



# Empowerment of people with complex support needs

Report



@InclusionEurope



@InclusionEurope



[youtube.com/user/inclusion-europe](https://youtube.com/user/inclusion-europe)

Rue d'Arlon 55  
B-1040 Brussels, Belgium  
Telephone: +32-2-502 28 15  
[secretariat@inclusion-europe.org](mailto:secretariat@inclusion-europe.org)  
[www.inclusion-europe.org](http://www.inclusion-europe.org)



Co-funded by the European Union

This report was funded by the European Union. The EU bears no responsibility for the contents of the report.

## Contents

Executive Summary.....	4
Introduction .....	6
1- Every life has value and should be respected .....	7
Benefits .....	7
Problems.....	8
Solutions .....	9
2- Everyone can flourish and increase/gain control over their lives .....	12
Benefits .....	12
Problems.....	14
Solutions .....	14
3- Everyone can contribute to the community .....	19
Benefits .....	19
Problems.....	19
Solutions .....	20
4- Every family has the right to an ordinary life.....	25
Benefits .....	25
Problems.....	25
Solutions .....	26
What should be done? .....	29
At EU level.....	29
In Members States .....	29
In Inclusion Europe movement .....	30

# Executive Summary

---

Inclusion Europe is fighting for the rights of all people with intellectual disabilities and their families across Europe. Through this position paper, Inclusion Europe reaffirms the need for the Inclusion movement, the authorities and the whole community to include people with complex support needs and their families, who are often the most excluded.

## Every life has value and must be respected

The inherent value and dignity of one's life is universal and unconditional. It has been recognised by all human rights treaties. More than an obligation, the inclusion of the most vulnerable enhances the whole society that benefits from it.

People with complex support needs are frequently perceived as unable to live in the community. They have always been used to justify the existence of segregated places and special services. They constitute one of the most invisible minorities and face an aggravated level of exclusion.

The social perception of people with complex support needs and the clichés about them need to be tacked from the youngest age. We need to multiply the interactions between the general population and people with complex support needs where they take an active role in their lives and the community to fight stereotypes.

## Everyone can flourish and increase/gain control over their lives

Why? Inclusion Europe strongly believes in the importance of enabling self-determination for everybody and the positive impact that has on one's quality of life. Regardless of the disability or the level of the need for support, everyone with adequate support can flourish.

What is the problem? Due to the lack of solutions provided, people with complex support needs live in large institutional settings or rely solely on their families for support and care.

How to improve that? People with complex support needs must have access to individual support and tailor-made services that can respond to their specific situation and their expectations.

## Everyone can contribute to the community

Why? Making the community and services more inclusive for people with complex support needs will improve quality of life for everybody.

What is the problem? The more mainstream-oriented services or activities become, the more people with complex support needs are excluded from participating.

How to improve that? To ensure full inclusion communities and mainstream systems (political, economic, social and cultural) must be designed to include all of their citizens. An assessment of the activities and services' inclusiveness that are being offered is needed as well as a strong complaints mechanism to ensure their full accessibility to everyone.

## Every family has the right to an ordinary life

Why? Support to family enables them to flourish and access opportunities on an equal basis with all families. Families are key actors in enabling the inclusion of their relatives in the community. The experience and knowledge of families greatly enhances the quality of support provided

What is the problem? Families are also discriminated against, they experience social and financial exclusion due to the lack of support. Family carers often feel that their work is not recognised or valued by service-providers, their workplace, public authorities and wider society.

How to improve that? Adequate short and long-term family support services should be available to meet the different types and level of support families will need at different stages of their lives and during transitional periods. It is important that they can be fully involved in decision/actions undertaken for their relatives and have an opportunity to share knowledge with professionals and learn from them.

# Introduction

---

People with intellectual disabilities with complex support needs have a significant intellectual impairment and experience difficulties in communicating. They have these often in combination with other difficulties like physical and/or sensory impairments, specific health/ medical and mental health conditions or issues. The support required to live a full life is described as complex because it can meet one or several of the following characteristics:

- **Diverse:** Permanent assistance is needed in most aspects of life such as communication, decision-making, mobility, planning, emotional support, health and personal care;
- **Intense:** 24/7 support; 1:1 assistance; requires good knowledge of the person who receives support, often built over time
- **Crucial:** Life threatening safety concerns, specific health conditions, challenging self-harming behaviour.

Due to these characteristics, the support has to be person-centred and provided by supporters who have been specifically trained by families and others including the person's former supporters to support the person, and to communicate in a competent and respectful way.

## Legal and policy framework

**Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD)** stipulates the 'equal right of all persons with disabilities to live in the community, with choices equal to others'. The **General Comment on article 19** clarifies that the article "extends the right 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 requirement". The UNCRPD Committee declared in its General Comment on article 12 that '*Supported decision-making must be available to all. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making*'. The **General Comment on article 4.3 and 33** (participation) makes several references to people with complex support needs and underlines the importance of their participation in the policy-making processes.

In addition to the rights enshrined in the CRPD, the **UN Convention on the Rights of the Child (CRC)** also recognises the fundamental right of all children, regardless the level of their disability, to preserve their family relations and to live included in the community. The **2030 Agenda for Sustainable Development Goals (SDGs)** highlights the objective "by 2030, empower and promote the social, economic and political inclusion of all irrespective of age, [...] disability."

