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Pond, Aleks (Health)

From: McIntyre, Rebecca (Health)
Sent: Tuesday, 4 June 2019 5:02 PM
To: [redacted] Aloisi, Bruno (Health); [redacted] Axell, Anita; Bicket, Robyn; Bingham, Jaime (Health); [redacted] Bowrah, Victoria (Health); Braun, Helen (Health); Burvill, Stefanie (Health); Calvin, Sam (Health); [redacted] Charles, Amanda; Chief Psychiatrist; Donley, Mandy; [redacted] Dunne, Ellen; Gibson, Sally; Kaur, Tej; Kipling, Wendy; Kirkham, Anna; [redacted] Lewis, Llew (Health); McIntyre, Shirley-Anne (Health); [redacted] Nagle, Dannielle (Health); [redacted] Ratnayake, Priyani; Redmond, [redacted] Rogers, Lee-Anne (Health); Rugendyke, Amy; Kerr, Sheridan; Shuhyta, Amber; Simon, Michelle; Smith, Meghan (Health); Sweetman, Rebecca (Health); Wafer, Matthew (Health); Walker, Janelle (Health); [redacted] Lee, Melissa (Health)
Cc: Kingsford, Susan; Mackey, Patricia; Garrington, Catherine; Niovanni, Steven (Health); Grace, Karen (Health); Colliver, Deborah (Health); Roberson, Bronwyn (Health); Furner, Catherine (Health); Waterson, Rebecca (Health); Arya, Dinesh (Health); Santillan, Diego
Subject: Mental Health Services for People with Intellectual Disability
Attachments: Mental Health Service for People with DD_Agenda.docx; Mental Health Services for People with Developmental Disability - FINAL .docx; Attachment C - National Recommendations.pdf

UNOFFICIAL

Hi All,

Apologies for the delay in getting these out to you all - please find attached:

- Agenda for tomorrow's meeting;
- Paper to inform tomorrows discussion; and
- the National Roundtable Recommendations (for background).

Please also note location: **ACT Health 4-6 Bowes St Phillip – Level 2 Conference Centre, Room 1**

Regards,

Rebecca McIntyre
Senior Policy Officer|Mental Health Policy|
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Level 3, 2-4 Bowes Street, Woden 2606.

ACT Government | ACT Health

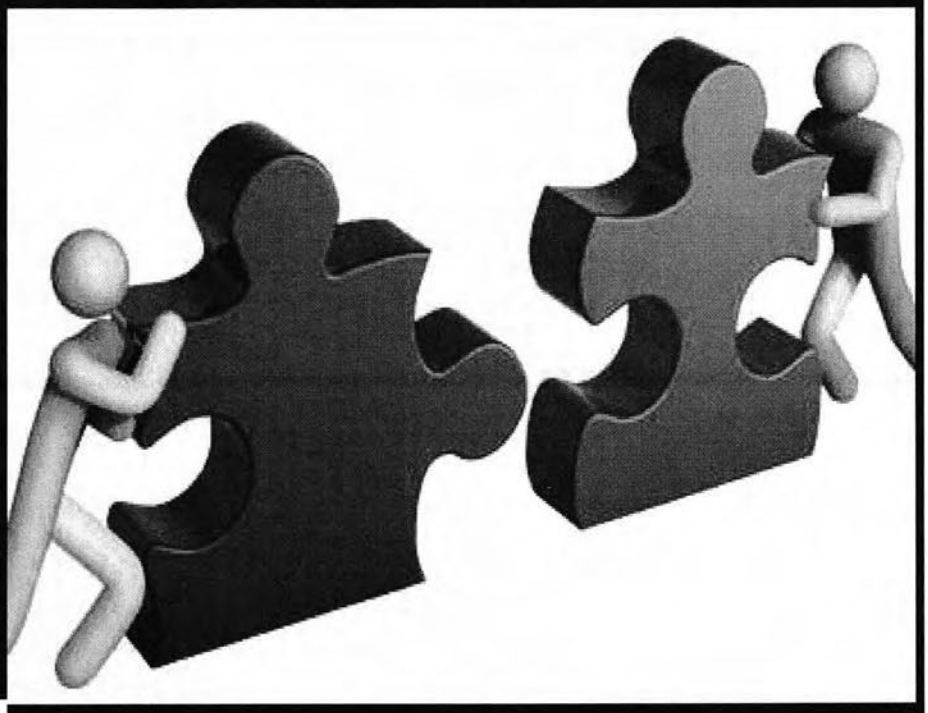
AGENDA
Mental Health Services for People with Developmental Disability Stakeholders Workshop 2

3:00 – 5:00 pm
Wednesday 5 June 2019
ACT Health, 4-6 Bowes St
Conference Centre Room 1 (Level 2)

1. **Welcome and apologies**
2. **Introductions**
3. **Discovery Session**
4. **Prioritization**
5. **Check Against Need**
6. **Workshop Concludes**

ACT Government | ACT Health

Mental Health Services for People with Developmental Disability



Key Elements and Directions for Future Action: *for Discussion*

June, 2019

Contents

Introduction

Drawing on the Recommendations from the 'National Roundtable on the Mental Health of People with Intellectual Disability, 2018 Communique' (Roundtable Recommendations) and the 'Mental Health Services for People with Intellectual Disability (ID) Discussion Paper', this paper outlines examples and potential future actions identified under the eight key elements proposed by the Roundtable Recommendations to improve mental health (MH) service delivery for people with Developmental Disability (DD), and their families and carers, in the ACT.

For the purposes of this paper, people with DD include those with (ID and Autism Spectrum Disorder (ASD).

It is intended that the information in this paper will form a springboard for discussion at a stakeholders' workshop being held on Wednesday 5 June 2019. This discussion by subject matter experts will complement the best practice information provided in this paper to inform development of a final Strategic Direction for Mental Health Services for People with DD in the ACT.

Existing Services

There are several touch points where a person with DD may also present with MH needs in the ACT. Each of these points can be envisaged as a point of opportunity for MH early intervention and prevention; or as a gateway for referral to mental health services including the dedicated multidisciplinary 'Mental Health Service for People with Intellectual Disability' (MH-IDS) depending on assessment of need. Currently, services for people with DD and MH needs in the ACT include:

Primary Care

GPs can be seen for 'mental health assessment' and treatment and are able to refer people to private allied health providers through the Better Access to Mental Health Services scheme, to mainstream government mental health services and to the MH-IDS where required.

Medicare (Commonwealth) *Item 707* entitles people with ID to an annual health assessment from a GP, at full subsidy. This is a prolonged health assessment (at least 60 minutes) to meet the specific needs of people with ID including:

- comprehensive information collection, including taking a patient history; and
- an extensive examination of the patient's medical condition, and physical, psychological and social function; and
- initiating interventions or referrals as indicated; and
- providing a comprehensive preventive health care management plan for the patient.

GPs are also a valuable source of support for carers and families who may be experiencing trauma or distress as a result of supporting someone with DD and MH needs.

ACT Education Directorate

Schools play a major role in assisting young people with DD, including the identification and management of mental health issues and referral as required. There are a number of supports available to school students with DD and MH needs. These include:

School psychologists

Provide valuable services to students that address educational, social, emotional and behavioural needs, either individually or in groups.

Psychologists can also support parents and teachers to manage issues that can affect students' educational progress and adjustment.

Allied Health

Network Student Engagement Teams (NSETs) provide support to each school region, to improve student engagement and outcomes. These interdisciplinary teams work with other school supports (teachers, support staff; community and government agencies etc.) to build capacity and to engage every student in meaningful, relevant learning, enabling them to

fulfil their potential. This includes assisting schools to work with students who have complex needs and challenging behaviour.

NSET teams include hearing and vision support partners; inclusion officers; occupational therapists; physiotherapists; speech language pathologists; allied health assistants; senior psychologists; social workers and 'support at preschool' teachers.

Community Programs

Carers ACT[1]

Carers ACT offer a range of supports and services designed to nurture, connect and empower carers. Practical support includes short-term replacement care when you need a break; counselling, educational workshops, social and therapeutic activities and advocacy.

Child Development Service (Community Services Directorate)

A free, service that provides assessment, referral, information and linkages in relation to child (0-6 years) developmental concerns[2] (e.g. ID and ASD). This includes psychological services and Child Health Medical Officers accessible through a comprehensive intake and screening process. The CDS can also provide:

- Autism assessment for children aged up to 12 years, with a referral from a paediatrician or psychiatrist;
- information about how to access private support providers in the ACT;
- referral of families to the NDIA Early Childhood Early Intervention service, should children require early intervention supports.

Community Paediatric and Child Health Service (CP & CHS) (Canberra Health Services)

Following GP referral, CP & CHS provide assessment and treatment for young people under the age of 16 with:

- suspected or established developmental delay or disability;
- suspected biological, medical and developmental causes of behavioural or emotional disturbances;
- intellectual or physical disability or chronic medical conditions that interfere with development or education; and/or
- a risk of developmental problems from prematurity, neonatal complications or complex problems that require management plan.

Child and Adolescent Mental Health Services (CAMHS); Adult Community Mental Health Services (ACMHS); Older Person's

1 https://www.carersact.org.au/fact-sheets/

2 https://www.communityservices.act.gov.au/childdevelopmentservice/referrals

Community Mental Health Services (OPCMHS) (Canberra Health Services

People with DD may present with MH needs to any of the community MH services that operate in the ACT. These services deliver assessment and treatment as appropriate, with consultation and liaison from the MH-IDS as required, and/or referral to the MH-IDS if indicated.

Specialist Mental Health Service for People with Intellectual Disability (MH-IDS)

The MH-IDS is a specialist, cross-agency, consultation liaison service that provides comprehensive clinical assessment and psychiatric treatment to people with DD and MH needs. This service collaborates with treating practitioners, families, support persons and other relevant agencies. Referrals can be made by contacting the MH-IDS team, through a GP or other community support provider as outlined above.

The MH-IDS team can provide MH expertise, training and education to community professionals and support persons assisting people with DD and known or suspected mental illness (MI).

