

South Western Sydney Local Health District

Disability and Carers Strategy 2017-2022

Leading care, healthier communities

support
quality
believe in myself
CAREERS
communication
opportunity
respect
equity
employment
access to care
involve
safety
empower
information
confidence



Health
South Western Sydney
Local Health District



supported by **SWSLHD**
Consumer and Community Participation

Acknowledgements

We would like to acknowledge the contributions of the Consumer and Community Council, community representatives, health consumers, carers and health staff in the development of this Strategy.

Front Cover

The Disability and Carers Strategy was developed in consultation with consumers, carers and health service staff. The words and phrases on the front cover were captured throughout the consultation process and represent the voices, needs and wants of consumers, carers and staff members across the District.

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ISBN 978 1 74079 2264

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September 2017





Foreword

South Western Sydney Local Health District (SWSLHD) serves one of the most rapidly growing and culturally diverse communities in New South Wales (NSW). We work to provide a healthcare service that is person-centred, consistently safe, equitable and responsive to the rapidly developing needs of our communities. We also value and strive to support the highly skilled, passionate and committed people who work to provide exceptional care to our patients, their carers and other consumers every day. We care about and are committed to providing an exceptional experience for everyone who interacts with our organisation.

The District understands that people with a disability have additional challenges in accessing the care that they need. The SWSLHD Disability and Carers Strategy, in conjunction with the Transforming Your Experience (TYE) Strategy aims to positively shape our organisation and culture so that patients and staff with a disability and our consumers and staff who have carer responsibilities have access to safe, high quality services and opportunities. The Strategy will guide our efforts to create exceptional experiences.

Carers are acknowledged as providing very valuable care to older and frail people, those with chronic health conditions, and people with disabilities. SWSLHD recognises that carers are an integral partner in the provision of safe, quality healthcare. Health services can only become more responsive and effective if we actively consult with both the consumers and the people who care for them. This Strategy aims to guide the District and all staff in ensuring that carers are valued and recognised, and that services and workplaces provide them with support.

The District congratulates all involved in developing the Disability and Carers Strategy. The implementation of the Strategy will be overseen and supported by the SWSLHD Disability and Carers Committee and the individual facilities and services within SWSLHD. The Consumer and Community Council (CCC) were also integral to the development of the Strategy and in supporting the implementation.

Amanda Larkin
Chief Executive
South Western Sydney Local Health District



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Our Vision

Leading care, healthier communities
Equitable and dignified access to services
Employment for people with disability
Respect for and valuing of carers

Our Values

Collaboration
Openness
Respect
Empowerment



1. Introduction

SWSLHD is committed to ensuring that all community members have access to safe, high quality and personalised care. It is acknowledged that people with a disability often face greater disadvantage and significant barriers in realising this aim.

As both a healthcare provider and a major employer in south western Sydney, SWSLHD recognises their responsibility to have a process for reviewing and improving access and quality of services to address the needs of consumers and employees. As an active initiative to guide positive change for all consumers, SWSLHD has commenced an improvement process called Transforming Your Experience (TYE). The initiative is underpinned by four focus areas:

- Consistent delivery, quality and safe care
- Personalised, individualised care
- Respectful communication and genuine engagement
- Effective leadership and empowered staff

The SWSLHD Disability and Carers Strategy has been developed in alignment with TYE, and a range of legislation and plans relating to people with a disability and carers. Carers play a vital role as 'partners in care'. Identifying and partnering with carers acknowledges their role in the Local Health District (LHD) and assists staff to provide optimum care and necessary support.

Disability: 'a long term physical, psychiatric, intellectual or sensory impairment that, in interaction with various barriers, may hinder the person's full and effective participation in the community on an equal basis with others'.

NSW Disability Inclusion Act 2014

Carer: 'an individual who provides ongoing personal care, support and assistance to any other individual who needs it because that other individual has a disability (consistent with the Disability Services Act 1993); has a medical condition (including a terminal or chronic illness); has a mental illness; or is frail and aged'.

NSW Carers (Recognition) Act 2010

The District decided to develop a combined document to outline the relevant strategies for improving the quality of care and inclusion for both groups in recognition of the synergy of the issues they face and many of the resultant strategies.

As per state requirements, the Disability and Carers Strategy captures the LHD's commitment to improving access to services and facilities and provides a broad set of strategies to better meet the needs of patients, community and staff with a disability as well as carers and staff members who also have carer responsibilities. While the Strategy is closely aligned to the *NSW Health Disability Inclusion Action Plan (DIAP) 2016-2019* and the *NSW Health Carers Strategy 2014-2019*, it also includes specific strategies for the LHD to assist in addressing localised needs and priorities.



2. Vision and Principles

A vision of leading care, healthier communities underpinned by equitable and dignified access to services as well as employment for people with a disability; and respect for and valuing of carers

The Principles informing how SWSLHD staff will care for and work with people with disability and carers are founded on the NSW Health CORE values of Collaboration, Openness, Respect and Empowerment as well as the principles in the *NSW Health Disability Inclusion Plan 2016 – 2019*¹, the *NSW Carers Strategy 2014-2019*² and the SWSLHD TYE Strategy. SWSLHD will:

1. Embed a culture of **person-centred care** which places people with disability, their carers and families at the centre of decision-making regarding their care to ensure that their rights to independence, choice, control and inclusion are respected and upheld. People with disability, their carers and families will be well informed about the care and services they can expect and will participate in every stage of decision-making.
2. **Quality healthcare** will be delivered in a safe manner and environment ensuring all reasonable adjustments are made **to support participation and consumer safety**.
3. **Respectful communication and meaningful engagement** to elevate the voices of people with a disability and carers through participation in planning and designing health services.
4. **Work in collaboration** with private, public and not-for-profit sectors to achieve integrated care for people with disability and carers.
5. **Recognise and respond to the needs of diverse and vulnerable communities**, including hidden carers, people with a disability, younger populations, people from culturally and linguistically diverse (CALD) backgrounds including refugees and Aboriginal and Torres Strait Islander peoples and people who identify as lesbian, gay, bi-sexual, transgender or intersex.
6. **Acknowledge the changing and dynamic landscape** created by National Disability Insurance Scheme (NDIS) reform by being open and responsive to change and building realistic, sustainable systems and services.
7. Provide education and training to staff that supports a **culture of inclusion**.
8. Improve **accountability** by measuring success against the NSW Health Performance Framework and the feedback of our consumers, carers and their families.



3. Policy and Strategic Context

3.1 People with Disability

The *NSW Disability Inclusion Act 2014* defines disability as ‘a long term physical, psychiatric, intellectual or sensory impairment that, in interaction with various barriers, may hinder the person’s full and effective participation in the community on an equal basis with others’³. The Act requires government agencies to consult, involve and plan with consideration of those living with disability to ensure a fully inclusive society. It acknowledges that people with disability have the same human rights as other community members and that government and the community have a responsibility to facilitate and exercise those rights. It seeks to promote the independence and social and economic inclusion of people with disability; enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports and services; provide safeguards in relation to the delivery of support and services for people with disability; support, to the extent reasonably practicable, the purposes and principles of the United Nations Convention on the Rights of Persons with Disabilities⁴; and provides responsibilities to the government during and following the transition to the NDIS. The Act requires government agencies to develop and implement a disability strategy that focuses on the operation of mainstream and targeted services and report on implementation.

