IASW
Irish Association of Social Workers

Submission to the Disability Action Plan Framework

Summary points

This submission is provided by the Irish Association of Social Workers' (IASW) Special Interest Group called Social Workers in Disability (SWID). The Irish Association of Social Workers is the national professional body for social workers in the Republic of Ireland. Under the umbrella of IASW, membership of Special Interest Groups (SIG), is open to members of the IASW. The SIGs highlight priority issues for social work and for the Association.

The Social Workers in Disability SIG addresses issues for social workers in physical and sensory, ID and neurological conditions in the range of acute to community services. SWID is a SIG for any social worker working in these areas as well as social workers who have an interest in disability services.

Our consultation process was completed in two stages:

1. Discussions at our September SIG meeting. This framework was added to our agenda for discussion.
2. Email submission process by our members. Our secretary contacted our members through the medium of email. We impose a deadline for the requested feedback to ensure that we obtained all commentary before the submission deadline.

Social Workers in Disability would like to highlight the following areas as priorities for the 2022-2025 planning period:

- Increased Access to Home Care;
- Increase range of in-home services;
- Workforce Planning in relation to professional carers;
- Housing supports, Assisted living and Transitional Living Units;
- Community based services for adults with disabilities;
- Increased Social Work and other services in Children's Disability Services;
- Respite services for children with disabilities.

1. Homecare support services

Access to Home Care

The lack of a statutory entitlement to home care has been one of the biggest barriers to persons with disabilities living their lives with maximum independence within the community. Nursing Home care is available on a statutory basis, but home care is not. The Fair Deal scheme continues to steer persons with disabilities towards nursing home care which is against all Government policies.

Homecare budgets need to increase substantially and cover personal assistants and in home respite services.

Social Workers in Disability Services are also highlighting an issue whereby persons who have suffered significant disabilities following a stroke or a brain tumour are not eligible for disability services. The reasoning is that these clients have a medical condition and not a disability.

Range of supports

For those recovering from injuries such as Acquire Brain Injuries and Strokes, who could continue to make progress, services such as Rehabilitation Assistants are key. This allows for training and capacity building with a view to reducing the level of support required over time.

A major barrier for persons with cognitive disabilities who are physically well, is the bias towards proving physical care: those who need personal assistance (PA) due to severe memory or executive disabilities find it much more difficult to access support services.

For those with complex disabilities such as Spinal Cord Injury or late-stage MS, night-time care needs to be an option. Often there is a blanket refusal to consider home care if this is required, effectively pushing people towards nursing home care

A centralised budget is required for those with complex disabilities (for example, those on home ventilation) as local Disability Services are unable to meet these needs from their usual funding budgets. There is a wide variation between CHO areas as to how these situations are managed. This cohort often require a combination of nursing and PA, and this requires bespoke arrangements and lengthy negotiations with various sections within health care and disability services.

This frequently leads to months of delays in leaving hospitals and in some cases, the result is the person "living" in acute care facilities.

Shortage of carers

Social Workers are experiencing acute shortages in terms of staffing in homecare agencies. Even when the funding can be secured for a HCP, clients are often left in hospitals or other settings as staff cannot be sourced. The need to adequately value and pay staff in this sector is an urgent one and should form part of any workforce planning initiatives.

Family carers' health is deteriorating due to delays in dealing with requests for increase in home care hours. The deferral of health appointments and other procedures result in frequent health crises for carers. For the person with disabilities, their care needs are then not being fully met e.g. personal care, physio exercises or leaving the house. As Social Workers, we work with the person within their environment and family system, and outcomes for clients are greatly improved if carers are involved and supported.

2. Housing

The national housing crisis has disproportionately affected persons with disabilities and their families. Sourcing rental properties which accept the HAP payment, and which are accessible for those with physical needs is an enormous challenge. Housing waiting lists particularly for single persons are at unprecedented levels.

Assisted Living

There are over 2,000 people living in residential institutions or campuses who are awaiting transition to community settings: progress in implementing the *Time to Move on from Congregated Settings* (2011) Report has been slow and in the interim a new congregation sector has formed. The Recent Ombudsman Report *"Wasted Lives: Time for a better future for younger people in nursing homes" (2021)* states that there are 1,320 people under the age of 65 years supported by the Nursing Home Support Scheme. It further states that "many are paying for nursing home care despite the fact that it is clearly not their will and preference to continue living there." The state is providing a "top up payment" to a considerable number of these individuals who would prefer to use the funding to live in the community. The need to transition younger people inappropriately placed in Nursing Homes and other institutions as well as prevention of further inappropriate placements is a key priority. This requires a substantial investment in assisted living services for those with intellectual or physical and sensory disabilities in community-based housing units with adequate staffing.

Transitional Living Units

Care locations are needed between acute/inpatient rehabilitation units and a longer-term housing solution. For example, those who have acquired spinal, or brain injuries often do not have a history with disability services and are therefore not on housing lists for accommodation. Others need extra time before they can transition to a fully independent living arrangement and currently their only option is often a nursing home for older persons. Those in nursing homes are not entitled to usual community services such as physiotherapy and can therefore deteriorate physically as well as psychologically. These individuals generally do not receive case management services to transition out and can become institutionalised.

Housing Adaptation Grant (HAG)

For those with acquired injuries, the waiting times for Housing Adaptation Grants and the contribution required from the individual and/or their family can be major barriers. For those who would have qualified, it is not possible to retrospectively apply for the grant.

3. Community Based Services for Adults with Disability

Access to services

The lack of Community Rehabilitation Teams in most CHO areas as well as insufficient staffing in Primary Care Teams means that it is extremely difficult to access community-based physiotherapy, occupational therapy, social work, case management and psychology services, speech and language and dietetics. This has led to longer lengths of stay in acute care facilities and reduced ability to maximise independence post-discharge. It also leads to reliance on inappropriate supports like PAs in absence of assessment to review FEDS (Feeding, eating drinking recommendations) and behaviour support plans for example)

Day Services

Provision of day services needs to increase and services for those who acquire a disability who have no history with disability services. The lack of a planned onward care plan for school leavers is a critical issue and a source of huge concern to many parents/carers.

Access to Respite

The level of respite available to adults with disabilities declines significantly when they move to adult services. There are limited respite centres to offer multiple stays throughout the year including weekend respite. The availability of respite centre with nursing support is minimal resulting in people with medical needs or those who require nursing support being excluded from respite stays.

Requests for in home respite has been turned down by HSE in some areas. Family carers do not get sufficient physical and emotional respite from their caring role. Family carers are the backbone of care provision in Ireland as evidenced in the *National Carers' Strategy 2012* and need services in their own right.

4. Children's Disability Services

Access/Workforce Planning

While the principle behind Progressing Children's Disability Services (PDS) is for equal access regardless of disability, the reality on the ground is that the Early Intervention and Children's School Age Teams are under-resourced. In many areas there is one Social Work post for 400-500 families. Many of these posts are not senior grades. Given the critical role of Social Work in terms of adjustment counselling, family centred care and safeguarding, this is wholly unsustainable. The long-term outcomes for siblings and families has been affected by the dearth of family services including respite care.

Respite care

There is an urgent need for increased availability of day and overnight respite care for children with disabilities across many CHOs. With reconfiguration to the new PDS CDNT structures taking place in many areas of the country, children who were receiving respite with their previous service providers may continue to get those services, but it leaves a very large cohort of complex children without any clear pathway to accessing day or overnight respite care. This is a priority need for many families and without which many families will go into crisis or placement breakdown. Central planning and funding in each CHO for an equitable and well-resourced respite service needs to take place as a matter of urgency.

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