



Caring for People with Disabilities who are Ageing

Response to the Issues Paper on the Development of an
ACT Government Policy Framework for People with
Disability who are Ageing

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Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We recognize the displacement and disadvantage they have suffered since European settlement. We offer our respects to their Elders, and celebrate the continuation of the Ngunnawal people's living culture.

Carers ACT sincerely thanks all Carers who have contributed to the research and consultation activities which inform our policy and representation work.

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 caring families living in the Australian Capital Territory. These families provide ongoing care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail.

Carers ACT currently provides direct support to over 5,000 families through our counseling, information, respite support, education, social support and case co-ordination services. Our services were assessed in 2009 to meet HACC and NCCP accreditation standards at a level of excellence.

Carers ACT has a constitutional mandate to represent the voices of Carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for.

Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All Carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

Caring for People with Disabilities who are Ageing

General Comments

Carers ACT welcomes the development of an ACT Government policy framework for people with a disability who are ageing. Appropriate recognition and support is especially critical for people with disabilities who are experiencing younger onset of age-related conditions, such as Aboriginal people. Families who provide care and support to people with disabilities who are ageing often face additional challenges due to changes in needs and altered capacity to provide care. Planning for future care is a critical issue for many families, as they need surety that the person they care for will be appropriately supported if they are no longer able to provide that care due to their own ageing or other circumstances.

Recognition of wellbeing issues in people with disabilities is an important issue. Anxiety and depression may increase with ageing, but are often overshadowed by other health concerns. With these factors in mind, as well as the need to better recognize the level of disability experienced by many people with mental illness, Carers ACT recommends that the Legislative, Policy and Service Delivery Context on page 3 include the Mental Health (Treatment and Care) Act 1994, especially as the definition of disability given at endnote *i* on page 24 includes 'psychiatric impairment'.

Needs of People with Disabilities who are Ageing

Q5A Is this a comprehensive picture of the distinct needs of people with disability who are ageing in the ACT? Are there other needs? If so, what are they?

The AIHW (2000) data presented in the stage 1 issues paper presents a reasonably comprehensive profile of the ageing issues common to many people with disabilities. However, it does not sufficiently identify or recognize other contributing risk factors which may affect the wellbeing of people with disabilities who are ageing. The issue of premature ageing is also a significant factor affecting many Aboriginal people with disabilities, and is a strong concern for Carers participating in consultation activities at Carers ACT. They consider that early identification of risk factors for premature ageing and implementation of culturally appropriate care is critical for improving the health of Aboriginal people with disabilities in the ACT.

The ACT also has a significant proportion of people from diverse cultural and linguistic backgrounds. Carers ACT offers assistance to Carers from many different nationalities and cultural backgrounds and runs 15 cultural support groups. Many families from diverse cultural and linguistic backgrounds report that they can struggle to obtain access to needed healthcare for the person they care for, due to language barriers, differing cultural concepts of disability and care, or a lack of culturally-appropriate healthcare options. These barriers become more complex with age, especially as older people are more likely to revert to their native language as they experience the reduced memory capacity associated with increased age.

The issue of the cumulative impact on health from poor wellbeing is also missing from this section of the issues paper. Carers participating in consultation activities consistently report that they are concerned about the social isolation and lack of appropriate support to enable social inclusion on a daily basis. Few people with disabilities have sufficient access to daily exercise options. Most families caring for a person with a disability are solely or mostly reliant on government income support. This leaves people with

disabilities and their carers at increased risk of poor diet due to the effects of long term poverty and the increasing cost of living in the ACT.

Families are also concerned that people with disabilities may also be more likely develop complications or chronic conditions associated with long term side-effects of medications needed to treat ongoing conditions, such as epilepsy. Lifelong medication use often leaves people with disabilities with residual toxicity effects or complications from increased tolerance factors. Also under-addressed is the longer term complications and premature ageing effects caused by the disabilities themselves. For example, many people with cognitive disabilities or mental illness suffer from lifelong anxiety conditions, which can leave them at higher risk of developing chronic conditions such as heart disease or immune disorders.

