Introduction:
The Disability Federation of Ireland, DFI welcomes the opportunity to speak to the Committee on Personal Assistant Services and thanks the Committee for the invitation.

The Disability Federation of Ireland is a representative umbrella body. We have more than 120 member organizations which provide support services to people with disabilities. DFI works to make Ireland fairer for people with disabilities.

Dr. Joanne McCarthy, Senior Executive Officer in Policy and Research in DFI and Mr. Garry Toner, expert by lived experience of disability, are together making this submission to the Committee on behalf of the Disability Federation of Ireland, DFI. Dr. Joanne McCarthy will set out the broader issues and policy context. Mr. Garry Toner will bring these issues to life by sharing her own lived experience.

The right to Personal Assistant Services:
The right to live valued and independent lives in the community is central to existing domestic policies. But this commitment has been given new impetus by Ireland’s ratification of the United Nations Convention on the
Rights of Persons with Disabilities, UN CRPD this year. On the 19th April 2018 the UN CRPD entered into force in Ireland.

Personal Assistant services are a cornerstone to the programme of personalised supports that will enable this to become a reality for many people with disabilities.

Article 19(b) of the UN CRPD specifically identifies the right to personal assistance, as part of ensuring a person can lead an independent life. It states:

‘States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

... b) Persons with disabilities have 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;’

This article means that a person with a disability has:

- the **right** to live where they want.
- the **right** to be fully included in the community. And that:
- States **must provide** the supports needed to achieve these outcomes, including **Personal Assistance**.
- All mainstream community services should be available to people with disabilities.

**The Irish Policy Context:**

**Value for Money and Policy Review of Disability Services in Ireland (2012):** Recommendation 6.13 of the Value for Money and Policy Review of Disability Services in Ireland explicitly recognised the role of Personal Assistant services as ‘supports to facilitate access to mainstream services in the following areas:**
education, employment, housing, transport, healthcare and community inclusion’.¹

That Review is an evaluation of the efficiency and effectiveness of the HSE-funded statutory and non-statutory disability services in Ireland. It was conducted by the Department of Health and the HSE. It makes a range of recommendations about how these services should be structured.

**Transforming Lives Programme (Ongoing):** Transforming Lives is the national reform programme to implement the recommendations of the Value for Money & Policy Review. The vision of Transforming Lives is:

‘To contribute to the realisation of a society where people with disabilities are supported;

(a) to participate to their full potential in economic and social life, and
(b) to have access to a range of quality personal social support and services that enhance their quality of life and well-being.’²

**National Disability Inclusion Strategy (2017-2021):** Similarly, the National Disability Inclusion Strategy aims to support people with disabilities to live fulfilling lives and enabling them to participate fully in the activities of their communities.

**Task Force on Personalised Budgets (2017-2018):** ‘One of the Government’s key objectives is to provide people with disabilities with services and supports which will empower them to live independent lives, provide them with greater independence in accessing the services they choose, and enhance their ability to tailor the supports required to meet their needs and plan their lives. To achieve this aim, the Programme for Government provided a commitment to the establishment of a Task Force on Personalised Budgets.'³ The Taskforce held its plenary meeting in October 2017. The Taskforce completed its work and submitted its report to the Minister for consideration in Spring of this year. DFI represented on that Task Force. But research has shown the introduction of a

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Personalised Budget model will lead to the need for a greater provision of PA services, allowing more people who need these services to access them.\(^4\)

DFI contends that none of these rights, recommendations, policies, programmes and strategies cannot be realised without proper provision of Personal Assistant Services for people with disabilities.

For any real change to occur, a strong commitment of resources and funding for Personal Assistant services. Disability spending must be reformed to provide such person-centred services. Currently, although €1.772bn has been allocated to disability services in 2018, €1bn was spent on residential services\(^5\) that caters to just 1.3% of people with disabilities. Only 0.3% of all people with disabilities get a Personal Assistant Service.

**What are Personal Assistant services and Why are they Important?:**

There is no set definition of Personal Assistant services – also referred to as PA services. This is perhaps in part due to the nature of the service as being person-centred and adaptive to the individual person with disabilities. It will mean different things to different people. However, the lack of a common understanding of the term PA service is a very serious problem, leading to inconsistencies in standards and quality of service provision.