Hospital Services

Acute Mental Health Unit (AMHU); Mental Health Short Stay Unit (MHSSU); Older Person's Mental Health Inpatient Unit (OPMHIU)

People with DD and undiagnosed or diagnosed MI or disorder may also be admitted to AMHU, MHSSU or OPMHIU in relation to an acute mental health crisis.

People admitted to hospital for issues not specific to their mental health, may have access to consultation liaison mental health services where a mental health issue is also identified during their time in hospital.

Consultation and liaison with, or referral to the MH-IDS may also be indicated from any of these units.

NDIS

The Health Directorate and Canberra Health Services aims to work closely with the NDIA and NDIS providers to ensure functional support is available in relation to psychosocial disability. Given the high incidence of diagnostic overshadowing when DD is present, it can be difficult to determine the cause of disability and the appropriate response through the NDIS or other support services.

People with both DD and MH needs are also likely to intersect with the complex pathway work being done by the NDIA. Further exploration and advocacy around the functional impacts of multiple disability including NDIS system gaps and eligibility issues is required (e.g. those not eligible or choosing not to utilise the NDIS; ~ 62, 000 people with ID; only 6,000 have an NDIS package).

Key Elements and Directions for Future Action

This section builds on the 'eight elements of an effective MH system for people with intellectual disability' arising from the second National Roundtable on Intellectual Disability with best practice and example models that could be applied or adapted to the ACT context to improve MH services for people with DD.

Element 1: Inclusion

The National Roundtable highlighted a need to include people with DD and their families and carers in planning, service design and evaluation and to ensure MH support models are appropriate for the needs of people with DD. Examples include:

a) Disability Inclusion Action Plans (NSW)

Disability Inclusion Action Plans (DIAP) outline the intention and actions that Government Departments and Agencies will take to remove barriers to access of Government information, services and employment for people with disability; as well as to foster the promotion of the rights of people with disability in relation to equitable access to services. DIAPs include key areas for action and outcomes such as:

- Developing positive community attitudes and behaviours towards people with disability;
- Creating more liveable communities for people with disability;
- Achieving a higher rate of meaningful employment participation by people with disability through inclusive employment practices; and
- Achieving more equitable access to mainstream services for people with disability through better systems and processes.

Under the *Disability Inclusion Act 2014*, all NSW Government Departments, other Government agencies and all local councils are required to develop DIAPs.[3] This could be a valuable option to implement in the ACT.

Examples include: NSW Department of Education and Training[4].

b) Use of Accessible Information & Communications

Clear and consistent information about MH for people with DD and their families and carers has the potential to greatly increase access to these services. Examples include:

3 https://www.facs.nsw.gov.au/inclusion/advisory-councils/disability/inclusion-plans

4 https://www.studentswithnospeech.org.au/wp-content/uploads/2018/08/NSW-DoE-Disability-Inclusion-Action-Plan-2016-2020.pdf

The Foundation for people with learning disabilities (part of Mental Health Foundation UK) resources to improve service accessibility:

Easy Read guides to health conditions[5];

and

Improving Access to Psychological Therapies (IAPT)

A program outlining psychological therapies with reasonable adjustments to better support people with moderate learning disabilities and an associated 'Learning Disabilities Positive Practice Guide'[6].

Being a Healthy Woman - for Women with Intellectual Disability

A NSW Government Department of Health resource that aims to assist women with DD to learn more about their health including resources for families, carers and health professionals[7].

3DN UNSW's Accessible Resources:

Going to the Doctor

An accessible resource list for people with Intellectual Disability[8];

and

Psychotropic Medication

Resources for people with DD and their carers[9].

5 https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/easy-read

6 C:/Users/Rebecca%20McIntyre/Downloads/FPLD-positive-practice-guide_1.pdf

7 https://www.health.nsw.gov.au/disability/Pages/being-a-healthy-woman.aspx

8 https://3dn.unsw.edu.au/content/going-doctor

9 https://3dn.unsw.edu.au/content/psychotropic-medication

Element 2: Prevention and Timely Intervention

a) Adapted MH Screening and Assessment Tools

Early identification of MH through diagnostic tools that are effectively adapted for people with DD are valuable in to ensure people get the right help at the right time, delivered in an accessible way. Promotion of increased use of these resources by key stakeholders including GPs, carers and community agency workers would make a positive contribution to identification of MH issues, facilitating improved early intervention and prevention, and therefore more effective support provision for people with DD and MH needs. Examples include:

I-Can

The Centre for Disability Studies (CDS) developed the I-Can[10] assessment tool to support people with disabilities and MH concerns and their families and carers. I-Can provides an accessible, holistic assessment based on the WHO ICF (World Health Organisation International Classification of Functioning Disability and Health[11]) framework and can provide:

- a costing estimate (to assist with NDIS transition);
- ensure quality services integrated with health care plans; and
- support families and carers to co-ordinate and liaise with support and health professionals and assist Government bodies to allocate resources and predict future costs.

The I-CAN is used in many settings, including:

- An independent needs assessment when applying to the NDIS;
- Resource allocation for individual funding packages;
- Community support for people with intellectual disabilities;
- Supported living for people with MH concerns;
- Planning for the move to community living for people leaving congregate settings; and
- Support expert evidence at legal hearings.

PAS-ADD

PAS-ADD (Psychiatric Assessment Schedule for Adults with Developmental Disabilities)[12] can help health and social care staff working with people with DD to identify MH problems.

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10 http://www.i-can.org.au/

11 https://www.who.int/classifications/icf/en/

12 http://www.pas-add.com/

Four assessments are available, all of which can provide diagnosis under both ICD 10 and DSM IV (TR). Psychiatric interviews are also based on ICD-10 criteria[13]. This checklist is designed to help carers recognise likely MH problems in people with ID. It also overcomes communication challenges by combining information from self-reports of individuals with intellectual disabilities and from key informants (family or carers). Tools include:

PAS-ADD Checklist

A 25-item questionnaire to help care staff and families decide whether an individual's mental health may require further assessment.

Mini PAS-ADD

A MH assessment tool for health and social care professionals who don't have a background in psychology or psychiatry.

ChA-PAS

A tool to assess the MH of children and adolescents, for professionals who don't have a background in psychology or psychiatry.

PAS-ADD Clinical Interview

A comprehensive tool for the clinical assessment of MH problems in people with DD.

Hayes Ability Screening Index (HASI)

Widely used in Australia and in the UK, USA, Canada, Norway and The Netherlands, the HASI is a brief, individually administered screening index of intellectual ability.

HASI was developed primarily to provide a short and effective instrument to indicate the possible presence of ID amongst persons in contact with the criminal justice system to determine those who need to be referred for further diagnostic assessment. The HASI is administered individually, appropriate for use with people aged from 13 to late adulthood. The person's score indicates a result of "refer for further assessment/diagnosis" or "no referral".

In police settings, during detention or police interviews, the HASI is designed to screen for vulnerability in victims/complainants/suspects/offenders, so that appropriate provisions for intellectual ability may be enacted.

It is important to note that this is not a diagnostic tool for intellectual disability, and therefore can be administered by non-psychologists (e.g. probation and parole personnel, police, solicitors and barristers, corrective services staff, juvenile justice workers, alcohol and other drug counsellors, forensic and correctional MH professionals) in 5-10 minutes.

HASI saves valuable time and resources and can assist in protecting vulnerable people involved with the justice system. It correctly screens for ID in 82% of cases and correctly excludes non-disabled clients in 72% of cases, correlates significantly with standardised tests of cognition and adaptive behaviour and is culture and gender fair.

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13 WHO, 1992

Learning Disability Screening Questionnaire (LDSQ)[14] and the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q)[15]

The LDSQ and CAIDS-Q provide a quick screen of adults and children/adolescents for intellectual disability. These instruments can be completed quickly placing minimum demands on the individual, carer or professional administering it, and provide a valid and reliable indication. As such, they are designed to be of use to a wide range of professionals, families and carers in a range of settings, including health, social care and criminal justice services.

The LDSQ and CAIDS-Q can be completed directly with the individual or by someone who knows him or her well. These tools deliver high levels of accuracy identifying people who have ID with 91% - 97% accuracy.

b) Early Intervention and Prevention Programs

Healthy Mind e-Program

Delivered by Black Dog Institute, Healthy Mind is a mental health self-help app for individuals with borderline to mild ID. It combines core aspects of Cognitive Behavioural Therapy (CBT) with accessible and engaging tools to manage psychological distress and make life easier to handle for people living with ID. This program utilises the benefits of multi-media communication (visual, audio & text) through electronic means to support people with and DD and their supports. This program begins trial in June 2019, aimed to be available Australia wide end of 2020.

Stepping Stones, Triple P (Positive Parenting Program)[16]

Provides support through offering a self-regulation framework for parents to support parental self-sufficiency, self-management skills, personal agency and problem-solving skills. The 10 session *Standard Stepping Stones Triple P* can be individually administered and can be complemented by supervision and agency support.

Synapse[17]

MH resources for carers, particularly in relation to depression, including signs to watch out for and strategies for prevention and support resources.

c) Trauma Informed Practice

Trauma can arise from single or repeat adverse events that threaten to overwhelm a person's ability to cope. Many trauma survivors show remarkable resilience. However, many are left struggling with their health, wellbeing, emotions, relationships and sense of self and identity and as a result have increased vulnerability to mental health issues and mental

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14 https://gcmrecordsllp.co.uk/about/the-learning-disability-screening-questionnaire-ldsq/

15 https://gcmrecordsllp.co.uk/the-child-and-adolescent-intellectual-disability-screening-questionnaire-caids-q/

16 Sanders, Mazzucchelli & Studman, 2009

17 https://synapse.org.au/information-services/mental-health-depression-carers.aspx

illness. There is a disturbingly high level of exposure to traumatic life experiences for people with DD, from life circumstances such as poverty and domestic violence through to violence and abuse that people experience in care settings. Trauma not only affects victims but also those with whom they are in contact such as family and carers. For these reasons, services for people with DD and/or MH needs, their families and carers must be trauma sensitive and informed at all stages of the treatment and support journey[18].