Issues of guardianship and decision-making for treatment and care also need to be addressed under the framework. Families often find that they have significant difficulty in managing affairs if the person with disabilities loses their capacity for independent decision-making. Many families say that they find an enduring power of attorney to be more suitable to their needs, but this can only be accomplished while the person still has capacity. Generally, there needs to be more education and support for people with disabilities and their families/carers about their best options in relation to decision-making.

Q5B What data collection activities are needed to inform future levels of need for people with disability who are ageing?

Reliance on purely nationally collected data is not sufficient for the ACT. Figures published by the Australian Bureau of Statistics often have difficulty achieving statistical significance because of the small sample sizes collected from the ACT. Similarly, reliance on MDS data about service usage does not provide valid measurements of unmet need. Data collection needs to be comprehensive, with sufficient detail to assess the actual depth and breadth of need in the community. The ACT Government needs to invest in the regular collection of comprehensive data on support needs, care capacity and service satisfaction levels. This data collection would be best collected by an independent agency to avoid perceptions of bias or self-interest, and to reassure Carers that negative reports would not affect their receipt of current or future services.

Carers of people with disabilities who are ageing typically have a long term care role. Many Carers report that they are reluctant to engage with processes about asking for services, as they feel discouraged by past experiences where they have not obtained the support they needed. While it does take time and commitment to rebuild client trust following a negative experience, many Carers would welcome opportunities to re-engage in meaningful and honest discussion regarding their needs, where there is potential for achieving a realistic outcome and there is sufficient funding available to support the needed level of care. Whole of family assessment is critical to assessing both support needs and capacity to provide care, as care situations can vary greatly.

Service Access Issues for People with Disabilities who are Ageing

Q6A For people with disability aged under 65 who are prematurely ageing, what are the difficulties experienced accessing the ACT disability service system or the ACT aged care system?

Lack of flexibility in funding guidelines and insufficient levels of funding are the two biggest problems preventing people with disabilities who are ageing from receiving the level of care and support that they need to maintain optimum health, wellbeing and social inclusion. The AIHW (2000) factors discussed in

the issues paper are all relevant to families in the ACT, with the exception of regional access issues. Carers commonly report problems that have resulted from the fragmentation of the service system, as even finding who can help can be difficult at times. Silo division of issues into 'aged' versus 'disability' and inflexibility in eligibility criteria for programs also creates barriers for families.

Families say that they are constantly fighting perceptions that they are 'double-dipping' when trying to access supports or to increase the flexibility of services to enable them to better meet the needs of the person with a disability. They feel that the burden of proof is often placed on the family especially when dealing with issues of premature ageing. Access to independent assessment of needs would help to alleviate some barriers to access. The Aged Care Assessment Team will see people with disabilities aged under 65, who are otherwise at risk of entering residential aged care, but the team works on a crisis-priority system which makes routine and preventative assessment almost impossible to obtain in a timely manner.

Q6B What needs to be done in order to improve access to the ACT disability service system and the aged care system for people with disability under the age of 65 who are prematurely ageing?

Access to the ACT disability service system and the aged care system needs to be restructured to better support collaboration and end the 'ping-pong' effect as people get bounced back and forth by departments seeking to shift responsibility. Disability services and aged care services need to accept and report on their joint responsibility to people with disabilities who are ageing. They also need specific floor targets of minimum service delivery and key performance indicators relating to achieving real outcomes for clients (which are measured by the clients' themselves).

For example, one option could be the establishment of co-managed services, where a case coordinator could be allocated from either disability services or aged care support to take the lead and deliver continuity of contact to the client regardless of their age. However, the overall service provision is supported equitably with matched funding from the other department to determine and deliver a flexible plan based on the client's assessed needs.

