



Element 8: MULTIPLE DISADVANTAGE

All Elements include specific focus on contributors to multiple disadvantages including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, CALD backgrounds and contact with the criminal justice system.

Recommendation 1: Develop national minimum standard for universal services access for people with intellectual disability

A national minimum standard for access to health and human services for people with intellectual disability would overcome key barriers to accessing services. High level agreement with this approach would need to be canvassed.

This Recommendation seeks to develop and deliver a high level agreement on national minimum standards and could be sought specifically for people with intellectual disability, or more broadly for people with disability, with a strong emphasis on people with intellectual disability.

Suggested pathways

1. Determine through sector consultation, whether initiative should seek intellectual disability specific Standard, or broader disability Standard
2. Determine feasibility of the inclusion of this standard in revisions of the National Disability Strategy (for example, in principles, approaches or relevant components of outcomes)
3. Seek broad-based support for initiative, including financial support, by seeking state-based Ministers to champion. COAG support seen as essential for success
4. Formation of an advisory group inclusive of all stakeholders – e.g. consumers, family members, member groups of professionals, etc.
5. Determine a work plan including timeline for consultations, research, drafts for public comment, finalisation for Standards and implementation plan
6. Implementation phase with strong communication strategy, stakeholder and community engagement, and evaluation.

Potential timeline

Suggestions 1–2 by the end of 2019; suggestions 3–5 by mid-2021; suggestion 6 to take an additional 24–48 months.



Element 8: MULTIPLE DISADVANTAGE

Continued...

Recommendation 2: Establish national guidelines for cross- agency collaboration for people with intellectual disability and mental health needs

The goal of this Recommendation is the production and implementation of national guidelines for cross-agency collaboration at local, state and commonwealth levels. Cross-agency collaboration is key to ensuring cohesion of multiagency supports for people with intellectual disability, and is critical for people with multiple disadvantages.

Suggested pathways

1. Map relevant stakeholders in each state, and collate exemplars of cross-agency collaboration in Australia
2. Identify international best practice models, through field research – e.g. Churchill Fellowship
3. Determine capacity for individual agencies – e.g. NDIS, health, education, corrections, etc. to support cross-agency collaboration, seeking opportunities where appropriate (e.g. the NDIS Pathway for people with complex needs)
4. Determine feasibility of establishing cross-agency collaboration as a key approach incorporated within revisions of the National Disability Strategy
5. Produce national guidelines for cross-agency collaboration, and facilitate implementation at a local and state level in key agencies.

Potential timeline

Suggestions 1–4 by the end of 2019; suggestion 5 by the end of 2020.



Element 8: MULTIPLE DISADVANTAGE

Continued...

Recommendation 3: Disability, justice and mental health guidance within the NDIS

A greater understanding is required of the needs and factors that influence outcomes for people with intellectual disability who have contact with the justice system. Interagency collaboration is a concrete step likely to underpin quality service provision to people with intellectual disability who have contact with the justice system. An important initial step is to ensure that the NDIS pathway for people with complex needs has the capacity to cater to the needs of people who have contact with the justice system.

Suggested pathways

1. Assess NDIS complex needs pathway and ensure strong consideration of multiple disadvantage
2. Conduct scoping work to identify gaps and best practice within all relevant agencies and service providers
3. Review the NDIS legislation to enhance focus on people with multiple disadvantage, ensure availability of service providers delivering specific supports in this area
4. Undertake analysis of linked data to examine trajectories of those with multiple disadvantage to understand drivers and outcomes
5. Consult and develop potential proposals for capacity building projects in this area.

Potential timeline

Suggestion 1 by the end of 2018; suggestions 2-5 by the end of 2020.

APPENDIX 2

Attendee list

A list of attendees can be viewed [here](#).

Partnerships for Better Health Project

A detailed description of the National Health and Medical Research Council (NHMRC) funded Partnerships for Better Health Project "Improving the mental health outcomes of people with intellectual disability" (APP 1056128) can be viewed [here](#).

Pre-roundtable survey results summary

A summary of the barriers and enablers identified in the pre-survey can be found [here](#).

Roundtable program, speaker biographies and video highlights

The National Roundtable program and speaker biographies can be viewed [here](#).

Roundtable video excerpts can be viewed [here](#).



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY



Council for
Intellectual Disability



Daly, Kelly (Health)

From: Lee, Melissa (Health)
Sent: Wednesday, 14 November 2018 2:58 PM
To: actmhc; Aloisi, Bruno (Health); Andrea Gledhill; ANU CMHR; Axell, Anita; Bicket, Robyn; Bingham, Jaime (Health); Bonnie Millen; Bowrah, Victoria (Health); Braun, Helen (Health); Burvill, Stefanie (Health); Calvin, Sam (Health); Campbell, AliceC (Health); Carol Archard; Charles, Amanda; Chief Psychiatrist; Donley, Mandy; Dr Meredith Sisson; Dunne, Ellen; Gibson, Sally; JacksonHope, David (Health); Kaur, Tej; Kipling, Wendy; Kirkham, Anna; Laurent Anthes; McIntyre, Shirley-Anne (Health); Mental Health Community Coalition; Purity Goj; Ratnayake, Priyani; Redmond, Margaret; Rogers, Lee-Anne (Health); Rugendyke, Amy; Kerr, Sheridan; Shuhyta, Amber; Simon, Michelle; Smith, Meghan (Health); Sweetman, Rebecca (Health); Wafer, Matthew (Health); Walker, Janelle (Health); ZedThree Specialist Centre
Subject: Agenda and Terms of Reference Mental Health Services for People with Intellectual Disability [SEC=UNCLASSIFIED]
Attachments: Mental Health Services for people with Intellectual Disability Discussion Paper V1.0 29181108.docx; TOR - ACT Strategy Mental Health Services for People with Intellectual Disability 20181114.docx

Hello Everyone,

Please see attached an Agenda and draft Terms of Reference for discussion at tomorrow's meeting.

Warm Regards

Melissa

Melissa Lee | Senior Policy Officer
 P: 02620 75994 | M: [REDACTED] E: Melissa.Lee@act.gov.au
 Mental Health Policy | Policy, Partnerships and Programs
 Health Policy and Strategy | ACT Health | ACT Government
 Level 4, 2-6 Bowes Street, WODEN | GPO Box 825, Canberra ACT 2601 | act.gov.au

"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."



TERMS OF REFERENCE

ACT Health Mental Health Services for People with Intellectual Disability Working Group

The Minister for Mental Health, Minister Shane Rattenbury and ACT Health are committed to developing an action plan for improving the provision of mental health services for people with Intellectual Disability and Autism Spectrum Disorders in the ACT. This action plan will consider appropriate responses to the National Roundtable Recommendations on the Mental Health of People with Intellectual Disability (2018) and options to improving the range of services available to those with intellectual disability and/or autism spectrum disorders, their families and carers.

Role	<p>The purpose of the ACT Health Mental Health Services for People with Intellectual Disability Working Group is to discuss and develop a strategy for mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders where appropriate, in the ACT, to be submitted to the Minister for Mental Health, that will inform actions under the ACT Mental Health and Suicide Prevention Plan.</p>
Reporting Mechanism	<p>The ACT Mental Health Services for People with Intellectual Disability Working Group will discuss and develop the strategy for mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders where appropriate, in the ACT. The resultant strategy will be submitted to the Minister for Mental Health for consideration and will inform the development of an action plan for mental health services for people with Intellectual Disability in the ACT.</p> <p>Where necessary the committee may choose to make out-of-session determinations and decision via electronic means such as e-mail or via teleconference.</p> <p>An agenda, including all relevant attachments, will be distributed to all committee members at least 2 working days prior to the scheduled meetings.</p> <p>Minutes and action items will be distributed within 3 working days of the scheduled meeting to ensure action items can be completed in a timely manner.</p> <p>Minutes, action items and briefings for the Minister for Mental Health will be managed by ACT Health Mental Health Policy.</p>
Functions	<p>The ACT Health Mental Health Services for People with Intellectual Disability Working Group is responsible for the development of the draft strategy mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders in the ACT.</p> <p>This strategy will:</p> <ul style="list-style-type: none"> • aim to identify service gaps, and explore opportunities to achieve greater coordination and effectiveness of services across primary health care, community agencies and specialist services in supporting those with Intellectual Disability and Autism Spectrum Disorder to access the right mental health services at the right time.

