

National Disability Strategy Consultation 2024

Submission from Care Alliance Ireland

February 2024

Introduction

Care Alliance Ireland are pleased to have this opportunity to make a submission to the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) as the Department develops the next iteration of the National Disability Strategy for 2024 and beyond.

We understand that the National Disability Authority and DCEDIY are encouraging all disability stakeholders, including families and organisations, to make submissions as part of this consultation process. We are keen not to create a lengthy submission, nor to be seen to be attempting to 'talk over' disabled voices in the development of the Strategy. We also are focussing our comments and suggestions specifically to those relating to family members and care. Therefore, we will be keeping this submission brief, but are very willing to meet and discuss the points we make in this Submission to enable a deeper discussion of these topics.

Caring and disability – language use

We are keenly aware that there is a tension between disability and family care, in particular given the history of paternalism towards disabled people from the medical, social and family systems within the State. This tension is not necessarily a bad thing, and enables meaningful conversations to take place regarding various aspects of disabled identity, family systems, the medical and social models of disability, and other topics. These are important conversations to have to enable progress.

T +353 1 874 7776

E info@carealliance.ie
W www.carealliance.ie



@CareAllianceIrl

A Coleraine House
Coleraine Street
Dublin 7, Ireland
DO7 E8X7

Registered Company No
461315
Charity Registration No
20048303
CHY No 14644



We of course understand in Care Alliance that many disabled people have no need for family members to provide 'care' in the way it is often conceptualised. In addition, many family carers themselves are disabled and provide care and support to their family members and friends¹.

However, to dismiss the concept of care and family involvement as not in keeping with the social model of disability is unhelpful. Furthermore, to assert that all care is inherently paternalistic does a disservice to those disabled people who have significant care needs. The dual concepts of 'care' and 'disability' can cause significant conflict when it comes to not only policy but also operational challenges. From the outset, disability was conceptualised as a *defect* or an intrinsic problem located within a person, rather than as a problem of accessibility. This can be seen as the core difference between the 'medical' model of disability and the 'social' model. More recent policy documents position Ireland toward the social model of disability, looking to widen access to society for a group that has traditionally been excluded. Many of the difficulties with access to employment, health, education and other issues are not because of a persons disability, but because of societal attitudes towards them. This is to be welcomed.

However, many would argue that disability is a complex phenomenon that is both a 'problem' at the level of a person's body and a complex and primarily social phenomenon. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while other aspects are almost entirely external. While both medical and social responses to the problems associated with disability can be appropriate, we cannot wholly reject either kind of response. A better model, in short, is one that synthesises elements of the medical and social models, without making the mistake that each model makes

¹ Care Alliance Ireland, 'Intellectual Disability, Caring and Role Reversal' (Care Alliance Ireland, 2015).
<https://bit.ly/3k1yoHU>

in reducing the whole complex notion of disability to only one of its aspects. These forms of models of disability attempt to marry the positives and critical elements of each of the medical and social models into a unified approach that borrows much from systems theory; the person with a disability cannot be viewed in isolation from society, but also cannot be viewed without due consideration of certain physical or psychosocial 'impairments' which will impact upon their daily lives.

We cannot deny that there are some disabled people who need significant help with eating, healthcare, hygiene and other daily tasks, due to the nature of their specific conditions. Others will need some help with some aspects of life, and some will need relatively few. This is equally as true for older persons and those with other conditions across the lifespan.

The most recent (and currently out of date) National Disability Inclusion Strategy (2017-2022) uses the word 'carer' once in the entire strategy (and this is in reference to carers in nursing homes and residential settings). 'Family' is used twice, one of which is in the introduction of the Strategy. This policy therefore does not take into account people with disabilities who require significant support from family members and trained health and social care staff on a daily basis. This can be seen from the most recent figures from the National Ability Supports System (NASS), which states that 45% of those registered on the NASS report having a 'primary carer', with 92% of those living with that primary carer².

Therefore, one of the key recommendations we have for the next National Disability Strategy is to include families, carers and supporters within the language of the Strategy, to reflect the reality of significant numbers of disabled people in Ireland today who do require some level of care, in whatever format it takes.

² Claire Casey et al., 'Overview of People Engaging with Disability Services, 2022' (Health Research Board, 2023).