Alternatively, following a suitable assessment, people with disabilities who are prematurely ageing could be allocated a 'package' comprised of a care percentage from disability services and a care percentage from aged care support. The responsibility for case coordination and service delivery could be initially weighted more towards disability to provide, with a 'support' component from aged care. The system could then move to predominantly aged care responsibility at an agreed age with the 'support' component delivered by disability services.

Each system can be designed to maximize resource efficiency and reduce duplication. Removal of barriers preventing access to specialist support, and the pooling of resources has the potential to greatly enhance outcomes for people with disabilities and their families. However, it is important that compliance and reporting systems are also reformed, to prevent resources from being absorbed by services needing to report to multiple parties using different formats for each.

Q6C How should this be done?

The structural reform of service delivery to people with disabilities who are ageing needs to be done with the ongoing participation of people with disabilities and their families/carers. The identification of clear, specific goals and pathways needs to be prioritized. The proposed framework needs to focus on real, measurable outcomes rather than making broad statements of aspiration.

Q6D What needs to be done in order to better respond to the needs of young people who are living, or at risk of entering, residential aged care settings?

Carers ACT acknowledges the significant achievement already achieved in the ACT by moving young people with disabilities out of residential care facilities. It is important that continuity of long term care continues to be achieved for these young people, without unfair care loads being placed on their families. A greater focus on both preventative care and whole-of-family support is also vital to prevent young people from prematurely entering residential aged care settings.

While independent living is a goal for many young people, there need to be a variety of options which suit individual preferences while also meeting the care and support needs of the person with a disability. These facilities could offer younger people with disabilities an age-appropriate environment where they have regular access to meaningful and enjoyable activities, the opportunity to learn new skills, and the security of a long term home.

Q6E How should this be done and whose responsibility is this to progress?

The Commonwealth and ACT Governments must make a joint commitment to investing in the development of innovative, small scale accommodation which is attached to or within other residential facilities, or part of a community living or cluster housing project. Such innovative homes could also take advantage of the economies of scale enjoyed by larger facilities, such as shared capital costs, administrative costs, maintenance and some staffing costs (e.g. training and recruitment).

Q6F Noting that this is a five year agreement ending in 2001, what should be the next steps?

The ACT Government needs to commence immediate discussions with families who are caring for a young person with disabilities who is at risk of prematurely entering residential aged care, and involve them in discussions with the Commonwealth on providing a realistic, long term scheme to enable the needed level of care and support.

Accommodation

Q7A Are new forms of accommodation needed to support people with disability who are ageing? What are the key elements?

Families who have participated in consultations with Carers ACT consistently ask for only a few things in regard to accommodation:

1. Safety
2. Security of tenure
3. Regular, meaningful activity
4. Daily social contact with a peer group of choice
5. Quality health care that promotes wellbeing
6. Opportunities for ongoing family involvement (with a focus on relationship enjoyment and maintenance rather than solely on care provision)

Q7B Do people with disabilities who are ageing have issues accessing appropriate modifications where they rent privately or through public housing?

Families discussing their concerns with Carers ACT consider that the private rental market has so few opportunities for people with disabilities that it is almost non-existent. Rental costs in the ACT are at a premium, and as most people with disabilities are dependent upon income support, the cost of a reasonable property is out of reach. People without permanent attachment to the workforce are also not seen as desirable tenants, especially when landlords can pick and choose due to very low vacancy rates. Modifications for disability are done at the family's expense and they can also be legally required to pay for removal of modifications at the end of the tenancy. This places an unfair and inequitable burden on many families which prevents use of the private rental market.

Concerns about public housing raised by Carers include the difficulty of obtaining suitable accommodation and the very lengthy waiting lists. Many Carers report that people with disabilities are often placed in single accommodation in large unit blocks and are highly vulnerable to exploitation from undesirable persons. This is especially concerning for many people with intellectual disability, cognitive disorders or mental illness who can often lack insight into their own vulnerability and take people at face value. Reports from Carers include the person with disabilities experiencing the theft of money, possessions and food; experiencing ongoing persistent exploitation from people with drug or alcohol issues; or being the victim of bullying, assault and sexual exploitation.

