

# Senate Community Affairs References Committee

# NSW Submission to the Inquiry into Planning Options and Services for People Ageing with a Disability

This submission outlines the key themes and issues surrounding planning options and services for people ageing with a disability, and the policy frameworks under which support services for people with a disability and their carers are provided. In addition, an overview of the current services and initiatives that the NSW Government is providing in response to the care and support needs of people with a disability and their carers as they age is presented.

# 1. Background

On 25 November 2009, the Australian Government Senate referred the following matter to the Community Affairs References Committee for inquiry and report by 2 September 2010.

#### Terms of Reference

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

#### 2. The need for planning options and support services

The NSW Government understands the importance of planning options and services for people with a disability as they are ageing. It also acknowledges the significant role that carers play in supporting people with a disability.

People with a disability are experiencing a longer life-span and, when this is added to the overall ageing population and the increase in workforce participation of female carers, it is evident that in the future there will be an increasing gap between the number of informal/family carers able to care for people with a disability and the numbers requiring care. This has the potential to increase demand on formal care support services, such as respite and supported accommodation (Keyzer and Carney, 2009; Pierce and Bigby, 2007).

When considering future planning options and support services for people with a disability who are ageing, it is essential to engage with and support their carers.

However, it is also critical to recognise that not all people with a disability are being cared for within the family home, with some having lived most of their adult lives in group homes, supported accommodations and/or in independent living arrangements.

It is important to recognise that each individual's circumstances will be different and not to assume a one-size fits all approach. This submission acknowledges the range of living arrangements and experiences of people with a disability.

The older carer cohort appears to require the most assistance with future planning, yet is less likely to have formal support arrangements in place and less likely to engage with professionals for assistance with future planning and other care needs. It has been suggested that only one third to one half of the current cohort of older carers make comprehensive plans for the future (Bigby and Ozanne, 1999; Carers Vic, 2008).

Lack of future planning is not as prominent in the younger cohort of carers. Research has indicated that younger carers of children with a disability are more likely to have already created networks of support and initiated future planning activities (DiMarzio Research Pty Ltd, 2008).

It is important that planning options be considered at the earliest possible stage with an emphasis on future/long-term support needs.

Literature suggests that future planning should consider the following elements:

- Current and future accommodation and support needs of the person with a disability; and
- Legal requirements and financial arrangements of the person with a disability, their family and carers.

A number of **barriers** for planning options have been identified and need to be considered for future policy and program development:

- The range of supported accommodation options can be limited and places may only become available when a family is in crisis. This in turn may place additional stresses on the person with a disability, their families and carers at a time when they may not be thinking about the best interests of all concerned.
- Some older carers have advised that they do not know where to go to obtain assistance, information and support about planning for the future (Bigby and Fyffe, 2009; Keyzer, and Carney, 2009; Laragy, 2007; N-Carta Group, 2007).
- There is a need to develop a range of information resources for carers and families surrounding planning options that cover legal and financial issues together with long-term support options.
- Research also indicates there is a significant unmet need for legal service practitioners with an understanding of the needs of people with a disability, their families and carers (Carney and Keyzer 2007a; 2007b).

The NSW Government would like to highlight the following **key issues** for consideration by the Inquiry:

#### **Funding**

The Australian Government has recently requested the Productivity Commission to undertake an inquiry and report by 31 July 2011 on the cost, cost effectiveness, benefits and feasibility of a National Disability Long-term Care and Support Scheme in Australia. In requesting this inquiry, the Australian Government acknowledged the current major investment of the Commonwealth along with States and Territories, in disability specific support. However it was recognised that there remain levels of unmet demand for disability services and that demographic change and an anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades. The NSW Government supports the consideration of alternative approaches for sustainable funding of disability services.

## **Early Intervention**

To maximise the potential of people with a disability to live as independently as possible and participate fully in community life, early intervention is required to ensure that clients receive the most appropriate and timely support.

# Intellectual Disability

The aged care needs of people with an intellectual disability, who often experience early onset of age-related needs, including dementia, need to be considered when planning for their needs as they age.

#### **Workforce Shortages**

To address the above priorities the NSW Government recognises that the disability sector must be sustainable in the long-term, and strategies to strengthen the sector need to be implemented. In order to do this, all levels of government and the non-government/private sector need to work together. ADHC has developed a number of industry development strategies to improve the capacity of the disability system.

