

**Care Alliance Ireland Submission to the Department of Children, Equality,
Disability, Integration and Youth**

Consultation on the departmental Statement of Strategy 2021-2023.

November 2020

Care Alliance Ireland are pleased to have the opportunity to make a submission to the Department of Children, Equality, Disability, Integration and Youth Consultation on the departmental Statement of Strategy 2021-2023.

This short submission to the Department concerns how the work of the Department needs to take into consideration the needs of Irelands 391,000 family carers¹. The responsibilities of the Department encompasses multiple sectors which family caring in some way impacts.

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.

Disability

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. There are also large numbers of young people in caring roles within their own families. 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.

¹ **Central Statistics Office**, ‘Irish Health Survey (IHS) 2015 Results’ (Central Statistics Office, 2016), <https://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/>; **Care Alliance Ireland**, ‘Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports’ (Care Alliance Ireland, 2017), ([link](#)).

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 families 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 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.

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 in particular with disabilities, the language around caring can be problematic – and we acknowledge this tension as healthy. However, we have also found that this disconnect

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.

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

causes real policy challenges, which must be addressed⁴. In this regard one of the key actions/outcomes we would recommend for the Departmental strategy is to ensure that the Department is involved in the upcoming development of an updated National Carers Strategy (per commitments in the current Programme for Government), and that actions from the Strategy are embedded within the operations of the Department as a whole.

Youth

It is difficult to quantify exactly how many young people are providing care in Ireland, as various surveys have estimated differing numbers based upon the methods used to collect the data. A school-administered survey indicated that 11.5% of 10 to 17 year-olds identify as carers⁵ which would equate to approximately 60,000 young carers nationally. The wording of the survey question was as follows:

"Do you provide regular unpaid personal help for a family member with a long-term illness, health problem or disability? (Includes problems which are due to old age. Personal help includes help with basic tasks such as feeding or dressing)" with response options 'Yes' and 'No'."

However, according to the most recent census figures (2016) there are 3,800 children aged less than 15 years reported as providing care⁶. The census is completed by an adult member of the household, and for this reason there may be some reluctance to report on caregiving among those under the age of 18. This may be due to concerns about privacy or perceived stigma.

Young carers can lose out on education and employment opportunities due to their responsibilities, along with experiencing significant isolation and other negative impacts⁷, and it is the responsibility of the Department to ensure that these are addressed as a

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

⁵ Mary Callaghan, Eimear Keane, and Michael Molcho, 'Short Report- HBSC Ireland: Young Carers in the 2014 HBSC Study', February 2016.

⁶ Central Statistics Office, 'Census 2016 Summary Results - Part 1' (Central Statistics Office, 2017).

⁷ Saul Becker and Fiona Becker, 'Young Adult Carers in the UK. Experiences, Needs and Services for Carers Aged 16-24' (The Princess Royal Trust for Carers, 2008); Care Alliance Ireland, 'Engaging with Young Carers: A Virtuous Circle', 2018, ([link](#)).

matter of urgency. We also encourage the Department to ensure that the positive aspects of being a young carer are also celebrated where appropriate.

We ask that the Department include Young Carers as a priority group in the Strategic Plan, and to create actions which will compliment those in any upcoming National Carers Strategy. We also ask that in the new strategy, explicit reference is made to the importance of an integrated and life cycle approach to disability and caring.

About Care Alliance Ireland

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 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 Ireland. 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 95 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.

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