



Care Alliance Ireland Submission to the Oireachtas Joint Committee on Justice, Defence and Equality regarding the Disability Act (2005) and the National Disability Strategy Implementation Plan (2013-2015)

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Introduction:

Care Alliance Ireland is an Alliance of over 100 not-for-profit organisations who support Family Carers. This includes disability services and support organisations within the multiple spheres of disability-intellectual, physical, sensory, motor, hidden, and the mental health sector.

What We Do: 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 act as a distribution channel for information on Family Carer issues. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support Family Carers. We commission relevant research that supports focussed and quality interventions in the lives of Family Carers.

Care Alliance Ireland welcomes the opportunity from the Oireachtas Joint Committee on Justice, Defence and Equality to make this submission in respect to its consideration of the Disability Act 2005, and the National Disability Strategy Implementation Plan 2013-2015.

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Background

There are approximately 274,000 Family Carers in Ireland¹. A carer is defined as a person who provides unpaid personal help for a friend or family member with a long term illness, health problem or disability². 4.1% of the population identified themselves as a carer in the 2011 Census³. However, it must be acknowledged that many people may not classify themselves as a carer but will say that the care they provide is a normal part of being a family member and is a duty attached to being a relative or friend of the person requiring care. Therefore, the true number of carers in Ireland remains unknown.

There are 595, 335 people with disabilities in Ireland⁴. This includes people with intellectual, sensory, hidden, motor and neurological disabilities, and mental health concerns. There is a symbiotic relationship between disability and caring- people take on the role of Family Carer due to a person in their family needing extra support and care for whatever reason.

Due to the nature of this relationship, policy which effects people with disabilities naturally effects Family Carers, and vice-versa. Currently in Ireland, there are two major pieces of policy which therefore effect both groups of people, namely the National Disability Strategy⁵ and the National Carers Strategy⁶. These policies (and their attendant pieces of legislation etc.) should be working harmoniously, however it is clear that in many cases, they are directly in opposition. This has led to a situation whereby Family Carers are being left out of conversations pertaining to their loved ones and the people they care daily for⁷. Instead of being seen as "partners in care⁸" as advocated by the National Carers Strategy they

¹ Department of Health, "The National Carers' Strategy" (Department of Health, 2012).

² M McCarron et al., "Between Worlds: The Experiences And Needs Of Former Family Carers" (TCD School of Nursing & Midwifery, 2011).

³ Central Statistics Office, "Profile 8: Our Bill of Health (Census 2011)" (Dublin, 2012), <http://www.cso.ie/en/census/census2011reports/census2011profile8ourbillofhealth-healthdisabilityandcarersinireland/>.

⁴ Ibid.

⁵ Department of Justice, Equality & Law Reform, "National Disability Strategy" (Dublin, 2004).

⁶ Department of Health, "The National Carers' Strategy." (Department of Health, 2012)

⁷ Care Alliance Ireland understand that the term "care for" has connotations of paternalism and may be seen to be in opposition to the rights based advocacy agenda for people with disabilities. The term is used to include all kinds of support given by families towards a person with a need for that extra support due to a disability.

⁸ Department of Health, "The National Carers' Strategy." (Department of Health, 2012)

are often excluded from the very decisions that affect both their loved ones and them.

This submission looks at the Disability Act (2005) and the National Disability Strategy Implementation Plan (2013-2015) through the lens of Family Carers, with direct comparison to the National Carers Strategy (2012) where appropriate. Points and action of relevance to Family Carers will be discussed and recommendations for action to remedy the gaps between them and the National Carers Strategy (2012) suggested.

Disability Act 2005

The main part of the Act which directly impacts Family Carers in their role is Part Two: Assessment of Need, Service Statements and Redress.

This part of the Act is concerned with the provision of assessment "*to determine, in respect of a person with a disability, the health and education needs (if any) occasioned by the disability and the health services or education services (if any) required to meet those needs.*"⁹

Ten years after this legislation was enacted, the provision of these assessments has yet not begun for people with disabilities born before 1st June 2002¹⁰. According to data provided by the Irish Census of 2011, this means that up to 560,000 people with disabilities or disabling conditions do not have access to this service¹¹. This means that thousands of family supporters and family carers are unable to request (or support their caree through) an assessment of their child's, brother's, sister's, parent's or other family member's needs, nor can they request a statement of services available to address their family members' needs. This is causing a distinct concern for family carers as they struggle to provide the support necessary to those they care for. As it is the case that Family Carers report significantly higher levels of stress and depression¹², along with often feeling "drained" physically and emotionally¹³ by their role, it is critical that Government move to fully enact this part of the legislation.

⁹ Oireachtas na hEireann, *Disability Act 2005*, 2005.

¹⁰ Inclusion Ireland, "Assessment of Needs (AoN) under the Disability Act 2005" (Inclusion Ireland, 2014), <http://www.inclusionireland.ie/content/page/assessment-needs-aon-under-disability-act-2005>.

¹¹ Central Statistics Office, "Profile 8: Our Bill of Health (Census 2011)." This figure reflects 2011 data.

¹² Liam O'Sullivan, "Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance" (Combat Poverty Agency, 2008).

¹³ The Carers Association of Ireland and Royal College of Psychiatrists, "The Health of the Carer in Ireland" (The Carers Association, 2009).

Even for those who are eligible for an assessment of need as the Act currently stands commenced, there are widespread reports of unacceptably long waiting times, a lack of transparency, and a lack of redress in a timely fashion¹⁴. In failing to commence this Part of the Act in full, thousands of family carers are left caring for their loved one without the supports in place which would allow those they care for to become as independent as possible.

