People with Disability in South Western Sydney

Vulnerable Communities No. 1 September 2016



Health South Western Sydney Local Health District

South Western Sydney Local Health District

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ISBN 9 7817 4079 206 6

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Demographic and health characteristics

Disability can be acquired at birth or early in life, or may be the result of accident, illness or injury throughout life. Rates increase with age, with approximately 40% of people having some form of disability by the time they are 70 years old. Disability is caused by a range of conditions, including intellectual, physical, cognitive, sensory, neurological impairments or mental illness. What people with disability have in common is the disadvantage and discrimination that many experience as a result.

The Australian Bureau of Statistics *Survey of Disability, Ageing and Carers (SDAC)*. Disability is defined as any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months. Based on the 2012 SDAC:

- 18.5% of the population have disability i.e. 4.2 million Australians; 6% have a severe or profound disability ¹
- 81% of respondents (3.4 million people) indicated that a physical condition was the condition that caused them most problem. Diseases of the musculo-skeletal system and connective tissue (e.g. back problems and arthritis) were most frequently reported (33%)
- About 1 in five respondents (19%) reported mental or behavioural disorders as the condition causing them most problems. Other problems reported were intellectual and developmental disorders (5.6%), depression and mood disorders (3.8%) and dementia (2.1%)
- Children were most likely to have asthma or an intellectual or developmental disorder; people of working age a back problem, a disease of the nervous system or mood disorders; and older people arthritis and related disorders and diseases of the circulatory system.
- For those aged 15 64 years with a severe or profound core disability (sometimes or always needing help with mobility, self-care or communication):²
 - 51% rated their health as poor or fair compared to 6% of people without disability; and were substantially less likely to report excellent or very good health
 - Were 3.3 times as likely as those without a disability to have 3 or more long-term health conditions
 - 50% had a mental health condition (compared to 8% without disability), often acquired before the age of 25 years
 - Were 4 times as likely to have arthritis, often acquired before the age of 45 years
 - 70% were overweight or obese (compared to 60% of those without a disability); with obesity 1.7 times as likely. There is also an increasing trend to overweight
 - 46% reported no exercise (compared to 31% of those without disability)
 - Were twice as likely to smoke (31% compared to 15%), with smoking more likely to occur before the age of 18 years compared to those without disability
 - Were 20 times as likely to experience a high level of psychological distress (22% compared to 1%).

Disability impacts on employment.¹ People aged 15-64 years with disability had lower workforce participation (53%) and higher unemployment rates (9.4%) than people without disability (83% and 4.9% respectively). Lower employment rates and an older profile contribute to people with disability aged 15+ years being more likely to live in a household in the lowest two household income quintiles than those without disability (48% compared with 22%).

Education and participation in social or community activities can also be affected by disability. The 2012 SDAC found that people with disability aged 15+ years living in households were less likely to have a tertiary qualification (bachelor degree or higher) (13% compared with 25%); 60% needed assistance with at least one everyday activity, and of these 61% had their needs fully met; and were less likely to participate in a cultural, recreational or sporting activity away from home in the previous 12 months (20% of people with disability aged 15-64 years living in households compared with 79%). ¹

Access to health services is impacted by physical and organisational barriers e.g. inadequate transport, lack of assistance with communication and discrimination. In Victoria:

- 55% of women aged 50-69 years with an intellectual disability had a mammogram in the last 2 years (compared to 76% of the general population)
- 14% of women aged 20-69 years with intellectual disability were screened for cervical cancer compared to 71% of the general population.³

Use of community services

National and state governments fund disability support services to improve the lives of people with disability, and their carers, and ensure that they have the opportunity to participate in the community. Disability support services include accommodation support, community support (such as therapy, early intervention and counselling), community access (such as life skills development and holiday programs), respite (including home and centre based and flexible respite), open and supported employment, advocacy and information services (including self-help groups) and other support (including research and training and development). An estimated 321,531 people nationally used disability support services under the National Disability Agreement in 2013-14.⁴ The profile of service users was:

- 74% were aged under 50 years
- 59% were male, and males tended to be younger than females
- 87% were Australian born with only 9% born in predominantly non-English speaking countries
- 6% were Aboriginal and Torres Strait Islander people
- 54.5% had an intellectual or learning disability, 47.6% had a physical/diverse disability, 27.7% had a psychiatric disability and 20.8% had a sensory/speech disability
- 68% needed assistance in activities of daily living, 82% with activities of independent living and 86% with activities of work, education and community living
- 70% of people aged 15+ years in the labour force were unemployed. The most common form of income was the Disability Support Pension (65%)
- 54% live with their families, 24% live with others and 22% live alone
- 68% had an informal carer. Most frequently female (86%) and usually their mother. Only 9% were cared for by a spouse

The most commonly used disability support services were community support (44%), employment (41%), community access (18%), accommodation support (14%) and respite (12%). The most growth in services between 2009/10 - 2013/14 was in accommodation support which grew by 16%.