For example, the understanding and perception of what a Personal Assistant service is varies across HSE areas. Some areas understand the ‘PA service’ in terms of provision of social supports, which support people to participate in their communities, etc.. Others see it as just a ‘personal care’ service. But this is to conflate it with Home Help services which provide this kind of domestic and personal care. In fact, some people who apply for a PA service are provided with Home Support hours instead. This slippage between service types is deeply problematic. It camouflages the true demand for PA service, and undermines any count of unmet need. But it also has serious implications for the individual. If the person accepts these hours, he/she is provided with a service that does not support independent living as per the PA model of service. But they may be removed from any waiting list for PA services that exists.

But Personal Assistant services are a critical part of living an independent life for many people with disabilities. They support and enable people to

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\(^4\) HRB (2016) Individualised budgeting for social care services for people with a disability: International approaches and evidence on outcomes and experiences

engage in everyday tasks such as socialising, education, and employment.

They also support a person to live in the community in a living situation of their choosing, rather than relying on family, residential care or congregated settings.

For example, over 1000 people with disabilities under the age of 65 are living inappropriately in nursing homes for older people.\(^6\) DFI is currently conducting research into this, as there is a lack of information and data on this issue. But we can at this point deduce that a lack of proper community based supports is a significant contributing factor.

**Key Facts and Figures:**
It is useful to reiterate that only 0.3% of all people with disabilities get a Personal Assistant Service.

The numbers of people in receipt of the PA Service and Home Supports Service for 2017 are detailed below.

**KPIs, 2017, and 2010**

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2017</th>
</tr>
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<tbody>
<tr>
<td>Number of adults with a physical / sensory disability in receipt of a PA service</td>
<td></td>
<td>2,255</td>
</tr>
<tr>
<td>No of people with a disability in receipt of Home Support Services (ID and / or Autism and Physical and Sensory)</td>
<td></td>
<td>7,126</td>
</tr>
<tr>
<td>No. of persons with physical and/or sensory disability benefiting from Personal Assistant/Home Support hours</td>
<td>12,628</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12,628</strong></td>
<td><strong>9381</strong></td>
</tr>
</tbody>
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Source: HSE National Service Plan 2017, and HSE National Service Plan, 2011

Notwithstanding the definitional issues / conflation of PA and Home Support data, the above figures show that overall there has been a drop of over 25 per cent in the numbers in receipt of PA and Home Supports combined, between 2010 and 2017.

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\(^6\) Per HSE data. In particular, as of August 2015, 1,047 people under the age of 65 are in receipt of NHSS funding (i.e. are in nursing homes)
In terms of the PA service, the majority of people receive between 1 and 5 hours – 957, and between 6 and 10 hours – 538. There was only a target of 256 people to receive between 21 and 40 hours in 2017\(^7\).

When understood at a macro level only 5% of the HSE’s Disability budget went on PA and Home Support Services, meanwhile 85% is spent on residential and day services\(^8\).

**Cost / Benefit of PA Services versus Residential Facilities:**
Research from Sweden has shown that the cost of a placement for an individual with extensive functional impairments in a group home often exceeds the cost of personal assistance\(^9\). This does not take into account the fact that personal assistance often leads to greater flexibility and freedom of choice for the individual.

The cost per year of a Fair Deal nursing home (for the government) is between €45,968 and €108,628. The cost per year of a high end private nursing home (not paid for by the government) is €312,000.\(^{10}\)

The cost per year of a 24 hour PA service from the IWA is €200,054.40, while 40 hours a week of PA is €47,632/year.

**Issues and blockages:**

**Lack of Investment:** Over the period of austerity, funding for the PA service was reduced, as it was not seen as essential for people to participate in community activity / work / training / leisure while Home Supports were provided as a minimum service so that the person could be supported in basic needs, i.e. getting up and dressed, as opposed to being left in bed all day.

There has been no additional funding for PA services since 2008 and thus no new PA hours are being created. People who are on waiting lists must wait for a person to die before they can get any new hours. An example of this was where an individual who was in receipt of 65 hours per week passed away. These hours were then recycled amongst 6 individuals, who had a genuine need, but this does not facilitate a PA model of service.

Some people are on waiting lists for more than 5 years, after which their file is archived (Communication with Gary Lee, CIL, meeting in DFI 2016).

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\(^7\) Expected Activity figures in the HSE Social Care Division Operational Plan 2017.