Trauma informed practice is a strength based framework founded on five core principles: safety, trustworthiness, choice, collaboration and empowerment as well as respect for diversity. Responding to people in a way that does not retraumatise and understands the potential impact of past trauma on behaviour and mental wellbeing requires specific upskilling of the workforce. BlueKnot Foundation have developed *Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery*[19] compiling recent national and international research in the trauma field. This resource is officially recognised as an Accepted Clinical Resource by The Royal Australian College of General Practitioners. BlueKnot also deliver a range of training and workshops[20] in this field.

d) Support for Primary Care

Opportunities to support GPs to provide improved MH services and navigate referral pathways for people with DD and MH needs should also be explored, including capacity building of the Capital Health Network (CHN) to assist this part of the service sector. This includes investment in workforce development such as awareness and capacity building, access to mentor programs and promotion of available resources.

e) Prevention of Self-harm and Suicide

More information needs to be collected on the extent of self-harm and suicide, however there are indications that prevalence is well above general population.

The ACT LifeSpan Suicide Prevention Framework and the collaboration with Black Dog Institute provides an opportunity to identify some actions in this area.

f) Adjusted Teaching and Assessment Strategies

A range of teaching and assessment strategies[21] developed by the Australian Disability Clearinghouse on education and training (ADCET), adjusted to meet the needs of students with MH and DD.

CASEA (CAMHS And Schools Early Action)

A Victorian developed, school based early intervention program for young people (5-12 years) with challenging behaviours and/or emerging conduct disorder. The program supports development of positive social, emotional and behavioural strategies, problem

18 https://www.blueknot.org.au/Workers-Practitioners/For-Health-Professionals/Resources-for-Health-Professionals/Trauma-Informed-Care-and-practice

19 https://www.blueknot.org.au/resources/Publications/Practice-Guidelines

20 https://www.blueknot.org.au/Training-Services

21 https://www.adcet.edu.au/inclusive-teaching/specific-disabilities/intellectual-disability/

solving and learning to get along with others. The program involves group work (for parents and children separately) and capacity building support for school staff.

One possibility could be to expand this program based on broader CASEA models e.g. CASEA at the Royal Children's Hospital Melbourne provides professional development for teachers and child group program content; other providers offer parent and broader school community programs; and to include multi-agency responses to DD.

Resilience and Wellbeing (RaW)

An early intervention program for secondary college students with challenging behaviours and emerging conduct disorder. The program includes content around self-monitoring and emotions, emotional regulation, self-talk and coping, problem solving and positive communication skills.

Giant Steps[22]

Originating in Canada,[23] Giant Steps is a Government subsidised private school for students aged 4 – 21 years old (preschool, primary and secondary schools) with autism spectrum disorders. Curriculum is adapted to meet the needs of students in an individualised, intensive, interdisciplinary and holistic fashion. Classes provide additional services that:

- Differentiate instruction and instructional materials to ensure accessibility and academic achievement;
- Leverage educational technology;
- Promote self-determination and autonomy; and
- Are strength-based and provide options to promote engagement.

The Canadian Giant Steps includes conferences, workshops and work placements (college & university) a resource and training centre to support the ASD community including reference books, academic material and therapeutic products for borrowing. Personalised consultations can also be arranged for individuals or groups at home or at school.

In Australia, Giant Steps has been adopted in Sydney and Melbourne, combining music, occupational and speech therapy. The program also offers professional development for staff and other health professionals; and outreach services including private speech, occupational and music therapies, educational support, parent training and training for professionals and providers within the community. There is also a Community College component for young adults.

EBSST (Emotion-Based Social Skills Training)[24]

An emotional skills program that aims to support the well-being of young people with ASD and to prevent the onset or escalation of MH concerns by developing skills in understanding own and others' emotions and emotional regulation. For example:

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22 https://giantsteps.net.au/about-giant-steps/

23 https://giantstepsmontreal.com/our-school/programs/

24 https://www.schn.health.nsw.gov.au/files/attachments/ebsst_workshop_brochure_-_final_27_3_15.pdf

Westmead Feelings Program' (WFP)[25]

A program for schools that aims to develop teacher emotional competence in children with ASD and mild intellectual disability, as well as parent and teacher social skills and parent mental health.

Social and Emotional Learning (SEL)

SEL is the process through which children and adults understand and manage emotions, set and achieve positive goals, feel and show empathy for others, establish and maintain positive relationships and make responsible decisions. Examples of these types of programs include:

Stop Think Do[26]

A capacity building training that aims to develop emotional intelligence and social skills in children and adolescents; behaviour management skills for teachers and parents; and provides support to devise individual plans for learning and behaviour change.

Be You[27]

Provided by Beyond Blue, combining the previously known PATHS (Promoting Alternative Thinking Strategies) and Social Decision Making/Problem Solving (SDM/PS)[28] programs, this is a classroom based SEL program for elementary school students that aims to reduce aggression and behaviour problems, and teaches social awareness and decision-making skills to students, teachers, carers and families.

The Alert Program[29]

A program that aims to teach self-regulation designed for people with ASD or challenging behaviours.

The Secret Agency Society

A collection of resources for clinical services; families and schools. This includes the secret agent computer game; helpful thought Missile Action game; challenger board game and secret message transmission device game to support children aged 8-12 to develop social and emotional skills.

Behavioural Approaches

Behavioural approaches acknowledge that the way we think affects the way we respond. Methods such as CBT aim to change unhelpful thoughts or cognitive processes to more helpful thought processes, allowing the client to create positive change emotionally, physiologically and behaviourally. An example program is:

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25 https://www.acer.org/au/westmead-feelings-program/research

26 http://www.stopthinkdo.com/bg_focus.php

27 https://beyou.edu.au/

28 https://youth.gov/content/social-decision-makingproblem-solving-program

29 https://www.alertprogram.com/new-to-alert-program/

Cool Kids[30]

A Cognitive Behavioural Therapy program that aims to teach children and parents skills that address anxiety disorders, adapted to suit the learning style and challenges that arise for children who also have ASD.

g) Social Inclusion Programs

The Up the Hill Project (Flinders University)

A peer mentor program[31] promoting inclusion and support for people with a disability in University. Supported by Flinders University College of Nursing and Health Sciences, the program encourages the participation of adults with a range of disabilities including ID in the social and educational lifestyle of university to develop social skills, social networks and experience a range of educational opportunities and activities.

Uni 2 Beyond

A Sydney University mentoring program that supports students to participate in university life, make social connections through a mentoring program, and to work towards individual learning outcomes matched to the individual's interests. As non-enrolled students, participants do not pay tuition fees.

30 https://www.mq.edu.au/about/campus-services-and-facilities/hospital-and-clinics/centre-for-emotional-health-clinic/programs-for-children-and-teenagers/expandable-information/asd-cool-kids-program/Cool-Kids-ASD-Program-Flyer_2018.pdf

31 https://www.flinders.edu.au/engage/community/clinics/up-the-hill-project

Element 3: Access to Skilled Services

a) Improving Accessibility

Referral pathways, roles and responsibilities and capacity building of services supporting people with DD and MH needs must be clearly articulated and committed to in order to ensure people get access to the right services when they need them. This means upskilling of disability focussed staff to identify and respond appropriately to mental health issues and upskilling of mental health focussed staff to respond more effectively to people with DD. Service and referral pathway mapping and better integration of DD and MH education and training will make a positive contribution to improving services for people with DD and MH needs in the ACT. This could include:

Clear, Consistent and Accessible Communication & Information

Resources appropriate to the ACT context and sectors should be compiled, made accessible and readily available for people with DD and their families, carers, support and treatment providers. Information gaps can then be identified, and additional resources developed as required.

In order to make this information accessible, research highlights that consistent easy to understand language should be used to describe MH issues to people with DD and their families and carers.

Strategies to improve service and information accessibility[32] include the use of reasonable adjustments such as alternative communication methods (visual, audio, electronic devices) where appropriate. There are many resources available that provide guides to creating accessible communication when sharing information and providing treatment to people with DD. There are also many exsiting resources containing accessible information about mental health, mental illness, MH promotion, self-help strategies and information on services and treatment options. Examples include:

Communicating with people with a learning disability[33]

A Mencap UK resource to guide effective communications with people who have DD.

Augmented and Alternative Communication

Depending on the person's level of function and preferences there are a range of alternative and augmented communication methods that can make information more accessible[34]. Examples[35] include low-tech; no tech; alternative access modes such as switches, keyboards and eye-gaze approaches; and the use of symbols and images.

b) Upskilling of services

32 *Accessible Mental Health Services for People with an ID,* P.27

33 https://www.mencap.org.uk/sites/default/files/2016-12/Communicating%20with%20people_updated%20%281%29.pdf

34 https://www.asha.org/NJC/AAC/

35 https://www.communicationmatters.org.uk/page/what-is-aac

SchoolLink

Delivered as a partnership between the Children's Hospital at Westmead, MH-KIDs, The NSW Department of Education and Training and the Ageing Disability and Home Care, Department of Human Services NSW (ADHC), the four year pilot aims[36] to:

- Develop a communication plan to raise awareness to a wider constituency on the MH needs of children and adolescents with an intellectual disability;
- Develop better understanding of criteria for identifying children and adolescents who have an ID and MH needs;
- Support improvements in pathways to care for children and adolescents with an intellectual disability;
- Develop a learning module to address the needs of school and MH staff working with children and adolescents with MH problems and disorders and an intellectual disability;
- Support school and MH staff who work with students with MH problems and disorders and an intellectual disability;
- Support the development of prevention and early intervention programmes/strategies for students with an ID in SSPs; and
- Develop a multidisciplinary framework for working with children and adolescents with MH problems and disorders and an ID across agencies.

c) Accessible Information on Referral Pathways to Assist Service Navigation

The need for accessible services includes accessible information to facilitate navigation of referral pathways and the service system for people with DD and MH and their families and supports; as well as accessible avenues for feedback related to patient satisfaction with care received. Examples of this include:

NSW Agency for Clinical Innovation's (ACI's) resources:

Accessing NSW Health Services for People with Intellectual Disability[37]

Guideline's to the Pathways to Care for children and adolescents with intellectual disability and challenging behaviour and/or mental health problems

36 http://www.schoollink.chw.edu.au/about-us/

37 https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0015/201732/Accessing-Health-Services-2017.pdf

Element 4: Specialist Services Support Mainstream Mental Health Services

a) MH-IDS Consultation Liaison and Provision of Mentoring Services

The ACT is fortunate to have a specialist Mental Health and Intellectual Disability Service that attempts to meet the needs of this population. Promotion of the role of this service in consult liaison and mentoring to mainstream services should be included as part of the approach to upskilling services.