Initial National Disability Insurance Scheme (NDIS) data profiles clients as younger, Australian born, non-Indigenous with a higher need for assistance. This profile probably reflects the choice of NDIS transition sites.⁴

People with disability in care

Some people with disability live in supported residential care services such as group homes, residential centres, assisted boarding houses, and also residential aged care facilities.

The profile of residents in care was:

- 30 years less life expectancy for people in disability services than the general population and 20 years earlier for those in assisted boarding houses
- 84.5% intellectual disability, 59% sensory disability, 49.4% physical disability and 43.5% psychosocial disability. A small number had a neurological disability, acquired brain injury and autism

- 74% of disability services residents needed assistance with mobility, 65% assistance in communication and 74% assistance with meals; and 66% had swallowing difficulties
- Only 23.8% had all their teeth and 43.5% some teeth
- Only 44.8% were in the healthy weight range. Less than 1/3rd of assisted boarding house residents met this criteria
- Of people in disability services, 71% had some level of incontinence, 69% constipation and 62% gastrooesophageal reflux. Other health issues included epilepsy (48%), recurrent respiratory infections (46%) and osteoporosis (36%). The major health issues for assisted boarding houses residents were hypertension, high cholesterol and constipation
- Very high rates of smoking by boarding house residents (86%) compared to disability services residents (15%)
- Most residents had received an influenza vaccination; however fewer had a pneumococcal vaccination i.e. only 32% of disability services residents and 21% of boarding house residents
- 68% of disability service residents and 35% of boarding house residents had a comprehensive health assessment in the year prior to death

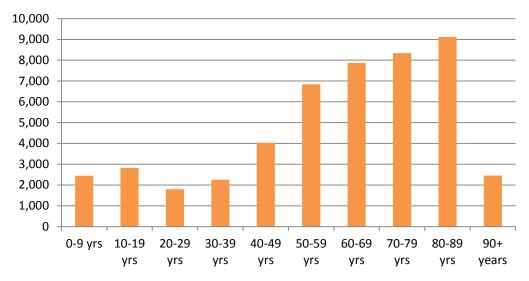
The NSW Ombudsman reports annually on the deaths of people with disability living in or temporarily absent from residential care (i.e. group homes, residential centres, assisted boarding houses, and other accommodation for people with disability, such as centre-based respite). ⁵ Heart disease (mainly ischaemic heart disease), cancer (lung and bowel) and respiratory diseases (aspiration, pneumonia, COPD and emphysema), digestive system diseases and choking were the main causes of death. Contributing to early death were risk factors of smoking, poor diet and lack of physical activity, problems with swallowing and eating, other chronic health problems, conditions such as cerebral palsy and epilepsy and multiple medications.

Concerns about hospital care included inadequate support e.g. understanding by health staff about the person's support needs, inattention to critical information provided by disability staff e.g. eating and drinking requirements, poor communication between the agencies and confusion around roles; poor coordination and transfer of care; an inadequate response to complex needs; poor access to chronic disease management and preventative health programs; and poor end of life care and decision making.⁵

People with disability in south western Sydney

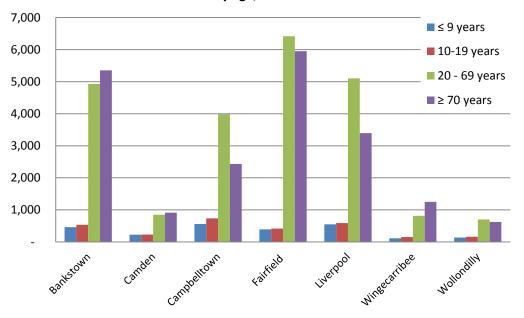
The 2011 ABS Census of Population and Housing identified almost 48,000 people living in south western Sydney with a profound or severe disability i.e. needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication because of a disability, long term health condition (lasting six months or more) or old age. As such, people with disability represent 5.7% of the local population. Bankstown and Fairfield local government areas (LGAs) had the highest proportion of people with disability.

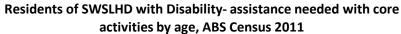
The diagram following shows that disability increases as people age. 47.5% of people with disability were aged 20-69 years and a further 41.5% were aged 70+ years. In comparison, children aged nine years and under represented only 5.1% of all people with disability and young people aged 10 - 19 years represented a further 5.9%.⁶



Residents of south western Sydney with disability, ABS Census 2011

There is geographic variation across south western Sydney in the age of people with disability. The diagram following indicates that people with disability tend to be younger in the Macarthur region, with 17.8% aged 19 years and younger, compared to only 6.2% in this age group in Fairfield LGA. The number of residents with disability in Wingecarribee LGA tends to be larger and older than in Wollondilly LGA, even though the overall populations are similar in size. Detailed data is provided in Appendix A.⁶