The *NSW Anti-Discrimination Act 1977*⁵ specifically states that it is against the law to treat a person with a disability unfairly or to harass a person because of their disability. This includes discrimination because of equipment or assistance needs, including the need for an assistance dog; and indirect discrimination which disadvantages people with disability.

The *National Disability Strategy (NDS) 2010-2020*⁶ seeks to improve the lives of people with disability, their families and carers. It covers six priority areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing. Arising from the Strategy is the NDIS, the national system of support focused on the needs and choices of people with disability. The NDIS commenced roll out in SWSLHD on 1 July 2016. SWSLHD has registered as a provider to support access to care during the transition.

The *NSW Disability Inclusion Plan 2015*⁷ is the NSW Government’s commitment to identifying and breaking down the barriers which prevent people with disability from enjoying the same opportunities and choices as everyone else. It aligns with the NDS and obligations under the United Nations Convention on the Rights of Persons with Disabilities. The Plan has four focus areas aimed at creating long term change and consistent efforts from government and the wider community: developing positive community attitudes and behaviours; creating liveable communities; supporting access to meaningful employment; and improving access to mainstream services through better systems and processes.



The *NSW Health Disability Inclusion Action Plan 2015-2019*¹ outlines actions that will be taken by NSW Health to ensure inclusion of people with disability in all aspects of healthcare planning, delivery and evaluation at an individual and systemic level.

NSW Health has issued a number of policies and guidelines which focus on improving services for people with disability and their carers. These policies include:

- *Responding to Needs of People with Disability during Hospitalisation (PD2017_001)* provides guiding principles, protocols and procedures expected to be in place in NSW public hospitals for admitted patients. This policy requires NSW Health organisations and staff to provide services to people with disability that are inclusive, person-centred and accessible.
- *EnableNSW - Assistive Technology for Communication, Mobility, Respiratory Function & Self-Care (PD2011_027)* outlines the provision of assistive technology to people with permanent or long term disability. The policy provides procedures and guidance to assist health staff in processing applications and determining requests for EnableNSW services.
- *Wayfinding for Healthcare Facilities (GL2014_018)* provides specific information about the development of wayfinding strategies and introduces a number of tools that can be used to design and improve wayfinding systems for healthcare facilities.
- *Recruitment and Selection of Staff to the NSW Health Service* sets out the mandatory standards to be applied when recruiting and selecting staff for employment in NSW Health, including people with disability.
- *The Australian Charter of Healthcare Rights* describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe. The Charter applies to all health settings anywhere in Australia, including public hospitals, private hospitals, general practice and other community environments. It allows patients, consumers, families, carers and service providers to have a common understanding of the rights of people receiving healthcare.



3.2 Carers

The *NSW Carers (Recognition) Act 2010*⁹ defines a carer as ‘an individual who provides ongoing personal care, support and assistance to any other individual who needs it because that other individual has a disability (consistent with the Disability Services Act 1993); has a medical condition (including a terminal or chronic illness); has a mental illness; or is frail and aged’. The legislation recognises the valuable social and economic contribution that carers make to the community and the people they care for. The Act requires government agencies to take action to increase awareness and inclusion of carers in the health service, and reflect principles of the NSW Carers Charter in all work carried out.

NSW Carers Charter

1. Carers make a valuable contribution to the community

- (a) NSW recognises the valuable social and economic contribution that carers make to the community.
- (b) Carers should have the same rights, choices and opportunities as other Australians.
- (c) Carers’ unique knowledge and experience should be acknowledged and recognised.
- (d) The relationship between carers and the people they care for should be respected.

2. Carers’ health and wellbeing is important

- (a) Carers should be supported to enjoy optimum health and wellbeing and to participate in family, social and community life, employment and education.
- (b) Carers should be supported to balance their caring role with other roles, such as work and education.

3. Carers are diverse and have their individual needs

- (a) The diverse needs of carers should be acknowledged and recognised in policy, programs and service delivery, taking into consideration culture and language, age, disability, religion, socio-economic status, place of residence, gender identity and sexual orientation.
- (b) Aboriginal and Torres Strait Islander values, heritage and concepts of caring should be respected and valued.
- (c) The additional challenges faced by carers who live in rural and remote areas should be acknowledged and recognised.
- (d) Children and young people who are carers should be supported to reach their full potential.

4. Carers are partners in care

- (a) The choices, views and needs of carers and of the people they care for should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.
- (b) Carers should be referred to, and assisted to access appropriate supports and services.
- (c) Support for carers should be timely, responsive, appropriate and accessible.



The *NSW Carers Strategy 2014-2019*² seeks to improve the position of carers in NSW, with a vision that carers and caring are respected and valued, carers have the time and energy to care for themselves; and carers have the same rights, choices and opportunities as other community members. The Strategy focuses on five areas: employment and education; carer health and wellbeing; information and community awareness; carer engagement; and improving the evidence base.

Family and Community Services Leave, Personal/Carers Leave and flexible work practices are outlined in NSW Ministry of Health Policy Directive *Leave Matters for the NSW Health Service*.

3.3 South Western Sydney Local Health District

The *SWSLHD Strategic and Healthcare Services Plan Strategic Priorities in Healthcare Delivery to 2021*¹⁰ identifies people with disability and carers as groups experiencing disadvantage, requiring additional support to access health services. In order to address this disadvantage, Strategy 3.4.6 of the *SWSLHD Corporate Plan 2013-2017 Directions to Better Health*¹¹ required the development of the Disability and Carers Strategy.

