

**ANED 2018-19**

**Task 1.2**

**Living independently and being included in the community<sup>1</sup>**

Country: Spain

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<sup>1</sup> Available at: [https://ec.europa.eu/employment\\_social/empl\\_portal/ede/ES-ANED%202018-19-Country%20report%20%20Living%20independently\\_final%20for%20web.docx](https://ec.europa.eu/employment_social/empl_portal/ede/ES-ANED%202018-19-Country%20report%20%20Living%20independently_final%20for%20web.docx)

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## PART A – Factual information and statistical data

### 1 Current situation and direction of travel

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

##### 1.1.1 Current figures

Long-term care in Spain is characterized by low intensity of residential care, high levels of informal care, and low level of community care.<sup>2</sup> Data from the largest and most recent survey on the situation of people with disabilities in Spain (EDA 2008)<sup>3</sup> estimated that 3.85 million people with disabilities reside in homes and around 269,000 people with disabilities live in institutions. That is, although less than 7 % of Spanish people with disabilities live in institutions, in absolute numbers, almost 300,000 people live in institutions. Out of this total, 60.5 % are older than 80 years of age.<sup>4</sup> Of the group living in institutions, 222,260 are over 65 years old and of these 162,894 are over 80 years old. If we analyse separately those who live in residences for the elderly, in centres for people with disabilities, and in psychiatric or geriatric centres, the number of people with disabilities who live in an institution is almost 36,000 (0.9 % of that 3.85 million people with disabilities), and 91 % of them have intellectual disabilities, in contrast to approximately 216,000 people who live in institutions for the elderly, and approximately 17,000 people who live in psychiatric facilities.<sup>5</sup> In absolute numbers, 20 % of people with intellectual disabilities live in an institution.<sup>6</sup>

The document “The right to independent life and its realization in Spain: a distant horizon for people with disabilities?”<sup>7</sup> states there is no updated data about the entire population with disabilities. There has not been a survey like AGE since 2008 but we

<sup>2</sup> Huete, A. (dir). (2015). Observatorio Estatal de la Discapacidad. Institucionalización de las personas con discapacidad en España. Madrid: Observatorio Estatal de la Discapacidad. 2015. Available at: <https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

<sup>3</sup> Instituto Nacional de Estadística (2008). Encuesta de Discapacidad, Autonomía personal y situaciones de Dependencia (EDAD). Available at: [http://sid.usal.es/estadisticas\\_edad2008.asp](http://sid.usal.es/estadisticas_edad2008.asp).

<sup>4</sup> Huete, A. (dir). (2015). Observatorio Estatal de la Discapacidad. Institucionalización de las personas con discapacidad en España. Madrid: Observatorio Estatal de la Discapacidad. 2015. Available at: <https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

<sup>5</sup> Huete, A. (dir). (2015). Observatorio Estatal de la Discapacidad. Institucionalización de las personas con discapacidad en España. Madrid: Observatorio Estatal de la Discapacidad. 2015. Available at: <https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

<sup>6</sup> Verdugo, M.A., Navas, P., Martínez, S., & Sainz, F. (2016). Todos somos todos. Derechos y calidad de vida de las personas con discapacidad intelectual y mayores necesidades de apoyo. Informe Ejecutivo. Available at: <http://www.plenainclusion.org/sites/default/files/30-11-16-todossomos-todos-informeejecutivo.pdf>.

<sup>7</sup> Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

can analyse the statistics of the System for Autonomy and Care for Dependency. In the report published on 31 January 2019<sup>8</sup> we see that of the 1,057,190 beneficiaries of the benefit system, 166,658 (12.58 %) lived in an institution. In previous years the figures were as follows (see Table 1).

Table 1. Percentage of people living in institutions

Date	People living in institutions	Total beneficiaries	Percentage
December 31, 2010 <sup>9</sup>	119,253	654,499	15.27 %
December 31, 2011 <sup>10</sup>	122,040	741,713	13.30 %
December 31, 2012 <sup>11</sup>	125,792	764,969	13.10 %
December 31, 2013 <sup>12</sup>	130,424	753,842	13.80 %
December 31, 2014 <sup>13</sup>	135,346	745,720	14.55 %
December 31, 2015 <sup>14</sup>	148,382	796,109	14.87 %
December 31, 2016 <sup>15</sup>	151,719	865,564	14.19 %
December 31, 2017 <sup>16</sup>	157,174	954,831	13.34 %
December 31, 2018 <sup>17</sup>	166,579	1,054,275	12.61 %

That is to say, the trend, is to slightly reduce the number of places in institutions. And (the report says) we know that the waiting lists to obtain places in institutions are still very long. We do not know the ages of the people who occupy those places in residences. The System for Personal Autonomy and Care for Dependency offers the same range of services to octogenarian people, and to minors and young people who are just beginning their lives. The type of benefit is not broken down by age or type of

<sup>8</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 31 de enero de 2019, <http://www.imerso.es/InterPresent1/groups/imerso/documents/binario/estsisaad20190131.pdf>.

<sup>9</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2010, <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20101201.pdf>.

<sup>10</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2011 : <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20111201.pdf>.

<sup>11</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2012 : [http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/im\\_070847.pdf](http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/im_070847.pdf).

<sup>12</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2013 : [http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/im\\_082047.pdf](http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/im_082047.pdf).

<sup>13</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2014: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20141231.pdf>.

<sup>14</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2015: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20151231.pdf>.

<sup>15</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2016: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20161231.pdf>.

<sup>16</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2017: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20171231.pdf>.

<sup>17</sup> Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2018: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20181231.pdf>.

disability. We also do not know if it is a person with disabilities who applies for a place in a residence or their legal representatives, when they are minors or are legally incapacitated, nor how many cases involve involuntary placement (Article 763 of the Civil Procedure Act).<sup>18</sup> Yet, according to data included in Table 2, whereas at-home services (e.g. telecare, home help) and some financial aid linked to services (Economic benefit linked to service) have increased, the economic benefits aimed at families have experienced a significant reduction. In some instances, the reduction of economic aids associated to the Spanish financial crisis could help explain those changes.

Table 2. Beneficiaries and types of services (years 2013-2019)

	2013	2014	2015	2016	2017	2018	2019
Beneficiaries	75,3842	745,720	796,109	865,564	954,831	1,054,275	1057,190
Prevention Dependence and Promotion of Personal Autonomy	2.2	2.5	3.0	3.6	3.9	4.0	4.0
Telecare	12.7	12.4	14.1	15.4	15.8	17.0	17.0
Home help	12.8	14.3	14.8	16.0	16.5	17.9	17.9
Day / Night Centres	7.4	7.9	8.5	8.0	7.7	7.2	7.2
Residential Care (Institutions)	13.8	14.6	14.9	14.2	13.3	12.6	12.6
Economic benefit linked to service	7.6	7.9	8.4	8.5	9.4	10.0	10.0
Economic benefit for Family Care	43.2	40.3	36.1	33.8	32.7	30.8	30.8
Economic benefit for personal assistant	0.2	0.2	0.3	0.5	0.6	0.5	0.5

Source: Developed with Data obtained from IMSERSO available at: [http://www.imserso.es/imserso\\_01/documentacion/estadisticas/info\\_d/estadisticas/es\\_t\\_inf/inf\\_gp/index.htm](http://www.imserso.es/imserso_01/documentacion/estadisticas/info_d/estadisticas/es_t_inf/inf_gp/index.htm)

It also seems that these residences are institutions with a medical model of service delivery approach. The 2008 INE survey revealed that people had very little capacity to decide on their daily lives (for example, the percentage of those who could decide when to get up and when to go to bed, what to eat and when and with whom to share his or her room was very low).<sup>19</sup> Each autonomous community has its own accessibility laws that contain general principles, objectives and definitions on what accessible housing is. The technical norms are regulated by national laws.

