



**Victorian Parliament's Family and Community Development Committee:  
Inquiry into Social Inclusion and Victorians with a Disability**

**Carers Victoria**

**Submission February 2014**

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### **About Carers Victoria**

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for a person with a disability, mental illness, chronic health issue or someone with an age-related condition. The people being cared for could be a parent, child, spouse, grandparent or a friend.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

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## 1. Inquiry scope: Family members and carers are critical stakeholders<sup>1</sup>

Family members and carers have a strong interest in this inquiry into social inclusion and Victorians with a Disability because:

- they care deeply about the wellbeing, rights and opportunities of/for their family member with the disability
- they themselves as carers are often severely affected by the social exclusionary impacts associated with disability and the caring role (Section 4 of this submission will cite the compelling evidence within the research literature of the social exclusion experienced by many carers in comparison with that experienced by the broader community. The evidence demonstrates how stigma and social exclusion can affect the whole family, not just the individual with a disability. The task of caring can often undermine the health, workforce participation, income levels, and social connections of caring families), and
- when families are isolated themselves, they in turn find it harder to resolve the social inclusion challenges faced by their family member with the disability. Conversely, carers can be crucial and effective facilitators of social inclusion for the person with a disability.

These circular and reinforcing connections capture the essential interdependence and interrelatedness of the lives of people with a disability and their families/carers.

This interrelatedness also applies to the concept of social inclusion; all too often the social inclusion of the person with a disability is related to that of their carer and vice versa. Social inclusion has a *relational* aspect to it. Of particular concern are entire families that are socially excluded, sometimes across generations and over lifetimes.

The Family and Community Development Committee will receive numerous submissions emphasising the importance of choice and control for people with a disability. Often this is assumed to be synonymous with independence. What frequently receives less attention is the fact that the vast majority of people with a severe or profound disability in Victoria live in the family home, whether by choice or necessity.<sup>2</sup> For many, this is the context informing this discussion.

Carers Victoria suggests to the Committee, therefore, that any framework to analyse and explore the socially exclusionary impacts of disability in the lives of Victorians must be sufficiently complex and represent the lived experience. It must include the impacts experienced *by both people with a disability and their family/carers* – particularly those who provide intensive and long-term care.

Economically secure families can provide the baseline practical and material means (for example, housing, utilities, transport, income supplementation for extra

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<sup>1</sup> This submission often loosely uses the term 'carer' interchangeably with 'family members'. This reflects some of the definitional issues with the term 'carer'. Most, but not all, carers are family members while many family members providing care do not identify with the term 'carer'. 'Family' is also intended to be inclusive and broad, encompassing the concept of 'family of choice'.

<sup>2</sup> In 2003, of the 97.5% of people with severe and profound limitations under 65 who lived in the community, 84% lived with family (AIHW Bulletin 61, 2003)

expenses) for the development of the person with the disability.<sup>3,4</sup> In doing so, carers buffer their family members against the socially excluding effects of disability.

Furthermore, informed, connected and skilled caring families often have the following to support the social inclusion of their family members with a disability:

- knowledge of and access to economic resources and systems such as education, training and employment
- knowledge of and access to mainstream agencies and services such as health, housing, income maintenance, law and advocacy services, transport, leisure and recreation services
- social capital, the facilitative influence and advantages flowing from the totality of the relationships of the caring family
- strong networks of emotional support from wider family and close friends and neighbours, and
- access to competent and responsive disability services for the benefit of the person with the disability, and access to specialist carer services to enhance their own capacity in the caring role.

## **2. Definitions and terminology**

Carers Victoria welcomes the opportunity to provide commentary and views about some of the terms used in the inquiry submission guide.

### **a. Disability**

The focus on a National Disability Insurance Scheme (NDIS) has resulted in much welcome attention upon definitional issues surrounding the nature of disability. There is now a great deal of consensus that definitions of disability should be consistent with the World Health Organisation's International Classification of Functioning, Disability and Health.<sup>5</sup> This is based upon a social model of disability and so takes into account the potential disabling effects of environmental and social factors.

The trial of the NDIS uses a definition of disability that uses functioning as its guiding principle rather than disability type or diagnosis. The intention here is to build a more logical and equitable service system based upon a person's need for support.

