



Údarás Náisiúnta Míchumais
National Disability Authority

Trevor Moore
Home Support Reform Unit
Department of Health

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04 August 2022

Public consultation on draft regulations for providers of home support services

Dear Trevor,

The National Disability Authority is writing to you to submit feedback on the Department of Health's public consultation on 'Draft Regulations for Providers of Home Support Services'.

As per our previous submission, because the NDA is better placed to comment on some areas of the regulations than others, we are submitting our feedback in this letter rather than through the survey.

We wrote to you in response to a closed consultation on a previous version of these draft regulations in January, and the general comments we submitted then remain applicable.

We note again that the majority of home support services users would be persons with a disability, and therefore that the legislation and policy relating to persons with disabilities is applicable. This includes:

- The [Outcomes Framework for Disability Services](#) approved by the Department of Health and the Health Service Executive (HSE);
- The HSE '[A National Framework for person-centred planning in Services for Persons with a Disability](#)'; and
- 'A Quality Framework: Supporting Persons with Disabilities to achieve Personal Outcomes' developed under the Transforming Lives programme by Working Group 4, which is relevant for all services for adults with a disability, including day, residential, home and community services.

The comments further below are specific to the current version of these draft regulations.

Definitions

Definition of ‘Personal Assistance’

The HSE defines Personal Assistance as follows:

“Definitions: Personal Assistant (PA): is employed by the person with a disability to enable them to live an independent life. The PA provides assistance, at the discretion and direction of the person with the disability, thus promoting choice and control for the person with the disability to live independently” (National Physical and Sensory Disability Database – Description of Services). Employed by: for the purposes of this KPI means that the service user has full control over the recruitment and day to day direction of their PA. The service user may devolve responsibility for employment administrative arrangements e.g. Garda vetting, references, insurance, tax returns and salary payment, to a service provider such as CIL, IWA.”¹

The draft Home Support Regulations defines ‘Personal Assistance’ as:

“a package of support delivered to an adult to optimise his or her functional independence, health and well-being, occupational and social engagement.”

Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) makes specific reference to “personal assistance”. In its General Comment Number 5, the UNCRPD Committee defines personal assistance as:

“person-directed/“user”-led human support available to a person with disability and is a tool for independent living.”

The UNCRPD Committee further refers to a person with a disability [using a Personal Assistance service] being the “centre of the decisions concerning the assistance”; notes that the “service must be controlled by the person with disability”; and notes that the personal assistance must be “self-managed” (Committee on the Rights of Persons with Disabilities, 2017, General Comment No. 5 - Living independently and being included in the community).

Additionally, ‘choice and control’ is one of the quality of life outcome domains the Department of Health and the HSE approved for Irish disability services for adults.

¹ Health Service Executive Disability Services Key Performance Indicator Metadata 2022, HSE, 2022. Available at: <https://www.hse.ie/eng/services/publications/kpis/key-performance-indicators-acute-metadata-2022.html>

Based the above, the NDA advises that the definition of “Personal Assistance” in the draft regulations does not adequately reflect the emphasis on “direction” and “choice and control” contained in the existing definition of PA used by the HSE nor the emphasis on control, decision-making and self-direction in the UNCRPD Committee’s definition. It also does not reflect the quality of life outcome domains the Department of Health and the HSE approved for Irish disability services for adults, of which ‘choice and control’ is one. The NDA therefore advises that the definition of “Personal Assistance” in the draft regulations needs to be amended to include a greater emphasis on choice, control and self-direction. Furthermore, if the definition of “Personal Assistance” is amended to reflect the emphasis on choice, control and self-direction, this is likely to necessitate further changes to other aspects of the draft regulations, such as: needs assessment and personal support plan (6); service provision (8); and qualifications, training and development (12).

Definition of ‘needs assessment’

The draft Home Support Regulations defines ‘needs assessment’ as follows:

“a comprehensive standardised assessment of the health, personal, psychological, physical, and social care needs of a person seeking home-support.”

The above definition of ‘needs assessment’ refers to “comprehensive standardised assessment”. The NDA advises that there is no existing “comprehensive standardised assessment” in operation in disability services nor is there an agreed tool identified for disability services. The Department of Health requested the NDA to conduct a review of needs assessment tools which are used internationally to allocate resources (such as support hours) to people with disabilities. An overview of that work is available on the NDA website².

It is also noted that regulation 6(1), which refers to assessment, does not refer to a standardised assessment but to a “comprehensive assessment carried out by a health professional”.

The NDA advises that the definition of and references to ‘needs assessment’ in the draft regulations needs to be revisited for consistency, and to further clarify whether there is a specific tool or assessment to be used or whether a service provider creates their own assessment. If the intention is that a service provider creates their own assessment, this would lead to inconsistency across service provision and would likely be problematic for all stakeholders.

