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ACTION FOR COMMUNITY LIVING

SUBMISSION TO THE PRODUCTIVITY COMMISSION DISABILITY CARE AND SUPPORT INQUIRY

AUGUST 2010

Action for Community Living

Action for Community Living is a disability advocacy organisation that seeks to empower people with disabilities to play an active role in the process of social and political change that leads to a more inclusive society. A primary focus of our work is advocating for systemic change to enable people with disabilities to fully participate in all areas of community life.

Action for Community Living provides both individual and systemic advocacy, including specialist advocacy for people with acquired brain injury. We also provide leadership development and training for people with disabilities through a program called Leadership Plus. Inclusive Leisure Victoria is a program of Action for Community Living that advocates for inclusive sport, recreation and leisure environments across Victoria.

Action for Community Living is the lead agency in Disability Rights Victoria (DRV), a consortium of cross-disability advocacy organisations that work together to provide individual and systemic advocacy for people with disabilities across regional and metropolitan Victoria.

Action for Community Living's individual advocates are often called on to provide advocacy support for people with disability who have problems (often at crisis level) obtaining appropriate disability support. The chronic under-funding and consequent rationing of disability support is a major factor in these problems.

At the systemic level we have been involved for many years in advocating for adequate funding and an entitlement system for disability support. Advocacy activities include:

- a research project investigating community living solutions for people with high support needs who also have significant and complex health needs. This project produced the *Living Well* report in 1999¹ (attached).
- active involvement in the Disability Support and Housing Alliance which produced the *Living not Existing* report in 2001² (attached). Amongst

¹ Attendant Care Coalition (1999) *Living Well: Community living solutions for Victorians with a disability who have significant health needs*, Melbourne

² Disability Support and Housing Alliance (2001) *Living not Existing: Flexible support and housing for people with a disability*, Melbourne

other things this report advocated the introduction of individualised funding for disability support.

- on-going support for the Attendant Support Action Group (ASAG), a group of people with disabilities working to achieve improvements in the quality and availability of disability support.

Introduction

The *Shut Out* report³, issued in 2009 by the Australian Government, powerfully highlights the significant disadvantages faced by people with disabilities in most spheres of life including support for core activities. Transformational change in the area of disability support is long overdue. We congratulate the Federal Government on commissioning the Inquiry and welcome the opportunity to contribute to the Commission's work on this issue.

Our submission is informed by our advocacy work and relates particularly to our area of expertise, that is, the needs and rights of people with a disability and full participation and quality life in the community for people with disabilities.

Context for the development of the new scheme

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) should be the framework for the design of the new system. This requires a paradigm shift from a view of disability informed by medical assumptions of loss or incapacity to one based on human rights and a social model of disability, i.e. defines disability in terms of disadvantage and asserts that changes in the built environment and social policy are needed to enable inclusion of people with disabilities in the community.

The development of the new scheme must sit within the context of the National Disability Strategy. The Strategy (currently in draft form) aims to guide public policy and “bring about change in mainstream services and programs as well as community infrastructure so that people with disability have the same opportunities as other Australians”.⁴ Personal and community support is a major element of the Strategy.

³ National People with Disabilities and Carer Council (2009) *Shut Out: The Experience of People with Disabilities and their Families in Australia*, Commonwealth of Australia, Canberra

⁴ Council of Australian Governments (2010) *National Disability Strategy 2010-2020*, Commonwealth of Australia, Canberra

Entitlement to long-term care and support

An entitlement to needed disability support is an essential and basic step in upholding the rights of people with disabilities. Having ratified the United Nations Convention on the Rights of Persons with Disabilities, Australia is obligated to “take measures to the maximum of its available resources” to ensure that people with disabilities have full enjoyment of their human rights. While it is recognised that governments have finite resources it is unacceptable that many people with disabilities in Australia are still without even the most basic support services.

People with disabilities are entitled to the same opportunities as others for a quality life in the community. All people in our society use a range of funded and unfunded infrastructure and direct supports. People with disabilities may require additional supports to enable them to attain a quality of life commensurate with others in the community. A new scheme must address the disadvantage that people with disability experience relative to people without disability. If people with disabilities require support to do or be involved in ordinary activities that other people do without support then this should be available at no cost.

Current processes for determining allocation of severely rationed funding encourage a ‘competitive misery’ system, in which people feel they must convince funders that their situation is worse than others competing for the same funds. An entitlement system would go a long way to overcoming this.