In practice there are additional cultural and systemic barriers to using this approach consistently. There is a need for continual vigilance against the 'de-differentiation' of people with a disability which can assume that all people with a disability have similar needs, wants and aspirations. Neither should the need to differentiate be understood as being primarily about disability type or subgroup. This would assume, for example, that all people with an intellectual disability have a common set of needs as a group that is different from, say, the needs of people with a physical disability.

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<sup>3</sup> Beer, A. and Faulkner, D. (2009) *The housing careers of people with a disability and carers of people with a disability*, AHURI

<sup>4</sup> Ilsley, B., *Invisible Care: Access to Carer Payment and Carer Allowance by Victorian carers of a person with a mental illness* Carers Victoria Second Edition 2013

<sup>5</sup> World Health Organisation (2001). International Classification of Functioning Disability and Health.

Recent debates about disability make it clear that mental illness can result in long lasting impairment and reduced functioning, that is, disability. People with a psychiatric or psychosocial disability<sup>6</sup> are often included in broad legislative and policy documents about disability. In practice, silos remain; stakeholders and governments can tend to include this group in theory but not in practice for historical and systemic reasons.

Carers Victoria often takes a particular focus upon advocating for families of a person with a decision making disability. People with intellectual or cognitive limitations can lack a voice in policy debates. Often it is their families who speak up on their behalf, both on a daily, practical basis and in advocacy circles. This dynamic is complex and a sometimes fraught one: 'carers' can be viewed as lacking the authority to take on such a role.

## **b. Social Inclusion and participation**

Carers Victoria welcomes this opportunity to clarify and discuss the relationships and tensions between some of the key concepts, for example:

- definitions of social inclusion and participation and how these relate to the notion of 'a good life'
- independence and connection
- importance of control and choice, and their limits, and
- role of mainstream and specialist services in relation to social inclusion.

Social exclusion re-emerged as a policy concept in the 1990s in Europe.<sup>7</sup> It is often described in economic or material terms: access to basic needs and processes as, commonly, education and employment. The term 'social exclusion' can be seen as a broad concept that to some extent replaced 'poverty' as a discourse. Sub-distinctions of 'deep' and 'wide' social exclusion, geographical or locational social exclusion also emerged. In the early 2000s, the South Australian government and, subsequently the Rudd Government of 2007, made social inclusion a key social policy priority.

'Social participation' can again refer to the processes, such as employment and education, necessary for social inclusion. The term can sometimes be used ambiguously in relation to people with a disability, instead being understood as referring to a person's participation in the community in contrast to specialist disability settings. Social participation can be broader than social inclusion in that it can also refer to participation in civic, rather than economic, activities such as being part of a club or public institutions. It can also be interpreted as understanding that participation in society can be relational rather than only individual.

Although the concept of social exclusion is sometimes contested, it still holds value for maintaining a focus upon the economic and material needs of people with a disability. It may also have value in being, to some degree, objectively

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<sup>6</sup> National Mental Health Consumer and Carer Forum (2011). 'Unravelling psychosocial disability', a position statement by the National Mental Health Consumer & Carer Forum on psychosocial disability associated with mental health conditions. Canberra: NMHCCF.

<sup>7</sup> Buckmaster, L and Thomas, M. (2009), *Social inclusion and citizenship-towards a truly inclusive society*, Parliamentary Library, Parliament of Australia.

measurable. Social participation has merit in emphasising individuals as active subjects, rather than passive objects of exclusion. Participation requires connection with other entities, groups and individuals. Social participation and social inclusion are interrelated: social capital developed through participation can facilitate getting a job and vice versa. It can be difficult to participate in broader society for an individual that has no money for transport or recreation.

Citizenship involves participation in civil society and often involves interaction with institutions. Examples include voting, legal access, upholding of rights. Citizenship requires empowerment and a 'voice'. Again, citizenship relies upon material needs being met (social inclusion), but social inclusion (narrowly interpreted) may not be sufficient to ensure citizenship.

