



**Discussion
Paper 6**



**Disability and
Family Carer Policy
- Challenges and
Responses**

April 2017

1. Introduction

A working definition of 'disability' is crucial to any research, policy development or service provision in the field. There are many definitions of disability (Iezzoni & Freedman, 2008), some directly contradicting others. These differences originate from the different theoretical viewpoints which have been and are still being used to articulate what 'disability' is. These 'competing' models – though such competition is not explicitly stated in many cases – contribute to the confusion which often accompanies policy work and service provision in the disability-specific sector and those sectors closely connected – such as family caring.

Recent developments and discussions within the disability and family caring sectors in Ireland only highlight the challenges of obtaining a general consensus on the conceptualisation of disability¹.

The purpose of this paper, as with all papers in this series, is to ask questions with the aim of stimulating debate and critical thinking within the sector. This is particularly true as regards questions that may be uncomfortable for some readers.



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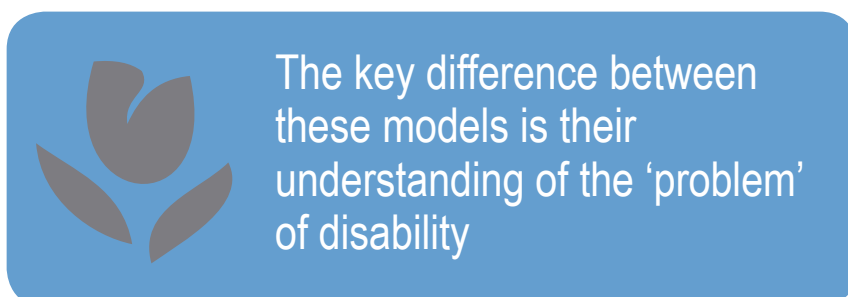
¹ We note that the term 'Family Carer' can be problematic when used in the sphere of disability, owing to its inherent paternalistic overtones. In this paper the term 'Family Carer' will be used to indicate any family member who assumes parental responsibility (when the person with disability is under 18), acts as a guardian or provides a level of care throughout a person's life. Where families are discussed, the assumption is made that those being cared for have some connection with those who use the term 'Family Carer' to describe themselves and the role they play. We also encourage readers to read the first paper in this Discussion Paper Series, entitled 'Defining Carers' (<http://bit.ly/1Lk4WHm>), for a fuller discussion of the nuances of language and family care.



2. Models of Disability

Briefly, three main theoretical frameworks currently co-exist (somewhat uneasily) in the field of disability (Iezzoni & Freedman, 2008). These are the medical model, the social model and (to a lesser extent) the ecological model. Historically there are other models which have been at the forefront at different times, such as the moral (Barnes, 2010) and religious models (Miles, 1995).

The key difference between these models is their understanding of the ‘problem’ of disability, and consequently how they inform the kind of work that is needed to alleviate the related issues. The medical model locates that problem within the person him/herself – the person ‘has’ the disability and therefore the way to alleviate the related problem is to ‘fix’ the person or create ways for the person to adapt to live within the non-disabled world (Smith, 2009). This risks a person with a disability being seen as fundamentally ‘wrong’ in some way (Barnes, 2010). Although the medical model has largely been abandoned by researchers – at least in the social science field – those in the medical field still push for ‘cures’ for intellectual disabilities, and controversies such as that regarding early in-utero testing for chromosome disorders which can lead to intellectual disabilities illustrate that the medical view of people with intellectual disabilities still has some purchase.



The key difference between these models is their understanding of the ‘problem’ of disability

The social model of disability has been placed as the ‘opposite’ to the medical model – it grew from a movement largely credited to researchers in Lancaster and Leeds Universities in the 1970s. These researchers – common names in disability research such as Barnes, Shakespeare and Barton among others – believed that the problem of disability did not reside within people with disabilities themselves but within a social system which did not take account of their needs and forced them to adapt, rather than the system adapting to them. An example which illustrates this key difference of the social model of disability is that of a public building with steps leading up to the entrance. According to the medical model, the problem is with the person with a mobility problem being unable to navigate the stairs. For the social model, the problem

lies with the inaccessibility of the building – the design of the entrance to the building is inherently exclusive. The social model of disability has been widely accepted by policy makers over the last twenty years as the basis for many innovations in policy and service provision in the field.

A third major theory which attempts to frame disability is the ecological model. This model attempts 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.

The differing definitions of disability, while seemingly academic, can have far-reaching consequences for people with disabilities and their families when applied to social policy and the organisational and delivery models of health and social care services. This is particularly the case for issues affecting people with intellectual disabilities. As outlined below, even the definition of ‘intellectual disability’ being used can have a huge impact on how services for people with disabilities and their Family Carers are supplied.