On 29 November 2018, the Plenary of the General Council of the Judiciary has approved a report that endorses the draft law prepared by the Ministry of Justice to reform civil and procedural legislation on disability issues. The purpose is to adapt this legislation to the rights set forth in the Convention and, more specifically, in Article 12,

<sup>18</sup> Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

<sup>19</sup> Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

which states that persons with disabilities have full legal capacity, and obliges States to implement appropriate measures that allow people with disability, having access to the support necessary in each case to fully exercise their legal capacity. It is expected that this draft will have positive consequences for the right to choose who and where to live.<sup>20</sup>

According to the Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU<sup>21</sup> Spain has a broad variety of institutional services for people with disabilities: Sheltered housing, care homes, group homes, and day centres. It also has a broad variety of community-based services for people with disabilities: In-home, Day care centres, Residential, Foster care, Family support/respite care, Personal assistance, Direct payments/personal budget/individual budget, Peer support/counselling, Befriending. As the document states, concerning the level of user control of services, low levels of autonomy are found in relation to foster care in Spain where children seem to have little control over decisions relating to the family in which they will be placed.<sup>22</sup> Also, persons with disabilities who receive personal budgets and cash payments are earmarked for particular types of services or for services authorized by the governments from the autonomous communities. Community-based services are typically funded by municipalities, drawing on funds they receive from the State, although in some cases, users are asked to contribute directly to funding services, including day care centres and in-home support.<sup>23</sup>

### 1.1.2 Trend since 2013

There is a trend, although not at a very rapid pace, to increase the number of places of residence in institutions.<sup>24</sup> In 2011, the UN Committee on the Rights of Persons with Disabilities expressed their concern at the lack of resources and services to guarantee the right to live independently and be included in the community.<sup>25</sup>

<sup>20</sup> DOTCOM: the Disability Online Tool of the Commission (Spain). Available at: [https://www.disability-europe.net/dotcom?l%5B%5D=31&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=list](https://www.disability-europe.net/dotcom?l%5B%5D=31&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=list).

<sup>21</sup> FRA (2017). Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU November 2017. Available at: [https://fra.europa.eu/sites/default/files/fra\\_uploads/2017-10-independent-living-mapping-paper\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf).

<sup>22</sup> FRA (2017). Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU November 2017. Available at: [https://fra.europa.eu/sites/default/files/fra\\_uploads/2017-10-independent-living-mapping-paper\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf).

<sup>23</sup> FRA (2017). Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU November 2017. Available at: [https://fra.europa.eu/sites/default/files/fra\\_uploads/2017-10-independent-living-mapping-paper\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf).

<sup>24</sup> <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

<sup>25</sup> Consideration of reports submitted by States parties under Article 35 of the Convention. Concluding observations of the Committee on the Rights of Persons with Disabilities (September 2011): <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICaQhKb7yhslxq2MuiDp%2FqMKQ6SGOn0%2FNZ5trZrfgNmKdTjE%2FScMKF96xMrtyzhDx7aguCpqdK4xQVGCY502yRGHBFyeVZXNw00SiVNraxD5auFDv%2FVv2m>.

This is still true in Spain. The CERMI (Spanish Committee of Representatives of People with Disabilities) published its annual report in April 2017 on the compliance of our country with the UN Convention on the rights of persons with disabilities during 2016.<sup>26</sup> Here, CERMI argues that in relation to Article 19: Right to live independently and to be included in the community, the lack of resources and services is worrisome, particularly in rural areas where placement in residential facilities is the only possibility. On the other hand, there is concern about the restriction of the scope of aid for personal autonomy both in relation to people with disabilities who are eligible, as well as in the field of activity for which personal assistance can be utilized (only education and work).<sup>27</sup>

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

### 1.2.1 Current figures

The right to choose where and with whom to live requires physical conditions of the homes that make it possible. Most people in Spain live in multi-unit housing or apartment buildings, and there are several laws applicable to these living arrangements, both public and private properties. The owner or the landlord is responsible for meeting the requirements for an accessible building. There is funding support available for different adaptations and removal of barriers that can be requested by disabled people to adapt their houses, or by a community of owners if additional adaptations (e.g. elevators, ramps, etc.) are required.<sup>28</sup>

Concerning money invested, we do not have specific information, because, as mentioned earlier, Spain has a very complex and disperse system of services and support, and data are not disaggregated.<sup>29</sup> There is money available at national and regional level to make housing accessible.

Spain is a decentralized country. There are 17 Autonomous Communities (CCAA). The Autonomous Communities have exercised their competences in social assistance in very unequal and uncoordinated ways. That means that, in Spain, there are 18 systems for social services (17 run by the CCAA and an additional one run by the Ministry of Health, Social Services and Equality (MHSSE) (*Ministerio de Sanidad, Servicios Sociales e Igualdad, MSSSI*) for the Autonomous Cities of Ceuta and Melilla. The CCAA Social Services are financed by the CCAA (although there might be contributions of the users). In addition, there is the Social Security which covers health services and cash payments for retirement, unemployment, disability, under certain

<sup>26</sup> CERMI (2017). Derechos Humanos y Discapacidad. Informe España 2017. Available at: [https://www.cermi.es/sites/default/files/docs/colecciones/Informe%202017%201\\_0.pdf](https://www.cermi.es/sites/default/files/docs/colecciones/Informe%202017%201_0.pdf).

<sup>27</sup> CERMI (2017). Derechos Humanos y Discapacidad. Informe España 2017. Available at: [https://www.cermi.es/sites/default/files/docs/colecciones/Informe%202017%201\\_0.pdf](https://www.cermi.es/sites/default/files/docs/colecciones/Informe%202017%201_0.pdf).

<sup>28</sup> DOTCOM: the Disability Online Tool of the Commission (Spain). Available at: [https://www.disability-europe.net/dotcom/?l%5B%5D=31&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=list](https://www.disability-europe.net/dotcom/?l%5B%5D=31&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=list).

<sup>29</sup> Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

conditions, and certain family situations. Social Security has the same rules in all the Spanish territory. The Social Security is financed by the national administration (although there are contributions of working citizens and their employers). Finally, there is the System for the Autonomy and the Attention to Dependency (SAAD) created in 2007. The SAAD was originally intended to cover dependency situations of people 80 years old or more. Later, people with disabilities of all ages were covered, but the SAAD framework has not the spirit of the UN Convention on the Rights of Persons with Disabilities, although it was designed in parallel to the Convention. The SAAD could have been included in the Social Security, but it was decided by the Government first, and the Parliament later, not to do so. Therefore, it is a universal system but managed by a Territorial Board in which there are representatives of both the national administration and the CCAA. The town halls also have certain competences when they are big enough. There are national, regional and local level laws. The result is extremely complex. The SAAD is financed by both the national administration and the CCAA. The SAAD services and cash payments are integrated in the CCAA social services and users pay part of the cost whether for all or for some of the services, in an amount that is different in each Autonomous Community, sometimes reaching more than 90 % of the cost. Therefore, it is impossible to give a complete and accurate picture of the Spanish situation.

### 1.2.2 Trend since 2013

This information is not available.

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

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

In Spain, segregated residential options continue to be the main option for people with the most severe intellectual disabilities, and public administration organisations spend most resources on these. However, there are choices for disabled people to live independently in their own homes and in the community, resulting from the passing of the Law 39/2006, of 14 December on Promotion of Personal Autonomy and Care for Dependent Persons, and the Law 51/2003 of 02 December 2003 on equal opportunities, non-discrimination, and universal accessibility for persons with disabilities. However, there are no structured policies promoting independent living that follow the UN Convention on the Rights of Persons with Disabilities; only some groups of people with disabilities and some disability associations are playing a role in promoting independent living.

In addition, there are important differences among Autonomous Communities in applying new Acts and in developing new regulations to facilitate independent living. Law 39/2006 could be considered a significant new proposal for future policies to support people living in the community rather than in institutions as it regulates the basic conditions that should guarantee equality in the promotion of personal autonomy and care for dependent persons, by creating a System for Autonomy and Care for Dependency (SAAD). With the SAAD, all elderly or disabled people who cannot fend

for themselves will be attended to by government, by ensuring access to public social services and economic performance more suited to their needs. People with mental health conditions may be deprived of their liberty and made to stay in an institution for which a legal decision is needed.<sup>30</sup>

In Spain, most people with disabilities live in the community. Only those with the most severe disabilities live in institutions. Some people with disabilities from rural areas move to a residential facility in larger towns in order to obtain better services. The rights to choose where and with whom to live requires physical conditions of the homes that make it possible. Most people live in multi-unit housing or apartment buildings, and there are several laws applicable to these living arrangements, both public and private properties. The owner or the landlord is responsible for meeting the requirements for an accessible building. There is funding support available for different adaptations and removal of barriers that can be request by disabled people to adapt their houses, or by a Community of owners if additional adaptations (e.g. elevators, ramps, etc.) are required.

Financial support is also important to prevent some people with disabilities from being forced to live in an institution due to the lack of individualized human, and technical support. In this regard, several laws determine the different types of services and aids available for people with disabilities, depending their level of disability.

