**The role of Personal Assistance in supporting the right of children and young people with disabilities to grow up in a family**

**Written contribution of the European Network on Independent Living[[1]](#footnote-1) to the Call for Inputs by the UN Special Rapporteur on the Rights of Persons with Disabilities on the care and support for children with disabilities within the family environment and its gendered dimension, April 2025**

**I. Introduction**

The focus of this submission is on the potential of Personal Assistance to support children and young people with disabilities and their families[[2]](#footnote-2), to prevent placements in residential care settings, and to facilitate the transition of young disabled people into adulthood. The submission highlights the experience of countries in Europe where personal assistance is available to families, and that of children and young people. Finally, the submission sets out the characteristics of personal assistance, with the aim to raise awareness about its role in supporting children and young people with disabilities and their families.

This submission was initially prepared for the Day of General Discussion on children in alternative care, held during the 81st Session of the Committee on the Rights of the Child in September 2021. It was updated to include additional information to make the case for introducing personal assistance for children and young persons with disabilities.

**II. The right to live independently and being included in the community**

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of all disabled people[[3]](#footnote-3) to live independently and being included in the community. States Parties are obliged to provide them with “access to a range of in-home, residential and other community support services, **including personal assistance** necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community” (Article 19b, emphasis added). The General Comment 5, on Article 19 CRPD, makes it clear that:

“For children, the core of the right to live independently and being included in the community entails a right to grow up in a family.”[[4]](#footnote-4)

When discussing services that support the right to independent living, General Comment 5 requires Governments to “provide adequate support services to family carers so they can in turn support their child or relative to live independently in the community.”[[5]](#footnote-5) It goes on to note that:

“The existence of **adequate and age-sensitive support services for girls and boys with disabilities** is of vital importance for the equal enjoyment of their human rights (art. 7). Respecting the **evolving capacities of children with disabilities and supporting them in having a say in choices** that have an impact on them is critical. It is also important to **provide support, information and guidance to families** (art. 23) to prevent institutionalization of children with disabilities and to have inclusive policies on adoption to ensure equal opportunities to children with disabilities.

When it comes to social interactions and relationships with peers, **teenagers may prefer personal assistance or professional sign language interpreters to informal support provided by relatives**. States parties should establish innovative forms of support and accessible services for children and adolescents with disabilities through personal contact or through their organizations.” [emphasis added][[6]](#footnote-6)

Guidelines on deinstitutionalisation, including in Emergencies, published by the Committee on the Rights of Persons with Disabilities in 2022, highlight the importance of children’s participation in decisions that concern them and state that children cannot “choose” to live in an institution. The Guidelines point to support services in the community important for the realisation of the right to family life and independent living of children with disabilities. They include personal assistance, peer support, inclusive education, accessible information for families and children. The Guidelines add that:

“**Training of professionals**, including child-protection professionals, on the human rights model of **disability is key to preventing situations in which families are advised or encouraged to place their children in an institution**.” [emphasis added][[7]](#footnote-7)

**III. Protecting the right to family life and preventing institutionalisation**

In 2021, a coalition of disabled people’s, children’s rights and other organisations published a Call for action[[8]](#footnote-8) to Protect the right to family life and prevent institutionalisation for all children. This Call, supported by a large number of signatories was published in response to continued placement of children in institutional settings, including in family-type and family-based homes, as well as children’s villages.

We are concerned that, despite our efforts, this negative trend of placing children with disabilities in institutions has continued. For example, a recent report on independent living[[9]](#footnote-9) in the European Union revealed that in 10 EU Member States, the population of children in residential institutions increased in the last 10 years. Moreover, in countries that report a decrease, such as Romania[[10]](#footnote-10) and Bulgaria[[11]](#footnote-11), there is evidence of children being moved from large institutions into other types of residential care settings. It is unacceptable that well-intentioned strategies, such as the European Child Guarantee, still allow for the placement of children into institutional care in some circumstances (Article 10(d)).

Therefore, it remains of great relevance to ensure that the standards on the right to family life and independent living of children with disabilities, set in the UN CRPD and accompanying guidance are applied in the work of the Children’s Rights Committee, in the drafting and implementation of children’s rights policies at the national, European and international level, as well as in the work of UN agencies, such as UNICEF.