Considerations for capacity building of this service include:

- Increasing capacity to provide services to people under 17 years.
- Increasing capacity to outreach to mainstream services as mentors (e.g. Clinical Coordinator role being established in NSW outlined in Collaboration section c)).
- Increase capacity to be a conduit for Positive Behaviour Support expertise (possible partnership with Forensic Mental Health Services and Community Services Directorate).

Element 5: Collaboration

Literature highlights the importance of integrated multi-agency approaches to provide appropriate support for people with DD and MH needs.

Examples of effective collaborative responses that could provide a model to improve support for people with MH and DD needs in the ACT include:

a) Care Coordination and Case Management

Care coordination[38] involves planning a person's care and support and sharing information with everyone who has a role in it, to facilitate the safest, most appropriate, efficient, and effective care. Care coordination includes:

- assessment of a person's physical and mental condition;
- education and support for the person and their carer;
- communication with health and community care providers;
- helping the person get community care and support services; and
- planning for the future.

Care coordination may involve a personalised care plan identifying the services needed, when they will be supplied and key responsibilities of each party. Care Plans could include the carer, the person being cared for and a doctor, or a team of many health care professionals working together.

A case manager or care/support coordinator may be included in the care plan (e.g. NDIS Plans), as the role responsible for contacting people and organising services i.e. managing the care being accessed. The carer may often take on this role. Examples of existing models include:

'Complex Case Management Program' - Education Directorate

More information from Education required to determine what this looks like.

b) Multi-Agency Responses

Integrated Service Response Program

The Integrated Service Response Program (ISRP) is run by the Office for Disability in the ACT Community Services Directorate. Two skilled staff members provide short term coordination support for people who have high or complex needs. The program may also provide funding for people with disability to purchase emergency supports and services from non-government providers.

The program works with the NDIA and service providers to resolve crises and highly complex situations for people with intensive support needs. It will connect individuals with

38 https://www.carergateway.gov.au/care-co-ordination-and-case-management

mainstream services, for example the health and education systems. The program ensures everyone is working together behind the scenes to support people who have intensive support needs and. The program works closely with the National Disability Insurance Agency (NDIA) and has a direct line to key decision makers. ISRP provides short term coordination and will not provide ongoing case management or support coordination.

There may be potential for this model to be adapted or extended to meet the needs of a broader range of people with DD and MH needs.

MACNI (Multiple and Complex Needs Initiative)[39]

A Victorian initiative, MACNI supports people aged 16 years or older with multiple and complex needs (e.g. MI/MH & DD). Support involves development of a care plan including individual needs and goals across areas of stable housing, health, wellbeing and safety, and increased social connectedness; therapeutic goals; enhanced discharge planning from acute inpatient settings and provides a platform for long-term engagement in the service system[40].

39 https://services.dhhs.vic.gov.au/multiple-and-complex-needs-initiative

40 file:///C:/Users/Rebecca%20McIntyre/Downloads/adult-intensive-complex-care-packages.pdf

Element 6: Workforce Development and Support

Literature highlights the importance of professional training and education to support the delivery of mental health promotion, prevention and intervention to people with DD and MH needs. Improving mental health literacy increases the capacity of people working with or caring for people with DD to most effectively provide support, and early intervention for MH issues. Developing adequate expertise and access to specialist resources across the mental health and disability workforce will also be required. Examples to increase capacity of disability and mental health service providers include:

a) For the mental health and disability workforce

Access to MH services for people with DD often relies on carers (resources at Section B) and GPs recognising signs of mental ill-health[41]. Capacity building resources to promote effective identification and support to manage mental ill-health for people with ID, at all touch points including carers, universal health care services (primary care, GP & Allied Health), community organisations and mainstream services. There are many existing free resources[42] available to build capacity, including the following examples:

Intellectual Disability Mental Health Core Competency Framework

A manual developed by UNSW 3DN (Department of Developmental Disability Neuropsychiatry), for Mental Health Professionals and an accompanying Toolkit for mainstream MH professionals.

Intellectual Disability Mental Health e-Learning[43]

An e-Learning website developed by UNSW's Department of Developmental Disability Neuropsychiatry (3DN) provides a free training resource to improve MH outcomes for people with an ID. Health professionals can work through learning modules at their own pace. The site is designed to be an interactive education resource for anyone with an interest in DD and mental health.

Information on Disability Employment Western Australia (IdeasWA)[44]

Provides links to a series of downloadable resources that can be used as training material. Titles include Caring Together, Challenging Behaviour Tip Sheets, Personal Care Support in Disability Services, Care Support Worker Training and Training provider/Service provider relationships.

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41 Evans et al 2012, p. 1099

42 https://3dn.unsw.edu.au/the-guide

43 www.idhealtheducation.edu.au

44 **www.ideaswa.net/training-manuals.html**

Centre for Developmental Disability Health Victoria (CDDHV)[45]

Working with the Royal Australian College of General Practitioners (RACGP) to develop online educational activities on the health and healthcare of people with a developmental disability[46].

New South Wales Government

Has developed useful resources including the 'Intellectual Disability Mental Health First Aid Manual'[47] to assist direct care staff to better support the people they are caring for.

Positive Behavioural Support (PBS)

Working with people with challenging behaviours is a significant gap in services. Developing expertise in this area is critical for services who support people with behaviours of concern, and/or DD and/or MH issues including within justice services, forensic services and disability support

PBS is a scientific approach that aims to protect a person's rights and to promote quality of life for them and their families. PBS is different from popular behaviour management programs in that it is purely positive and proactive. It carries out an individualised comprehensive assessment of the person and the behaviour, closely matching the intervention to the assessment considering the function of the person.

Positive Behaviour Support (PBS) Plans

To identify, understand and asses the behaviour(s) of concern and develop, implement and review a behaviour support plan (BSP).

Research suggests that the quality of BSPs is an important aspect of the quality and effectiveness of support provided to people with disability who demonstrate challenging behaviours; has been found to lead to reductions in challenging behaviour; and is associated with reductions in the use of restrictive practices and seclusion[48]. There are a range of resources and expertise accessible to the ACT community including:

Positive Behaviour Support Guides

See examples delivered by Mind Australia[49].

State developed resources including:

- ACT[50];

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45 www.cddh.monash.org

46 www.gplearning.com.au

47https://mhfa.com.au/sites/default/files/2nd-Edn-ID-MHFA-Manual-Sept-2012-small.pdf

48 Webber, Richardson & Fester (2012)

49https://www.mindaustralia.org.au/sites/default/files/Mind%27s_approach_to_working_with_people_who_have_a_dual_disability.pdf p. 13

50 https://www.communityservices.act.gov.au/quality-complaints-and-regulation/office-of-the-senior-practitioner/positive-behaviour-support-plans-factsheet

- South Australia[51];
- Western Australia[52]; and
- Queensland[53].

Commonwealth Department of Education and Training Resources

For example:

National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector;[54]

and

Planning for Personalised Learning and Support: A National Resource[55]

Increasing access to expertise in PBS and developing BSPs is an urgent need for the ACT service system. Innovative approaches to capacity building are required to support this specialised and complex work. This need sits across sectors and suggests the need for a joint response between mental health, disability and forensic services.

Clinical Co-ordinator Roles

New South Wales has recently increased availability of clinical coordinators across services.

ACT HD is seeking more information on these roles from NSW.

A similar role could be established for the ACT, scaled to fit the size of the jurisdiction, to support better integration and co-ordination of care for people with DD and MH needs.

This could be implemented in a number of ways:

- by increasing the capacity of the MH-IDS team;
- by embedding specialist or upskilled positions in mainstream services or key areas such as the Capital Health Network.

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51 https://dhs.sa.gov.au/__data/assets/pdf_file/0020/55604/positive-behaviour-support-guide-south-australian-disability-sector.pdf

52http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Positive%20Behaviour%20Support%20Information%20Sheet%20for%20Disability%20Sector%20Organisations.pdf

53 https://www.communities.qld.gov.au/disability/service-providers/centre-excellence/positive-behaviour-support

54 https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector

55https://docs.education.gov.au/system/files/doc/other/planningforpersonalisedlearningandsupportnationalresource.pdf

This approach would ensure adequate specialist knowledge of unique needs of people with DD and MH are understood and catered for across the MH service system and facilitate collaborative approaches within services.

b) For Families and Carers

Support for families/carers should be integrated with education and training for GPs by way of holistic integrated care provision. Practice models to support families and carers include:

Signposts for Building Better Behaviour

A training program for professionals supporting young people including those with ID&/or ASD and MH needs. The program targets early childhood (3-5 years); middle childhood (6-12 years) and Parents and covers topics including assessing child behaviour, promoting positive behaviours (to replace difficult behaviours), working together as a team and dealing with stress in the family.

Be You[56]

(see description in 'early intervention' section)

Emotion based social skills training (EBSST)[57]

For children with ASD and/or mild intellectual Disability, aged between 8-12 years. An example provider is the Children's Hospital at Westmead, presented by Behaviour and Allied Health Services. The program aims to develop children's capacity to label their emotions, notice the emotions in other people and to use a range of coping strategies. Material covers 'understanding emotions', 'problem solving and perspective taking', and 'managing emotions' through comprehensive teacher and parent education, facilitated by hospital clinicians.

Monash Health

UK resources including:

Depression in Adults with Intellectual Disability Checklist
(to provide additional information for GP assessment); and

Personal Health Records for People with Developmental Disability.