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A basic search for definitions of ‘intellectual disabilities’ will uncover definitions which can be easily identified as having their roots in particular theories, as outlined above. One such is the definition by the American Association on Intellectual and Developmental Disabilities (AAIDD), recognisable as rooted in the medical model:

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills.

This disability originates before the age of 18.

Source: (AAIDD, 2011)



Another is the current United Nations definition which is drawn from the social model and recognises the interplay between disability and societal attitudes and policy:

Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

Source: (United Nations, 2006)

However, in practice, neither of these definitions completely takes account of all the nuances of intellectual disability. People with intellectual disabilities have impairments that result in lower than average IQ scores (Barnes, 2010) and often need extensive support in everyday tasks. However, that does not tell the whole story of the challenges they face. In tandem, simply stating that society is responsible for the disabling of people with intellectual disabilities does not take into account that there are some tasks and types of learning which people with intellectual disabilities find more difficult – or indeed impossible. An ecological approach attempts to combine the two approaches in a way which acknowledges both the difficulties which impairments can cause and the social intolerance which makes life more difficult (Iezzoni & Freedman, 2008).

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 in reducing the whole complex notion of disability to only one of its aspects. We would argue that it is the ecological model of disability which best encapsulates the challenges faced by people with disabilities, in particular with regard to the disabling actions of society. This model is also the best as regards the challenges faced by families due to the sometimes intense level of support that people with intellectual and/or physical disabilities require to live the best possible life.

3. Disability and Family Care in Irish Social Policy

There are often significant tensions between the ‘Family Carer’ community and those advocating for people with intellectual disabilities (whether that is at a professional level or within the growing community of self-advocates). At the core of this tension seems to lie a fundamental difference of opinion as to the ‘model’ of disability from which definitions and policy should be drawn.

For many years, people with disabilities were seen as incapable of self-care, at any level. Medical and health and social care professionals often encouraged families to ‘abandon hope’ of their children with intellectual disabilities caring for themselves and living independent lives. We have evidence of thousands of Irish people with intellectual disabilities being cared for in large residential institutions and rarely, if ever, returning home or living independently (Hughes, 2014). As the social model of disability came to the fore in the 1980s and 1990s, and theoretical standpoints such as Social Role Valorisation (Wolfensberger, 2000) highlighted the contributions which people with intellectual disabilities can, with support, make to society, the ‘pendulum’ of policy in this sector has swung far away from the traditional medical model. While this is no way a negative outcome, it does have significant impact on the families of people with disabilities, in particular, intellectual disabilities.

A rudimentary examination of the current (under review) National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group, 2013), which guides the development of services and supports for people with disabilities, reveals the language use shown in Table 1 below.

Table 1
Language use in the National Disability Strategy Implementation Plan (NDSIP)

Keyword	Usage within the NDSIP
Family	0
Carer	0
Advocate	0
Caregiver	0
Staff	5
Supporter	74



This highlights the move towards an exclusively social model of disability. It is hard to argue that people with disabilities, particularly adults, should not be given the same opportunities to live independent lives away from parental 'control' as those without disabilities, and that is not the purpose of this paper. However, this standpoint does not take into account people with disabilities who require significant support from family members and trained medical staff on a daily basis. This overreliance on the social model of disability, without acknowledgement of the high medical and support needs that some individuals have, risks people with these higher support needs and their families being increasingly left out of the dominant narrative around self-advocacy and independent living.

The National Carers Strategy (Department of Health, 2012) positions Family Carers and family members as 'Key Partners in Care', and does not differentiate between Family Carers caring for older people and those caring for people with disabilities, or between long-term or complex illness and other conditions which necessitate care in the home. The Strategy advocates much more involvement by families in the care and support of their loved ones. However, actions in the NDSIP ostensibly push in the opposite direction. Herein lies the difficulty of relying on one particular model or definition of disability without due regard being given to the nuanced experience of individuals and families. The difficulty is also arguably reflected in the significant 'silo' mind-set that appears dominant in many aspects of health and social care delivery and leadership. This is entirely at odds with the concept of integrated care, one of the concepts currently ubiquitous in health care policy documents².



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² See <http://www.hse.ie/eng/about/Who/clinical/integratedcare/> for full details of the HSE's commitment to Integrated Care.

