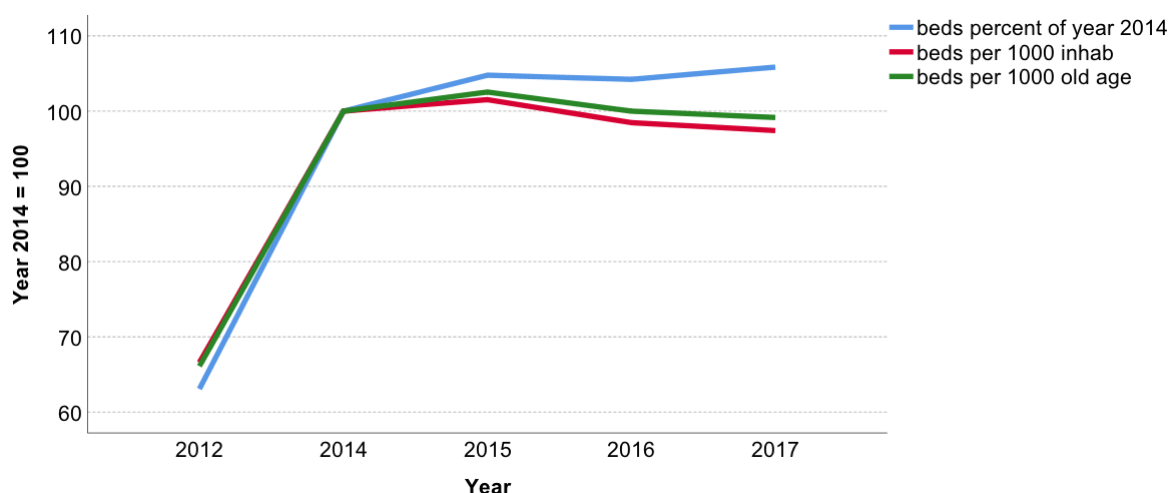
¹¹² OECD 2019 (OECD. stat Home page) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.
https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

¹¹³ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every

Figure 5: long-term care recipients (LTC) in institutions or at home, broken down by age group (per cent)

| LTC recipients 2016 | Age group | In institutions % | At home % |
|---------------------|-------------|-------------------|-----------|
| Female | All ages | 1,2 | 1,8 |
| | 65 and over | 7,4 | 8,6 |
| | 80 and over | 19,9 | 17,3 |
| Male | All ages | 0,4 | 1,3 |
| | 65 and over | 2,9 | 5,7 |
| | 80 and over | 9,0 | 13,5 |
| All | All ages | 0,8 | 1,8 |
| | 65 and over | 5,4 | 7,3 |
| | 80 and over | 16,0 | 15,9 |

Source: Authors' own presentation based on OECD data LTC recipients¹¹⁴

Figure 7: changes in number of beds in nursing / residential care facilities, per 1,000 inhabitants and per 1,000 inhabitants aged 65 or older (2012-2017)

