Government of **Western Australia**
Department of **Health**

Neuropsychiatry and Developmental Disability Mental Health Sub Network Establishment Report

Including outcomes of the Neuropsychiatry and Developmental Disability Mental Health Sub Network Inaugural Open Meeting

20 June 2016

better health ▪ better care ▪ better value

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Neuropsychiatry and Developmental Disability Mental Health Sub Network

The Mental Health Sub Networks were established to support the Mental Health Network (MHN) in engaging with and delivering outcomes for specific cohorts of mental health service users.

This report outlines the process of establishment of the Neuropsychiatry and Developmental Disability Mental Health Sub Network Steering Group, with a focus on the outcomes of the Open Meeting that will inform the Group's work.

Open Meeting

The MHN in conjunction with the Mental Health Commission (MHC) hosted the Neuropsychiatry and Developmental Disability Mental Health Sub Network Open Meeting on 20 June 2016.

The Open Meeting was attended by 89 people, including mental health service consumers, families, carers, mental health advocates, health professionals, university academics, service providers and organisations. The participants were highly engaged and motivated throughout the meeting and actively contributed to information collected.

The Open Meeting program is available in Appendix A.

The panel members spoke to a number of issues and possible solutions highlighting the following:

- complexities of diagnosis and negative impact of labelling patients
- need for collaboration between services in order to address mental health and intellectual disabilities and to reduce retelling of story and inappropriate referrals
- need for improved systems and communication channels to deal with the complexity of intellectual disability and mental health needs
- insufficient support for individuals and families

The workshop session captured the common issues raised by participants, as identified by the Open Meeting facilitator:

- Poor communication, information sharing and a lack of collaboration and coordination between services.
- Limited specialised expertise in the workforce to manage the complex needs of people with mental health and developmental disability including a need for more training and education across a number of disciplines and settings.
- Need for a more multidisciplinary approach to meet complex needs, including increased integration with paediatricians, psychiatrists, neurologists and clinical psychologists.
- Additional specialist liaison neuropsychiatry positions are needed.
- Prescriptive and inflexible eligibility criteria prevent access to effective care.
- Funding models such as Medicare and National Disability Insurance Scheme (NDIS) do not capture the complexity of patients and funding is then insufficient to provide integrated care and thus encourages services to take on efficient (less complex) clients.
- Difficulty managing clients with co-morbidities across services.
- Difficulty accessing specialist services including a lack of awareness of existing services.
- Difficult transition from child and adolescent to adult service.
- Need for increased in-reach and outreach services across the sector.
- Need for greater peer networks, and carer and family support services.
- A lack of data linkage amongst areas of health, mental health and disability means people and families having to retell their stories.

- The integration of contemporary understandings, models and treatments is required to provide more holistic care.
- Improved medication review processes are required.
- A need to ensure the Sub Network engages and seeks commitment from all stakeholders.

The workshop included an opportunity for the participants to nominate which issues and gaps they considered to be highly important. The three most highly rated items were:

- Poor communication between departments (i.e. working in 'silos').
- Too few professionals with expertise.
- Poor data linkage amongst areas of health, mental health and disability means clients and families having to retell stories.

The themed outcomes from the workshop session are outlined under Workshop outcomes with the detailed participant input, including the rating, available in Appendix B.

Steering Group

At the conclusion of the Open Meeting, expressions of interest were called for from individuals to join a Steering Group to drive the work of the Sub Network.

All nominations were considered by the Implementation Group and the names of the successful applicants presented to the MHN Executive Advisory Group for final approval. A list of the Inaugural Steering Group for the Neuropsychiatry and Developmental Disability Mental Health Sub Network is available in Appendix C.

The information collected from the Open Meeting workshop will be used to guide the Neuropsychiatry and Developmental Disability Mental Health Sub Network Steering Group in the development of their work plan and to inform and support the MHC in the delivery of the *Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025* (Plan). The Neuropsychiatry and Developmental Disability Mental Health Sub Network will also be engaged to support consultation undertaken by the Department of Health on the planning of health services.

Introduction

Mental Health Network

The establishment of the Mental Health Network (MHN) was undertaken by the Department of Health with the support of Professor Bryant Stokes, Acting Director General, Department of Health in partnership with Mr Timothy Marney, Mental Health Commissioner, Mental Health Commission (MHC).

The MHN was launched during Mental Health Week in October 2014. The MHN is led by Co-Leads Dr Helen McGowan and Ms Alison Xamon.

The MHN EAG membership includes consumer and carer representatives as well as representatives from the Department of Health, MHC, Office of Mental Health, Primary Care, Mental Health Clinician Reference Group, Office of the Chief Psychiatrist, Western Australian Primary Health Alliance (WAPHA) and the Western Australian Association of Mental Health.

The objective of the MHN Executive Advisory Group (EAG) is to support and guide the MHN to undertake the following:

- Contribute to improving the mental health and wellbeing of Western Australians.
- Draw upon a community of practice approach to share information, engage with the sector and community, foster collaboration and develop partnerships.
- Engage with organisations and individuals to support innovation and change.
- Develop an agreed set of strategic priorities across the mental health sector.
- Promote system change including continued development of a person-centred and recovery orientated culture, with better integrated and connected services.
- Promote adoption of recognised best practice across the sector.

The Mental Health Sub Networks structure was created to support the MHN to meet these objectives.

Mental Health Sub Networks

The Sub Networks are intended to focus on the needs of a particular cohort, be task orientated and to deliver products by bringing together the right people, from the community sector, Health, consumers, carers and other interested parties. A structured approach was taken to engagement and the establishment of each of the Sub Networks.

A prerequisite to the establishment of each Sub Network included confirmed sponsorship from a health service, identified co-ordinators and support of key stakeholders within the sector prior to progressing the development of the Sub Networks.