**The Council of Europe highlighted in its 2017-2023 strategy** that “Persons with multiple, complex and intersecting impairments face additional barriers and are at higher risk of institutionalisation, exclusion and poverty (...).” Through the general higher risk of institutionalisation acknowledged by the Council of Europe for this category of people, the link is directly established with the consequences of poverty and exclusion

At the European level, the importance of the enjoyment by all persons with disabilities of their right to live in the community appears in different texts. In this way, the **2014-2020 Multiannual Financial Framework**, highlighting the priorities on the way European Structural Funds should be spent, enshrines the transition from institutional care to community-based services as a priority. The European Pillar of Social Rights specifically pointed the importance of the right to income support that ensures living in dignity, services that enable to participate in the community. It also emphasised the importance of affordable long-term care services, targeting precisely home-care and community-based services.

# 1.

## Every life has value and should be respected

### Benefits

The inherent value of the dignity of one's life has been recognised by all the modern human rights treaties, regardless of the diverse cultures without any exception. It is **universal and unconditional**.

The universality of human rights implies for everyone to be valued and recognised in one's right to exist in the community with peers. It is particularly crucial when it comes to the right to live in the community to ensure that persons with complex needs are not excluded from society and are given equal opportunities to flourish. Article 19 of the CRPD stipulates the 'equal right of all persons with disabilities to live in the community, with choices equal to others'.

At the European level, the importance of the enjoyment by all persons with disabilities of their right to live in the community appears in different texts. In this way, the Committee of Ministers underlined in a recommendation to Member States the priority of "*ensuring equal rights for people with disabilities and promotes a human-rights based, anti-*

*discriminatory approach to improving the lives of all people with disabilities, including children and those with enduring and/or complex support needs*.<sup>1</sup>

## Improving life of the most vulnerable enhances the whole society

The interaction of children with complex support needs with their families and non-disabled peers is fundamental for their development. It is also crucial for the cohesion of a society that all citizens have the opportunity to meet each other and to live in an inclusive environment that welcomes its population in all its diversity. This approach will strongly impact on future generations in the way disability is perceived and benefit the community as a whole by promoting values of respect, solidarity and inclusion. As Inclusion International president Sue Swenson underlined *"Inclusive education paves the way to understand human rights"*.

## Problems

**People with complex support needs have always been used as the exception to justify the existence of segregated places and special services**, creating a distinction and hierarchy between them and the other citizens.

People with complex support needs are often seen as 'children', as 'incapable' of making their own choices and decisions about their life.<sup>2</sup> Indeed, there are claims that institutions provide better care or ensure better health, people are happier 'with their own kind', or that people with 'severe' disabilities, 'complex' health or 'behavioural issues' cannot be supported in community. Due to the social barriers they face, people with complex support needs constitute one of the most invisible groups in modern societies.

An Inclusion Europe study<sup>3</sup> conducted in twelve countries demonstrated that people with complex support needs are one of the most excluded groups of citizens. The research showed that the perception of a person with complex support needs as being incapable of taking on socially accepted mainstream roles in life presented a significant barrier to their participation. This finding strongly relates to the acknowledgement by the CRPD Committee of , the *"presumption that persons with high support requirements are*

---

<sup>1</sup> Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities, Preamble.

<sup>2</sup> For more explanation on the discrimination, see The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs, volume 1.

<sup>3</sup> In 2007, the European Union commissioned a Study to identify the specific risks of discrimination faced by people with severe disabilities and/or complex support needs. Extensive research and analysis was carried out in Germany, France, the United Kingdom, Italy, Spain, Poland, Lithuania, the Czech Republic, the Netherlands, Belgium, Sweden and Romania. The comparative analysis of the twelve National Reports demonstrates that people with severe disabilities and/or complex support needs and their families are at a high risk of being discriminated against in all Member States and in all aspects of their lives.



*unable to live independently and be included in the community. Particularly, persons with intellectual impairments, are often assessed as being unable to live outside of institutionalized settings."*<sup>4</sup>

## Solutions

**Supporting people with complex support needs to take an active role in their lives.** It is crucial to give people with complex support needs control over their lives to the maximum extent, involving them fully in decisions and activities. Opportunities for each person to be recognised as an individual, as an actor in their own and other's lives, as the subject of rights and not a passive recipient of support will challenge the stereotypes.

**The social perceptions and stereotypes about people with complex support needs need to be tackled from the youngest age.** In this way, the interaction of children with complex support needs with other children is key. Moreover, the fact of growing up in their family is also fundamental for their development. Neither the inclusion in schools with other children nor family life should be compromised because of the extent of the support that needs to be provided. This approach could have strong impacts on future generations in the way disability is perceived.

**Multiply the interactions between people with complex support needs and other members of the community.** Beyond inclusion in schools, inclusion in public places and general events will enable more interactions and the shared experiences of people living together and participating in common activities.

---

<sup>4</sup> CRPD Committee, Draft general Comment N°5 on article 19, Para 20

## Promising practices

### Plena Inclusion, Todos somos Todos, 2016

Plena Inclusion launched a campaign called “Todos somos todos” on active support for people with complex support needs. According to national statistics, 0.15% (65.000 people) of the general population is recognised as people with complex support needs. This campaign of awareness-raising aims at promoting rights of people with complex support needs and their families, highlight their particular situation and express recommendation on how to better support them.

The campaign highlights 4 specific aspects:

- Families
- Leisure time
- Education and employment
- Support to inclusion.

A broader study from Plena Inclusion and Inico on the inclusion of people with complex support needs has been released and is available [here](#). (Spanish)

Position paper on inclusion of people with complex support needs [here](#).

Find more information on the campaign [here](#).