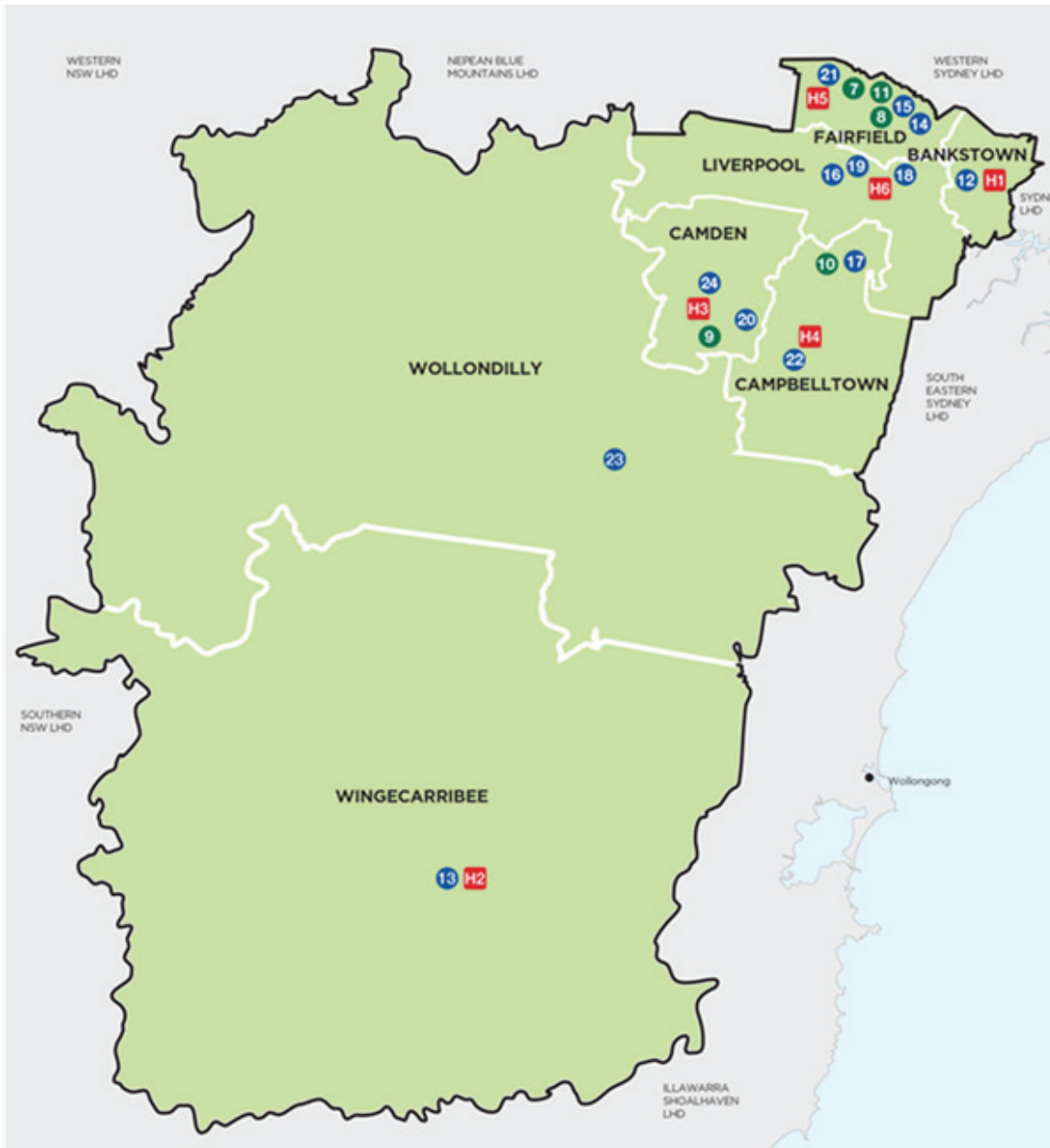
In addition, the *SWSLHD Mental Health Strategic Plan 2015-2024*¹², *SWSLHD Health Improvement for Children, Young People and Families Plan 2016-2025*, and other SWSLHD plans focusing on Aboriginal and Torres Strait Islander peoples and advanced care planning and end of life care include targeted actions for people with disability and carers.

The TYE Strategy underpins all services within the LHD.



4. South Western Sydney Communities

SWSLHD is responsible for improving and maintaining the health of an estimated 939,460 people living in south western Sydney and the Southern Highlands i.e. the local government areas (LGA) of Canterbury-Bankstown (former Bankstown LGA suburbs only), Fairfield, Liverpool, Campbelltown, Camden, Wollondilly and Wingecarrabee. The geographical coverage of SWSLHD is reflected in the following map.



Hospitals	Affiliated Health Organisations	Major Community Health Centres	Integrated Primary & Community Care Centres
H1 Bankstown-Lidcombe Hospital	7 Braeside Hospital	12 Bankstown	24 Oran Park
H2 Bowral and District Hospital	8 Karitane	13 Bowral	
H3 Camden Hospital	9 Karitane @ Camden	14 Cabramatta	
H4 Campbelltown Hospital	10 Scarba - South Western Sydney	15 Fairfield	
H5 Fairfield Hospital	11 Service for the Treatment & Rehabilitation of Torture & Trauma Survivors (STARTTS)	16 Hoxton Park	
H6 Liverpool Hospital		17 Ingleburn	
		18 Liverpool	
		19 Miller	
		20 Narellan	
		21 Prairiewood	
		22 Rosemeadow	
		23 Tahmoor	



The facts provided in the below sections about people with disability (4.1) and carers (4.2) have been obtained from various sources that have been acknowledged in section 10 of this Strategy. The sources include current available information from areas including the Australian Bureau of Statistics (ABS), Australian Institute of Health and Welfare, Carers Australia and other key groups.

4.1 Facts about People with Disability

- Disability can be acquired at birth or early in life, or as the result of accident, illness or injury throughout life.
- 18.5% of people in Australia report a disability and 6% a severe or profound disability¹³
- In 2011, about 48,000 people living in south western Sydney had a profound or severe disability needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication i.e. 5.7% of the SWSLHD population. Disability increased with age with 41.5% of people with disabilities aged 70 years and over¹⁷.
- 5.9% of people of working age in south western Sydney receive a disability support pension (compared to 5.6% for NSW). Fairfield LGA has the highest proportion of disability support pension recipients (7.1%)¹⁸.
- Compared to people without disability, people with disability of working age with a severe or profound disability are more likely to rate their health as poor or fair (50% compared to 6%); three times more likely to report three or more long term health conditions; more likely to report a mental health condition (50% compared to 8%); four times as likely to have arthritis; twice as likely to smoke; and much more likely to experience high psychological distress (22% compared to 1%)¹⁴.
- People aged 15-64 years with disability have lower workforce participation (53%) and higher unemployment rates (9.4%) than people without disability (83% and 4.9% respectively); and were also less likely to have a tertiary qualification or participate in cultural and recreational activities¹³.
- People living in residential care e.g. group homes have a life expectancy of 30 years less than the general population. The most common disabilities were intellectual (84.5%), sensory (59%), physical (49.4%) and psychosocial (43.5%) and the most common health problems were incontinence, constipation and gastro-oesophageal reflux. They had a high need for assistance with mobility, communication and meals. For people living in assisted boarding houses, hypertension, high cholesterol and constipation were the major health issues¹⁶.
- Access to health services is impacted by physical and organisational barriers e.g. inadequate transport, lack of assistance with communication and discrimination.
- Disadvantage can compound for people with disability, for example, lower educational attainment, fewer housing options, unemployment, transport barriers and discrimination.
- Additional barriers and disadvantage can be experienced by vulnerable groups including people from CALD backgrounds, Aboriginal and Torres Strait Islander peoples, or people who have low socio-economic status.



4.2 Facts about Carers

- 2.7 million Australians identified as carers in 2015.
- Approximately 77,104 people in south western Sydney are carers (9.2%). The largest number of carers are in Bankstown and Fairfield LGAs, but the highest proportion of carers are in Wingecarribee where 10.4% of people identify as carers¹⁷.
- About 49% of carers living in south western Sydney are employed on a full time or part time basis.
- Carers are more likely to be female (61.6%) and aged 20-59 years (73.7%)¹⁷.
- Primary carers were more likely to live with a disability themselves (37.8%) compared with non-carers (15.7%).
- Carers provided an estimated 1.9 billion hours of care in Australia in 2015, with a replacement value of \$60.3 billion. Propensity to provide care has decreased in recent years and is predicted to deteriorate further as the population ages, families get smaller and as workforce participation by women and older people increases¹⁹.
- Hidden carers do not usually identify as carers or recognised as carers by health professionals or the community¹⁷. In SWSLHD there are:
 - Approximately 3,400 young carers aged 19 years and under (4.4% of carers in south western Sydney);
 - Approximately 1,200 Aboriginal carers (1.5% of carers). 56% of these carers live in Campbelltown and Liverpool LGAs;
 - About 8,000 carers from CALD backgrounds who do not speak English well or at all (10.4%). Approximately half of these carers live in the Fairfield LGA.
- Compared to the general population, research on carer health indicates:
 - Carers are at greater risk of mental health problems with lower energy levels²¹;
 - Carers have higher levels of depression and stress than non-carers²²;
 - Carers of a person with a core activity limitation experience a change in their wellbeing (38.8%)²³.
- According to the ABS, 72.5% of carers are not satisfied with their caring role, 36.5% felt weary and lack energy, 11.7% felt angry or resentful of their role, 27.6% felt worried or depressed and 27.5% reported that their sleep was frequently interrupted²³;
- Barriers to access experienced by carers from CALD backgrounds include lack of health literacy, cultural appropriateness of services and lack of awareness about services available²⁰;
- Carers of people at end of life were more likely to have poor health if they perceived they did not get enough support from health services and if the deceased family member did not die in the carer's preferred place of death²⁴.