Carers Victoria commends the following publication: 'Social inclusion and social citizenship-towards a truly inclusive society'<sup>8</sup>. It provides a relatively succinct analysis and critique of the various concepts before the Committee, many of which are of particular relevance to people with a disability and their families. For example, social exclusion's focus upon workforce participation can provide a useful lens for promoting the employment opportunities for people with a disability. No-one would argue that this is not important. At the same time, a focus upon employment as the only way to be included would carry two main problems:

*...if social integration is only really possible through paid employment, then this means that those people who are not currently engaged in work, or who are unable to do so, are regarded as less than full members of society. Second, if exclusion and marginality are viewed primarily as exclusion and marginality from paid work, then questions of low pay and poor working conditions are treated as marginal; all that really matters is workforce participation.<sup>9</sup>*

The same paper goes on to make a case for bridging the gaps between social inclusion, participation and citizenship and their respective limitations through the strengthening and use of the conceptualisation of 'social citizenship'.

*Social citizenship is concerned with the resources necessary for membership and participation in society. Importantly, though, under a social citizenship framework social resources are not granted by the state out of benevolence or other motives but rather are conferred as a right of citizenship.<sup>10</sup>*

As applied to the National Disability Insurance Scheme, introduction of the scheme is important not just out of charity or for economic reasons but because people with a disability have the right to belong to society.

### **c. A 'good life'**

The conceptualisation of having a 'good life' can also provide an umbrella for this range of terms. Of course, the definition of having a good life is necessarily and inherently subjective and is, therefore, difficult to inform policy or operationalise. However, it is also the most important.

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<sup>8</sup> Ibid.

<sup>9</sup> Ibid. page 12

<sup>10</sup> Ibid. page 29

A good life will usually have the following elements:

- basic material needs are met
- choice and autonomy about the way you live your life and the decisions within it
- citizenship and rights
- sense of connection and relationships with others. This is necessary for a sense of belonging, both in relation to other people (friends, family, workmates and so on) and society more broadly, and
- sense of meaning and purpose.

Although 'a good life' may seem to be a lofty and vague ideal, for people with a disability and their families, it is highly relevant. The term 'quality of life' also comes close to encompassing this aspiration, although this too can focus upon material indicators rather than including relational and more subjective factors. The introduction of an NDIS carries the promise that people with a disability will have greater choice and control over the supports they receive. The list given above suggests that this is a crucial element of having a good life but is insufficient. Some academics, for example Professor Fiona Williams from Leeds University, have highlighted that having choice as an individual consumer does not provide the collective voice that is needed to drive participation and citizenship.<sup>11</sup>

This inquiry is a very welcome opportunity to, in part, discuss the limits and limitations of a single focus upon service delivery and the choices that surround it. Choice about disability supports may not by itself result in the end to economic disadvantage, stigma and discrimination faced by many people with a disability. A much broader and aspirational policy framework and agenda remains as important as ever.

### **3. Carers and their profile**

Carers provide unpaid care and support to a family member or friend needing assistance with a disability, mental illness, chronic health issue or age-related frailty.

Each caring situation is different. Carers come from all walks of life, all age groups and all cultures. They may be spouses, partners, parents, sons or daughters, siblings, friends, nieces or nephews or neighbours. *Many people identify themselves in terms of these family relationships and may not identify themselves as 'carers'.*

According to the Survey of Disability, Ageing and Carers (ABS 2013), there are some 773,400 informal carers in Victoria (or 13.6% of the total population), 217,800 (3.8%) of whom are 'primary carers'.<sup>12</sup> The 'primary carer' is defined as the carer within the household who provides the majority of ongoing care to the person requiring assistance.

The caring role is not evenly balanced across gender lines. Australia-wide, of the 769,800 'primary carers', 536,700 or 70% are female and 233,100 or 30% are

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<sup>11</sup> Williams, F. (2009), *Claiming and Framing in the Making of Care Policies: The Recognition and Redistribution of Care*, United Nations Research Institute for Social Development (UNRISD)

<sup>12</sup> Australian Bureau of Statistics (ABS), Survey of Disability Ageing and Carers (SDAC) 2013, Table 36- 1&2.

male.<sup>13</sup> The same ABS (2013) survey estimated that there were 74,800 carers under the age of 15 years Australia-wide, while there were an extra 231,200 informal carers between the ages of 15 and 25 years.