	<ul style="list-style-type: none"> • indicate priority areas for development across the continuum of care, from community-based through to tertiary services with priority given to evidence-based treatment options. • identify and consider short-term and long-term mental health service planning in the ACT that is inclusive and able to respond to the range of challenges identified for people with intellectual disability and Autism Spectrum Disorder.
Membership	<p>ACT Health invites members on the basis of relevance and expertise in support of the Working Group's functions. This Working Group will consist of:</p> <ul style="list-style-type: none"> • Senior representatives from ACT Health with mental health and/or intellectual disability expertise; • Senior representatives from ACT Health with policy expertise; • A representative from the Office for Mental Health and Wellbeing; • Senior representatives from the Office for Disability; • ACT Senior Practitioner; • A representative from Child Development Services (CSD); • A representative from the Education Directorate; • Senior representatives from Justice and Community Services; • A representative from the Centre for Mental Health Research; • A representative from the Capital Health Network; • A representative from the ZedThree Specialist Centre; • A representative from Human Rights Commission; • A representative from Mental Health Consumers ACT; • A representative from Carers ACT; • A representative from Mental Health Community Coalition of the ACT; <p>The Working Group Chair will be the Director of Mental Health Policy, Policy, Partnerships and Programs, ACT Health.</p> <p>The ACT Health Mental Health Services for People with Intellectual Disability Working Group may invite other attendees at the Chair's discretion.</p>
Secretariat	Secretariat functions will be managed by the ACT Health Mental Health Policy Unit.
Agenda requests	<p>The secretariat is to receive requests for agenda items 3 working days before the meeting, unless otherwise advised.</p> <p>Papers are to be distributed no later than 2 working days before the meeting.</p>
Meeting Frequency	<p>It is intended that the strategy will be developed over three meetings. Additional working group meetings will be held if required.</p> <p>The planned meetings will be held on:</p> <ul style="list-style-type: none"> • Thursday 15th November 2108 • Xxx • xxx
Meeting Format	There will be a standing agenda with additional items to be agreed with the Chair prior to each scheduled meeting.
TOR Review Frequency	As required.
Quorum	<p>50% plus 1, excluding the Chair.</p> <p>In the case of absences, a proxy may be nominated by the absent member.</p>

TOR Approved	The draft TOR will be reviewed at the first Working Group meeting on Thursday 15 th November 2018
Review	To be confirmed.

Daly, Kelly (Health)

From: Lee, Melissa (Health)
Sent: Wednesday, 14 November 2018 3:03 PM
To: actmhc; Aloisi, Bruno (Health); Andrea Gledhill; ANU CMHR; Axell, Anita; Bicket, Robyn; Bingham, Jaime (Health); Bonnie Millen; Bowrah, Victoria (Health); Braun, Helen (Health); Burvill, Stefanie (Health); Calvin, Sam (Health); Campbell, AliceC (Health); Carol Archard; Charles, Amanda; Chief Psychiatrist; Donley, Mandy; Dr Meredith Sisson; Dunne, Ellen; Gibson, Sally; JacksonHope, David (Health); Kaur, Tej; Kipling, Wendy; Kirkham, Anna; Laurent Anthes; McIntyre, Shirley-Anne (Health); Mental Health Community Coalition; Purity Goj; Ratnayake, Priyani; Redmond, Margaret; Rogers, Lee-Anne (Health); Rugendyke, Amy; Kerr, Sheridan; Shuhyta, Amber; Simon, Michelle; Smith, Meghan (Health); Sweetman, Rebecca (Health); Wafer, Matthew (Health); Walker, Janelle (Health); ZedThree Specialist Centre
Subject: RE: Agenda and Terms of Reference Mental Health Services for People with Intellectual Disability [SEC=UNCLASSIFIED]
Attachments: Agenda - Mental health services for people with intellectual disability 15nov18.docx

Apologies,

Agenda paper attached

Melissa

P: 02620 75994 | M: [REDACTED] E: Melissa.Lee@act.gov.au

From: Lee, Melissa (Health)
Sent: Wednesday, 14 November 2018 2:58 PM
To: [REDACTED] Aloisi, Bruno (Health) <Bruno.Aloisi@act.gov.au> [REDACTED]
 [REDACTED] ANU CMHR [REDACTED] Axell, Anita
 <Anita.Axell@act.gov.au>; Bicket, Robyn <Robyn.Bicket@act.gov.au>; Bingham, Jaime (Health)
 <Jaime.Bingham@act.gov.au>; [REDACTED] Bowrah, Victoria (Health)
 <Victoria.Bowrah@act.gov.au>; Braun, Helen (Health) <Helen.Braun@act.gov.au>; Burvill, Stefanie (Health)
 <Stefanie.Burvill@act.gov.au>; Calvin, Sam (Health) <Sam.Calvin@act.gov.au>; Campbell, AliceC (Health)
 <Alice.C.Campbell@act.gov.au> [REDACTED] Charles, Amanda
 <Amanda.Charles@act.gov.au>; Chief Psychiatrist <ChiefPsychiatrist@act.gov.au>; Donley, Mandy
 <Mandy.Donley@act.gov.au>; [REDACTED] Dunne, Ellen
 <Ellen.Dunne@act.gov.au>; Gibson, Sally <Sally.Gibson@act.gov.au>; JacksonHope, David (Health)
 <David.JacksonHope@act.gov.au>; Kaur, Tej <Tej.Kaur@act.gov.au>; Kipling, Wendy <Wendy.Kipling@act.gov.au>;
 Kirkham, Anna <Anna.Kirkham@act.gov.au>; [REDACTED] McIntyre, Shirley-Anne
 (Health) <Shirley-Anne.McIntyre@act.gov.au> [REDACTED]
 [REDACTED] Ratnayake, Priyani <Priyani.Ratnayake@act.gov.au>; Redmond, Margaret
 <Margaret.Redmond@act.gov.au>; Rogers, Lee-Anne (Health) <Lee-Anne.Rogers@act.gov.au>; Rugendyke, Amy
 <Amy.Rugendyke@act.gov.au>; Sheridan Kerr <Sheridan.Kerr@act.gov.au>; Shuhyta, Amber (Health)
 <Amber.Shuhyta@act.gov.au>; Simon, Michelle <Michelle.Simon@act.gov.au>; Smith, Meghan (Health)
 <Meghan.Smith@act.gov.au>; Sweetman, Rebecca (Health) <Rebecca.Sweetman@act.gov.au>; Wafer, Matthew
 (Health) <Matthew.Wafer@act.gov.au>; Walker, Janelle (Health) <Janelle.Walker@act.gov.au>; ZedThree Specialist
 Centre [REDACTED]
Subject: Agenda and Terms of Reference Mental Health Services for People with Intellectual Disability
 [SEC=UNCLASSIFIED]

Hello Everyone,

Please see attached an Agenda and draft Terms of Reference for discussion at tomorrow's meeting.

Warm Regards

Melissa

Melissa Lee | Senior Policy Officer

P: 02620 75994 | M: [REDACTED] E: Melissa.Lee@act.gov.au

Mental Health Policy | Policy, Partnerships and Programs

Health Policy and Strategy | ACT Health | ACT Government

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AGENDA

ACT Health Mental health services for people with Intellectual Disability Working Group

Thursday 15 November 2018

2:30-4:30pm

Training Room 1, Level 1

1 Moore St, Canberra City, ACT

1. Acknowledgement of Country

We wish to acknowledge the traditional custodians of the land we are meeting on, the Ngunnawal people.

We wish to acknowledge and respect their continuing culture and connections to the land.

We would also like to acknowledge and welcome Aboriginal and Torres Strait Islander peoples who may be here today.