### Pacte polyhandicap, Unapei, France, 2016

Unapei released a white book on people with multiple disabilities and citizenship to raise the awareness of discrimination they face together with their families. Unapei launched after this publication a campaign around a national pact on people with multiple disabilities to better involve regional actors in France (health agencies, authorities, organisations.)

More information [here](#).

### Pictures exhibition and cooperation with youth and senior clubs, APEHM, Luxembourg

Apehm organised exhibition to raise the awareness of the general population of people with disabilities, including people with complex support needs. One exhibition “Pictures for Life” was organised together with the Ministry and another one took place in the big market place of Luxembourg.

Apehm also collaborates with youth and seniors’ clubs in various activities to enable young people attending day care centres provided by APEHM can visit youth centres

regularly and spend time together in joint activities. As a part of this collaboration, a project called Inkluso Art is planned for 2018.

More information [here](#).

## Lebenshilfe Austria, Guidelines on participation of people with complex support needs

Following a meeting with the Ministry of Social Affairs in 2018, Lebenshilfe Austria will develop in 2019 four guidelines to foster the participation of people with complex support needs in advocacy and influence of their own lives. The guidelines will reflect on the importance of enabling self-determination through a consequent person-centred approach and the need to define new procedures and solutions than cannot be defined in the same way as for people with mild or moderate intellectual disabilities.

More information [here](#).

## Testimonies, stories

### Luke, Australia

*Luke a boy with complex support needs. He is non-verbal. He started his education in a special school however his family noticed that he would light up when-ever he saw kids from the mainstream school where his siblings attended. Luke started to spend some time at the school and those around him notice a remarkable difference in him. Once making the decision to enrol Luke full time in mainstream school, his parents hit many road blocks. However, with vision and persistence, Luke now attends mainstream school full time. Luke enjoys music, drama and hanging out with the boys.*

*More information [here](#). Source: Australia, <https://www.19stories.org>*

## 2.

# Everyone can flourish and increase/ gain control over their lives

## Benefits

**Inclusion Europe strongly believes in the importance of enabling choice for everybody and the impact on one's control and quality of life**

Inclusion Europe has always promoted the importance of self-determination for all people with intellectual disabilities regardless of their disability and need for support. The expression of decisions, even simple, can contribute to increase the overall quality of life of the individual, particularly when the decisions relate to the lived environment. They also greatly improve the support provided by professionals and lead to innovative and respectful practices.

Similarly to the universal aspect to the right to live independently, the right to make one's decisions cannot be taken from a person because of the level of required support or any other reason.

**Regardless of the disability or the level of the need for support, everyone with adequate support can flourish.**

Research consistently demonstrates the benefits of community living and the harmful effects of institutionalisation, and that people with complex support needs, people who are 'medically fragile', and persons of advanced age (who have lived in the institution for many years) can all be successfully supported in community.<sup>5</sup>

Studies conducted in numerous countries by Inclusion International have highlighted the following outcomes for people with disabilities in the community as compared to institution life:

- Maintained or improved health and health care;
- Increased independence and adaptive skills;
- Decreased/elimination of challenging behaviour; and

---

<sup>5</sup> Common European Guidelines on the Transition from Institutional to Community-based Care (2012, p. 111).

- Increased family involvement and support (even if they had previously opposed resettlement from the institution).<sup>6</sup>

### **Empowering means also less reliance on support, it is more financially sustainable for the community**

The European Expert Group on the Transition from Institution to Community-based Care<sup>7</sup> (of which Inclusion Europe is a member) has developed the Common European Guidelines to provide practical advice about how to realise the transition from institutional to community-based care.<sup>8</sup> The Guidelines specifically highlights that as the life expectancy of people with complex support increases, new services need to be developed to meet their needs for support to live in the community.<sup>9</sup> It also states that governments continue to allocate funds for institutions based on the perception that they are a cheaper option for people with complex support needs<sup>10</sup> despite evidence that 'community-based care is, overall, more cost-effective than institutional care'.<sup>11</sup>

The Council of Europe highlighted in its new strategy that "Persons with multiple, complex and intersecting impairments face additional barriers and are at higher risk of institutionalisation, exclusion and poverty (...)." <sup>12</sup> Through the general higher risk of institutionalisation acknowledged by the Council of Europe for this category of people, the link is directly established with the consequences of poverty and exclusion. By preventing persons from being included in the society and contributing towards it, the existing model increases the cost of exclusion that is a strong counter-argument to the sustainability of institutions in a long-term perspective.<sup>13</sup>

Less reliance on families for all the support of their relative and they can live more ordinary family lives, by helping people with complex support needs, the quality of life of their relatives will be greatly improve, meaning that can be more involve in the society, have a job.

---

<sup>6</sup> Inclusion International. *Inclusive Communities = Stronger Communities. Global Report on Article 19: The Right to Live and Be Included in the Community.* (Inclusion International, 2012, p. 85).

<sup>7</sup> See more about the European Expert Group on the Transition from Institution to Community-based Care at: <https://deinstitutionalisation.com/> (accessed 18 October 2016).

<sup>8</sup> Common European Guidelines on the Transition from Institutional to Community-based Care (2012), available at: <http://deinstitutionalisationguide.eu/> (accessed 18 February 2016).

<sup>9</sup> Ibid, pg. 33.

<sup>10</sup> Ibid, pg. 50.

<sup>11</sup> Ibid, p.51. See also JAG (2006), The price of freedom of choice, self-determination and integrity, A Report from the Knowledge Project: A cost analysis of different forms of support and service to people with extensive functional impairments. Stockholm: JAG.

<sup>12</sup> Council of Europe, Disability Strategy 2017-2023, para 67.