“When we need to see the neurologist for my child, my husband and I need to take a day off work, the parking is terrible and we need two people to physically go anywhere. These appointments are stressful and tiring. It is like planning to go on a picnic without the picnic enjoyment and relaxation” Carer reflections



5. SWSLHD Services

SWSLHD works in collaboration with local general practitioners and other primary healthcare practitioners to provide a comprehensive range of health services to the local community. SWSLHD services are provided through local hospitals and community health centres, with clinicians working in collaboration with other service providers.

5.1 Mainstream Services

SWSLHD public hospitals include Bankstown-Lidcombe Hospital, Bowral and District Hospital, Campbelltown Hospital, Camden Hospital, Fairfield Hospital and Liverpool Hospital. In addition, affiliated facilities include Karitane (specialising in support for families), Braeside Hospital (specialising in palliative care, rehabilitation and aged care psychiatry), STARTTS (Service for the Treatment and Rehabilitation of Torture and Trauma Survivors) and South West Sydney Scarba (specialising in child protection).

Other SWSLHD related facilities and services based primarily in the community offer a range of prevention, early intervention, assessment, acute/post-acute treatment, health maintenance and continuing care services designed to improve or maintain the health and wellbeing of individuals and communities. Key locations include Bankstown, Liverpool, Cabramatta, Carramar, Prairiewood, Miller, Hoxton Park, Ingleburn, Narellan, Campbelltown, Rosemeadow, Oran Park, Tahmoor and Bowral.

Ensuring integrated care in SWSLHD is a key focus which refers to a smooth and continuous transition between services, experienced by both the service user and the provider. Services are responsive to all of the persons needs where providers are connected and work together as a healthcare neighbourhood. Care is evidence based, person-centred and supported with the use of modern information systems.

Another key area of focus includes providing services in the home. In NSW, Hospital in the Home is defined as a range of service delivery models providing (acute and post-acute) care that is delivered in home (including residential aged care facilities), clinic or other settings as a substitution or avoidance of hospital. The need for the delivery of acute care in the home as an alternative to care in a hospital setting is being driven by advances in medicine, increased pressure on the healthcare system and evidence of improved health outcomes for patients who spend less time in hospital.

5.2 Targeted Services

SWSLHD medical specialties and services are grouped into “clinical streams” to support healthcare. These streams bring together health professionals with knowledge, skills and expertise in similar health problems or focused on similar populations. Although clinical streams operate across the District, services may not be provided in every hospital or Community Health Centre due to the highly specialised nature of the care and expertise required.



Some clinical streams have a stronger focus on people with disability or carers providing assessment, treatment, case management and/or referral to general practitioners and community services including:

- SWSLHD Mental Health Services;
- SWSLHD Aged Care Services and Rehabilitation Services;
- SWSLHD child focused services such as Paediatrics and Neonatology, Allied Health and Child, Youth and Family services;
- SWSLHD Carers Program which assists SWSLHD staff to recognise the practical needs of carers and respond in a timely and professional manner;
- SWSLHD Brain Injury Service which has six service components including the Inpatient Unit, Community Outreach Services, Head2Work (vocational program), Transitional Living Unit, Community Living Unit (respite and short term accommodation service) and the Spasticity Management Service;
- SWSLHD Palliative Care Service which provides physical, psychological, social and spiritual support for clients and their families and where possible, this care is delivered to clients in their preferred location which may be at home, in hospital, palliative care unit or a residential aged care facility.

Other clinical streams have a broad role, with specialist units, teams and staff who provide healthcare to people with specific disabilities. These staff may have a high level of training or a strong interest in working with people with disabilities and carers.

SWSLHD also funds and works alongside a number of non-government organisations (NGOs) to provide a range of health services for local residents, including people with disability.





6. Consultation and Identified Strategic Issues

The key focus areas highlighted in this Strategy respond to issues identified through NSW Health DIAP, patient journey experiences, consultations with the SWSLHD Consumer and Community networks, carer groups, local agencies and SWSLHD services. Consultations were undertaken in 2016 and 2017. Feedback was also collected through the complaints mechanism, case conferencing and as a result of quality initiatives undertaken.

In order to align the SWSLHD plans with current legislation and relevant health plans, it was decided to:

- Adopt the format of the NSW DIAP and the NSW Carers Strategy i.e. the same focus areas;
- Add localised responses to locally identified issues;
- Ensure that clinical components are included to support safe, quality care.

6.1 Consultation

Opportunities to participate in the consultation process were made available broadly across both internal and external stakeholders of south western Sydney including:

- Consumers across the District;
- CCC;
- Councils that fall within the LGAs of south western Sydney;
- Government agencies including the Department of Family and Community Services (FACS);
- Primary Health Network (PHN);
- NDIS;
- NGOs servicing target groups and contracted services;
- Clinical Directors within SWSLHD;
- General Managers and employees of facilities and services within SWSLHD.

Methodology for gaining feedback included:

- Structured questions delivered via surveys and focus groups;
- Group consultations and individual interviews;
- Patient and carer experience (PACE) interviews;
- Patient complaints and incident reviews;
- Feedback through family and case discussions.

The patient interviews were analysed using PACE processes. It must be acknowledged that there was significant challenge in identifying patients with a disability or who had a designated carer through analysis of the Electronic Medical Record (eMR). To compensate, a broad brush approach was used to capture appropriate participants. Strategies included approaching patients in various clinical areas who were likely to have a disability and offering patients and consumers with the opportunity to be interviewed by staff. The first strategy resulted in a focused review only of patient/carer opinion and the second approach potentially excluded those consumers with a 'silent disability' (i.e. not visible).

The consultation with staff who had a disability or carer responsibilities was also challenging as this information is also not captured in staff records. Surveys were distributed across facilities with staff volunteering to identify and contribute. Very similar themes were identified across both consumers and staff.



6.2 Themes Identified

Consultation revealed mixed feedback. While some patients and their carers reported caring, supportive staff who acknowledged and addressed their individual needs, others had a less positive experience. Similarly, some staff with disabilities or caring responsibilities, reported a supportive workplace with flexibility and workplace accommodation of their needs, others believed that their needs did not appear to be considered or addressed and that there was little flexibility. The findings from the consultations have been integrated and analysed for themes needing to be addressed in order to improve the experience of the patients and staff with a disability and carers accessing our services or working within SWSLHD.