What should be covered

It is essential that a disability care and support scheme is funded to cover the real costs of the supports needed to ensure the human rights and full participation of people with disabilities in the life of the Australian community. This includes the political, civil, social, cultural & economic areas as set out in the various articles of the UN Convention on Rights of Persons with Disabilities.

‘Supports’ could include physical, cognitive and behavioural support in the full range of life ‘arenas’ (home and family, friendships and social life, community activities, education and employment) as well as aids and equipment, home and vehicle modifications and assistance for people to set up and manage their supports. The submission by the Victorian Coalition of ABI Service Providers / Victorian Brain Injury Recovery Association (Section 5.1) provides

a comprehensive list of supports that should be included. Action for Community Living endorses this list.

All existing obligations and commitments by governments, non-government organisations and the private sector to non-discrimination and inclusion of people with disability within the broader community and delivery of human services should be maintained outside this scheme, i.e. costs of removing barriers to inclusion must not be shifted to individuals.

Eligibility

A long-term care and support scheme should be available to all people who are born with or acquire a disability who have on-going additional needs related to their disability, regardless of the cause of the disability. We note the term “people with a severe or profound disability” in the Inquiry Terms of Reference and concur with the definition of people with a severe or profound disability contained in the report of the Disability Investment Group⁵, i.e. “those who always or sometimes need help with a core activity or task”. This includes people with psychosocial disabilities.

The scheme should be available across a person’s lifespan to promote continuity of support systems (funded and informal) and on-going independence. Over their lifetime people with disability develop strong informal support networks and effective means for meeting their support needs. These should not be jeopardised by forcing people to move into the aged care system when they turn 65.

While recognising that initially the scheme may need to be restricted to those who acquire their disability before the age of 65, Action for Community Living believes that, in the long term, it would be preferable to include people who have disability-related needs regardless of their age. Needs and support strategies are similar across the lifespan. Operating two systems addressing the same needs seems inefficient use of resources.

⁵ Disability Investment Group (2009) *The Way Forward: A New Disability Policy Framework for Australia*, commonwealth of Australia

Means testing

Action for Community Living believes the disincentives to workforce participation and high administration costs inherent in a means-tested scheme would far outweigh any savings to be made.

A high proportion of people with disabilities exist on very low incomes (e.g. Disability Support Pension, low paid jobs) and face higher than normal living expenses due to disability-related costs. It is hoped and expected that a new scheme would increase workforce participation by people with disabilities. It would be counterproductive to build disincentives to employment into the scheme.

Assessment

An assessment system has to provide a framework for funders to provide money, however it must also allow for the complexity of people's lives. Responding to people's needs involves family, friends and community as well as identification of appropriate services and supports. Universal assessment systems have traditionally used inflexible tools that compartmentalise people's lives. The assessment process should be a holistic process that looks at all aspects of a person's life where support may be required to enable their full participation. Needs should be looked at in the context of the person's aspirations and goals and the social environment in which they live. Location may impact on the availability of mainstream and specialist disability supports so allocation of funding will need to reflect this.

The person with disability must be central and they (and where appropriate their family/supporters) must be directly involved in the process of assessment and planning. The process should be assisted by someone who is aware of eligibility/funding issues but independent of both funder/s and service providers. Assessment personnel require an understanding and extensive knowledge of disability and its impacts, not just the medical or clinical aspects of disability.

The approach to decisions about the amount of financial support and service entitlements outlined in the submission by People with Disabilities (PWD) has merit. The work of the Victorian Disability Services Division in this area is also useful although the approach so far seems unnecessarily complex and bureaucratic. Self assessment models have worked effectively in other countries, notably the UK. The research evidence, here and internationally, demonstrates greater effectiveness and efficiency in programs that trust the

individual and family capacity to make good decisions around assessment of need, how needs are met and purchasing of supports.

Planning and coordination

The planning process should be directed by the person and their nominated “supporters” (if desired/needed). If the person is not able to nominate because of cognitive impairment then their key supporters should be involved. Supporters may be family, partner, friends, advocates.

Many people will need/want assistance with co-ordination of services and resources. This may be in the initial planning, on an on-going basis or at particular stages of their lives. Some people may need assistance with organising overall services and resources. Some people may need assistance to co-ordinate discrete aspects of their services/resources.