<sup>13</sup> Different studies looked at the cost of exclusion of persons with disabilities vs the gains of their inclusion. See for example CBM and International centre for evidence in disability, Cost of Exclusion and gains of inclusion report 2015.

## Problems

**Due to the lack of solutions, people with complex support needs live in large institutional settings or rely solely on families to provide all care and support.**

The Special rapporteur pointed out in her annual report the high discrimination faced by persons with complex support needs while accessing services: *'While all persons with disabilities face challenges in accessing support, those with high support needs are disproportionately affected by the lack of appropriate services.'*<sup>14</sup>

In most European countries, many people with complex support needs continue to live in isolated institutional settings that are not in compliance with the CRPD. Very often, they did not have the opportunity to choose where they live and with whom. They also do not receive adequate support or have the chance to select the type of services they want or need.

In many countries, families are the only support people with disabilities can rely on. Very often, families play a key role in preventing institutionalisation and in facilitating social inclusion of their family member – especially when they themselves have the necessary support. For example, families are especially important during the main transition periods in life – in childhood (such as starting school, going through puberty etc.) and from childhood to adulthood (such as leaving school, going to university, finding employment, starting a family etc.). From early on in life, families are essential in helping their family member develop independent living skills, facilitating their development and social inclusion.

Regardless of the social stereotype attributed to persons with complex support needs, the aforementioned research highlighted that because of *"the lack of adequate inclusive service systems, they often spend their lives with insufficient support at home with their families or in large residential institutions"*.<sup>15</sup>

## Solutions

**Everyone should be able to choose the type and the extent of the support they want**

This can only be implemented by supporting all persons with disabilities to express their will and preferences in the decisions that matter to them instead of what has been perceived as being in their best interests. This principle and the observational, empathic and communication skills needed to put it into practice apply especially when the person requires high levels of support.

---

<sup>14</sup> Special Rapporteur, annual report on access to rights-based support for persons with disabilities A/HRC/34/58, para 18.

<sup>15</sup> The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs, Volume 1, p.6

Self-advocacy organisations are playing a key role in the process of decision-making to support persons who require high support to express their views in different aspects of life such as the right to live independently and being included in the community. Self-advocacy must focus on one very important principle: self-determination of people with an intellectual disability. Everyone must have the possibility to be involved in all decisions that affect their life. Regardless of the level of the support required, self-determination should be the core principle.

For persons who have a greater difficulty in communicating, trusted support in the interpretation and communication of their will and preferences and at the point of decision making are essential. There are some cases where it is not possible to be sure about a person's will and preferences. In that case, families and professionals will gather information to try to interpret the will and preferences in a process that could be described, not as supported decision-making but as "facilitated decision-making" or "co-decision-making".<sup>16</sup>

For people who may not communicate in traditional ways, families have been relied on as the sole support that can understand their child's ways of communicating. Families need support to strengthen the network supporting their child and to understand how an individual's will and preferences can be ascertained to articulate the decisions an individual is expressing and to identify and manage any conflict of interest that may arise.

**People with complex support needs especially need individual support and tailor-made services that can meet their specific situation and their expectations.**

All services should be person-centred, especially for people with complex support needs who are more likely to be denied control over the service they are provided with. States Parties in Europe should extend the knowledge about person-centred planning to all European countries to make it a common approach in working with people with complex support needs.

Person-centred plans are a proven method to ensure one gets the support one needs, when it is needed and delivered in the way it is wanted. While supports are essential for people with complex support needs to thrive in their communities, it is important to make sure that institutionalised supports are not simply transferred from institutions into the community. Where services do exist, they often continue to create separate "disability-specific" options that are both segregated and isolating and fail to promote inclusion in the way that the CRPD intended.

Sweden has a unique system in the way it has recognised in 1994<sup>17</sup> the right to personal assistance as a personal right, having a huge impact on lives of people with complex

---

<sup>16</sup> Inclusion Europe, Safeguards in the exercise of legal capacity, 2017

support needs and their families who did not have to choose the option of institutional care anymore.

The empowerment of persons with complex support needs can also be achieved through the allocation of personal budgets enabling more flexibility in the way they can use them. Previous research by Inclusion Europe has pointed out examples of personal budgets used by people with complex support needs.<sup>18</sup> The personal budget contributes to improving the self-determination of the beneficiaries who can decide on the personal assistance: employ the personal assistant(s) themselves and decide the way the assistance is arranged. Respectful support of the will and preferences of the person should be provided to persons with complex support needs to help with their budget management.

## Promising practices

### JAG organisation, Sweden

The association JAG (meaning "I") was formed in 1992 by a small group of people who felt compromised when it came to living like anybody else, because of their need for assistance. They also had a hard time asserting themselves on traditional disability issues. All members of JAG have intellectual disabilities and limited autonomy. Prior to the Swedish legislation about personal assistance, the JAG association ran an intense campaign. In 1994, personal assistance became an individual right in Sweden.

JAG board is composed of people receiving complex support who are leading the organisation. When a person is unable to supervise his/her own assistants JAG appoints a person called a service guarantor who will ensure the supervision of the assistants.

More information [here](#).

---

<sup>18</sup> The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs, Volume 4, p.32.



## Project PA, Enable Scotland, Scotland

Following years of campaigning for the introduction of the Social Care (Self Directed Support) (Scotland) Act 2013, which enshrined in legislation the rights of people who have a learning disability not only to live in their own community, but also to direct their own support, ENABLE Scotland developed Project PA in 2013.