Source: Authors' own presentation based on OECD data¹¹⁵

year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

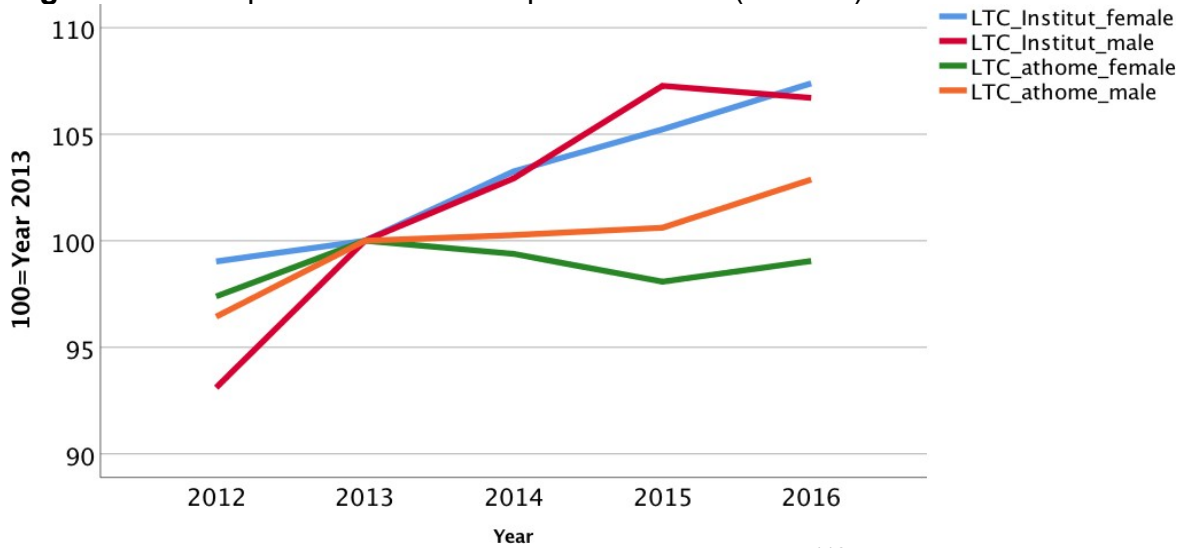
¹¹⁴ OECD 2019 (OECD.stat Home page) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

¹¹⁵ OECD (2019) Data prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

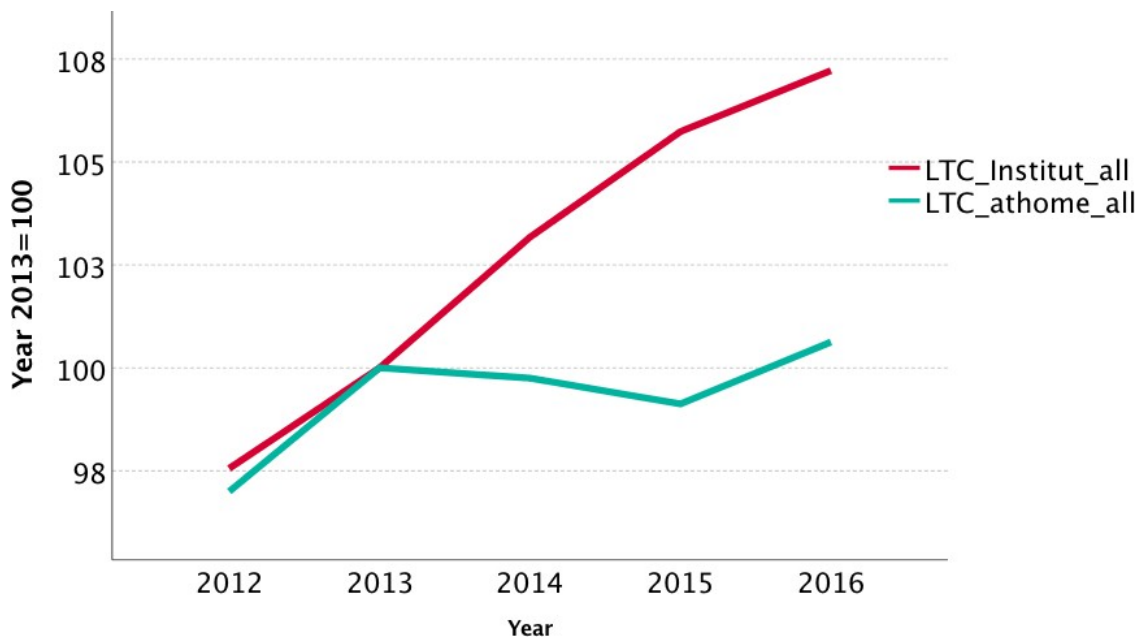
https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

Figure 8: developments in care compared to 2013 (=100 %)