The MHN Co-Leads took a leadership role in networking with individuals and organisations to identify and establish the Sub Networks.

An Implementation Group of key stakeholders was then formed to assist in the organisation of an Open Meeting, including the selection of appropriate panellists to provide snapshots of key sector issues. The aim of the Open Meeting was to give the broad community the opportunity to actively participate in the formation of the Sub Network and provide critical input to shape its priorities moving forward.

At the conclusion of the Open Meeting, expressions of interest were called for from individuals to join a Steering Group to drive the work of the Sub Network.

Each Mental Health Sub Network Steering Group is required to have representation from:

- consumers
- carers or family members
- community managed organisations
- public community mental health services
- inpatient public mental health services
- inpatient and community private mental health services
- primary health services
- agencies delivering prevention and promotion programs and initiatives
- MHC
- mental health professionals from a range of disciplines including:
  - peer workers
  - allied health
  - nursing
  - medical
  - psychology
  - psychiatry
- individuals and agencies working in regions across the state including:
  - rural and remote and metropolitan districts/regions (particularly relevant for cross-sectoral working groups)
- individuals and agencies working with different age cohorts (relevant for cross-age cohort working groups), including:
  - infant children
  - adolescents
  - youth
  - adults
  - older adults
- the sponsoring organisation.

All nominations were considered by the Implementation Group and the names of the successful applicants presented to the MHN EAG for final approval. In order to keep the Steering Groups at workable sizes, applicants were selected on the basis of their ability and willingness to represent the concerns of multiple cohorts.

A list of the Inaugural Steering Group for the Neuropsychiatry and Developmental Disability Mental Health Sub Network is available in Appendix C.

Neuropsychiatry and Developmental Disability Mental Health Sub Network Open Meeting

Stakeholders for the neuropsychiatry and developmental disability mental health services in Western Australia met for the inaugural open meeting of the Neuropsychiatry and Developmental Disability Mental Health Sub Network at The Boulevard Centre, Floreat on 29 July 2016.

A total of 89 people attended the Open Meeting including mental health service consumers, families, carers, mental health advocates, health professionals, university academics, service providers and organisations.

- 81 people registered to attend the Open Meeting.
- 89 people attended the Open Meeting (10% more than registered).
- 41 organisations were recorded as having representatives at the meeting.

Open meeting process

The energy and good will demonstrated throughout the establishment of the Neuropsychiatry and Developmental Disability Mental Health Sub Network continued to develop momentum throughout the Open Meeting.

The Open Meeting program is available in Appendix A.

Following the acknowledgement to country given by Mental Health Co-lead Ms Alison Xamon, Mental Health Commissioner, Mr Timothy Marney presented Mental Health – The Big Picture, The Open Meeting heard overviews from Dr Helen McGowan, regarding the MHN; and Dr Rachel Zombor gave an overview of the Neuropsychiatry and Developmental Disability Mental Health Sub Network and some key concerns of the sector.

Panellists recommended by Neuropsychiatry and Developmental Disability Mental Health Sub Network Implementation Group then shared snapshots of key issues and perspectives in the neuropsychiatry and developmental disability mental health sector.

The outcomes of the panel discussion and workshop session as captured by the facilitator are themed and summarised below.

Panel discussion

The Panel consisted of representation from the following perspectives:

- Consumer — Ms Storme McLeod (with support from Ms Maxine Drake)
- Family Representative — Ms Jaquie Mills
- Psychiatrist — Dr Lynn Jones
- Disability Services Commission — Ms Kathryn Falloon
- Mental Illness Fellowship WA — Ms Monique Williamson

The following points were captured by the facilitator during the panel session:

- This is a watershed meeting and an exceptional process for reform leadership; I believe it's the start of something very important.
- It took a long time to identify Storme's acquired brain injury (ABI) and it meant dealing with a lot of systems and processes as she didn't 'fit' any clear eligibility criteria.
- It's easy to fall between the gaps but how can we fix anything if no one talks with each other in the system?
- The mental health system couldn't do anything for me because it was a brain injury, at least that's the way it looked, so it didn't fit the eligibility and no one was willing to work outside the box.
- Looking at alternatives with other services (neurology and psychiatry) was life changing; it was hard for that specialist to work Storme's needs through the system but it was such a great outcome for her.
- Our organisation welcomes complexity where other organisations refuse it, so for a lot of our patients we're the 'last chance'.
- We don't require a 'certificate' or label of mental illness (MI); one of our guiding principles is that 'people are people are people':
  - you don't have to be authorised by a psychiatrist, we try to see the person and work from that frame.
- We don't care where to attribute the behaviour because it's an issue either way, so it needs to be addressed; unfortunately, a lot of funders are still preoccupied with this labelling.
- Treatable physical health conditions need to be addressed and are often forgotten due to a focus on developmental disabilities.