Services and supports

Many of our member organisations and other disability specific organisations will have made submissions to this consultation process. Within these submissions will be significant levels of information specific to the groups of disabled people they are working to support with regards to issues such as education, employment, mental and physical health, housing, transport and more. We cannot claim, in Care Alliance, to be experts in the support needs of disabled people across the multifaceted disability sector.

However, it is clear in recent research from our colleagues in Family Carers Ireland that the majority of family carers do not feel that the people they care for- regardless of age, gender or disability – are sufficiently supported across the lifespan³. In our discussions with our member organisations, and family carers we support through our Online Family Carer Support Group, we can see this is still the case. Therefore, the service and support availability for disabled people, such as commitments to address growing waiting lists for assessments and therapies must be prioritised in the next Disability Strategy.

We realise that this is a relatively nebulous policy ask for the next Disability Strategy, however given the expertise located elsewhere in disability organisations and disabled people themselves, it is important that the feedback and submissions made by them be taken into consideration. For most, if not all family carers, if the supports exist for those they care for and support, in an accessible, timely and appropriate level for them to realise their full potential (in whatever form that may be), the lives of those family carers will improve.

³ Family Carers Ireland, 'The State of Caring 2022' (Family Carers Ireland, 2022).

Cross Strategy Implementation

Our final point in this brief submission to the consultation is to highlight how critical it is that this next iteration of the National Disability Strategy is developed in harmony with existing, published Strategies, and those currently in development across Government.

As discussed earlier in this submission, there is little to no mention of families, or carers, in the current National Disability Inclusion Strategy. We discussed earlier the disservice this does to the families who are providing often significant levels of care and support to disabled people with regards to their physical and mental health in particular.

However, of particular concern is that the current NDIS was developed, written, and published during a time when the National Carers Strategy (NCS) (also due for renewal) was being implemented. The opening statement of vision for the NCS was that family carers would be 'recognised and respected as key care partners'⁴. Yet, five years later, upon publication of the NDIS, it was clear that no effort had been made to ensure that these two National strategies complemented each other, even though clearly they should, given the strong links between disability and care. We have published a paper on this topic which should be of interest to policy makers and highlights, in more detail, this particular issue⁵.

To develop this next Strategy without significant referencing to existing Strategies across the sector is not an acceptable course of action. Disability is such a cross-cutting issue that the actions in Strategies such as the National Dementia Strategy, Sharing the Vision, Young Ireland, the National Positive Ageing

⁴ Department of Health, 'The National Carers' Strategy' (Department of Health, 2012).

⁵ Care Alliance Ireland, 'Disability and Family Carer Policy - Challenges and Responses.' (Care Alliance Ireland, 2017). <https://bit.ly/2I6PZkJ>

Strategy, and many more must be taken into consideration when developing the next Disability Strategy.

With specific regard to the NCS, the current Strategy is significantly out of date, and the publication of a new NCS was committed to in the Programme for Government⁶. It appears that the development of this new Strategy has stalled or at the very least been significantly delayed. We recommend that the NCS and this new Disability Strategy be developed and published together (or at least covering similar timeframes), as disability and care are so closely linked.

Conclusion

We in Care Alliance are pleased to make this submission to the development of the next National Disability Strategy. We were disappointed to see so little inclusion and discussion of family care, and care and support in general, in the current Disability Inclusion Strategy. This is an opportunity to ensure that the rights of disabled people, many of whom are themselves carers for others, are upheld. It is also an opportunity to ensure that the family members and supporters of disabled people are seen as key care partners, per the current National Carers Strategy.

Submitted by

Zoe Hughes

Senior Policy & Research Officer

Care Alliance Ireland

www.carealliance.ie

zoe@carealliance.ie

086 8834942

⁶ Government of Ireland, 'Programme for Government - Our Shared Future', 2020.

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.

There are in the region of 500,000 family carers in the Republic of Ireland⁷. 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 85 member organisations⁸ 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.

We work with organisations to provide better information and supports to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions.

We deliver a number of carer specific projects; namely an Online Family Carer Support Project and Re-Emerge, a back to paid employment project.

We commission relevant research that supports focused and quality interventions in the lives of Family Carers.

⁷ Central Statistics Office, 'Irish Health Survey 2019 - Carers and Social Supports'.

⁸ See <https://www.carealliance.ie/List-of-members> for a full list of current membership.