### **Economic value of caring**

According to a report prepared for Carers Australia by Access Economics, informal carers within the community provided 1.32 billion hours of care in Australia in 2010.<sup>14</sup>

When calculating the replacement cost to Australian society if all current informal community care was delivered through formal care systems, Access Economics conservatively estimated this figure to be \$40.9 billion per year. This is equivalent to 60% of the health and community sector budget for that year or 3.2% of annual Gross Domestic Product (GDP).<sup>15</sup>

## **4. Carers and social exclusion – the evidence**

While the situations of individual carers and families are diverse, there is a strong and growing body of evidence in the literature that health, social and economic problems disproportionately affect the caring population in comparison to the general population.

Research studies confirm that carers experience:

- comparatively poorer physical health (e.g. chronic illnesses, including cardiovascular conditions, diabetes, asthma and muscular-skeletal conditions)

An Australian Institute of Family Studies (AIFS 2008) research study found that 'almost twice as many carers were in poor physical health than the general population. These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories, except when aged 65 years or more'.

- poorer mental health (e.g. higher rates of stress, anxiety and depression)

Again the AIFS (2008) research found that 'carers had significantly worse mental health and vitality and higher rates of depression than the general population'. Female and male carers experienced rates of clinical depression of 19% and 13% respectively in comparison to rates of 11% and 8% rates in the wider population.

In fact, in their Deakin University study on carer health and well-being, Cummins and Hughes (2007) concluded that 'carers have the lowest collective well-being of any group that we have yet discovered'.

- severe financial disadvantage (lower household incomes, lower employment participation rates, lower full-time employment and higher household expenditures related to the illness or disability in the family)

'The labour force participation rate for primary carers (42%) and other carers (63%) was lower than that for non-carers aged 15 years or more (69%).'

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<sup>13</sup> Australian Bureau of Statistics, (2013), Survey of Ageing, Disability and Carers, Table 33, 1.

<sup>14</sup> Access Economics (2010), The economic value of informal care in 2010, Carers Australia.

<sup>15</sup> Ibid.

(ABS 2013.) Unsurprisingly, the carers in the workforce were also found to be much more likely to be in part-time employment than non-carers in the workforce.

Furthermore, 'almost two thirds (65%) of primary carers resided in a household with equivalised gross household income in the lowest two quintiles, compared with 36% of non-carers'. (ABS 2013.)

At the very least, the impact of disability on families can be concluded to be a *risk factor* for poverty.

And,

- poorer social connection and greater exclusion from a range of normal life opportunities and activities.<sup>16</sup>

Edwards's (undated) work highlighted the comparative social isolation of carers as a group. His data revealed that 'eighteen per cent of carers have face-to-face social contact with friends or relatives outside of the household once or twice every three months, or less often than this' and 'almost half of interviewed carers wanted more face-to-face social contact when asked whether they would like to get together with friends or relatives outside of the household'.

It is important to stress that social interaction not only contributes to emotional well-being but is an important source of social capital, the resources, opportunities and influence that flow from social engagement.

The above examples are just a part of a growing body of national and international evidence, underlining the vulnerability and disadvantage of family carers as a segment within society.

## **5. What do caring families need in order to promote the social inclusion of their family member with a disability?**

From constant consultation with the carer community, Carers Victoria has identified the following priorities for caring families in their role of supporting the social inclusion of their family members:

- Family employment supports

Caring families need better and more responsive supports to promote household workforce participation. These supports include additional and more flexible provision of respite, vocational training and retraining services, and employment placement services.

In particular, targeted education about the *Carers Recognition Act 2012* principle that a carer should 'have the effect of his or her role as a carer on his or her participation in employment and education recognised and

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<sup>16</sup> \*(Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N. and Kingston, M. 2008, *The Nature of Impacts of Caring for Family Members with a Disability in Australia*, Research Report No. 16, Australian Institute of Family Studies, Commonwealth of Australia, Canberra; Cummins, R. A., et al. *The wellbeing of Australians: Carer health and wellbeing*, Deakin University, Carers Australia and Australian Unity Melbourne 2007; September 2008, Survey of Disability, Ageing and Carers, ABS 2013). Edwards, B. 'Caring for families caring for a person with a disability', Family Relationships Quarterly Issue 11, Australian Institute of Family Studies <http://www.aifs.gov.au/afrc/pubs/newsletter/n11pdf/n11b.pdf>

considered in decision-making' is vital for caring families to establish their economic base.