- There is still a lot of debate around medication in the system and it's often difficult for patients to find the middle road between over and under medication.
- I was part of the development of a United Kingdom (UK) service that worked really well in a collaborative sense; it was a small service focused on the mental health needs of under 18's with intellectual disabilities at a local level:
  - everyone was trained in mental health and disability care
  - the psychiatrists and paediatricians were in the same team, which was critical because families didn't have to retell their story.
- We tackled comorbidity and severe challenging behaviours through a different Model of Care to the standard teams; it was done in schools and homes to reduce trips to hospitals and mental health services:
  - it meant we could speak with teachers and parents regularly to spot behaviours and educate on the mental health aspect early
  - this was done at no extra cost.
- There is varying support for individuals but very few services focus on both the intellectual disability and mental health needs of individuals:
  - limited access across Government and Non-Government Organisation (NGO) services, and General Practitioners (GPs) often struggle with complex issues resulting in people admitted to inpatient mental health systems.
- High levels of psychotropic medication with few official diagnoses of mental health exist; these medications are often prescribed for behaviour control.
- The systems and communication channels are not equipped to deal with the complexity of intellectual disability and mental health needs; there is a lack of coordination and collaboration which means patients fall between the gaps:
  - supporting joint development of training on positive behaviours would increase collaboration between services
  - joint mental health diagnostic assessments and interventions are an opportunity also.
- The focus in schools needs to be increased as Post Traumatic Stress Disorder from behaviour control in schools is a major issue:
  - special education often takes a compliance focus to controlling behaviour
  - there seems to be an acceptance that social isolation for intellectually disabled students in schools is the norm and this leads to mental health issues.
- Adults experience a low quality of life, particularly in group homes where they receive little choice over what they eat or listen to; frequent changes of staff are also very disruptive.
- There is a need for better support for families with children with challenging behaviour as they're stressed, tired and excluded socially and can't find time nor energy to address the development of mental health issues.

Following a networking break the meeting resumed with a workshop session facilitated by an external provider.

Workshop outcomes

Participants were asked to consider the panel presentations and take into account their own knowledge and experience of the sector to answer the following questions:

- What do you see as key issues, challenges and gaps in service delivery that are still to be resolved in the neuropsychiatry and developmental disability mental health space?
- For this issue, what potential solutions would you propose?

Responses were shared in real time via GroupMap - allowing cross pollination of ideas from all participants. The participants were highly engaged and motivated throughout the meeting and actively contributed to information collected.

The following points were captured during the workshop session by the facilitator, summarised and themed:

Poor communication, information sharing and a lack of collaboration and coordination between services:

- Lack of collaboration and coordination between the services, departments and agencies (i.e. working in 'silos').
- Communication protocols on discharge are poor.
- Communication and funding streams lacking.
- Lack of efficient and direct communication of budget in areas of need for mental health, including disabilities.
- Poor integration between leadership in services, such as between mental health and disability.
- Lack or absence of communication between agencies at an individual person level.
- Lack of care coordination.
- Bouncing around with limited informal and formal supports.
- Need for dedicated case management services that work with people across settings and agencies.
- Service standards are needed (e.g. different service providers need to work as a team).

Limited specialised expertise on the complex needs of people with mental health and developmental disability, including a need for more training and education across a number of disciplines and settings:

- Too few professionals with expertise in mental health and developmental disability or acquired brain injury (ABI).
- Lack of specialised knowledge regarding complexity of developmental disabilities among psychiatry and psychology services.
- Need for more training of psychiatrists with specialist skills in neuropsychiatry and developmental disability and then provide ongoing mentoring and support.
- Need for more skilled allied health with training in general health, disability and mental health.
- Nursing and allied health training and experience is needed.
- Inappropriate inpatient expertise (e.g. no nursing specialists).
- Education and guidelines for hospital staff needed.
- Grow primary care expertise in neuropsychiatry and developmental disability.
- Lack of training for police in disability and mental health and lack of support for their training.
- In UK and Ireland it is a subspecialty with separate accreditation and non-subspecialty management can be harmful, such as misuse of psychotropic medication.
- Lack of knowledge about, and access to, assessment tools such as Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD).
- Broader understanding and training, plus service delivery for people with frontal lobe impairment of any cause.
- Undergraduate and postgraduate training in neuropsychiatry and developmental disability across disciplines is needed. General Practitioner (GP) learning modules and seminars needed.
- Medical trainee rotation needed (GPs, psychiatrists, physicians).
- No academic unit.
- Lack of access to specialists for diagnosis of disability e.g. neuropsychologists.
- Large cohort of adults with developmental disorders who missed childhood diagnosis.

Need for a more multidisciplinary approach to meet complex needs, including increased integration with paediatricians, psychiatrists, neurologists and clinical psychologists:

- It is essential to work in Multi-Disciplinary Teams (MDT) (currently lacking).
- Focused purpose of MDT.
- Many MDTs are missing key elements such as neurology, psychiatry, and clinical psychology.
- Lack of simultaneous or integrated diagnostic services. People have to attend multiple specialty clinics for related needs.
- Lack of integrated care with paediatricians, psychiatrists and child psychiatrists.
- Integration of neurological, psychiatric and disability expertise at the State Epilepsy Service.
- Lack of comprehensive services for complex needs (e.g. intellectual disability).
- Disability liaison nurse positions should be funded at general hospitals.
- Incorporate family, GP, nurses (very few mental health nurses), and other mental health professionals.
- A multidisciplinary approach, family attention, functional networks, psycho-education of health professionals and more funding are all needed.

More specialist liaison neuropsychiatry positions are needed:

- Specialist neuropsychiatry liaison to State Neurosurgical Service needed.
- Specialist neuropsychiatry liaison to the State Head Injury Unit should be funded.
- Lack of funding for liaison psychiatry across the lifespan to detect complex neuropsychiatric needs early and manage effectively.
- More neuropsychology and neuropsychiatry services needed.
- Funding needed for better liaison between neurology, psychiatry and neuropsychiatry.

Prescriptive and inflexible eligibility criteria prevent access to effective care:

- Eligibility criteria are too prescribed and narrow, and have no flexibility.
- "It’s not mental health - it's behaviour".
- Need for a better understanding within NDIS about thorough and fair assessment of people with complex needs.
- No assessment process as clinicians don't want to see people with a disability.
- Such specific and excessive criteria for services make them inaccessible.
- Eligibility dependent on permanence and duration, or episodic. Intersection between disability and traditional mental health doesn't work well.
- Need for a better understanding of variable presentations of neurodevelopmental disorders such as Attention Deficit Hyperactivity Disorder (ADHD) as consequences of a lack of treatment throughout the lifespan are profound.
- When there is essentially a mental health issue but mental health services deny.
- Threshold issue - need to have too high level of need before receiving support.
- No services willing to engage and denied access to services.
- Reluctance to admit for inpatient assessment.
- Community mental health services should be firmly directed to accept referrals of people with intellectual disability and behavioural disturbance where there is a need for rationalising psychotropic prescribing.