Source: Authors' own presentation based on OECD data¹¹⁶

Figure 9: Increase of Care recipients in institutions or at home

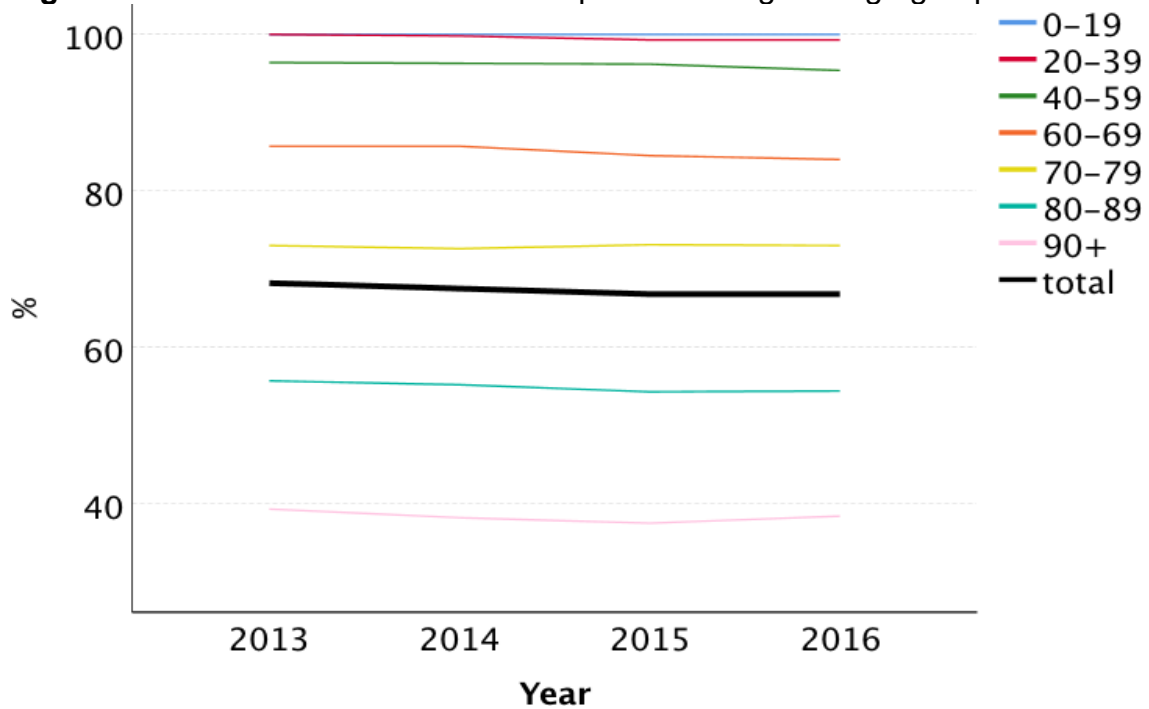


Source: Authors' own presentation based on OECD data¹¹⁷

¹¹⁶ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.
https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

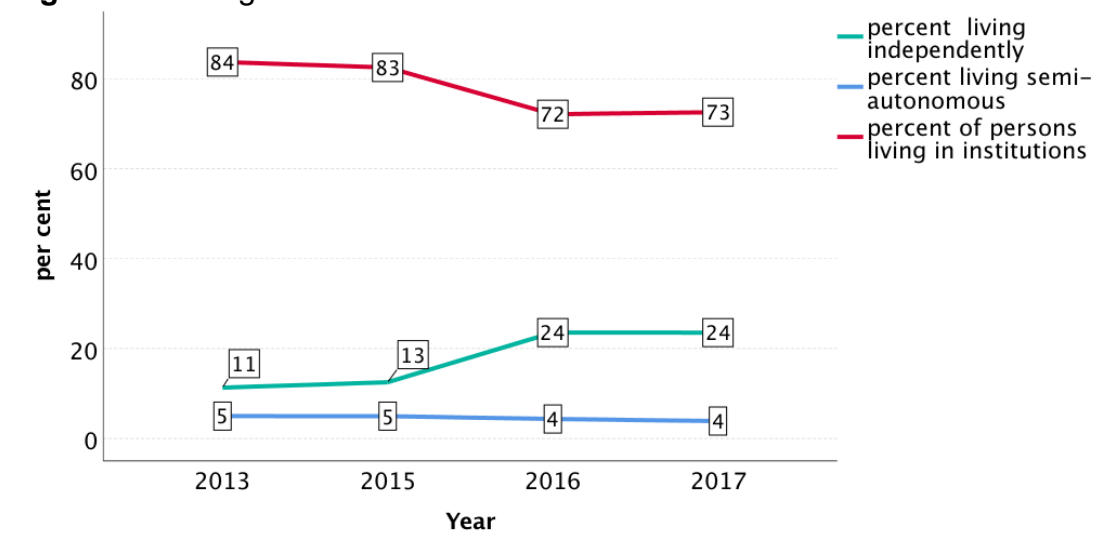
¹¹⁷ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.
https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