Carers ACT has also heard from families who have been very happy with the placement achieved for the person with disabilities in quality units or houses with friendly neighbours. However, they too have experienced problems with the recognition and acceptance of their ongoing care role by Housing ACT. The staff members of Housing ACT can be quite sympathetic, but they are bound by the guidelines associated with public housing, which can fail to appropriately recognize the needs of the disability support situation. For example, the size of the property may need room to consider the delivery of the care role. Many people are placed in one bedroom properties with no room for paid or unpaid care support workers to sleep over if needed, despite the fact that medication, or toileting requirements may require regular attendance during the night.

Q7C What needs to be done to better inform people with a disability about planning for and accessing housing options?

Families consistently request options that enable people with disabilities to 'age in place'. They want timely placement in suitable accommodation (which has capacity to meet changing needs) with transition support, as this would enable family involvement while parents are still alive/able. Carers feel that the current system is crisis-driven and reactive, rather than enabling and encouraging of families to plan for the future needs of people with disabilities who are ageing. Indeed, some families feel that significant pressure is put on them to keep caring at a level past their physical and emotional capacity as the current supported accommodation structure is not aligned to a philosophy of choice. Families participating in discussions with Carers ACT state that the current system seems to revolve around a polemic of 'family care' versus 'abandonment to the system'.

Q7D Whose responsibility should this be to progress?

This is the responsibility of the ACT Government, particularly for Disability ACT and Housing ACT to find ways to work together and to progress innovative solutions with the support of TAMS and Treasury.

Draft Disability (Access to Premises – Buildings) Standards

Q7E As private homes are outside the scope of premises standards, what needs to be done in the ACT to ensure new residences are built to be responsive to the changing needs of people with a disability?

The ACT Government can legislate to require that a greater proportion of all new land developments be built to Universal design principles. There should also be incentives for people who retrofit houses with disability modifications, similar to the ‘Green’ initiatives recently delivered.

Q7F Whose responsibility should this be to progress?

The ACT Government.

New Initiatives

Q7G For people with a disability who are ageing what difficulties are experienced in accessing appropriate accommodation? What is needed to overcome these difficulties?

The biggest difficulty relates to enabling ageing in place. As stated previously, the silo approach and inflexible funding criteria are the two biggest inhibitors of the delivery of responsive, quality care delivered according to the person with disabilities’ needs. Similarly, adoption of rigid single-model or prescriptive policies which dictate the only ‘right’ way to deliver accommodation services also fail to meet the needs of people with disabilities, and their families, in a fair and equitable manner. One size does not fit all.

Even though the ACT has a relatively small jurisdiction and revenue base, it is vitally important that people with disabilities have access to a reasonable amount of choice about how and where they want to live their lives. Innovative accommodation developments could include the development of mixed support communities, similar to that already available in retirement communities, where people can progress to higher levels of support according to their needs. People with disabilities could begin in a semi-independent environment, and progress through to higher care facilities (if needed) within a mixed residential care model at a single location. Such a model would enable the maximum continuity of overall environment and provide an easier transition. People with disabilities, especially those with intellectual and cognitive often benefit strongly from consistency in environment and a degree of familiarity with the people who live and work in their environment.

A mixed model could also offer day programs or cottage-style respite support to people who live with their families as a way of generating more income for the development, and engendering a positive degree of daily engagement with the wider community. Environment is also critical to the wellbeing of people with disabilities. Any new accommodation initiative needs to include opportunities for people with disabilities to engage in productive activity, learning, healthy eating and exercise on a daily basis. A

healthy indoor and outdoor environment will promote their good health and prevent the development of lifestyle-related illnesses and medical conditions.

Q7H Whose responsibility should this be to progress?