4. Challenges

What, in practical terms, does this apparent disconnect between the issues facing people with disabilities and those facing their families mean? While many issues are social and structural, and therefore can be ‘solved’ by an increase in awareness and understanding as posited by the social model of disability, many cannot be, and to attempt to do so or to attempt to ignore them is damaging.

4.1 Supporting both families and people with disabilities

It is true that disability and caring are ‘two sides of the same coin’. Without people to care for, ‘Family Carers’ simply would not exist, and certainly not as a specific group with its own challenges and support requirements. The reason why someone is identifiable in any way as a Family Carer is because of disability or illness – the focus of which is, naturally, the ill or disabled person. The primary reason why Family Carers come into contact with services is their relationship with an ill or disabled person.



Overarching disability policy – in direct contrast to policy specifically concerning Family Carers – may direct those same services to exclude parents of adults with intellectual disabilities from decisions

Services which support people with intellectual disabilities (in particular) face a dilemma. Their primary focus is to support the person who directly avails of their services, and those individuals are often supported in turn by parents or other family members. Many of these services see the benefit of providing supports to family members, and do so to the best of their ability. However, overarching disability policy – in direct contrast to policy specifically concerning Family Carers – may direct those same services to exclude parents of adults with intellectual disabilities from decisions. While such decisions are not the responsibility of those parents, given that their children are adults, a more holistic approach would be beneficial here. On the ‘other’ side are carer support organisations; these also must become more comfortable with and supportive of the rights of people with disabilities to make decisions without recourse to family members³. Operational challenges can

³ It is anticipated that the Assisted Decision Making (Capacity) Act (2015) will have a positive impact on both people with disabilities and their families. Families will have a role in supporting their loved ones to make decisions in matter that affect them.



also emerge when statutory funding of not-for-profit organisations is insufficiently flexible to facilitate and acknowledge (through funding) the identification both of those in need of care and the wider family as clients in their own right. The imminent use of Carer Needs Assessments (initially within older persons' services) in the content of the Single Assessment Tool may address some of these current obstacles.

It is becoming increasingly clear that some families, in particular families of people with intense medical and personal care needs, are confused and angry at increasing moves towards the 'ideal' goals outlined in disability policy – those of deinstitutionalisation, increased independence, etc. We in Care Alliance Ireland see these elements of disability policy as vital to ensuring that people with disabilities are encouraged and supported to live a life of their own choosing. However, many families do not receive sufficient support to stay actively involved in the life of the person needing care. In some cases they appear not to be made aware of what independent or community living means for their family member. In most cases it does not mean living alone, without support. Generally it means the person living in the community, being supported in the best possible ways to live a life of their own choosing, in a manner more tailored to the individual than life in the large-scale 'institutions' of the past. We acknowledge that many families and people with multiple disabilities are very happy with existing services, which they feel are now being threatened by this nebulous, confusing and poorly executed policy of 'deinstitutionalisation'.



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Organisations and services that attempt to support both people with disabilities and their Family Carers to the spirit and letter of overarching national policies will soon find themselves advocating for actions that are diametrically opposed to those policies. This only compounds the 'lines' drawn between people with disabilities and their family members, to the detriment of all.

4.2 Communication difficulties

The danger of working solely within a social or medical model of disability is seeing the various facets of disability and people with disabilities purely from one viewpoint. As discussed above, claims that the ‘problem’ rests entirely with people with disabilities or entirely with society are harmful to those with disabilities, whether intellectual, social, physical or any combination of these. The claim that disability would not exist if society was organised differently is a fallacy. The impact of disability would no doubt be lessened and the understanding of the needs, skills and potential of people with disabilities increased, but it would not eliminate the impairments, which would still impact upon peoples’ lives.

A debate which has been taking place in Ireland in recent times concerns this issue with particular reference to individuals with multiple and complex care and support needs. A series of articles published in the Kerryman newspaper in February and March of 2017⁴ illustrate just how far apart many families and disability advocacy services are on this issue. Many families of people with significant care needs, who have been the main providers of care and advocacy for their family members throughout their lives, take a practical view of topics such as independent living, viewing it through a lens that does not share many characteristics with the social model of disability. The contrary is the case with most disability advocates. In addition, there are reports that families of people in these living arrangements are simply receiving letters in the post informing them that their child will be moved into the community⁵ - of course this will be a cause of upset and concern. This inadequate level of communication must be addressed, and families encouraged to “buy in” to this changing policy as much as possible.



There are some very positive instances of individuals with significant disabilities and support needs living in independent, supported living arrangements

It is increasingly obvious that families feel that the unique issues which concern their family members, who may have significant communication and decision-making difficulties, are simply not recognised by those advocates and policy

⁴ (Fitzpatrick, 2017; O’Shea & Healy, 2017).