Project PA was a seminal organisational redesign project which developed the operating model and staffing structure central to the delivery of ENABLE Scotland's model of excellent quality, flexible, personalised social care services and support.

Project PA set out to effectively transition all frontline staff from Support Workers (or equivalent support roles) to Personal Assistants (PAs) linked to the principals of personalisation and Self-directed Support.

Outcomes of Project PA included the successful renegotiation of more than 1,400 contracts of employment through positive collaboration with the UNISON trade union and ensuring that all frontline staff at ENABLE Scotland were paid more than the then-Scottish Living Wage two years before the Scottish Government implemented its policy of the Living Wage for social care workers.

For the people we support, this means all individuals supported by ENABLE Scotland are aligned to fully personalised support plans with measurable outcomes and a bespoke support team.

More information [here](#).

## NHS, Education for Scotland, *Working with People who have a Learning Disability and Complex Needs: The Essentials'*

The document aims to offer workers supporting people with learning disabilities and complex needs opportunities to develop their knowledge, skills and values in ways that maximise the involvement of service users and families and increase health and wellbeing.

More information [here](#).

## Moorgate Mill, Blackburn, England

Moorgate Mill in Blackburn, England, a development of 20 apartments designed for people with complex support needs, has incorporated a communications platform, telecare sensors (including flood, fire and smoke detectors), and other controls (such as automatic door openers, blind/curtain openers, and lighting and heating controls) into their design. Twenty-four hours extra care provision is provided, enabling more choice and control than residential or care homes. The development also ensures that support

packages will be person-centred and reviewed regularly to ensure it continues to meet the needs of the individual.

More information [here](#).

## **Servicio de Vida Independiente Asprodes - Plena Inclusión Castilla León, Spain**

T.G.J is a twenty-one-year-old person with a generalised development disorder and a cerebral paralysis in process of incapacitation. He was living in his family home until 2015. At that time, he considered becoming independent of his family and contacted the service of independent life.

This decision by persons with functional diversity implies extra expenses compared to those persons without functional diversity. The cost derived from the basic necessities, such as food, dwelling and studies, common to any student of his age, must include also the cost of a professional who can support him daily in the following areas: physical support for his personal hygiene and meals, supervising of clothes, management of the time for the social interactions and accompanying in all his movements.

In 2016, after the assessment carried out by technicians of the administration, he was recognised as having a degree 3 of dependency. This meant he is entitled to a linked provision of support that he may use for the following services: daily care, residential services, service of personal promotion, home help service, service in night-time centre, and personal care.

T.G.J decided to use the support to employ a personal assistant. Personal Assistants are recognised in the law of personal autonomy of 2006 and, although it is the best valued resource for the persons with disabilities, it is not yet well known, and the number of provisions addressed to personal assistance is tiny.

The impact that this support has had on the quality of life of T.G.J has been very positive. He decided to live in a residence hall where he is supported by his personal assistant in a personalised manner. The opportunities of relationships with peers have increased. He participates in an active way in the university community, he has the opportunity of living in the community and exercising his role as citizen.

More information [here](#).

# 3.

## Everyone can contribute to the community

### Benefits

**Inclusion Europe believes that making the community more inclusive for people with complex support needs will improve their quality for everybody.**

Inclusion Europe has always defended and promoted this vision, affirming that inclusion benefits all. High quality services will lead to the improvement of the society, enriched by more diversity while ensuring equal opportunities to all its members. By ensuring that services (housing, hospitals, schools, libraries, social services..), community events and activities are accessible to people with complex support needs, we make sure that they will be accessible for everyone.

### Problems

**The more mainstream-oriented services become, the less people with complex needs tend to be part of the target group**

The concept that communities should be organised to ensure the inclusion of all its citizens is not a new idea, yet for many people with complex support needs, there are no single or simple adaptations which enable them to participate on an equal basis with others. While self-advocates tend not be included enough in broader frameworks, discussions, event, people with complex support needs are completely invisible from those. This exclusion is intimately linked to the aforementioned negative perception of this group as not being capable to take over socially accepted mainstream roles in life.

The lack of access to education, to vocational trainings, to customised employment make people with complex support needs less likely to contribute in a mainstream environment and further create the conditions of their extremely high level of exclusion. In Spain a study led by Plena Inclusion found that 96% of the 63.610 people with complex support needs are unemployed and only 8% of them had a working experience.

## Solutions

**In order to ensure full inclusion, communities and mainstream systems (political, economic, social and cultural) must be designed to include all of their citizens.**

Persons with complex support needs have to be consulted and involved in the creation or modification of services to ensure their inclusiveness. If the services are designed, created, provided and assessed with the involvement of all people at different stages, it will ensure that no one is left behind. In this way, co-production methodology has proved to be useful in creating specific support services in cooperation with users. It should be transposed to general services but also the organisation of events in the community.

**An assessment of the activities and services' inclusiveness that are being offered is needed.**

People with complex support needs must be involved and consulted, not only in the provision of their own specific support but being given a chance to participate in the society through accessible general services (housing, hospitals, schools, libraries...). In this way, the revised social charter of the Council of Europe acknowledged the need for Member States to "encourage the participation of individuals and voluntary or other organisations in the establishment and maintenance" of the social welfare services.<sup>19</sup>

This approach should be applied to all, starting with the development of self-advocacy and organisations of self-advocates as well as inclusive organisations in which family members with and without disabilities represent all people with intellectual disabilities and enable full participation in their activities, regardless of the level of a person's support needs.

In case of non-involvement of people with complex support needs and their families in the creation of new services, there should be a comprehensive complaint mechanism to point out the existing lack of accessibility.

