

8 Needs of ageing people with a disability

Assessing needs—both those common to all ageing people and those unique to people ageing with disability—is crucial for service planning in order to identify service target groups, develop new services and modify current services.

8.1 Needs common to the general ageing population

Most people, at least until very late in their life, do not experience losses of functional ability that seriously affect their social, physical or cognitive behaviour (McPherson 1990). However, people with a disability may have experienced losses of functional ability at different stages of their lives, depending on the nature and time of onset of their specific disabilities. Older people differ in terms of the rate and degree of biological and psychological change that they experience.

The range of life circumstances and individual characteristics among older people with a disability is similar to that found among older people generally (Ashman & Suttie 1995). There are needs common to all older people, related to their biological, psychological and social ageing. Older people tend to have a greater requirement for health, social, psychological and various other support services, including accommodation, recreation and leisure, mobility, finance, advocacy and family support. Some of the typical needs that result from biological, psychological and social ageing are outlined below.

Biological ageing

As a result of biological ageing, assistance may be required in the following areas (Janicki et al. 1985; Suttie 1995: 16–17):

- Signs of ageing—assistance with grooming and personal care such as podiatry, hairdressing and skin care.
- Sensory deficits (e.g. vision, hearing)—access to regular assessments, medical services, augmentative devices (e.g. glasses, hearing aids), adapted environments (e.g. placement of furnishings) and large-print materials.
- Fitness, muscle tone and strength—need for continued opportunities for exercise and recreation, and rehabilitation services.
- Mobility—ambulatory aids (e.g. sticks, wheel chairs), assistance with learning to use aids, adapted environments (e.g. handrails, ramps and bathroom grip rails), safety monitors, transportation and rehabilitation services.
- Diet—adequate diet and nutrition assistance, Meals-on-Wheels or access to nutrition sites.
- Physical illness and disease—access to health care and monitoring services, medical assistance including dental services, education about the signs of impending illness and disease.

- Dementia—medical services, increasing levels of supervision and support to carers.
- Other mental disorders (e.g. depression)—access to health care and monitoring services, awareness of causes of stress and stress-reduction strategies.

Psychological ageing

Needs for assistance as a result of psychological ageing may include (Suttie 1995: 33–34):

- Personality development (e.g. some people may have personality problems as they age)—opportunities for reminiscence and life review.
- Motivation (e.g. decline due to lack of stimulation, the value put on the perceived usefulness of the task)—stimulation in personally valued experiences, a variety of activity options and opportunities for new experiences.
- Changes in cognition and intelligence—need for continued practice to maintain/learn skills and interest areas.
- Personal control and choice—opportunities to have input into decisions affecting the individual and a range of options.

Social ageing

Needs for assistance as a result of social ageing may arise in the following areas (Suttie 1995: 23–24):

- Transition from work to retirement (changes in financial status, social roles, social network)—pre-retirement planning/advice, opportunities for part-time or voluntary work, assistance in leisure time preparation.
- Social network and role changes—opportunities for social contacts and inter-generation contacts, continuing links with the community and valued role at home and in the community.
- Social effects of biological ageing (e.g. increased loss of social contacts due to mobility difficulties, health problems and sensory losses)—transportation and mobility assistance to maintain community contact and support in facilitating contacts.

8.2 Special situations of older people with an early onset disability

The above section reviewed some common needs of an ageing population. People with an early onset disability may age more rapidly and thus have higher support needs at an earlier age than older people generally (see Chapter 7). For people with an early onset disability, support needs vary depending on the nature of the disability and stage of the ageing process. For example, an older person who has been blind since birth or early childhood will have needs that are quite different from one who has an intellectual disability. Therefore, only limited comparisons can be made between people ageing with an early onset disability and people who acquire disability as they age.

In many respects, differences between people living in institutions and people living in the community do not relate specifically to health care needs, but rather to factors such as independent living skills (Anderson 1989) and—probably more importantly—the availability of informal carers.