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

To our knowledge, there is no mention of deinstitutionalization, as considered in this report, in any of the projects co-financed by the ESF. There is no mention of deinstitutionalization in documents such as the Partnership Agreement with the European Commission, National Reform Programme, National Poverty Reduction Strategy, National Disability Strategy, etc. There is no document for Spain in the “Community Living for Europe: Structural Funds Watch country profiles”.

However, in the document: “Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds” by the Structural Funds Watch, it states that<sup>31</sup> Institutional care is commonplace in Spain (...), The United Nations Committee on the Rights of Persons with Disabilities has highlighted the increase in the institutionalisation of people with disabilities in Spain (...), and the Council of Europe Commissioner for Human Rights has raised concerns about institutionalisation in Spain.<sup>32</sup> There is an agreement to include alternative services to

<sup>30</sup> DOTCOM: the Disability Online Tool of the Commission (Spain). Available at: [https://www.disability-europe.net/dotcom?l%5B%5D=31&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=list](https://www.disability-europe.net/dotcom?l%5B%5D=31&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=list).

<sup>31</sup> Crowther, N., Quinn, G. & Hillen-Moore, A. (2017). Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds. Ireland: Community Living for Europe: Structural Funds Watch. Available at: [https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw\\_opening-upcommunities-november-2017\\_final.pdf](https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw_opening-upcommunities-november-2017_final.pdf).

<sup>32</sup> Crowther, N., Quinn, G. & Hillen-Moore, A. (2017). Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds. Ireland: Community Living for Europe: Structural Funds Watch. Available at:

institutionalization of people with mental health issues in the New National Strategy of Mental Health of the National Health System (for the period 2017-2022).<sup>33</sup>

Living independently and being included in the community is considered more an issue for societal groups such as Roma, migrants, etc. It is also perceived as an issue associated to poverty, so the laws and different programs are aimed at promoting employment, health, education, social services... for vulnerable groups. Living in the community in Spain is more a matter of being eligible for different aids, as those explained earlier in this report. It is not considered a priority at governmental level.

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

There are no relevant strategies as defined in the guidelines of this report.

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

There are no relevant strategies as defined in the guidelines of this report.

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

As mentioned earlier, The CERMI (Spanish Committee of Representatives of People with Disabilities) has published its annual report in April 2017 on the compliance of our country with the UN Convention on the rights of persons with disabilities during 2016. In this regard, CERMI argues that in relation to Article 19: Right to live independently and to be included in the community, the lack of resources and services is worrisome, particularly in rural areas where placement in residential facilities is the only possibility. Also, there is concern about the restriction of the scope of aid for personal autonomy both in relation to people with disabilities who are eligible, as well as in the field of activity for which personal assistance can be utilized (only education and work).

The Associative Movement of Full Inclusion (Plena Inclusión; <http://www.plenainclusion.org/>), on people with intellectual disabilities, is committed to developing the following proposals as a framework for its actions concerning social inclusion:<sup>34</sup>

- Calling for the end of the model of segregated welfare services and promoting its transformation towards a model of supports and services based on the quality of

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[https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw\\_opening-upcommunities-november-2017\\_final.pdf](https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw_opening-upcommunities-november-2017_final.pdf).

<sup>33</sup> Proposición no de Ley presentada por el Grupo Parlamentario Socialista, sobre la actualización de la Estrategia Nacional de Salud Mental del Sistema Nacional de Salud [Boletín Oficial de las Cortes Generales. Congreso de los Diputados XII Legislatura (10 de mayo de 2017). Pps. 79-80]. Available at: <http://www.infocoonline.es/pdf/BOCG-12-D-150.pdf>.

<sup>34</sup> Plena Inclusión (2016). Posicionamiento de Plena inclusión sobre personas con discapacidad intelectual o del desarrollo con grandes necesidades de apoyo. Available at: <http://www.plenainclusion.org/informate/actualidad/noticias/2016/posicionamiento-de-plena-inclusion-sobre-personas-con>.

life, full citizenship, adaptation to the needs of the person and inclusion in the community.

- Implementing a strict monitoring of compliance with the basic rights established by the UN Convention of rights, developing actions of social complaints and demand of dignified living conditions for all.
- Support families so that all their members can develop their life goals, promoting among them an active role in the vindication of these supports.
- Work with the environment to advance in the coordination and training of a social, health, educational, justice, ... network centred on the person and with technical and ethical competences that ensure good support.
- Promote public policies that favour inclusion and exercise of the rights of all persons and their families.
- Demand the development of systems to collect data on the population with the most significant disabilities or, at least, guarantee that the reality of these people is reflected in the different general and specific surveys on disability. Ensure that all models and proposals for full inclusion include people with great support needs and their families.<sup>35</sup>

### **3 Implementation and monitoring**

#### **3.1 Summary of relevant calls for proposals**

To our knowledge, there are no relevant calls for proposals in this specific regard.

#### **3.2 Summary of relevant projects funded**

To our knowledge, there are no relevant EU funded projects on promoting transitions from institutions to community living for people with disabilities– The projects are focused on promoting social inclusion of disadvantaged population (Roma, ex-prisoners).<sup>36</sup>

Many projects in Spain are carried out by representative entities of people with disabilities as well as other vulnerable groups, thanks to the subsidies granted to 0.7 % of the IRPF (Income Tax Physical Persons). These subsidies are intended to carry out programs to meet social interest purposes. For example, in the 2017 call the total number of beneficiary entities was 2,000, with 5,000 projects financed. Since the 2017 call, 20% of the funds go to eligible activities at the state level and 80 % to the CCAA to subsidize social assistance programs. For example, for the 2018 call, there is a total of EUR 49,282,767 for state subsidies and EUR 202,688,592.66 for regional grants. In February 2018 the resolution of the call corresponding to the IRPF of 2017 was published. This resolution includes aid for programs of dissemination, awareness and empowerment of people with comprehensive health care needs and grants have been granted for associations of people with physical disabilities, intellectual disabilities, guardianship foundations. There are also programs to attend to these groups or to

<sup>35</sup> Plena Inclusión (2016). Posicionamiento de Plena inclusión sobre personas con discapacidad intelectual o del desarrollo con grandes necesidades de apoyo. Available at: <http://www.plenainclusion.org/informate/actualidad/noticias/2016/posicionamiento-de-plena-inclusion-sobre-personas-con>.

<sup>36</sup> European Social Fund. Spain Projects. Available at: <http://ec.europa.eu/esf/main.jsp?catId=46&langId=es&keywords=&theme=0&country=378&list=1>.

carry out investigations in this regard. Half of the state actions receive amounts of less than EUR 40,000 with 12 % of regional projects receiving amounts of less than EUR 10,000. The Table below includes some of the projects funded by the Spanish government throughout the subsidies granted to 0.7 % of the IRPF.

<b>Entity</b>	<b>Program</b>	<b>Amount</b>
Fundacion Cruz Blanca	“We are”. Society awareness and empowerment program for dependent, elderly and disabled people)	8.000,00
Confederacion Plena Inclusión España Full Inclusion Confederation - Spain	Social awareness and empowerment for the rights of people with Intellectual or developmental disability	125.000,00
CNSE-Confederacion Estatal De Personas Sordas CNSE-State Confederation of Deaf People	Vidasor- Video Assistance and Accompaniment Service for Deaf Seniors	30.374,00
Federacion Nacional Aspaym (Asociación De Paraplejicos Y Grandes Discapacitados Fisicos) Association for People with Spinal Cord Injury (ASPAYM)	Digital Platform for Affordable Housing Management throughout the National Territory	16.000,0
Federacion Nacional Aspaym (Asociación De Paraplejicos Y Grandes Discapacitados Fisicos) Association for People with Spinal Cord Injury (ASPAYM)	Comprehensive care for people with spinal cord injury in accessibility and support products for their social inclusion	32,000
Confederación española de personas con discapacidad física y orgánica Spanish Confederation of People with Physical and Organic Disability	State strategic program of temporary housing services	95,000
Confederacion Plena Inclusión España Full Inclusion Confederation - Spain	Applied research for the implementation of services focused on people with intellectual or developmental disabilities and their families	550.000
Federación Española de Daño Cerebral Spanish Federation of Brain Injury	Social plasticity DCA: Action for the reconstruction of new projects of dignified life and inclusion of people with ACD in the community	20.000
Plataforma Representativa Estatal De Personas Con Discapacidad Fisica State Representative Platform for People with Physical Disabilities	State observatory of personal assistance and independent living	60.000,00
Provivienda	Collaboration in health protection policies through the promotion of decent housing	80.000,00
Confederación española de personas con discapacidad física y orgánica Spanish Confederation of People with Physical and Organic Disability	Comprehensive care program for people in centres dependent on IMSERSO through support services for independent living	480.7000
Federacion Nacional De Asociaciones ALCER (Asociación Para La Ayuda	Promotion and training of volunteers for their intervention in	7.000

Contra Las Enfermedades Del Riñón) National Federation of Associations ALCER (Association for Help IN Kidney Diseases)	the assisted floors program of the National Federation ALCER	
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### 3.3 Overview of other relevant measures since 2013

To our knowledge, there are no programs in Spain funded by the EU or other sources that are related to deinstitutionalization of people with disabilities. There are not specific measures aimed at deinstitutionalizing people with disabilities. As mentioned earlier, in Spain the right to live in an institution is claimed by different groups with disabilities. A significant proportion of the elderly who live in dependency situations require of institutions to live. Old people with significant intellectual disabilities and comorbid physical conditions consider the institutions their homes.