Family-led groups such as Community Living Inc. are already working with families and people with disabilities to develop a clearer idea of current and future needs. The group is also working hard to develop feasible models which have the support of many families in the ACT. The ACT Government needs to work with the Commonwealth to find ways to support initiatives which are being led by the people who have the most at stake in making them work – people with disabilities and the families who care for them.

Ageing in Place

Q8A What is required to enable people with disability to be adequately supported to age in place in the ACT? If not what are some of the difficulties?

See item 7G above.

Q8B What needs to be done in order to support people with disability to age in place?

See item 7G above.

Q8C Whose responsibility should this be to progress?

See item 7H above.

Information and Futures Planning

Q9A Do people with disability who are ageing have adequate access to information and future planning?

Information received from family Carers in the ACT indicates that there is a need for greater consistency in access to information and future planning support. The system can work quite well for those people who are well-engaged and in receipt of regular service delivery, but many others miss out on even basic information and support. People with disabilities who are particularly disadvantaged are those experiencing social isolation and depression, those who are Aboriginal, and those who come from diverse cultural and linguistic backgrounds.

Carers ACT offers support to Mature Age Carers (people aged 65+ who are caring for a son or daughter with a disability). This program has been highly successful in encouraging Carers to get involved in planning for the future, and includes case coordination support, social contact and regular education sessions. The program also offers access to respite support through the Fraser House respite facility, which offers a day program as well as overnight respite.

Q9B What needs to be done in order to enhance people with disabilities access to information and future planning?

There are currently a number of 'innovative initiatives' that engage families in information, education and limited planning. However, these initiatives may often fall short in getting families to develop tangible plans. Future Planning programs need to provide families with access to all of the appropriate support they need. This includes supports such as: access to family mediation (where other siblings need to be involved because, if the parent Carer has not made adequate provisions before they die, they may have to make decisions regarding the care for their sibling with a disability); and access to the legal and financial advice needed to develop future plans. Incentives which encourage families to make financial provisions for the future care and accommodation of a family member with a disability will be perhaps the most effective way to get families to take action.

Also, any strategy to enhance access to information and future planning supports needs to incorporate multiple communication strategies. Carers differ in their preferred method of contact according to factors such as age, cultural background, gender and personal preference. Television and radio campaigns have proven to be the most effective means of advertising, but word of mouth is often the strongest motivator in the community. Many people, especially those from diverse cultures, appreciate someone coming to sit and have a chat to their group about new options. This strategy enables them to build trust and makes it more likely that they will engage in new activities. The internet is a growing area for information dissemination, and is often highly cost effective, but an effective communication strategy should not rely on the provision of just another website for people to access.

Q9C Whose responsibility should this be to progress?

Incentive schemes to assist families in future planning activities need to be a joint Commonwealth and ACT Government initiative. Service providers and community organizations can help to promote information to existing client groups, but the Commonwealth and ACT Governments are best placed to have the resources needed to fund any media campaigns.

Supporting Ageing Carers

Q10A What difficulties do ageing carers experience accessing adequate support?

Many of the issues facing ageing carers have been detailed above, but their primary concern still overwhelmingly relates to the question "What will happen to the person I provide care for, when I am no longer able to do it?"

People with disabilities, who are cared for by ageing Carers, are vulnerable to sudden changes in circumstance; such as a family crisis, a change in their own health which increases support needs, or the illness or death of the Carer. Many Carers need support to develop appropriate emergency care and succession plans. They also need assurance that there will be a person or organization which will take on the responsibility for implementing the succession plan for the person with disabilities, and that they will do as good a job as if it were their own son or daughter, parent or sibling in need.

Carers ACT is also aware that supports to ageing Carers can be inhibited or restricted by a general lack of flexibility in the funding guidelines. A client-centred focus is not always well supported by existing

funding agreements, as often a narrow list of ‘approved’ supports have to be delivered in a way that maximizes service efficiency rather than in ways that best suit the client’s need.