2. Introductions and welcome

3. Apologies

4. Draft Terms of Reference

5. Discussion Paper Brief Overview (Melissa)

6. Discussion/Comments

- From Discussion Paper
- Roundtable Recommendations
- Other

7. Next Steps

Daly, Kelly (Health)

From: Lee, Melissa (Health)
Sent: Wednesday, 23 January 2019 1:48 PM
To: McIntyre, Shirley-Anne (Health); Walker, Janelle (Health); Burvill, Stefania (Health); Smith, Meghan (Health); Ratnayake, Priyani; ZedThree Specialist Centre; Furner, Catherine (Health); Kipling, Wendy; Charles, Amanda; Bingham, Jaime (Health); Donley, Mandy; Kerr, Sheridan; Gibson, Sally; Rogers, Lee-Anne (Health); Mental Health Community Coalition; Laurent Anthes; ANU CMHR; Carol Archard; Redmond, Margaret; Chief Psychiatrist; Rugendyke, Amy; Simon, Michelle; Lewis, Llew (Health); Aloisi, Bruno (Health); Braun, Helen (Health); Bicket, Robyn; Purity Goj; Bonnie Millen; Shuhyta, Amber; Kaur, Tej; Kirkham, Anna
Cc: Bowrah, Victoria (Health); Dunne, Ellen; Ord, Jon (Health); Wafer, Matthew (Health); Edge, Natalie (Health); Office for Mental Health and Wellbeing
Subject: Mental Health Services for people with Intellectual Disability Strategy Working Group Minutes and updates
Attachments: Minutes - Mental Health Services for people with Intellectual Disability Working Group - 151118 v3.docx; TOR - ACT Strategy Mental Health Services for People with Intellectual Disability 20190122.docx

UNCLASSIFIED

Dear Strategy Working Group,

Please find attached the draft minutes from the initial working meeting held on 15th November 2018. Apologies for the delay in distributing these.

FOR ACTION:

Please let me know of any corrections to the minutes

Please review the latest draft of the Terms of Reference and indicate your acceptance (or not with feedback)

Please Contact Melissa Lee if you would like to set up a meeting to discuss your thoughts, priorities for action in the strategy.

NEXT MEETING

I hope to have a first draft of the Strategy complete by mid-February and convene a second meeting of the working group a couple of weeks after (end of February beginning of March).

Many thanks for your interest and input

Melissa

Melissa Lee | Senior Policy Officer, Mental Health Policy
 P: (02) 5124 9780 | MOB: [REDACTED] F: (02) 6174 5560
 E: melissa.lee@act.gov.au

NOTE: Work days are Mon-Thur

Policy, Partnerships and Programs | Health Systems, Policy and Research | ACT Health Directorate
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 Care ▲ Excellence ▲ Collaboration ▲ Integrity

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ACT Health Mental health services for people with Intellectual Disability Working Group

Minutes

Thursday 15 November 2018

Attendees:

Chair

- Amber Shuhyta, Director of Mental Health Policy, ACT Health

Members

- Melissa Lee, Senior Policy Officer, Mental Health Policy
- Carol Archard, Carers ACT
- Shirley-Anne McIntyre, Manager, Mental Health Service for People with Intellectual Disabilities
- Dr Peter Wurth, Psychiatrist, Mental Health Service for People with Intellectual Disabilities
- Janelle Walker, Mental Health Service for People with Intellectual Disabilities
- Meghan Smith, Mental Health Service for People with Intellectual Disabilities
- Stefanie Burvill, Mental Health Service for People with Intellectual Disabilities
- Dr Priyani Ratnayake, Mental Health Service for People with Intellectual Disabilities
- Purity Goj – ACT Mental Health Consumer Network
- Bonnie Millen – Advocacy for Inclusion
- Wendy Kipling – Senior Manager, Office for Disability
- Michelle Simon – Child Development Service
- Rebecca Sweetman – Child Paediatrics and Child Health Services
- Sheridan Kerr – Office of Senior Practitioner
- Robyn Bicket – Disability Justice Strategy Project team
- Lee-Anne Rogers- Change Leader, Office for Mental Health and Wellbeing
- Alice Campbell – Mental Health Policy
- Amy Rugendyke - ACT Corrective Services
- Vicky Bowrah – Acting Director CAHMS
- Sally Gibson – Office of the Senior Practitioner
- Jaime Bingham, Forensic Mental Health Services, Justice Health Services

Minutes

- Natalie Edge, Executive Assistant, Office for Mental Health and Wellbeing
-

1. Acknowledgement of Country

The traditional custodians, the Ngunnawal people and Aboriginal and Torres Strait Islander peoples were officially welcomed and acknowledged.

2. Introductions and Welcome

Thank you to all for attending at such short notice. There has been a lot of discussion around mental health and intellectual disability coming from the National Roundtable as

well as some contact with the Minister in regard to services. This meeting is an opportunity to discuss a strategic approach to providing those services. It is hoped that this Working Group will pull together the strategic direction and some actions that might flow out of that. It will ultimately sit under the ACT Mental Health and Suicide Prevention Plan and align with some of the other strategies such as the Disability Justice Strategy.

The role of the group today is to look at the discussion paper and discuss initial comments on the key issues and areas to address. The Mental Health Policy team then intends to put together an options paper detailing the priorities for the sector. A second meeting will be held early next year to finalise options and discuss the strategies going forward. A third meeting will then be held finalise the strategy. There will be some out of session consultation and review required also.

3. Apologies

- Bruno Aloisi (OD, Adult Community Mental Health)
- Helen Braun (OD, Adult Acute Mental Health)
- Dr Llew Lewis (Adult Community Mental Health)
- Zedthree Specialist Centre
- Luis Salvador-Carulla ANU CMHR
- Tej Kaur (Education)
- Lauren Anthes (CHN)
- David Jackson Hope (Operational Director, Rehabilitation and Specialty Services)

4. Draft Terms of Reference

Question raised whether there is value in having separate strategies for autism and intellectual disability. The majority of people identified with autism spectrum disorder also have an intellectual disability (about 70%), group advised it would be appropriate to address these groups within this strategy. It was agreed that 'where appropriate' would be removed from the 'Role' section of the Terms of Reference.

The Chair reported that a representative from Canberra Health Services should also be included in the working group.

Zedthree have been invited to ensure that the private sector is included in the working group. Dr Alex Lim of Zedthree has indicated he is keen to be a part of the working group.

A GP Representative was also raised as someone who should be part of the working group. Amber will approach GP Liaison unit for a GP representative.

NDIA input will also be required. Wendy will provide a contact person to discuss representation of the NDIA in the working group.

Actions:

1. 'Where appropriate' to be removed from Terms of Reference
2. Invite representative from Canberra Health Services
3. Contact GP Liaison Unit for a GP Representative.
4. Invite representative from NDIA.

5. Discussion Paper Brief Overview

Melissa provided a brief overview of the Discussion Paper to working group members.

6. Discussion / Comments

a. From Discussion Paper

- Feedback has been obtained from ANU on statistics being used – using Population Health statistics may overestimate the numbers – this may be something that needs to be looked at.
- The complexity section highlights the need for some levels of expertise in terms of assessment of people who have multiple needs, both in terms of mental health services having expertise in intellectual disabilities and other services having expertise in mental health.
- Access to services is also an identified issue for the mild to moderate intellectual disability range and a need for mental health services. Issues have been identified around the development of strategic policy.
- Disability in the Justice system – lots of work happening in that space in terms of the Disability Justice Strategy as people within the justice system have multiple needs, multiple disabilities and multiple conditions and are much more disadvantaged.
- There is a section on people with borderline intellectual functioning. This is a group that often slips through the gaps of services.
- Most services would be familiar with the section outlining the Current ACT Context and that we need to be working together better and having better relationships in terms of how people move through services.
- Complexities in comprehensive assessment is also a big gap in service. How do we develop an assessment process, so that it is not assessments done in isolation? Sometimes there is pressure from schools, communities, societies to find an autism diagnosis as the pathway is clear for treatment and has better resources.
- Diagnostic over-shadowing is also a problem.
- The final section outlines strategies to create a more effective system. There are also questions at the end to consider in discussions.
- The NDIS has also changed the way advocacy is performed - not able to support those without NDIS funding. There are not a lot of services available for those who do not qualify for NDIS. Some people also choose not to engage with NDIS. There is an assumption that NDIS has solved everything, but it hasn't. Housing, child Protection, outreach and social supports need to be considered. Some people will have a huge NDIS plan that is not used because there has not been adequate coordination and the staff in the sector haven't got the capacity to work with complexity and mental health issues added to that.
- CHHS is still working the same way regardless of NDIS. Disability ACT and Therapy ACT previously serviced clients but now CHHS does not know who to contact. NDIS system was used to replace existing systems not support them. Huge gaps have been left.
- Custody – people are being held in remand for a long period of time or denied bail due to NDIS issues. Documentation is complex and needs to be simplified. Justice has the same sorts of issues. How do we dovetail Health strategy with the Justice strategy?
- Early supports – education and youth are required. Fragmentation was raised as an issue.
- Recruitment and sustainability of staffing is also an issue. Social intervention at school level would be useful. Build awareness and increase access before the ED presentation.

b. Roundtable Recommendations.

c. Other

7. Next Steps

Out of session feedback to be sent to Melissa Lee in next 2-3 weeks.
Melissa and MHP team will also be available for consultations and will arrange meetings with specific teams/services over the next couple of months.