**Constraints on the Service:** PA services are only offered during certain hours, or on a rigid schedule, or time slots of less than an hour are provided. These restrictions to the service mean that a person will only receive hours to allow them get up, get washed, and dressed. This is effectively a Home Support service and not a PA service. A limited service does not allow a person get out of their home, to participate in social, employment, education activities etc. The person must plan their lives around the limited hours they will be receiving services. Delivering services in this way is often oppressive, and tied to a medical model approach, making the person’s impairment the problem, rather than the way that impairment interacts with society.

A reduced service can also have a negative impact on a person’s disability as well as their health and well-being.

There are significant issues regarding funding streams and transferability of services. For example, students may receive PA services to assist them in attending third level education. But these services can be confined to educational participation. And might not extend to independent living. Similarly, once these people leave third level education, and try to transition to employment, people can loose their entitlements to personal assistant services. To confine PA services in this way is to misunderstand the point of PA services; to enable people to live their lives on an equal basis as their able-bodied peers. There needs to be systemic, joint up service provision.

Finally, PA services should be lead and directed by the person with a disability. But not everyone has the capacity or desire to be an employer or manager. This should not preclude them from receiving a PA service which is person-centred and supports the person to live a life of their own choosing. Any models of PA service must take this into account so that they can adapt to the individual’s capacity and desire to be a Leader.

**Lack of Standardised Assessment:** There is no national standardised assessment of need for PA or Home Supports services. There are different assessment procedures in different HSE local areas around the country. Experience shows that the assessment process is opaque, and those applying have no way of knowing why they have received their outcome.

**Inadequate Data:** Returns on current number and hours of PA and Home Supports to HSE local offices are not reliable due to inconsistent application of definitions and level of validation of actual service provided. The collection of data on unmet need, i.e. waiting lists is inconsistent across HSE local offices.
Data provided to DFI by one organisation showed that in November, 2017, in one area alone in Cork city, South Lee, there were 45 people waitlisted for services. Another organisation showed that in 2014 an average number of hours provided was 4.5 hours, and that a Leader would typically get 24 hours. The organisation estimated that about 1,000 of their service users had an unmet need for an enhanced service.

**Recruitment of Personal Assistants:** The current challenges in recruiting Personal Assistants has been raised by a number of voluntary disability organisations.

**Oversight / Quality Issues:** The issue of an individual being refused a service from two service providers recently came to the attention of DFI. The HSE local office reported that it was not their responsibility to govern the delivery of service. There currently exists a lack of clarity on responsibilities as well as oversight on the relationship of service provider and the person with a disability.

HIQA’s recent discussion paper notes the increased risks where community services are unregulated in areas such as quality of service, safety, rights, quality of life, discrimination and responsiveness of services.\(^{11}\)

**Conclusion:**
Personal Assistant services are the cornerstone of person-centred, community based service provision. They enable a person to live with dignity and in a life of their choosing. It is of utmost necessity to put in place a robust programme to provide Personal Assistant services and thereby deliver on the current policy commitments and direction at national and international level.

**Recommendations:**
- There is an urgent need to invest in the PA service.
- Cost / benefit data shows that investing in the PA service makes more sense. Further analysis of data is needed to compare the cost of PA service versus residential facilities.
- There is a need for an overarching policy for PA services and reform of service delivery.
- A key point to stress is that the concept of independent living needs to be incorporated into the definition and into service delivery. People with disabilities should not be refused a PA service on the

\(^{11}\) HIQA (2017) Exploring the Regulation of Health and Social Care Services.
basis that they neither wish to nor have the skills to be an employer / manage their own service.

- Better data is clearly needed to track the level and type of unmet need for PA service across the country. This should be done at an administrative level within the HSE, to develop a consistent, standardised, method for collecting data on unmet need at CHO level.

  Dr. Joanne McCarthy and Mr. Garry Toner

  On behalf of the Disability Federation of Ireland, DFI
DFI is about making Ireland fairer for people with disabilities.

We work to create an Ireland where everyone can thrive, where everyone is equally valued.

We do this by supporting people with disabilities and strengthening the disability movement.

There are over 120 member organisations in DFI. We also work with a growing number of other organisations that have a significant interest in people with disabilities.

DFI provides:

- Information
- Training and Support
- Networking
- Advocacy and Representation
- Research, Policy Development and Implementation
- Organisation and Management Development

Disability is a societal issue and DFI works with Government, and across all the social and economic strands and interests of society.

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