National Disability Strategy Implementation Plan 2013-2015

The National Disability Strategy was launched in 2004 to underpin the governments' commitment to improving the lives of people with disabilities in Ireland. Further to this, in 2013 the Implementation Plan was launched which consists of four high level goals, each broken into constituent parts. We focus on how the plan is not reaching a number of key overarching actions, primarily due to a lack of cohesion with the National Carers Strategy. As discussed above, it is crucial that both strategies work together- not side by side, and not in opposition- to create a society where both people with disabilities and those you care for and support them are able to do so without difficulty.

Below are some of the main objectives and key related actions which are of concern to family carers in respect to the support role they play to their family member with a disability.

Objective 1(b): People with disabilities are treated with dignity and respect

Ensure delivery of disability and mental health awareness training to staff, particularly frontline staff, including through NDA e-learning training module.

Whilst we acknowledge that many HSE staff are receiving training around mental health and disability, there have been reports from carers that in front line settings, certain groupings of staff¹⁵ do not know, nor begin to engage with people with disabilities regarding their mental health needs, in particular attributing psychiatric and mental health issues as behavioural and the result of their disability. In some cases, refusal to write appropriate referrals or consult with outside experts is causing

¹⁴ Inclusion Ireland, "Implementing the National Disability Strategy: Inclusion Ireland Position Paper" (Inclusion Ireland, 2013).

¹⁵ In particular, mental health staff who feel they do not have the training or knowledge to work with patients who have intellectual disabilities.

delays to discharges from acute hospitals, directly contravening the HSE's own integrated care and discharge planning policy¹⁶. This in turn makes the work of family carers far more difficult, leading to issues of further stress and worry for those carers.

Objective 2(b) People with disabilities get the quality supports and services they need to be independent

Support the provision of advocacy services for persons with disabilities and mental health difficulties.

The National Advocacy Service is a very positive service for people with disabilities, and is a service used by family carers to ensure that the person they support has access to independent support and advocacy. However, Care Alliance Ireland is aware of some family carers struggling to access the NAS for a person who has high support needs and who may not be able to request the service for themselves¹⁷. In all cases it is vital that the NAS understands that family carers should be recognised, as per the National Carers Strategy as being "partners in care", and a key part of the advocacy process. This is not happening.

In addition, the current waiting times of the NAS are unacceptably long¹⁸, and given that many people do not engage the services of the NAS until they are at a crisis point, allowing such long waiting times is having a highly negative effect on both people with disabilities and family carers.

It also must be noted that as it stands, the NAS has no statutory authority, unlike the Personal Advocacy Service, provided for in the Citizens Information Act (2007) and a core component of the National Disability Strategy (2004). It is vital that the PAS is enacted as soon as possible, to ensure that people with disabilities can access a service which does have statutory authority. For those older parents caring for their adult child with a disability it would be highly comforting and stress-relieving to know that such a service is available to their loved ones.

¹⁶ Health Service Executive, "Integrated Care Guidance: A Practical Guide to Discharge and Transfer from Hospital" (HSE, 2014).

¹⁷ For example where a person has been diagnosed with a significant intellectual disability, experience severe mental health difficulties, is non-verbal or non-traditionally communicative.

¹⁸ Cormac Cahill, "Aras Attracta Scandal," *The Irish Times*, December 17, 2014.

Objective 4(b) People with disabilities get the education and training that enables them to reach their potential

Ensure effective supports for children with special education needs.

It is clear that there is a large deficit in the needs of children with special educational needs, and the services which are actually available. As an example, speech & language therapy is an integral support for education, and yet there are massive shortfalls in supply of speech and language therapists across Ireland, with local and regional differences meaning that access to educational supports is often dependent on where you live¹⁹. For parents wishing to support their child to do as well as possible in education, this is very difficult. They are often faced with having to privately fund this therapy, which has an impact on the family as a whole.

As with most of the actions contained in the NDSIP, little to no mention is given to the inclusion of parents and/or family carers in the planning and supply of educational supports. Education of children is not contained to the classroom, and yet little to no support is given to parents to continue the education of their child elsewhere.

Key Recommendations

- 1) Closer attention must be paid to the relationship between disability and family caring. It is vital that throughout the National Disability Implementation Plan the role of parents and family carers is given due consideration. The National Disability Strategy (along with the Implementation Plan) and the National Carers Strategy should complement each other, yet in many it is clear that they do not.
- 2) Part 2 of the Disability Act 2005 must be implemented in full, and needs assessments made available to all people with disabilities, regardless of date of birth.
- 3) It must be possible for family carers to engage the National Advocacy Service directly and without delay. At all points of the advocacy journey the progress should be shared with family carers, and family carers recognised as a key part of the process.

¹⁹ Pauline Conroy and Simon Noone, "The Case of Speech and Language Therapy: A Working Paper Prepared for and by Inclusion Ireland" (Inclusion Ireland, September 2014), <http://www.inclusionireland.ie/sites/default/files/attach/article/1158/thecaseofspeechandlanguagetherapy1.pdf>.

Conclusion

Whilst it is noted that the Disability Act 2005 and the National Disability Strategy Implementation Plan has provided a secure policy foundation for people with disabilities, these policies have not been enacted in a manner which most benefits either people with disabilities themselves, nor their families and family carers.

It is clear that government, whilst creating the National Carers Strategy did not take the existing related policies wholly into account, leading to the current situation whereby clashes are continuing between people with disabilities, healthcare and allied staff, and family carers. This is not in the best interests of any of these separate but connected groups of individuals. The lack of enactment of the above discussed elements of the Act and Plan is impacting on families who are working hard to take up the shortfall in service provision. This is clearly not living up to the government's own strategy for family carers which aims to see family carers as "Partners in Care."²⁰

²⁰ Department of Health, "The National Carers' Strategy." (Department of Health, 2012)