

**May 2023**

**NDA Submission to Department of Health on Regulations for Providers of Home Support Services**

# Section 1. About you

**Organisation Name: National Disability Authority**

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**Organisation Description (ie. members, service users, disability or older person services):**

The National Disability Authority (NDA) is the independent statutory body, providing evidence-based advice and research to Government on disability policy and practice and promoting Universal Design.

Given our remit we have not completed the tick boxes below. Where we have an observation on the wording of a particular regulation based on our previous work we have simply made that observation.

# Section 2. Feedback on Draft Regulations for Providers of Home Support Services

## General (Introduction, Definitions)

Do you agree with the requirements set out in?

|  |  |  |  |
| --- | --- | --- | --- |
| Insert x in the appropriate box | Yes | No | Unsure |
| Introduction |  |  |  |
| Definitions |  |  |  |
| **Comment (optional)**  “Decision Supporter” is defined in the definitions sections but decision-making capacity (as per the ADMA Act 2015) is not defined nor is reference to the guiding principles of the 2015 Act included in the revised draft regulations. The guiding principles, including presumption of capacity, requirement to maximise capacity, right to make unwise decisions, etc., will be important in relation to how home support is provided to many people whereas decision-making support arrangements are likely to be relevant to a minority of those who will use home support. The NDA advises that regulations should define decision making capacity (as per the 2015 Act) in the definitions section and note that those who use home support will be presumed to have decision-making capacity in the “Service Provision” Section.  The term “Personal Support Plan” is not the term used in regulations for residential services (S.I. No. 367/2013 - Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013.) nor is it the term used in the HSE’s National Framework for Person Centred Planning in Services for Persons with a Disability (2018) which has been rolled out to Adult Day Services but which is intended to be rolled out to all disability services. The HSE’s framework defines a “personal plan” as containing both a Person-Centred Plan and Personalised Care and Support Plan(s). We discuss Personal Support Plans further below under the “Service Provision” heading but in terms of definitions the NDA advises that consideration should be given to using the language contained in the HSE’s National Framework for Person Centred Planning. | | | |

## **Service Provision**

Do you agree with the requirements set out in regulations 1 - 8 under Service Provision?

|  |  |  |  |
| --- | --- | --- | --- |
| Insert x in the appropriate box | Yes | No | Do you currently meet these requirements (yes, partially, no) |
| 1. Statement of Purpose |  |  |  |
| 2. Principles of Service Delivery |  |  |  |
| 3. Service agreement between Provider & Service User |  |  |  |
| 4. Needs Assessment |  |  |  |
| 5. Personal Support Plan |  |  |  |
| 6. Service Delivery |  |  |  |
| 7. Safeguarding and Protection |  |  |  |
| 8. Medication Management Support |  |  |  |
| **Comment (optional)**  As noted above the NDA advises that consideration be given to having a common language across the regulations and HSE Person Centred Planning Framework. In the HSE framework it is noted that person-centred planning is about “what is important to a person, what really matters to them, from their perspective. Personalised care and support plans are about what is important for the person, the support they need to stay healthy, safe and well”. The current draft regulation mention that “personal support plans “include **reference to** service user priorities, preferences and goals”. The HSE’s Framework (and the evidence base which underpinned the Framework) shows that many people will need support and information in formats which are accessible to them to be able to make choices and that service providers need appropriate structures and trained staff to support the process of people with disabilities making choices about what they want in life and what supports they need from providers to achieve those goals. The NDA advises that the language of personal support plans being required to only have “reference to” service users’ priorities, preferences and goals is a much weaker requirement that the HSE’s Framework. The NDA suggests that “reference to” be replaced by “informed by”.  The NDA notes that the Department are awaiting the outcome of the Working Group on PA services and that the current thinking is that only Personal Assistance services which are primarily delivered in the home will be covered by the regulations. However, that would still mean that a cohort of people with disabilities who have an expectation that they will be facilitated to lead or self-direct their support (as per the current HSE definition of PA and UNCRPD Committee’s General comment No.5 on Article 19 - the right to live independently and be included in the community definition) are likely to find the language in the current draft (e.g. that the Personal Support Plan will “include reference to service user priorities, preferences and goals”) does not meet their expectation that they lead / self-direct how they are supported.  The NDA therefore advises that there needs to be a greater focus in the regulations on choice and people who receive home support / PA services having a say in how they are supported.  An issue which has emerged in disability services in relation to needs assessment and person centred support planning is services / staff having the appropriate communication skills to ensure that people with disabilities (with significant communication difficulties) are facilitated to participate in developing their plan. The draft regulations mention completed personal support plans being accessible to the person receiving home support but the NDA advises that the regulations should be clearer that providers need to ensure that staff developing the plans need to have the skills to ensure that the person with a disability is meaningfully included in developing the plan.  The section on personal support plan makes no reference to coordination or joint plans across service areas. It would not be uncommon that a person with an intellectual disability would attend an adult day service and also have some home support hours (which may or may not be with the same provider of the adult day service). Feedback from those working in the frontline disability services is that where there is no coordination between, for example, adult day service and home support providers that outcomes are suboptimal and that support plans across the service areas should be coordinated or that there should be one joint plan. The NDA therefore advises that a reference is added to the draft regulations around the need to coordinate with other service providers providing support to the person using home support.  Line 5 (2) (“Development of a personal support plan shall involve the service user [and family carer if any]”) may need to be nuanced. While including family members and other natural community supports in the development of a personal support plan may be appropriate for many people it may not be for some. The NDA advises that it should be clarified that the “shall” in draft regulation 5 (2) does not apply to family members. It would be more appropriate to say that family members “may” be involved where this is the preference of the person receiving home support. How family members can be involved should be in line with the ADMA Act 2015 and the HSE National Consent Policy, 2022.  In relation to safeguarding, draft regulation 7 (9) requires services providers to provide people receiving home support with a “list of the contact details of organisations that provide advocacy and support services”. The NDA suggests that the HSE’s Safeguarding and Protection Teams should be explicitly referenced here in addition to “advocacy and support services” as they are the people with the statutory function to protect those people who are receiving HSE / HSE funded services.  In relation to 6 (1) (service delivery) the NDA advises that “preferences” be added to reflect the fact that people who receive home support should have a say in how they are supported. The NDA advises therefore that 6 (1) should read, “..in accordance with the needs **and preferences** of the service user…”. | | | |