As well as ensuring optimal services and support for people with DD, research highlights the need to support carers and families as they often experience trauma resulting from their caring role. Examples of this support include Information and Counselling Services to support people to work through challenges, for example:

Carers ACT

(see section on early intervention)

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56 https://beyou.edu.au/

57 https://www.interactionservices.org/events/event/emotion-based-social-skills-training/

Stepping Stones Triple P (SSTP)

(see section on early intervention)

Aspect Victoria (VIC) Positive Behaviour Support Program[58]

A free program for parents/carers of children and young adults diagnosed with autism aged 6 – 25 years of age and living at home. The three tiered program offers:

- Positive Behaviour Support Workshops - Group training and information.
- Post Workshop Consultation - Short term additional assistance for families needing support with their individual behaviour support plan following attendance at a workshop
- Individual Behaviour Support Coordination – a 'wrap around' team approach provides support to a small number of families with a child or young person with complex needs. Individuals requiring this level of support may be of significant risk of family breakdown

Positive Partnerships[59]

Delivered by Autism Spectrum Australia (Aspect), this program provides professional development for teachers, principals and other school staff; workshops and information sessions for parents and carers; and online learning modules and other resources including resources in different languages for parents from culturally and linguistically diverse backgrounds and resources developed in consultation with Aboriginal and Torres Strait Islander communities. Resources include a planning matrix to support development of a shared understanding of individual strengths and needs; and a 'Transition Plan' resource to support students with ASD to cope with change.

58 https://www.betterhealth.vic.gov.au/health/servicesandsupport/autism-spectrum-disorder-support-services

59 http://www.positivepartnerships.com.au/

Element 7: Data

a) Clearly Defined Outcomes

Evaluation and monitoring of outcomes of mental health services provided to people with DD through mental health support services will improve data, creating an evidence base to inform further service development.

Based on the NSW Framework to improve the health care of people with intellectual disability[60] the following outcomes are suggested as a starting point for the ACT:

People with intellectual disability, their families and carers:

- Have MH problems identified in a timely way;
- Have timely access to the range of MH services they require;
- Are assisted by health professionals who understand and know how to respond to their particular needs;
- Have a healthier lifestyle; and
- Are healthier.

Health Care Providers:

- Understand the needs of people with ID and their carers;
- Know how to communicate effectively with people who have an ID and adapt their ways of working to respond to their needs;
- Recognise the contribution of carers and support their health care needs;
- Are proactive in promoting the health and wellbeing of people with ID and their carers;
- Promote and facilitate interagency co-ordination and collaboration.

Data collection around these outcomes would also be valuable information to inform an evaluation of the need to expand the existing MH-IDS.

b) Improved Data Collection

Data collection practices must also be improved, recognising that only those with the most complex need would be accessing the specialist MH-IDS. Capturing MH support for people with DD at other touchpoints would provide a valuable data source to inform future strategic planning.

60 NSW Health, 2012

Element 8: Multiple Disadvantage

a) Disability, Mental Health issues and the Justice System

Disability Justice Strategy and Building Communities Not prisons

There are clear synergies between the Disability Justice Strategy, aimed at promoting equality and inclusion in the justice system in the ACT by addressing physical, attitudinal, communication and social barriers to equitable access to justice services for people with disability and their carers, and their ability to live contributing lives; justice reinvestment through 'Building Communities Not Prisons' which aims to prevent, or divert people from, incarceration where possible to reduce the requirement for ever increasing prison populations; and the work that can be done through this strategy in terms of Positive Behaviour Support and responding to people in Forensic Health Services (community and detainees).

The ACT Health Directorate will work closely with the Community Services Directorate and Justice and Community Safety on the implementation of these strategies to ensure the needs of people with DD and MH needs are adequately addressed.

Forensic ID and Mental Health

People with ID are over-represented in the criminal justice system, and those adults who also have a mental disorder often contend with multiple challenges. Options offered to courts are limited to admission to hospital and community care options are limited. The ACT currently does not have a designated forensic ID team nor support workers in the Justice and Community Safety Directorate that are equipped to support the needs of this group. Capacity building in this area is a key point to be addressed in ACT's Justice Disability Strategy and potentially further complemented through this work. Example models include:

Victorian Department of Health and Human Services[61]

Provide and fund services for people with a disability who are, or are at risk of, becoming involved in the criminal justice system. The Disability Intake and Response Service assesses eligibility (under the Disability Act 2006). Other services in this area include the Disability Forensic Assessment and Treatment Service.

The Good Lives[62]

A strengths-based model, employed in many Forensic Community Teams across the UK. These teams:

- Provide timely and accessible intervention to clients with active and ongoing forensic and psychiatric, psycho-social, behavioural or pharmacological needs, and consultation to the people who support them,
- Promote the qualities and values of the 'Good Lives' model.

---

61 https://services.dhhs.vic.gov.au/criminal-justice-services

62 https://www.goodlivesmodel.com/information.shtml

- Enable the highest level of independence possible, in the least restrictive way.
- Prevents and avoids unnecessary hospitalisation.
- Facilitates timely discharge from hospital inpatient forensic care.
- Signpost and navigate assessment of need for family and carers to help support them with the demands of caring and involvement with the criminal justice system.
- Respond to trauma experienced by carers.

Virtual Specialist ID Forensic Service

Some research[63] suggests the value of a virtual team who can provide specialist advice, supervision and training for community staff in managing service users with DD and forensic risks. This support could include undertaking assessments, informing management strategies or signposting where needed. This arrangement could provide support for primary care/mainstream services; general community support services; specialised community DD services; and specialist in-patient services as needed.

This model has potential applicability for the ACT context, given the small size of our jurisdiction, limitations of expanding on site services in instances of fluctuating demand; and the possibility of an opportunity to draw on NSW established specialist expertise in this area.

b) NDIS & Multiple Diagnosis

Diagnostic Overshadowing of MH issues, particularly mild to moderate mental health needs, for people with DD frequently occurs.

To ensure effective MH service delivery for people with ID, ACT Health Directorate will need to work closely with NDIS services in the ACT to ensure the needs of people with DD and MH needs are adequately provided for, particularly in instances of multiple diagnoses and/or disabilities. This work will also need to revisit eligibility requirements around enduring functional impairment to ensure people who have DD also have their MH needs and psychosocial disability support needs adequately catered for.

63 Devapriam & Alexander, 2012

Conclusion

This paper has provided information around eight key elements to assist the development of future actions to comprehensively improve mental health services for people with DD in the ACT.

This information will be discussed at a stakeholders workshop on Wednesday 5 June 2019.

The content from this discussion will complement best practice approaches identified to feed into development of a final Strategic Direction for Mental Health Services for People with DD in the ACT.

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ACKNOWLEDGMENT OF COUNTRY

ACT Health acknowledges the Traditional Custodians of the land, the Ngunnawal people. ACT Health respects their continuing culture and connections to the land and the unique contributions they make to the life of this area. ACT Health also acknowledges and welcomes Aboriginal and Torres Strait Islander peoples who are part of the community we serve.

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If English is not your first language and you need the Translating and Interpreting Service (TIS), please call 13 14 50.

For further accessibility information, visit: www.health.act.gov.au/accessibility

www.health.act.gov.au | Phone: 132281 | Publication No XXXXX

Daly, Kelly (Health)

From: McIntyre, Rebecca (Health)
Sent: Friday, 14 June 2019 12:40 PM
To: [redacted] Aloisi, Bruno (Health); [redacted] Axell, Anita; Bicket, Robyn; Bingham, Jaime (Health); [redacted] Bowrah, Victoria (Health); Braun, Helen (Health); Burvill, Stefanie (Health); Calvin, Sam (Health); [redacted] Charles, Amanda; Chief Psychiatrist; Donley, Mandy; [redacted] Dunne, Ellen; Gibson, Sally; Kaur, Tej; Kipling, Wendy; Kirkham, Anna; [redacted] Lewis, Llew (Health); McIntyre, Shirley-Anne (Health); [redacted] Nagle, Dannielle (Health); [redacted] Ratnayake, Priyani; Redmond, Margaret; [redacted] Rogers, Lee-Anne (Health); Rugendyke, Amy; Kerr, Sheridan; Shuhyta, Amber; Simon, Michelle; Smith, Meghan (Health); Sweetman, Rebecca (Health); Walker, Janelle (Health); [redacted] Lee, Melissa (Health); Rob Woolley; Glanville, Emma (Health); Singhal, Deepa (Health)
Cc: Kingsford, Susan; Mackey, Patricia; Garrington, Catherine; Niovanni, Steven (Health); Grace, Karen (Health); Colliver, Deborah (Health); Roberson, Bronwyn (Health); Furner, Catherine (Health); Waterson, Rebecca (Health); Arya, Dinesh (Health); Santillan, Diego; Esther Chelimo
Subject: Mental Health Services for People with Intellectual Disability
Attachments: MH ID Meeting templates for further consultations.pdf; Attachment C - National Recommendations.pdf

UNOFFICIAL

Good Afternoon all,

Following the workshop last Wednesday 5 June, please find attached the questions discussed on the day.

I am providing these as an opportunity for comment including afterthoughts for those of you who were able to attend on the day; and as an opportunity for those who were unable to attend to provide comment to have input into to feed into the draft strategic direction paper for mental health service for people with Intellectual disability (and/or Autism Spectrum Disorder) in the ACT.

I have also attached the National Routable Recommendations to which the ACT Strategy will build upon, for reference if required.