Theme	Subthemes	Examples/Quotes
Access to care	Emotional support	“The best thing was ICU saved my life and rehab gave me life back. They empowered me to do what I could. The nursing staff had confidence in me; this helped me to believe in myself. I had to focus on my progress and do my personal best; this helped me to see the light at the end of tunnel”.
		“When I’m in pain, I think that some of the nurses feel it too. They really do care”.
		“Feel mum is safe in hospital, nurses are around and less worrying for us”.
		“I felt anxious at night because there were less nurses and he (father) felt that staff didn’t treat him well because of his high level of needs - he felt that he was a burden”.
	Coordination and integration of care	“Good services from nurses and doctors and they can cope with your disability - MS. It can be very stressful being in hospital; they worked as well as they could to look after you”.
		“The left hand didn’t know what the right hand was doing”.
		“Monday, the whole team comes around: if you have any questions, everyone is there to answer. I think that it’s good - it keeps you informed”.
		“I gave all the information to Pre-admission Clinic so that my son’s feeds could be all sorted. Nothing was done with this information. It meant that he went 36 hours without food. What is the point of having a Pre-admission Clinic if they don’t do anything with that information?”.
		“I manage a Supported Accommodation Unit. It was a pleasure to see the Admissions to Discharge Program working. All (John’s) information travelled with him. His Top 5 was clearly displayed at each bed and staff read it”.



Theme	Subthemes	Examples/Quotes
Access to care	Appropriate facilities	"I got lost one time as my vision is not good. I think signage could be bigger for vision impaired people".
		"There were no carer facilities on the ward or the hospital - not even somewhere to go to the toilet".
		"There is no room for even a chair by each bed let alone easy access to equipment".
		"The parents lounge is great- I can have a cup of coffee and have a few minutes break when my son is asleep. There should be more facilities for carers".
		"When we need to see the neurologist for my daughter, my husband and I need to take a day off work, the parking is terrible and we need two people to physically go somewhere. These appointments are stressful and tiring. It is like planning to go on a picnic without the picnic enjoyment and relaxation".
	Reasonable adjustments	"Some of our older buildings don't have lifts. This means that you can't apply for jobs there if you can't walk up-stairs".
		"There is a lot of red tape in just getting simple adjustments to your desk. It shouldn't take that long".
		"The TV was so small, Dad couldn't see it. He couldn't hear it through the little speaker either".
		"I couldn't reach or press the Nurses bell and there was no other way to call them".
Involvement of patient, friends and family	"They listened to me as my son's carer; they worked as a team and took family into consideration when caring. We didn't have to sit and wait for too long".	
	"In the gym the physio staff were attentive to my partner's needs, and he felt they took on board his feedback and suggestions, this made him feel valued".	
Respect for patient values and expressed needs	Staff knowledge and skills	"Nobody seemed to know how to deal with a blind person".
		"I didn't know how to talk to someone who couldn't talk back. We need to know the client's needs but really it would be best to learn what THAT client needs".
		"No one on the ward knew how to set up the equipment. That resulted in my son not getting fed for 36 hours".



Theme	Subthemes	Examples/Quotes
Information and education	Communication	“Sometimes language can be a barrier, and communication is not always clear”.
		“A challenge has been reaching out for help and navigating the healthcare system. I am a project manager and felt often like I was in a big black hole. I was often given the wrong information and felt like I was going around in circles. Often my mum is passed on with her cancer and this is difficult for continuity of care. I have become my mums secretary. Has been ok as I can take on the role as her carer but for someone on their own this would make their journey even more difficult when they are unwell to navigate the health system”.
		“The nurses encourage my husband to be involved in my care by explaining to him how the machines work. He volunteers with another carer on the ward by making cups of tea for patients and other carers”.
		“Nurses taking the time to come and explain my mum’s care to me”.
		“It is hard to get information about available services and what I need to know when going home with my husband”.
Quality and safety information	Access to data	It is challenging to be able to properly evaluate our care or measure success or satisfaction or track incidents as the data systems don’t identify issues as disability or carers”.





Across the two strategy streams of disability and carers, there are common themes in key areas that need to be addressed and embedded into all operations of the health service. Throughout the consultation, consumers and staff reflected that they wanted to be included in decisions, to be asked for their wants, needs and opinions, to be able to access appropriate information and in an appropriate manner and to be treated with respect and courtesy.

Diagram 1: Key improvements areas identified as a result of consultation.