- Income maintenance advocacy

The most financially disadvantaged, caring families experience higher unemployment and underemployment, and are often entirely dependent on the income they receive from Commonwealth Government social security benefits, (especially the Carer Payment and the Disability Support Pension). Given the current reviews of the monetary level of these working age payments, any opportunity for state government advocacy on behalf of caring families and people with disability would draw attention to the need.

- Education and skill development for caring families

Caring families need education, training and skill development to become confident and informed in promoting the choices, opportunities and wellbeing of their family member. Priority areas for their education and training include:

- supported decision making training for families, especially in the presence of severe and profound disabilities. (The Committee's attention is drawn to current reform being undertaken in relation to supported decision making and guardianship by the Victorian Law Reform Commission), and
- Social Role Valorisation training. Supporting the family member to achieve meaningful and valued social roles for their life.

- Intensive direct family supports for transitions and crises

Caring families constantly identify the need for more intensive direct support services during times of major transitions or crises for their families, when life-changing decisions press upon the person with the disability and their carers.

- Effective and responsive disability services

Caring families need ongoing access to disability services, which are not only person-centred in the provision of support to the family member with the disability, but are also truly engaged with and responsive to families and carers. This carer engagement by disability services would ideally be guided by the service principles and strategies recently documented in Occasional Paper No. 2, of the Office of the Disability Services Commissioner, *Developing policy principles and strategies to support families of adults with a disability and disability service providers to work more effectively together*.

It is strongly recommended that sufficient funding resources are made available by government to implement the required cultural service change in disability services across the state, as identified in the above ODSC document.

- Access to housing

A matter of utmost urgency for caring families and people with a disability is, and has long been, the need for greater access to affordable and appropriate housing, so that people with a disability and their families have real choices about the lives they lead. 'Appropriate' housing includes such factors as proximity to services, transport, family and friends.

With the real prospect of the expanding NDIS providing more people with disability funds for independent living support, the state government has a

crucial role in finding a matching increase in affordable housing stock, across the full range of tenure arrangements.

- Advocacy services for families as a whole

Given the high and pervasive levels of social exclusion reported in the literature in relation to carers and the person with the disability, the establishment of a new state-wide program of individual and systemic advocacy services *for families as a whole* deserves serious consideration by government.

- Effective and responsive mainstream services:
  - a) Caring families need mainstream services, such as health, housing and education, to be effective and responsive to people with a disability and their families/carers.<sup>17</sup>
  - b) Where such mainstream agencies need supplemental supports to be effective in meeting the special needs of people with disabilities and their caring families, care should be taken to retain the overall universality in the nature of the service provided.<sup>18</sup>
- Ongoing public education about equal opportunity

Because of the stigma, isolation and discrimination they and their family member can suffer, carers always identify the need for ongoing community education about disability, caring and equal opportunity, to create the social atmosphere in which all people can exercise the full range of their rights and choices as citizens.

## 6. Conclusion

The Parliamentary Committee is to be congratulated on convening this Inquiry into Social Inclusion and Victorians with a Disability.

Victoria has a progressive record of disability reform over the past twenty-five years or so with its commitment to a more inclusive, less discriminatory society, where people with disability can exercise their rights and choices and pursue opportunity alongside their fellow citizens. Rapid deinstitutionalisation, successive State Disability Plans, The *Disability Act 2006*, the creation of the Office of the Disability Services Commissioner and the *Carers Recognition Act 2012* have been important milestones along the journey.

Yet the problem of social exclusion for Victorians with a disability and their caring families remains pervasive and often subtle. As a society, there is still much to learn and more progress to achieve.

Government, business, the not-for-profit sector and the wider community must continue to pursue the overarching goal of social inclusion through a careful strategic planning and evaluation framework. The focus of this planning and evaluation framework must be improved (aggregated) social outcomes for people with a disability and their families, especially in the areas of health, education, employment, housing, income, leisure and social connection.

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<sup>17</sup> Bigby, C., & Fyffe, C. (2013), *Specific disability services and the mainstream – what do we mean? Making mainstream services accessible and responsive to people with intellectual disability: What is the equivalent of lifts and Labradors?* Proceedings of the Seventh Roundtable on Intellectual Disability Policy, La Trobe University

<sup>18</sup> Ibid.

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