A draft strategy document will be sent out following further input and prior to a second working group meeting (February 2019).



TERMS OF REFERENCE

ACT Health Mental Health Services for People with Intellectual Disability Working Group

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Role	<p>The purpose of the ACT Health Mental Health Services for People with Intellectual Disability Working Group is to discuss and develop a strategy for mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders, in the ACT, to be submitted to the Minister for Mental Health, that will inform actions under the ACT Mental Health and Suicide Prevention Plan.</p>
Reporting Mechanism	<p>The ACT Mental Health Services for People with Intellectual Disability Working Group will discuss and develop the strategy for mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders where appropriate, in the ACT. The resultant strategy will be submitted to the Minister for Mental Health for consideration and will inform the development of an action plan for mental health services for people with Intellectual Disability in the ACT.</p> <p>Where necessary the committee may choose to make out-of-session determinations and decision via electronic means such as e-mail or via teleconference.</p> <p>An agenda, including all relevant attachments, will be distributed to all committee members at least 2 working days prior to the scheduled meetings.</p> <p>Minutes and action items will be distributed within 3 working days of the scheduled meeting to ensure action items can be completed in a timely manner.</p> <p>Minutes, action items and briefings for the Minister for Mental Health will be managed by ACT Health Mental Health Policy.</p>
Functions	<p>The ACT Health Mental Health Services for People with Intellectual Disability Working Group is responsible for the development of the draft strategy mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders in the ACT.</p> <p>This strategy will:</p> <ul style="list-style-type: none"> • aim to identify service gaps, and explore opportunities to achieve greater coordination and effectiveness of services across primary health care, community agencies and specialist services in supporting those with Intellectual Disability and Autism Spectrum Disorder to access the right mental health services at the right time. • indicate priority areas for development across the continuum of care, from community-based through to tertiary services with priority given to evidence-based treatment options.

	<ul style="list-style-type: none"> • identify and consider short-term and long-term mental health service planning in the ACT that is inclusive and able to respond to the range of challenges identified for people with intellectual disability and Autism Spectrum Disorder.
Membership	<p>ACT Health invites members on the basis of relevance and expertise in support of the Working Group's functions. This Working Group will consist of:</p> <ul style="list-style-type: none"> • Senior representatives from Canberra Health Services with mental health and/or intellectual disability expertise; • Senior representatives from ACT Health with policy expertise; • A representative from the Office for Mental Health and Wellbeing; • Senior representatives from the Office for Disability; • Representative from the ACT Office of the Senior Practitioner; • A representative from Child Development Services (CSD); • A representative from the Education Directorate; • Senior representatives from Justice and Community Services; • A representative from the Centre for Mental Health Research; • A representative from the Capital Health Network; • A General Practice representative; • A representative from the ZedThree Specialist Centre; • A representative from Human Rights Commission; • A representative from ACT Mental Health Consumers Network; • A representative from Carers ACT; • A representative from the ACT Mental Health Community Coalition; • A representative from Disability advocacy <p>The Working Group Chairperson will be the Director of Mental Health Policy, Policy, Partnerships and Programs, ACT Health Directorate.</p> <p>The ACT Health Mental Health Services for People with Intellectual Disability Working Group may invite other attendees at the Chair's discretion.</p>
Secretariat	Secretariat functions will be managed by ACT Health Mental Health Policy.
Agenda requests	<p>The secretariat is to receive requests for agenda items 3 working days before the meeting, unless otherwise advised.</p> <p>Papers are to be distributed no later than 2 working days before the meeting.</p>
Meeting Frequency	<p>It is intended that the strategy will be developed over three meetings. Additional working group meetings will be held if required.</p> <p>The planned meetings will be held on:</p> <ul style="list-style-type: none"> • Thursday 15th November 2018 • February 2019 • xxx
Meeting Format	There will be a standing agenda with additional items to be agreed with the Chair prior to each scheduled meeting.
TOR Review Frequency	As required.
Quorum	<p>50% plus 1, excluding the Chair.</p> <p>In the case of absences, a proxy may be nominated by the absent member.</p>

TOR Approved	To be distributed with minutes from meeting of 15/11/2018.
Review	To be confirmed.

Pond, Aleks (Health)

From: Luis Salvador-Carulla <luis.salvador-carulla@anu.edu.au>
Sent: Saturday, 26 January 2019 10:36 PM
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Cc: Bowrah, Victoria (Health); Dunne, Ellen; Ord, Jon (Health); Wafer, Matthew (Health); Edge, Natalie (Health); Office for Mental Health and Wellbeing
Subject: RE: Mental Health Services for people with Intellectual Disability Strategy Working Group Minutes and updates
Attachments: Comment GuidesID Canada Framework.pdf; IMPJ4495_WISH_Autism_Report_WEB.pdf; Reed et al ICD-11 Overview World Psychiatry 2019.pdf; Mingming Zhou ID Adv Effects19.pdf

Hi Melissa

Thanks a lot for sending me the minutes and ToR. I take this opportunity to send you our CMHR-ANU recent contributions in the area of developmental disorders:

- 1.- Collaboration with the Canadian Family Physician Association to produce the 2018 "Consensus guidelines for primary health care of adults with developmental disabilities"
- 2.- Collaboration with the Consensus group on Borderline Intellectual Functioning to produce the Girona international declaration on BIF
- 3.- Use of the POMONA 15 checklist to assess health status in ID (a series of papers)
- 4.- WISH declaration on ASD in the context of neurodevelopmental disorders: AUTISM A GLOBAL FRAMEWORK FOR ACTION. This may be relevant for establishing the relationship between ASD and ID in care provision for DD in ACT
- 5.- New criteria of "Disorders of Intellectual Development" in ICD-11 (WHO) (in Reed)
- 6.- Secondary analysis of databases as part of VIDEA: adverse effects of drug treatment in hospitalised PWID

Best regards

Professor Luis Salvador-Carulla, MD, PhD.

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Subject: Mental Health Services for people with Intellectual Disability Strategy Working Group Minutes and updates

UNCLASSIFIED

Dear Strategy Working Group,

Please find attached the draft minutes from the initial working meeting held on 15th November 2018. Apologies for the delay in distributing these.

FOR ACTION:

Please let me know of any corrections to the minutes

Please review the latest draft of the Terms of Reference and indicate your acceptance (or not with feedback)

Please Contact Melissa Lee if you would like to set up a meeting to discuss your thoughts, priorities for action in the strategy.

NEXT MEETING

I hope to have a first draft of the Strategy complete by mid-February and convene a second meeting of the working group a couple of weeks after (end of February beginning of March).