Some important differences between ageing people with an early onset disability and older people with late onset disability are identified in the literature (e.g. Anderson 1989; Ashman & Suttie 1995; Bigby 1992; Gatter 1996; Suttie 1995). Special situations of ageing people with an early onset disability may include:

- They are more likely to have low levels of functional ability, which is often the main reason they require care, particularly residential care.
- They are less likely to use community services and facilities or participate in community activities without assistance.
- They are more likely to have low levels of education, particularly those with an intellectual or learning disability.
- Many of them have never been married and hence have no spouse or children. It is these family members who provide most informal support to older people with a late onset disability. Those relying on informal support from aged parents or carers are at risk of losing their support.
- They are more likely to live in residential care and less likely to live alone or live with their families.
- They are less likely to have good social networks outside the family or their place of residence.
- They may be particularly disadvantaged due to lack of good communication skills. Many have difficulty expressing their needs or may require assistance to identify their needs.
- They have low participation rates in both formal and informal day activities and leisure programs, partly due to factors such as lack of good communication skills and informal support networks, partly because few opportunities or choices are available.
- The effects of long-term placement in residential care (including some group homes) may have reduced their capacity to engage in community activities.
- They are more likely to have participated in supported employment. For those who have been in supported employment, this may have not only provided occupation throughout their adult life, but also have been the main source of their lifelong social relationships.
- They are more likely to be dependent on pensions and not have any retirement income.
- They are much less likely to be home owners.

Thus, while most older people share common problems, people with lifelong disability are likely to have some additional disadvantages.

8.3 Special needs of older people with an early onset disability

Ageing people with an early onset disability, in particular intellectual disability, are reported to need a different range of psychological and social supports, although their physical support needs may be quite similar to those of the general ageing population. The nature of services required by older people with an early onset disability may also differ from those required by their younger counterparts. The literature indicates that the special needs of older people with an early onset disability are as follows (e.g. Gething et al. 1999; Gatter 1996; Bigby 1992):

- They have a high need for formal support services, particularly accommodation support services, since they often do not have good informal support networks and may lack independent living skills.
- They have a high need for age-appropriate day activity and leisure programs. Separate specialist activity programs may be required in addition to, or instead of, community-based services designed for older people generally.
- Appropriate activity services may be required for people with an early onset disability who have previously worked in either supported employment or open employment.
- They have a high need for assistance in choosing, locating, negotiating access and travelling to community-based programs, and may also require short-term or ongoing assistance in order to participate in chosen activities.
- They have a high need for assistance in expanding their social networks beyond their families and parents' peer group.
- They may need special assistance in personal financial planning. The extra costs incurred by people with lifelong disability can mean that they face old age with few financial resources.
- The impact of disability changes throughout the life span and needs for support tend to increase with ageing. Therefore, reassessment of needs should be available to ageing people with a lifelong disability and they should be involved in initiating reassessments as required.

8.4 Factors contributing to restricted access to services

Apart from the special characteristics and needs of ageing people with an early onset disability reviewed in earlier sections, there are other factors that prevent these people from adequately accessing supports and services (e.g. Williams & Chad 1998). These factors can be summarised as follows:

- Many people with a lifelong disability heavily rely on others to provide adequate and appropriate support. This can indirectly cause unintentional exclusion from community-based services and activities.
- Individuals with inappropriate or intrusive behaviours are not welcomed in general community-based services and activities.
- Ageing people with a lifelong disability are often perceived as being incompatible with present client groups.
- Some services are not designed to provide a five-day structured program and full-time access is not an option.
- The location of services may make them inaccessible to some people with a lifelong disability.
- Personal financial constraints may limit access to services.
- The resources required to meet the emerging needs of older people with an early onset disability are diverse and complex.
- People ageing with disability may be excluded from specific services by restrictive program restrictions/requirements due to limited funding sources.

- Some people have difficulty in accessing appropriate services because of the regional division of administrative responsibilities.
- There is a lack of trained staff aides to support older adults with intellectual disability.