**IV. Personal assistance – a key tool for independent living**

Personal assistance is considered by many disabled people to be a key tool for independent living[[12]](#footnote-12). ENIL’s *Fact Sheet on Personal Assistance[[13]](#footnote-13)* explains what a personal assistant does:

“The personal assistant is an individual contracted by the disabled person to provide them with support in different aspects of daily life – such as personal care, household tasks, assistance at school, university or workplace, driving, interpretation and so on. These tasks are customised to the individual needs of the user and assigned by the user. The job of a personal assistant does not always require any particular qualifications or previous experience and can be performed by people of different ages and backgrounds. The key requirement is that the prospective personal assistant is considered by the user him/herself as suitable for the job. The major difference between a personal assistant and a carer is that in the case of personal assistance, the service is designed and managed by the service user directly.”

Personal assistance is defined, in the General Comment 5, as a “person-directed/’user’-led human support available to a person with disability”[[14]](#footnote-14). The General Comment 5 goes on to list key characteristics, which distinguish personal assistance from other types of support (such as home care):

* Funding must be provided based on each person’s support needs, following an individual needs assessment, and must allow for hiring of assistants from the open labour market. It must be controlled by and allocated to the disabled person, so they can pay for the assistance they need.
* Personal assistance must be controlled by the disabled person, who should decide by whom, how, when, where and in what way the service is delivered.
* Personal assistants must be recruited, trained and supervised by the person using the service. Disabled people should not be forced to share assistants, unless that is their decision.
* Disabled people must be able to decide to what extent they control the service and, even if the someone else manages it for them, they should be in the centre of decisions. For those who cannot manage the service by themselves, supported decision making can be used.

Considering that a key characteristic of personal assistance is that is must be controlled by the disabled person themselves, the question arises how it may be used by children and young people with disabilities. In this respect, the *Model National Personal Assistance Policy[[15]](#footnote-15)*, developed as part of the project European Center for Excellence in Personal Assistance (ECEPA), explains that, in the case of children, children “might need support from third parties” to manage their personal assistance.

Importantly, with regard to children and young people, the aim of personal assistance is not to replace parenting responsibilities. Rather, personal assistance should “cover **assistance needs over and above the parental responsibility that would apply in the case of a non-disabled child**” [emphasis added].[[16]](#footnote-16) This means that any support needs a child has because of their impairment, whether it is their “basic needs” (such as feeding, using the toilet, personal hygiene, getting dressed), social and communication needs, or any medical needs (such as changing the feeding tube, taking medication etc.), can be done by a personal assistant. Personal assistance can also be used to support children with disabilities to attend mainstream schools, where personal assistants may perform similar activities as at home, as well as support the child with taking notes and taking part in school activities. Although some countries have assistants assigned to children with disabilities at school, often these assistants only support the child with school related tasks (such as taking notes) and are not allowed to help children use the toilet, for example.

In relation to who can work as an assistant, in some countries family members are allowed to work as personal assistants, while in others this is restricted. Whereas some parents may want to be paid to work as personal assistants for their children, it is important that this does not limit the child’s ability to enjoy the same opportunities as their non-disabled siblings or peers.

The advantages and disadvantages of employing family members as personal assistants (for children and young people with disabilities) were explored in a doctoral thesis on Independent Living and personal assistance in Europe’s Nordic countries[[17]](#footnote-17):

“For instance, previous studies have suggested that “parents are the persons best capable of knowing what their children mean and want, since no one else could be more competent in interpreting their often complicated signals of communication” (Askheim, 2003, p. 327). On the other hand, there are concerns that family involvement shifts the power to the family member in control of the arrangement, rather than the individual in receipt of personal assistance (Ungerson, 1999). **A study of children who use personal assistance found that “they perceived that they lack control over their own lives and they feel tied when trying to liberate themselves from their parents and become independent”** (Sk r & Tam, 2001, p. 927).” P99

Whether it is family members or others working as personal assistants, it is important that such decisions are guided by what works best for the child and the family, and not by financial restrictions. For example, where budgets for personal assistance are small, this forces family members to work as personal assistants and does not allow them to hire assistants from the open labour market. This may limit the child’s right to live independently and to be included in the community, and will also affect the family’s ability to care for other siblings, get respite or to seek other employment opportunities.

Being able to have as personal assistants people other than parents – someone closer in age - is especially important for young disabled people, as this can play an important role in helping them become independent and transition into adulthood; when they will continue using personal assistance and may take on additional responsibilities as employers[[18]](#footnote-18).