Many thanks for your interest and input

Melissa

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NOTE: Work days are Mon-Thur

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Approaches to primary care of adults with intellectual and developmental disabilities

Importance of frameworks for guidelines

William F. Sullivan MD CCFP(COE) FCFP PhD John Heng MA

Luis Salvador-Carulla MD PhD Sue Lukersmith PhD MEdg Ian Casson MD MSc FCFP

People with intellectual and developmental disabilities (IDD), or *intellectual disability (intellectual developmental disorder)* in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition,¹ make up 1% to 3% of the Canadian population and are encountered in most family medicine practices.² Research in Ontario shows that they visit family physicians and enjoy similar continuity of primary care as patients without IDD.³ Yet they have been called the “invisible 3%” in health care.² They are more likely to live in poverty, have higher rates of visits to emergency departments and stays in hospitals, and receive lower rates of preventive care screening compared with those without such disabilities.^{2,4,5}

People with IDD have general health care needs like the rest of the population. They might have comorbid or secondary physical and mental health conditions that are preventable or that can be well managed. The manifestations of distress and illness in people with IDD can vary from those typically encountered by family physicians. For example, symptoms of reflux esophagitis might present as a change in behaviour. There can also be compounding factors affecting their health and functioning. For example, antiepileptic medication might decrease cognitive abilities. Family physicians might need to adjust their approaches to communication, assessment, and intervention to care appropriately for people with IDD. Research shows that physicians can gain confidence and improve such care as they become knowledgeable regarding the unique health needs and challenges faced by this group of patients.^{6,7}

One recommendation of the *World Report on Disability* was to develop person-centred, evidence-based guidelines for assessing and treating people with disabilities, a vulnerable group in society.⁸ Such guidelines can be useful for identifying specific health needs and challenges, assisting the decision making of family physicians with their patients with IDD and their caregivers, providing the knowledge base for training family physicians and other health care professionals, and highlighting gaps in research for further investigation. In advancing knowledge, such as developing guidelines, Salvador-Carulla and others have proposed that “framing of scientific knowledge” (which this article refers to as *adoption of a framework*) is a distinct type of research methodology that is essential in areas of health care in which there are high levels of variability, complexity, and uncertainty.⁹

Such frameworks are explicit principles that are derived by a consensus of experts in a field to aid interpretation and evaluation of data derived from empirical, observational, and other studies. They have a valid basis in the clinical experience and knowledge of these experts.

Health disparities framework

In 2006, *Canadian Family Physician* published “Consensus guidelines for primary health care of adults with developmental disabilities” (hereafter referred to as *the guidelines*).¹⁰ These guidelines drew attention to the reality that adults with IDD have a high risk of poor health and premature death owing in part to health disparities unique to adults with IDD.^{11,12} The 2006 guidelines, and their revision in 2011,¹³ sought to increase primary care providers’ capacity to identify these disparities and address them through preventive and other health care interventions.

The health disparities framework adopted by the 2006 and 2011 guidelines is based on the ethical principle that health care is a fundamental human right and that access by all to the highest standard of health care possible in their community is part of the common good. Hence, addressing health disparities unique to adults with IDD is a matter of good medical practice and social justice. These principles have been affirmed by the United Nations’ Convention on the Rights of Persons with Disabilities, which the federal government of Canada ratified on March 10, 2011, with agreement by every province and territory. Article 25 of the Convention stipulates that people with disabilities have the “right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”¹⁴ States are obligated to provide health care that people with disabilities need “specifically because of their disabilities.”¹⁴ Health care professionals have the responsibility to provide care of the same quality to people with disabilities as to others and to fulfil that responsibility through “training and the promulgation of ethical standards.”¹⁴ Hubert H. Humphrey has said that

the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life, the sick, the needy and the handicapped.¹⁵

These words apply not only to governments but also to those involved in the provision of health care.

Health complexity framework

The revised 2018 guidelines published in *Canadian Family Physician*,¹⁶ together with this special issue of articles on certain recommendations,¹⁷ are also shaped by a health complexity framework. This approach involves accounting for multiple, interacting, and often compounding factors that influence the health and functioning of people with IDD. These factors include their health characteristics, environments, communication challenges, systems of health care, and social supports. In providing primary care to adults with IDD, family physicians often make decisions under conditions in which there are high levels of uncertainty¹⁸ and ambiguity.¹⁹ To make the best possible decisions under such conditions, family physicians need knowledge derived from research on a patient's local context and from the practical wisdom of experienced clinician experts.²⁰ Family physicians also need to understand the preferences and values of patients and their caregivers to deliberate with them regarding intervention options that are appropriate for the circumstances of these patients and that are acceptable to them. These distinct types of knowledge form a basis for each of the 2018 guideline recommendations just as each type of knowledge addresses a different basis for clinical decisions in complex health care.²¹

Relational and person-centred care framework

The 2006, 2011, and 2018 guidelines, and the articles in this special issue, all adopt a relational and person-centred care framework in forming recommendations.²² In the 2018 guidelines, this framework is made explicit in the new section on approaches to care, which begins with a guideline on person-centred care (guideline 1).¹⁶ This approach is defined as one in which health care relationships put the person with IDD

at the centre of communication, planning, and decisions regarding care. This might require more time than that allocated to the typical office visit, getting to know the patient as a person and the patient's community, and engaging additional supports.¹⁶

The important concepts here are the relational aspect of health care and the central place of the person with IDD. These concepts are evident, for example, in the revised guideline on decision making (guideline 3).¹⁶ This guideline highlights supported and shared decision making as a way for adults with IDD to contribute optimally to decisions affecting their health care with the support of their family physicians and trusted caregivers. This approach to health care decision making might also avoid the need for legal appointment of others to make decisions on behalf of a patient who is assessed to lack

some aspect of decision-making capacity (eg, a guardian who might not know such a patient well).

The relational and person-centred care framework also shapes the guideline on behaviours that challenge (guideline 27).¹⁶ Such behaviour often emerges from an interaction between a person with unique needs and his or her environment. They might signal the absence of necessary environmental accommodations or insufficient supports. Behaviours that challenge can be the way a person with IDD communicates distress.²³ Guideline 27 presents a comprehensive and systematic approach by which family physicians and others can assess the causes (which might be multiple) of a person with IDD's distress.¹⁶

The relational and person-centred care framework of the 2018 guidelines also shapes a new guideline regarding life transitions (guideline 12).¹⁶ These are life phases during which people with IDD require different or greater supports, such as during their transitions to adolescence, adulthood, frailty, and the end of life. People with IDD can develop decision-making, coping, and other life skills for these transitions with the support of others. Continuity in core relationships in health care, and a coordinated care plan for moving toward different and new supports, can minimize the distress of people with IDD and their caregivers and provide beneficial support during these important periods of change in their lives.

Because people with IDD benefit especially from holistic, biopsychosocial approaches to health care and from support from others for their developmental and caregiving needs, integration of their primary health care should cover the various health and allied health care specialties that are engaged, as well as their network of supports.²⁴ Family physicians play a key role in this integration as the central hub for the timely provision and coordination of all physical and mental health care needs of adults with IDD. They also provide a stable and core health care relationship on which these patients, their families, and other caregivers can rely. The objectives of the Patient's Medical Home model that the College of Family Physicians of Canada has articulated²⁵ can be used in conjunction with the 2018 guidelines as standards for relational and person-centred primary care of adults with IDD.

Conclusion

Frameworks are a type of knowledge that can inform the development of guidelines. By applying health disparity, health complexity, and relational and person-centred care frameworks, the 2018 guidelines and this special issue of related articles both provide practical recommendations regarding beneficial assessments and interventions and also help to orient and shape the practices of family physicians. The principles that form these frameworks are applicable not only to developing guidelines for primary care of adults with IDD, but also those for primary care of other groups who are vulnerable in society and have similar needs. ✱

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Competing interests

None declared

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The opinions expressed in commentaries are those of the authors. Publication does not imply endorsement by the College of Family Physicians of Canada.

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Cet article se trouve aussi en français à la page S12.

Innovations and changes in the ICD-11 classification of mental, behavioural and neurodevelopmental disorders

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Following approval of the ICD-11 by the World Health Assembly in May 2019, World Health Organization (WHO) member states will transition from the ICD-10 to the ICD-11, with reporting of health statistics based on the new system to begin on January 1, 2022. The WHO Department of Mental Health and Substance Abuse will publish Clinical Descriptions and Diagnostic Guidelines (CDDG) for ICD-11 Mental, Behavioural and Neurodevelopmental Disorders following ICD-11's approval. The development of the ICD-11 CDDG over the past decade, based on the principles of clinical utility and global applicability, has been the most broadly international, multilingual, multidisciplinary and participative revision process ever implemented for a classification of mental disorders. Innovations in the ICD-11 include the provision of consistent and systematically characterized information, the adoption of a lifespan approach, and culture-related guidance for each disorder. Dimensional approaches have been incorporated into the classification, particularly for personality disorders and primary psychotic disorders, in ways that are consistent with current evidence, are more compatible with recovery-based approaches, eliminate artificial comorbidity, and more effectively capture changes over time. Here we describe major changes to the structure of the ICD-11 classification of mental disorders as compared to the ICD-10, and the development of two new ICD-11 chapters relevant to mental health practice. We illustrate a set of new categories that have been added to the ICD-11 and present the rationale for their inclusion. Finally, we provide a description of the important changes that have been made in each ICD-11 disorder grouping. This information is intended to be useful for both clinicians and researchers in orienting themselves to the ICD-11 and in preparing for implementation in their own professional contexts.

