

**Care Alliance Ireland Submission to the Joint Oireachtas Committee on
Disability Matters
November 2020**

Care Alliance Ireland are pleased to have the opportunity to make a submission to the Joint Oireachtas Committee on Disability Matters to inform their future work.

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland.

We exist to enhance the quality of life for family carers. We achieve this by supporting our 95 member organisations in their direct work with family carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

There are in the region of 391,000 family carers in the Republic of Ireland¹. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions. We work with our member organisations and other agencies to support them in their work with family carers.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland’s family carers. Our membership is comprised of both large and small, regional and national organisations.

This short submission to the Committee concerns people with disabilities, and their family carers across the life course.

We are open to appearing before the Committee should it prove useful, to discuss these matters in more detail.

¹ Central Statistics Office, ‘Irish Health Survey (IHS) 2015 Results’ (Central Statistics Office, 2016), <https://www.cso.ie/en/releasesandpublications/ep/p-ih/irishhealthsurvey2015/ct/>.

Note: we have consulted with our membership whilst preparing this submission, however it should not be seen as a reflection of the views of each individual organisation. We have encouraged our members to make their own submissions, and anticipate that a number will do so.

Introduction

Caring and disability are issues of relevance across the life-course, with varying levels of care and support received from family and friends across all ages. As such, there are family carers providing care for children, adults and older people with disabilities, along with family carers who themselves develop disabilities. Whilst it is not necessarily accurate to assume that all people with disabilities require significant levels of care, it is the case that many will. For others, the care and support provided by family members will be instrumental in maximising their independence.

Whilst the data is a few years old, we in Care Alliance asked family carers why the person they care for requires care (respondents could choose multiple reasons)²;

36.89% had a physical disability

31.07% had an intellectual disability

19.41% had an autism spectrum disorder

21.42% had a neurological condition such as Parkinsons or MS

30.10% had a long-term condition (such as stroke, diabetes asthma etc).

There are many thousands of family members of children and adults with disabilities who identify as family carers. These family members are looking for supports for their loved ones in education, health, social care, independent living and various other areas. They themselves may have a disability.

Care and disability are, as we in Care Alliance have long said, two sides of the same coin. There are many families, in particular families of those with significant, complex medical needs, who are struggling. We in Care Alliance Ireland are an umbrella body, with

² Zoe Hughes and Liam O’Sullivan, ‘Defining and Profiling Family Carers: Reflections from Ireland’, *International Journal of Care and Caring* 1, no. 3 (2017): 421–27.

membership drawn from across the disability, mental health, ageing, addiction and community sectors³. Our membership comprises of most, if not all, the major disability not-for-profit groups and service providers including St. Michaels house, Cheshire Ireland, The Irish Wheelchair Association, DEBRA Ireland, Inclusion Ireland, and others. We partner each year with other organisations to deliver National Carers Week - the partners for 2020 included the Central Remedial Clinic, Acquired Brain Injury Ireland, the Disability Federation of Ireland, MS Ireland, St. Michaels House and Spina Bifida Hydrocephalus Ireland.

In the past, discussion of issues facing family carers has been seen to exist solely in the realm of older people and mental health – we call for an end to this siloing of policy and funding, and believe this Committee has to opportunity to discuss this as part of its upcoming programme of work.

Policy Disconnect

For many years now we have been highlighting the lack of cohesion across governmental departments regarding caring and disability in particular. We appreciate that for many adults with disabilities, the language around caring can be problematic – and we acknowledge this tension as healthy. However, we have also found that this disconnect causes real policy challenges, which must be addressed⁴.

Family members provide core supports for people with disabilities across the lifespan – however in reviewing the current National Disability Inclusion Strategy (NDIS) this is not immediately apparent. In fact, there is only one mention of the word ‘carer’ in the entire strategy, and it is in reference to paid care workers in residential settings. There are two mentions of the word ‘family’.

Whilst we agree that the focus of disability policy and services must remain the person with a disability, to remove the family carer from policy is unacceptable. It also directly

³ <https://www.carealliance.ie/List-of-members>

⁴ Care Alliance Ireland, ‘Disability and Family Carer Policy - Challenges and Responses.’ (Care Alliance Ireland, 2017).

contradicts the National Carers Strategy, which includes in its vision statement the commitment that “carers will be recognised and respected as key care partners”⁵.

Across the scope of the NDIS, there are many instances where the goal of consultation with people with disabilities ‘and their representatives’ is included (for example Action 32, 33 etc.). However, it is unclear as to how families of people with disabilities are being included.

A consistent concern which many of our member organisations and families of people with considerable and multiple disabilities and cognitive impairments have, raised, is that overall, it seems like the majority of actions contained in the strategy, along with their ensuing actions, are specifically focussed on people with lower levels of intellectual disability in particular. The focus on decongregation, inclusive education etc. has meant that many families of people with significant extra support needs are left with little to no supports in the areas of independent living, education and pathways to work.

We believe that a core priority of policy must be to include family members of people with disabilities in a more meaningful way – in particular those families who support their members with disabilities to live at home, in the community. Whilst we support wholeheartedly the prioritisation of people with disability in policy, disability and family care and family support are two sides of the same coin. As so many adults with disabilities live at home, with family who support them, it is crucial to understand the family support needs as a whole, rather than the person with disability in isolation.

Conclusion

In order to keep this submission short and concise, as requested by the Committee, we have refrained from including discussion of every individual issue facing family carers of people with disabilities, and indeed those family carers who they themselves have disabilities. These include the issue of the concerns of parent carers of adults with intellectual disabilities who they themselves may require care; the provision of supports and services for people with disabilities beyond those concerned primarily with employment and independent living; issues relating to transport and housing; and others.

⁵ Department of Health, ‘The National Carers’ Strategy’ (Department of Health, 2012).

However, we include below a short reading list of previous reports from Care Alliance Ireland which highlight the connection between disability and caring, and involve more detail which we believe may be of significant interest to the Committee.

As previously stated, we are open to appearing before the Committee to discuss these or other issues, as relevant and useful.

Key Recommendations:

1. Examine the relationship between family care and disability, and move away from the siloing of disability, older people, and family care
2. Ensure that family members are not excluded from policy discussions which impact their family members with disabilities
3. Expand discussion of disability to include people with significant and complex disabilities and medical needs
4. Acknowledge that disability policy needs to expand beyond discussions of employment and independent living, and involve family carers in the development of this policy
5. Ensure that upcoming disability policy is developed in conjunction with the updated National Carers Strategy (as identified as upcoming in the Programme For Government)

References:

Defining Carers: <https://bit.ly/32fr7y8>

Intellectual Disability and Role Reversal: <https://bit.ly/3k1yoHU>

Disability and Family Carer Policy – Challenges and Responses: <https://bit.ly/2I6PZkJ>

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