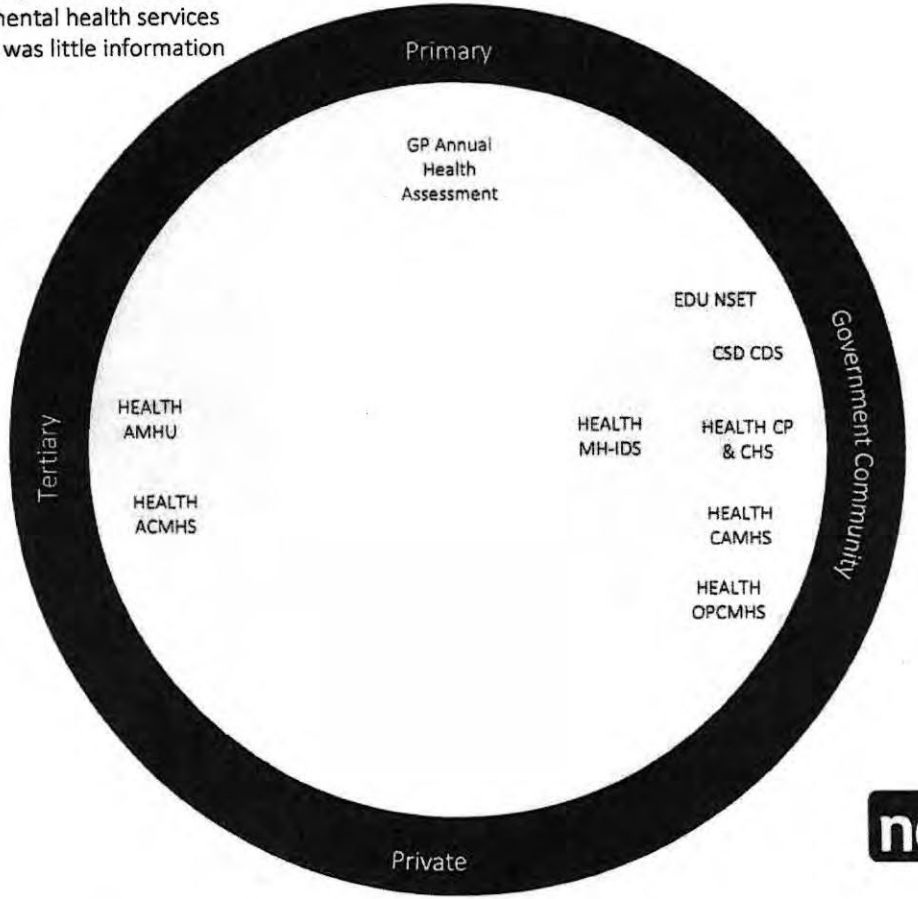
Kind Regards,

Rebecca McIntyre
Senior Policy Officer|Mental Health Policy|
ACT Health |ACT Government|Ph: (02) 5124 9924|
Level 3, 2-4 Bowes Street, Woden 2606.
Care ▲ Excellence ▲ **Collaboration** ▲ **Integrity**
"We acknowledge the traditional custodians of the ACT, the Ngunnawal people. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and region."

This slide was a reminder of the key elements and recommendations from the Roundtable in 2018. We used it to compare what services were in place in the ACT (slide 2) and the opportunities for improvement (slide 3)

ACT Service System

We used this diagram to discuss the different services that were currently available in the ACT.
NDIS is outside the circle as while it influences what happens in service delivery, it is not a service provider.
We did discuss the lack of pathways for people with intellectual disability to access mental health services from the private sector as there was little information available.



ndis

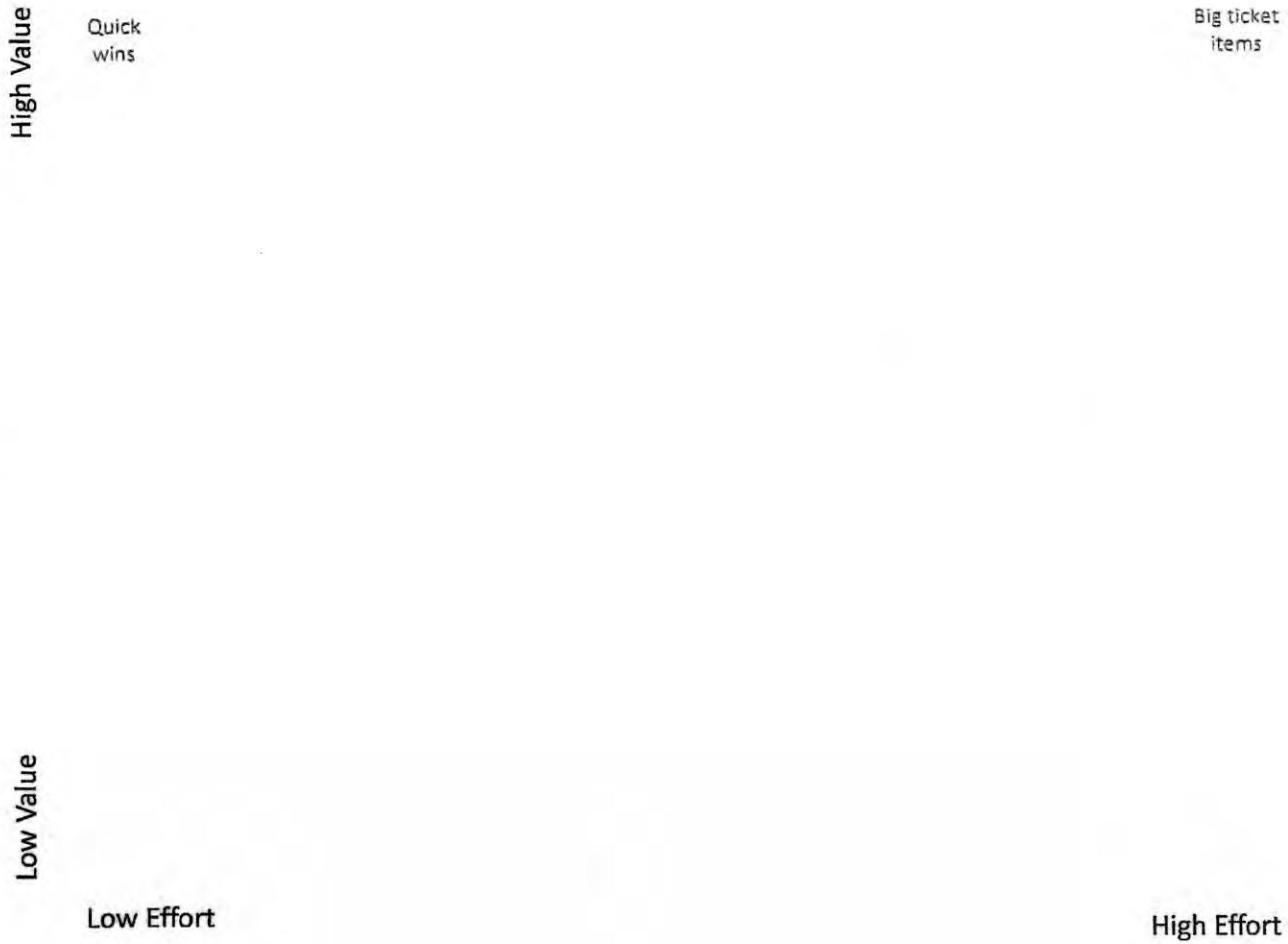
Each of the themes on the left is aligned to the Roundtable themes, and we discussed what is missing from the ACT service system and ideas to close and remedy the service pathways.

	What is missing from the ACT service system to address this?	What else could we try?
Inclusion		
Prevention and timely intervention		
Access to skilled services		
Specialist services support mainstream mental health services		
Collaboration		
Workforce Development and support		
Data		
Multiple disadvantage		

What would make the best impact?

Instructions
For each idea, plot on the effort/value graph to get an idea of value of each idea.

From the ideas captured on the previous page, we then charted them to understand the possible impact and effort required to change access and quality of service.



Daly, Kelly (Health)

From: Lee, Melissa (Health)
Sent: Thursday, 27 June 2019 12:52 PM
To: actmhcn; Aloisi, Bruno (Health); ANU CMHR; Axell, Anita; Bicket, Robyn; Bingham, Jaime (Health); Bonnie Millen; Bowrah, Victoria (Health); Braun, Helen (Health); Burvill, Stefanie (Health); Carol Archard; Charles, Amanda; Chief Psychiatrist; Donley, Mandy; Dr Meredith Sisson; Dunne, Ellen; Gibson, Sally; Kaur, Tej; Kipling, Wendy; Kirkham, Anna; Laurent Anthes; Lewis, Llew (Health); McIntyre, Rebecca (Health); Nagle, Dannielle (Health); Purity Goj; Ratnayake, Priyani; Redmond, Margaret; Rob Woolley [redacted] Rogers, Lee-Anne (Health); Rugendyke, Amy; Shuhyta, Amber; Simon, Michelle; Smith, Meghan (Health); Sweetman, Rebecca (Health); Walker, Janelle (Health); ZedThree Specialist Centre; [redacted] Garrington, Catherine; Kerr, Sheridan; Kingsford, Susan; ANU CMHR; Bonnie Millen; Roberson, Bronwyn (Health); Santillan, Diego; [redacted] Coombe, Kaitlyn; Jennifer Bennett; Arya, Dinesh (Health); Mackey, Patricia; Glanville, Emma (Health)
Subject: Stakeholder Meeting - Mental Health Services for People with Intellectual Disability

UNCLASSIFIED

Hi All,

Just confirming that we are meeting this afternoon at 2:30pm, Conference Room 3, Level 2, 2 Bowes St, Woden

For those needing help to get into building, I will be in the foyer of 2 Bowes St, to help people access level 2, from around 2:25pm.

You can also call me on [redacted] for assistance.

Many Thanks to those who are able to attend today

Melissa

Melissa Lee |Assistant Director, Mental Health Policy
P: (02) 5124 9780 | MOB: [redacted] **F:** (02) 6174 5560
E: melissa.lee@act.gov.au
Policy, Partnerships and Programs | Health Systems, Policy and Research | ACT Health Directorate
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Care ▲ Excellence ▲ Collaboration ▲ Integrity

"We acknowledge the traditional custodians of the ACT, the Ngunnawal people. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and region."

MINISTERIAL BRIEF

ACT Government

Canberra Health Services

UNCLASSIFIED

To:	Minister for Health	**Tracking No.: MCHS19/312**
From:	Bernadette McDonald, Chief Executive Officer, Canberra Health Services	
Subject:	Meeting with [redacted] and [redacted] about people with autism spectrum disorder attending emergency departments in the ACT	
Critical Date:	8 August 2019	
Critical Reason:	Meeting is scheduled for this date	

- CEO .../.../...

Purpose

To provide you with information for your meeting with [redacted] and [redacted] on 8 August 2019.

Recommendations

That you:

1. Note the information in the letter from [redacted] at Attachment A; and

Noted / **Please Discuss**

2. Note the information contained in this brief.

Noted / **Please Discuss**

Rachel Stephen-Smith MLA 8/8/19

Minister's Office Feedback

Please provide an update by 18 August on work plans for progressing [illegible] CHS more [illegible] + particularly for ASD assessment + protocols / guidance. Thank you

Background

1. [redacted] wrote to Minister Fitzharris on 10 June 2019, requesting to meet with the Minister about people with autism spectrum disorder (ASD) attending emergency departments at ACT hospitals. This letter is provided at Attachment A.