Key words: International Classification of Diseases, ICD-11, diagnosis, mental disorders, clinical utility, dimensional approaches, culture-related guidance

(World Psychiatry 2019;18:3–19)

In June 2018, the World Health Organization (WHO) released a pre-final version of the 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11) for mortality and morbidity statistics to its 194 member states, for review and preparation for implementation¹. The World Health Assembly, comprising the ministers of health of all member states, is expected to approve the ICD-11 at its next meeting, in May 2019. Following approval, member states will begin a process of transitioning from the ICD-10 to the ICD-11, with reporting of health statistics to the WHO using the ICD-11 to begin on January 1, 2022².

The WHO Department of Mental Health and Substance Abuse has been responsible for coordinating the development of four ICD-11 chapters: mental, behavioural and neurodevelopmental disorders; sleep-wake disorders; diseases of the nervous system; and conditions related to sexual health (jointly with the WHO Department of Reproductive Health and Research).

The mental disorders chapter of the ICD-10, the current version of the ICD, is by far the most widely used classification of mental disorders around the world³. During the development of the ICD-10, the WHO Department of Mental Health and Substance Abuse considered that different versions of the

classification had to be produced in order to meet the needs of its various users. The version of the ICD-10 for statistical reporting contains short glossary-like definitions for each disorder category, but this was considered to be insufficient for use by mental health professionals in clinical settings⁴.

For mental health professionals, the Department developed the Clinical Descriptions and Diagnostic Guidelines (CDDG) for ICD-10 Mental and Behavioural Disorders⁴, informally known as the "blue book", intended for general clinical, educational and service use. For each disorder, a description of the main clinical and associated features was provided, followed by more operationalized diagnostic guidelines that were designed to assist mental health clinicians in making a confident diagnosis. Information from a recent survey⁵ suggests that clinicians regularly use the material in the CDDG and often review it systematically when making an initial diagnosis, which is counter to the widespread belief that clinicians only use the classification for the purpose of obtaining diagnostic codes for administrative and billing purposes. The Department will publish an equivalent CDDG version of ICD-11 as soon as possible following approval of the overall system by the World Health Assembly.

More than a decade of intensive work has gone into the development of the ICD-11 CDDG. It has involved hundreds of content experts as members of Advisory and Working Groups and as consultants, as well as an extensive collaboration with WHO member states, funding agencies, and professional and scientific societies. The development of the ICD-11 CDDG has been the most global, multilingual, multidisciplinary and participative revision process ever implemented for a classification of mental disorders.

GENERATING THE ICD-11 CDDG: PROCESS AND PRIORITIES

We have previously described the importance of clinical utility as an organizing principle in developing the ICD-11 CDDG^{6,7}. Health classifications represent the interface between health encounters and health information. A system that does not provide clinically useful information at the level of the health encounter will not be faithfully implemented by clinicians and therefore cannot provide a valid basis for summary health encounter data used for decision making at the health system, national and global level.

Clinical utility was, therefore, strongly emphasized in the instructions provided to a series of Working Groups, generally organized by disorder grouping, appointed by the WHO Department of Mental Health and Substance Abuse to make recommendations regarding the structure and content of the ICD-11 CDDG.

Of course, in addition to being clinically useful and globally applicable, the ICD-11 must be scientifically valid. Accordingly, Working Groups were also asked to review the available scientific evidence relevant to their areas of work as a basis for developing their proposals for ICD-11.

The importance of global applicability⁶ was also strongly emphasized to Working Groups. All groups included representatives from all WHO global regions – Africa, the Americas, Europe, Eastern Mediterranean, Southeast Asia, and Western Pacific – and a substantial proportion of individuals from low- and middle-income countries, which account for more than 80% of the world's population⁸.

A shortcoming of the ICD-10 CDDG was the lack of consistency in the material provided across disorder groupings⁹. For the ICD-11 CDDG, Working Groups were asked to deliver their recommendations as "content forms", including consistent and systematic information for each disorder that provided the basis for the diagnostic guidelines.

We have previously published a detailed description of the work process and the structure of the ICD-11 diagnostic guidelines⁹. The development of the ICD-11 CDDG occurred during a period that overlapped substantially with the production of the DSM-5 by the American Psychiatric Association, and many ICD-11 Working Groups included overlapping membership with corresponding groups working on the DSM-5. ICD-11 Working Groups were asked to consider the clinical utility and global applicability of material being developed for the DSM-5. A goal was to minimize random or arbitrary differences between the ICD-11 and the DSM-5, although justified conceptual differences were permitted.

INNOVATIONS IN THE ICD-11 CDDG

A particularly important feature of the ICD-11 CDDG is their approach to describing the essential features of each disorder, which represent those symptoms or characteristics that a clinician could reasonably expect to find in all cases of the disorder. While the lists of essential features in the guidelines superficially resemble diagnostic criteria, arbitrary cutoffs and precise requirements related to symptom counts and duration are generally avoided, unless these have been empirically established across countries and cultures or there is another compelling reason to include them.

This approach is intended to conform to the way clinicians actually make diagnoses, with the flexible exercise of clinical judgment, and to increase clinical utility by allowing for cultural variations in presentation as well as contextual and health-system factors that may affect diagnostic practice. This flexible approach is consistent with results of surveys of psychiatrists and psychologists undertaken early in the ICD-11 development process regarding the desirable characteristics of a mental disorders classification system^{3,10}. Field studies in clinical settings in 13 countries have confirmed that clinicians consider the clinical utility of this approach to be high¹¹. Importantly, the diagnostic reliability of the ICD-11 guidelines appears to be at least as high as that obtained using a strict criteria-based approach¹².

A number of other innovations in the ICD-11 CDDG were also introduced by means of the template provided to Working Groups for making their recommendations (that is, the "con-

tent form"). As a part of the standardization of information provided in the guidelines, attention was devoted for each disorder to the systematic characterization of the boundary with normal variation and to the expansion of the information provided on boundaries with other disorders (differential diagnosis).

The lifespan approach adopted for the ICD-11 meant that the separate grouping of behavioural and emotional disorders with onset usually occurring in childhood and adolescence was eliminated, and these disorders distributed to other groupings with which they share symptoms. For example, separation anxiety disorder was moved to the anxiety and fear-related disorders grouping. Moreover, the ICD-11 CDDG provide information for each disorder and/or grouping where data were available describing variations in the presentation of the disorder among children and adolescents as well as among older adults.

Culture-related information was systematically incorporated based on a review of the literature on cultural influences on psychopathology and its expression for each ICD-11 diagnostic grouping as well as a detailed review of culture-related material in the ICD-10 CDDG and the DSM-5. The cultural guidance for panic disorder is provided in Table 1 as an example.

Another major innovation in the ICD-11 classification has been the incorporation of dimensional approaches within the context of an explicitly categorical system with specific taxonomic constraints. This effort was stimulated by the evidence that most mental disorders can be best described along a number of interacting symptom dimensions rather than as discrete

categories¹³⁻¹⁵, and has been facilitated by innovations in the coding structure for the ICD-11. The dimensional potential of the ICD-11 is most clearly realized in the classification of personality disorders^{16,17}.

For non-specialist settings, the dimensional rating of severity for ICD-11 personality disorders offers greater simplicity and clinical utility than the ICD-10 classification of specific personality disorders, improved differentiation of patients who need complex as compared to simpler treatments, and a better mechanism for tracking changes over time. In more specialized settings, the constellation of individual personality traits can inform specific intervention strategies. The dimensional system eliminates both the artificial comorbidity of personality disorders and the unspecified personality disorder diagnoses, as well as providing a basis for research into underlying dimensions and interventions across various personality disorder manifestations.

A set of dimensional qualifiers has also been introduced to describe the symptomatic manifestations of schizophrenia and other primary psychotic disorders¹⁸. Rather than focusing on diagnostic subtypes, the dimensional classification focuses on relevant aspects of the current clinical presentation in ways that are much more consistent with recovery-based psychiatric rehabilitation approaches.