**V. The role of Centers for Independent Living in supporting families**

ENIL’s Myth Buster on Personal Assistance[[19]](#footnote-19) highlights the role of Centers for Independent Living in facilitating access of disabled people to personal assistance, including by providing support to parents or carers whose children have personal assistant(s).

Centers for Independent Living, or other organisations which use the term Independent Living in their work must comply with the following principles:

* **Solidarity:** this includes, among other, working so that disabled people can have the resources to live independently and recognising Independent Living as a basic human right; sharing or exchanging information, advice, support and training in appropriate form, free of charge for disabled people, or where there is a charge, ensuring disabled people have the resources to pay for these services;
* **Peer support:** this includes using peer support and the tool for sharing information, experiences and insights in order to make disabled people aware of the audio, visual and cultural, psychological, social economic and political oppression and discrimination they are exposed to; empowering disabled people by assisting them to acquire the skills to manage their social and physical environment with the goal of full equality and participation in their families and society;
* **Deinstitutionalisation:** this includes opposing all types of institutions; it means that those use promote or accept personal assistance services that require disabled person or live in a special setting or force the disabled person to live by the routine or others may not use the term “independent Living”;
* **Democracy and self-determination:** this means that membership with voting rights is reserved for disabled people only, that disabled people are favoured for paid and unpaid positions within the organisation and that they represent the organisation in meetings and the media.

During a webinar ENIL organised on support for families of adults with intellectual disabilities, the family members emphasised the importance of having guidance, training and support on Independent Living throughout their child’s life and during transition into adulthood[[20]](#footnote-20). Unfortunately, in many countries, support directed at facilitating Independent Living is not available, leaving parents on their own to navigate complex systems of benefits, support and services (where such exist), as well as having to deal with systemic barriers in access to childcare, education, healthcare, transport etc. For this reason, CILs, as well as cooperatives on Independent Living and personal assistance, must be adequately supported and funded, in order to exercise their function of supporting disabled children, young people, adults, as well as family members.

**VI. Experiences of European countries in providing personal assistance to children and young people with disabilities**

According to ENIL’s *Independent Living Survey* (2020)[[21]](#footnote-21), out of the 43 countries in Europe for which information was collected, in 21 countries personal assistance is available to children with disabilities[[22]](#footnote-22). However, in the majority of countries personal assistance budgets are limited and do not respond to the real needs of individuals in need of assistance. In countries where the number of assistance hours is limited, it may not allow some children to grow up in a family.

There are also other restrictions, related to who is eligible for personal assistance (for example, only children with certain impairments), and what the assistance can be used for. It may be, for example, that assistance is only available in school settings, not in a child’s home.

Among all European countries, the Nordic countries (Sweden and Norway) are perceived as leaders in personal assistance, and were among the first and few to close large institutions for disabled people, and introduce personal assistance. Despite the negative trends and deterioration of rights in recent years[[23]](#footnote-23), the Swedish state policy promotes children’s right to grow up in a family:

“[…] it is important from a child rights perspective to take measures to enable children with disabilities to live at home even if they are in great need for help and supervision […] **personal assistance for children and young people should always be considered as an alternative to living outside the parental home**. From a child rights perspective, it is particularly worrying that some children are granted accommodation for children [in group settings] instead of state assistance allowances or personal assistance. To be placed at a special accommodation for children means that the child is separated from his or her family and cannot grow up in his or her home environment.” [emphasis added][[24]](#footnote-24)

The experience of families of children with disabilities using personal assistance has been extremely positive. A European study evaluating the system of personal assistance in Sweden notes the benefits for families and describes how the system works:

“The value of receiving assistance for the individual is extremely high. We can show that **parents of children with disabilities experience better health because they are able to enter the labour market**. Parents of children receiving assistance allowance receive sick pay, unemployment benefit or social benefit to a lesser extent than others do. The JAG association confirms this, as more of the members’ parents have entered the regular labour market, and in spite of the fact that parents have a possibility to work as assistants for their children, they do this (in 2005) to a lesser extent than in 1995.” [emphasis added][[25]](#footnote-25)

“Parents to children needing assistance (up to 12 years of age) are obliged to provide the same level of care parents to non-disabled children are obliged to provide. Assistance is provided for care outside this. Family members can be employed as assistants on the same conditions as other employees. However, if they share a household with the assistance user, they cannot be employed directly by him/her, due to tax regulations. They have to be formally employed by an external employer. The assistance user is of course free to start a company or an economic association, which as a legal person can function as employer in these cases.”[[26]](#footnote-26)

A more recent study, on the experiences of families in Norway and Sweden recorded similar findings. Notably, it found that personal assistance was especially beneficial for children with disabilities considered to have “complex medical needs”.