Funding models such as Medicare and NDIS do not capture the necessary complexity to provide integrated care and thus encourage taking on efficient (less complex) clients:

- Funding systems such as Medicare do not capture complexity and thus discourage taking on complex clients.

- The NDIS funding model focuses on the individual's needs, not the system around the individual (it is deficit driven).
- Issues often stem from funding models whereby one agency needs to take primary responsibility, so it's hard to provide integrated and holistic care when the overarching funding models don't support that.
- A push in hospitals to discharge quickly without assessment and comprehensive discharge plans.

Difficulty managing clients with co-morbidities across services:

- Dominant diagnosis drowns out other co-morbid conditions.
- GPs overloaded and overburdened by complex needs.
- Difficulty managing patients with co-morbidities in general hospital. Typically one aspect of a person is unable to be addressed or is ignored.
- Psychiatric residential facilities are often unable to manage (and therefore accept) people who have co-occurring physical and/or medical conditions.
- Clients with dual diagnosis not wanting involvement with mental health services.
- Needs analysis for people with needs at the interface of health and mental health.
- No acknowledgement that there can be co-morbidity.
- Patients with physical or medical issues often can't be managed in a mental health unit (MHU) because it's seen as a ‘risk’.
- People with ABI being inappropriately placed in mental health hospitals.
- Capacity is needed to provide physical rehabilitation in mental health settings (and mental health care to those receiving physical or medical care).

Difficulty accessing specialist services including a lack of awareness of existing services:

- Prohibitive cost of private services and a lack of public services.
- No dedicated state wide neuropsychiatric inpatient facility.
- Need for appropriate residential and respite facilities including developmental, ABI and early onset dementia.
- Specialist neuro-oncology services are needed for behavioural disturbance in people with benign and malignant brain tumours, including respite and hospice care.
- More appropriate inpatient mental health facilities for clients with developmental disabilities.
- Lack of intensive based community mental health support.
- Lack of community support services and residential accommodation for people in their 50s with cognitive and behavioural issues.
- Lack of residential options for adults with complex needs.
- Lack of subspecialty services.
- Increase specialist resources for assessment and care of people with functional neurological disorders (conversion etc.).
- Huge need for specialist inpatient unit with highly trained professionals, as well as outpatient services for follow up.
- Lack of services for traumatic brain injury and palliative neuropsychiatric care.
- Lack of services in rural and remote areas.
- Residential care is often not pleasant to reside in.
- Issues regarding transport and access to services, and a lack of in the home services.
- Difficulty accessing the integrated network.
- Difficulty accessing social needs (residential option).
- Difficult to know what services exist.

- Lack of clinical pathways into and out of services.

Difficult transition from child and adolescent to adult service:

- Difficult transition from child and adolescent to adult service, including disability services and mental health.
- Need to develop a care transition roadmap for professionals and consumers (e.g. child to adult sectors).

Need for increased in-reach and outreach services across the sector:

- Statewide services with in-reach and outreach funding need to build capacity across health and mental health.
- Bilateral in-reach (disability into mental health units, mental health into disability).
- In-reach care to home and residential care to prevent admission to unfamiliar and risky hospital environments.
- Insufficient resources for outreach into the community; can professionals not go to the person?
- Capacity is needed for specialty skilled allied health to provide outreach and in-reach.

Need for greater peer networks, and carer and family support services:

- Lack of carer support groups and respite services for clients with developmental disability and mental health issues.
- Insufficient informal supports.
- Need to address the social isolation of families.
- Address the social isolation of people with developmental disability and mental illness (e.g. circles of friends or microboards).
- Often there is a need for a mentor or advocate for families.
- Education of families and carers in relation to care pathways.
- Developmental disability peer support networks hosted by key agencies are needed.
- Lack of peer support (e.g. clients who have previously had a stroke and are further down their rehab volunteering to assist stroke patients in hospital).
- Need to provide holistic support that addresses quality of life for the client and people around the client.

A lack of data linkage amongst areas of health, mental health and disability means people and families having to retell their stories:

- Poor data linkage amongst areas of health, mental health and disability means there is duplication of paperwork and people having to retell story.
- Accessible electronic health records across sectors, jurisdictions and disciplines are needed.
- Data linkage needed in Electroconvulsive Therapy (ECT).

The integration of contemporary understandings, models and treatments are required to provide more holistic care:

- Professional development in schools to learn about contemporary responses to challenging behaviour and restrictive practices.
- A lack of contemporary Models of Care and learning from other jurisdictions nationally and internationally.
- Need to incorporate emerging physical treatments (e.g. Deep Brain Stimulation (DBS)).
- Not enough good evidence or international agreement around treatments for people with multiple issues.

- Change the approach to more ‘healing the body via the mind’ focused.
- Clinical research program and integration into clinical model of care to improve outcomes with evidence.
- Contemporary understanding to medical reality needed.
- Contemporary thinking to clinical practice and international best practice is lacking.
- Increased level of examination ECT and data linkage review of how ECT is used.
- Liaison models (like WA Eating Disorders Outreach and Consultation Service (WAEDOCS)).

Improved medication review processes are required:

- Medication review panels for long term use of psychotropic drugs are required that have independent representation aside from the prescribers.
- Process needed to go through significant medical review (importance of medication review) with detox (planned withdrawal) to determine if possible to reduce or cease medication.
- Use of medication questionnaire?