#### 3. NSW Government services, programs and initiatives

The roles and responsibilities of the Commonwealth and the States and Territories in relation to the provisions of services to the aged and disabled has recently been altered by the recent National Health and Hospitals Network (NHHN) Agreement signed at COAG in April 2010.

Under this Agreement the Commonwealth will take full funding and program responsibility for the aged care system covering basic home care through to residential care. Responsibilities in relation to the Home and Community Care (HACC) program will alter with the Commonwealth responsible for the funding and programs for persons 65 years and older, or 50 years and older for indigenous persons. The States will assume responsibility for funding and regulating community care services currently delivered under HACC for persons under the age of 65 years, or under 50 for indigenous persons.

Thus the services that are currently provided in NSW which assist those the subject of this Inquiry and which are described in this submission may be modified as the new NHHN Agreement is implemented over the coming years.

## Current NSW Services, programs and initiatives

To ensure that NSW is well placed to meet the challenges and opportunities the ageing population presents, the NSW Government has introduced a comprehensive whole-of-government strategy, *Towards 2030: Planning for our changing population*. This initiative responds to the challenges faced by people as they age and supports older people to continue to participate fully in community life, including strategies for people who are ageing with a disability.

For people who are ageing with a disability, *Towards 2030* includes strategies to improve the management of chronic and complex health conditions, support carers in their caring role, and improve the provision of specialist supports for older people with complex needs, and health and aged care services generally.

Through Ageing, Disability and Home Care (ADHC) the NSW Government is focused on improving and expanding a broad range of disability support services for people with a disability, their families and carers. Under *Stronger Together*, the NSW Government's 10-year plan to improve disability services, more than \$1.3 billion in additional funding has been provided over the first five years.

There are a number of broader support services for people with a disability, their families and carers that are currently being provided. These include case management, respite, domestic assistance, personal care, therapy, post school programs, counselling and information services. Some of these services are specifically targeted to support people with a disability who are ageing and their carers. We recognise, however, that there is a need to do more.

ADHC recognises the need to provide a range of choices for people with a disability who are ageing and their carers. A number of strategies are being implemented across program areas within the agency that have a focus on early intervention and long-term planning strategies for this cohort of clients. Our overall approach is to support effective outcomes for people with a disability and their carers.

Case management services are being delivered under the *Support Coordination* program for ageing parent carers aged 60 years and over, and 45 years and over for Aboriginal carers, which have a focus on engaging with older parent carers, identifying current and future support needs and providing support for future planning. A Futures Planning project to assist older carers to put in place plans for a future time when they are no longer able to care is being piloted in Northern NSW. A number of supported accommodation models to meet the needs of people with a disability who are ageing have been developed. Day Program initiatives have also been developed in response to the growing number of people with a disability living beyond middle age.

The above has outlined some key initiatives that have been developed in response to the planning needs of people with a disability who are ageing. More details in relation to these services and additional program initiatives can be found at **Appendix A**.

The NSW Department of Health leads the implementation of the *NSW Carers Action Plan 2007-2012*, and has initiated policy and a range of programs to improve the lives of people with a disability and their carers.

In addition, the Department provides a range of programs and services, such as older people's mental health services, the Family and Carers Mental Health Program, EnableNSW and Dementia Services Planning in response to the needs of people with a disability, their families and carers.

Housing NSW reports that older people and people with a disability make up a significant proportion of the social housing population in NSW. As of 30 June 2009, 34 per cent of current public housing tenants (including those in Aboriginal Housing Office properties) had a household member with a significant disability. In addition, almost 30 per cent of public housing tenants had the age pension as their main source of income. In response, Housing NSW has a range of services and programs to meet the specific needs of clients who are older and/or who have a disability.

### 4. Conclusion

This submission has set out the key issues surrounding planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and has broadly outlined the current services, programs and initiatives available in NSW. The NSW Government acknowledges that older carers are concerned about the future care and accommodation arrangements for their family members with a disability. We recognise the need to expand and develop future planning and support services for people with a disability who are ageing, including options for those who are being cared for outside of the family home.