“Most [parents] insisted that **personal assistance was the only way to meet their son or daughter’s health requirements** and that all other services were inadequate.” [emphasis added][[27]](#footnote-27)

This is a significant finding, as especially children with “complex medical needs” are often placed in residential care settings, including long-stay “hospitals”, under the pretext of receiving treatment which cannot be provided at home. In the study, cited above, parents described the benefit of having a personal assistant, as opposed to being cared for by different health professionals, with several noting that their child would not be alive “if they had remained in the traditional service system because parents had no control over the way in which the service was arranged and managed.” Another mother, whose daughter has “complex medical needs”, was quoted in the study, explaining the improvement in her daughter’s health and well-being after leaving a group home. She noted that her daughter was both healthier and happier in every way.[[28]](#footnote-28)

ENIL is not aware of similar studies from other countries, but it is likely due to the novelty of personal assistance schemes and laws in many European countries. In addition, as stated above, in at least half of the countries in Europe, personal assistance, where it exists, is limited to disabled people of working age. There is, therefore, a need to both expand and improve access to personal assistance for children and young people, to evaluate and promote existing personal assistance schemes and their benefits to children, young people and their families.

The voices of children and young people with disabilities, in relation to decisions made about their support, are particularly important, and are still missing. In this respect, a doctoral dissertation on the involvement of children and young people in decisions made about their personal assistance[[29]](#footnote-29), in Sweden, is of great interest.

Finally, a report by Grant Thornton, published in April 2024, **compared the costs of Personal Assistance and other interventions in Sweden**[[30]](#footnote-30). One of the cases studies included was that of a 12-year old girl with multiple disabilities living with her family. The child – Lisa – lives with her family and needs support with all daily activities, with communication, during school hours and during the night. The report costed the expense of having personal assistance (100 hours/week) for Lisa, in comparison to a children’s home (an institution), support provided by the family (where they have to stop working), and a consultant-supported foster care. The conclusion was as follows:

“In summary, it can be stated that personal assistance, a children's home according to LSS, and consultant-supported foster care cost society between 123,039-142,701 Euros per year. The analysis shows that personal assistance costs society approximately 142,218 Euros per year, a children's home according to LSS costs approximately 141,220 Euros per year, and consultant-supported foster care costs approximately 123,039 Euros per year. Having relatives stop working incurs a higher cost compared to personal assistance.”

What this report shows is that, in addition to the human rights arguments and an obligation to ensure all children can grow up in a family, there is also an economic argument for personal assistance, even for children with very high support needs.