### 3.4 Monitoring mechanisms and approaches

#### 3.4.1 Monitoring mechanism(s)

To our knowledge, there are no programs in Spain related to deinstitutionalization.

#### 3.4.2 Measurement and data collection

To our knowledge, there are no programs in Spain related to deinstitutionalization.

## 4 Impact and outcomes

### 4.1 Progress against explicit targets and milestones

To our knowledge, there are no programs in Spain related to deinstitutionalization.

### 4.2 What is replacing institutional care?

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

People with disabilities are mostly out of institutional care. Only those with the most severe intellectual disabilities, are living in institutions. There are no plans to move these persons out of the institutions, as those facilities are perceived as the best alternatives for those persons. No debate on how this attitude fits with Article 19 of the CRPD has been started. The same can be said concerning institutionalized elderly population. The profile corresponds to very old people, with significant cognitive or physical impairments. There is not social pressure nor social movement aimed at deinstitutionalizing people with the most significant disabilities, even though, as stressed by some organisations,<sup>37</sup> this is contrary to Article 19, which extends the right

<sup>37</sup> Rodríguez Rodríguez, P., Ramos Feijóo, C., García Mendoza, A., Dabbagh Rollán, V.O., Mirete Valmala, C., & Castejón Villarejo, P. (2017). La atención en domicilios y comunidad a personas con discapacidad y personas mayores. Guía de innovación según el Modelo AICP. Madrid:

to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements.

Some initiatives as “mi Casa” (my home) project, are being developed by Plena Inclusion “to develop housing models in the community for all people, especially those who have greater support needs and who are generally excluded from inclusive and more personalized housing models.”<sup>38</sup>

#### 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?

Measures consist of removing physical barriers of buildings, providing personal assistants, financial support, community services, etc., for the vast majority of people with disabilities. Additional supports consist on Education, Health, and Social Services, which are universal and public in Spain.

### 4.3 Satisfaction levels among persons with disabilities

Some private projects have been implemented in this regard. For example, Fundación Pilares (2017),<sup>39</sup> a private and NGO, is developing a project for people with disabilities and the elderly to live in their community. The first results of the evaluation (2014-2015) show, among others, improvements in the quality of life, well-being and satisfaction of both the people served and their families’ caregivers.

Pallisera et al. (2018)<sup>40</sup> conducted a qualitative research study on the situation of people with intellectual disabilities with respect to their right to independent living. The authors analyse the barriers, supports and challenges that affect the exercise of this right, through 10 focus groups and 22 individual interviews to people with intellectual disabilities, and 5 focus groups with families and 33 individual interviews with professionals. The results of the research highlight the need to guarantee the universality of the right to independent life (it is a right and not a privilege), offer personalised quality support and develop training and awareness-raising actions on rights with the different actors involved. Navas et al. (2017)<sup>41</sup> published a research on

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Fundación Pilares. Available at: <http://www.fundacionpilares.org/docs/publicaciones/fpilares-guia02-domicilios-comunidad-2017.pdf>.

<sup>38</sup> More info at: <http://www.plenainclusion.org/informate/actualidad/noticias/2018/celebramos-el-primer-seminario-del-proyecto-mi-casa-sobre-los>.

<sup>39</sup> Rodríguez Rodríguez, P., Ramos Feijóo, C., García Mendoza, A., Dabbagh Rollán, V.O., Mirete Valmala, C., & Castejón Villarejo, P. (2017). La atención en domicilios y comunidad a personas con discapacidad y personas mayores. Guía de innovación según el Modelo AICP. Madrid: Fundación Pilares. Available at: <http://www.fundacionpilares.org/docs/publicaciones/fpilares-guia02-domicilios-comunidad-2017.pdf>.

<sup>40</sup> Pallisera, M. et al. (2018): “Retos para la vida independiente de las personas con discapacidad intelectual. Un estudio basado en sus opiniones, las de sus familias y las de los profesionales”. Revista Española de Discapacidad, 6 (1): 7-29. doi: 10.5569/2340-5104.06.01.01. Available at: [https://www.cedd.net/redis/index.php/redis/article/view/370/pdf\\_99](https://www.cedd.net/redis/index.php/redis/article/view/370/pdf_99).

<sup>41</sup> Navas Macho, P., Verdugo Alonso, M.A., Martínez Torres, S., Sainz Modinos, F., & Aza Hernández, A. (2017). Derechos y calidad de vida en personas con discapacidad intelectual y mayores necesidades de apoyo [Rights and quality of life of individuals with intellectual disability

Rights and quality of life of individuals with intellectual disability and extensive support needs. They conclude that disparities observed indicate the urgency of improving the knowledge about the living conditions of people with more significant ID and drive better practices in the provision of supports.

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and extensive support needs]. Siglo Cero, 48 (4), 7-66. Available at:  
<http://revistas.usal.es/index.php/0210-1696/article/download/scero2017484766/18532>.

## 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

In 2017, the UNCRPD<sup>42</sup> asked Spain to provide information on efforts, including legislative reforms, to ensure that laws, policies and procedures, mainly those related to the recognition and identification of disability, including the Personal Autonomy Promotion Act, employ a human rights-based approach to disability, and to review the requirements for recognition of dependency and the system for evaluating it in order to bring them into line with the Convention. They also requested Spain describe in detail the funding, the amount of resources used by Autonomous Communities and the proposed measures for making services and economic benefits for personal care available more quickly for accredited persons, making these available to more persons in need of them and guaranteeing equal coverage in all Autonomous Communities irrespective of the place of residence of the persons with disabilities. In addition, Spain should indicate how the generalized system of co-payment by individuals for support services is regulated, and what happens to persons with disabilities who are unable to provide the requisite contribution. Finally, to confirm whether the elimination of co-payment in all Autonomous Communities is envisaged.

The UNCRPD asked as well to explain the measure to guarantee nationwide the recognition of the right of persons with disabilities to choose their place of residence and have access to a range of social services, community support and other services for daily living, including personal assistance on the basis of individual requirements, rather than in pre-determined quantities. Also, to indicate whether it is intended to regulate personal assistance and whether there is any distinction between that system and that of the caretaker.<sup>43</sup>

To answer these questions, the report presented by Spain in 2018 on the follow-up of the actions that are being carried out regarding the safeguarding of the rights of persons with disabilities stated in the CRPD, some actions that are being carried out.<sup>44</sup> For example: (1) Start-up of a working group to analyse the provision of personal assistance and to propose the modification of the provision of care in the environment and / or the provision of home help. (2) Proposal to develop a new type of economic benefit aimed at hiring professional caregiver for people who are currently being treated at home and who either do not have family members or who do not have the availability to take care of themselves living with the beneficiary. It would therefore be

<sup>42</sup> UN CRPD (2017). List of issues prior to the submission of the combined second and third periodic reports of Spain. Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/107/99/PDF/G1710799.pdf?OpenElement>.

<sup>43</sup> UN. CRPD. (2017). List of issues prior to the submission of the combined second and third periodic reports of Spain. Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/107/99/PDF/G1710799.pdf?OpenElement>.

<sup>44</sup> UN CRPD (2018). Informes periódicos segundo y tercero combinados que España debía presentar en 2018 en virtud del artículo 35 de la Convención. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPrICAqhKb7yhsIxq2MuiDp%2fqMKQ6SGOn0%2fM4rP4Sn04ITU2hnYsbysiJg%2fxfpTWmXHihRhuR7jOTgZj9F0rGUx5uDEEPk8d0jgsBRMI07efi1K3EB%2f1Pr1%2b1>.

a new economic benefit that would allow the dependent to be attended at home, under parameters of professionalism and public control.