A need to ensure the Sub Network engages and seeks commitment from all stakeholders:

- Stakeholders need to be engaged and a commitment from Department of Child Protection and Family Support (CPFS), Department of Education and GPs to participate.
- Form subgroups by specific areas joining the wider networks.
- Sub network consultation with NDIS needed.
- Stakeholders (GPs, Primary, Department of Education and CPFS) need to ensure a high level of representation from the Education Department.
- Systemic approach is needed to ascertain which changes are needed in each part of the system (e.g. policy, facilities and people with mental health conditions.).

Other issues:

- Capacity issues around decision making.
- Consideration and review of ECT with standard of practice/ terms of reference to include disability and not exclusive to mental health.
- Four specific unique features of this patient group are:
  - diagnostic overshadowing;
  - atypical phenotypic expression of common psychiatric disorders (i.e. depression presents differently);
  - misclassification of underlying disorders as aggression or oppositionality and rapid escalation of complication; and
  - Deliberate Self-Harm (DSH), Self-Injurious Behaviour (SIB) Overdose (OD) Substance abuse.
- Lots of people are discouraged with the process of going through mental institutions.
- Recognising that many people move in and out of mental illness
- Avoid unnecessary complications prolonging hospitalisation.
- Differentiating patients who need episodic care and integrated chronic care.
- Domain in what is considered as therapeutic has been reduced.
- Focus is on behaviour without clear analysis.
- Insufficient support and understanding of individuals who become involved with the justice system.
- Long appointment and assessment process for Autism Spectrum Disorder (ASD) diagnosis.
- Systematic career histories and engagement.
- Increase the recognition of the role of neuropsychologists.

Issues rated highly by participants

Participants were invited to identify the issues they believed were important by using the ‘like’ indicator in GroupMap. The points below are the issues and gaps identified by the wider group of participants as highly important.

- Poor communication between departments (i.e. working in 'silos').
- Too few professionals with expertise.
- Poor data linkage amongst areas of health, mental health and disability means clients and families having to retell stories.
- Need for more skilled allied health with training in general health, disability and mental health.
- A push in hospitals to discharge quickly without assessment and comprehensive discharge plans.
- Undergraduate and postgraduate training in neuropsychiatry and developmental disability across disciplines is needed.
- Accessible electronic health records across sectors and disciplines are needed.
- It is essential to work in multidisciplinary teams (MDT) (currently lacking).
- Funding systems such as Medicare do not capture complexity and thus discourage taking on complex clients.
- Lack of carer support groups and respite services for clients with developmental disabilities and mental health issues.
- Need for more training of psychiatrists in neuropsychiatry and developmental disability and then provide ongoing mentoring and support.

Next steps

The information collected from the Open Meeting workshop will be used to guide the Neuropsychiatry and Developmental Disability Mental Health Sub Network Steering Group in the development of their work plan and inform the MHC to support the delivery of the Plan. The Neuropsychiatry and Developmental Disability Mental Health Sub Network will also be engaged to support consultation undertaken by the Department of Health on the planning of health services.

In addition to working on identified projects, the Steering Group will work to foster engagement and communication in the neuropsychiatry and developmental disability mental health sector.

Developments, issues for broader discussion and achievements will be reported back to the broader Neuropsychiatry and Developmental Disability Mental Health Sub Network membership via the Health Networks.

Appendix A: Open Meeting program

Department of Health
Mental Health Commission
GOVERNMENT OF WESTERN AUSTRALIA

Neuropsychiatry and Developmental Disability Mental Health Sub Network Inaugural Open Meeting

9.30am Friday 29 July 2016

The Boulevard Centre, 99 The Boulevard, Floreat

Time	Program	
9.00am	Registration	
9.30am	Introduction Acknowledgement of Country	Ms Alison Xamon
9.35am	Mental Health-The Big Picture	Mr Tim Marney
9.45am	Overview of Mental Health Network	Dr Helen McGowan
9.55am	Overview of Neuropsychiatry and Developmental Disability Mental Health Sub Network	Dr Rachel Zombor
10.05am	Panel discussion – identifying issues and possible solutions in the neuropsychiatry and developmental disability mental health sector	Ms Storme McLeod – Consumer Ms Jaquie Mills - Family Representative Dr Lynn Jones - Psychiatrist Ms Kathryn Falloon – Disability Services Commission Ms Monique Williamson – Mental Illness Fellowship WA
10.25am	Networking break	All
10.50am	Reflect and build on themes	Mr Will Bessen
11.45am	Joining the Neuropsychiatry and Developmental Disability Mental Health Sub Network and Steering Group	Ms Alison Xamon
11.55am	Concluding remarks and acknowledgements	Dr Brad Hayhow
12.00pm	**Close and Networking**	

Appendix B: Detailed participant input

The table below captures the individual issues and respective solutions raised by participants in the workshop session using the iPad technology.

The 'liked' indicator was used as a method to ensure the feedback component of the session was targeted to key areas within the available time frame and is also displayed.