Definition of ‘Personal Support Plan’

The HSE person-centred planning framework, ‘[A National Framework for Person-Centred Planning in Services for Persons with a Disability](#)’, makes a distinction between a ‘person-centred plan’ and a ‘personalised care and support plan’, and identifies both together as a ‘personal plan’. The ‘person-centred plan’ is about what is important **to** a person, and the ‘personalised care and support plan’ is about what is important **for** the

² Resource allocation models for disability services: assessment of four systems, NDA, 2015. Available at: <https://nda.ie/publications/disability-supports/resource-allocation-project/>

person. The definition of a 'personal support plan' in regulation 6(1) uses different but similar terminology and a different 'definition' (it is not defined in 2), which may be problematic.

Regulation 6(1) states that the personal support plan **should** set out in detail the services that the service provider shall provide to meet the assessed home support needs of the service user and **should** take into account any goals that the service user indicates he or she wishes to achieve, and any preferences indicated by the service user. We would advise that, for person-centred, outcomes focussed services, it is critical that the goals and wishes of the person are identified, recorded, addressed and reviewed.

Views of people who use Home Support, including Personal Assistance

The NDA acknowledges that the Department made efforts to ensure that those who use Home Support, including those who use PA services, were made aware that the consultation was taking place and we acknowledge that the Department extended the deadline for the consultation.

However, the NDA believes that it is very important that those who use Home Support, including those who use PA services, be supported in appropriate ways to have their voice included in the consultation process. While providers may engage with those who use their service in developing their organisations' consultation responses, the NDA does not believe that that is an adequate basis for the voice of people who use Home Support, including those who use PA services, to provide input into the consultation.

The NDA believes that engaging with those who use services is always worth doing but in the case of the current consultation we believe that it is crucial for a number of reasons. Firstly, as there is no national policy on Personal Assistance, the service delivery model varies across regions and organisations³. In this context the regulations and subsequent HIQA standards will have a very significant impact on how services are delivered and will therefore impact on those who rely on Home Support and PA support. Secondly, NDA-commissioned research shows that those who use Personal Assistance have mixed views on the appropriateness of regulation of PA services^{Error!}
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Two recent NDA documents, one of which we published on our website in June 2022 and the other of which is due to be published later this year, provide further information and advice on consulting with persons with disabilities. The first paper is ['Engaging and consulting with persons with disabilities in the development and](#)

³ This research has been carried out by the ESRI as part of the NDA-ESRI [Joint Research Programme on the experiences of persons with disabilities across key policy areas](#), but is not yet published. The NDA has requested permission from the ESRI to share the relevant papers with the Department of Health, and are attached but not for wider circulation for the moment as they are being reviewed for a peer reviewed journal publication

[implementation of legislation and policy](#)⁴. The second paper is ‘Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making’, and we attach a pre-publication version of this to our submission; please note that this latter document is not for wider circulation.

The NDA remains available to advise or assist you and your colleagues if you were to consider consulting directly with those who use PA services.

Qualifications

Draft Regulation 12 sets out the minimum qualifications for Personal Assistants. While the NDA agrees that it is important that Home Support workforce have the skills and competencies to perform the role, we would also point out that, in the research we commissioned on Personal Assistance³, a significant minority (approximately a fifth of people who use Personal Assistance) were either neutral or opposed to minimum qualifications for PAs. About half of those (10% of those surveyed) strongly disagreed with the idea of minimum qualifications for PAs. Why there are a minority of people who use Personal Assistance who strongly disagree with the idea of minimum qualifications for PAs is not specifically answered in the NDA-commissioned research. However, from our engagement with people who use PA services, we understand that some people (probably a minority) believe that personal compatibility and shared interests are more important than qualifications. A Disability Federation of Ireland document on PA services⁵ quotes a number of PA service users who express this perspective:

“In my experience the job of a PA is individual-based, and a qualification such as FETAC is a one size fits all approach that won’t suffice in today’s climate. Personal traits and skills are far more important than a qualification”.

“Quality in a PA is about their value system. No one can teach willingness to be patient, flexible and to listen.”

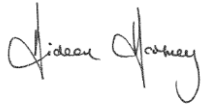
The NDA is not advising on whether the regulations set minimum qualifications. However, we do feel that the issue of minimum qualifications outlined above provides a clear example of the need for the Department to engage directly with people who use PA services.

We are very happy to discuss the comments above further with you and your colleagues, and to provide assistance to the Department in its further development of these important regulations.

⁴ This paper is available on the NDA website at the following URL:
<https://nda.ie/publications/others/uncrpd/engaging-and-consulting-with-disabled-people-in-the-development-and-implementation-of-legislation-and-policy.html>

⁵ Source: Disability Federation of Ireland, 2014, Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities

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A handwritten signature in black ink, appearing to read 'Aileen Hartney'.

Dr. Aileen Hartney

Director, National Disability Authority