Figure 10: Number of beneficiaries independent living and age group 2013-2016



Source: Compilation by the author, based on data of the social insurance (*Securité social 2017*)¹¹⁸

Figure 11: Living situation of Persons with disabilities



Source: compilation by the author based on data delivered by the Ministry of Family Affairs¹¹⁹

¹¹⁸ Rapport Général sur la Sécurité Social au Grand-Duché de Luxembourg 2016

http://www.mss.public.lu/publications/rapport_general/rg2016/rg_2016.pdf;

http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf.

¹¹⁹ Ministry of Family affairs -MFI (2017) <https://gouvernement.lu/dam-assets/fr/publications/rapport-activite/minist-famille-integration-grande-region/2017-rapport-activite-famille/2017-rapport-activite-famille.pdf>.

Extracts from the 2018 coalition agreement:¹²⁰

- The coalition confirms that national legislation will be adapted in line with the standards defined by the UN Convention on the Rights of Persons with Disabilities (2006). A complete revision of national law on the protection of adults will be carried out with the aim of strengthening the autonomy of persons subject to a protection measure. The Hague Convention of 13 January 2000 on the International Protection of Adults will be ratified. People with special needs must be able to participate in all aspects of life in society. Efforts to implement the UN Convention on the Rights of Persons with Disabilities (CRDPH) will be intensified to enable persons with disabilities to effectively exercise their rights.
- The principle of "Design for all", embodied in Article 2 of the CRPD, must allow everyone to participate freely and independently in society. Barrier-free access will continue to be promoted in all areas, including public transport, cultural and leisure facilities. A law on accessibility to all places open to the public, public roads and collective housing buildings and repealing the law of 29 March 2001 on accessibility to places open to the public, as well as three implementing regulations, will improve the accessibility of places open to the public, public roads and collective housing buildings for people with disabilities. Barrier-free access will also have to be translated into virtual space.
- A study will be launched to analyse the living conditions of people with disabilities in Luxembourg. The purpose of the study is to assess, on the one hand, the measures and services that already exist and, on the other hand, to determine which services and offers should be put in place in Luxembourg in order to ensure the autonomy of disabled people. This study will also provide more detailed and reliable statistics on the situation and needs of people with disabilities. Among other things, it is necessary to analyse the relevance and consistency of the provisions on income for people with severe disabilities.

Milestones, concerning the psychiatric reform and decentralisation in Luxembourg, mentioned in the first national report, points 143 - 146):¹²¹

- A big shift towards decentralizing psychiatric care has taken place in Luxembourg since 1994. From 1994 onwards, persons with disabilities living in psychiatric hospitals have been transferred either to special institutions for persons with disabilities or, where possible, to sheltered accommodation. The mental health reform in Luxembourg, which gained renewed momentum in 2005, can be summarized as follows: "de-institutionalization, decentralization, destigmatisation and prevention."
- In order to meet demand, small non-hospital facilities (for 8-10 persons) were established to accommodate psychiatric patients. These facilities work as a network. As mental illness is often a chronic condition, the facilities continue to collaborate closely with the hospital network. They provide various mental health

¹²⁰ Coalition accord 2018 <https://gouvernement.lu/de/publications/accord-coalition/2018-2023.html>.