Some ageing carers also face barriers around the increasing dominance of internet-based information systems as a means for learning about new services or supports. They often feel overlooked, or that they find out about new schemes just by chance. It is important that there are multiple pathways to accessing support, including call centres (staffed by real people not automated inquiry systems) and information centres where Carers can drop in to talk to someone.

It is also important to recognize that many Carers have built up great skills in self-reliance after years of coping alone, and they may be somewhat reluctant to reach out or accept assistance. It is vital that services have the capacity to engage with Carers over time to build trust and encourage them to reach beyond the family home to meet the changing needs of the person they care for if that is now needed.

Despite the issues paper referring to the *Caring for Carers* policy, Carers ACT notes that Action Plans related to the implementation of the policy have been discontinued by the ACT Government. Departments now have to meet the policy’s broad aspirational statements within their annual KPIs and are not required to report specifically on progress towards achievement of the policy’s goals. The ACT Government committed to providing a Charter for Carers under its 2008 election promises, but has yet to meet this promise.

Q10B What needs to be done in order to better support ageing carers?

It is firstly important to recognize that Carers have their own needs for support, which result from their caring role, and these needs are separate to the needs of the person with disabilities. Access to current and correct information is critical, especially in regard to available supports, future planning and legal/financial issues. Many Carers experience the cumulative effects of a lifetime of care provision, such as poverty, chronic injuries and poor health, and low personal wellbeing. They need access to an equitable and peaceful retirement, where they can enjoy their family relationships and choose their own level of care support, rather than be expected to keep providing care 24/7 until they die.

There are existing services to support ageing Carers in the ACT, and continuity of funding for these support programs is vital for ensuring that needs are met in the long term. Carers ACT provides the ACT Commonwealth Carelink and Respite Centre service, which offers a call centre service to help people link to information and services to enable them to keep living independently in their own homes and prevent premature entry to residential aged care. Carers ACT also offers a Mature Age Carers support service which offers case coordination to assist with access to information, respite and support services. The Mature Aged Carers Program is funded by the Australian Government Department of Family, Housing, Community Services and Indigenous Affairs (FaHCSIA) and the ACT Department of Disability, Housing and Community Services (DHCS) through the Commonwealth State and Territory Disability Agreement (CSTDA).

Q10C Whose responsibility should this be to progress?

Support to ageing Carers is the shared responsibility of the Commonwealth and ACT Governments working in partnership with families and the wider community.

Community Participation

Q11A Do people with disability who are ageing have adequate access to community activity?

Carers generally report that they can struggle to achieve sufficient access to community activity for people with disabilities in the ACT. Common barriers include lack of places in existing services, lack of activities that meet the person's interests, transport and cost issues. There is also a perception that people with disabilities who are older tend to receive 'in-home' supports rather than be actively encouraged and enabled to participate in the wider community. Carers consistently place a high value on community participation opportunities and would like to see the development of meaningful participation opportunities which can accommodate changing needs as the person with disabilities ages.

Q11B What needs to be done in order to enhance their access to community activity?

Carers ACT offers a respite program for people with disabilities who have ageing Carers which provides day, overnight and Host Family respite options. The respite program is supported by a Living Skills Program for participants to help develop and maintain daily living and personal care skills. The program can also offer transport support and is flexible to enable the continuation of community activities which the person with disabilities is already involved or to support the development of new interests.

Increased funding to better support community participation is critical for improving services to people with disabilities and their families. Continuation of funding to existing programs is also required, especially those which assist in preparing people with disabilities for the transition into other support arrangements if their Carer is no longer able to provide care.

Q11C Whose responsibility should this be to progress?

Services to people with disabilities and their carers are the joint responsibility of the Commonwealth and ACT Governments through the Commonwealth State and Territory Disability Agreement (CSTDA). However, people with disabilities, Carers and the community sector all have strong interest in progressing increased services to enable better community access.

Transitioning from Supported Employment

Q11D Do people with disability who are ageing have adequate access to employment opportunities and support to plan their retirement?