It also reports on existing initiatives such as:<sup>45</sup> (1) the one developed in the Community of Madrid. Different types of assistance resources are combined in attention to the physical, family and social situation of the person with disability and the needs that this has derived from their disability and / or dependency. (2) Specific resources to avoid the institutionalization of people with disabilities and facilitate their permanence in their community environment. Among them: places in pensions for people with mental illness; the sheltered flats for people with mental illness as well as for people with disabilities; transition flats for independent living; telecare and home help or community social care teams in the case of people with mental illness living in their home. (3) The Community of Madrid has an Office of Independent Living (OVI), through which a network of personal assistants is organized to provide assistance and support to people with physical disabilities in situations of dependency and great motivation to have an independent life. Currently serving 72 users (50 % men and 50 % women) who develop an active educational or work life. The work of these personal assistants focuses on assistance and support, following the guidelines and instructions of the user with disabilities, related to facilitating and making possible this training or work activity. Other functions from those who perform home help or personal care. (4) In the Autonomous Community of Castile and Leon, there are, among many others, these two ways of promoting independent life: the promotion of personal assistance and the development of a network of integrated housing in the community, all of this as a complement to numerous actions to promote employment among people with disabilities.

The Concluding Observations from the Committee on the above-mentioned report will issue following Spain's hearing scheduled for March 2019. At present, we can refer to the previous Concluding Observations, issued in 2011.

The consideration from the CRPD of reports submitted by States parties under Article 35 of the Convention and the Concluding observations of the Committee concerning Living independently and being included in the community (Article 19) in Spain (2011), reflect that the Committee was concerned at the lack of resources and services to guarantee the right to live independently and to be included in the community, in particular in rural areas. It was further concerned that the choice of residence of persons with disabilities was limited by the availability of the necessary services, and that those living in residential institutions are reported to have no alternative to institutionalization. Finally, the Committee was concerned about linking the eligibility of social services to a specific grade of disability. This is still true in Spain.

The Committee encourages Spain to ensure that an adequate level of funding is made available to effectively enable persons with disabilities: to enjoy the freedom to choose their residence on an equal basis with others; to access a full range of in-home, residential and other community services for daily life, including personal assistance;

<sup>45</sup> UN CRPD (2018). Informes periódicos segundo y tercero combinados que España debía presentar en 2018 en virtud del artículo 35 de la Convención. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhs1xq2MuiDp%2fqMKQ6SGOn0%2fM4rP4Sn04ITU2hnYsbysiJg%2fxfpTWmXHihRhuR7jOTgZj9F0rGUx5uDEEPk8d0jgsBRMI07efi1K3EB%2f1Pr1%2b1>.

and to also enjoy reasonable accommodation so as to better integrate into their communities.

The Committee is concerned that the law for the promotion of autonomy limits the resources to hire personal assistants only to those persons who have level three disabilities and only for education and work.

The Committee encourages the State to expand resources for personal assistants to all persons with disabilities in accordance with their requirements.

The Committee takes note of the legal regime allowing the institutionalization of persons with disabilities, including persons with intellectual and psychosocial disabilities (“mental illness”). It is concerned at the reported trend of resorting to urgent measures of institutionalization which contain only ex post facto safeguards for the affected individuals. It is equally concerned at the reported abuse of persons with disabilities who are institutionalized in residential centres or psychiatric hospitals.<sup>46</sup>

## 5.2 Recent observations by other official European and international bodies

As stated by Interlink project,<sup>47</sup> Spain is a state composed of 17 Autonomous Communities. Spain has a decentralized health and social system where Regional Ministries of Health are fully responsible for providing health and social care to the population. This welfare model, with separate health care and social services and their interventions, has changed under the new national dependency system which came into force in 2006 and established for the first time specific rights of dependent people and their caregivers. The challenges facing the new dependency care system include, in theory, coordinating the decentralised autonomous system and the state system to manage financial benefits, services and programmes, or setting up regional agencies and dependency assessment bodies that will use national criteria. In the social field, the private sector dominates the care provision. In the health sector, the provision of LTC services is mainly public.<sup>48</sup> Municipalities have almost no impact on LTC planning. Regional governments supervise the care delivery in LTC.

Different international organisations stress the need to deinstitutionalize people with disabilities and people in disadvantaged situations in Europe. Some of those organisations are: COFACE (Confederation of Family Organisations in the EU),<sup>49</sup> EASPD (European Association of Service Providers for People with Disabilities),<sup>50</sup>

<sup>46</sup> UN CRPD (2011). Consideration of reports submitted by States parties under Article 35 of the Convention. Concluding observations of the Committee on the Rights of Persons with Disabilities. Spain. Available at:

<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhslxq2MulDp%2FqMKQ6SGOn0%2FNZ5trZrfqNmKdTjE%2FScMKF96xMrtyzhDx7aguCpqdK4xQVGCY502yRGHBFyeVZXNw00SiVNraxD5auFDv%2FVv2m>.

<sup>47</sup> Interlinks, Health systems and long-term care for older people in Europe. Modelling the interfaces and links between prevention, rehabilitation, quality of services and informal care. Available at: <http://interlinks.euro.centre.org/countries/spain>.

<sup>48</sup> See Pathways for long term care provision in Spain, at: [http://interlinks.euro.centre.org/sites/default/files/ES\\_Mrs.LTCarerev.pdf](http://interlinks.euro.centre.org/sites/default/files/ES_Mrs.LTCarerev.pdf).

<sup>49</sup> <http://www.coface-eu.org/category/disability/deinstitutionalisation/>.

<sup>50</sup> <https://www.easpd.eu/en>.

EDF (European Disability Forum),<sup>51</sup> ENIL/ECCL (European Network on Independent Living/European Coalition for Community Living),<sup>52</sup> ESN (European Social Network),<sup>53</sup> Inclusion Europe,<sup>54 55 56</sup> Lumos,<sup>57</sup> Mental Health Europe,<sup>58</sup> Mental Health Initiative Open Society Foundations.<sup>59</sup>

### 5.3 Observations and recommendations by national human rights bodies

In February 2019, the Spanish NHRI (Defensor del Pueblo de España) submitted its list of questions for the upcoming hearing on Spain in March 2019,<sup>60</sup> including the following statement on Article 19:

Article 19.- Right to live independently and to be included in the community

...the important effort made by public administrations to develop the System for Autonomy and Care for Dependency should be noted. These efforts have not been sufficient in all cases to guarantee beneficiaries the enjoyment of the benefits and services that correspond to them and that legally have the consideration of subjective rights. The normative changes, the difficulties of certain requirements in a context of serious delays in the processing of applications and the reduction in the amount of benefits, mean that the first decade of implementation of the Law of Dependence is not, on balance, as positive as it should have been.

Significant differences remain in the way in which the participation of the beneficiaries in the cost of the services they receive is calculated according to the territorial Administration responsible for providing them.<sup>61</sup>

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

No relevant information available.

## 6 Views and perspectives of civil society including DPOs

### 6.1 UNCRPD civil society shadow and alternative reports

<sup>51</sup> <http://www.edf-feph.org/search/node/deinstitutionalization>.

<sup>52</sup> <https://enil.eu/> y <http://community-living.info/>.

<sup>53</sup> <https://www.esn-eu.org/>.

<sup>54</sup> <http://www.inclusion-europe.eu/>.

<sup>55</sup> <https://www.inclusion-europe.eu/wp-content/uploads/2017/07/Submission-to-the-Draft-General-Comment-No-5-on-Article-19.pdf>.

<sup>56</sup> <https://www.inclusion-europe.eu/people-with-complex-support-needs-how-they-can-live-in-the-community/?highlight=deinstitutionalization>.

<sup>57</sup> <https://www.wearelumos.org/>.

<sup>58</sup> <https://mhe-sme.org/>.

<sup>59</sup> <https://www.opensocietyfoundations.org>.

<sup>60</sup> Defensor del Pueblo de España, List of issues, February 2019, available at:

[https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFR%2fESP%2f34071&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFR%2fESP%2f34071&Lang=en).

<sup>61</sup> Defensor del Pueblo de España, List of issues, February 2019, available at:

[https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFR%2fESP%2f34071&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFR%2fESP%2f34071&Lang=en), p10 (informal translation of Spanish original).