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## APPENDIX A

# **New South Wales Government Programs**

The following is not a comprehensive list of services, programs and initiatives, but rather gives an overview of current initiatives developed by the NSW Government and its agencies in response to the support needs of people ageing with a disability, and their families and carers.

# Ageing, Disability and Home Care, Department of Human Services NSW (ADHC)

## My plan, my choice: Packaged Support for Older Carers

The 'my plan my choice' program is currently being piloted in Northern NSW.

This Individualised Support program is being provided to 30 older carers of people with disabilities and their families, and will give greater choice and control in determining the services they receive and how they receive them. 26 per cent of the families are Aboriginal.

'My plan my choice' enables older carers to be the key decision-makers about the supports they seek. It focuses on activities around daily routines, health and wellbeing, accessing community activities and decision-making. Carers have access to a Support Planner (to assist them to identify their needs and what supports are available), and a Support Intermediary (to purchase those supports).

## Futures Planning for Older Carers of Adults with Disabilities

A Futures Planning project has been undertaken in Northern NSW to assist older carers of a person with a disability to put in place plans for a future time when they are no longer able to care. The project was a response to feedback that most carers had nothing in place. They reported being too busy in the caring role to undertake this planning, unaware of what was available or where to start the process

In its first phase, the Aged Services Learning and Research Centre (ASLaRC) at Southern Cross University worked with carers identified by ADHC's Local Area Support Co-ordinators to help them prepare these plans. The plans include matters such as drafting of wills, establishing trusts and talking with other family members to get a clear agreement about who will take on the caring and/or guardianship role when the carer is no longer able to care. In the second phase of the project, ASLaRC trained a number of service providers to undertake the futures planning role with carers.

Due to the success of the pilot project, ADHC, in conjunction with Southern Cross University, has expanded the pilot to a larger number of ageing parent carers in Northern NSW.

### **Support Coordination Program for Older Parent Carers**

The Support Coordination Program for Older Parent Carers initially funded under a Bilateral Agreement with the Australian Government is a case management service. This program is targeted to older parent carers aged 60 years and over, and 45 years and over for Aboriginal parent carers, who are caring for their son and/or daughter with a disability.

The key components of the program include:

- identifying and engaging hidden older parent carers;
- identifying current and future support needs;
- future planning;
- case management;
- facilitated carer support;
- assistance for older parent carers to address issues of emergency care and planning of transition from parental care through a comprehensive plan; and
- coordinating access to flexible and meaningful respite opportunities for adults with a disability.

To further improve support services for this group of clients ADHC is planning to work closely with service providers to develop early intervention strategies for the future planning needs of older parent carers, the sons and daughters they are caring for and their families.

A component of the *Support Coordination Program* is the **Carer Assistance Packages (CAPs)**. Each package is funded for a maximum of \$5,000 per family per annum.

CAPs recognise that adults with a disability who have been living in a close long-term parental care relationship may not have had the opportunity to develop independent living skills, to build their own social networks or to engage in social and community activities. Similarly, older parent carers may have become isolated over time or may not have had the opportunity to build informal support networks.

The Packages are designed for one-off purchases and subject to the service or resource not being available under another program which can be used for the following:

- programs or supports in developing skills for daily living or social skills (for example self development, cooking classes etc);
- counselling support;
- pursuing goals and interests (i.e. facilitating access to sporting, cultural and social activities);
- facilitating cultural connections;
- costs incurred in emergencies, for example; procurement of emergency flexible respite if required where no other alternatives such as Carer Respite Centres are available;
- one-off purchase of household or other equipment;
- supporting informal networks/maintaining informal friendships over time; and

mentoring.

CAPs cannot be used for direct payments to family members as a form of income support.

## Support Coordination for Older Parent Carers Toolkit

A toolkit has been developed to assist service providers to engage hidden carers and facilitate social networks for older parent carers, specifically *Support Coordination* services.

The Toolkit includes:

- Fact Sheets:
- Posters in community languages;
- CD and DVD; and
- Television and radio community service announcements.

#### Supported Accommodation

ADHC has developed a number of accommodation support models that may meet the needs of some people with a disability who are ageing or who have ageing carers.