Carers have indicated to Carers ACT that there is not sufficient access to employment opportunities in the ACT. Indeed, they say that there is very little for people with disabilities to do once they are post-school age. Existing supports within the ACT are piecemeal and offer only a few hours per week. Carers often struggle to obtain places for the people they care for, and face barriers relating to travel and cost to keep them there. Many Carers have told Carers ACT want meaningful activity for the people they care for 'not adult-sized babysitting services in front of a television'. They would like to see increased paid workforce participation for people with disabilities to assist them in achieving a better quality of life overall and to enable them to plan for a meaningful retirement.

Q11E What needs to be done in order to enhance their access to employment opportunities and retirement planning?

The Government used to be a significant employer of people with disabilities, but these positions have been significantly reduced. Carers would like to see a realistic range of jobs offered specifically for people with disabilities, with appropriate support and training to enable successful long term participation.

The ACT needs to look to businesses within and outside of the border to see how people with disabilities can better achieve an equitable level of participation. Often businesses are very open to employing people with disabilities, but don't know where to begin. There are also successful overseas business models which have mostly employed people with disabilities and never received any government funding. However, in the ACT issues such as mobility access, transport and post-school transitional

funding will need to be realistically supported to enable greater participation. A greater cohesion between the Education Department and DHCS also needs to be achieved to foster a smoother transition from school to post-school environments for people with disabilities.

Q11F Whose responsibility should this be to progress?

Support for increased workforce participation is the shared responsibility of the Commonwealth and ACT Governments working in partnership with people with disabilities and the business community.

Access to Mainstream Health Services

Q12A For people with disability who are ageing what are the difficulties experienced in accessing generic health services in the ACT?

Access to primary health care is a significant issue for everyone in the ACT, due to the shortage of general practitioners. However, people with disabilities and their Carers experience additional disadvantage in obtaining sufficient care, due to many of the factors discussed in the issues paper. For example, a person with cognitive impairment may struggle to articulate where pain is being experienced. It is also too easy to miss early warning signs for emerging problems when other healthcare priorities are created by the main disabilities.

Carers participating in consultations with Carers ACT consistently express concern about access to healthcare, due to a lack of 'disability friendly' services and the time and costs issues involved. Of particular concern are dental services, the management of chronic health conditions, mental health treatment and care, and services for people from culturally diverse backgrounds.

Q12B What needs to be done in order to enhance to generic health services?

Potential options to improve access to generic health services could include: increased disability awareness training, a website or directory listing access and availability of parking for people with mobility issues. Improved funding for community transport services is also a high priority issue for the ACT.

Q12C Whose responsibility should this be to progress?

This is the shared responsibility of ACT Health, Disability ACT and DHCS.

Disability and Aged Care Workforce Issues

Q13A Do community and government agencies have adequate knowledge and skills in supporting the needs of people with a disability who are ageing?

The revisions to the Community Services Training Package will certainly help to improve the skills and knowledge of people who undertake the training. Yet, there also needs to be a strategy for ensuring that skills and knowledge to enhance services to people with disabilities are extended to those people who have other qualifications and/or who are working in the sector.

ACT Health incorporates education from Carer and Consumer groups to support their orientation processes for all new staff. For Carers ACT, this has proved very successful in improving 'Carer-awareness' and in educating new workers on available supports to Carers.

Q13B What needs to be done in order to enhance skill and knowledge sharing across agencies that support people with disability who are ageing?

As poor or ill-informed attitudes from people working for community or government agencies/departments still continues to be a factor in complaints or advocacy requests from Carers, it is clear that a culture change in some areas will need more than an induction/orientation approach. Skills based training and knowledge sharing needs to be extended to be a regular part of training for all staff in regular contact with people who have disabilities. This training also needs to be supported by clear pathways for clients to provide feedback on worker performance.

Q13C Whose responsibility should this be to progress?

Workplace training and assessment is the responsibility of each employer.