Issue	Proposed solutions	Likes
• Poor communication between departments (i.e. working in 'silos').	• Confidential client file that 'travels' with clients from agency to agency and integrated subspecialties teams that can address this.	7
• Too few professionals with expertise.	• Increased consultation services. • Sub specialty training and expertise essential. • Cross discipline expertise is needed. • Offer scholarships for people to undertake further training. • Relevant units and training at university.	7
• Poor data linkage amongst areas of health, mental health and disability means having to retell story.		6
• Need for more skilled allied health with training in general health, disability and mental health.		5
• A push in hospitals to discharge quickly without assessment and comprehensive discharge plans.	• On the other hand it is important to return to familiar environment and carers and avoid iatrogenic harm.	5
• Undergraduate and postgraduate training in neuropsychiatry and developmental disability across disciplines is needed.	• This was on offer in Australia and New Zealand but got rid of in the 1980s. The UK and Ireland still provide this tertiary training.	5
• Accessible electronic health records across sectors and disciplines are needed.		4
• It is essential to work in MDT (currently lacking).		4
• Funding systems such as Medicare do not capture complexity and thus discourage taking on complex clients.	• Good example of overarching policy work needed.	4
• Lack of carer support groups and respite services for clients with	• Extension of services, specialist	4

Issue	Proposed solutions	Likes
developmental disability and mental health issues.	groups and support.	
• Need for more training of psychiatrists and then provide ongoing mentoring and support.		4
• Capacity issues around decision making.	• Agreed philosophy.	3
• Developmental disability peer support networks hosted by key agencies are needed.	• For both individuals and families and carers. • Not hosted by service provider.	3
• Eligibility criteria are too prescribed and narrow, and have no flexibility.		3
• GP's overloaded and overburdened by complex needs.	• GP rep on sub network committee. • More education and training.	3
• Lack of care coordination.		3
• Lack of simultaneous or integrated diagnostic services. People have to attend multiple specialty clinics for related needs.	• Establish a one stop centre. • Staff have worked with this model and have had huge success.	3
• Professional Development in schools to learn about contemporary responses to challenging behaviour and restrictive practices.	• Needs to be a consistent approach across government organisations in regard to positive behaviour support.	3
• Prohibitive cost of private services and a lack of public services.	• Lack of integrated public services is crucial.	3
• "It's not mental health - it's behaviour".		2
• No academic unit.		2
• Lack of accessible electronic records across jurisdiction.		2
• More appropriate inpatient mental health facilities for clients with developmental disability.		2
• Bouncing around with limited informal and formal supports.		2
• A lack of contemporary Models of Care and learning from other jurisdictions nationally and		2

Issue	Proposed solutions	Likes
internationally.		
• Need to incorporate emerging physical treatments (e.g. DBS).		2
• In UK and Ireland it is a subspecialty with separate accreditation and non-sub speciality management can be harmful, such as misuse of psychotropic medication.		2
• Insufficient informal supports.	• Actually the richness of life is all about the informal supports we have. This provides structure, purpose, hope, connection. Sometimes one outing a week can be sufficient. It's the glue that keeps things together.	2
• Insufficient resources for outreach into the community; can professionals not go to the person.		2
• Lack of integrated care with pediatricians.		2
• Lack of integrated care with psychiatrists and child psychiatrists.	• And joint neurology / psychiatry clinics (i.e. true neuro-psychiatry liaison).	2
• Issues regarding transport and access to services, and a lack of in the home services.		2
• Lack of clinical pathways into and out of services.		2
• Lack of collaboration and coordination between the services.		2
• Lack of collaboration with other services.	• An agreement on admission for collaboration with other services. • Changing of criteria of what constitutes mental illness. • Joint appointments? • Single point of liaison and contact. • Shared interagency education and training.	2
• Lack of flexibility in disability criteria.	• Improve understanding of criteria. • Place responsibility on service provider to provide an alternative service if a person doesn't meet their	2

Issue	Proposed solutions	Likes
	criteria. • Diagnostic barriers are a problem in terms of expertise, cost and exclusions.	
• Lack of intensive based community mental health support.		2
• Lack of knowledge and skills in mental health and developmental disability.	• Specialist training, education and networking.	2
• More neuropsychology and neuropsychiatry services needed.		2
• No dedicated statewide neuropsychiatric inpatient facility.	• Have a 10 bed facility or service where clients can have respite or present daily for company or adjustment to medications.	2
• Not enough good evidence or international agreement around treatments for people with multiple issues.		2
• Stakeholders need to be engaged and a commitment from CPFS, Department of Education and GPs to participate.		2
• Standard mental health clinicians do not have specialist knowledge in the treatment of people with an intellectual disability or an ABI.	• Access to knowledge and training for contemporary disability training for clinicians. • Rationing of care has an impact on access to services.	2
• Systemic approach is needed to ascertain which changes are needed in each part of the system (e.g. policy, facilities and people with mental health conditions.).		2
• The NDIS funding model focuses on the individual's needs, not the system around the individual (it is deficit driven).	• Awareness about how funding can be used. • Need funding and programs for carers and awareness about these. • Need carer health and mental health plans to recognise the carer's mental health issues.	2
• Difficult transition from child and adolescent to adult service, including		2

Issue	Proposed solutions	Likes
disability services and mental health.		
• Difficulty accessing the integrated network.	• Triage system with knowledge of the network. • Better governance around the network allocations and linkage around funding for shared care. • Flexibility around geographical cut off. • Having more in-reach oriented services. • Dynamic adjustment to new services and closed services.	1
• Need for appropriate residential and respite facilities including developmental, ABI and young onset dementia.		1
• Lack of funding for liaison psychiatry across the lifespan to detect complex neuropsychiatric needs early and manage effectively.		1
• Need for a better understanding of variable presentations of neurodevelopmental disorders such as ADHD as consequences of a lack of treatment throughout the lifespan are profound.		1
• Need for a better understanding within NDIS about thorough and fair assessment of people with complex needs.		1
• Broader understanding and training, plus service delivery for people with frontal lobe impairment of any cause.		1
• Need to develop a care transition roadmap for professionals and consumers (e.g. child to adult sectors).	• Transition officers and care coordinators across the gap?	1
• Communication protocols on discharge are poor.		1
• Consideration and review of ECT with standard of practice/ terms of reference to include disability and		1