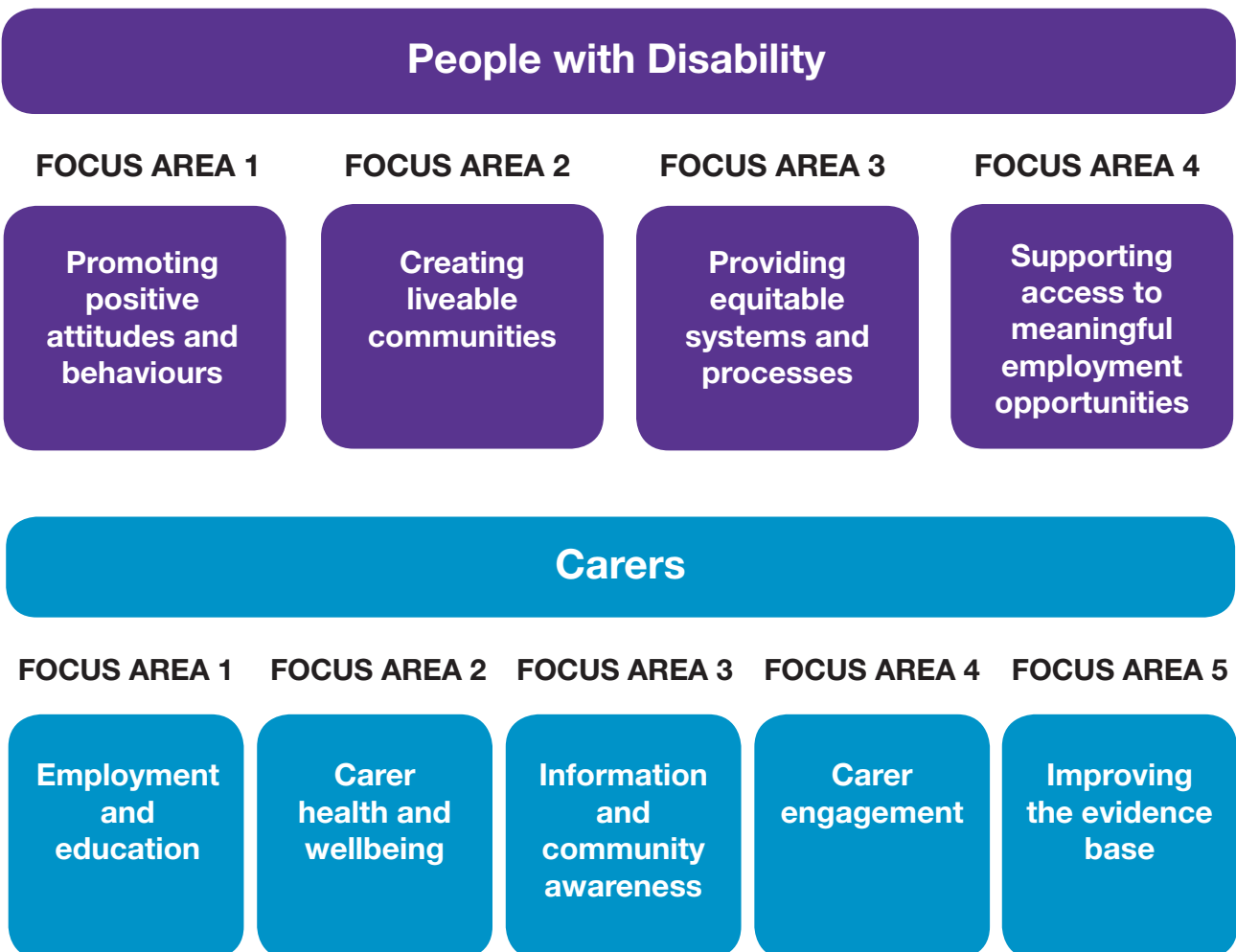


7. Implementation and Measuring Outcomes

The SWSLHD Framework for action for people with disability and carers is represented in Diagram 2. It defines the key areas of work which SWSLHD services will address during the life of this Strategy. It is based on directions in the NSW Health DIAP and NSW Carers Strategy. For people with disability, SWSLHD will address four focus areas and for carers, there are five focus areas. Within each focus area are actions, with timeframe and responsibility allocated.

The SWSLHD Disability and Carers Committee will oversee implementation of this Strategy providing overarching governance. The Committee will also monitor progress, identify emerging issues and escalate issues as necessary. This Committee reports to the SWSLHD Clinical and Quality Committee. Progress will also be discussed within the context of the NSW Health Performance Framework and NSW Health Policy.

Diagram 2: SWSLHD Framework for action for people with disability and carers.





8. Implementation Actions

8.1 People with Disability

FOCUS AREA 1

Promoting positive culture attitudes and behaviours to promote inclusion for people with a disability

Actions		Responsibility	Timeframe	Link to plans	
Strategy 1: Communicate and reflect on the importance of a culture of disability inclusion					
1.1	Promote disability inclusion	a. Opportunities to share learnings and stories from people with disability describing their experience with SWSLHD services.	General Managers, Media & Communications	Ongoing	DIAP 1.1a
		b. Embedding the Don't DIS my ABILITY campaign into focused communications.	Media & Communications	Ongoing	DIAP 1.1b
		c. Acknowledge and celebrate key dates including International Day of People with Disability.	Media & Communications, Facility Disability and Carers Committees	Annually	DIAP 1.1c
1.2	Disability inclusion is a regular item on leadership meeting annual agendas to discuss actions and/or detail progress. Leadership meetings are to include, but are not limited to: <ul style="list-style-type: none"> • SWSLHD & Ministry of Health • Performance Review Meeting • SWSLHD Board Meeting • SWSLHD Clinical & Quality Council • Facility & Service Clinical Councils • TYE Implementation Groups 	All leadership teams	December 2017	DIAP 1.2	



Actions	Responsibility	Timeframe	Link to plans	
Strategy 2: Review, amend and develop training resources to build disability confidence in our staff				
2.1	SWSLHD materials to: <ul style="list-style-type: none"> • Be reviewed (including existing training courses), amended and developed in partnership with people with disability, their carers and families to build awareness and exposure of staff to the experience of people with disability. • Focus on the critical importance of person-centred service delivery rather than specific disability types, to acknowledge the diversity of the experience of people with disability. 	Director Centre for Education and Workforce Development (CEWD)	March 2018 thereafter annually	DIAP 2.1
2.2	Capture and monitor training compliance for disability focused training modules.	Director CEWD	December 2017 thereafter annually	
2.3	Embed TYE expectations in all care provided for people with a disability.	TYE Coordinator General Managers	Ongoing	
2.4	Promote identification and documentation of all disabilities and need for adjustments in care, services and equipment.	All clinical leads	Ongoing	
2.5	Provide education at each facility on alternative communication strategies and working with Australian Sign Language (AUSLAN) interpreters.	Speech Pathology and Occupational Therapy Managers	Ongoing	
2.6	Ensure that principles and actions in the Disability and Carers Strategy are reflected in other LHD plans and frameworks including the future 'Equity Framework'.	Director Planning	Ongoing	





FOCUS AREA 2

Creating liveable communities

Actions		Responsibility	Timeframe	Link to plans
Strategy 3: Embed disability inclusion as a priority in the planning and design of new and refurbished facilities				
3.1	Promote disability inclusion principles through compliance with the Australasian Health Facilities Guidelines Part C: Design for Access, Mobility, Work Health & Safety and Security.	Manager Capital Works	Ongoing	DIAP 3.1
3.2	The principles of disability inclusion to be embedded within the design and functional brief for all capital projects (less than \$10m), including the critical importance of consulting with stakeholders from commencement of the planning and design process as relevant including: <ul style="list-style-type: none"> • People with disability, their carers and families; • Local Council; • Transport for NSW; • NSW Infrastructure and Planning. 	Manager Capital Works	Ongoing	DIAP 3.2
3.3	Audit SWSLHD facilities in respect to disability access and investigate options to improve disability access for existing workspaces.	Manager Capital Works	Ongoing	DIAP 3.1
3.4	Ensure clinical areas have sufficient space for easy and safe access of mobility equipment, carer facilities and 'reasonable adaptations'.	All clinical leads	Ongoing	
Strategy 4: Elevate the voices of people with disability, their carers and families in facility design and planning processes				
4.1	Review and address the SWSLHD Infrastructure Post Occupancy Evaluation results relating to user respondents with a disability and their carers.	Director Operations (Manager Capital Works)	Ongoing	DIAP 4.1
4.2	Consult with people with a disability and carers via the CCC on planning, policy and resource development.	All leadership Teams Planning	Ongoing	DIAP 4.1



Actions	Responsibility	Timeframe	Link to plans	
Strategy 5: Identify and address key shortfalls in facility design identified by people with disability				
5.1	Improve wayfinding within facilities and services by: <ul style="list-style-type: none"> • Promoting the Wayfinding for Healthcare Facilities Guideline as a resource for designers and planners in master planning; • Ensure facilities and services are aware of and action where possible the Wayfinding for Healthcare Facilities Guideline; • Include representation from people with disability, their carers and families in facility planning to identify opportunities for improvements in wayfinding. 	Director Operations (Manager Capital Works)	Ongoing	DIAP 5.1
5.2	Changing Places* and disability accessible toilets are to be considered in all new and refurbished healthcare facility functional briefs.	Director Operations (Manager Capital Works)	Ongoing	DIAP 5.2
5.3	Review facility Transport Access Guides to include information for people with disability.	Facility Disability and Carers Committees	December 2018	
5.4	Inform and work with local councils to address problems with paths and streets adjacent to SWSLHD facilities and leading to nearest transport links.	Facility Disability and Carers Committees/ Directors Corporate Services	Ongoing	

*Note from the NSW DIAP: the intent of a Changing Places toilet is to provide a purpose-built environment where carers can attend to the personal needs of those in their care. It is likely that only one or two rooms would routinely be provided for each hospital campus however, this decision will be site specific (e.g. after-hours access, hospital size etc.). Changing Places toilets are different from disability accessible toilets and will routinely include a height adjustable changing bench and a ceiling mounted hoist.



“It is hard for staff to understand that a hospital is a frightening place for my son. You are all comfortable being here. He is terrified. Even getting his tooth fixed is a major event in our family’s life” Carer



FOCUS AREA 3
Providing equitable systems and processes

Actions		Responsibility	Timeframe	Link to plans
Strategy 6: Provide support to consistently improve disability inclusion and extend existing good practice in delivering person-centred care to people with disability across the system				
6.1	Utilise the suite of resources to be developed by the Integrated Care Branch, Ministry of Health (MoH) to support disability inclusion across policy and service delivery settings. The resources will reflect the commitments of the DIAP and the legislative principles which underpin it, and establish clear expectations with regard to strategic focus, implementation and performance reporting.	Director Allied Health, SWSLHD	Ongoing	DIAP 6.1
6.2	Promote a person-centred service delivery model of care. This will be supported by a range of programs that support coordinated care including Essentials of Care, TOP 5 program**, In Safe Hands program***, Patient Reported Measures, REACH, 7 Safety Essentials and the TYE Strategy.	Director Allied Health, SWSLHD	Ongoing	DIAP 6.2
6.3	Implement MoH Policy Directive: Disability – People with a Disability: Responding to Needs During Hospitalisation.	Director Allied Health, SWSLHD	Ongoing	
6.4	Ensure that disability and carer considerations and needs are included in clinical handover and admission/discharge planning.	Director Nursing and Midwifery and Allied Health	Ongoing	DIAP 6.2
6.5	Develop and implement an alert in the eMR to flag patients with a disability.	Information Management & Technology Department (IM&DT)	December 2017	
6.6	Ensure availability of alternate call facilities for inpatients unable to utilise the nurse call buttons.	Facility Disability and Carers Committees	April 2018 and Ongoing	
6.7	Implement ‘the Essentials’ via the ‘self-assessment process’ to continue to improve the hospital experience and pathways to care for people with intellectual disability.	District and Facility Disability and Carers Committees	March 2018	DIAP 6.2



Actions	Responsibility	Timeframe	Link to plans	
Strategy 7: Service delivery organisations will engage meaningfully with people with disability, their carers and families and relevant key partner agencies				
7.1	Implement MoH guidelines for community engagement with people with disability, their carers and families. The guidelines are to: <ul style="list-style-type: none"> • Reflect NSW Health's Consumer and Community Engagement Framework. • Reflect the SWSLHD Consumer and Community Participation Framework; • Promote collaboration and integration of services to facilitate seamless pathways through the NSW Health system; • Outline requirements for engaging with local disability NGOs and other partner agencies including FACS, Housing and Accommodation Support Initiative providers, Police and Justice, Aboriginal Medical Services or similar. 	Chief Executive	2018	DIAP 7.1
7.2	Continue to promote and support timely engagement with NDIS and My Aged Care to support consumer access to services.	NDIS Steering Committee, Director Allied Health, Director Aged Care & Rehabilitation	Ongoing	Service Agreement
7.3	Develop and implement monitoring systems to capture and report relevant data regarding Provider activities and NDIS related patient flow issues.	NDIS Steering Committee, Director Allied Health	December 2017	Service Agreement
Strategy 8: Deliver enhanced services and build greater accountability by improving data collection and reporting on disability inclusion				
8.1	Review and address the Bureau of Health Information disability focused annual report of patient perspectives on the care people with disability receive through NSW Health.	Director Clinical Governance, Director Allied Health	Annually	DIAP 8.2
8.2	Investigate and implement mechanisms to identify incidents and complaints that involve persons with a disability or carers.	Director Clinical Governance, Director Allied Health	June 2018	DIAP 8.2



Actions		Responsibility	Timeframe	Link to plans
Strategy 9: Ensure all service users have the same access to information regarding their treatment and care				
9.1	All SWSLHD related websites to comply with W3C Web Content Accessibility Guidelines level 'AA'.	Director IM&TD	Ongoing	DIAP 9.1
9.2	Ensure feedback and complaints mechanisms are accessible to people with disability. This may include a range of formats and alternative avenues.	Director Clinical Governance	Ongoing	DIAP 9.2
9.3	Promote the use of the health resources identified by the DIAP Governance Group.	Director Allied Health, SWSLHD	Ongoing	DIAP 9.3
9.4	Improve pathways to SWSLHD web-based resources, including 'patient rights and responsibilities' information and complaints mechanisms.	IM&TD Media & Communications	July 2018	
9.5	Include disability access to all projects to improve health information across SWSLHD.	Leadership teams, Consumer & Community Councils	Ongoing	
9.6	Develop and promote strategies to improve patient and carer understanding of Australian Charter of Healthcare Rights.	Disability and Carers Committee	July 2018	

**The TOP 5 program is aimed at patients identified with a cognitive or other disability that impacts their ability to communicate and advocate on their own behalf. It is a simple process that encourages health professionals to engage with carers to gain valuable non-clinical information to help personalise care. Where this document refers to TOP 5, similar initiatives may be substituted to achieve the same outcome, for example Communication Care Cues.

***The In Safe Hands program provides a platform for building and sustaining efficient and effective healthcare teams within a complex healthcare environment. It enables teams to address daily challenges of patient care and empowers them to make good decisions based on understanding the full scope of a patient's care. All members of a healthcare team are then better placed to solve problems as they arise.



FOCUS AREA 4

Supporting access to meaningful employment opportunities

Actions		Responsibility	Timeframe	Link to plans
Strategy 10: Review recruitment practices to support inclusion and increased employment of people with disability, and support employees with disability to advance their careers				
10.1	Promote the requirements of the existing recruitment policy that outlines recruitment practices that support the employment of people with disability through targeted communications with convenors and recruitment panels.	Director Workforce	Annually	DIAP 10.1
10.2	Commence implementation of the training program developed by Health Education and Training Institute (HETI) to: <ul style="list-style-type: none"> • Provide information regarding alternative interview practices suitable for people with disability; • Build capability for all managers to ensure that the needs of people with disability are met in the workplace. 	Director Workforce	May 2018	DIAP 10.2
10.3	Support and foster mentoring partnerships for employees with disability, including support for career advancement.	Director Workforce	Ongoing	DIAP 10.3
10.4	Implement new developments in corporate software systems to address the access needs of people with disability who are part of the health workforce.	Director Workforce/ Director IM&TD	Ongoing	DIAP 10.4
10.5	Conduct formal workplace assessments for new employees with a disability and existing staff with an acquired disability to ensure 'reasonable adjustments' of the workplace, role and equipment to support the successful employment of staff with a disability.	Director Operations (Manager Capital Works)	Ongoing	DIAP 10.4
10.6	Ensure that work requirements and selection criteria reflect true requirements of position descriptions.	Director Workforce	Ongoing	DIAP 10.1
10.7	Partner with disability employment agencies to develop and implement strategies to increase employment opportunities for people with a disability.	Director Workforce	July 2018	DIAP 10.1
10.8	Include information about employment and people with a disability on the SWSLHD website.	Director Workforce, Media & Communications	July 2018	DIAP 10.1



8.2 Carers

FOCUS AREA 1

Employment and education

Actions		Responsibility	Timeframe	Link to plans
Strategy 1: Use of existing workplace flexibility by carers and their employers and enable carers to recognise the skills and expertise they bring to employment and training				
1.1	Redevelop the 'managers guide to supporting working carers' and circulate to SWSLHD managers. Information to be housed on the 'Managers Help Centre' portal.	Director Workforce/ Carers Program	April 2018	Carers Strategy 1.1
1.2	Work in partnership with Human Resources to develop information for new staff on 'Carer Awareness' and include in the facility orientation information package.	Director Workforce/ Director Allied Health	April 2019	Carers Strategy 1.2

FOCUS AREA 2

Carer health and wellbeing

Actions		Responsibility	Timeframe	Link to plans
Strategy 2: Carers experience good health and wellbeing				
2.1	Increase awareness about the supports and services available to carers via the distribution of the 'Information for Carers' booklet and promotion of the 'Carer Support Group Database' and Carers Program website.	Carers Program	Ongoing	Carers Strategy 2.1 & 2.3
2.2	Partner with organisations such as Western Sydney Migrant Resource Centre, One Door Carer Mental Health Services, PHN and various other carer networks to facilitate initiatives that aim to improve knowledge, understanding and practical ways to wellbeing for carers.	Carers Program	Ongoing	Carers Strategy 2.1
2.3	Develop and implement mental health lifestyle programs for mental health carers and consumers that aim to address key areas such as nutrition, exercise, smoking, drug and alcohol use, immunisation and screening.	Director of Nursing, Mental Health	Ongoing	SWSLHD Mental Health Strategic Plan 6..3



FOCUS AREA 3
Information and community awareness

Actions		Responsibility	Timeframe	Link to plans
Strategy 3: Embed and improve information for carers in the trusted systems they frequently use and carers feel the broader community understands their experience				
3.1	Redevelop Carer and Family boards with up-to-date information in English and top five languages in each facility.	Carers Program	December 2017	Carers Strategy 3.2
3.2	Redevelop the 'Carer Services Directory' for Aboriginal and Torres Strait Islander carers in partnership with Aboriginal Health.	Carers Program/ Aboriginal Health	June 2018	Carers Strategy 3.4
3.3	Mental Health: support consumers, carers and staff to increase knowledge and skills related to recovery.	Director, Mental Health	Ongoing	SWSLHD Mental Health Strategic Plan 3.2
3.4	Develop 'Mental Health Carer Information Kit' in partnership with District Mental Health Services.	Carers Program & Mental Health	June 2018	Carers Strategy 3.2
3.5	Participate in key events that raise awareness and understanding of carers, such as Carers Week, Multicultural Health Week, Seniors Week, Mental Health Month and International Day of People with Disability.	Carers Program	Ongoing	Carers Strategy 3.1
3.6	Promote key information and messages relating to carers in media like District News, Carers Program Newsletter and District Bulletin Board.	Carers Program	Ongoing	Carers Strategy 3.1
3.7	Mental Health: develop staff capacity to provide culturally appropriate care to Aboriginal and Torres Strait Islander consumers and carers building on Respecting the Difference.	Director, Mental Health	December 2018	



FOCUS AREA 4

Carer engagement

Actions		Responsibility	Timeframe	Link to plans
Strategy 4: Continue to improve the ways we involve carers as partners in care delivered to their loved ones				
4.1	Promote and encourage staff to complete the HETI online training, 'Partnering with Carers' and 'Let's Talk Disability'.	Carers Program	Ongoing	Carers Strategy 4.1
4.2	Take-part in the implementation of TYE initiatives across the District to continue to improve delivery and quality of individualised patient and carer services.	Carers Program	Ongoing	Carers Strategy 4.1
4.3	Engage with existing committees such as CCC and Mental Health Consumer, Carer and Community Council to gain greater involvement of carers in local decisions about the design and delivery of services.	Carers Program	Ongoing	Carers Strategy 4.3
4.4	Carry out an audit of existing equipment and facilities to cater for carers staying overnight, and make recommendations to improve availability and access in each facility.	Carers Program	June 2018	DIAP 3.1
4.5	Mental Health: support each consumer to develop an individual, recovery-focussed plan which is developed in collaboration with families/carers and other support services as required.	Mental Health	Ongoing	



FOCUS AREA 5
Improving the evidence base

Actions		Responsibility	Timeframe	Link to plans
Strategy 5: Carers policy and practice is informed by quality evidence				
5.1	Utilise existing data and research about carers from sources such as the Carers NSW survey, ABS and Department of Social Services to shape the development and delivery of programs, services and resources for carers.	Carers Program	Ongoing	Carers Strategy 5.1
5.2	Continue to conduct regular consultation with carers, staff and key stakeholders across the District to identify gaps, issues and opportunities for improvements for carers.	Carers Program	Ongoing	Carers Strategy 5.1



“As a carer, one of the biggest struggles is trying to navigate the system in order to access the assistance that does exist. All too often though, the assistance is just not there to access”

“I really value when the carer can stay and help; it makes it so much easier to understand what the patient needs and what I can do to make him feel better. They are the expert in their loved one’s care” Staff member feedback



9. Acronyms

ABS	Australian Bureau of Statistics
CCC	Consumer and Community Council
CALD	Culturally and Linguistically Diverse
CEWD	Centre for Workforce Development
CORE	Collaboration, Openness, Respect and Empowerment
DIAP	Disability Inclusion Action Plan
eMR	Electronic Medical Record
FACS	Family and Community Services
HETI	Health Education Training Institute
IM&TD	Information Management & Technology Department
LGA	Local Government Area
LHD	Local Health District
MoH	Ministry of Health
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
NGO	Non-Government Organisation
NSW	New South Wales
PACE	Patient and Carer Experience
PHN	Primary Health Network
STARTTS	Service for the Treatment and Rehabilitation of Torture and Trauma Survivors
SWSLHD	South Western Sydney Local Health District
TYE	Transforming Your Experience



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Carers Program

The Carers Program works closely with SWSLHD staff to improve the responsiveness of the needs of carers and to recognise and empower carers in their role as valued members of the healthcare system. The role of the Carers Program is to:

- Assist health staff to recognise the practical needs of carers and respond in a professional and timely manner.
- Educate health staff about their legal obligations to support carers.
- Promote carer participation in the planning, design and delivery of services and resources.
- Provide information and resources for health staff and carers on a range of topics to improve knowledge and promote carer wellbeing.

Work carried out by the Carers Program is aligned with the Carer (Recognition) Act 2010 and NSW Carers Strategy 2014-2019.

Information for Carers Booklet

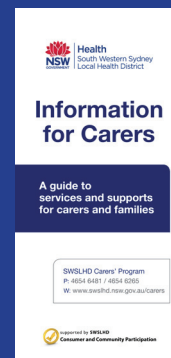
A practical guide that provides information about services and support for carers and families.

To download a copy visit:

www.swslhd.health.nsw.gov.au/carers

To request hardcopies phone:

4654 6265



More information for carers and staff can be found on the Carers Program website:
www.swslhd.health.nsw.gov.au/carers.





Health
South Western Sydney
Local Health District



supported by **SWSLHD**
Consumer and Community Participation

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