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1. The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organizations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalization, democracy, self-representation, cross disability and self-determination. For more information, visit: [www.enil.eu](http://www.enil.eu) [↑](#footnote-ref-1)
2. A family may not necessarily be the immediate biological family, but could include extended family, kinship care, foster care, substitute family care, or any family environment in which the child can establish stable emotional bonds. Source: Position Paper: The Right to Live and Grow up in a Family for all Children. Available from: <https://enil.eu/wp-content/uploads/2018/12/DRI-Right-to-Family-December-2018.pdf> [↑](#footnote-ref-2)
3. ENIL prefers the term ‘disabled people’ over ‘persons with disabilities’ or ‘people with disabilities’, in order to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability. [↑](#footnote-ref-3)
4. General comment No. 5 (2017) on living independently and being included in the community, paragraph 37. Available from: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfzOy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh> [↑](#footnote-ref-4)
5. General Comment 5, paragraph 67. [↑](#footnote-ref-5)
6. General Comment 5, paragraph 75 and 76. [↑](#footnote-ref-6)
7. Guidelines on deinstitutionalization, including in emergencies (CRPD/C/5), 10 October 2022. Available from: <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=rT7wxFUixMTpLbxNjdWUwKtYM1zmWl4zW9gq0fhnSwanhYc1qyDn6Ed2gCZAXBYReblDUoQxUmcQfzgpZhydZw%3D%3D> [↑](#footnote-ref-7)
8. Call to action (2021). Available from: <https://www.driadvocacy.org/reports/call-action-protect-right-family-life-prevent-institutionalization-all-children> [↑](#footnote-ref-8)
9. Eurofound (2024), Paths towards independent living and social inclusion in Europe. Available from: <https://www.eurofound.europa.eu/en/publications/2024/paths-towards-independent-living-and-social-inclusion-europe> [↑](#footnote-ref-9)
10. According to their Facebook page, Hope and Homes for Children Romania built 130 family-type homes in the last 25 years. [↑](#footnote-ref-10)
11. Disability Rights International (2019), A Dead End for Children: Bulgaria’s Group Homes. Available from: <https://www.driadvocacy.org/reports/dead-end-children-bulgarias-group-homes> [↑](#footnote-ref-11)
12. ENIL defines Personal Assistance as “a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.” Available at: <https://enil.eu/independent-living/definitions/> [↑](#footnote-ref-12)
13. Available from: <http://enil.eu/wp-content/uploads/2016/06/FAQ_Personal_Assistance.pdf> [↑](#footnote-ref-13)
14. General Comment 5, Definitions, paragraph 16d. [↑](#footnote-ref-14)
15. Independent Living Institute, 2004, Model National Personal Assistance Policy. Available from: <https://www.independentliving.org/docs6/ratzka200410a.html> [↑](#footnote-ref-15)
16. *Ibid.* [↑](#footnote-ref-16)
17. Brennan, Ciara, 2017, The Nordic Experience of Independent Living and Personal Assistance: A Human Rights Approach, the University of Iceland: Faculty of Social and Human Sciences, page 99. [↑](#footnote-ref-17)
18. National Collaborative on Workforce and Disability (NCWD), Making the Move to Managing your Own Personal Assistance Services (PAS): A Toolkit for Youth Disabilities Transitioning into Adulthood, available from: <http://www.ncwd-youth.info/publications/making-the-move-to-managing-your-own-personal-assistance-services-pas-a-toolkit-for-youth-with-disabilities-transitioning-to-adulthood/> [↑](#footnote-ref-18)
19. ENIL (2022), Myth Buster on Personal Assistance. Available from: <https://enil.eu/wp-content/uploads/2023/06/Myths-Buster_Personal-assistance_web_low-res-1.pdf> [↑](#footnote-ref-19)
20. See here: <https://youtu.be/39rEOXEarT4?si=iggwPhmjIrdfVD2y> [↑](#footnote-ref-20)
21. Available from: <https://enil.eu/independent-living/independent-living-survey/> [↑](#footnote-ref-21)
22. According to information provided by ENIL’s members, these countries are: Austria, Azerbaijan, Belgium, Bulgaria, Croatia, Cyprus, the Czech Republic, Finland, Iceland, Ireland, Latvia, Malta, the Netherlands, Norway, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden and the United Kingdom. [↑](#footnote-ref-22)
23. Independent Living under Threat in Europe: Sweden, see: <https://enil.eu/news/independent-living-under-threat-in-europe-sweden/> [↑](#footnote-ref-23)
24. Academic Network of European Disability Experts - ANED, 2018 – 2019, Living independently and being included in the community, Sweden, page 18. Available from: <https://www.disability-europe.net/theme/independent-living> [↑](#footnote-ref-24)
25. Westberg, Kennet, 2010, Personal Assistance in Sweden, page 19. [↑](#footnote-ref-25)
26. *Ibid*, page 25. [↑](#footnote-ref-26)
27. Ciara Brennan, Rannveig Traustad ttir, James Rice & Peter Anderberg (2016) Negotiating independence, choice and autonomy: experiences of parents who coordinate personal assistance on behalf of their adult son or daughter, Disability & Society, 31:5, 604-621, DOI: 10.1080/09687599.2016.1188768, page 613. Available from: <http://dx.doi.org/10.1080/09687599.2016.1188768> [↑](#footnote-ref-27)
28. *Ibid, page 613.* [↑](#footnote-ref-28)
29. Hultman, Lill, 2018, Live life! Young peoples’ experience of living with personal assistance and social workers’ experiences of handling LSS assessments from a Child persective, Karolinska Institutet, Stockholm, Sweden. [↑](#footnote-ref-29)
30. The full report, in Swedish, is available from: <https://assistanskoll.se/_up/Assistansens-samhallskostnader---Rapport-2024-04-09.pdf> [↑](#footnote-ref-30)