These include:

- Disability Housing and Support Initiative (operated in partnership with Housing NSW), which provides accommodation and support to people with a disability through innovative and flexible models that meet a range of people's needs and preference.
- Innovative models being developed under the Innovative Accommodation Framework including Intentional Communities transitional units, client directed supported accommodation and semiindependent supported living models.
- Emergency Response, which provides funding for immediate or interim support for people with a disability, their families and carers who are in crisis while working to restore people to their regular, safe living arrangement or to achieve a more stable and secure living arrangement.
- Group homes, which offer support to people with high needs, including those with complex health and aged care requirements.

People who have an older carer are identified as a priority target group in the ADHC *Allocation of Places in Supported Accommodation* policy. This policy articulates the process through which people access supported accommodation services in NSW.

ADHC's **Ageing in Place (AIP) research initiative** responds to the need for an evidence based action plan to better meet the needs of people ageing with a disability, including ageing specific service responses that build on existing service strengths.

The AIP initiative addresses goals outlined in *Stronger Together*, the NSW Government's 10-year plan to provide greater assistance and long-term practical solutions for people with a disability and their families, to increase assistance and options for people with a disability to live at home, as well as increase the range of specialist accommodation services, including options that promote ageing in place.

Key to achieving these outcomes is engaging in research on the effects of ageing on people with an intellectual disability, also an identified priority under *Stronger Together*. It is essential that people with a disability receive quality support, informed by good practice and research.

The AIP initiative responds to service goals reflected in *Towards* 2030 – planning for our changing population and improvements in services and programs for Specialist Accommodation Support. It also demonstrates an active contribution to achieving disability specific strategic priorities.

Over the next 18 months, the AIP research initiative will deliver:

- an options paper identifying the service types that best accommodate specific ageing needs, including people with a disability who are ageing, to further increase the evidence informing the development of new service models that ADHC committed to in *Stronger Together*; and
- a service system action plan advising the development of ageingspecific service responses building on existing strengths.

Stronger Together confirms the NSW Government's commitment to the closure or redevelopment of large residential centres (LRCs) over time.

In response and within the *Innovative Accommodation Framework*, ADHC is developing new models to provide replacement homes for people as LRCs close. ADHC aims to develop responsive and flexible models for people moving out of LRCs which will meet the needs of clients as they age.

One new model that will commence in the second half of 2010 will provide a specialist accommodation service for people with an intellectual disability who have complex age-related needs, including early onset dementia. This centre will not only provide specialist ageing support for 96 residents but will also include four new respite beds.

#### **New Directions in Day Programs**

New Directions in Day Programs was introduced by ADHC during 2008/09, responding to a growing number of individuals with a disability living beyond middle age and transitioning into retirement. It aims to meet the needs of those who require new service delivery options other than those available in traditional government or non-government provided day programs. Central to this aim is the recognition that a continuum of support needs to be provided to people as they age, including opportunities for futures and retirement planning.

The *Life Choices* Program, one of the two initiatives introduced under the *New Directions in Day Programs*, assists people with a disability who are:

- aged 25-54;
- having an intellectual, psychiatric, physical or sensory disability;
- eligible for a service under the NSW Disability Services Act 1993;
- assessed as eligible by ADHC;
- having moderate to very high support needs;
- resident of NSW; and
- not undertaking paid employment for more than 8 hours per week, full time vocational education or higher education.

Life Choices aims to assist people with moderate to very high support needs to achieve their goals and participate as valued and active members of society. It provides flexible day programs and activities that meet individuals' goals, health and activity levels, life stage, interests, and changing support needs. It provides support for longer term future planning for adults with a disability, their families and carers. It also increases the availability of, and access to, culturally-appropriate and responsive supports and activities for Aboriginal people and people from culturally and linguistically diverse (CALD) backgrounds.

Another new program, *Active Ageing*, responds to the needs and interests of older people aged 55-64, people over 45 with early onset ageing and Aboriginal people aged between 40 and 64 years with early onset ageing or requiring specialised service provision. The *Active Ageing* Program aims to:

- promote an active and healthy older life;
- maintain participants' capacity to participate in community life and to remain independent;
- promote opportunities for participation in meaningful activities and ongoing personal development;
- support participants to develop and sustain social networks and interactions;
- facilitate future planning for older life; and
- provide a respite effect for families and carers.