**Assistive or integrated technology may play a role in facilitating participation in the community for all through improved communication independence.**

Assistive or integrated technology plays a crucial role in communicating with people with complex support needs but also enables them to contribute in the community. In this way, Augmentative and Alternative Communication enables people who are non-verbal or may have difficulties in communication to interact more easily and express their will and preferences. The aforementioned flats in Moorgate Mill equipped with communications platform, telecare sensors, that enabled people with complex support needs to live and participate in the community constitute an example of the use of technology to include people and overcome concerns about safety.

---

<sup>19</sup> Revised social charter, article 14.2.

## Promising practices

The **'Life in the Community'** project, which took place in the UK, found that people who have complex support needs have a better lifestyle when they have opportunities to develop relationships with people other than paid staff and to integrate into their local communities. Some of the key messages from the 'Life in the Community' work are:

- **Circles of support** (where a group of people that know the individual well work together to develop a person-centred plan) offer an effective way of finding out what a person with complex support needs might like changed in their life;
- **Having control over decisions about money** (and the support to enact the decisions) allowing for more choice and control about what to do, when to do it and how to do it;
- In order to meet and spend time with people other than paid staff, **support staff need to be able to develop strong community connections** and help the individual learn the skills they need to participate; and
- Commissioners and care managers should **provide personalised funding** in addition to funding services that have a community connecting role.

## UK, Raising our Sights Guides, Mencap and PMLD Network

Raising our Sights, by Professor Jim Mansell, was published in March 2010 with recommendations that aim to make sure people with profound and multiple learning disabilities (PMLD) and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives.

Following this study, several Raising our Sights Guides have been released by Mencap and PMLD Network to support people with complex support needs, their families and the support persons to implement the recommendations.

List of guides (can be found [here](#))

- How-to guide 1: advocacy
- How-to guide 2: clinical procedures
- How-to guide 3: communication
- How-to guide 4: health
- How-to guide 5: housing
- How-to guide 6: personalisation
- How-to guide 7: support for families
- How-to guide 8: training the workforce
- How-to guide 9: what people do in the day
- How-to guide 10: wheelchairs
- How-to guide 11: commissioning

## **“Empleo Personalizado para personas con más necesidades de apoyo y necesidades compleja”, Plena inclusión, Spain**

Plena inclusión has continued to work on the methodology called "Personalized Employment", thanks to which people with intellectual disabilities who have greater support needs can access the labor market.

This methodology explores the talent of the person and the job opportunities of the environment in which they live, thus seeking forms of personalized employment.

In 2017, this project was carried out in 10 federations, 73 people with great support needs have been supported, 19 hirings have been obtained and, in addition, professionals from 9 entities have participated. With this methodology, an employment rate of 26% has been reached.

Explanation of the project Customised Employment [here](#).

## **#ENABLEtheVote, Enable Scotland**

ENABLE Scotland has made it a priority to support people who have learning disabilities to exercise their right to vote, and to do so informed and empowered about the issues, candidates and parties that are up for consideration.

Enable Scotland produced factsheets and holding accessible hustings meetings to support people who have learning disabilities in engaging with the issues and casting their vote the way they choose. This includes information in formats which are accessible for people with complex support needs, including sensory impairment, and support for non-verbal individuals to communicate their opinions and their choice of who to vote for.

These campaigns proved highly successful, with 80% of people who have a learning disability who engaged with #ENABLEtheVote telling they would definitely vote in the 2016 Scottish Parliament Election, and in 2017, 91% said they would definitely vote in the local council election. It is significantly higher than the 46.9% of the total electorate who actually voted in the local council elections across Scotland.

More information [here](#).

## **Motor Activities Training Program (MATP), Sožitje, Slovenia**

Inclusion Europe member Sožitje is very involved in the creation of recreational activities for its members through the important event taking place in Slovenia every year: The Special Olympics gathering many persons with and without disabilities together. Within this event, the MATP program has been created to ensure the accessibility of sporting activities to people with complex support needs.

As people cannot perform to the same extent physical actions and/or follow rules in the same way, MATP focuses on training and participation rather than competition through 7 activities that are used to teach sports. The activities are Mobility (leads to gymnastics), Dexterity (leads to athletics/softball), Striking (leads to softball/bowling), Kicking (leads to football/soccer), Manual Wheelchair (leads to athletics), Electric Wheelchair (leads to athletics), Swimming (leads to aquatics).

Through these activities, people with complex support needs can be better included in community-based programs and activities like the daily training activities and official Special Olympics, they can develop their sensory awareness, their fitness, recreational skills and through an adequate support, try to reach their best potential.

More info [here](#).

## **Vit'Anime "Jeux et loisirs pour les adultes polyhandicapés », Wallopoly asbl and AP asbl, Belgium**

The project has been created by Wallopoly, support services for people with complex support needs and their families and AP, association of parents and professionals around the person with a complex support need.

It aims to develop tools to improve the support of people with complex support needs through better access to recreational activities. The project aims at the creation of recreational activities. A website has been created with resources of existing games, accessible places for people with complex support needs and their families. Guidelines and materials are also available to support the creation and design of recreational activities, games. The project fosters the cooperation between families and professional to create activities and share as equal actors their knowledge.

More information [here](#).