To ensure that any professional involvement adds value and that the individual retains control of the process, planning and co-ordination assistance should be provided by someone who:

- ♦ understands and is committed to the principle of self-determination
- ♦ provides planning and co-ordination assistance rather than controlling the process
- ♦ is a skilled listener to people who may use a variety of communication means
- ♦ is familiar with the range of services
- ♦ has knowledge of the challenges faced by others in similar situations
- ♦ is creative in developing service/resource solutions where none currently exist.

Power and decision making

Individual level

Action for Community Living believes that the scheme’s approach should start with an assumption that most people with disabilities will be able to self-direct (with the assistance of ‘supporters’ if desired) and should therefore have control over how their funding is used, within agreed parameters. This includes having the flexibility to meet their support needs in the way that best suits them, the choice to directly employ their own support workers or to purchase their support services through an agency of their choice.

Flexibility

The current system of discrete programs, with their own strict eligibility/priority criteria and guidelines, create complexities and barriers for people with disabilities. Managing and juggling services and ‘working the system’ become an all-consuming struggle instead of a means to enhance quality of life. An individualised approach, with flexibility in program and funding guidelines so that individuals’ needs can be met in the least disruptive way, will significantly improve the quality of life of people with disabilities.

Improvements in flexibility could include:

- allocation of a single package which allows the individual to choose variations to disability supports as long as overall expenditure does not inflate.
- ability to vary arrangements as needs or circumstances fluctuate, including capacity to ‘carry over’ funds, emergency or ‘sudden deterioration’ funds.

Funding administration could be implemented in a variety of ways to suit people’s needs. The administration of the funding can be with a maximum of self-management by the person or with the assistance of paid or unpaid supporters (family members, friends, advocates, guardians). Options should include a financial intermediary model, as well as direct payments, where people with disabilities can have maximum control over their own funding and service arrangements.

People who have decision-making impairments may need varying degrees of support in managing their funding. The Victorian Law Reform Commission is currently undertaking a review of the Guardianship and Administration Act. Their work, particularly on the issue of supported decision-making would provide useful information and insights for the Productivity Commission Inquiry.

Scheme level

Action for Community Living supports the establishment of an independent national body to administer the scheme, e.g. as outlined in the Disability Investment Group report.

It is essential that people with disabilities and Disabled People’s Organisations (DPOs) be involved in all levels of governance in a new funding model. Article 4.3 of the CRPD states:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Action for Community Living supports the recommendation by the Australian Human Rights Commission that in considering mechanisms to include involvement of and consultation with disability representative organisations in scheme governance and operation, the Productivity Commission consider:

- needs for funding, technical support and capacity building measures to enable disability representative organisations to participate effectively
- the role of an NDIS or similar scheme in providing a sustainable and adequate funding base for disability representative organisations to enable them to engage in systemic advocacy in support of identification and elimination of barriers in Australian society and to participate in and contribute to monitoring of progress in implementation.

Funding source

Action for Community Living supports the development of a nationally funded and administered disability support system, with funding levied specifically through the taxation system at a level sufficient to provide improved assistance for citizens with disability throughout Australia. Revenue needs to be raised separately and distributed solely for the purpose of delivering the individual supports that people with disability require. A separately funded and administered scheme offers some protection to changes in governments and their policies.

Issues that will need to be addressed / additional infrastructure to make the scheme work

Workforce issues

It has become increasingly difficult to recruit and retain good quality staff to work with people with disabilities in a range of settings. The impact of this is particularly serious in the provision of personal care services where staff shortages and inadequacies create severe problems for people in very basic areas of their lives. People with disabilities who use disability support report on-going problems, e.g.

gaps in care provision (unfilled shifts); workers being rostered to work without adequate training; constant demand on users to train new staff in their specific care needs. This impacts particularly severely on people who have high support and/or complex care needs.

Workforce problems in part relate to the inadequate level of funding. This has contributed to the current structure of in-home and community based support work. Work is casual, isolated and low paid. Training and worker support practices vary between service providers however many workers receive very little if any support. Training is often inadequate.

These issues are being examined and worked on by state governments, National Disability Services (NDS) and others in the disability sector. If a new scheme is to work in practice there will need to be on-going research and concerted effort on recruitment and retention strategies. While level of pay is only one factor in this complex problem it is a major one. Adequate funding levels to enable better working conditions for disability support staff (including pay, support, training) will be critical in the effective functioning of the new scheme.