Program participants are able to choose centre-based options, individual community-based options or the self-managed model of delivery of day programs. Participants are offered a minimum of 18 hours of activities and support per week for 48 weeks of the year, such as physical activity and sport, recreation, social networks, therapeutic activities such as art or music therapy, learning and education, independent living, leisure activities and community access activities such as shopping, banking etc. People with a disability with higher support needs are supported with intensive assistance through services, including personal care, help with meals and medication, or behaviour support.

### Home and Community Care (HACC) Program

The HACC Program is an Australian and State Government initiative under the auspices of the *Home and Community Care Act 1985*. The Australian and State Governments jointly fund the program with the Australian Government contributing approximately 60 per cent of Program funding.

ADHC, through the HACC Program, is currently providing and developing a range of initiatives for people with a disability who are ageing and their carers.

The HACC Program's target group is frail aged people, younger people with a disability, and their carers, and as such is a key provider of community care services.

## The HACC Program aims to:

- provide a comprehensive, coordinated and integrated range of basic maintenance and provide support services for frail aged people, younger people with a disability and their carers;
- support people to be more independent at home and in the community, thereby enhancing their quality of life and/or preventing or delaying their inappropriate admission to long-term residential care; and
- provide flexible, timely services that respond to the needs of consumers.

The HACC Program's overall objective is to enhance the independence of people in the HACC target group and to avoid or delay their premature admission to long-term residential care through the provision of basic maintenance and support services. It could be considered to be at the early intervention end of a continuum of care spectrum for people within the HACC target group.

The HACC Program funds 19 different service types. Clients may be eligible to access multiple service types ranging from home modifications to carer and client respite, and personal care to domestic assistance.

Carers are identified as a specific target group in the HACC Program which acknowledges that they need support, recognition and assistance in their role. The HACC Program also funds a number of services, such as respite care, which are specifically designed to support carers in their role. HACC funded services, such as centre-based day care and social support, although not specifically targeted at carers can also have a respite effect for carers.

There are many current initiatives underway with longer-term focuses which are likely to impact on people with a disability who are ageing and their carers. These initiatives aim to streamline access to information and services, streamline assessment, provide consistency across jurisdictions, streamline and improve continuity of care and identify any inadequacies in the choice and funding of planning options currently available to people with a disability who are ageing and their carers.

## Housing NSW, Department of Human Services NSW

Housing NSW has a range of services and programs to meet the specific needs of clients who are older and/or who have with a disability. These include:

## Social housing

- The provision of subsidised public housing with special income eligibility provisions that consider expenses related to a medical condition, disability or injury. Priority housing is available to those who have urgent housing needs. Applicants aged 80 years or more, or 50 years or more if Aboriginal, receive accelerated progression on the Housing Register.
- Public housing tenants with a disability may be entitled to an extra
  bedroom above the standard entitlement if they need an extra room to
  accommodate a family member or carer, or to store medical equipment, or
  if, for example, they are a couple and the disability requires them to sleep
  separately.
- The provision of appropriate housing that meets the needs of tenants.
   Housing NSW Design Requirements released in 2009 emphasise three main principles:
  - Universal design;
  - Robust construction; and
  - Environmental sustainability.
- Disability modifications (such as handrails and ramps) are provided for tenants living in existing public housing to ensure that older tenants or tenants with a disability have housing suited to their needs. In 2008/09, Housing NSW spent \$5.16 million to modify approximately 1,900 dwellings.
- Partnerships under the Housing and Human Services Accord have been developed with organisations/agencies providing support services to improve the planning, coordination and delivery of services to assist social housing tenants to sustain their tenancies.

#### Assistance to maintain or access housing in the private rental sector

- The **Special Assistance Subsidy** provides eligible clients who have a mental or physical disability with a rental subsidy to enable them to live in the private market. In the year to 30 June 2009, this program provided 1,133 subsidies at a cost of \$7.65 million.
- The Private Rental Brokerage Service assists homeless people with complex needs, including intellectual or physical disability, mental or physical illness, to find and keep tenancies in the private market. In the year to 30 June 2008, 69 of the 692 approved applications were for people with a mental illness, 18 were for people with a physical disability, nine were for people with an intellectual disability, and six were for people with a physical illness.