Poor English skills can compound the barriers experienced by people with disability. The 2011 Census identified 14,304 people with disability with poor language skills i.e. who could not speak English or could not speak English well. English language skills varied across the District i.e. 51.2% of Fairfield residents with disability, 33.1% of Liverpool residents and 30.1% of Bankstown residents had poor language skills, compared to only 1% of Wingecarribee residents. ⁶

Disadvantage and multiple disadvantages can compound. For people with disability, lower educational attainment, fewer housing options, unemployment, transport barriers and discrimination amplify physical, mental, intellectual and health problems and may result in social isolation.⁶

In June 2014, 28,784 south western Sydney residents aged 15-64 years received a Disability Support Pension i.e. 5.9% of this age group (compared to 5.6% for NSW). Fairfield LGA had the highest proportion of DSP recipients (7.1%) and Camden LGA (3.1%) and Wollondilly LGA (3.6%) the lowest.⁷

Disability Policy

The <u>Disability Discrimination Act 1992</u> aims to eliminate discrimination against an individual in relation to work, accommodation, education, access and social participation; to ensure people with disability are treated in the same way as the general community and to promote the rights and acceptance of people with disability.

The Council of Australian Government's *National Disability Strategy 2010-2020* sets a vision for an "inclusive Australian society that enables people with disability to fulfil their potential as equal citizens". The strategy identifies the need to create more inclusive and accessible communities; improve rights protection, justice and legislation; enhance economic security; personal and community support; learning and skills and health and wellbeing.⁸

Disability reform is occurring across Australia through the implementation of the <u>National Disability</u> <u>Insurance Scheme</u> (NDIS).

A range of NSW Ministry of Health policies focus on people with disability, including *NSW Ministry of Health Policy Directive: Responding to Needs of People with Disability during Hospitalisation* (currently under review) which provides guiding principles and policies, protocols and procedures required for admitted patients with the aims of describing roles and increasing sensitivity and adaptability.

Disability support in SWSLHD

SWSLHD provides a range of support services and infrastructure to assist people with disability to access health services, particularly hospitals. Examples include dedicated parking, accessible toilets, interpreters (including Auslan), communication aids and equipment.

Disability and Carers Committees operate for the whole District and each facility to advocate for the continued improvement of services and supports to people with disability and carers accessing health services. The <u>Consumer and Community Participation Networks</u> also undertake a similar role.

<u>SWSLHD Patient Liaison Officers</u> are available at each of the District's hospitals to provide support and information for people with disability and their carers.

SWSLHD also provides an extensive range of services to support people with disability. A range of allied health services such as physiotherapy, occupational therapy and speech pathology support are available for children and adults in hospital and community settings. Medical rehabilitation services are also provided.

A number of other government and non-government agencies provide local people with disability with assistance in terms of income, housing, care and support.

Working with People with Disability

There is no standard approach to working with people with disability as each person will have their own unique requirements and capabilities. The availability of carer support is also variable.

Reports on assessment and care of people with disability recommend:

- Comprehensive health assessments and medication reviews by General Practitioners, which include physical health, oral health and mental health needs
- Referral to medical specialists as appropriate
- Completing a risk profile identification prior to hospital admission where possible and discharge planning beginning at admission⁹
- Ensuring access to health promotion information and programs in appropriate formats¹⁰
- Ensuring access to disease prevention services such as immunisation and screening^{8,9}
- Partnerships between people with intellectual disabilities and support agencies (including health services), wit¹⁰
- Use of visual and other aids to support communication ¹¹
- Recognition of the role and insight of carers, particularly in relation to behaviour changes which may indicate pain or deterioriation
- Carer support

Resources

- Disability Support Pension
- <u>National Disability Insurance Scheme</u>
- People with a Disability: Responding to Needs During Hospitalisation
- <u>Provision of Services to People with an Intellectual Disability & Mental Illness MOU & Guidelines</u>
- NSW Health Service Framework to improve the health care of people with intellectual disability, 2012
- Agency for Clinical Innovation Intellectual Disability Network
- Working with People with Intellectual Disabilities in a Healthcare Setting
- Etiquette Tips when working with people with disability

Appendix A

Table 1: Age of People with Disability in South Western Sydney (ABS Census 2011)

Local					
Government	≤ 9 years	10-19 years	20 - 69 years	≥ 70 years	Total
Area					
Bankstown	461	534	4,930	5,352	11,277
Camden	227	230	850	912	2,219
Campbelltown	559	736	3,985	2,436	7,716
Fairfield	396	417	6,417	5,951	13,181
Liverpool	552	592	5,103	3,395	9,642
Wingecarribee	113	151	815	1,250	2,329
Wollondilly	137	163	701	622	1,623
SWSLHD	2,445	2,823	22,801	19,918	47,987

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