⁵ Personal communication with staff member from Inclusion Ireland, March 2017.



makers who focus (rightly) on the abilities that have for so long been overlooked as regards people with intellectual disability. This leads to frustration on both sides in the attempt to work together to provide the best possible supports for people with disabilities. However, there are some very positive instances of individuals with significant disabilities and support needs living in independent, supported living arrangements. These positive experiences often are not communicated to anxious parents as examples of how supported independent living can work for their loved ones⁶.

4.3 Families of people with intense care needs feel increasingly isolated

As previously discussed, within current Irish national disability policy, Family Carers ostensibly do not exist. This exclusion from the main policy conversation on disability illustrates how isolated many families feel. This is particularly stark as 70% of people with an intellectual disability, for example, live at home with parents or other family members (Doyle & Carew, 2016). Therefore, a large majority of people directly affected by this policy have the support and care of family members.



As previously discussed, within current Irish national disability policy, Family Carers ostensibly do not exist

The emergence of a new advocacy group for parents caring for children with significant care needs⁷ and individual parent bloggers⁸ raising issues of concern makes clear that there is a minority group of families who feel left out of the conversation around disability and Family Carer policy, rights and supports. Most of these Family Carers are advocating for actions that are, technically, part of existing Family Carer policy in Ireland – for example, Strategic Goal 1 of the National Carer Strategy (2012):

Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for.

⁶ See for example (O’Keeffe, 2016).

⁷ For example, *Profound Ireland* (<https://profoundireland.wordpress.com/>).

⁸ Such as *Transitioning Angels* (<https://transitioningangels.com/>), and *Often Called Cathy* (<https://oftencalledcathy.wordpress.com/>).

5. Responses

Having identified some of the key challenges brought about by this disconnect between policies affecting people with disabilities and those affecting Family Carers, we ask: what are the potential responses to these issues?

5.1 Concerted effort to tie policies together

Within the next 12 months, an updated National Disability Policy Implementation Plan and a refreshed National Carers Strategy are expected. Carer support organisations and Family Carers have been involved throughout the consultation process for this refreshed NDSIP. It is vital that the various policies influencing the types of services that individuals receive work together rather than against each other. This also goes for policies such as the National Positive Ageing Strategy, the National Dementia Strategy, A Vision for Change and others. The onus is on policy makers at government level to cross-reference each social policy with others which relate to them. This is not to say that changes cannot be made, or that new policy must be beholden to prior related policy, but simply that an attempt must be made to blend policies together, or at least to identify which policy elements may 'override' another. Policies which are diametrically opposed to each other cannot co-exist happily, and consequences such as those outlined in this paper will arise.

5.2 Increase in communication

One of the key ways to address the sense of isolation and confusion that many families of people with disabilities – in particular those with significant support and care needs – experience is to ensure good communication between families, people with disabilities, advocacy groups and policy makers. This includes listening to, and hearing, views which may seem completely alien and diametrically opposed to those held by the organisation or individual in question. Some Family Carers of people with intellectual disabilities do not acknowledge the skills, rights and responsibilities of their family members with disabilities. This often comes from a place of concern for their safety and welfare, yet can lead to infantilisation and inappropriate levels of control over adults (Williams & Robinson, 2001). Likewise, we would encourage disability-support organisations to listen to the views of Family Carers in tandem with the individuals themselves, and to cultivate a mutually respectful relationship in order to reach the end goal for all involved – a positive outcome and the best possible living situation for the individual with intellectual disability.



6. Conclusion

Current disability policy and Family Carer policy are, in many ways, diametrically opposed. While the National Disability Policy Implementation Plan pushes for less and less parental involvement in the lives of adults with disabilities, the overarching goal of the National Carers Strategy is increased involvement and acknowledgement of the pivotal role of Family Carers. This, along with different theoretical viewpoints of disability, has contributed to a number of challenges for both sectors. It must be remembered that the main desire of all concerned – people with disabilities, their families, and support organisations – is the best life possible for the individual with a disability. In order to achieve this goal, the challenges outlined above must be addressed, and dialogue must remain open and respectful at all times.



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Guiding support for family carers

Care Alliance Ireland

CHY No: 14644

Charity Registration No: 20048303

Company No: 461315

Registered office:

Coleraine House, Coleraine Street,
Dublin 7, D07 E8XF, Ireland.

Telephone: +353 (0)1 874 7776

info@carealliance.ie

www.carealliance.ie

[@CareAllianceIreland](https://www.instagram.com/CareAllianceIreland)