The dimensional approaches to personality disorders and symptomatic manifestations of primary psychotic disorders are described in more detail in the respective sections later in this paper.

Table 1 Cultural considerations for panic disorder

- The symptom presentation of panic attacks may vary across cultures, influenced by cultural attributions about their origin or pathophysiology. For example, individuals of Cambodian origin may emphasize panic symptoms attributed to dysregulation of *khyl*, a wind-like substance in traditional Cambodian ethnophysiology (e.g., dizziness, tinnitus, neck soreness).
- There are several notable cultural concepts of distress related to panic disorder, which link panic, fear, or anxiety to etiological attributions regarding specific social and environmental influences. Examples include attributions related to interpersonal conflict (e.g., *ataque de nervios* among Latin American people), exertion or orthostasis (*khyl cap* among Cambodians), and atmospheric wind (*trung gió* among Vietnamese individuals). These cultural labels may be applied to symptom presentations other than panic (e.g., anger paroxysms, in the case of *ataque de nervios*) but they often constitute panic episodes or presentations with partial phenomenological overlap with panic attacks.
- Clarifying cultural attributions and the context of the experience of symptoms can inform whether panic attacks should be considered expected or unexpected, as would be the case in panic disorder. For example, panic attacks may involve specific foci of apprehension that are better explained by another disorder (e.g., social situations in social anxiety disorder). Moreover, the cultural linkage of the apprehension focus with specific exposures (e.g., wind or cold and *trung gió* panic attacks) may suggest that acute anxiety is expected when considered within the individual's cultural framework.

ICD-11 FIELD STUDIES

The ICD-11 field studies program also represents an area of major innovation. This program of work has included the use of novel methodologies for studying the clinical utility of the draft diagnostic guidelines, including their accuracy and consistency of application by clinicians as compared to ICD-10 as well as the specific elements responsible for any observed confusion¹⁹. A key strength of the research program has been that most studies have been conducted in a time frame allowing their results to provide a basis for revision of the guidelines to address any observed weaknesses²⁰.

Global participation has also been a defining characteristic of the ICD-11 CDDG field studies program. The Global Clinical Practice Network (GCPN) was established to allow mental health and primary care professionals from all over the world to participate directly in the development of the ICD-11 CDDG through Internet-based field studies.

Over time, the GCPN has expanded to include nearly 15,000 clinicians from 155 countries. All WHO global regions are represented in proportions that largely track the availability of mental health professionals by region, with the largest proportions coming from Asia, Europe and the Americas (approximately equally divided between the US and Canada on the one hand and Latin America on the other). More than half of GCPN

members are physicians, predominantly psychiatrists, and 30% are psychologists.

Approximately a dozen GCPN studies have been completed to date, most focusing on comparisons of the proposed ICD-11 diagnostic guidelines with ICD-10 guidelines in terms of accuracy and consistency of clinicians' diagnostic formulations, using standardized case material manipulated to test key differences^{19,21}. Other studies have examined scaling for diagnostic qualifiers²² and how clinicians actually use classifications⁵. GCPN studies have been conducted in Chinese, French, Japanese, Russian and Spanish, in addition to English, and have included an examination of results by region and language to identify potential difficulties in global or cultural applicability as well as problems in translation.

Clinic-based studies have also been conducted through a network of international field study centers to evaluate the clinical utility and usability of the proposed ICD-11 diagnostic guidelines in natural conditions, in the settings in which they are intended to be used¹¹. These studies also evaluated the reliability of diagnoses that account for the greatest proportion of disease burden and mental health services utilization¹². International field studies were located in 14 countries across all WHO global regions, and patient interviews for the studies were conducted in the local language of each country.

OVERALL STRUCTURE OF THE ICD-11 CHAPTER ON MENTAL, BEHAVIOURAL AND NEURODEVELOPMENTAL DISORDERS

In the ICD-10, the number of groupings of disorders was artificially constrained by the decimal coding system used in the classification, such that it was only possible to have a maximum of ten major groupings of disorders within the chapter on mental and behavioural disorders. As a result, diagnostic groupings were created that were not based on clinical utility or scientific evidence (e.g., anxiety disorders being included as part of the heterogeneous grouping of neurotic, stress-related, and somatoform disorders). ICD-11's use of a flexible alphanumeric coding structure allowed for a much larger number of groupings, making it possible to develop diagnostic groupings based more closely on scientific evidence and the needs of clinical practice.

In order to provide data to assist in developing an organizational structure that would be more clinically useful, two formative field studies were conducted^{23,24} to examine the conceptualizations held by mental health professionals around the world regarding the relationships among mental disorders. These data informed decisions about the optimal structure of the classification. The ICD-11 organizational structure was also influenced by efforts by the WHO and the American Psychiatric Association to harmonize the overall structure of the ICD-11 chapter on mental and behavioural disorders with the structure of the DSM-5.

The organization of the ICD-10 chapter on mental and behavioural disorders largely reflected the chapter organization

originally used in Kraepelin's Textbook of Psychiatry, which began with organic disorders, followed by psychoses, neurotic disorders, and personality disorders²⁵. Principles guiding the ICD-11 organization included trying to order the diagnostic groupings following a developmental perspective (hence, neurodevelopmental disorders appear first and neurocognitive disorders last in the classification) and grouping disorders together based on putative shared etiological and pathophysiological factors (e.g., disorders specifically associated with stress) as well as shared phenomenology (e.g., dissociative disorders). Table 2 provides a listing of the diagnostic groupings in the ICD-11 chapter on mental, behavioural and neurodevelopmental disorders.

The classification of sleep disorders in the ICD-10 relied on the now obsolete separation between organic and non-organic disorders, resulting in the "non-organic" sleep disorders being included in the chapter on mental and behavioural disorders of the ICD-10, and the "organic" sleep disorders being included in other chapters (i.e., diseases of the nervous system, diseases of the respiratory system, and endocrine, nutritional and metabolic disorders). In ICD-11, a separate chapter has been created for sleep-wake disorders that encompasses all relevant sleep-related diagnoses.

Table 2 Disorder groupings in the ICD-11 chapter on mental, behavioural and neurodevelopmental disorders

Neurodevelopmental disorders
Schizophrenia and other primary psychotic disorders
Catatonia
Mood disorders
Anxiety and fear-related disorders
Obsessive-compulsive and related disorders
Disorders specifically associated with stress
Dissociative disorders
Feeding and eating disorders
Elimination disorders
Disorders of bodily distress and bodily experience
Disorders due to substance use and addictive behaviours
Impulse control disorders
Disruptive behaviour and dissocial disorders
Personality disorders
Paraphilic disorders
Factitious disorders
Neurocognitive disorders
Mental and behavioural disorders associated with pregnancy, childbirth and the puerperium
Psychological and behavioural factors affecting disorders or diseases classified elsewhere
Secondary mental or behavioural syndromes associated with disorders or diseases classified elsewhere

The ICD-10 also embodied a dichotomy between organic and non-organic in the realm of sexual dysfunctions, with “non-organic” sexual dysfunctions included in the chapter on mental and behavioural disorders, and “organic” sexual dysfunctions for the most part listed in the chapter on diseases of the genitourinary system. A new integrated chapter for conditions related to sexual health has been added to the ICD-11 to house a unified classification of sexual dysfunctions and sexual pain disorders²⁶ as well as changes in male and female anatomy. Moreover, ICD-10 gender identity disorders have been renamed as “gender incongruence” in the ICD-11 and moved from the mental disorders chapter to the new sexual health chapter²⁶, meaning that a transgender identity is no longer to be considered a mental disorder. Gender incongruence is not proposed for elimination in the ICD-11 because in many countries access to relevant health services is contingent on a qualifying diagnosis. The ICD-11 guidelines explicitly state that gender variant behaviour and preferences alone are not sufficient for making a diagnosis.

NEW MENTAL, BEHAVIOURAL AND NEURODEVELOPMENTAL DISORDERS IN THE ICD-11

Based on a review of the available evidence on scientific validity, and a consideration of clinical utility and global applicability, a number of new disorders have been added to the ICD-11 chapter on mental, behavioural and neurodevelopmental disorders. A description of these disorders as defined in the ICD-11 diagnostic guidelines and the rationale for their inclusion are provided below.