## **Staffing**

Do you agree with the requirements set out in regulations 9 & 10 under Staffing?

|  |  |  |  |
| --- | --- | --- | --- |
| Insert x in the appropriate box | Yes | No | Do you currently meet these requirements (yes, partially, no) |
| 9. Staffing Requirements |  |  |  |
| 10. Education and Training |  |  |  |
| **Comment (optional)**  The NDA welcomes that fact that the current draft regulations are less prescriptive than the previous draft and allow for the education and training requirement to be linked to an analysis of the service delivery context and requirements. | | | |

## **Corporate Governance**

Do you agree with the requirements set out in regulations 11 - 13 under Corporate Governance?

|  |  |  |  |
| --- | --- | --- | --- |
| Insert x in the appropriate box | Yes | No | Do you currently meet requirements (yes, partially, no) |
| 11. Service Management |  |  |  |
| 12. Records and Reporting |  |  |  |
| 13. Financial Procedures |  |  |  |
| **Comment (optional)** | | | |

## **Corporate Oversight**

Do you agree with the requirements set out in regulations 14 - 18 under Corporate Oversight?

|  |  |  |  |
| --- | --- | --- | --- |
| Insert x in the appropriate box | Yes | No | Do you currently meet requirements (yes, partially, no) |
| 14. Policies and Procedures |  |  |  |
| 15. Complaints Management |  |  |  |
| 16. Infection, Prevention and Control |  |  |  |
| 17. Health and Safety |  |  |  |
| 18. Quality Assurance |  |  |  |
| **Comment (optional)**  15 (3) refers to making the complaints procedure documents available in hard and soft copy. The NDA advises that the requirement should be to make complaints procedures documents available in appropriately accessible formats.  In relation to 16 (2) it may be worth acknowledging that in addition to compliance with infection prevention and control policies and procedures some service users may have specific requirements/preferences for infection prevention and control arrangements within their home. The NDA advises therefore that 16 (2) should read “…policies and procedures and service users’ needs and preferences….”.  In relation to 17 (3) to 17 (6) (risk assessment) it should be acknowledged that risk assessments should be carried out in conjunction with the service user. Home support users have the right to make decisions, including unwise decisions. What is risky and how to mitigate risk can be seen differently by service providers and people with disabilities (and their family members). Therefore, how risk is perceived and its mitigation planned for needs to involve the person who will be subject to the risk mitigation plans. The NDA advises that 17 (3) to 17 (6) be revised to reflect that risk assessment, risk mitigation planning and risk monitoring are activities which should be conducted collaboratively with the person who uses home support.  In relation to 18 (2) on quality assurance the NDA advises that the requirement to establish an **ongoing** **process** for consulting with service users should be clarified (18 (2) currently reads as if the requirement may only be to have consulted on a once-off basis with services users within the first 12 months of service). | | | |

# Section 3. Impact of Regulations

Please indicate your level of agreement with the following statement:

***The overall impact of the proposed home support regulations will be positive*:**

1. Strongly Agree (b) Agree

(tick one option from (a), (b), (c), (d) or (e))

(c) Neither Agree nor Disagree

(d) Disagree (e) Strongly Disagree

|  |
| --- |
| **Comment (optional)**  In our previous submission on the draft regulations the NDA highlighted the potential risks associated with Personal Assistance services being included under regulatory arrangements which are primarily aimed at regulating Home Care services. Our concern was related to the fact that Personal Assistance services have a different purpose and focus to Home Support. Personal Assistance services are a support to allow someone to be active in social and economic life in addition to being a support to remain living independently at home. Even when Personal Assistance services are partly delivered to support someone to live independently in their own home there is an expectation that the person with a disability will be involved in choosing and self-directing their support. In short, Personal Assistance services is a different model of service to home support so there is a risk that even well-drafted Home Support regulations and associated standards may not be fully suitable for Personal Assistance services.  Based on the above, the NDA welcomes the fact that the HSE has established or will shortly establish a Working Group on Personal Assistance services which will consider among other things how Personal Assistance services will be regulated.  The NDA advises that in considering the impact of the regulations that the issue of including Personal Assistance services under the Home Support regulations is considered once the PA Working Group has concluded its work and that the question be looked at again after the first year of regulation to ensure that the regulation of Personal Assistance services is not having any negative unintended consequences. |

Thank you for completing this questionnaire. Return to HSRConsultation@health.gov.ie