The European Network on Independent Living (ENIL) and the Federación Vida Independiente (FEVI), a federal network of Spanish organisations promoting Independent Living, in their Report on the Implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in Spain (released 14 February 2019)<sup>62</sup> express their concerns with regard to Article 19 CRPD, stating that “As organisations led by disabled people and focusing on disabled people’s access to the right to live independently and to be included in the community, ENIL and FEVI are deeply concerned about Spain’s lack of progress in implementing Article 19 CRPD since the country’s initial review in 2011. Our key concerns in Spain, in relation to access to Independent Living are: a) Minimal progress towards independent living and failure to adopt a strategy and a concrete plan of action for deinstitutionalisation; b) Continued use of public funds to build new residential institutions for disabled people, and c) Extreme difficulty in accessing personal assistance for disabled people” (page 3). They also refer to the Spanish report by the Academic Network of European Disability Experts<sup>63</sup> in which is stated that “progress on de-institutionalisation and the development of support for long-term community support services” is a concern, and economic constraints affect access to services and benefits, especially for those with lower support needs”. In addition, they mention that: “Other services offered by the state such as telecare, day care centres, night care centres, and home services, are not user-led” (page 4). They continue in their report stating that: “Despite the increasing number of people in long-stay residential institutions, Spain does not have a deinstitutionalisation strategy in place, nor an action plan. This means that there is no political will at the moment to put in place community-based alternatives to institutional care, such as personal assistance, and close down existing institutions. It is of great concern that most, if not all institutions, are developed in partnership with organisations of and for disabled people. This is used to legitimise the continued segregation of disabled people, despite being in violation of the UN CRPD and the European laws and policies on social inclusion” (page 4). Latter in their report they affirm that. “ENIL and FEVI have found substantial evidence of increasing public investment into the building of new long-stay residential institutions for disabled people. It is of an even greater concern that many of these new institutions have benefited from partnerships with organisations of or for disabled people in Spain” (page 5), and “While many of the institutions occupy contemporary buildings, with a lot of space and modern facilities, and some claim to provide “personal assistance”, all of the long-stay residential institutions retain many of the institutional care characteristics (...) In particular while they offer disabled people some degree of choice and control over their lives, “these choices are limited to specific areas of life and do not change the segregating character of institutions”. (page 6). Finally, ENIL and FEVI, call on the CRPD Committee to include the following recommendations in its observations to the Spanish Government. In order to ensure compliance with Article 19 CRPD, Spain must (pp. 9-10):

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<sup>62</sup> Report on the Implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in Spain, Submitted by the European Network on Independent Living (ENIL) and Federación Vida Independiente (FEVI): [https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT\\_CRPD\\_CSS\\_ESP\\_33\\_976\\_E.docx](https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT_CRPD_CSS_ESP_33_976_E.docx).

<sup>63</sup> Verdugo, M.A. and Jenaro, C., European Semester 2017/2018 country fiche on disability, Academic Network of European Disability Experts, page 30, at: <https://www.disability-europe.net/country/spain>.

- a. As a matter of priority, put in place a strategy for deinstitutionalisation, with specific timeframes and an adequate budget, in order to facilitate the closure of all long-stay residential institutions and the development of quality community-based alternatives that promote social inclusion and participation, for all groups of disabled people.
- b. Stop using public funds to build new long-stay residential institutions for disabled people. Instead, funds should be used to develop accessible and affordable housing solutions, including social housing and supported living that facilitate independent living and social inclusion.
- c. Allocate sufficient resources for the development of person centred and user-led services for all disabled people, such as personal assistance.
- d. Revise eligibility criteria and funding for personal assistance, in line with the human rights model of disability, to ensure that all disabled people in need of personal assistance can benefit from this service. Furthermore, the right to personal assistance, as defined in the General Comment No 5, should be enshrined in law, in order to ensure equal access and to avoid discrimination based on the place of residence (i.e. post code lottery).
- e. Ensure that all disabled people have access to peer support, in order to be able to make informed choices about their life and put in place the necessary services to follow these choices.
- f. Together with organisations that promote Independent Living (such as Centres for Independent Living), develop and run awareness raising campaigns about the right to live independently and to be included in the community, targeting policy and decision makers, disabled people and their representative organisations, families of disabled people, service providers, media and the general public.”

Arnau Ripollés (2017), from the Civil Society Organisation IPADEVI<sup>64</sup> states that Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for the situation of dependency, although it has the "Economic benefit of personal assistance, the main philosophy of resources and services which it offers is traditional (welfare and institutionalizing) and, therefore, contrary to the Human Rights Approach promoted by the United Nations, through the 2006 Convention.

European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP), in their report from 2017<sup>65</sup> state that ENUSP is concerned that Spain has failed to comply with the recommendation of the Committee on the Rights of Persons with Disabilities concerning the need for Spain to review its laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; repeal provisions that authorise involuntary internment linked to an apparent or diagnosed disability; and adopt measures to ensure that health-care services, including all mental-health-care services, are based on the informed consent of the person concerned.

<sup>64</sup> Arnau Ripollés, S. (2017). Personas LGTBQI+ y diversidad funcional en España. Aportaciones del instituto de paz, derechos humanos y vida independiente (IPADEVI): [https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT\\_CRPD\\_ICSP\\_ESP\\_268\\_84\\_S.doc](https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT_CRPD_ICSP_ESP_268_84_S.doc).

<sup>65</sup> European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) ENUSP Proposals for the List of issues on Spain, CRPD Committee. Available at: [https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT\\_CRPD\\_ICSP\\_ESP\\_268\\_82\\_E.doc](https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT_CRPD_ICSP_ESP_268_82_E.doc).

CERMI (2016), in its report: 2006-2016: 10 years of the International Convention on the Rights of Persons with Disabilities - Balance of its application in Spain,<sup>66</sup> raises several needs for improvement:

1. In relation to forced deinstitutionalization and in order to end it, it is necessary to adopt a State Strategy of Inclusion in the Community that allows institutionalized people to benefit from inclusive life formulas in the community. This requires having public support to make effective their election. Also and in line with that expressed by ENUSP, CERMI states that a rethinking of the non-voluntary internment due to psychic disorder that separates the forced internment from the condition of person with a disability and that determines the emergency situations in which a person (with or without a disability) could be admitted without your consent. This regulation shall be made by organic law, in compliance with the Constitutional Court Sentences 132/2010 and 141/2012. Therefore, it is necessary to regulate the forced internment of people with mental illness art. 763.1.2 LEC, including alternatives to the incarceration of mental patients that facilitate the recovery and social reintegration of these people (p.270).
2. There is a need to regulate the rights of institutionalized people to prevent degrading treatment, in which there is a greater risk of violating their rights and having fewer possibilities to exercise legal protection mechanisms. On the other hand, it has been verified the existence of practices that violate fundamental rights in public residences (page 110).
3. It is necessary a system of attention that is oriented towards a model of autonomous and independent life, that favours the inclusion in the community. In this sense, it is necessary that the Law for the Promotion of Personal Autonomy and Attention to Persons in Dependence acquire an approach oriented to the Convention and that territorial inequalities be overcome. The data show a clear tendency to favour institutionalization in the face of independent life and in community with the resources that are necessary. The system restricts benefits for study or work and excludes that they can support access to leisure or culture, which reflects a welfare model. It is also necessary to strengthen the associative movement in line with the purposes of the Convention, aimed at favouring the participation of people with disabilities in the design, application and monitoring of the policies that affect them (page 111).
4. Lack of accessibility in homes, lack of an elevator, and others that prevent the maintenance of an independent and autonomous life (page 112).
5. It is necessary to adapt all the services, benefits and support resources so that they are accessible in equal conditions for all people in rural areas (page 112).
6. Children with disabilities have less support to ensure their independence and autonomy and children under three years of age lack it because the comprehensive care plan for children under three years of age as provided for in the law has not been approved (page 111).

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<sup>66</sup> CERMI (2016) 2006-2016: 10 años de la Convención Internacional sobre los Derechos de las Personas con Discapacidad – Balance de su aplicación en España. Available at: [https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT\\_CRPD\\_NHS\\_ESP\\_33289\\_S.pdf](https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ESP/INT_CRPD_NHS_ESP_33289_S.pdf).

## 6.2 ‘Grey literature’ at the national level

The quality of community services provided to people with disabilities is based on: (1) the compliance with the quality standards concerning housing; (2) the quality of life experienced by people with disabilities in this regard.