Issue	Proposed solutions	Likes
not exclusive to mental health.		
• Data linkage needed in ECT.		1
• Difficulty managing patients with co-morbidities in general hospital. Typically one aspect of a person is unable to be addressed or is ignored.		1
• Disability liaison nurse positions should be funded at general hospitals.		1
• Dominant diagnosis drowns out other comorbid conditions.		1
• Education and guidelines for hospital staff needed.		1
• Form subgroups by specific areas joining the wider networks.		1
• Four specific unique features of this patient group are: diagnostic overshadowing, atypical phenotypic expression of common psychiatric disorders (i.e. depression presents differently), misclassification of underlying disorders as aggression or positionality and rapid escalation of complication, and DSH SIB OD substance abuse.		1
• Funding needed for better liaison between neurology, psychiatry and NP.		1
• Grow primary care expertise in neuropsychiatry and developmental disability		1
• In-reach care to home and residential care to prevent admission to unfamiliar and risky hospital environments.		1
• Lack of access to specialists for diagnosis of disability e.g. neuropsychologists.		1
• Lack of coordination between	• Care program approach type model.	1

Issue	Proposed solutions	Likes
services.		
• Lack of community support services and residential accommodation for people in their 50s with cognitive and behavioural issues.	• Neuropsychiatric services across both ABI and some alcohol related. Services are too small at present and we need to expand these services. • A need for safe community activities for people who have behavioural issues to participate in. • How can NGOs invest in training if contracts are so unstable and short term? How do services step up? • In the UK there is a royal college of psychiatrists specialising in learning disability.	1
• Lack of comprehensive services for complex needs (e.g. intellectual disability).	• Establish a dedicated MDT for intellectual disability.	1
• Lack of knowledge about, and access to, assessment tools such as PAS-ADD.	• Education and training, promotion of materials and networking.	1
• Lack of residential options for adults with complex needs.		1
• Lack of subspecialty services.		1
• Lack of training and exposure of the complex cases.	• Integration of training in mental health and university programs.	1
• Large cohort of adults with developmental disorders who missed childhood diagnosis.	• Specialist adult diagnostic clinic.	1
• Liaison models (like WAEDOCS).		1
• Lots of independent groups without good integration.	• Having a functional network model without too many players as it gets diffused and means too many differing opinions which hinders progress. • Increased number of mental health professionals such as neuropsychologists and neuropsychiatrists are needed on the group.	1
• Lots of people are discouraged with the process of going through mental	• Focusing on positive activities and cognitions.	1

Issue	Proposed solutions	Likes
illnesses.		
• Many MDTs are missing key elements such as neurology, psychiatry, and clinical psychology.		1
• Lack of medical school exposure in the curriculum.		1
• Medical trainee rotation needed (GP, psychiatrists, physicians).		1
• Medication review panels for long term use of psychotropic drugs are required that have independent representation aside from the prescribers.		1
• A multidisciplinary approach, family attention, functional networks, psychoeducation of health professionals and more funding are all needed.		1
• Need to address the social isolation of families.	• Peer partner programs.	1
• No assessment process, as clinicians don't want to see people with a disability.		1
• Process needed to go through significant medical review (importance of medication review) with detox (planned withdrawal) to determine if possible to reduce or cease medication.		1
• Psychiatric residential facilities are often unable to manage (and therefore accept) people who have co-occurring physical and/or medical conditions.		1
• Recognising that many people move in and out of mental illness.	• Having more community services available rather than the client coming to the hospital.	1
• Services and supports for those with mental health and disability issues are separated.		1
• Specialist neuro-oncology services		1

Issue	Proposed solutions	Likes
are needed for behavioural disturbance in people with benign and malignant brain tumours, including respite and hospice care.		
• Specialist neuropsychiatry liaison to state neurosurgical service needed.		1
• Specialist neuropsychiatry liaison to the state head injury unit should be funded.		1
• Increase specialist resources for assessment and care of people with functional neurological disorders (conversion etc.).	• High proportion of neurological patients present this way, especially non-epileptic seizures. • High prevalence with limited research; would be good public sector research program.	1
• Statewide services with in-reach and outreach funding need to build capacity across health and mental health.		1
• Sub network consultation with NDIS needed.		1
• Such specific and excessive criteria for services, makes them inaccessible.	• Make a level of accessibility and informal services available.	1
• Difficulty accessing the integrated network.		0
• Address the social isolation of people with developmental disability and mental illness (e.g. circles of friends or microboards).		0
• Inappropriate inpatient expertise (e.g. no nursing specialists).		0
• Avoid unnecessary complications prolonging hospitalisation.		0
• Bilateral in-reach (disability into MHU, mental health into disability).		0
• Capacity is needed for specialty skilled allied health to provide outreach and in-reach.		0
• Capacity is needed to provide		0

Issue	Proposed solutions	Likes
physical rehab in mental health settings (and mental health care to those receiving physical or medical care).		
• Change the approach to more 'healing the body via the mind' focused.	• Logic and quantum. • Logic equals what's wrong and you fix it; • Quantum equals what's going well and you expand it. • Holistic approach to intervention, not just via the typical medical model, changing the emphasis on traditional physical therapies.	0
• Clients with dual diagnosis not wanting involvement with mental health services.	• Offer alternative pathways (e.g. GP or Mental Illness Fellowship Western Australia (MIFWA) and Hospital in The Home (HITH)).	0
• Clinical research program and integration into clinical model of care to improve outcomes with evidence.		0
• Communication and funding streams lacking.		0
• Community mental health services should be firmly directed to accept referrals of people with intellectual disability and behavioural disturbance where there is a need for rationalising psychotropic prescribing.		0
• Contemporary understanding to medical reality needed.		0
• Contemporary thinking to clinical practice and international best practice is lacking.		0
• Differentiating patients who need episodic care and integrated chronic care.		0
• Difficult to know what services exist.	• Develop more service provision models like Complex Needs Coordination Team but with broader scope.	0
• Difficulty accessing social needs	• Underdeveloped or nonexistent area	0