2. [redacted] notes in her letter that [redacted] would also be attending the meeting.

Issues

3. In her letter, [redacted] states that the Canberra based Facebook group, CASPER (Canberra Autism Spectrum Parents and Relatives), which provides information and support for parents of people with autism spectrum disorder, had raised a number of complaints about people with ASD and their carers attending ACT emergency departments.

4. [redacted] notes that the following issues:

   i. Medical staff being blasé about patients' concerns about how sick their ASD person is, especially when the patient knows their child best and many ASD people have high pain thresholds;
   ii. Medical staff not taking advice from parents on how best to deal with their person and their needs;
   iii. Unnecessary wait times for an ASD person who is obviously agitated and whose behaviour escalates in the waiting room which causes annoyance and irritation for others waiting; and
   iv. No quiet space for ASD people and carers to wait.

5. [redacted] and [redacted] would also like to discuss with you the development of protocols to improve the experience for people with ASD and their families who attend ACT emergency departments.

6. Further information and links to resources have been provided by [redacted] in her letter, which includes advice to professionals and parents of people with ASD.

Addressing the issues raised

7. In regard to medical staff not taking concerns seriously and not taking advice from patient/carers, Canberra Health Services (CHS) is able to review these matters if specific examples can be provided, along with consent for release of information by the individuals concerned, through the CHS Consumer Feedback and Engagement Team (CFET) – HealthFeedback@act.gov.au or via phone at (02) 5124 5932.

8. Canberra Hospital Emergency Department nursing staff triage patients based on clinical presentation, and patients presenting with agitation will contribute to this clinical assessment. The triage process will not however prioritise over clinical life threatening conditions that may result in delays for those with less urgent clinical presentations.

9. Unfortunately, there is no separate quiet area to wait in the Canberra Hospital Emergency Department. There are a number of patient groups where specific areas for waiting may be of benefit, including patients with ASD, aged care patients, better facilities for mental health presentations, and better facilities for those with infectious diseases or who are immunosuppressed.

10. The new Surgical Procedures, Interventional Radiology and Emergency (SPIRE) Centre, to be built on the Canberra Hospital campus, will deliver a total of 114 emergency department treatment spaces — 39 more treatment spaces than what is currently available. SPIRE is a significant investment that will meet the ongoing demand for high quality, free public healthcare for the people of Canberra. Potentially, a separate and quiet waiting space for patients will be available within SPIRE.

11. CHS are supportive of the development of a protocol for care of the ASD patient in the Emergency Department.

Financial Implications

12. Not applicable.

Consultation

Internal

13. Division of Critical Care.

Cross Directorate

14. Not applicable.

External

15. Not applicable.

Work Health and Safety

16. Not applicable.

Benefits/Sensitivities

17. Not applicable.

Communications, media and engagement implications

18. Not applicable.

Signatory Name:	Lisa Gilmore	Phone:	47135
Action Officer:	Lisa Gilmore	Phone:	47135

Attachments

Attachment	Title
Attachment A	Letter from [redacted] to Minister for Health - Accident and Emergency at both Canberra Hospitals and people with autism spectrum disorder (ASD).

[redacted]

Minister for Health
fitzharris@act.gov.au
GPO Box 1020,
Canberra, ACT 2601

Ms Vicki Dunne (Opposition Health Shadow)
dunne@parliament.act.gov.au
GPO Box 1020,
Canberra, ACT 2601

Dear Minister, Fitzharris

Accident and Emergency at both Canberra Hospitals and people with autism spectrum disorder (ASD)

On Facebook, there is a group called CASPAR which provides information and support for parents of people with autism spectrum disorder (ASD)_here in Canberra. On this group there have been a number of recent posts complaining about the general ignorance and pervasive indifference toward carers and people with ASD they care for when dealing with the accident and emergency (A&E) departments at both Canberra Hospitals.

Recent issues have been:

- Medical staff being blasé about a parent' s concerns about how sick their ASD person is especially when the parent knows their child best and many ASD people have high pain thresholds
- Medical staff not taking advice from parents on how best to deal with their person and their needs
- Unnecessary wait times for an ASD person who is obviously agitated and whose behaviour escalates in the waiting room which causes annoyance and irritation for others waiting
- No quiet space for ASD people and carers to wait.

These concerns need to be addressed and have been raised before. This has been ongoing now for about 30 years since the memorandum of understanding (MOU) that was signed between the then ACT Autism Association and the ACT health agency improved things for a time for people with ASD attending the A&ES. The things that were done were simple such as families phoning ahead to the A&E that they were bringing their child in and the triage nurse ensuing that wait times for such people were kept to a minimum when possible.

Commented [JO1]:

Parents and carers do understand that their person has to wait their turn before someone with bleeding, heart attack or stroke but it is easier to prioritise people with ASD or for that matter most mental disabilities before those who have the mental capacity to wait quietly and not disturb others. Please find a list of resources as Appendix A which provides advice on how other accident and emergency areas are being supportive of people with ASD and their carers which could be followed by Canberra casualty departments and probably the wider health service.

[redacted] and I wish to arrange a meeting with you to discuss the development of such protocols to make the experience of A&E attendance more positive for people with ASD and their families. This should then be followed by developing protocols to make the hospital experience easier for those with ASD and their families.

Appendix A covers a list of resources that illustrate twat some other jurisdictions have done to improve the experience of people with ASD when interacting with the health system

Your sincerely

[redacted]

10 June 2019

Appendix A

Accident and emergency advice for both professionals and parents

Patients with autism spectrum disorders: guidance for health professionals
http://www.autism.org.uk/professionals/health-workers/guidance.aspx
This information is aimed at all health professionals who may meet an adult or child with autism for reasons other than their autism. Doctors, nurses, paramedics, dentists and opticians may find this useful. A lot of this advice will also be useful to hospital staff who are caring for an in-patient with an autism spectrum disorder. Covers what is autism and how to approach and treat those with autism.

Protocol for Children and Adults with Autism Spectrum Conditions
http://www.rcht.nhs.uk/DocumentsLibrary/RoyalCornwallHospitalsTrust/Clinical/SafeguardingAdults/CareChildrenAndAdultPatientsWithAutismSpectrumDisorder.pdf
This Protocol has been subject to an Equalities Impact Assessment Screening and all aspects will enhance equality. To ensure adherence to these principles the main areas of focus will be: To enable staff at the acute Trust to develop a better understanding of people with ASD and to equip them to deal more effectively with the needs of each individual. To clarify for residential and other ASD staff attending the hospital with a person with ASD their supporting/caring role and the boundaries between their caring role and the nursing role of the professional hospital staff.

Top Ten Tips a Nurse Should Know Before Caring for a Hospitalized Child with Autism Spectrum Disorder
http://www.medscape.com/viewarticle/840671
Sharing information obtained through repeated encounters with this population may lead to a less stressful and safer hospital stay for the child with autism, the family, and the pediatric nurse. Items about which the nurse should be aware when caring for a child with autism include the symptoms of autism spectrum disorder, the importance of family involvement, identifying the best way to communicate with the child, minimizing change, incorporating the child's home routine into the stay, creating a safe environment, identifying emotional disturbances, involving a multi-disciplinary team of experts on admission, listening to the family, and creating a record of this information to be shared among staff members.

How Nurses Can Create An Autism Friendly Emergency Room
http://allnurses.com/emergency-nursing/how-nurses-can-969840.html
Learn in this article how as an Emergency Room nurse, you can make simple changes to the environment, your assessment and interactions with the patients' parents, to increase the quality of care you will be able to deliver to this vulnerable population.

Treating Autistic Persons in the Emergency Room
http://autismandtherapy.com/treating-autistic-persons-in-the-emergency-room/#.WCsHcfl9600
Advice from expert doctors on how to treat autistic persons in the emergency room.

Valuable Ways to Prepare Your Child with Autism for a Hospital Stay
https://www.autismparentingmagazine.com/valuable-ways-to-prepare-your-child-with-autism-for-a-hospital-stay/
Advice on how to choose a hospital for treatment and prepare your child to go to hospital.

Slowing Down the ER to Improve Care for Patients With Autism
http://www.medpagetoday.com/emergencymedicine/emergencymedicine/56584

That's why a small but growing number of hospital ERs across the country are implementing accommodations for these patients, hoping to improve the quality of care they provide while also adding efficiency.

Working with people with intellectual disabilities in healthcare settings
http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf
People with intellectual disabilities have the same right as other community members to health care. Summary of communication **tips** that may help when talking to people with an intellectual disability.

10 Ways to Help Prepare Your Special Needs Child For A Hospital Emergency Visit
http://www.friendshipcircle.org/blog/2013/08/06/10-ways-to-help-prepare-your-special-needs-child-for-a-hospital-emergency-visit/
Here are some practical tips you can follow now that can make things go as smoothly as possible for your child with special needs, should the need to visit an emergency room arise in the future.

Tips for ER staff on treating children
http://www.kidspeace.org/tips-for-er-staff-on-treating-children-with-autism

Suggestions from the KidsPeace experts include both changes to the physical environment of the emergency room and advice on how the staff should interact with the patient and their family

Background information on what some medical centres are successfully doing

Improving Care for Patients with Autism Spectrum Disorder in the Acute Care Setting
http://patientsafetyauthority.org/ADVISORIES/AdvisoryLibrary/2014/Dec;11(4)/Pages/141.aspx
The Western Pennsylvania Autism Services, Education, Resources, and Training Collaborative developed this resource to help healthcare facilities improve care for people with autism.

Autism and developmental disability: Management of distress/agitation
http://www.rch.org.au/clinicalguide/guideline_index/Autism_and_developmental_disability__Management_of_distress/agitation/
This aim of this guideline is to provide clinical practice tips for the inpatient management of anxiety, and agitation in young people with developmental disabilities (including autism) who may require medical or surgical care.