On the compliance with the quality standards on housing, the Autonomous Communities or the competent Administration, certify the centres and contracted services to pay attention to people in situations of dependency so they can perceive the linked economic benefit. Similarly, private entities will be certified for each of the centres and services that they provide. Quality requirements and standards are established in the following areas: a) material and equipment; b) human resources.

On the quality of life experienced, a study by Huete and colleagues (2015)<sup>67</sup> showed that people with disabilities face additional expenditures on the acquisition of goods and general services (such as having to spend more on transportation), or expenses in goods and services specifically related to disability, such as technical assistance and support products, home adaptations to improve accessibility, or staffing personal assistance. In addition, the average income of people with disabilities is often below the average for the whole population. Another aspect that has a great impact on households with low and medium incomes refers to indirect taxes. Also, it is important to check the rise in taxes, returning to reduce taxes from 21 % to 4 % of primary products in the household budget, for example, and materials related to children, such as diapers and day care services, and adult hygiene such as sanitary napkins and adult diapers. Electricity and other basic supplies for housing have very high rates and generate increasing energy poverty.

## 6.3 Pan-European and international civil society organisations

In nearly all OECD countries, between half and three quarters of all formal long-term care (LTC) is provided in home-care settings, with a substantial share of these suffers from dementia-related problems.<sup>68 69</sup> Very elderly users are less likely to receive home care than younger ones. Nevertheless, more than half of the care recipients aged 80 years or over receives care at home in most countries, and only a third of all LTC users receives care in institutions. In contrast, 62 % of total LTC expenditure occurs in institutional settings. LTC spending accounted for 1.5 % of GDP on average across 25 OECD countries in 2008 (In Spain it accounted for 0.7%). This variation reflects differences in care needs, the comprehensiveness of formal systems, and family caring cultures. Spending on LTC in institutions is higher than spending at home, even in countries like Spain. Whatever the LTC system of a country, most care is provided by family carers (and friends), as part of an ongoing social relationship. Across the OECD, more than one in ten adults aged over 50 provides informal (usually unpaid) help with

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<sup>67</sup>

<http://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

<sup>68</sup> OECD (2011) Help Wanted? Providing and Paying for Long-Term Care. Available at: [https://read.oecd-ilibrary.org/social-issues-migration-health/help-wanted\\_9789264097759-en#page1](https://read.oecd-ilibrary.org/social-issues-migration-health/help-wanted_9789264097759-en#page1).

<sup>69</sup> OECD (2011) Help Wanted? Providing and Paying for Long-Term Care. Available at: <http://www.oecd.org/health/health-systems/Help-Wanted-Policy-Brief.pdf>.

personal care to people with functional limitations. Much of this informal care is of low intensity: just over half of carers are involved in caring activities involving less than ten hours per week. This low intensity of caring is particularly prevalent in Northern European countries and Switzerland. In contrast, in Southern Europe, the Czech Republic and Poland, more than 30 % are intensive carers (supplying more than 20 hours per week), rising to over 50 % in Spain and over 60 % in Korea. This large variation signals not only different government policies on family obligations, but also cultural and societal attitudes.<sup>70</sup>

## 7 Academic research

A report by Verdugo and Navas (INICO, 2017)<sup>71</sup> states that, according to data from 2008, people with intellectual disabilities and greater limitations continue to experience situations of social exclusion. 20 % of people with intellectual disabilities continue to live in institutions: 31,482 people out of a total of 155,981, with more than half (16,591) people with severe and profound intellectual disabilities. Eliminating these exclusion scenarios implies 'rethinking' the supports they receive. The report on the Spanish case prepared by the PSICOST<sup>72</sup> group indicates that 71 % of the places in residential environments for people in situations of dependency are aimed at people with intellectual disabilities. The percentage of residential places destined to population with intellectual disability that do not show dependence increases up to 81 %. The dependency aids perceived by people with more severe intellectual disabilities usually consist of residential care, as opposed to other types of economic benefits.

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<sup>70</sup> OECD (2011) Help Wanted? Providing and Paying for Long-Term Care. Summary and conclusions. Available at: <http://www.oecd.org/els/health-systems/47887770.pdf>.

<sup>71</sup> Verdugo, M.A., Navas, P., Martínez, S., & Sainz, F. (2016). Todos somos todos. Derechos y calidad de vida de las personas con discapacidad intelectual y mayores necesidades de apoyo. Informe Ejecutivo. Available at: <http://www.plenainclusion.org/sites/default/files/30-11-16-todosomostodos-informeejecutivo.pdf>.

<sup>72</sup> Mansell, Jim and Knapp, Martin and Beadle-Brown, Julie and Beecham, Jennifer (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: main report. University of Kent, Canterbury, UK. Available from: [https://www.researchgate.net/publication/30523444\\_Deinstitutionalisation\\_and\\_community\\_living-outcomes\\_and\\_costs\\_report\\_of\\_a\\_European\\_Study\\_Volume\\_2\\_Main\\_Report](https://www.researchgate.net/publication/30523444_Deinstitutionalisation_and_community_living-outcomes_and_costs_report_of_a_European_Study_Volume_2_Main_Report).

## PART C – Key points

### 8 Positive developments, including promising practice examples

In Spain, the vast majority of people with disabilities live in the community and with their families. As it is a country in which health, education and social services are public, people feel that their basic needs are met. In addition, residential / institutional care is usually focused on people with a significant decline and advanced age, in which the healthcare and health needs predominate, rather than training or otherwise.

However, it is necessary to advance in good practices, as there are still problems related to the differences in services and supports in the different regions of the country and the disadvantage in which people with disabilities in rural areas find themselves. There is also a lack of power of the end-user of the services, when choosing the services and supports that best respond to their needs, desires or interests. Legislation in this regard is considered as more assistance than promoter of capabilities, independence and self-determination. In addition, different groups of people with disabilities claim the need to replace large residential centres with smaller, more familiar housing alternatives included in the community.

Institutionalization, especially when it is prolonged, when it begins at an early age, when it is not chosen, when it is a situation forced by circumstances (for example, lack of accessible housing, lack of financial means, lack of educational resources or of another type in the place of origin), is associated with an inferior quality of life. This institutionalization reduces the possibilities of choosing and is also sometimes associated with bad practices and even mistreatment.

For all these circumstances, different groups with disabilities (physical, intellectual, mental health) demand the provision of more resources to create more familiar, smaller homes, where people can make decisions about all aspects of everyday life. They also request better financing of these alternatives, instead of the construction of large institutions. Some promising practices include:

- During the month of June 2017, Full Inclusion launched an awareness campaign to make visible the reality of these people and their families, show their different life situations and claim the full exercise of their rights. It does so by holding four days in different places in Spain. On these days there are claims related to the situation of discrimination of these people and their families, and a series of "life stories" that relate particular cases.<sup>73</sup> For them, Full Inclusion has launched the "Tod@s somos Tod@s" Project. With this positioning, Full Inclusion acquires the unwavering commitment to favour the real incorporation of ALL people, whatever their support needs, to society, and contribute to their being able to live their own lives with fullness and dignity. Full inclusion proposes:
  - Calling for the end of the model of segregated welfare services, and promoting its transformation towards a model of supports and services based on the quality of life, full citizenship, adaptation to the needs of the person and inclusion in the community.

<sup>73</sup> <http://www.plenainclusion.org/informate/campa%C3%B1as/todos-somos-todos>.

- Articulating a strict monitoring of compliance with the basic rights established by the UN Convention of rights, developing actions of social complaints and demand of dignified living conditions for all.
  - Supporting families so that all their members can develop their life project, promoting among them an active role in the vindication of these supports.
  - Working with the environment to advance in the coordination and training of a social, health, educational, justice, ... network centred on the person and with technical and ethical competences that ensure good support.
  - Promoting public policies that favour the inclusion and exercise of the rights of all persons and their families.
  - Demand the development of systems to collect data on the population with the most significant disabilities or, at least, guarantee that the reality of these people is reflected in the different general and specific surveys on disability.
  - Ensure that all models and proposals for full inclusion include people with great support needs and their families.<sup>74</sup>
- Concerning mental health, a proposition presented by the Socialist Parliamentary Group, on the update of the National Strategy of Mental Health of the National Health System, has been approved by the Congress. The proposition states that: "The Congress of Deputies urges the Government to: - Complete the evaluation of the National Strategy of Mental Health System National Health, in coordination with the Autonomous Communities and with the participation of professionals and representatives of patients and their families, with special emphasis on the evaluation of the implementation of recommended therapeutic measures, individualized intervention plans and care integrated and integral to mental illness patients by multidisciplinary teams that include family care. - On the basis of this evaluation, adopt for the period 2017-2022, a new National Strategy for Mental Health for the National Health System, which is in a position to be approved by the Interterritorial Council of the SNS, under principles of universality, equity, efficiency, solidarity and integration. This new Strategy must contemplate the multidimensional approach and the multi-professional response to mental illnesses, a community care orientation, with the due continuity of care, with the necessary care and support in the home, with benefits and alternative services to the institutionalization and giving an essential role to psychological and psychosocial interventions and prevention work, denouncing the therapeutic impoverishment and the pharmacological response as the main tool. Said Strategy must equip itself with the necessary resources to make it a reality from 2017-2022, contemplating the needs of human resources, its adequate training, the participation of society and patients and research."<sup>75</sup>

<sup>74</sup> Plena Inclusión (2016). Posicionamiento de Plena inclusión sobre personas con discapacidad intelectual o del desarrollo con grandes necesidades de apoyo. Available at: <http://www.plenainclusion.org/informate/actualidad/noticias/2016/posicionamiento-de-plena-inclusion-sobre-personas-con>.

