



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 Living¹ to the Day of General Discussion on Children's Rights and Alternative Care, June 2021

I. Introduction

The focus of this submission is on the potential of Personal Assistance to support children and young people with disabilities and their families², 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 of the Committee on the Rights of the Child (CRC Committee) and the children's rights community about its role in supporting children and young people with disabilities and their families.

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 people³ 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:

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

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>

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.

“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

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 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

III. Personal assistance – a key tool for independent living

Personal assistance is considered by many disabled people to be a key tool for independent living⁷. ENIL’s *Fact Sheet on Personal Assistance*⁸ 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

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%2fiSqmYQHwGkfkC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh>

⁵ General Comment 5, paragraph 67.

⁶ General Comment 5, paragraph 75 and 76.

⁷ 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/>

⁸ Available from: http://enil.eu/wp-content/uploads/2016/06/FAQ_Personal_Assistance.pdf

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”⁹. 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 it 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*¹⁰, 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].¹¹ 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 they 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,

⁹ General Comment 5, Definitions, paragraph 16d.

¹⁰ Independent Living Institute, 2004, Model National Personal Assistance Policy. Available from: <https://www.independentliving.org/docs6/ratzka200410a.html>

¹¹ *Ibid.*

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 countries¹²:

“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 employers¹³.

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

According to ENIL's *Independent Living Survey* (2020)¹⁴, out of the 43 countries in Europe for which information was collected, in 21 countries personal assistance is available to children

¹² 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.

¹³ 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/>

¹⁴ Available from: <https://enil.eu/independent-living/independent-living-survey/>

with disabilities¹⁵. 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 years¹⁶, 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]¹⁷

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]¹⁸

¹⁵ 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.

¹⁶ Independent Living under Threat in Europe: Sweden, see: <https://enil.eu/news/independent-living-under-threat-in-europe-sweden/>

¹⁷ 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>

¹⁸ Westberg, Kennet, 2010, Personal Assistance in Sweden, page 19.

“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.”¹⁹

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]²⁰

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.²¹

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.

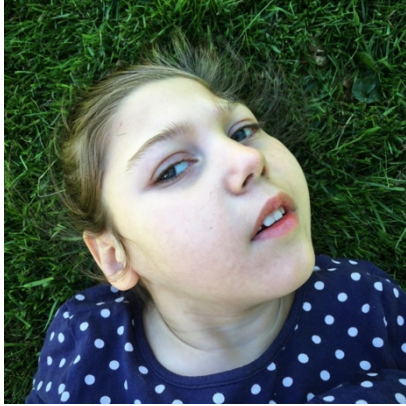
The voices of children and young people with disabilities, in relation to decisions made about their support, are particularly important, and are still missing. In this respect, a doctoral dissertation on the involvement of children and young people in decisions made about their personal assistance²², in Sweden, is of great interest.

¹⁹ *Ibid*, page 25.

²⁰ 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>

²¹ *Ibid*, page 613.

²² Hultman, Lill, 2018, Live life! Young peoples’ experience of living with personal assistance and social workers’ experiences of handling LSS assessments from a Child perspective, Karolinska Institutet, Stockholm, Sweden.



Maja Lorentz

My name is Maja Lorentz and I'm turning 7 in October [2017]. I live in Lund, which is in the south of Sweden. I live at home with my family, which consists of my mother and father, my older sister and my twin younger brothers.

A few days before being born, something happened that deprived me of oxygen for a prolonged period of time causing damage to my brain. I proved to be stronger than expected and survived, so that I could come home with my parents to meet the rest of the family. My injury left me with some challenges, so that I need help with practically everything, but with my personal assistants – everything is possible. My parents helped me the first two years, but they barely had any energy left, so that when my assistants came to the rescue, I got a chance to grow as an individual and learn new things.

I communicate emotionally since I can't really talk like most people nor control my hands that much, but I let the people I know well and who know what I mean and how I feel to help me with my communication. My hearing is crucial for me and after a while I learn to recognize my new friends when I hear them. I love being around my family, especially when we have people over and there's lots of children around, as well as at school with my friends.

I have been a member of the JAG Association for more than five years and have been fighting for the rights of people with functional variations – a fight that has been intensifying the last couple of years. JAG helps me to organize my personal assistance and is the employer of my personal assistants. It was an important part of choosing the right organizer of the service I needed for it to be focused on individual rights and not driven solely by profit. I, along with my parents, have also been active in local and national political keynotes, newspaper articles and try to use opportunities to bring the issues to light for the general public.

A testimony of Maja Lorentz given during ENIL's Freedom Drive in Brussels, in September 2017. The then 6-year-old Maja attended the Freedom Drive with her parents and friends from the JAG Association in Sweden²³, and was one of the keynote speakers during the conference "Independent Living: A Voice for All".

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²³ More information about personal assistance provided by JAG is available from: http://enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf