SA Health

SA Intellectual Disability Health Service

Model of Care

2020

Government of South Australia

SA Health

Acknowledgments

This Model of Care is the result of extensive consultation and collaboration with stakeholders from across South Australia. The System Design and Planning Branch within the Department for Health and Wellbeing would like to thank the many people who have contributed to the development of this Model of Care including the families and carers who generously gave their time and told their stories, the members of the Project Board for leading the work and the members of the Expert Advisory Group and others throughout our health system who gave their time and shared their knowledge and experiences. The willingness and enthusiasm of stakeholders to work together has made a complex piece of work both a pleasure and a privilege.

Traditional owners

We acknowledge Aboriginal people as the first Australians, traditional owners of South Australia, and we respect their ongoing living and spiritual relationship with the land and sea. We respect and celebrate the many Aboriginal peoples and lands across the state of South Australia.

A note on language

Throughout this document people with intellectual disability are also referred to as patients or clients. Persons, including family, who provide unpaid support and care to people with intellectual disability are referred to as carers and those who provide paid care and support to people with intellectual disability are collectively referred to as paid workers.

In addition, the term 'mainstream health services' has been used throughout this document to refer to those health services that are available to the general public and are not specialised centres of skill or knowledge relating to a particular group of people or condition. This includes primary practice, public and private hospitals, emergency and community health services and clinicians working in private practice.

Name of the specialised service

The current name of the specialised service, the Centre for Disability Health (CDH), does not describe the role and scope of the service as well as it could. For this reason, a new name is proposed for the service in this model of care.

Throughout the earlier part of this document when referring to the current state, the specialised service is referred to as the Centre for Disability Health (CDH). When referring to the recommended future state, the service is referred to by its proposed future name, the SA Intellectual Disability Health Service (SAIDHS).

Version Control

Version	Amendment	By Whom	Date
V0.1	First Draft for consultation	Stakeholders	8/5/2020
V0.2	Approved Final Draft	Project Board	18/6/2020
V1.0	Approved Model of Care	Strategic Planning, Investment and Infrastructure Committee	28/7/2020

Table of contents

1. Executive summary....4
2. Overview....6

PART A: CURRENT STATE ANALYSIS....7
3. Background....8
4. Intellectual disability and health....9
5 The current situation....12
6 Opportunities....17
7 Gaps and challenges....23
8 Summary of recommendations....28

PART B: PROPOSED FUTURE MODEL....30
9. Guiding principles....31
10. Objectives and outcomes....31
11. Enablers....32
12. Overview of tiered service model....33
13. Overview of the specialised services....35
14. Specialised service model of care....39

PART C: IMPLEMENTATION AND MONITORING....45
15. Implementation....46
16. Monitoring and evaluation....46
17. Appendices....46
18. Bibliography....50

Acronyms

NSW ACI	New South Wales Agency for Clinical Innovation
ACRPC	Aged Care, Rehabilitation and Palliative Care
ANZCA	Australian and New Zealand College of Anaesthetists
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CALHN	Central Adelaide Local Health Network
CAMHS	Child and Adolescent Mental Health Service
CDH	Centre for Disability Health
CEIH	Commission on Excellence and Innovation in Health
CHAP	Comprehensive Health Assessment Program
CN	Clinical Nurse
DAIP	Disability Access and Inclusion Plan
DHS	Department for Human Services
DHW	Department for Health and Wellbeing
ENU	Exceptional Needs Unit
FAQ	Frequently Asked Questions
FTE	Full Time Equivalent
GP	General Practitioner
HEI	Health Education Interface
HMR/RMMR	Home Medicines Review/Residential Medication Management Review
IDSC	Intellectual disability Services Council
ISG	Information Sharing Guidelines
LHD	Local Health District
LHN	Local Health Network
MBS	Medicare Benefits Schedule
NALHN	Northern Adelaide Local Health Network
NDIS/NDIA	National Disability Insurance Scheme/National Disability Insurance Agency
NGO	Non-Government Organisation
NQSC	NDIS Quality and Safeguards Commission
PAQ	Pre Appointment Questionnaire
PHN	Primary Health Network
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
RANZCGP	Royal Australia and New Zealand College of General Practitioners
RANZCP	Royal Australia and New Zealand College of Psychiatrists
SAAS	South Australian Ambulance Service
SACAT	South Australian Civil and Administrative Tribunal
SAIDHS	SA Intellectual Disability Health Service
SALHN	Southern Adelaide Local Health Network
SAMET	South Australian Medical Education and Training
WCHN	Women's and Children's Hospital Local Health Network

1. Executive summary

This document outlines a recommended Model of Care for delivery of health services for people with intellectual disability and complex health needs or behaviours in South Australia. This work is vitally important in protecting, supporting and upholding the rights of this vulnerable population of health consumers. The South Australian Intellectual Disability Health Service (SAIDHS), previously known as the Centre for Disability Health (CDH), will play a key role in not only providing these services but also in clinical leadership and building the capacity of mainstream health services to care for people with intellectual disability state-wide.

CDH is a specialised health service that was established in 2005 to provide health services for people with intellectual disability transitioning out of institutional care into the community. The service was transferred to SA Health from the Department for Human Services in 2017 due to the National Disability Insurance Scheme (NDIS) reforms.

A 2018 independent review of CDH made three recommendations:

1. Retention of a medical/health service for adults with intellectual disability and complex health needs or presentations
2. Development of a new, contemporary service model for the client group
3. Transition to a new agreed service model

In January 2019, the Northern Area Local Health Network (NALHN) approached the Department for Health and Wellbeing (DHW) seeking to collaborate on the implementation of the recommendations in the report that have a state-wide impact. DHW was supportive of all recommendations in the report and agreed to work in partnership with NALHN to deliver on the recommendations.

A project to deliver a new state-wide model of care was commenced in April 2019. While the new model of care was being developed, CDH has continued to operate under an interim service model.

The intended clinical benefits of the new model of care are:

- Access to appropriate and timely care and advice at the right time leading to better health outcomes for people with intellectual disability
- Increased equity of access to appropriate care across South Australia irrespective of postcode
- An appropriately skilled and resourced workforce able to deliver a high standard of care
- Improved service integration and navigation
- Greater service sustainability.

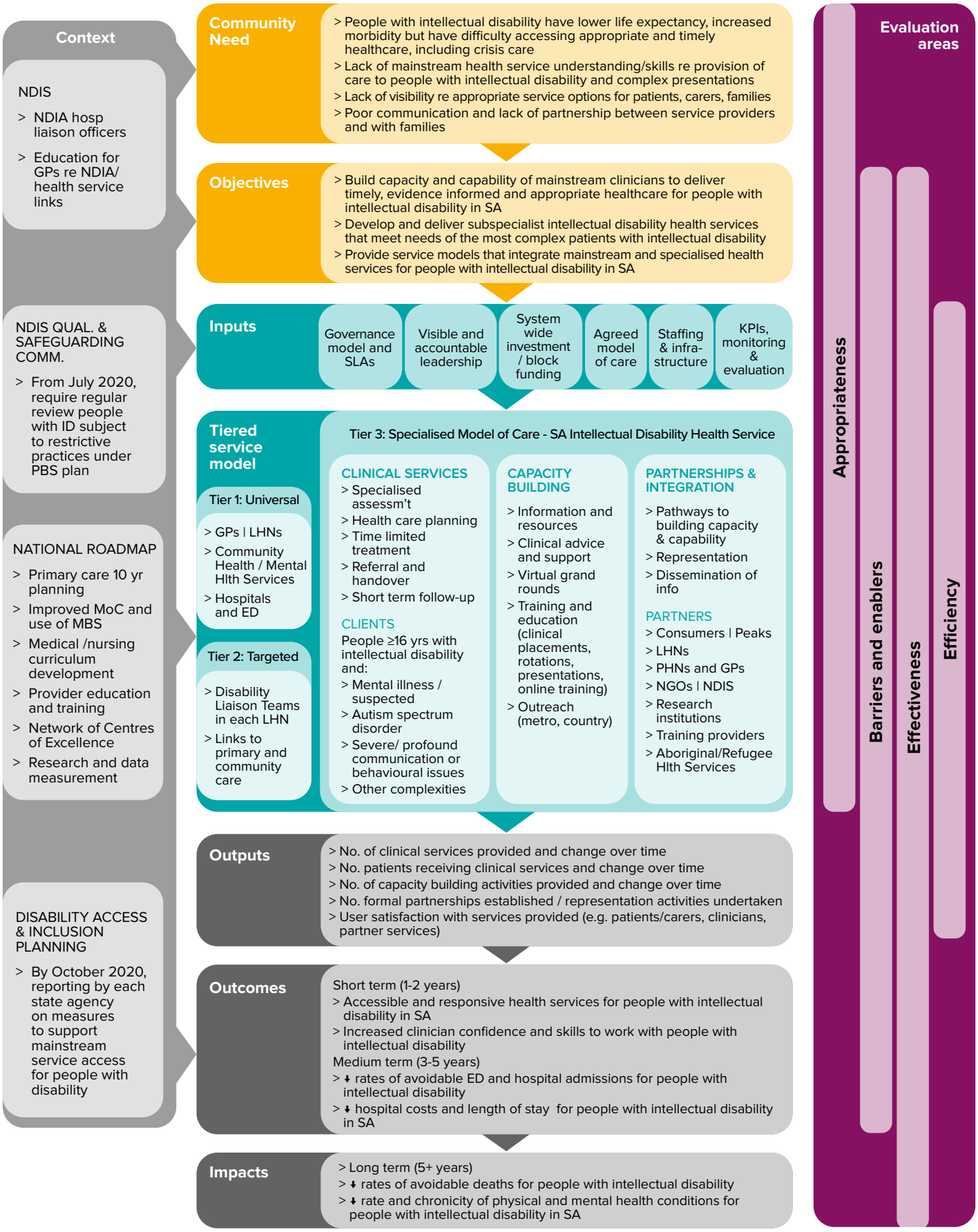
Throughout the process of building this model it has become evident that there is a system wide lack of expertise in and ability to 'think disability' across our health system. This presents a range of barriers to appropriate and timely health care for people with intellectual disability.

History has taught us that having separate disability health services has the potential to be counterproductive as mainstream services divest themselves of this responsibility and subsequently deskill in this area. As a result, there is an urgent need to build the capacity and capability of the existing mainstream health system to be able to meet the needs of people with intellectual disability and complex health needs or behaviours.

People with intellectual disability have a right to access inclusive mainstream services that meet their additional needs, as enshrined in the *SA Disability Inclusion Act 2018* and upheld by the South Australian Disability Inclusion Plan, Inclusive SA 2019-2023, the Statewide Mental Health Services Plan 2020-2025 and the SA Health Equity of Access to Health Care Policy Directive.

Many supportive policies and practices already exist in our system such as Disability Access and Inclusion Plans (DAIPs) and the establishment of disability and complex care teams and roles in some hospitals. However, more work is needed to connect these things in the minds of clinicians and consumers and to develop and improve our accountability in relation to care provision for people with intellectual disability. This model of care aims to do this and describes what should be in place to support the health of people with intellectual disability and complex health needs or behaviours in South Australia.

Figure 1. below presents a broad overview of the components of the proposed Model of care.



2. Overview

2.1 Purpose of this document

This document outlines a recommended Model of Care for the delivery of health services for people with intellectual disability in South Australia. In particular, this document describes how the SA Intellectual Disability Health Service (SAIDHS), previously known as the Centre for Disability Health (CDH), will provide clinical leadership in intellectual disability health and how it will partner with and build the capacity of mainstream health services in South Australia to deliver integrated, evidence based, person centred health care to people with intellectual disability and complex health needs and behaviours state-wide.

2.2 Drivers

This Model of Care has been developed in response to a need for more accessible health services for people with intellectual disability in South Australia and in response to the following drivers:

> When compared to the general population, persons with an intellectual disability have lower life expectancy, higher morbidity, greater chronicity and more difficulty finding and obtaining appropriate healthcare.

> This difficulty accessing timely and appropriate care is particularly acute where people with intellectual disability have complex health needs or behaviours (including co-existing mental health conditions).

> Due to a skills deficit in the health care system, health services are often not inclusive of neurological and developmental diversity and as such are not always able to effectively meet the needs of people with intellectual disability.

2.3 Document structure

To support the reader to engage with this content, a summary of how this document is sequenced is provided below:

Section	Content
Overview (this section)	Provides a general summary of purpose, aim, objectives and target audience
PART A: CURRENT STATE	
Background	Explains why this piece of work has been undertaken
Intellectual disability and health	Provides an overview of the health status of people with an intellectual disability and outlines existing health services provision for people with intellectual disability
Current situation	Outlines the current state of play and the landscape within which the new model will operate
Opportunities, gaps and challenges	Presents a number of opportunities for the new model as well as a number of challenges and gaps that will need to be addressed in the new model.
Recommendations	Summary of recommendations to address opportunities, gaps and challenges
PART B: PROPOSED FUTURE MODEL	
Principles, objectives and enablers	Outlines the agreed principles underpinning the new service model, and the objectives, planned outcomes and enablers of successful delivery
Overview of tiered model	Provides an overview of the tiered approach for service delivery for people with intellectual disability, with tiers reflecting differing levels of need from universal to targeted to specialised services
Specialised service model of care	Provides an overview of the specialised service model and structure, followed by a more detailed description of the model of care including clinical service delivery, capacity building and partnership development
Implementation	Provides a high level outline of first steps in implementing the new model of care
Monitoring and evaluation	Outlines the need for key performance indicators to be established as part of a monitoring and evaluation framework
APPENDICES AND BIBLIOGRAPHY	

2.4 Target audience

This document provides information for decision makers regarding a proposed future model of care for the delivery of health services for people with intellectual disability and complex health needs or behaviours in South Australia. Once endorsed this document will inform all SA Health clinicians, managers and leaders involved or responsible for the delivery of health services to people with intellectual disability. In addition, this document will provide useful guidance to people and organisations outside of SA Health who are involved in or provide healthcare for people with Intellectual disability.

PART A: CURRENT STATE ANALYSIS

This section of the document provides an analysis of the current state regarding access to and delivery of health services for people with intellectual disability and complex health needs in South Australia. Recommendations relevant to identified opportunities, gaps and challenges are also provided, with suggested agency responsibility for progression of these included in the summary table at the end of this section.

3. Background

CDH is a specialised health service that was established in 2005 to provide health services to people with intellectual disability transitioning out of institutional care into the community. The service was set up by Intellectual Disability Services Council (IDSC) and Adelaide North East Division of General Practice and managed under the auspices of the Department for Communities and Social Inclusion (now Department for Human Services (DHS). The primary focus of the service when first established was provision of the following services for people with intellectual disability:

- Delivery of clinical services (both physical and mental health)
- Provision of education and training for students (with links to education providers)
- Research (with links to research institutions)

The state-wide service was initially available in three locations: Strathmont Centre at Oakden, Modbury Hospital at Modbury and Highgate Park at Fullarton. By 2008 the service was also seeing people with physical disabilities, acquired brain injury and progressive neurological disease due to changing arrangements for care which had combined accommodation, health service and disability support. Services were provided for children, adolescents and adults, and care was ongoing.

The service was transitioned from DHS to the Department for Health and Wellbeing (DHW) in December 2017 as a result of the National Disability Insurance Scheme (NDIS) reforms and so that the service was preserved given its expertise and its importance in providing specialised health care for an underserved population.

Local governance of the service is currently provided by the Northern Adelaide Local Health Network (NALHN) under the Aged Care, Rehabilitation and Palliative Care (ACRPC) Division. At the time of transition to SA Health, the service was significantly reduced with the only remaining service location at Modbury Hospital. On transition a decision was made to separate paediatric and adult services, with paediatric positions being relocated back to the Women's and Children's Health Network. In addition, at the time of transition, there were no remaining links to education, training or research providers.

In 2018 NALHN contracted ZED Management Consulting to undertake an independent review of the CDH and provide recommendations and advice regarding its future role and model of care. NALHN sought to further understand the population group, the scope and demand for services, best practice models of care and pathways for people with disability that support access to mainstream or specialist services such as CDH.

The final report of the review of CDH was completed in October 2018 and found that the ability of the CDH to achieve its originating purpose had been significantly diluted by funding reductions and a lack of a clear service framework and model. The report emphasised the importance of a specialised service in supporting people with intellectual disability and complex health needs or behaviours, and outlined ten recommendations all of which were supported by NALHN. The recommendations fell under three broad categories.

- Retention of a medical/health service for adults with intellectual disability and complex health needs or presentations, and development of an interim service model and approach
- Development of a new, contemporary service model for the client group
- Transition to a new agreed service model.

In January 2019 NALHN approached DHW seeking to collaborate on the implementation of the recommendations in the report that have a state-wide impact. DHW was supportive of all of the recommendations in the report and agreed to work in partnership with NALHN to deliver on the recommendations.

A project to deliver on the recommendations was commenced in April 2019. While the new model of care was being developed, CDH has continued to operate under an interim service model.

4. Intellectual disability and health

4.1 Intellectual disability

Intellectual disability is a lifelong condition that originates between birth and age 18 that affects a person's ability to learn, communicate, retain information and undertake everyday activities. An intellectual disability can be caused by genetic conditions such as down syndrome or fragile x syndrome, problems during pregnancy and birth such as pre-eclampsia, hypoxia or prematurity, illness such as Rubella or environmental factors such as foetal alcohol spectrum disorder and is often but not always diagnosed in those with Autism Spectrum Disorder[1].

Depending on the severity of the intellectual disability there is a need for increasing levels of support and assistance from other people to carry out activities of daily life such as personal care, transport, shopping, decision making and accessing health care.

When intellectual disability co-occurs with other issues such as mental illness, multiple health conditions, communication difficulties or challenging behaviours or where there are complex situational factors such as lack of support, family/carer stress, involvement in criminal justice or the forensic system and multiagency involvement in care, individuals are said to have complex needs. Significant numbers of people with intellectual disability will experience complex needs at some time in their lives[2].

An important conceptual shift however is that it is not the person that is complex but the system. People are often classified as complex as they 'challenge the service system's capacity to respond to their support needs due to its structure, inability to integrate across agencies, resourcing or because of difficulties that the individual and service providers have in communicating with one another[3].

4.2 Health Status

Evidence shows that in comparison with the general population, people with intellectual disability have significantly poorer physical and mental health outcomes and greater difficulty obtaining health services[4] experiencing:

- Over twice the rate of avoidable deaths
- Twice the rates of emergency department and hospital admissions
- Hospital admissions costing twice as much
- Higher rates of physical health conditions
- Higher rates of mental health conditions[5]
- Poorer oral health

1 Achieve Australia, 2019 What is Intellectual Disability, available at: https://achieveaustralia.org.au/ndis-overview-and-faqs/intellectual-disability/
2 Australasian Society for Intellectual Disability 2019, Position Statement, Intellectual Disability and Complex Support Needs, available at: https://www.asid.asn.au/files/2459_final_asid_position_statement_id_and_complex_needs.pdf
3 NSW Family and Community Services, Ageing Disability and Home Care, Leading Clinical Practice and Supporting Individuals with Complex Support Needs in an NDIS Environment (2014) available at: https://engage.dss.gov.au/wp-content/uploads/2015/05/ATT-1-Leading-Clinical-Practice-and-Supporting-Individuals-with-Comp.pdf
4 NSW Health, 2012 Service Framework to improve the Health Care of People with Intellectual Disability, available at: https://www.health.nsw.gov.au/disability/Pages/health-care-of-people-with-ID.aspx
5 NSW Council for Intellectual Disability, 2019 The Health of People with Intellectual Disability, Budget and Federal Election 2019, Commitments sought from Australian Political Parties, available at: https://cid.org.au/wp-content/uploads/2019/06/Intellectual_disability_health_bid_200219.pdf

The data highlights a range of reasons for these poorer health outcomes including lower rates of primary and preventative health care, under diagnosis of chronic health conditions and lack of management of risk factors[6]. Perhaps of greatest impact is that the mainstream health system presents a range of barriers to people with intellectual disability including:

- Barriers to communication and understanding
- Poor knowledge of intellectual disability health needs
- Perceived negative attitudes to disability among health professionals
- Failure to identify health issues as distinct from disability issues (diagnostic overshadowing)
- Physical inaccessibility, time constraints, lack of knowledge and unhelpful attitudes[7]

This means that for many people with intellectual disability, healthcare regularly falls below an acceptable standard and significant long term distress, pain and suffering can result for both patients and carers. In addition, due to historical arrangements for the delivery of specialised health services for people with Intellectual disability outside of the health system, there may remain a perception amongst mainstream clinicians that there are 'special services' that address the health needs of this group and by inference that this is not the purview of the mainstream health system.

4.3 Health services for people with intellectual disability

There is limited evidence on the optimal organisation of healthcare services for persons with an intellectual disability[8]. A recent literature review undertaken by the University of New South Wales Social Policy Research Centre into current models of health service delivery for people with intellectual disability found that there are many models including those that are centralised, decentralised (hub and spoke), interdisciplinary, multidisciplinary, and those that focus specifically on a particular stage or need i.e. hospitalisation, post school transition, end of life.

The review concluded that whilst there is no clear evidence for an ideal model, services work best when they are flexible and integrated, drawing together aspects of both mainstream and specialist services and highlighting interagency collaboration[9].

The availability of a specialised intellectual disability service that provides advice, assessment, supervision and co-management has been shown to significantly improve the accessibility of mainstream health services for people with intellectual disability and complex health needs or behaviours. It improves the capacity to escalate care through appropriate channels, and provides defined pathways for either advice or referral which are key to integrated care and to delivery of 'right care, right place, and right time'[10].

An appraisal of the costs and benefits of specialised intellectual disability services was conducted by KPMG in NSW in 2009. It was concluded that small specialised intellectual disability health team/s were most likely to deliver the highest net benefit in terms of cost effectively delivering improved health outcomes for people with intellectual disability[11].

A recently developed model of care for specialised intellectual disability health teams in NSW completed in 2019 has successfully received additional ongoing funding to expand and change from 1 paediatric team and 2 adult teams to 6 teams that each take a life course approach (3 existing and 3 new teams located in Local Health Districts (LHDs)). In addition, a new specialised intellectual disability position (senior nursing or allied health) was also funded for each of the nine LHDs without a team. These new roles act as spokes to link patients with the specialised teams and to support capacity building initiatives within the LHDs.

Senior clinicians working in this area in SA have been consulted regarding their views on whether or not the future service should take a life course approach instead of having separate adult and children's services. There is general agreement that while any change to the existing arrangement should be carefully considered, there are likely to be a range of benefits in offering a life course approach for both clinicians and patients including:

- An approach that meets the needs of clients rather than the health system
- Addressing each person's developmental stage (unique to the individual) rather than their chronological age (arbitrary)
- The potential for a more attractive professional career path and working environment
- Potential for greater pooling of skills and resources.

6 Troller, J & Small, J 2017, Health Inequality and People with Intellectual Disability – Research Summary, available at: https://cid.org.au/wp-content/uploads/2019/07/Research-Analysis-Health-Status-of-People-With-Intellectual-Disability.pdf
7 Family and Community Services NSW, 2014 Person-Centered Health Care Assessments and the Development of Health Care Plans Practice Package, available at: http://www.adhc.nsw.gov.au/data/assets/file/0005/301775/1.-PC-Health-Care-Assessments-and-Dev-of-Health-Care-Plans-Practice-package.pdf
8 Balogh R, McMorris CA, Lunsky Y, Ouellette-Kuntz H, Bourne L, Colantonio A, Gonçalves-Bradley DC. Organising healthcare services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 2016, Issue 4. Art. No.: CD007492. DOI: 10.1002/14651858.CD007492.pub2
9 Guintoli, G Newton, B. Fisher, K.R. (2015) Current models of health service delivery for people with intellectual disability – Literature Review, Sydney: Social Policy Research Centre, UNSW Australi
10 The Essentials NSW
11 NSW Health (2009), Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership, KPMG

4.4 The role of carers in health care

"My brother does have a voice and that voice is me!"

The contribution of carers to the health and wellbeing of people with an intellectual disability cannot be overstated and has been amply demonstrated during this work. The detailed and personal knowledge that they hold about the people in their care is a vital asset to the delivery of person centered and safe care. The bonds that carers have with the people that they care for and the challenges that they often face advocating for those in their care can mean that they often bring significant emotion to interactions with the health system. However, carers should never be marginalised on this basis as they are faced with significant day to day challenges. Treating carers with dignity, compassion and respect will support them to meet these challenges and continue to support the people in their care to the best of their ability.

Carers and support workers deliver a significant amount of the healthcare recommendations made by clinicians and as such are key partners in successful healthcare, including providing follow up and maintenance care and seeking further care at points of deterioration or change. As such, carers should be consistently involved in the planning, design and delivery of health services for people with intellectual disability. The importance of carers is enshrined in the *Carers Recognition Act 2005* and SA Health has a range of policies in existence that support compliance with the Act including the SA Health Partnering with Carers Strategic Action Plan 2017-2020.

5. The current situation

5.1 The patient experience

A good measure of the current situation is the lived experience of people using our current health system. In depth interviews were conducted with carers and paid workers in order to understand the current health system in South Australia from the patient/carer perspective and to ensure that the design of solutions addresses any themes and issues identified. The following themes were identified and will support evaluation of the final model:

- Insufficient flexibility in mainstream service delivery options i.e. home visits, telehealth
- Lack of visibility of available, accessible health services and information relevant to the SA context leading to delays in receiving healthcare
- A perceived lack of respect for people's lived experience and a seeming lack of willingness to work in genuine partnership with families and carers resulting in delays to diagnosis and treatment
- Lack of follow up and communication between health professionals leading to gaps in service delivery
- Poor understanding of and unhelpful attitudes towards intellectual disability leading to distrust
- Inability of health professionals to discriminate between health issues and disability issues, leading to delays in appropriate care
- A lack of 'crisis' care options with clinical disputes over whether persons in crisis are displaying 'behavioural' or mental health issues and a subsequent lack of treatment for either
- Lack of consistency in individual clinician's approaches and attitudes, leading to variability in healthcare experience and outcomes for people with intellectual disability.

5.2 Context

Policy and legislation relevant to this model of care

International

United Nations Convention on the rights of persons with Disability – Article 25

National

National Disability Strategy 2010 – 2020

National Mental Health Strategy

National Carer Strategy

National Safety and Quality Health Service Standards

Australian Charter of Healthcare Rights

National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018

Aboriginal and Torres Strait Islander Health Performance Framework 2017

Cultural Competency in health: A guide for policy, partnerships and participation, NHMRC

National Statement on Health Literacy

State

SA Health and Wellbeing Strategy 2020 - 2025

Inclusive SA, State Disability Inclusion Plan 2019 - 2023

SA Health and LHN Disability Access and Inclusion Plans

SA Health Equity of Access to Health Care Policy Directive 2019

SA Health Mental Health Services Plan 2020 - 2025

SA Carers Recognition Act 2005

SA Mental Health Act 2009

Disability Inclusion Act (2018)

SA Health Guidelines for Clinical Services Offering Digital Telehealth Network Consultations

The Information Sharing Guidelines for Promoting Safety and Wellbeing 2013

Information Sharing Guidelines for Promoting Safety and Wellbeing: SA Health ISG Appendix Policy Directive

Child and adolescent Mental Health Service Model of Care

Local Health Network Community Mental Health Services Models of Care

5.1.2 Relevant national and state initiatives

National Disability Insurance Scheme (NDIS)

The development of this model of care has occurred against a backdrop of ongoing NDIS reforms which have introduced additional complexity to an already complex space. A significant impact of the NDIS has been the transition to an individualised funding model, the dismantling of block funded services and the separation of issues that are the remit of the health system and those that are the responsibility of the NDIS. Whilst this makes sense in theory and from a funding perspective, the impact on consumers and healthcare workers is significant and can result in delays and complications relating to treatment and discharge.

At the time of writing there are 6,800 NDIS participants with intellectual disability in South Australia highlighting the need for the future model to articulate implications and opportunities for service delivery.

A number of positive new NDIA initiatives are in progress that will help to support NDIA participants while they are in the health system including NDIA Hospital Liaison Officers as well as a program of education for mainstream health providers such as General Practitioners (GPs) to assist participants with the link between NDIA and mainstream health services.

NDIS Quality and Safeguards Commission – behaviour support and restrictive practices

The National Disability Insurance Scheme, through the activities of the NDIS Quality and Safeguards Commission (NQSC), from July 2020 will regulate and accredit support providers to ensure thorough and regular review of people with intellectual or developmental disability who are subject to restrictive practices by way of reporting and monitoring the use of restrictive practices and the requirement for positive behaviour support plans. This may include the need for a person to have a psychiatric assessment and/or review or an annual health check by their GP.

These rules are in place to safeguard vulnerable people, and protect them against the use of unnecessary and harmful restrictive practices. At present the NDIA is unable to share data regarding how many people in SA are subject to a restrictive practice. Within Disability Accommodation Services alone there are in excess of 120 clients with restrictive practices in place and they are but one provider of accommodation services across the state.

In the absence of access to psychiatric review, people with intellectual disability are at risk of inappropriate treatment, misdiagnosis and chemical restraint, inclusive of polypharmacy and all the risks associated with this. In addition, providers are at risk of being non-compliant with Restrictive Practice and Behaviour Support Rules 2018, which impacts their ability to deliver services to this group. This in turn can lead to adverse outcomes, long hospital stays and placement issues.

Reliable regular psychiatric services need to be accessible for this group, as is their human right. The requirement for annual review of chemical restraint has the potential to be a significant new demand for the specialised service.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

In April 2019 the Commonwealth Government announced the establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This will help to inform Australian governments, institutions and the wider community on how to prevent, and better protect people with disability from experiencing violence, abuse, neglect and exploitation in the future.

In December 2019 a 'Health Care for People with Cognitive Disability Issues Paper' was released in recognition that health is a key area of inquiry for the Royal Commission and that for people with cognitive disability there are often significant barriers to understanding in the healthcare setting that impact on informed consent, treatment options, experiences and outcomes. A Royal Commission interim report is due in October 2020 and a final report will be completed by April 2022. Any recommendations stemming from the Royal Commission will need to be considered by the Department for Health and Wellbeing, all LHNs and all non-government service providers involved in the provision of services to people with a disability.

National Roadmap for improving health services for people with Intellectual disability

In recognition of the poorer health status of people with intellectual disability and in response to the NSW Council on Intellectual disability 'Our Health Counts' Campaign, a national roadmap for improving health services for people with intellectual disability (the Roadmap) is under development by the Commonwealth Department of Health in partnership with the intellectual disability community and other stakeholders. The Roadmap will become an element of the Primary Health Care 10-year plan and will include among other things development of better models of care, better use of existing MBS items, medical and nursing curriculum development, a primary care enhancement program to support GPs, provider education and training, a network of centres of excellence on intellectual disability such as the current CDH, and research and data measurement to support continuing improvement.

Disability access and inclusion planning

South Australia's first Disability Inclusion Plan, Inclusive SA 2019-2023 was released in November 2019 after extensive consultation. The plan supports the *Disability Inclusion Act (2018)* and paves the way for a state-wide approach whereby each state authority including SA Health will be required to develop and report against a Disability Access and Inclusion Plan (DAIP). By October 2020, state authorities will need to show how they will implement measures to ensure that people with disability can access mainstream supports and services that they provide, or that are provided on their behalf. The Department for Human Services (DHS) has developed a Toolkit to support coordinated development of the plans across State and Local Government.

The existence of DAIPs and annual reporting has the potential to provide a very firm foundation for this model of care as they describe deliverable actions, roles and responsibilities. However, DAIPs will only deliver for people with disability if there is clear and visible leadership on these things at both a strategic and operational level both within DHW and in LHNs.

5.3 Current health services for people with intellectual disability

5.1.3 Centre for Disability Health service

The current Centre for Disability Health provides advice, assessment and consultation for adults with intellectual disability and complex health needs or behaviours. The current eligibility criteria are as follows:

Adults with intellectual disability and/or significant developmental disability who have heightened levels of complexity as a result of one or more of the following:

- Mental illness or suspected mental illness
- Autism spectrum disorder
- Severe or profound communication and/or behavioural issues
- Other disabilities or health conditions
- Other complexities or issues which have not been able to be managed in mainstream services.

The CDH does NOT provide the following services:

- emergency or mental health crisis services
- ongoing medical or psychiatric management
- IQ assessments
- case management.

The service includes specialised general practitioner, psychiatry and neurology services supported by specialised nursing staff. CDH aims to support mainstream medical and other health professionals provide health care to persons with intellectual disability and complex health needs or behaviours through provision of specialised advice and assessment, training and education. Plans are developed in liaison with families, current service providers and carers, and short term follow-up is provided by CDH if required. Individuals can be re-referred to the service if their medical or health needs change.

Referrals are accepted from the person's GP, other medical specialist or accommodation service provider. Self- referrals are accepted for people who don't have access to any of these. Services are generally provided at clinics based at the CDH site at Ingle Farm. The service is also able to provide telephone advice, home visits and regional clinics based on patient need, staff availability and service demand.

5.1.4 Current CDH service utilisation

A 4-week snapshot of service utilisation was undertaken in July-August 2019. A report was prepared from this which made a number of findings regarding:

- Reason for and appropriateness of referral to the CDH (based on current eligibility criteria)
- Source of referral to the CDH
- Patient residence by LHN and accommodation type
- Clinician seen and number of occasions of service for each referral to the CDH.

Data sources included:

- service utilisation data collected from referral letters, appointment and attendance records and file notes
- user experience data collected via a hard copy user experience survey at the completion of patient's appointments
- clinical vignettes collected via semi-structured interviews with CDH clinicians.

The report highlighted the following:

- 97% of referrals met the current eligibility criteria
- a majority of referrals were for the psychiatrist (70%) and the top three reasons for referral were patient behaviour change (78%), medication review (95%) or opinion/advice/assessment (89%) (noting that there was often more than one reason for referral)
- a pattern of multiple occasions of service within each episode of care, which has implications for the design of the service delivery model (i.e. many patients will need to be seen more than once in order for a comprehensive assessment and plan to be completed)
- the need for strong partnerships with accommodation service providers and local mental health services
- the need for the service to be more widely promoted and for data to be collected over a longer period to inform actual service demand and support future planning
- the importance of the service as a provider of specialised assessment and advice to support access to and appropriate care from mainstream services
- a high level of satisfaction with the services provided.

5.4 Population and staffing

As of September 2019, there were approximately 6,800 people with an intellectual disability registered with the NDIS in South Australia, with around 4,800 of these aged 18 and over[12]. The final report of the independent review of the CDH conducted in 2018 found that the estimated demand population for specialised services is likely to be between 2,800 and 3,000 people, based on the population of people with intellectual disability in SA aged 18 and over who also have severe/profound communication difficulties. Approximately one third of this population is estimated to reside outside of metropolitan Adelaide[13].

This figure is consistent with estimates used in other population modelling that found that the estimated number of people with intellectual disability needing access to specialised services is thought to be around 0.2% of the population[14]. This translates to around 2,800 people aged 18 and over in South Australia. If services include people aged 16 -17 who are transitioning to adult care this number is likely to be closer to 3,000.

The table below presents the estimated and actual geographic distribution of patients accessing the state-wide service provided by CDH. The distribution of estimated service demand population by LHN is based on current overall population distributions in SA. The overrepresentation of NALHN patients in current referral data, as shown in the table, is likely due to current location of the service in NALHN, historical location of intellectual disability services in Northern Adelaide, and a lack of awareness of the service across other LHNs.

12 National Disability Insurance Agency, Participant Data, available at: https://www.ndis.gov.au/about-us/data-and-insights/participant-data
13 ZED Management Consulting, 2018 Final Report, Review of the Centre for Disability Health, Version 1.0, Northern Adelaide Local Health Network
14 KPMG (2009) NSW Health: Analysis of costs and benefits of options for developing specialised intellectual disability health services – service framework to improve health care of people with intellectual disabilities

Table 1: Geographic distribution of estimated SA population aged ≥ 16 years requiring specialised intellectual disability health service, and actual referrals to CDH in 4 week period 2019[15]

LHN	Estimated total SA service demand population aged ≥ 16 years (n=3,000)	Referrals to CDH by LHN residence in 4 week period July-Aug 2019 (n=134)
NALHN	22%	54%
CALHN	28%	11%
SALHN	21%	25%
Regional LHN	29%	10%
TOTAL	100%	100%

The Centre for Disability Health currently has a total FTE 5.4, and is staffed as follows:

- Consultant Psychiatrist 1.0 FTE
- Consultant Neurologist 0.1 FTE
- General Practitioner 0.3 FTE
- RN2 1.0 FTE (vacant) and RN3 1.0FTE
- Administrative staff 2.0 FTE (1.0 FTE vacant).

The 2018 review of the CDH identified that current staffing levels are significantly lower per population than for other jurisdictions. In order to match minimum staffing levels in other jurisdictions that provide specialised services for this population, the CDH would need to double current psychiatry and GP/general physician FTE to allow for assessment, advisory and training/education services without any ongoing care provision[16].

As an indicator of staffing levels for an existing state-wide sub-specialist service, the SA Huntington's Disease Service with a similarly complex population of cognitive, physical and mental health needs, has an FTE of 2.0 for a client base of around 270 active life long clients[17]. If the CDH were to provide ongoing care, it would need to have at least 20 FTE to match this staffing ratio, based on the estimated population base. Although the CDH does not currently provide ongoing care, these numbers indicate that the current staffing levels of the CDH are unlikely to support a meaningful state-wide response.

15 Department for Health and Wellbeing, An Evaluation of the Population Health Needs, Demand and Supply in South Australia, 2018.
16 ZED Management Consulting, 2018 Final Report, Review of the Centre for Disability Health, Version 1.0, Northern Adelaide Local Health Network
17 The SA Huntington's Disease Service is a state-wide service located at Flinders Medical Centre within the Social Work & Counselling Service. It provides a social work service for people with Huntington's disease and their families/carers, community education about Huntington's disease, and a predictive testing program for people 'at risk' of Huntington's disease.

6. Opportunities

6.1 Improving health screening for people with intellectual disability

Health screening is an important way to pick up and address potential health problems early. When health screening is carried out at regular intervals such as through a Medicare funded annual health assessment the potential to positively impact long term health outcomes is significant.

The Medicare Benefits Schedule (MBS) Health assessment for people with an intellectual disability items have been developed in recognition of the additional time and needs that people with intellectual disability may have and provide a structured clinical framework for medical practitioners to comprehensively assess the physical, psychological and social function of patients with an intellectual disability and to identify any medical intervention and preventive health care required. Health Assessments can be conducted once every 12 months for each patient

The Comprehensive Health Assessment Program (CHAP) provides a highly relevant and validated assessment tool for this purpose. The CHAP is a licensed validated tool designed by Professor Nick Lennox at the University of Queensland which aims to help minimise barriers to healthcare for people with intellectual disability. The CHAP is used in Australia by various state governments, and other non-government organisations, and in other countries.

The CHAP prompts an annual comprehensive health assessment for adults with intellectual disability, including asking about problem behaviours, bowel and bladder health, sexual health, lifestyle and physical activity and mental health, via use of a two-part questionnaire. The first part of the questionnaire which records the patients' health history is completed by a carer or paid support person, and the person with intellectual disability. The CHAP is then taken to the person's GP who completes the second part of the questionnaire with the person and their family or carer. The GP is prompted to be aware of commonly missed, poorly managed or syndrome specific health conditions when performing a review of the person's health. On completion of both sections of the CHAP a health action plan can be agreed upon by the GP in collaboration with those involved in providing support or the person themselves[18].

The CHAP tool is available for download for a small fee per person and the onus is on the patient and family or carers to complete the first section of the tool prior to taking it to the GP. Given the importance of preventive health care in influencing health outcomes, the widespread use of such a tool presents a significant opportunity to impact health outcomes for people with intellectual disability and complex health needs.

Recommendation 1: Promote the need for an annual health assessment for people with intellectual disability using a validated tool such as the CHAP and the Health Assessment for people with an Intellectual Disability MBS items to increase health screening and assessment for people with intellectual disability in South Australia. This may include:

- A funding commitment or partnership between relevant stakeholders such as the PHNs, Non-Government Accommodation Service Providers and Wellbeing SA to license the CHAP for download for people with intellectual disability in South Australia (maximum of 500 licenses per organisation per year at $11 per license)
- Promotion of this tool and MBS items to patients and GPs
- Education, support and advocacy for its use by patients, carers, support organisations and GPs
- Evaluation of outcomes to support continued allocation of funding.

6.2 Communicating for safety

In keeping with the National Safety and Quality Health Services Standards (NSQHS), Communicating for Safety Standard (2nd. Edition), health services should aim to ensure timely, purpose-driven and effective communication and documentation that supports continuous, coordinated and safe care for patients. This is particularly important for those who have cognitive disability or require assistance with communication.

In addition to the need for a comprehensive care plan to be in place for all patients with cognitive disability there is a pressing need for more effective communication during urgent and unplanned care for people with intellectual disability and complex health needs or behaviours. This includes the need for a planned and coordinated approach to:

- Medical emergency
- Challenging behaviours
- Mental health 'crisis'.

18 Uniquest eshop, 2020, Comprehensive Health Assessment Program available at: https://eshop.uniquest.com.au/chap/

Options to assist the above may include but not be limited to development of a hospital passport for patients with intellectual disability and complex health needs or behaviours, understanding regarding information sharing guidelines and building the capability of the workforce to support people with complex communication needs to communicate in ways other than speech. These are discussed further below.

6.1.1 Hospital passport

People with intellectual disability in the United Kingdom have access to a 'hospital passport' to take with them when they are accessing National Health Service (NHS) providers. The hospital passport can be downloaded from hospital websites, and is designed to give hospital staff helpful information that isn't only about illness and health. It also includes information on patient likes and dislikes, how to best communicate with the person, how to tell if the person is in pain, how much physical contact the person is comfortable with, favourite food and drinks etc. It is suggested that for overnight stays, the passport is hung at the end of the bed for access by all staff involved in patient care.

The benefits of a 'hospital passport' for patients with intellectual disability and complex health needs or behaviours in SA was raised repeatedly in consultations with stakeholders during the development of this model of care.

Recommendation 2: To support patients who need to attend hospital, the development of a standardised Statewide Hospital Passport or mobile Application for people with intellectual disability and communication support needs such as the Hospital passport developed by the National Health Service in the UK or the My Health Memory Application developed by the Sydney Children's Hospital is a priority recommendation for SA Health and this should be developed and agreed in partnership with stakeholders as part of this model of care.

This document or App should be made available and promoted on the SA Health website and through Local Health Networks and its implementation should occur through a well-planned rollout supported by an education package for clinicians, patients and families and support organisations emphasizing the benefits and importance of the document or App to the hospital journey. For people living in group homes a Hospital Passport or App may complement but would not replace the day to day care plan.

6.1.2 Information Sharing Guidelines

For a range of reasons clinicians may have an unjustifiably rigid adherence to the principles of confidentiality relating to information at the expense of effective collaboration and partnership.

All children and adults have the right to appropriate, high quality, safe services before their situation reaches crisis point, and timely information sharing can support this. Consumers also have the right to privacy and the Information Sharing Guidelines (ISG) promotes that informed consent be sought whenever reasonable and practicable[19].

SA Health Clinicians are responsible for regularly updating awareness of their responsibilities under the Information Sharing Guidelines for Promoting Safety and Wellbeing: SA Health ISG Appendix Policy Directive and ensuring that they have an understanding of the role of South Australian Civil and Administrative Tribunal (SACAT) appointed Guardians for persons with intellectual disability.

6.1.3 Supporting people to communicate their needs in ways other than speech

People with intellectual disabilities may have mild, moderate or complex communication needs which means that they are unable to use speech to meet all of their communication requirements. When a person has complex communication needs, they may use a range of techniques and tools other than speech to communicate with others. The term described for such techniques is Augmentative and Alternative Communication (AAC). There are two types of AAC systems:

Unaided Communication – using the face, hands or body to communicate without additional equipment (this includes using sign language)

Aided Communication – using low or high tech equipment such as picture symbol charts or booklets or voice output communication aids or communication app on a tablet device.

People with complex communication needs are reliant on other people as communication partners, noticing and assisting them so they can communicate their needs and wants, this includes healthcare workers. People with complex communication needs are extremely vulnerable members of our community in particular when they are not adequately supported to communicate physical pain or any kind of distress including abuse or neglect or when carers or paid workers are used as surrogate or sole source of information in place of direct communication with the person.

19 SA Health 2019 Information Sharing Guidelines for Promoting Safety and Wellbeing: SA Health ISG Appendix Policy Directive

When pain or distress go undetected this can be 'communicated' through escalating behaviours of concern and further distress and suffering can be caused through attempts to manage the behaviour without identifying the root cause.

Recommendation 3:

All SA Health clinicians should be provided with disability awareness training, including how to identify and support patients with complex communication needs to access preferred methods of communication so that they can express their needs. To reinforce this as a priority such training could be included as an action within the Disability Access and Inclusion Plan of each Local Health Network.

Recommendation 4:

The specific needs of all people with complex communication needs should be addressed within SA Health Challenging Behaviour policies and procedures to ensure that behaviour related to pain or distress can be communicated and addressed quickly and appropriately.

Recommendation 5:

The future Model of Care should include a Speech Pathologist within the specialised service to support the team to communicate effectively with patients and to contribute to capacity building activities and resources related to complex communication.

6.3 Reducing medication-related harm associated with polypharmacy

Polypharmacy is defined as the use of five or more drugs at once, and is more prevalent in the elderly and people with disability. There are a number of issues with polypharmacy including:

- Increased risk of adverse drug reactions
- Reduced medication adherence
- Higher cost.
- Suboptimal prescribing including a 'prescribing cascade' (prescribing one drug to counteract the effects of another)[20].

It is paramount that both efficacy and adverse effects are regularly monitored when people with intellectual disability are prescribed multiple medications. This is particularly important in relation to the use of psychotropic drugs, including antipsychotics which are often used in people with intellectual disability for chemical restraint. A Pharmacist led Home Medicines Review (HMR) is a government funded, cost-effective and collaborative service whereby appropriateness of medications is assessed. HMRs can highlight the need for physical health and adverse effect monitoring as well as provide an opportunity to initiate deprescribing of psychotropics and polypharmacy generally[21] Residential Medication Management Reviews (RMMRs) are a similar service provided in aged care facilities.

HMRs and RMMRs have historically required a referral from a patient's GP. The CHAP tool discussed earlier could be used to identify patients who may benefit from a pharmacist-led medication review. In April 2020 the Commonwealth Department of Health revised the HMR and RMMR program rules to allow for a broader range of medical practitioners to initiate HMRs and RMMRs including general practitioners, specialist physicians (e.g. neurologists) and specialist psychiatrists.

HMRs are conducted by an HMR-accredited pharmacist in the patient's home and are a valuable way for medication related information to be compiled and communicated in a report that can inform future prescribing, monitoring and review of medicines, saving the prescriber a lot of time. It is also an opportunity to provide education to people with intellectual disability and their caregivers, and answer medicine-related questions. Given the shortage of psychiatrists with expertise in intellectual disability and the significant number of referrals to the CDH psychiatrist for medication review, HMRs and RMMRs have the potential to enhance team care and optimise use of resources.

Recommendation 6: Pharmacists should be integral to the new model of care using existing pathways to medication review. A pharmacist within the specialised service (SAIDHS) could provide staff/client education regarding medicines issues, undertake research/audits, develop medicine-related policies and undertake other clinical governance activities. The pharmacist could also have a coordination role with respect to linking the core team with pharmacists who are credentialled to conduct medication reviews in primary care.

20 Hilmer, S (2008) The dilemma of Polypharmacy, Australian Prescriber 31:1 available at https://www.nps.org.au/assets/3329b9a9869189c9-55ba22a4e022-e51b3f481f6c215a52bf7e527f951d083dcd0ae653390a6bc79e6343032a.pdf

21 Angley, M (2015) Medication reviews for people with intellectual disability are a key tool in addressing an access gap in an underserved population,writes Manya Angley Australian Journal of Pharmacy available at: https://ajp.com.au/columns/opinion/medication-reviews-for-people-with-intellectual-disability/

6.4 Supporting people to access the NDIS

There is a small but significant group of patients with intellectual disability who have not been able to access the NDIS due to the requirement for specialist opinion and diagnosis of disability as part of the NDIS access request process. This group includes but is not limited to people with undiagnosed intellectual disability and multiple sclerosis, epilepsy, adult intellectual impairment, closed head injury and/or concussion syndromes. At present there is nowhere in the adult system that is set up well for these patients to be assessed from a disability perspective, and accordingly this presents a potential pressure or opportunity for the specialised service should it be resourced to do so.

The Independent Assessment Pilot that the NDIA has been running in NSW is currently being expanded nationally and this will provide access for people with disability to an independent assessment of functional impact to inform access and reviews for the NDIS. Due to workforce and capacity issues there is likely to be an ongoing role for the specialised health service in the area of diagnosis to support NDIS access requests.

Recommendation 7: The new SAIDHS model of care should support eligible patients to receive a diagnostic assessment in support of an NDIS access request, where this has been unavailable through mainstream health or NDIS avenues.

6.5 Concurrent supports

People with intellectual disability benefit from being accompanied by a known carer or support worker while in hospital. This helps to alleviate anxiety stemming from unfamiliar people and environments, reduces communication barriers and facilitates a smoother exchange of information regarding care needs. It also supports delivery of person centered care while at the same time building relationships and capacity between health and community service providers.

The NDIA has recently agreed at a national level that the NDIS will fund these 'concurrent' supports to help an NDIS participant with complex health needs or behaviours of concern during a stay in a hospital setting. This doesn't include paid workers performing personal care tasks in hospital which is the role of the health care setting; however, an NDIS-funded support worker may be funded to accompany a participant through personal care tasks in hospital if it helps them to understand and stay calm.

In order to receive these supports in hospital the NDIS participant must have these supports in their participant plan and have a contractual arrangement with the NDIS service provider to provide the concurrent supports. These supports are not able to be provided 24/7.

Recommendation 8: Increase awareness amongst clinicians and service providers regarding the use of, availability and implications of concurrent supports in SA Hospitals.

6.6 Availability of information

Visibility regarding suitable health services and high quality health information and pathways for people with intellectual disability is currently low, fragmented and potentially outdated. This results in frustration and delays in accessing appropriate care, erodes trust in the system, and makes it difficult for consumers and clinicians to be proactive and self-sufficient in seeking out healthcare. South Australia previously had the Disability Information Resource Centre (DIRC) in Gilles Street that included a service directory that was updated annually. This resource was ceased in 2014 for reasons unknown. Much of the information required is already in existence having been developed by other organisations however work remains to make it visible, easily accessible and relevant to South Australian clinicians and families.

The need for a resource that lists disability skilled and accessible health services by area has been raised as a priority many times during our consultation with stakeholders and therefore should be considered a priority in any future resource for South Australia. Whilst there is a short term need is for this resource, the medium term goal is for all health services to be disability skilled and accessible.

In addition to the above resource, the HealthPathways project is a collaboration between Wellbeing SA and Adelaide and Country SA PHNs. *HealthPathways* provides information and guidelines for GPs and health professionals to support the consistent management of patients in the community. It includes information about available community services and, when required, details on referring patients to SA Health for care. At the time of writing, there are no health pathways available or in development as part of this project specific to patients with intellectual disability.

Recommendation 9: Responsibility for planning and developing an intellectual disability information resource should be identified as part of the early implementation phase of this project.

Recommendation 10: The Health Pathways project should adapt the following existing Health pathways to the South Australian context as part of early implementation including:

> Challenging Behaviours in Adults with Intellectual Disability HealthPathway

> Physical Health and intellectual disability HealthPathway.

In addition, a new Mental Health and Intellectual Disability Health Pathway should be developed.

6.7 Connecting people

Despite a lack of dedicated roles in intellectual disability across our health system there are a significant number of interested clinicians and people in other roles who can assist safe and quality care through communication and sharing of information, skills and knowledge regardless of location.

Recommendation 11: The establishment of an intellectual disability health clinical network or community of practice, interest group or network is recommended as part of this model of care. It is anticipated that the Commission on Excellence and Innovation in Healthcare (CEIH) Consumer and Clinical Partnerships directorate will be able to provide some guidance on the coordinated establishment of such a group.

In addition, the South Australian Intellectual Disability and Mental Health Network that was previously led by a CDH Psychiatrist and is part of the national Mental Health Professionals Network (MHPN) could provide a useful platform for sharing information and skills. This forum was previously well attended by both disability and mental health workers from various settings.

6.8 Taking a life course approach

The child with developmental disability and complex health needs or behaviours will become the adult with intellectual disability and complex health needs or behaviours and health services should be designed around the recognition of this fact. This means developing whole of life services or, where services are separate, investing in integrated transition processes between child and adult services.

The life course perspective views health as the product of risk behaviours, protective factors, and environmental agents that we encounter throughout our entire lives and that have cumulative, additive, and even multiplicative impacts on specific outcomes. It thus provides a construct for interpreting how peoples' experiences in their early years influence their later health and functioning.[22]

Risks arise when transition is approached as an event rather than a process that begins early and happens over time. This is in part due to healthcare transition often coinciding with a number of other life transitions from childhood to adulthood including an increase in risk taking behaviour, reduced compliance with rules and a greater focus on social influences rather than the influence of parents and other authorities. Risks of poor transition are exacerbated by:

> lack of visibility once a child has been 'discharged' from paediatric care

> a child or family failing to 'connect' well with an adult specialist.

> lack of understanding of the differences in the way services are provided and where

> handover on paper only.

When transition is suboptimal, links between patients and services can be broken entirely and be difficult to re-establish leading to lengthy periods between seeking healthcare. This has impacts on long-term health and wellbeing and increases the likelihood of emergency presentations.

Adolescent transition should always be based on the developmental readiness of the individual child but should commence as early as possible and be completed between the ages of 16 and 24.

In order to ensure that it is the child that is transitioned and not the paperwork, planning for transition should begin as early as possible and should have a focus on the development of knowledge and skills in self-management, navigation of the adult system, supporting ownership of health information such as through a digital health record or health passport and supporting new relationships to develop with adult clinicians and services well before actual transition.

22 Stella Yu, *The Life course approach to health*, American Journal of Public Health, 2006 available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1470580/

In order to continue to provide the highest quality care, paediatric, neurology and psychiatry clinicians must ensure that an early, planned and coordinated transition process is facilitated in partnership with family and carers, adult services and the General Practitioner. Where there are multiple services or specialists involved, a transition lead should be identified to coordinate the transition in liaison with each specialist service, the general practitioner and the family and carers.

In addition, it is well established that transition from paediatric to adult services is most successful when there is a “pull” rather than a “push” model, this involves a dedicated adult role (likely a nurse) to meet with relevant paediatric services on a regular basis to identify appropriate patients and start planning for transition with the child, their family and carers.

Relevant child and adolescent services that support children and adolescents with developmental disability and complex health needs or behaviours who may access the Centre for Disability Health as an adult include Child and Adolescent Mental Health Services (CAMHS), The Health Education Interface (HEI) and a range of LHN paediatric services that see children and adolescents with chronic and complex conditions and developmental disability.

Recommendation 12:

The SAIDHS Model of Care should take a life course approach by developing partnerships with relevant child and adolescent health services to strengthen and support a care continuum across the life course. This approach should be developed in partnership as part of the implementation phase of this work and should include:

- Development of a formal transition pathway and agreement between the SAIDHS and relevant paediatric health services. The transition pathway should be based on a ‘pull’ model whereby the SAIDHS visits paediatric services at agreed intervals to engage with and educate clinicians families and carers regarding health service provision during and post transition
- the service should support young people to transition with flexibility regarding the age at which this is initiated depending on individual circumstances and developmental readiness sometime between 16 – 24 years of age.
- ownership’ or responsibility for transition should be shared between child and adult services and this should be documented in an agreement regarding roles and responsibilities including for the child and their family/carers.

7. Gaps and challenges

7.1 Capacity of mainstream health services

At present, health professionals receive minimal or no training in intellectual disability health care.[23] In addition to a need for training regarding intellectual disability to be embedded in higher education curricula for all medical, nursing and allied health, the mainstream health workforce requires support to build and maintain the skills and confidence they need to engage and work effectively with patients with intellectual disability and complex health needs or behaviours through the availability of clinical advice, support and leadership and clinical placements and rotations. Without this, clinicians can be reluctant or feel unqualified to work with this patient group and these patients may consequently experience discrimination in healthcare be bounced around or fall through gaps in the health care system.

Consumer feedback indicates that where parents and carers are well educated, well-resourced and more connected, these barriers to access are greatly reduced. This highlights the potential of the mainstream to meet the needs of this patient group where barriers to communication and understanding are recognised, reduced or removed.

As discussed on page 16, a national roadmap for improving health services for people with intellectual disability is under development by the Commonwealth Department of Health, and is likely to address several of the above barriers to access particularly around primary health care. In addition, evidence regarding building mainstream capacity to provide services for people with intellectual disability has identified a number of other key elements or focus areas required for a holistic capacity building approach. These elements have been brought together in a preliminary model developed by the Sax Institute[24] that has a focus on leadership, organisational development, workforce and resource allocation.

Recommendation 13: Building the capacity of mainstream health services to meet the needs of people with intellectual disability should be a core element of the future model of care and there are a range of comprehensive resources available to support an evidence based approach to capacity building (see Appendix 1. Capacity building resources).

7.2 Behaviours of concern

All behaviour is an effort to communicate and this can be especially true for people with complex communication needs. Presentation of concerning behaviour by people with intellectual disability should not affect health care access, rather environments around the person with disability must be safe, conducive to effective communication and accessible in order to maximise equitable access to health care.

Due to the risk perceived by families and carers of complex behaviours and a lack of alternative 'crisis' options in the community, people with intellectual disability who are exhibiting escalating behaviours of concern, that are not responding to existing behaviour support strategies are usually transported to an emergency department (ED). If paramedics, health workers or carers do not feel skilled or supported in their ability to safely care for the person exhibiting the behaviours of concern, the behaviours may continue to escalate, or staff may respond with increased use of restrictive practices.

In the emergency department, communication barriers, information gaps and a lack of suitable low stimulus assessment areas can make assessment difficult. In addition, unfamiliarity, noise, lights and or prior traumatic experiences can further escalate unsafe behaviour, and even restrict the care that can be provided.

In addition, diagnostic overshadowing which is the misattribution of behavioural or mental health issues and their presentation to the person's intellectual disability[25] can result in patients with intellectual disability who are displaying behaviours of concern being discharged from the ED without inpatient treatment, diagnostic assessment or plans for follow up.

This has the effect of delaying treatment, results in multiple 'failed' presentations without clear treatment or behaviour management plans, and contributes to poor long term outcomes and significant distress for carers and workers who are left to manage from incident to incident.

Supporting a person with intellectual disability who is exhibiting behaviours of concern to communicate their needs requires real collaboration between clinicians, carers and paid workers who are well placed to recognise when a person's

23 NSW Council for Intellectual Disability, 2019 The Health of People with Intellectual Disability, Budget and Federal Election 2019, Commitments sought from Australian Political Parties, available at: https://cid.org.au/wp-content/uploads/2019/06/Intellectual_disability_health_bid_200219.pdf

24 Travaglia et al, 2017, Evidence Check, Capacity building and intellectual disability health services, Sax Institute, available at: https://www.health.nsw.gov.au/disability/Documents/evidence-check-cbidh.pdf

25 Whittle, E.L et al, Access to mental health services: The experiences of people with intellectual disabilities. J Appl Res Intellectual Disability. 2019; 32:368-379. https://doi.org/10.1111/jar.12533

behavioural presentation deviates from their baseline level of functioning. In addition, the availability of pre prepared documentation that highlights key patient information and preferred communication methods such as a Hospital Passport can support safer and more effective clinical care.

In 2019 the Department for Health and Wellbeing initiated work to bring together key stakeholders to review and update existing Preventing and Responding to Challenging Behaviour policy directive and toolkit resources which are located on the SA Health website. The program of work will include development of a series of challenging behaviour topics to showcase good practice initiatives and new resources and tools across SA Health. Workforce Health and Safety has led this work as many incidents were placing staff and patients at risk.

As part of this work there remains a need to develop content and awareness to support clinicians and staff to identify underlying causes of behaviour such as pain or distress in people with complex communication needs so that these can be addressed quickly and appropriately and de-escalation achieved.

Recommendation 14:

As part of the Challenging Behaviour work now being led by DHW Safety and Quality, new resources for generalist clinicians should be developed regarding

1. Supporting people with complex communication needs who are displaying behaviours of concern to help with identification of underlying causes of behaviour such as pain or distress.
2. The need for all people with intellectual disability exhibiting ongoing behaviours of concern where an underlying cause has not been identified, to receive a comprehensive physical and mental health assessment in partnership with existing health and/or NDIS teams. This will assist with multidisciplinary diagnosis, support access to treatment, planning and care options and reduce the risks of short and longer term harm. The SAIDHS as the specialised service can provide this assessment or partner with and provide advice to existing health or NDIS supports to enable this to occur.

This information should be developed with input from key stakeholders and incorporated into the SA Health Challenging Behaviour suite of resources.

Recommendation 15: Hospital avoidance strategies for people with intellectual disability and complex behavioural presentations in South Australia should be developed to reduce unnecessary hospitalisation.

7.3 Mental Health

At all stages of life, people with an intellectual disability are at least 2-3 times more likely to have a mental illness than the general population with the prevalence of mental illness in people with an intellectual disability estimated to be between 30-50%[26]. Despite this significant burden, mental health disorders are often poorly recognised and treated in people with intellectual disability. This patient group can experience major barriers when trying to access mental health services[27].

The recently released SA Health Mental Health Services Plan 2020-2025 states that 'people with a [intellectual] disability will be able to access 'local mental health services' that will in turn be supported by a sub- specialist disability mental health service. The sub-specialist service will provide supervision, advice, assessment and co-management as well as rotating training placements to upskill the broader workforce, including training and education programs.' The Plan also notes that the existing Centre for Disability Health will be the provider of this specialised service.

Local mental health services which should be accessible by people with intellectual disability include primary mental health services commissioned by the Adelaide and Country SA Primary Health Networks. PHN mental health services are commissioned in alignment with a stepped care model, facilitating provision of care across the continuum from early intervention, to mild, moderate, or chronic/complex related care. Anecdotal evidence collected during this project indicates that access to these services for people with intellectual disability remains limited. Data on local primary mental health service use by people with intellectual disability, and a better understanding of limitations to service use, would be useful to inform future service planning.

Current SA Health Community Mental Services that provide specialist mental health services to those with who require a higher level of care based on acuity, complexity, severity or risk, currently identify several conditions/diagnoses including intellectual disability as 'non-core' business. For people with intellectual disability, some Community Mental Health Service models of care specify that if they have presenting mental health issues, these may be better addressed in a sub-specialist service like the CDH. This position is at odds with the SA Health Mental Health Services Plan 2020-2025 and whilst it may be an acceptable response for planned care, it provides no option for mental health emergency or 'crisis' situations.

26 Cooper, S.A. et al, Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. The British Journal of Psychiatry, 2007. 190(1): p.27-35
27 Whittle, E.L et al, Access to mental health services: The experiences of people with intellectual disabilities. J Appl Res Intellectual Disability. 2019; 32:368-379. https://doi.org/10.1111/jar.12533

Emergency Mental Health Care for people in South Australia is accessed via Emergency Departments or the SA Health Mental Health Triage line. The Triage line operates 24 hours a day, 7 days a week and is:

> the main point of access into SA Health mental health services

> provides advice and information in a mental health emergency or crisis situation

> is staffed by mental health clinicians

> will assess and refer to acute response teams where appropriate.

Anecdotal evidence collected during this project suggests that people with intellectual disability (or their carers or support workers) who contact the SA Health Mental Health Triage line are directed to the CDH (which does not provide crisis or 24-hour care and has no inpatient facilities) or to an emergency department. This is a current service gap impacting on the individuals and families of people with an intellectual disability.

Other conditions identified by LHN Mental Health Services as 'non-core' business and in need of a more specialised approach when they co-occur with mental illness have had designated mental health inpatient capacity created to support management of urgent mental health issues. These conditions include acquired brain injury, drug and alcohol related issues and dementia services. Specialist inpatient capacity for people with these conditions and co- occurring mental illness has been established to provide specialised skills, knowledge and environmental adjustments for these patient groups in recognition of their additional complexity.

No such specialist inpatient capacity currently exists for people with intellectual disability and co-occurring mental illness, despite a higher incidence of mental illness and other complexities in this patient population.

Recommendation 16: This model of care should articulate how local, community, acute and specialised mental health services will integrate to ensure that mental health services in South Australia are accessible for people with intellectual disability. This should include how equity of access to urgent mental health care will be provided within existing settings and through existing access points and should articulate how the specialised service will support local urgent mental health care delivery (see appendix 3).

Recommendation 17: An additional piece of work should be undertaken by SA Health to further understand the need for and requirements of an acute mental health inpatient service for people with intellectual disability in South Australia with consideration of the following:

> What should a mental health inpatient stay look like for this patient group, including how this can occur within existing acute settings?

> What should a step down community mental health option look like for this patient group?

> What is the population group that requires access to such a service (number, presentation types)?

7.4 Lack of options for pre-procedural sedation to support health procedures

Prior to transfer to SA Health, CDH supported some patients who were identified as requiring sedation prior to certain procedures including dentistry, podiatry, Botox and blood tests through the provision of midazolam. While this clinic is no longer part of the CDH the question remains as to how to support people with extreme anxiety and limited communication skills in addition to their intellectual disability that may prevent them from accessing such necessary procedures.

People who require sedation for blood testing in order to monitor use of antipsychotic medications are at risk of multiple undiagnosed side effects in the absence of such sedation. These patients may be prescribed additional medications and/or precluded from accessing helpful medications that require regular blood monitoring. The CDH prepared a report regarding a range of possible options that were explored with SA Health in 2018. However, this did not result in a solution and there is no current data on the need for such an option and the impact of its being unavailable. Consequently, there may remain a need for pre-procedural sedation protocols that are in alignment with national health standards and guidelines set by the Australian and New Zealand College of Anaesthetists (ANZCA). This would allow for provision of routine medical procedures to this client group and allow administration of such pharmacological supports without the need for the reporting of such as a restrictive practice in the absence of other behaviours of concern.

Recommendation 18: It is recommended that SA Health further explore the need for pre-procedural sedation for people with intellectual disability and extreme anxiety, and how such sedation may be accessed and identify the implications for health and other outcomes should access not be readily available to pre-procedural sedation.

7.5 Recruitment and retention

Issues with attracting and retaining appropriately skilled clinicians to the Centre for Disability Health have highlighted the need to design a Model of Care that recognises the specific needs of clinicians and identifies those factors that will support a sustainable and rewarding work environment. The potential for professional isolation and burnout, the need for adequate supervision and succession planning for business continuity will all need to be addressed as part of this model.

Recommendation 19: The views and experience of SAIDHS staff should be sought regularly and through a range of formal and informal mechanisms as part of the monitoring and evaluation plan for this model of care and information collected should be used to inform ongoing service planning and improvement with a view to building a supportive, attractive and sustainable working environment.

7.6 Lack of data to support service planning and evaluation

Intellectual disability is not a health condition and therefore it is not routinely coded in hospital and other health service data. This makes accurate data collection difficult, and leads to difficulty making statements about service use and demand in general. In their recent report on people with disability in Australia (2019), the Australian Institute of Health and Welfare (AIHW) notes that critical data gaps limit the ability to present a comprehensive and insightful picture, including about pathways through and across multiple service systems and the extent to which these contribute to positive outcomes for people with disability. This also presents difficulties regarding planning for future services.

A recent large data linkage study[28] in NSW that links data sets across multiple health and human services aims to build one of the largest cohort of people with intellectual disability internationally. This will enable analysis of patterns of service use across multiple different service systems, giving valuable information about physical health, mental health and service use profiles of people with intellectual disability and those with other neuropsychiatric and developmental disorders.

Under the National Roadmap for Improving the health of people with Intellectual Disability, research, data and measurement will also be a key platform for tracking the health outcomes of people with intellectual disability, and assessing the efficacy of initiatives to improve them. Recommendations include:

- a focus on increasing the Australian evidence base on the health of people with intellectual disability;
- building a national data asset on the health of people with intellectual disability; and
- embedding an outcomes based focus, and using Patient-Reported Experience Measures and Patient-Reported Outcome Measures.

28 Reppermand et al, 2019 https://bmjopen.bmj.com/content/bmjopen/9/9/e031624.full.pdf

The NSW Agency for Clinical Innovation Intellectual Disability Health Network released a position statement on the need for an intellectual disability minimum data set. It has made the following recommendations to NSW Health to improve health outcomes by addressing health system efficiencies:

1. an identification/alert system for people with intellectual disability is coded on notes and in a data collection system
2. an appropriate minimum data set be established for people with an intellectual disability
3. the data set is an integrated part of the e-records systems and allows for linkages with other data such as NDIS and primary health care records such as Personal Electronic Health Records.[29]

The Centre for Disability Health has implemented a standard CHIS data collection system that will support ongoing analysis of the type, number, reason and source of referrals received in addition to information collected in pre appointment questionnaires and patient experience and outcomes measures.

In addition, a number of new data collection initiatives are underway in SA Health that will support better understanding of health services use by people with intellectual disability including the following:

> As of July 2020 the SA Health Sunrise system will include a new data field identifying NDIS participants presenting at emergency departments and being admitted to hospitals however this does not as yet allow for indication of the type of disability.
> As of January 2020, data specific to challenging behaviour and restrictive practices and people with intellectual disability is available through the SA Health Incident Management Safety Learning System (SLS) and data requests may be made by contacting safetylearningsystem@sa.gov.au
> A challenging behaviour dashboard is in development in the Quality Information and Performance (QIP) Hub and this is inclusive of patient data regarding intellectual disability.

Recommendation 20: It is recommended that as part of a monitoring and evaluation plan for this model of care an intellectual disability identification system and intellectual disability minimum data set be agreed for SA Health that will provide the capacity to identify and monitor services delivered to people with intellectual disability and support service planning and evaluation.

29 NSW Agency for Clinical Innovation, Intellectual Disability Health Network, 2014 *Position Statement on the importance of a NSW intellectual disability minimum data set* available at: https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/276817/position-statement-data-set.pdf

8. Summary of recommendations

Table 2: Summary of recommendations and proposed responsibilities from current state analysis

Recommendation		Responsible
1	Promote the need for an annual health assessment for people with intellectual disability using a validated tool such as the CHAP and the Health Assessment for people with an Intellectual Disability MBS items to increase health screening and assessment for people with intellectual disability in South Australia. This may include: > A funding commitment or partnership between relevant stakeholders such as the PHNs, Non-Government Accommodation Service Providers and Wellbeing SA to license the CHAP for download for people with intellectual disability in South Australia (maximum of 500 licenses per organisation per year at $11 per license) > Promotion of this tool and MBS items to patients and GPs > Education, support and advocacy for its use by patients, carers, support organisations and GPs > Evaluation of outcomes to support continued allocation of funding.	Wellbeing SA, PHNs
2	To support patients who need to attend hospital, the development of a standardised Statewide Hospital Passport or mobile Application for people with intellectual disability and communication support needs such as the Hospital passport developed by the National Health Service in the UK or the My Health Memory Application developed by the Sydney Children's Hospital is a priority recommendation for SA Health and this should be developed and agreed in partnership with stakeholders as part of this model of care. This document or App should be made available and promoted on the SA Health website and through Local Health Networks and its implementation should occur through a well-planned rollout supported by an education package for clinicians, patients and families and support organisations emphasizing the benefits and importance of the document or App to the hospital journey.	DHW
3	All SA Health clinicians should be provided with disability awareness training, including how to identify and support patients with complex communication needs to access preferred methods of communication so that they can express their needs. To reinforce this as a priority such training could be included as an action within the Disability Access and Inclusion Plan of each Local Health Network.	LHNs
4	The specific needs of all people with complex communication needs should be addressed within SA Health Challenging Behaviour policies and procedures to ensure that behaviour related to pain or distress can be communicated and addressed quickly and appropriately.	DHW WHS & Safety and Quality
5	The future Model of Care should include a Speech Pathologist within the specialised service to support the team to communicate effectively with patients and to contribute to capacity building activities and resources related to complex communication.	DHW
6	Pharmacists should be integral to the new model of care using existing pathways to medication review. A pharmacist within the specialised service (SAIDHS) could provide staff/client education regarding medicines issues, undertake research/audits, develop medicine-related policies and undertake other clinical governance activities. The pharmacist could also have a coordination role with respect to linking the core team with pharmacists who are credentialled to conduct medication reviews in primary care.	DHW
7	The new SAIDHS model of care should support eligible patients to receive a diagnostic assessment in support of an NDIS access request, where this has been unavailable through mainstream health or NDIS avenues.	DHW
8	Raise awareness regarding the use of, availability and implications of concurrent supports in SA Hospitals so that over time more people are aware and have these supports in their plans and as part of their contracts with service providers.	NDIS, LHNs

Recommendation		Responsible
9	Identify responsibility for development of an information resource for South Australia regarding intellectual disability and health that includes information regarding services, health and wellbeing topics, and education and training for patients, families, paid workers and clinicians.	DHW
10	Develop and promote the following existing HealthPathways for South Australia: > Challenging Behaviours in Adults with Intellectual Disability HealthPathway > Physical Health and intellectual disability HealthPathway. In addition a new Mental Health and Intellectual Disability HealthPathway should be developed	Wellbeing SA, PHNs
11	Establish an intellectual disability health clinical network or community of practice for South Australia.	SAIDHS
12	The SAIDHS Model of Care should take a life course approach by developing partnerships with relevant child and adolescent intellectual disability health services to strengthen and support a care continuum across the life course. This approach should be developed in partnership as part of the implementation phase of this work and should include: > Development of a formal transition pathway and agreement between the SAIDHS and relevant paediatric services. The transition pathway should be based on a 'pull' model whereby the SAIDHS visits paediatric services at agreed intervals to engage with and educate clinicians families and carers regarding health service provision post transition > the service should support young people to transition somewhere between 16-25 years based on individual and developmental readiness > ownership' or responsibility for transition will be shared between child and adult services and this should be documented in an agreement regarding roles and responsibilities.	SAIDHS
13	Include in the new model of care how the new SAIDHS will build the capacity of mainstream health services to meet the needs of people with intellectual disability in South Australia.	DHW
14	As part of the Challenging Behaviour work being led by DHW Workforce Health and Safety and Safety and Quality, new resources for generalist clinicians should be developed regarding: 1. Supporting people with complex communication needs who are displaying behaviours of concern to help with identification of underlying causes of behaviour such as pain or distress. 2. The need for all people with intellectual disability exhibiting ongoing behaviours of concern where an underlying cause has not been identified, to receive a comprehensive physical and mental health assessment. This will assist with multidisciplinary diagnosis, support access to treatment, planning and care options and reduce the risks of short and longer term harm. The SAIDHS as the specialised service can provide this assessment or partner with and provide advice to existing health or NDIS supports to enable this to occur. This information should be developed with input from key stakeholders and incorporated into the Challenging Behaviour suite of resources.	DHW
15	Develop recommended hospital avoidance strategies for people with intellectual disability and complex behavioural presentations.	Wellbeing SA
16	Articulate how local, community, acute and specialised mental health services will integrate to ensure that mental health services in South Australia are suitable and accessible for people with intellectual disability including how equity of access to urgent mental health care will be provided within existing settings and through existing access points and how the specialised service will support local urgent mental health care delivery (see Appendix 3.).	DHW

Recommendation		Responsible
17	Undertake a project to further understand the need for and requirements of an urgent mental health inpatient capacity for people with intellectual disability in South Australia with consideration of the following: > What should a mental health inpatient stay look like for this patient group? > Including how this can occur within exiting acute settings. > What should a step down community mental health option look like for this patient group? > What is the population that require access to such a service?	DHW/OCP
18	Further explore the need for pre-procedural sedation for people with intellectual disability and extreme anxiety, and understand the resultant health outcomes and impacts where this is unavailable.	DHW
19	The views and experience of SAIDHS staff should be sought regularly and through a range of formal and informal mechanisms as part of the monitoring and evaluation plan for this model of care and information collected should be used to inform ongoing service planning and improvement with a view to building a supportive, attractive and sustainable working environment.	DHW
20	As part of a monitoring and evaluation plan for this model of care, an identification system and minimum data set should be identified and agreed for SA Health that will provide the capacity to identify and monitor services delivered to people with intellectual disability. This should include the role and use of My Health Record and should inform future service development.	DHW

PART B: PROPOSED FUTURE MODEL

This section of the document outlines the proposed future model of care for delivery of health services for people with intellectual disability and complex health needs in South Australia. It reflects findings from the current state analysis and recommendations, including extensive input from stakeholder consultations and four workshops conducted with an Expert Advisory Group.

9. Guiding principles

The guiding principles for the delivery of health services for people with intellectual disability below were developed by the NSW Agency for Clinical Innovation (ACI), Intellectual Disability Health Network. The expert advisory group established to guide this work for South Australia have agreed that these principles will underpin the proposed model of care and be used to plan, develop and evaluate specialised services for people with intellectual disability and complex health needs or behaviours in South Australia.

1. Collaboration within and between government and non-government agencies (e.g. schools, supported accommodation services) supports the health outcomes of a person with intellectual disability
2. People with intellectual disability can access the same range and quality of health services as other people
3. Health services recognise the poorer health outcomes for people with intellectual disability
4. Health services provide early diagnosis and intervention to enable optimal outcomes
5. Health services support the cultural and social inclusion of people with intellectual disability and their carers
6. Health services are delivered in a person and family centered way
7. Health services for people with intellectual disability are co-designed and integrated across primary, mainstream and specialised care
8. Health services are delivered by appropriately trained staff
9. Specialised health services and the integration of their expertise within mainstream services can improve health outcomes for people with intellectual disability
10. Data is required to inform ongoing health service development, policy and models of care[30]

10. Objectives and outcomes

10.1 Goal

People with intellectual disability in South Australia have equity of access to compassionate, high quality health services that are appropriate to their needs.

10.2 Objectives

The specific objectives of this model of care are to:

1. Develop a sub specialist intellectual disability health service that meets the needs of patients with intellectual disability and complex health needs or behaviours.
2. Describe service models of access that integrate mainstream and specialised services for people with intellectual disability in South Australia.
3. Build the capacity and capability of mainstream clinicians to deliver timely, evidence informed and appropriate healthcare to people with intellectual disability across South Australia
4. Develop and implement a data collection strategy to support evaluation and planning of services
5. Identify a suitable and sustainable governance model for the delivery of specialised services state-wide

30 NSW Ministry of Health (2012) Service Framework to Improve the Health Care of People with Intellectual Disability available at: https://www.health.nsw.gov.au/disability/Pages/health-care-of-people-with-ID.aspx

10.3 Outcomes

Short term (1-3 years)

> Accessible and responsive health services for people with intellectual disability across South Australia

> An increase in confidence and skills among SA clinicians to work effectively with people with intellectual disability in existing settings

Medium term (3-5 years)

> A reduction in rates of avoidable emergency department and hospital admissions for people with intellectual disability in South Australia

> A reduction in the cost of hospital admissions and length of stay for people with intellectual disability in South Australia

Long term (5+ years)

> A reduction in the rates of avoidable deaths for people with intellectual disability in South Australia

> A reduction in the rate and chronicity of physical and mental health conditions for people with intellectual disability in South Australia

11. Enablers

Fundamental to the ability of this model of care to achieve its stated objectives are the following foundational enablers:

> Visible and accountable leadership on disability health in South Australia (as distinct from NDIS)

> System wide investment in a compassionate culture and universal and human centered design approaches

> Deep, attitude changing learning opportunities for health care providers

> A basis of ongoing block funding to support services that are not viable or sustainable under other funding models such as activity based funding

> Availability of suitable technology to support service delivery (eg. Telehealth)

> Data collection and analysis capability for service planning and improvement

> Endorsement of the model by all Local Health Networks

12. Overview of tiered service model

A tiered service model is proposed for delivery of health services for people with intellectual disability and complex health needs or behaviours in SA. An overview of the model is presented in figure 1. below, and assumes that people with intellectual disability will access and move back and forth between tiers and access more than one tier at a time rather than be identified with one tier. A description of each of the service tiers is provided below.

Figure 1: Tiered health service delivery model for people with intellectual disability in SA

12.1 Tier 1: Universal services

All people with intellectual disability have a right to access universal (mainstream) health services including general practices, community based health services, hospital and emergency services, local mental health services and state-wide services. This cohort of people is 'everyone's business' and universal services should provide a firm foundation for the provision of more targeted or specialised services. Universal services should have at minimum, processes in place to support clinicians and staff to:

1. Be trained in and supported to provide healthcare to all people with intellectual disability including learning about the rights of people with disability
2. Identify and record patients with intellectual disability on admission or arrival or referral to the service
3. Link patients who have intellectual disability with targeted services as soon as possible to enable optimal service provision and integration and prevent delays in treatment and discharge.
4. Partner with people with complex communication needs and their carers to support them to communicate their needs in ways other than speech
5. Identify those patients who require and are eligible for a specialised service response and refer them to specialised services (i.e. SAIDHS) as early as possible.

12.2 Tier 2: Targeted services

Each LHN should have in place a disability and complex care hospital liaison team or role to support the additional healthcare needs and complexity of people with intellectual disability and as part of the implementation of local Disability Access and Inclusion Plans. In metropolitan LHNs this is likely to be a small team of Senior Nursing and or Senior Allied Health clinicians and in country LHNs due to staffing constraints and smaller numbers this may be a role that is also involved in coordinating care for older or more complex patients.

Targeted services within LHNs should provide an expert consultative service to wards, units and departments in the care of patients with physical, sensory, intellectual and / or multiple disabilities or complexity who will require reasonable adjustments to care and service integration. Targeted services can link patients with suitable community based services, hospital outpatient's services, carers, care facilities, GPs and community-based services.

These services are complementary but distinct from the dedicated NDIS teams that have been established by some networks aimed at completing the highly time-consuming specialised NDIS assessment, preplanning and discharge planning roles essential to facilitate sustainable discharge for patients with complex needs from inpatient settings.

Disability and complex care liaison teams or roles should be able to receive referrals from all over the hospital as well as pre-admission from the community (NGOs and other providers). Disability liaison Teams or roles and or dedicated NDIS teams should be highly visible and regularly promoted across all divisions and information regarding local LHN disability contacts should be made available on the SA Health website.

All people with intellectual disability should be linked with targeted services on admission or arrival to a mainstream service. In addition to those things outlined under universal services above, targeted services will:

1. Assist to make universal services more accessible and effective for people with intellectual disability and will be provided by experienced and knowledgeable clinicians.
2. Help to build the capacity of the mainstream to provide appropriate services to people with intellectual disability through a partnership arrangement with the specialised service
3. Identify and refer those clients who require a specialised service response to the SAIDHS as soon as possible.

12.3 Tier 3: Specialised services

Due to their specific needs or due to the complexity of their co-morbidities, some people will require additional support for issues or complexities that are not managed by universal and targeted services. The specialised service tier will be provided by the SAIDHS, and will include clinical advice and support, second opinion and where required comprehensive assessment, time limited treatment and health care planning in partnership with existing health care and/or dedicated NDIS teams to support optimal ongoing care in the community by existing services. Time limited treatment provided by the SAIDHS will be focused on stabilising presenting issues and supporting the assessment and planning process.

Plans will be developed in liaison with families, current service providers and carers, and short-term follow-up will be provided where required. On completion of a referral to the specialised service, patient care will be handed back to the primary care physician and to the day to day care provider for ongoing care. Individuals can be re-referred to the service if their medical or health needs change.

The specialised services tier will integrate and partner with universal and targeted services for the purposes of capacity building, linking clients with services, information sharing and communication.

13. Overview of the specialised service

13.3 Services provided

Key services provide by the SAIDHS are:

- Provision of a time limited specialised assessment and planning service to address health issues for people with intellectual disability aged 16 years and over
- Provision of education and training, advice, support and information for mainstream clinicians
- Provision of advice, support and information for consumers, paid workers and carers
- Development and maintenance of strong collaborative links and pathways with primary health services, LHN services, research and education providers to build capacity and capability.

Other services include:

- Review of restrictive practices for clients with a restrictive practice or chemical restraint
- Assessment of intellectual disability to support an NDIS access request.

13.4 Target group

People accepted to the specialised service for assessment, intervention and planning will be people aged 16 years and over with confirmed or suspected intellectual disability and/or significant developmental disability who have heightened levels of complexity as a result of one or more of the following:

- Mental illness or suspected mental illness
- Autism spectrum disorder
- Severe or profound communication and/or behavioural issues
- Other co-morbidities
- Other complexities or issues which have not been able to be managed in mainstream services including but not limited to people involved in the justice system and young people under Guardianship of the Minister.

Information regarding eligibility criteria for potential referrers will be clearly indicated on the SAIDHS website.

13.5 Life course approach

SAIDHS will take a life course approach to the health and wellbeing of people with intellectual disability by building strong links with child and adolescent intellectual and developmental disability health and mental health services to reinforce and support a care continuum. This approach will be developed as part of the implementation phase of this work and will include development of formal transition pathways between child and adult services.

13.6 Staffing

The SAIDHS will be staffed by clinicians with skills, knowledge, experience and an interest in intellectual and developmental disability health. An interdisciplinary service is proposed, with a mix of disciplines, roles and FTE as outlined in the table below. The recommended number and mix of clinical staff reflects key findings and recommendations from the current state analysis, including extensive stakeholder consultations and comparison with other specialised health service models however this model of care describes a new and relatively untested state for SA. For this reason there will be flexibility within the proposed new clinical positions and FTE and these new positions will initially be temporary (12 months) so that staffing mix can change until service needs are better determined.

The recommended staffing model represents a significant increase to current staffing. It is proposed that the growth to this new service will be undertaken over 3 years to provide a stable development of the service and to ensure that the detailed service model is able to be developed in consultation with disability carers and service providers to ensure best possible care for this client group.

Table 3: Recommended SAIDHS staffing model

Position	Class.	FTE	Role
Health Service Manager	AHP4/ RN3	1.0	> Responsible for overall service management > Ensures community engagement and education programs in place > Works with partners to establish service level agreements
Consultant Psychiatrist	MDO29G	2.0	> Responsible for all medical issues associated with intellectual disability and mental illness, including diagnoses and management of all bio-psycho-social aspects of the patient's condition including chronic diseases and complex interactions between disability and mental health > Comprehensive assessment of patient, focusing on careful bio psycho social review of past interventions, and consideration of potential interventional options
Consultant Physician/ GP Consultant	MDO29G	0.5	> Responsible for review of physical health issues and determination of appropriate diagnosis and management – especially focusing on chronic diseases and physical disability impacts
Consultant Neurologist	MDO29G	0.1	> Responsible for review of impact of epilepsy and other neurological conditions on the person's physical, intellectual disability and mental health concerns, with a particular focus on management of medication
Registrar (psychiatry)	TBC	1.0	> Training position to support increased capacity for this client group in mainstream mental health services
Clinical Nurse	RN2	1.0	> Role in gathering patient histories, evaluating health, disability and mental health issues that may impact patients and their response to treatment, and monitoring medications
Clinical Nurse Specialist (ID)	RN3	1.0	> Role in gathering patient histories, evaluating health, disability and mental health issues that may impact patients and their response to treatment, and monitoring medications > Co-ordination of care/ case management, education, and medical therapy
Clinical Psychologist	AHP3	TBD	> Facilitates treatment planning through comprehensive assessments of the patient's psychosocial functioning, including personality, psychopathology, social support, level of motivation, and coping resources. > Provides skills training and problem solving in particular with respect to behaviour management to families, carers and workers in patient's homes > Development of psychological interventions, including education > Works in partnership with existing health and / or NDIS teams to ensure care planning is comprehensive and not duplicated regarding the interface with NDIA.
Neuro Psychologist	AHP3	TBD	> Facilitates treatment planning through comprehensive assessment, diagnosis and neuropsychological intervention related to cognitive, emotional and behavioural effects of a range of brain based conditions > Provides education, training, support and information to clinicians, patients and staff > Works in partnership with existing health and / or NDIS teams to ensure care planning is comprehensive and not duplicated regarding the interface with NDIA.

Position	Class.	FTE	Role
Senior Occupational Therapist	AHP3	TBD	> Provides occupational therapy assessment of Activities of Daily Living relevant to the individual's goals and environment > Provides skills training and problem solving with respect to behaviour management and assessment of environment and adaptation as required > Works in partnership with existing health and / or NDIS teams to ensure care planning is comprehensive and not duplicated regarding the interface with NDIA.
Senior Speech Pathologist	AHP3	TBD	> Provides support to both patients and the multi-disciplinary team to enable a more effective communication and engagement with clients as part of the assessment and planning and intervention process > Provides training in use of high and low technology communication support options
Senior Pharmacist	AHP3	TBD	> Medication reviews and staff/client education regarding medicines issues, undertake research/audits, develop medicine-related policies and undertake other clinical governance activities and could have a coordination role with respect to linking the core team with accredited pharmacists in the community
Developmental Educator	TBC	TBD	> Provides support to the team > Capacity building / education role
Allied Health - training capacity (psych/ OT)	AHP2	TBD	> Direct support for patients – training position to support increased capacity in mainstream services
Carer consultant/ Peer support worker	TBC	TBD	> Provide support, advocacy for carers and consumers and to assist the SAIDHS to plan and develop accessible services
Administration	ASO2	2.0	> First point of contact for the service, > provides administrative support to the clinical team > supports clients to access the service > supports the health service manager in day to day operation of the service.
TOTAL FTE		**13.6**	

Staffing (Psychiatry)

Consultant Psychiatrists in this specialist area of work are in short supply in South Australia. There is currently no specialist training program to support development of this professional group. As a result, it will be important to grow the local expertise within the South Australian context.

To ensure that consultant psychiatry is provided in a consistent manner it is proposed that all metropolitan LHNs contribute staff to the specialist service. This should occur on a recharge basis to NALHN, with the originating LHN responsible for deployment of a suitable consultant psychiatrist to the SAIDHS at all times.

This will strengthen expertise and capacity within the state and create a pathway for those Psychiatrists who wish to develop expertise in this area and over time will develop a wider community of practice.

The suggested consultant psychiatrist staffing model is as follows:

- NALHN will employ 1.0 FTE lead Consultant Psychiatrist(s) trained in intellectual and developmental disability for the SAIDHS. This position will deliver clinical leadership and stability.
- SALHN and CALHN will each identify a Consultant Psychiatrist to work at the SAIDHS 0.5FTE.

It is proposed that all staff will work at the NALHN site. To support the long-term need for specialised psychiatry a training position will also be established for the SAIDHS. Funding will be provided for this Registrar position.

Staffing (Nursing)

It is recommended mental health nursing be in the skill set of at least one of the nursing positions.

13.7 Service location

The SAIDHS will initially base the delivery of services out of its current location at the Ingle Farm Recreation Centre. This new location provides a quiet and peaceful atmosphere, has ample parking close to the entrance and will have Telehealth facilities. Custom modifications have been made to support accessibility including disability access ramps and restroom facilities, a lowered reception counter and wide access doors to clinic rooms for wheelchair access.

As the service expands to include additional FTE, additional service locations will need to be identified. Any future relocation or expansion will be informed by data regarding service use, suitability of the current location and evaluation of consumer feedback.

14. Specialised service model of care

The SAIDHS will promote the delivery of person centered comprehensive care based on human rights, respect, collaboration and flexibility. Services will be provided by a multidisciplinary team and will take an interdisciplinary approach to service delivery. The model will comprise the following three elements with the consumer and their individual needs at the centre of decision making and service development:

> Clinical service delivery
> Capacity building program
> Partnerships and integration

These three elements are outlined in detail below.

14.1 Clinical service delivery

14.1.1 Intake and triage

> Referrals to the SAIDHS will be accepted from the person's general practitioner or medical specialist
> Referrals can also be accepted from patients' carers, nominees or supported accommodation providers if the person does not have access to their own GP
> For patients who do not have their own GP the SAIDHS will support these patients to link with a suitable GP
> All referrals should address the eligibility criteria and where possible should include a comprehensive medical history including discussion of investigations and current treatments
> Referrals to the SAIDHS for young people transitioning from paediatric services will be through a planned transition process developed and agreed between SAIDHS and paediatric services
> Referrals can be received via mail, fax or email using the referral template located on the SAIDHS website
> New referrals to the SAIDHS will require completion of a detailed Pre-Appointment Questionnaire (PAQ) by the SAIDHS Clinic Nurse prior to the appointment
> Once a referral is received, the Clinic Nurse will contact the person's family, carer, nominated support person and/or GP to obtain additional information as needed to complete this form including information regarding the most suitable appointment location and any specific requirements for appointments to ensure safety and effectiveness for patients and clinicians.
> Through the intake process the SAIDHS will identify the most suitable clinicians to undertake an initial assessment for each patient with attempts to provide consistency across visits to assist with relationship building and understanding of complex health needs or behaviours
> Referrals will be triaged for urgency and once triaged an initial appointment date and location will be agreed, wherever possible referrals will not be placed on a waiting list
> Referrals that do not meet the SAIDHS eligibility criteria will be redirected to an appropriate service and advice will be given to the clinicians in that service about options for treatment and care
> information collected at referral will be added to a data collection system.

14.1.2 Elements of care

For eligible clients for whom a referral is accepted the team will provide services outlined in the table below:

Elements of care	Description
Comprehensive assessment	A multidisciplinary/interdisciplinary assessment conducted by the SAIDHS team clinicians, Including review of existing diagnoses.
Health care planning	Following the assessment, a comprehensive health or mental health care plan will be developed with input from family and carers and other health relevant professionals. This can be provided as part of a detailed report to the general practitioner, carers and other health professionals (as needed) to support ongoing care.
Time limited treatment by SAIDHS team	The team will provide time limited therapy with the goal of addressing reasons for referral, stabilising current issues and informing care planning in partnership with existing health NDIS teams and / or community NDIS providers as appropriate. The time taken for treatment will vary and will be determined by the treating clinician but will focus on supporting the development of a comprehensive assessment and plan that can be handed over to the day to day care team and GP once completed.
Referral to other services	Clients will be referred to other medical specialists, therapists and support services for therapy and ongoing care
Handover for ongoing care	Once treatment has been completed and a comprehensive assessment and plan has this will be communicated in a handover with the patient's usual GP, family, carer and accommodation service and will provide a report outlining any implementation or monitoring recommendations for ongoing care.
Service Evaluation	Including Patient reported experience measures (PREMs), patient reported outcome measures (PROMs), and mental health patient and carer satisfaction measures
Short-term follow up and ongoing support	The Clinic Nurse and/or GP will contact the patient's usual GP and family or carer/ accommodation service to discuss any issues with the implementation of the health care plan and to address any queries at 3 months and 6 months' post referral completion. The SAIDHS will provide clinical advice and support as required to GPs and clinicians involved in ongoing care provision.
Re-referral to the SAIDHS	Patients can be re referred to the SAIDHS by a GP or medical specialist where circumstances have changed and any new issues are unable to be addressed by mainstream health services or the existing care plan.

14.1.3 Service delivery options

The location and mode of service delivery will be flexible and adaptable with a focus on responding to the expressed needs of patients and carers well as the capacity of the service to deliver services in a safe and timely manner. Services will be delivered in the following ways:

Clinic appointments

Clinic appointments will be offered for those that can travel to a clinic appointment safely and be comfortable in a clinic environment. Clinic appointments will initially be available between 8.30am and 4.30pm Monday to Friday at the Ingle Farm Clinic. Potential for co-located clinics within other LHNs will be explored as part of the implementation phase of this model.

Home visits

Clinicians will visit patients in their home or in the community where there are barriers to attending a clinic such as significant behavioural, safety, mobility, transport or staffing issues that would delay or impede the effectiveness of a clinic appointment. Home visits will be available to all patients residing in metropolitan LHNs and to support the safety and wellbeing of SA Health staff will be conducted in accordance with the SA Health Remote or Isolated Work Health and Safety Policy Guideline.

Telehealth

Digital Telehealth appointments will be offered for those patients who for a range of reasons are unable to attend the clinic or receive a home visit. This will include all clients residing in country LHNs and will be provided in accordance with the SA Health Guidelines for Clinical Services Offering Digital Telehealth Network Consultations.

14.2 Capacity building

Building the capacity of the mainstream health system to provide appropriate health care to people with intellectual disability is one of the pillars of this model of care. The SAIDHS will take a tiered approach to capacity building from less to more intensive to allow for consumers and clinicians to access the level of support that they need when they need it, thereby embedding and individualising learnings in existing day to day practice.

14.2.1 Information and resources

The SAIDHS will maintain an online presence on the SA Health website providing relevant service information, general information about intellectual disability and health, useful links to resources such as the Hospital Passport and FAQs. The development of a more comprehensive information resource will be explored as part of the implementation phase of this work. The SAIDHS will actively partner with any relevant stakeholders in its development and will promote this resource on its webpage (see Appendix 5. Intellectual Disability Health Online Resources examples).

14.2.2 Clinical advice and support

In order to confidently provide care to people with intellectual disability and complex health needs and to prevent delays in the provision of appropriate care, clinicians across South Australia may require advice, reassurance and support. For a range of reasons this may not be available within their current workplace.

Building on the availability of high quality online information and resources outlined above, the SAIDHS will also establish a clinical advice and support function to support clinicians across South Australia. This will provide the ability to speak with an experienced SAIDHS clinician via telephone or email or through video link for case conferencing.

In addition, the SAIDHS will establish a virtual grand round focused on case studies to build skills and knowledge such as is achieved via Project ECHO, a knowledge sharing network concept currently in use by the Queensland Department of Health to increase access to best practice, evidence based care for underserved populations.

The SAIDHS will deliver an agreed number of hours per year to the provision of capacity building activities as part of service level agreements reached between NALHN and other LHNs.

14.2.3 Training and education

In order to develop and embed capability across SA Health, the SAIDHS will develop a clinical training and education function. This should be resourced appropriately and have key performance indicators identified to support evaluation. Training and education will include the following:

1. Clinical Placements and rotations:

> A rotating psychiatry registrar position
> Allied health and nursing clinical placements

2. Topic specific presentations/workshops:

> The SAIDHS will develop and deliver a range of presentations/workshops and these will be provided both onsite, virtually and via an outreach program (see below)
> Topics will be identified in consultation with LHNs, PHNs and other stakeholders and through the collation of FAQs and will be developed in response to site specific needs.

3. Online training modules:

> Links to existing training modules such as the University of Queensland X Series in Intellectual disability Healthcare and Intellectual Disability Mental Health e-learning will be available via the SAIDHS website.

14.2.4 Outreach

The focus of the SAIDHS outreach program will be to develop the skills, experience and confidence of mainstream health staff in rural and regional areas in providing clinical service to people with intellectual disability. The outreach program will aim to develop relationships between the SAIDHS and mainstream LHN clinicians and will support the delivery of professional development and education in partnership with each LHN based on locally identified training needs. The following diagram illustrates the proposed outreach program for both country and metropolitan LHNs.

14.3 Partnerships and integration

Integration of the SAIDHS within the existing health system will be a focus of early implementation of this model of care. Indeed, this model of care will aim to 'plug in' to and support existing services to help make them more effective for people with Intellectual disability. Links will be formalised through:

- Development of pathways and supportive documentation that includes clear documentation of consent arrangements for example the development of a Hospital Passport for people with intellectual disability available for download and promoted to LHNs and non-government service providers to support effective communication
- SAIDHS representation on existing forums that discuss the health care needs of people with intellectual disability currently in hospital such as the monthly Interagency Disability and NDIS operational group meeting held at the RAH
- Documentation and dissemination of information regarding the roles and responsibilities of various agencies to build awareness, clarity and transparency regarding the system of support available to people with intellectual disability and their families.

There are a range of people, teams and services both within and outside of government with whom the SAIDHS should build links and partner with in the delivery of comprehensive and integrated care. These are outlined below.

14.3.1 Consumers

People with intellectual disability and their carers should be represented on both strategic and operational forums to support service planning, development and evaluation. In addition, service delivery should be evaluated after each referral using validated patient reported experience measures (PREMs), outcome measures (PROMs) and carer experience measures. To support effective partnerships with consumers the SAIDHS should work with relevant organisations such as the South Australian Council on Intellectual Disability to develop health and service information and strategies that build health literacy and are accessible for people with intellectual disability and their carers.

In addition, the SAIDHS should engage the services of a carer consultant to provide support, advocacy and to assist the SAIDHS plan and develop accessible services. This may involve linking in with existing carer consultants employed by NALHN.

14.3.2 Local Health Networks

Metropolitan

The SAIDHS should integrate with and build strong links with disability liaison and NDIS teams in metropolitan LHNs for the purpose of identifying, conducting and supporting capacity building activities within the LHNs. These activities include those identified in DAIPs as well as raising awareness of and linking people in with the SAIDHS for those who require additional support.

Country

To build capacity across the six country LHNs and support specialised service delivery to country clients, the SAIDHS should develop links with existing roles or clinical areas with strong synergies such as complex care and mental health roles that support integrated and complex care provision. These linking roles will provide support for local service delivery as well as being able to link eligible patients with the specialised service for telehealth appointments. Suitable clinical roles within each country LHN may be different based on local staffing arrangements t the aim of these links will be to support country LHNs provide access to evidence based best practice health care for people with intellectual disability and complex health needs or behaviours, and to plan for and deliver outreach services to each country LHN twice annually (see Appendix 2. Regional Local Health Networks 2019).

Mental Health Services

The SAIDHS will build strong links with all Local Health Network mental health services in order to support them meet the additional needs of people with intellectual disability and complex health needs or behaviours. The SAIDHS will take referrals from acute and community mental health services for those that meet the eligibility criteria for the SAIDHS (see Appendix 3. SA Intellectual Disability Health Services Integration with Mental Health Services).

Child and Adolescent Mental Health Services (CAMHS)

CAMHS is a state-wide service that provides mental health services to children and adolescents with moderate to severe, and complex emotional, behavioural and mental health difficulties across South Australia irrespective of any other diagnosis. Services provided are described in the CAMHS Model of Care. Services are primarily provided in the community, with some inpatient services. Young people with co-existing mental health and disability issues can access the CAMHS Developmental Disability Service with patients being seen on the basis of need and service criteria, not diagnosis.

In partnership with the CAMHS, the SAIDHS will develop a person centered youth transition pathway and processes to support a seamless transition from child to adult services.

Health Education Interface

The Health Education Interface (HEI) is a partnership between SA Health and the Department for Education that includes provision of specialised nursing and psychiatry consultancy to schools and preschools working with many of the most complex clients with developmental and intellectual disability and their families.

As patients reach a developmental age that is more suitable to an adult service they may require the support of the SAIDHS. This may occur between the ages of 16 and 24 and should be based on developmental rather than chronological age and in liaison with family and clinicians with good knowledge of and relationship with the young adult.

In partnership with the HEI, the SAIDHS will develop a person centered youth transition pathway and processes to support a seamless transition from child to adult services.

SA Dental Service

Dental service profiles indicate that people with disabilities suffer from poorer oral health when compared with the general population. For this reason, people with disabilities are identified as a priority population in the South Australian Oral Health Plan (2019-2026).

SA Dental Service provides specialist services for adult clients with an intellectual disability who are unable to receive care at a mainstream clinic. Eligible clients are referred from a Community Dental Clinic to the Special Needs Unit at the Adelaide Dental Hospital.

The disability sector is represented on the SA Dental Service Consumer Advisory Panel. This provides an opportunity for the representative to advise on effective client participation in oral health services, at a policy and strategic level, and advocate on behalf of the client group. The SAIDHS and SA Dental Service will likely share many of the same patients and should develop and invest in a supportive working relationship through existing forums.

14.3.3 Primary health

The SAIDHS will develop and promote supportive relationships with individual GPs who refer to the service. The SAIDHS will also develop partnerships with the two SA PHNs with a focus on how the SAIDHS can support existing capacity building programs and training initiatives and development of integrated care pathways between primary practice and the SAIDHS.

14.3.4 Non-government service providers

A significant majority of referrals to the SAIDHS will come from non-government service providers who provide varying levels of support and care to people with intellectual disability and complex health needs or behaviours including non-government primary mental health services and disability accommodation and support services. Accordingly, a significant focus of the SAIDHS will be on building links with these service providers in order to build capacity and to support information sharing and communication and develop effective processes. This may include:

- Attendance at or hosting of shared clinics
- Co-development/agreement regarding shared pathways and processes
- Attendance on shared operational forums
- Support to meet annual specialist review of restrictive practices requirements.

Clinicians working in private practice will also be important partners in high quality integrated service provision and will be surveyed and included in planned capacity building and service improvement activities.

14.3.5 Research institutions

The SAIDHS will seek to partner with local and interstate research organisations such as Health Translation SA, Flinders University Caring Futures institute, Torrens University and other interested organisations to contribute to research regarding the health and wellbeing of people with intellectual disability, evidence based approaches to care and the collection and evaluation of data relating to people with intellectual disability to support service planning and improvement.

14.3.6 NDIS

As the SAIDHS has significant work to do to implement a model of care that can support state-wide delivery of specialised health services, any decisions regarding whether or not to provide NDIS supports will be delayed until an informed decision can be made on how this would impact on the services ability to achieve its core functions.

In the interim, the SAIDHS will:

- Engage with Local Area Coordinators where required to or requested
- Provide input into NDIS participant planning, for example where evidence of disability is required or where a change in circumstances requires a plan update
- Apply for applicable NDIS Grants to support research and information, linkages and capacity building projects.
- Develop relationships with NDIS providers involved in the provision of supports to SAIDHS patients

14.3.7 Training and accreditation providers

Under the existing Northern Adelaide Local Health Network agreement, the SAIDHS will develop links with South Australia Medical Education and Training (SAMET) and Better Placed to support clinical education and training placements and rotations.

14.3.8 Representative and advocacy organisations

The SAIDHS will build relationships with the following peak consumer and carer organisations in SA to raise awareness of the service and to reach a wider audience and seek feedback as required on service planning, design and delivery:

- South Australian Council on Intellectual Disability (SACID)
- Carers SA
- Disability Advocacy and Complaints Service South Australia (DACSSA)

14.3.9.Aboriginal Health Services

The literature points to an increased rate of intellectual disability across the lifespan, from childhood, adulthood and old age, in Aboriginal and Torres Strait Islander peoples, with the prevalence from roughly two times the rate in childhood to five times the rate for people over 65 years of age.[31]

Data relating to the number of Aboriginal and Torres Strait Islander people needing access to the SAIDHS is currently unavailable and is needed to support service planning. It is recommended that this information is collected by the SAIDHS as part of the pre appointment questionnaire. Where it is identified that a person is of Aboriginal or Torres Strait Islander descent these patients should be given the opportunity to have an Aboriginal Health Worker present at appointments.

As SA Health employees, all staff of the SAIDHS are required to undertake mandatory Aboriginal Cultural Learning online course in order to support the delivery of culturally safe care as part of the SA Health Aboriginal Cultural Learning Framework.

The SAIDHS will also develop links with Aboriginal Health Services across SA including Aboriginal Hospital Liaison Officers who will be invited to contribute to the design and delivery of current and future services.

14.3.10 Refugee Health Service

The Refugee Health Service is a specialist health service for newly arrived refugees and asylum seekers in South Australia that focuses on new arrival families and individuals with complex health and psycho-social needs. The service provides:

- Health assessments and coordination of care for clients with multiple health issues
- Coordination of care required for complex conditions and infectious diseases
- Intervention to address acute and chronic physical/ psycho social consequences of torture, trauma and gender based violence
- Health literacy education and support, helping clients navigate the health system and self-manage health issues
- Support to enable timely access to the NDIS
- A daily nurse led ‘drop in clinic’ for clinical assessment and management.

The SAIDHS will build links with the Refugee Health Service to support eligible patients to access the SAIDHS and to enable the delivery of culturally appropriate services. Information regarding the need for an interpreter will be collected on referral and interpreters and translators will be engaged by the SAIDHS as required through the Interpreting and Translating Centre.

14.3.11 Exceptional Needs Unit

The Exceptional Needs Unit (ENU) is a team within the Department of Human Services that works to assist individuals and families navigate systems who may be stuck, facing complex responses or may be facing barriers to accessing appropriate supports. ENU clients have multiple and complex needs across multiple life domains that are not being met by mainstream services including mental or physical health needs, homelessness, offending histories, family challenges, social isolation and or disability. The SAIDHS will work in partnership with the ENU as required to support shared clients with an intellectual disability and exceptional needs to receive appropriate health supports.

PART C: IMPLEMENTATION AND MONITORING

This section of the document provides a high level outline of first steps in implementing the new model of care and provides comment on the need for a monitoring and evaluation plan to be established.

31 Parker et al, 2014 in Dudgeon et al (2014) Working together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice, available at: https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/working-together-aboriginal-and-wellbeing-2014.pdf

15. Implementation

Given the significant gap between the current state and the proposed future model of care, implementation will occur in a staged approach over a period of 3 years. An implementation plan will be developed outlining how this model of care will be rolled out over time and identifying responsibility for implementation activities. It will be essential that there is a continued collaboration between the SA Intellectual Disability Health Service and LHNs in developing pathways of care within the proposed tiered system through implementation planning. It is expected that at minimum the following will be commenced but may not be completed in the first year:

Action
1. Establish governance structure and accountability
2. Develop the workforce and infrastructure
3. Establish data collection and evaluation capability
4. Establish partnerships and links
5. Understand training needs and development of training content
6. Develop services
7. Promote the SAIDHS
8. Establish clinical placements and rotations
9. Progress the development of an information resource
10. Develop a detailed monitoring and evaluation framework.

16. Monitoring and evaluation

There are currently no key performance indicators to systematically monitor and manage how well the health system is looking after people with intellectual disability. A draft monitoring and evaluation framework and a set of key performance indicators is a high priority for early implementation.

17. Appendices

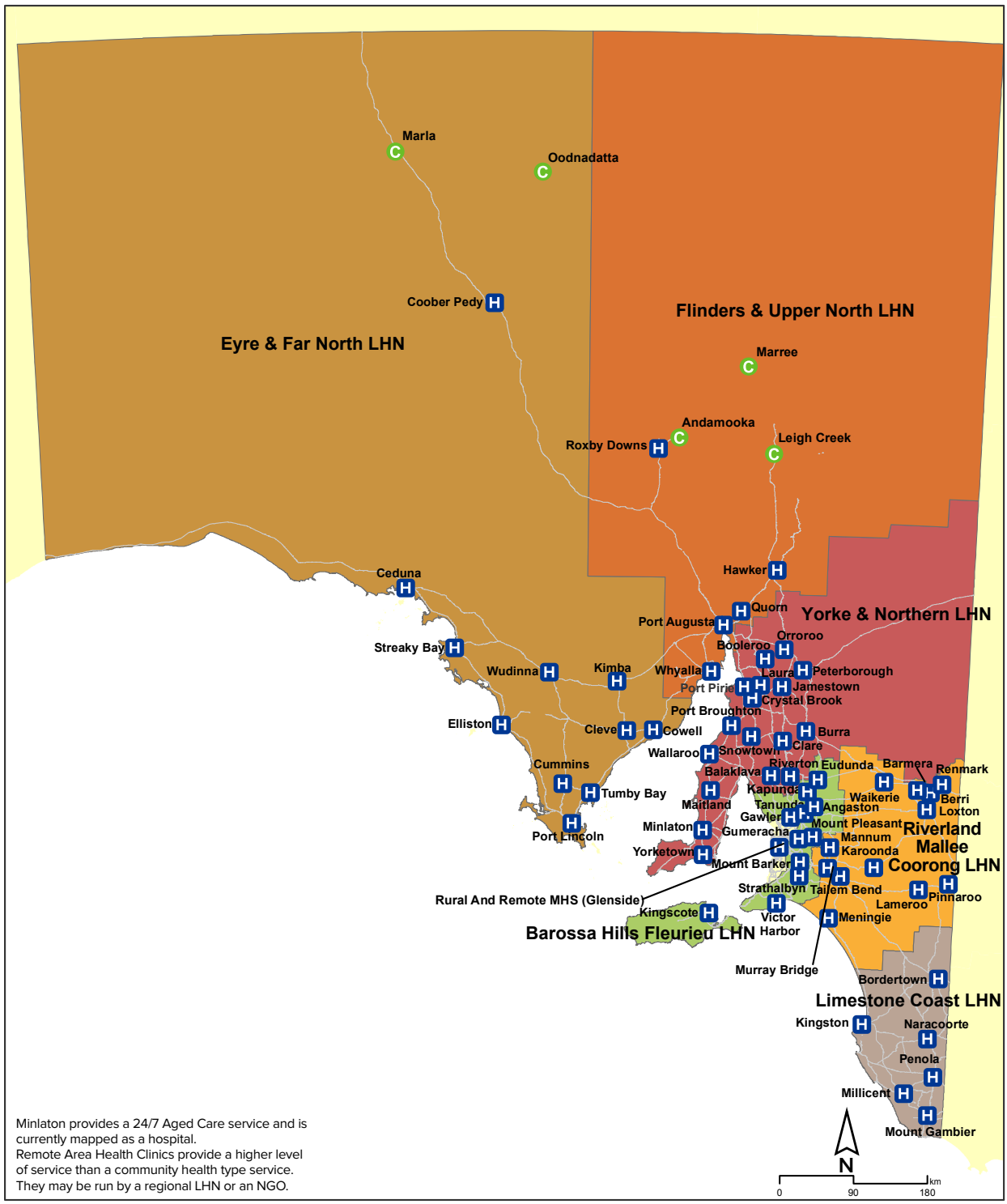
1 Capacity building resources

> Building capability in NSW Health Services for people with intellectual disability - The Essentials, NSW ACI (2017)

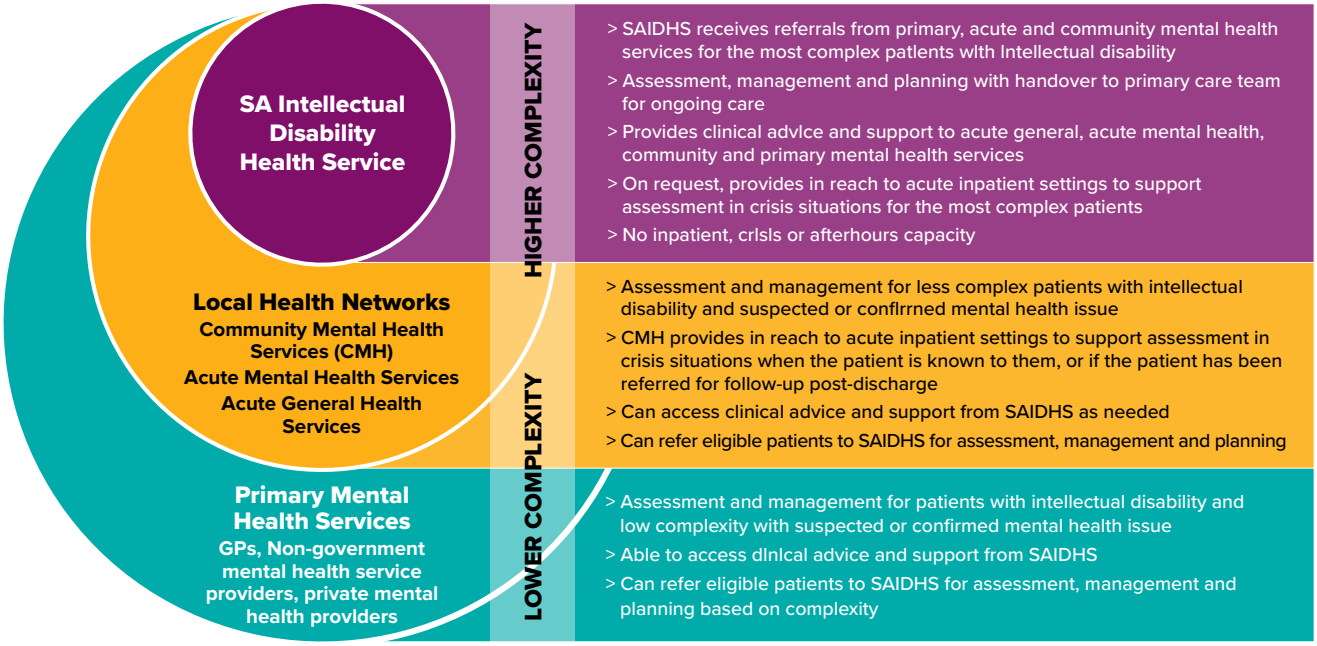
> The Guide, Accessible Mental Health Services for People with an Intellectual Disability, A Guide for Providers UNSW 3DN (2014)

> Evidence Check, Capacity Building and Intellectual Disability Health Services, Sax Institute (2017)

2 Regional Local Health Networks 2019



3 SA Intellectual Disability Health Service - Integration with Mental Health Services



4 My Health Information, for when I go to Hospital

People with intellectual disability were consulted on the final draft of the hospital passport. They told us that the term 'passport' was confusing and caused anxiety. They were worried that they might not be admitted to hospital without the passport. For this reason, this document will not be called a Hospital Passport and instead will be called *My Health Information, for when I go to hospital.*

This is MY HEALTH INFORMATION for when I go to hospital

To be filled in by me - or my mum, dad, carer or guardian - for when I go to hospital.

I have an intellectual disability and MY FULL NAME is:

.....

Date filled in: .....

Filled in by (full name):

.....

If I have to go to hospital, this document needs to go with me. It gives hospital staff important information about me.

It needs to hang on the end of my hospital bed and a copy should be put in my hospital notes.

This document belongs to me. Please return it when I leave hospital.

For nurses, doctors and other health professionals: please look at this document which includes the following information, before you admit me into hospital and treat me:

1. **Things you MUST KNOW about me**
2. **Things that are IMPORTANT to me**
3. **My LIKES and DISLIKES**

Government of South Australia
SA Health

1 Things you MUST KNOW about me

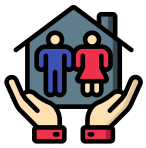
I like to be called:

.....

My birthday:

.....

Day / Month / Year (in full)



I live at:

.....

.....

My telephone number:

.....

How I communicate / what language I speak:

.....

You can help me to communicate by (how to talk with me):

.....

.....

.....

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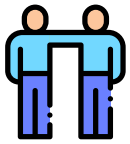
.....

.....

PAGE 2

1 Things you MUST KNOW about me

If I need more help you have permission to contact the following people:



My main contact person

Name: .....

Telephone number: .....

This person is my: .....
(mum, dad, support worker, home manager, other)

The people who mostly help me with my needs

Name: .....

Telephone number: .....

This person is my: .....
(mum, dad, support worker, home manager, other)

Name: .....

Telephone number: .....

This person is my: .....
(mum, dad, support worker, home manager, other)

My religion:

.....

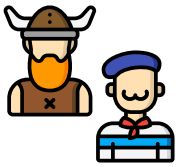
My religious/spiritual needs:

.....

.....

PAGE 3

1 Things you MUST KNOW about me



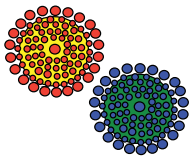
My culture/heritage/ethnicity:

.....

.....

.....

.....



I am Aboriginal or Torres Strait Islander:

☐ **YES** ☐ **NO**

My Doctor / General Practitioner (GP):

Name: .....

The address of the Doctor's clinic I go to:

.....

.....

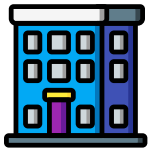
.....

The telephone number of the Doctor's clinic I go to:

.....

.....

1 Things you MUST KNOW about me



Other services/professionals that help me (for example counsellor, physio, medical specialist, dentist):

.....

.....

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.....

.....

My allergies:

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.....

.....

Special instructions for how to take my blood, give injections, blood pressure:

.....

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.....

.....

PAGE 5

1 Things you MUST KNOW about me

Do I have any problems with my heart?

☐ **YES** ☐ **NO**

Detail: .....

.....

.....

.....

Do I have any trouble breathing?

☐ **YES** ☐ **NO**

Detail: .....

.....

.....

.....

Do I have any problems with eating, drinking or swallowing?

☐ **YES** ☐ **NO**

Detail: .....

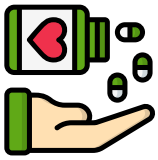
.....

.....

.....

PAGE 6

1 Things you MUST KNOW about me



My usual medicines:

1. ..... 6. .....

2. ..... 7. .....

3. ..... 8. .....

4. ..... 9. .....

5. ..... 10. .....

My medical history:

.....

.....

.....

.....

.....

.....

If I am scared or anxious, what should the doctor or nurse do to help me?

.....

.....

.....

.....

PAGE 7

2 Things that are IMPORTANT to me

How I like to take my medicine (whole tablets, crushed tablets, injections, syrup):

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.....

.....

.....

.....

How you will know if I am in pain:

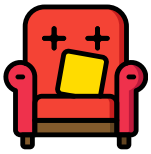
.....

.....

.....

.....

.....



How I like to sit and move around (posture in bed, walking aids):

.....

.....

.....

.....

.....

2 Things that are IMPORTANT to me

I need help to shower and get dressed:

☐ **YES** ☐ **NO**

Detail: .....

.....

.....

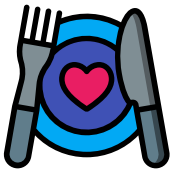
My seeing and/or hearing (problems with sight or hearing):

.....

.....

.....

.....



How I eat (for example food cut up, pureed, risk of choking, help with eating):

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.....

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How I drink (for example drink small amounts, thickened fluids):

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.....

.....

2 Things that are IMPORTANT to me

How I keep safe (for example, I need bed rails to stop me from falling out of bed; I have a positive behaviour support plan):

.....

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How I use the toilet (for example I use a special chair; I have a catheter):

.....

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.....

.....

How I like to sleep (time of going to bed and waking up, waking up in the night):

.....

.....

.....

.....

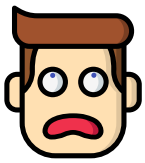
.....

3 My LIKES and DISLIKES

LIKES
(for example – what makes me happy, things I like to do, for example watching TV, reading, music, routines)

DISLIKES
(for example – don't shout, food I don't like, physical touch, unknown people)

Things I like:
(please do this)



Things I don't like:
(don't do this)

1. .....
2. .....
3. .....
4. .....
5. .....
6. .....
7. .....
8. .....
9. .....
10. .....
11. .....
12. .....
13. .....
14. .....

1. .....
2. .....
3. .....
4. .....
5. .....
6. .....
7. .....
8. .....
9. .....
10. .....
11. .....
12. .....
13. .....
14. .....

PAGE 11

NOTES

PAGE 12

CONTACTS AND USEFUL WEBSITES

In case of emergency please call triple zero (000)

SA Health Mental Health Triage 131 465

SA Intellectual Disability Health Service
Ingle Farm Recreation Centre
3/58 Beovich Road
INGLE FARM SA 5098
Telephone: 08 8397 8100

Email: HealthCentreforDisabilityHealth@sa.gov.au

Website: https://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Services/Health+Services+For/People+with+Disability/Centre+for+Disability+Health

Adelaide PHN Primary Mental Health Enquiry Line 1300 898 213

Health Direct Australia 1800 022 222

Medicines Information (SA Pharmacy) 8161 7555

Patient Assistance Transport Scheme 1300 341 684

Country Health Connect 1800 944 912

Icons made by Smashicons and Freepik from www.flaticon.com

This document is based on the NHS South West London Access to Acute Group Hospital Passport template located at www.nhs.uk

For more information
www.sahealth.sa.gov.au
Sensitive: Personal I1-A2

This document has been reviewed and endorsed by SQCAG* for consumers and the community July 2020.

*SA Health Safety and Quality Community Advisory Group

Interpreter

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PAGE 13

5 Intellectual Disability Health Online Resources – examples

> Understanding Intellectual Disability and Health – University of Hertfordshire, UK

> Centre for Developmental and Dual Disability – Monash University, VIC

> Queensland Centre for Intellectual and Developmental Disability – Mater Research Institute, University of QLD

> NSW Agency for Clinical Innovation - Intellectual Disability Health Network – NSW Government

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For more information

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