<sup>75</sup> Proposición no de Ley presentada por el Grupo Parlamentario Socialista, sobre la actualización de la Estrategia Nacional de Salud Mental del Sistema Nacional de Salud [Boletín Oficial de las Cortes Generales. Congreso de los Diputados XII Legislatura (10 de mayo de 2017). Pps. 79-80]. Available at: <http://www.infocoponline.es/pdf/BOCG-12-D-150.pdf>.

- Fundación Pilares (2017),<sup>76</sup> Foundation for Personal Autonomy, has proposed the Project Cuidarnos contigo<sup>77</sup> which is being developed in Madrid. This project has been financed by the Obra Social La Caixa and by the Ministry of Health, Social Services and Equality, through an IRPF call. The first results of the evaluation (2014-2015) show, among others, improvements in the quality of life, well-being and satisfaction of both the people served and their families care givers. This Project is in its second phase since 2016 and has been extended to two municipalities in Alicante. The program is based on the idea that caring for a person in situations of dependency and / or with disabilities is not easy, so they offer a support program for people in situations of fragility, disability or dependency and for care givers, based on a model of attention respectful of their dignity and rights. The program offers interviews at home to meet the person who needs support and for whom they are provided, their needs and wishes and assess the adaptability of the home. Depending on each case, they offer: (1) accompaniment and monitoring of the situation. Advice to the person and their family about community resources (public or private) that may be appropriate to their situation. (2) Management and provision of proximity services, depending on the possibilities and needs and demands of families: Services for family rest and support for the person; Podiatry, physiotherapy, hairdressing, etc. (4) Orientation and training on adaptations of housing and use of technology and support products. (4) Training at home for care and self-care (delivery of the Guide Caring, taking care of yourself and feeling good). (5) Organisation and promotion of individual and group activities (after-school, leisure, cultural, educational, etc.), among other things.<sup>78</sup>
- Under the project “Mi Casa” (My House),<sup>79</sup> Plena Inclusión wants to develop housing models in the community for all people, especially those who have greater support needs and who are generally excluded from these models. The project consists in the realization of Pilots for the development of models of housing and life in the community for people with great support needs in different parts of Spain. A project model of three years (2019-2021) is being developed in different parts of Spain in collaboration with INICO research centre at the

<sup>76</sup> Rodríguez Rodríguez, P., Ramos Feijóo, C., García Mendoza, A., Dabbagh Rollán, V.O., Mirete Valmala, C., & Castejón Villarejo, P. (2017). La atención en domicilios y comunidad a personas con discapacidad y personas mayores. Guía de innovación según el Modelo AICP. Madrid: Fundación Pilares. Available at: <http://www.fundacionpilares.org/docs/publicaciones/fpilares-guia02-domicilios-comunidad-2017.pdf>.

<sup>77</sup> Fundación Pilares (2015). Cuidarnos contigo. Memoria: Proyecto piloto de atención integral y centrada en la persona en el Distrito de Chamberí (Madrid), mediante gestión de casos (2014-2015). Madrid: Fundación Pilares. Available at: <http://www.fundacionpilares.org/docs/programas/cuidarnos-contigo/memoria-cuidarnoscontigo-2014-2015.pdf>.

<sup>78</sup> Fundación Pilares (2015). Cuidarnos contigo. Memoria: Proyecto piloto de atención integral y centrada en la persona en el Distrito de Chamberí (Madrid), mediante gestión de casos (2014-2015). Madrid: Fundación Pilares. Available at: <http://www.fundacionpilares.org/programas/cuidarnos-contigo/index.php>.

<sup>79</sup> Plena Inclusión (2018). Viaje de transformación. Experiencia de Gales. Modelos de vivienda y vida en la comunidad para personas con grandes necesidades de apoyo. Available at: <https://media-edg.barcelona.cat/wp-content/uploads/2018/05/24162501/PROYECTO-MI-CASA.pdf>.

University of Salamanca. According to Plena Inclusión,<sup>80</sup> in Spain there are already organisations that have opted for personalized housing models (small scale) and inclusion in the community for people with large support needs. In addition, other residential care centres, larger scale, more segregated and isolated, have committed to transformation processes to guide their professional practice towards personalization and inclusion. As of October 2017, there are already 32 residential services for people with large support needs who are developing these transformation processes, supporting a total of 1,145 people with disabilities, 1,216 professionals and 190 volunteers. The number of people per residential centre ranges from 140 to 5, with an average of 36 people. Despite the small group represented by people with large support needs compared to the general population (0.2 %), they need, given their support needs, a wide range of economic and human resources, requiring our Government to provide them priority when developing social policies for the provision of supports and services. That our Administration considers the needs of this group as a priority is a matter of urgency, since there is consensus when it comes to indicating an increase in the number of people that can be included in this population group, which will undoubtedly require a strategy as a social policy to guarantee access to appropriate resources.<sup>81</sup>

## 9 Negative developments including examples of poor practice

The main problems in Spain in relation to the right to live independently and to be included in the community are:

1. Complexity, incompatibility and regional inequality in relation to the provision of aid for the promotion of independent life and in the community for people with high support needs.
2. The offer of services (e.g. institutional care, day centres) is prioritized over economic benefits (e.g. money to pay a personal assistant), the amount of which is also generally insufficient. The services offered in the home are also insufficient for a person who requires continuous supervision. Finally, families or users opt for residential services versus home services.
3. Residential services are not, per se, a problem. The problem is more related to the management model. With the lack of respect for self-determination, individualisation, rights, inclusion and quality of life of its users.
4. Although the cost of a residential service is higher for the state, it is a cost that is usually subsidized for the user, so it is cheaper for the person with disability and high support needs to reside in an institution. This situation explains why the majority of people with the most severe needs are living in institutions.

<sup>80</sup> Plena Inclusión (2018). Viaje de transformación. Experiencia de Gales. Modelos de vivienda y vida en la comunidad para personas con grandes necesidades de apoyo. Available at: <https://media-edg.barcelona.cat/wp-content/uploads/2018/05/24162501/PROYECTO-MI-CASA.pdf>.

<sup>81</sup> Plena Inclusión (2018). Viaje de transformación. Experiencia de Gales. Modelos de vivienda y vida en la comunidad para personas con grandes necesidades de apoyo. Available at: <https://media-edg.barcelona.cat/wp-content/uploads/2018/05/24162501/PROYECTO-MI-CASA.pdf>.

## 10 Recommendations

1. Greater, better and more transparent use of public monies for the promotion of services consistent with the right to an independent life and included in the community.
2. More dissemination of results of studies, research, initiatives, financed with state, European, public funds, etc., that provide solid evidence on the results of deinstitutionalization of different groups with different personal and social circumstances.
3. Financing of research and experiences with European funds in relation to deinstitutionalization. Better access to these investigations and their results. More transparency and ease of consultation of such investigations and subsidized projects. We have not been able to find information on Spanish or European government pages about how European Structural and Investment Funds are being used to support community living for persons with disabilities, children and older persons. We find ourselves with the same problem highlighted by the FRA, when it states that: “Operational programmes do not include the level of detail required to identify the exact allocation and distribution of funds to support the transition from institutional to community-based support”. In sum, there is a big gap between the aims, goals, recommendations in the EU funding instruments, and their translation to specific local and national programmes. Smaller organisations that traditionally request funds for projects financed with 0.7 % of IRPF are discouraged from applying for European funds perceived as distant to their daily life and with great difficulty in their management.