Issue	Proposed solutions	Likes
(residential option).	of needs.	
• Domain in what is considered as therapeutic has been reduced.	• Agree on different models which are more flexible and not so prescriptive. • Look at informal supports and have a community understanding. Things like helping people move to sit outside in the sunshine, or have a cup of tea with family.	0
• Duplication of paper work required and people have to tell their stories again and again as information is not being shared between services.	• Online portal or client management system for sharing information.	0
• Education of families and carers in relation to care pathways.		0
• Efficient and direct communication of budget in areas of need for mental health, including disabilities.		0
• Eligibility dependent on permanence and duration, or episodic. Intersection between disability and traditional mental health doesn't work well.	• Increased recognition of different levels of need and support. • Increased flexibility in length of involvement depending on individual. • Continued government funding for people with different levels of need.	0
• Focus on behavior without clear analysis.		0
• Focused purpose of MDT.		0
• Gap in communication in what services exist.		0
• GP learning modules and seminars needed.		0
• Huge need for specialist inpatient unit with highly trained professionals, as well as outpatient services for follow up.		0
• Inclusion criteria to adapt and extend.	• Ensure flexibility of criteria.	0
• Incorporate family, GP, nurses (very few mental health nurses), and other mental health professionals.		0
• Increase the recognition of the role		0

Issue	Proposed solutions	Likes
of neuropsychologists.		
• Increased level of examination ECT and data linkage review of how ECT is used.		0
• Insufficient support and understanding of individuals who become involved with the justice system.	• Having more individuals who would provide support and disability advocacy.	0
• Integration of neurological, psychiatric and disability expertise at the State Epilepsy Service.		0
• Issues often stem from funding models whereby one agency needs to take primary responsibility, so it's hard to provide integrated and holistic care when the overarching funding models don't support that.		0
• Lack or absence of communication between agencies at an individual person level.		0
• Lack of peer support (e.g. clients who have previously had a stroke and are further down their rehab volunteering to assist stroke patients in hospital).		0
• Lack of services for traumatic brain injury and palliative neuropsychiatric care.	• Raising awareness and developing a training program for this area.	0
• Lack of services in rural and remote areas.		0
• Lack of sharing of information between services.	• Legislation changes to meet current needs.	0
• Lack of specialised knowledge regarding complexity of developmental disability among psychiatry and psychology services.		0
• Lack of training for police in disability and mental health and lack of support for their training.		0
• Lack of training for specialists in		0

Issue	Proposed solutions	Likes
health system.		
• Long appointment and assessment process for ASD diagnosis.		0
• Need for dedicated case management services that work with people across settings and agencies.		0
• Need to provide holistic support that addresses quality of life for the client and people around the client.	• A blend of medical and psychosocial models.	0
• Needs analysis for people with needs at the interface of health and mental health.		0
• No acknowledgement that there can be co-morbidity.		0
• No services willing to engage and denied access to services.	• Talking to people face to face.	0
• Nursing and allied health training and experience is needed.		0
• Often there is a need for a mentor or advocate for families.		0
• Patients with physical or medical issues often can't be managed in a mental health unit because it's seen as a ‘risk’.		0
• People with ABI being inappropriately placed in mental health hospitals.		0
• Poor integration between leadership in services, such as between mental health and disability.		0
• Reluctance to admit for inpatient assessment.		0
• Residential care is often not pleasant to reside in.		0
• Service standards are needed (e.g. different service providers need to work as a team).		0
• Stakeholders (GPs, Primary,		0

Issue	Proposed solutions	Likes
Department of Education and CPFS) need to ensure a high level of representation from the Education Department.		
• Systematic career histories and engagement.		0
• The way funds are distributed encourages taking efficient clients.		0
• Threshold issue - need to have too high level of need before receiving support.		0
• Use of medication questionnaire?		0
• When there is essentially a mental health issue but mental health services deny.		0

Appendix C: Inaugural Neuropsychiatry and Developmental Disability Mental Health Sub Network Steering Group

At the conclusion of the Neuropsychiatry and Developmental Disability Mental Health Sub Network Open Meeting, expressions of interest in joining the Steering Group of the Sub Network were called for. The Sub Network Implementation Group selected the following representatives to form the inaugural Neuropsychiatry and Developmental Disability Mental Health Sub Network Steering Group:

- John Brearley
- Lynn Jones
- Monique Williamson
- Brad Hayhow
- Kathy McCoy
- Bedrija Parsons
- Kathryn Falloon
- Rachel Skoss
- Jean Taylor
- Rachel Zombor (co-chair)
- Anthanasios Gaitatzis
- Taryn Harvey (co-chair)
- Peter Watts

Appendix D: Acronyms

Acronym	Definition
ABI	Acquired Brain Injury
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CPFS	Department of Child Protection and Family Support
DBS	Deep Brain Stimulation
DSH	Deliberate Self-Harm
EAG	Executive Advisory Group
ECT	Electroconvulsive Therapy
GP	General Practitioners
HITH	Hospital in The Home
MDT	Multidisciplinary Teams
MHC	Mental Health Commission
MHN	Mental Health Network
MHU	Mental Health Unit
MIFWA	Mental Illness Fellowship Western Australia
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
OD	Overdose

Acronym	Definition
PAS-ADD	Psychiatric Assessment Schedules for Adults with Developmental Disabilities
SIB	Self-Injurious Behaviour
UK	United Kingdom
WAEDOCS	WA Eating Disorders Outreach and Consultation Service

This document can be made available in alternative formats on request for a person with a disability.