People with high support / complex care needs often require support staff with specialised skills and training. A system of credentialing that recognises specialist skills and provides appropriate pay levels would assist in the recruitment and retention of skilled staff (see attached report – *Living Well*, Section 2.4.4).

Occupational health and safety issues

Over the past few years Action for Community Living has received an increasing number of complaints from people with disabilities about the serious impact on their lives of occupational health and safety regulations for workers and the way these are interpreted in the disability support situation. There is recognition by most stakeholders of the need for clear policies and guidelines in the area of occupational health and safety. However there is also considerable concern about the increasing rigidity of the current regulatory climate and the impact this has on people with disabilities trying to live an ordinary life in their own home and community. Given that the area of work (ie the support service) is about people's lives in their own homes and communities then there is need for some flexibility and recognition of individual circumstances rather than the rigid, 'blanket' approach commonly applied at the moment.

The development of the new system, and the level to which it is funded, needs to take account of the interface and inter-relationship between systemic and structural barriers to inclusion of people with disability in Australia and people's individual and personal support needs.

A number of supporting structures are required to underpin an individualised funding system. These include:

- ***Advice and information services*** to assist people with a disability and/or their support network to manage funds and support services, e.g. regionally based non-profit organisations run by people with disabilities to provide information and referral, peer support, independent living skills training, and possibly other services such as administration of funding.

Good models of such centres can be found in Canada, the UK and Europe. (Action for Community Living is currently researching models and intends to make a further submission to the Inquiry on this issue.)

- ***Appeals and complaints mechanisms*** must be part of the new system. Appeals mechanisms will be needed to ensure that people who disagree with decisions about eligibility, assessment and allocation of funding levels can gain an independent hearing. Mechanisms that include internal review, mediation opportunities (to avoid unnecessary resort to the legal system) and the capacity to take the appeal to an external, independent body seem to provide the best outcomes. Discussions with advocates and case managers indicate that the Victorian Transport Accident Commission and Centrelink appeals mechanisms, while not perfect, are useful models.

People with disability have the right to complain if purchased supports and services do not meet their obligations or achieve negotiated outcomes. A robust complaints mechanism must be at the heart of the quality assurance system that governs disability services in the new scheme. All quality assurance and complaints mechanism must reference the human rights outcomes required within the CRPD. The Disability Services Commissioner in Victoria is a useful model although its role has limitations because it can only take complaints about services funded under the Victorian Disability Services Act.

- **Community development and capacity building** to make access to informal support and community activities easier.

Community engagement, both through informal networks and development of services, needs to be nurtured through community development. Action for Community Living supports the strategy of funding community development workers to work with local communities to:

- mobilise and provide support for people with disabilities to enable participation and integration in the life of their local community.
- build and strengthen the community's capacity to provide support to people with disabilities and their families through a range of strategies, including networking, community education, and development of policies, partnerships and specific projects.
- develop a framework for integrated local community planning and coordination that engages and involves people with disabilities and their families, disability service providers and community organisations.
- work with existing networks of disability service providers to enhance their capacity to provide relevant and appropriate supports in the community and to develop local responses to needs
- improve access to information about relevant services and community activities available to people with disabilities in their communities.

This sort of community building approach currently occurs in Victoria through the *Rural and Metro Access Initiative*.

- **Research** funding needs to be allocated under this scheme to identify gaps and program failures and successes to inform progressive improvements in both structural reform and models for individualised support. Significant work and investigation is needed to better understand how a "mixed market", that blends purchased services, informal supports of family and community and an individual's own resourcefulness and strengths, can work effectively to achieve optimal outcomes.

Action for Community Living supports the concept of a National Disability Research Institute recommended in the Disability Investment Group report. Longitudinal research, evidence-based sector development and quality assurance are essential aspects of the new scheme.

- **Access to independent advocacy support**
Action for Community Living strongly supports the establishment of an

independent advocacy program that provides a range of advocacy approaches, both individual and systemic, to ensure that there is an effective capacity to protect and promote rights and well being in a new disability support scheme. This program must be funded and operated independently from the scheme itself, but needs to be easily accessible to those who are seeking, or may benefit from independent advice or assistance relating to any aspect of the new scheme.

Concluding comments

Action for Community Living strongly supports the directions of the proposed national disability care and support scheme. The long term support needs of people with disabilities can only be met with a system based around long term individualised funding and effective support options. We welcome the opportunity to contribute to the development of a new scheme and will continue our involvement with the Productivity Commission's Inquiry.