Pond, Aleks (Health)

From: Jacobs, Elissa (Health)
Sent: Wednesday, 4 September 2019 2:52 PM
To: Boyd, Kerry (Health)
Subject: Care of the Autism patient in the hospital setting [SEC=UNCLASSIFIED]
Attachments: Action Plan - Care of the Autism patient in the hospital setting.xlsx

Hi Kerry,

As per our discussion last Wednesday I have created an action plan regarding creating a clinical guideline for care of patients with Autism (please see attached). I thought this would be the easiest way to report on progress. The timeline is just an estimate. Please let me know of if I have left anything out

Cheers

Elissa

Elissa Jacobs | Clinical Psychologist – Manager Psychology
Phone: 02 5124 2045 | Mobile: [redacted] Fax: 02 5124 5528 | Email: elissa.jacobs@act.gov.au
Psychology – Acute Allied Health Services | Canberra Health Services | ACT Government
Building 15, Canberra Hospital | PO Box 11, Woden ACT 2606

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Care of Patients with Autism in the hospital setting:

ACTION PLAN: Clinical Guideline - clinical practice guidance for care of patients with Autism Spectrum Disorder (ASD) in the Emergency Department and those accessing hospital services

Goal	Recommended Action	Outcome	Stakeholders	Due Date	Status	Comments
Identify existing CHS guidelines/procedures relating to this population	Review of CHS Policy and Clinical Guidance Register - both in ED and hospital wide	CHS guidelines that specifically addresses care related to Autism or developmental delay : - 'Pre and Post-Operative Care of the Adult Special Needs Patient in Day Surgery Unit (DSU)/Day of Surgery Admission (DOSA)'				Relates to existing policies - such as the 'Restraint of a person policy' and 'Consent and Treatment policy'.
	Identify Stakeholders	CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface		20th September 2019	Completed	
		Autism specific service providers - Marymead Autism Centre, Autism Spectrum Australia, Autism Awareness Australia				
		Consumer/advocacy groups - Australian Autism Alliance, CASPER, Health Care Consumer Association				
Review existing resources	Review resources provided by CASPER (from meeting on the 8th August 2019)					
	Benchmark with other services			18th October 2019		
	Identify suitable external guidelines that may be able to be used or adapted for use at CHS - policy placeholders.					
Development of guideline	Review identified possible policy placeholders in consultation with stakeholders		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface	15th January 2020		
	If external guidelines are found to be appropriate, initiation request for placeholder on the policy register sent to executive for endorsement.		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface	15th Febuary 2020		
	Initiation request submitted to CHS Policy Committee for approval			15th March 2020		
	Please note: If external guidelines are not found to be appropriate will need to develop a guideline - this will extend time line significantly					
Implementation	Liaison with CHS stakeholders regarding appropriate communication strategies within each area		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface			
	Liaison with CHS stakeholders regarding whether staff education and training is required		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface	Apr-20		
	Identification of external training providers and costs Communication of endorsed policy			May-20		

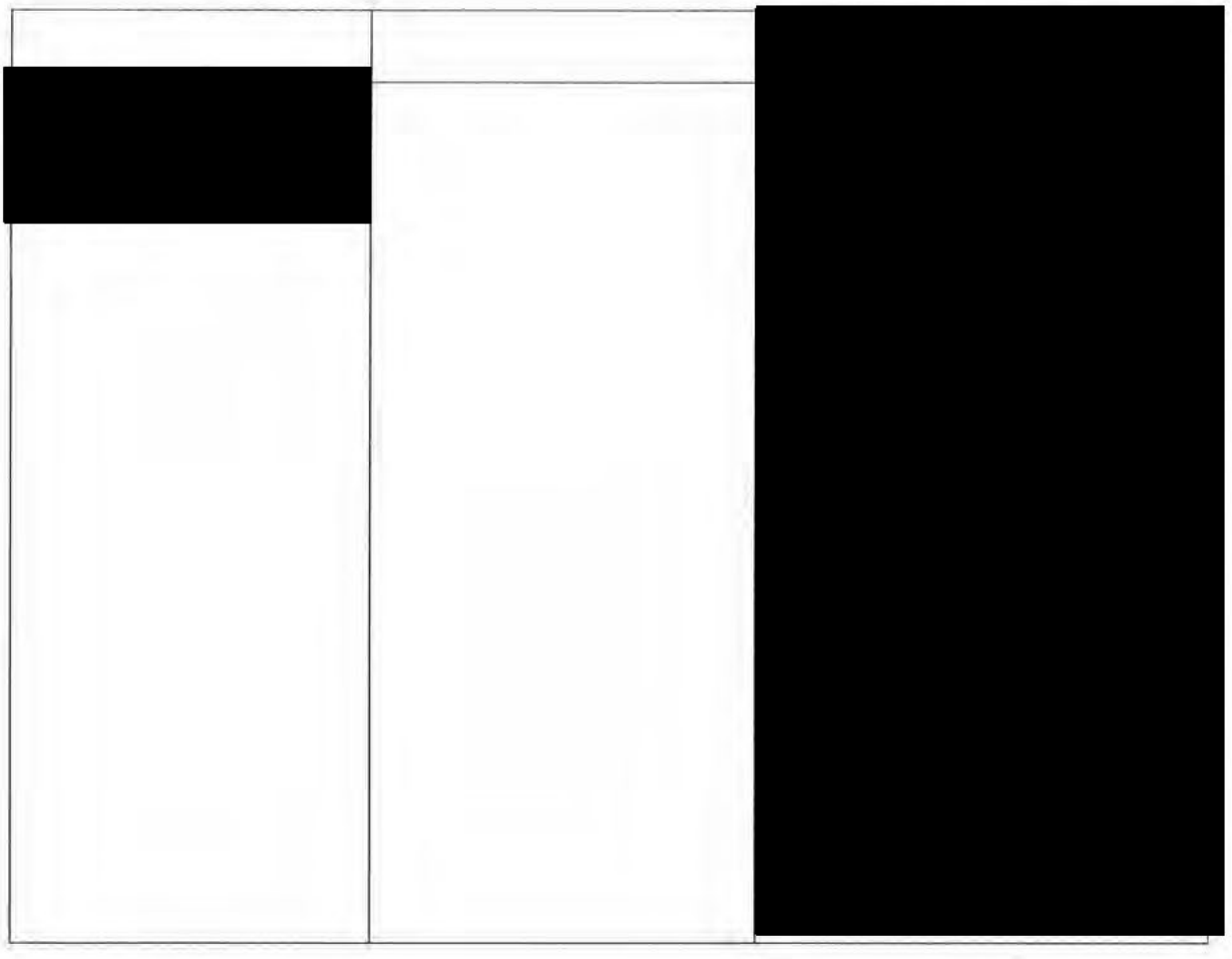
Catch up Bernadette and Kerry

17.9.2019

Topic	Papers	Comments
[redacted]		[redacted]
[redacted]		
[redacted]		

		[redacted]
[redacted]		
Care of the Autism patient in the Hospital Setting	**MCHS 19/312** Action Plan - Care of the Autism patier	Liz Chatham handed this over to EDAH following meeting held with [redacted] & [redacted] about people with Autism Spectrum Disorder attending the Emergency Departments in the ED. Asked to develop an action plan on how these clients may be supported on presentation to the ED and during admission. Action plan has been developed – for your consideration (Attached)

		Update – following discussion with the Minister.
[redacted]		[redacted]
	[redacted]	
[redacted]		[redacted]



Catch up Bernadette and Kerry

14.10.2019

Topic	Papers	Comments
[redacted]	Nil	[redacted]
[redacted]	[redacted]	
[redacted]		[redacted]

[redacted]

[redacted]

Care of the Autism patient in the Hospital Setting	**MCHS 19/312**  Action Plan - Care of the Autism patier	Liz Chatham handed this over to EDAH following meeting held with [redacted] & [redacted] about people with Autism Spectrum Disorder attending the Emergency Departments in the ED. Asked to develop an action plan on how these clients may be supported on presentation to the ED and during admission.

		Action plan has been developed – for your consideration (Attached) Update – following discussion with the Minister. No progress to date.
[redacted]		[redacted]
[redacted]		[redacted]

Care of Patients with Autism in the hospital setting:

ACTION PLAN: Clinical Guideline - clinical practice guidance for care of patients with Autism Spectrum Disorder (ASD) in the Emergency Department and those accessing hospital services

Goal	*Recommended Action*	*Outcome*	*Stakeholders*	*Due Date*	*Status*	*Comments*
Identify existing CHS guidelines/procedures relating to this population	Review of CHS Policy and Clinical Guidance Register - both in ED and hospital wide	CHS guidelines that specifically addresses care related to Autism or developmental delay : - 'Pre and Post-Operative Care of the Adult Special Needs Patient in Day Surgery Unit (DSU)/Day of Surgery Admission (DOSA)'			Completed	Relates to existing policies - such as the 'Restraint of a person policy' and 'Consent and Treatment policy'.
		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface		20th September 2019		
	Identify Stakeholders	Autism specific service providers - Marymead Autism Centre, Autism Spectrum Australia, Autism Awareness Australia Consumer/advocacy groups - Australian Autism Alliance, CASPER, Health Care Consumer Association				
Review existing resources	Review resources provided by CASPER (from meeting on the 8th August 2019)					
	Benchmark with other services			18th October 2019		
	Identify suitable external guidelines that may be able to be used or adapted for use at CHS - policy placeholders.					
Development of guideline	Review identified possible policy placeholders in consultation with stakeholders		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface	15th January 2020		
	If external guidelines are found to be appropriate, initiation request for placeholder on the policy register sent to executive for endorsement.		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface	15th Febuary 2020		
	Initiation request submitted to CHS Policy Committee for approval			15th March 2020		
	Please note: If external guidelines are not found to be appropriate will need to develop a guideline - this will extend time line significantly					
Implementation	Liaison with CHS stakeholders regarding appropriate communication strategies within each area		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface			
	Liaison with CHS stakeholders regarding whether staff education and training is required		CHS Divisions - Critical Care - Emergency Department, WYC - Paediatrics (hospital based), MHJHADS - ED and Mental Health Interface	Apr-20		
	Identification of external training providers and costs Communication of endorsed policy			May-20		