¹²¹ Initial report of Luxembourg implementing CRPD (2014).
https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FLUX%2F1&Lang=en.

services: (1) Psychiatric consultations and follow-up treatment; (2) supervised accommodation; (3) day-care centres; (4) meeting centres; (5) therapeutic workshops; and (6) information and prevention centres.

- Psychiatric consultations and follow-up treatment are organized in the different regions of the country. These services are aimed specifically at patients with mental disabilities who are experiencing social difficulties.
- Supervised accommodation consists of apartments where residents with mental disabilities are supported by professionals. These professionals help patients in various tasks and monitor their state of health. Supervised accommodation is run by non-profit organisations.
- Day-care centres for persons with mental disabilities organize day activities as part of therapeutic workshops for psychiatric patients deemed to be "too weak" to find work. These centres provide occupational and therapeutic activities for patients and personalized support (e.g. help in coping with daily tasks, assistance with administrative and social procedures, improving cognitive skills and autonomy, offering occupational therapy workshops aimed at possible social rehabilitation and entry to the job market).
- Meeting centres serve as points where persons with mental disabilities can meet and talk during the day. These centres are primarily targeted at patients who are unable to work in a therapeutic workshop or attend a day-care centre.
- In therapeutic workshops, patients are able to engage in an occupation. According to their abilities, they help to carry out certain tasks and make various items, proceeds from the sale of which go towards the running costs of the workshops. The work is designed to ensure that patients are not pressured to meet productivity targets as in normal workshops.
- Open and closed units for the mentally ill, including paediatric psychiatry services, have been set up in the hospitals in the three regions of the hospital system. Patients with mental disorders can now be committed only by the acute psychiatric services in general hospitals.
- In addition to day hospitals, the programme to decentralize psychiatric services provides for the setting up of day centres, accommodation and work spaces in different regions of the country, all of which has been achieved thanks to allocations from the State budget.
- The funding provided by the National Health Fund for psychiatric home care services since 2008 has allowed the residential care sector to grow further, and this, in turn, has expedited deinstitutionalization and reduced the stigma surrounding hospitalization in psychiatric wards.
- The neuropsychiatric hospital released from its duties relating to acute psychiatric care, can now devote itself wholly to be a rehabilitation facility.

The plans for its modernization have been approved and the first steps towards decentralization are being taken.

Implementation of Article 19 "living independently and being included in the community
Milestones:

- Training activities that specifically target persons with disabilities (for the purpose of empowerment) are constantly being improved.

- The “Life Academy” has been operated since 2011 by one of the management services accredited by the Ministry of Family (Ligue HMC — an association providing assistance to children, adolescents and adults with mental disabilities). The Life Academy operates as a discussion forum for persons with disabilities. Workshops for persons with disabilities are held twice a month, on topics such as “What are my rights and duties?” and “How can I express my opinion?”. The main purpose of the Life Academy is to increase the autonomy, self-determination and self-representation of persons with disabilities. The Academy’s underlying principle is that persons with disabilities are experts in the areas that concern them and that they should be involved in the discussions affecting them and be given the opportunity to make their own life choices. In 2012, 36 men and 18 women with mental disabilities or learning disabilities participated in the training sessions run by the Academy. Some 10 training sessions were offered to persons with disabilities and 16 training sessions and activities were subsequently organized by those persons for third parties.
- The Council of Workers with Disabilities of the Ligue HMC was established in 2011 and functions as a staff delegation. It comprises 11 members (eight men and three women), each of whom represents an occupational area within the organisation. It is one of the educational tools used to help workers with disabilities speak out in their professional lives.
- The Government aims to make information available in accessible formats so that persons with disabilities can stay informed independently, without needing to systematically seek help from others. It works in conjunction with Klaro, a resource centre for easy-to-understand language established in April 2012. Its role is to coordinate with, assist and support persons with communication difficulties and to organize courses in “easy-to-understand forms of communication and language” for government and public and private institutions. In 2012, the year that Klaro was established, 12 men and 11 women working for government, public or private institutions took part in two courses on easy-to-understand forms of communication and language run by overseas trainers. Two men and nine women participated in a training day at the beginning of 2013.
- Home-help services offer home-based care and material and psychological assistance for persons with disabilities and their families. The aim is to support independent living at home and to provide care tailored to the individual needs and expectations of the persons concerned.
- Where appropriate, dependency benefits contribute substantially to promoting the practice of independent living at home.
- Dependency insurance is part of the social security system alongside health insurance and functions according to the same principles. Everyone makes a mandatory contribution and any insured person who becomes dependent is entitled to receive dependency benefits.
- If the dependent person lives at home, care and assistance may be provided by a professional or private carer (chosen by the person with disabilities). Professional carer fees are paid directly by the insurer. If the carer is a private individual, a sum of money is paid to the dependent person so that he or she can pay that individual.
- In order to qualify for dependency benefits, the assistance required for basic day-to-day tasks must represent at least 3.5 hours per week and the state of dependency must be likely to last at least six months or be permanent. In 2011,