## Testimonies, stories

### Diego, Spain

*Diego completed an internship with a supermarket. Following his internship, the supermarket was confident he was prepared to work in any of the positions he had been trained during the internship.*

*Personalized employment is based on the talents and abilities that all people have and tries to connect people with the environments of their neighbourhoods where they normally operate, so that they can really develop that capacity. It is important to discover what people are interested in and to know their daily routine when considering employment. The association Aleph-TEA tried to give the opportunity to Diego to develop his talents in an environment that he enjoys, as is the supermarket. This is very important for Diego, because this link with the community and participation in his neighbourhood gives him another social role. Now they recognize him not only as a neighbour but as someone who works in the supermarket.*

More information [here](#).

### Sue Swenson, US

*When Charlie was in 9<sup>th</sup> grade he took a theatre class. One day, the teacher called me up in panic and said, "I'm afraid we must organise a meeting to create an individualised education programme for Charlie. The current situation cannot persist any longer. He is making noises all the time, he just moans." I replied, "Let's skip the meeting. If he moans, it means he is bored." The teacher called me back a week later to thank me for my advice: "In fact, all the children were bored." Obviously, as a theatre teacher he did not want to bore his students. Guess what? The theatre programme is winning awards in Minnesota now. Charlie is no longer there, but I think he had a bit to do with that!*

More information [here](#).



# 4.

## Every family has the right to an ordinary life

### Benefits

**Support to family enables them to flourish and access equal opportunities on an equal basis with all families.** Inclusion Europe has as an advocacy priority the support that all family members (parents, siblings, grand-parents and other relatives) should receive to enjoy their right, like anyone else, to have a normal life. The support provided to families will greatly improve their quality of life, their inclusion in the community and will give them the opportunities to work on the labour market.

**Families are key actors in enabling the inclusion in the community of their relatives.**

Very often, families play a key role in preventing institutionalisation and in facilitating social inclusion of their family member – especially when they themselves have the necessary support. For example, families are especially important during the main transitional periods in life – in childhood (such as starting school, going through puberty etc.) and from childhood to adulthood (such as going to university, finding employment, starting a family etc.). From early in life, families are essential in helping their family member develop independent living skills, facilitating their development and social inclusion.

**The experience and knowledge of families greatly enhance the quality of support provided** Family members who support their relative with a complex support need, due to the intense support they provide, develop expertise on the provision of support and tend to play a key role in the coordination of relevant support services. If shared, this expertise and knowledge can greatly contribute to the design, creation and provision of adequate, tailored-made services for people with complex support needs.

### Problems

**Families are also discriminated against, experience social and financial exclusion due to the lack of support from State.**

Families are often the only alternative to institutions in countries where there are not adequate support services in the community. They often lack information and

personalised support to be able to contribute towards the full inclusion of their relative with complex support needs in the community. As pointed out a former Inclusion Europe's policy paper on discrimination by association: "*The negative attitudes of society are often expressed against the whole family of the disabled child. As a result, the family is very frequently in danger of social exclusion.*"<sup>20</sup>

A recent study<sup>21</sup> found that more than 70% of family carers do not receive any financial compensation, 1 of every 3 respondents to the study is in a situation of poverty because of their caring role. Apart from the economic impact, the study also provides alarming figures on the psychological impact and the lack of the support. In this way, the study found that only 1 out of 6 respondents can access respite care where they live and only 1.3% of the people interviewed said they receive regular psychological support provided by the State.

A Plena Inclusión campaign aimed at highlighting the challenges faced by families of people with complex support and express recommendations. They created an infographic capturing the key figures following a study they realised on the support of persons with complex support needs. Families support to their relative can amount to 16 hours a day, there is an estimation of 47.129 euros per year for the cost of the support of a relative by the family (health, human support etc.). The study also finds that 55% of the family carers see experience health problems due their role of carer.

The extent of the support provided is a barrier to employment opportunities. The care of a person with complex support needs and its costs will reduce the economic activities of the persons who take care.<sup>22</sup> If the access to the labour market for family's needs to be improved, additionally maintaining parents in the labour market is a situation that cannot be overlooked.

**Family carers often feel that their work is not recognised or valued by service-providers, their workplace, public authorities and wider society**

Despite the intensity of the informal support provided by families and the expertise they develop, there is a lack of recognition by both service-providers and authorities.

## Solutions

**Adequate short and long-term family support services should be available**

Families of persons with complex support needs should be able to obtain the necessary support (information and advice) to find the best support for their relative, at every stage

---

<sup>20</sup>Inclusion Europe, [Discrimination by Association, The Situation of Family Carers of Persons with Intellectual Disabilities](#)

<sup>21</sup> Coface, [Who cares: Study on the challenges and needs of family carers in Europe](#).

<sup>22</sup> Inclusion Europe, "Discrimination by Association" The Situation of Family Carers of Persons with Intellectual Disabilities

of their life. States Parties should provide such support through short breaks (respite care) and other form of services to allow families with a dependent member to have the same opportunities as other families.<sup>23</sup> Short term solutions: “respite” care services can help short term but cannot replace personalised support that is needed long-term. Long term family support services include childcare, personal assistants, intensive supported living.

### Full inclusion of families in support network

The family role needs to be recognised, valued in networks gathering service providers, health, professionals. Several projects mentioned above like Raising our Sights based their approach on cooperation between families and service-providers to ensure the quality of the support provided. In Sweden, the organisation JAG specialised in the advocacy and support of persons with complex support needs employs personal assistants, including parents, siblings of JAG users and provides training for all of them. The organisation was created to provide an alternative model of personal assistance and make sure that parents would not have to experience the choice between supporting their relatives on their own or putting them in an institution.

## Promising practices

### Plena Inclusion, *Todos somos Todos*, 2016

This campaign of awareness-raising aims at promoting rights of people with complex support needs and their families, highlight their particular situation and express recommendation on how to better support them.