Tenancy Guarantees are provided to private landlords for clients who
have experienced difficulties in securing a private tenancy. In the year to
June 2008, 34 tenancy guarantees were issued to people who were
experiencing difficulty in obtaining appropriate accommodation because of
their disability.

#### NSW Department of Health

# NSW Carers Action Plan 2007-2012 (CAP)

More than one in ten members of the NSW community are carers. The NSW Government is committed to better supporting carers through encouraging collaboration between government agencies, non-government organisations, academia and with carers themselves. To support this collaborative approach, the NSW Government launched the NSW Carers Action Plan 2007-2012 (CAP) which is being implemented by the NSW Department of Health. The vision of the CAP is that the NSW Government will support carers to achieve physical and emotional wellbeing.

Older carers are recognised among 'hidden carers' in the CAP. The Department has assisted carers of people with disability through the development of recurrent state-wide grants to non-government organisations (NGOs) and recently expanded this assistance to reach carers from Aboriginal and culturally and linguistically diverse (CALD) communities.

A national 1800 24-hour **Telephone Assistance Line** gives aged care workers and carers 24-hour access to experienced health care professionals who can provide information, advice and referrals.

The **Family and Carer Mental Health Program** focuses on older carers and their mental health issues. The Department has established an Older Carers Mental Health Working Group supported by the Director of the Older Persons Mental Health Unit.

#### **NSW Dementia Services Framework**

The NSW Dementia Services Framework has been developed in consultation with key experts from aged care, primary health, community support services, mental health, and palliative care. It will identify evidence-based service models along the dementia pathway from risk reduction to palliative care and provide a crucial guide for future dementia service planning and investment in NSW.

Working with Area Health Services, the dementia policy team will identify service models to meet current challenges that include responding to the needs of people from CALD backgrounds and from Aboriginal communities, improving management of people with severe behavioural difficulties, improving hospital outcomes and reducing carer stress.

The team will identify the ideal service mix required across NSW as well as mechanisms for improved coordination of dementia service planning and delivery.

The team will also identify policy and planning issues in relation to other neurodegenerative disorders related to dementia, such as Parkinson's Disease or Huntington's Disease, and consider how to develop a coordinated service response. While research, diagnosis and treatment needs to remain disease specific, there are commonalities: support for carers and access to support services, the provision of timely information, access to diagnosis, encouragement of self-management, residential care and palliative care.

The Department also supports people with dementia through **Older Persons Mental Health Services**. Twelve Behavioural Assessment and Intervention
Services (BASIS) positions have been established across NSW. These
positions complement the Dementia Behaviour Management Advisory
Services project (funded by the Commonwealth) that is aimed at improving
care and quality of life of people with severe and persistent Behavioural and
Psychological Symptoms of Dementia.

The Department has developed two *mental health-aged care partnership* initiatives with residential aged care providers. These partnerships between Sydney South West Area Health Service and the residential aged care providers are jointly funded by the NSW Department of Health, the Australian Government's Department of Health and Ageing and the aged care providers and represent a new, best-practice model of care to address the needs of older people with severe and persistent behavioural and psychological symptoms of dementia and or mental illness for long-term care.

In 2007/08, the Australian Government funding of \$6.1 million was secured by the NSW Department of Health over two years under the *Dementia Behaviour Management Advisory Services (DBMAS)* Program. Following an evaluation of the Program, this funding was further extended to 2009/10. The DBMAS program aims to improve the care and quality of life of people with severe and persistent Behavioural and Psychological Symptoms of Dementia (BPSD) and their carers. The DBAMS program complements and builds on the Department's BASIS initiative.

#### Intellectual Disability Service Framework

The Service Framework to improve health care for people with intellectual disability aims to promote a broader understanding of the health needs of people with intellectual disability among health professionals and to improve the quality, range, consistency and accessibility of services to meet their health needs.

The primary output of specialised multi-disciplinary intellectual disability health teams is the patient's health care plan. The health care plan is to be developed in conjunction with the patient and their family/carer. The aim of a health care plan is to address the health needs of the patient and to improve their health and wellbeing.

The anticipated benefit of this approach is improved health and wellbeing for the patient. For families and carers, improved health and wellbeing for the person they care for may result in reduced carer responsibilities, enabling their greater participation in work or community activities.