dependency benefits accounted for a total of 69,604,286.43 acts of basic day-to-day care for persons with disabilities. Alongside care and assistance for basic day-to-day tasks, dependent persons may also be eligible for help around the house, including help with the laundry, for 2.5 or 4 hours per week, as well as for support and counselling where appropriate. In 2011, a total of EUR 7,645,179.05 was spent on domestic tasks and EUR 34,073,358.62 on support activities. Support is provided for a maximum of 14 hours or, for groups, for up to 56 hours per week (8 hours a day, 7 days a week). A total of EUR 11,988.74 was spent on counselling for persons with disabilities living at home. Dependency insurance covers the pension premiums for the carer (the close family member or friend who regularly assists the dependent person and who does not have a personal pension). Some 758 carers benefited from this arrangement in 2011.

- Persons who are completely blind, persons with spina bifida, persons with communication difficulties owing to serious hearing problems or dysarthria and persons who have undergone a laryngectomy receive a lump-sum cash payment once their diagnosis has been confirmed by a specialist doctor certified by the assessment and guidance unit. In 2011, a total of EUR 3,043,887.47 was paid to such persons.
- Assistive devices (e.g. walking frames, wheelchairs, special beds, adapted vehicles) and home alterations (e.g. walk-in showers, lifts, concrete ramps) have been made available to persons with disabilities with a view to maintaining or increasing their level of independence. The maximum amount that can be claimed stands at EUR 26,000. In 2011, the dependency insurance scheme paid out EUR 4,310,913.93 for assistive devices, EUR 36,000 of which went towards two guide dogs, one for a man in the 60-64 years age range and another for a woman in the 20-24 years age range (see section on article 20). A total of EUR 356,488.13 was spent on building surveys and EUR 697,912.26 on adapting the homes of persons with disabilities.
- If the applicant rents, dependency insurance can cover the additional costs of moving to an adapted or adaptable home (max. EUR 300 per month, up to a limit of EUR 26,000). In 2011, a total of EUR 8,400 was spent on rent subsidies.
- Alongside traditional accommodation and with a view to promoting the greatest possible independence of persons with disabilities, the Ministry of Family has supported the development of facilities that offer care in open and semi-open settings. In 2012, the capacity of these home-help services run by eight organisations accredited by the Ministry stood at 144 places.
- Such assistance takes different forms depending on the skills, capacities and background of the person with disabilities. For example, it may take the form of counselling or support intended to encourage and empower the person, or help in making arrangements to compensate for the person's disability so that he or she can enjoy high-quality independent living. These care measures are available on an ad hoc or regular basis, usually at the home of the person with disabilities.
- State-accredited accommodation services for persons with disabilities provide accommodation and/or support to groups of three or more persons with disabilities. The aim is to offer professional support to persons with disabilities using a comprehensive and coherent approach by providing them with, on the one hand, help and care as defined in the amended Act of 19 June 1998 on the introduction of dependency insurance and, on the other, tailored socio-educational support.