A broader study from Plena Inclusion and Inico on the inclusion of people with complex support needs has been released and is available [here](#). (Spanish)

Position paper on inclusion of people with complex support needs [here](#).

Find more information on the campaign [here](#).

---

<sup>23</sup> Inclusion Europe (2010), position paper: Living in the community. Available at: [http://inclusion-europe.eu/wp-content/uploads/2015/03/3.PP\\_Community-living.pdf](http://inclusion-europe.eu/wp-content/uploads/2015/03/3.PP_Community-living.pdf) (accessed 9 May 2017).

## Testimonies, stories

### Catriona, mother in the UK

*"Most parents, I am certain, have periods when they struggle to occupy their children in the holidays and when they fret over the whole business of juggling work and childcare and all the other commitments of life. But typical parents of typical kids have various options. There are holiday clubs, improving activities such as week-long art or drama 'camps', trips to stay with grandparents, reciprocal arrangements with other frazzled parents.*

*None of these are an easy option for a child like mine. Non-mobile, non-verbal, partially tube-fed, prone to seizures and feistily opinionated, she requires a high level of special provision wherever she goes. But she is no less keen on doing fun and interesting things and spending time with other children than are her typically developing peers. Spending the whole summer at home being cared for by adults makes her frustrated and sad. It also risks her losing some of the skills that she works so hard at school to develop."*

More information [here](#) about her experience as a mother. Source: [Website Special needs jungle](#), UK

### Paqui, mother in Spain

*My son's routine was one of constant self-injury, since he got up. Putting clothes or accompanying him to the bathroom was very complicated: he hit the walls, he looked for the peaks ...*

*It was very difficult to assume that the best thing for my son was that he was not with me, that he needed to be with people who could help him, and that I also needed help. But in the end I decided and looked for that support.*

*The professionals have been with him almost 24 hours and little by little they have managed to change their self-injurious behaviour habits, thanks to making it possible to communicate with pictograms.*

*My life has totally changed with the supports at home: I learned the language that I have to use with my son. And although I am still learning, now I see that I can be with him and make family life, relate in a normal way*

More on Plena Inclusion Website, Todos somos todos testimonies [here](#).

## José, The Netherlands

*"Families want their son or daughter (or brother/sister) with an intellectual disability to have a good life with friends, a roof over their head and to live in the society. There is one major concern though. Families work so hard to try to support their relatives, but they are afraid that, if they cannot provide support anymore, their relative with a disability will face abuse, neglect and loneliness when they live on their own. Families want security and safety first. For many parents that is the reason they have no other option than to agree with residential living option as nothing else is being provided in a secure way."*

## What should be done?

### At EU level

- Ensure that people with complex support needs can benefit from the implementation of European Structural Funds in Member States and are involved in their implementation as well as their monitoring (Partnership Agreement)
- Ensure full involvement of people with complex support needs and their families in deinstitutionalisation programmes and projects funded by the EU
- Ensure that people with complex support needs can benefit from the implementation of the Pillar on Social Rights in the areas of education, employment and social protection and can participate in the related discussions and events.
- Support the proposal for a work-life balance directive and ensure that it brings a positive change for family carers of people with complex support needs.
- Advocate for active monitoring of the transposition of the Accessibility Act that checks that it includes people with complex support needs in their access to products and services
- The role of assistive technology is under-developed for this group of people. The Horizon programme for research and development should support the development of new solutions such as AI for decision support and the innovative application of more mature technologies to support daily life and communication.

### In Member States

- o Governments must provide for people with complex support needs the necessary personal assistance and services to support living and inclusion in the community, and to prevent isolation or segregation from the community.
- o States must provide early intervention services to minimize the disabling effects of impairment and to further advance the inclusion of children with disabilities in society. Governments must develop active family support policies that strengthens and stabilizes families with complex caring roles.
- o People with complex support must have their will and preferences respected when making decisions about where, with whom and how they want to live. They

should be moving to supported decision-making and away from substitute decision-making.

- Governments and communities need to invest in self-advocacy and ensure people with complex support needs have their right to make decisions recognized. People with complex support needs to get involved as central actors in awareness-raising campaigns and show how they can participate.
- People with complex support should be involved in the planning of new social support services during the process of the deinstitutionalisation, including person-centred planning, direct payment, personal budget, development of personal assistant network, coordination of support, or the use of informal support system. Inclusive, informal support should be recognised as important as formal support, and flexibility should be possible in how to use personal budgets.
- States should guarantee accessibility within the community, regarding the built environment, transport, technical aids, information and communication by considering the accessibility needs of persons with complex support needs.
- Families should have the opportunity to get involved in mainstream platforms to share knowledge, experience and identify good practices. They should be trained and train on the importance of self-advocacy and how to build it.
- Professionals should engage closely with families to share experiences and good practices in supporting persons with complex support needs. Professionals who used to work in institutions should receive adequate training to work in community-based services or to find alternative career options.
- States should provide adequate support to family members such as short term “respite” care services, childcare services, personal assistants and other parenting support services.

## At Inclusion Europe

- Our movement needs to better represent all of its constituency and include more people with complex support needs in its work and activities
- The European Platform of Self-Advocates needs to be more inclusive and better represent people with complex support needs in its advocacy work as well as constituency. Peer support roles in decision-making and participation in the community for all must be developed in the self-advocate movement.
- Inclusion Europe members need to exchange practices and knowledge to provide solutions.
- Inclusion Europe and its members need to raise the awareness of the population regarding the importance of including everybody