- In Luxembourg, persons with disabilities live together in small groups of around 8 to 10 persons in specialized institutions spread across the whole country.
- The 2013 Agreement on Socio-Educational Support for Persons with Disabilities governs relations between the State and the bodies that manage accommodation and day-care services. It is in line with the principles underlying the Convention on the Rights of Persons with Disabilities and is designed to support the application of those principles.
- The aim of socio-educational support is to provide the persons concerned with an environment that is conducive to their well-being, their physical, sensory, intellectual and emotional independence, and their inclusion, socialization and education. It is an ongoing comprehensive and holistic form of support that covers day-to-day living, health and security issues, social and cultural activities, the development of the individual's physical, psychological, sensory and social abilities, and religious and philosophical guidance.
- Socio-educational support is based on the abilities of the individual concerned. It takes into account the lifestyle, available resources, history, family and social background, wishes and life choices of the individual and, where appropriate, their legal representative.
- Socio-educational support for each individual is defined in a "personalized socio-educational support plan". The services provided are determined on the basis of an initial evaluation and regular assessments of the needs, expectations and state of health of the person concerned, in consultation with that person and/or the person's family and friends.
- In 2012, the capacity of the 39 accommodation centres run by the 11 organisations accredited by the Ministry of Family stood at 787 beds, of which 49 were temporary. As at 31 December 2012, 35 beds were occupied by minors in centres run by four different organisations.
- Day-care services for persons with disabilities provide not just care and assistance but also socio-educational and therapeutic support in the form of a variety of activities tailored to the individual needs and expectations of the person with disabilities. Day-care services look after persons with disabilities who, owing to their disability or age, cannot regularly attend a vocational training course or hold down a permanent job. The aim is to provide professional and multidisciplinary support to persons with disabilities and to support families caring for a person with disabilities. In 2012, the capacity of the 16 day-care centres run by the 11 organisations accredited by the Ministry of Family stood at 435 places, of which 220 were for persons with disabilities not living in State-approved accommodation. Some 23 places were occupied by minors in centres run by four different organisations.
- The Home-based psychiatric service for adults and adolescents provides support in the person's home environment. It aims to provide psychiatric follow-up at home to any person with one or more mental disabilities. The service is made up of two distinct sections for different target groups. The first section focuses on follow-up treatment for adults, while the second section focuses on support for children/adolescents and their families. The second section, which has been operating since July 2009, offers support aimed at successfully reintegrating the child or adolescent into family and social life.

Taken from the First State Report of Luxembourg (*Examen des rapports soumis par les États parties en application de l'article 35 de la Convention - Rapports initiaux des États parties attendus en 2013 Luxembourg points 183-215*).¹²²

Shadow report: Authentic narrative about problematic housing in Luxembourg¹²³

An adult person (living in a specialized nursing home) reported of their experiences: The person in question needs assistance for all acts of daily life and thus relies nursing home staff for these acts, which include getting from or into their wheelchair, dressing, eating, washing. The person reported staff being continuously pressed for time. Five days a week, the person is 'put to bed' at 19 o'clock. Two nights a week bedtime is set at 21 o'clock. Accompaniment to social or cultural outings, such as going to a concert, has to be requested weeks or even months in advance. Accompaniment by staff is not guaranteed as staff can deny requests. When it comes to food, time and options are limited. There are supposed to be three different dishes to choose from, but this is not always put into practice. Ordering food from outside is possible but complicated, since the person in question needs assistance with eating, and assistance is only available during a brief period of time per meal. The person added that there are no community rooms open to residents for socializing which can result in isolation of residents.

¹²² First national Report implementing the CRPD Luxembourg (2015) <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/201/47/PDF/G1520147.pdf?OpenElement>.

¹²³ Shadow Report on Implementation of the United Nations Convention on the Rights of Persons with Disabilities Luxembourg 2016. https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fLUX%2f26160&Lang=en.