Catatonia

In the ICD-10, catatonia was included as one of the subtypes of schizophrenia (i.e., catatonic schizophrenia) and as one of the organic disorders (i.e., organic catatonic disorder). In recognition of the fact that the syndrome of catatonia can occur in association with a variety of mental disorders²⁷, a new diagnostic grouping for catatonia (at the same hierarchical level as mood disorders, anxiety and fear-related disorders, etc.) has been added in the ICD-11.

Catatonia is characterized by the occurrence of several symptoms such as stupor, catalepsy, waxy flexibility, mutism, negativism, posturing, mannerisms, stereotypies, psychomotor agitation, grimacing, echolalia and echopraxia. Three conditions are included in the new diagnostic grouping: a) catatonia associated with another mental disorder (such as a mood disorder, schizophrenia or other primary psychotic disorder, or autism spectrum disorder); b) catatonia induced by psychoactive substances, including medications (e.g., antipsychotic medications, amphetamines, phencyclidine); and c) secondary catatonia (i.e., caused by a medical condition, such as diabetic ketoacidosis, hypercalcemia, hepatic encephalopathy, homo-

cystinuria, neoplasm, head trauma, cerebrovascular disease, or encephalitis).

Bipolar type II disorder

The DSM-IV introduced two types of bipolar disorder. Bipolar type I disorder applies to presentations characterized by at least one manic episode, whereas bipolar type II disorder requires at least one hypomanic episode plus at least one major depressive episode, in the absence of a history of manic episodes. Evidence supporting the validity of the distinction between these two types includes differences in antidepressant monotherapy response²⁸, neurocognitive measures^{28,29}, genetic effects^{28,30}, and neuroimaging findings^{28,31,32}.

Given this evidence, and the clinical utility of differentiating between these two types³³, bipolar disorder in ICD-11 has also been subdivided into type I and type II bipolar disorder.

Body dysmorphic disorder

Individuals with body dysmorphic disorder are persistently preoccupied with one or more defects or flaws in their bodily appearance that are either unnoticeable or only slightly noticeable to others³⁴. The preoccupation is accompanied by repetitive and excessive behaviours, including repeated examination of the appearance or severity of the perceived defect or flaw, excessive attempts to camouflage or alter the perceived defect, or marked avoidance of social situations or triggers that increase distress about the perceived defect or flaw.

Originally called “dysmorphophobia”, this condition was first included in the DSM-III-R. It appeared in the ICD-10 as an embedded but incongruous inclusion term under hypochondriasis, but clinicians were instructed to diagnose it as delusional disorder in cases in which associated beliefs were considered delusional. This created a potential for the same disorder to be assigned different diagnoses without recognizing the full spectrum of severity of the disorder, which can include beliefs that appear delusional due to the degree of conviction or fixity with which they are held.

In recognition of its distinct symptomatology, prevalence in the general population and similarities to obsessive-compulsive and related disorders (OCRD), body dysmorphic disorder has been included in this latter grouping in the ICD-11³⁵.

Olfactory reference disorder

This condition is characterized by a persistent preoccupation with the belief that one is emitting a perceived foul or offensive body odour or breath, that is either unnoticeable or only slightly noticeable to others³⁴.

In response to their preoccupation, individuals engage in repetitive and excessive behaviours such as repeatedly checking

for body odour or checking the perceived source of the smell; repeatedly seeking reassurance; excessive attempts to camouflage, alter or prevent the perceived odour; or marked avoidance of social situations or triggers that increase distress about the perceived foul or offensive odour. Affected individuals typically fear or are convinced that others noticing the smell will reject or humiliate them³⁶.

Olfactory reference disorder is included in the ICD-11 OCRD grouping, as it shares phenomenological similarities with other disorders in this grouping with respect to the presence of persistent intrusive preoccupations and associated repetitive behaviours³⁵.

Hoarding disorder

Hoarding disorder is characterized by the accumulation of possessions, due to their excessive acquisition or to difficulty discarding them, regardless of their actual value^{35,37}. Excessive acquisition is characterized by repetitive urges or behaviours related to amassing or buying items. Difficulty discarding is characterized by a perceived need to save items and a distress associated with discarding them. The accumulation of possessions results in living spaces becoming cluttered to the point that their use or safety is compromised.

Although hoarding behaviours may be exhibited as a part of a broad range of mental and behavioural disorders and other conditions – including obsessive-compulsive disorder, depressive disorders, schizophrenia, dementia, autism spectrum disorders and Prader-Willi syndrome – there is sufficient evidence supporting hoarding disorder as a separate and unique disorder³⁸.

Individuals affected by hoarding disorder are underrecognized and undertreated, which argues from a public health perspective for its inclusion in the ICD-11³⁹.

Excoriation disorder

A new diagnostic subgrouping, body-focused repetitive behaviour disorders, has been added to the OCRD grouping. It includes trichotillomania (which was included in the grouping of habit and impulse disorders in ICD-10) and a new condition, excoriation disorder (also known as skin-picking disorder).

Excoriation disorder is characterized by recurrent picking of one's own skin, leading to skin lesions, accompanied by unsuccessful attempts to decrease or stop the behaviour. The skin picking must be severe enough to result in significant distress or impairment in functioning. Excoriation disorder (and trichotillomania) are distinct from other OCRDs in that the behaviour is rarely preceded by cognitive phenomena such as intrusive thoughts, obsessions or preoccupations, but instead may be preceded by sensory experiences.

Their inclusion in the OCRD grouping is based on shared phenomenology, patterns of familial aggregation, and putative

etiological mechanisms with other disorders in this grouping^{35,40}.

Complex post-traumatic stress disorder

Complex post-traumatic stress disorder (complex PTSD)⁴¹ most typically follows severe stressors of a prolonged nature, or multiple or repeated adverse events from which escape is difficult or impossible, such as torture, slavery, genocide campaigns, prolonged domestic violence, or repeated childhood sexual or physical abuse.

The symptom profile is marked by the three core features of PTSD (i.e., re-experiencing the traumatic event or events in the present in the form of vivid intrusive memories, flashbacks or nightmares; avoidance of thoughts and memories of the event or activities, situations or people reminiscent of the event; persistent perceptions of heightened current threat), which are accompanied by additional persistent, pervasive and enduring disturbances in affect regulation, self-concept and relational functioning.

The addition of complex PTSD to the ICD-11 is justified on the basis of the evidence that individuals with the disorder have a poorer prognosis and benefit from different treatments as compared to individuals with PTSD⁴². Complex PTSD replaces the overlapping ICD-10 category of enduring personality change after catastrophic experience⁴¹.

Prolonged grief disorder

Prolonged grief disorder describes abnormally persistent and disabling responses to bereavement⁴¹. Following the death of a partner, parent, child or other person close to the bereaved, there is a persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased, accompanied by intense emotional pain. Symptoms may include sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling that the individual has lost a part of one's self, an inability to experience positive mood, emotional numbness, and difficulty in engaging with social or other activities. The grief response must persist for an atypically long period of time following the loss (more than six months) and clearly exceed expected social, cultural or religious norms for the individual's culture and context.

Although most people report at least partial remission from the pain of acute grief by around six months following bereavement, those who continue experiencing severe grief reactions are more likely to experience significant impairment in their functioning. The inclusion of prolonged grief disorder in the ICD-11 is a response to the increasing evidence of a distinct and debilitating condition that is not adequately described by current ICD-10 diagnoses⁴³. Its inclusion and differentiation from culturally normative bereavement and depressive episode is important, because of the different treatment selection implications and prognoses of these latter disorders⁴⁴.

Binge eating disorder

Binge eating disorder is characterized by frequent, recurrent episodes of binge eating (e.g., once a week or more over a period of several months). A binge eating episode is a distinct period of time during which the individual experiences a subjective loss of control over eating, eats notably more or differently than usual, and feels unable to stop eating or limit the type or amount of food eaten.

Binge eating is experienced as very distressing and is often accompanied by negative emotions such as guilt or disgust. However, unlike in bulimia nervosa, binge eating episodes are not regularly followed by inappropriate compensatory behaviours aimed at preventing weight gain (e.g., self-induced vomiting, misuse of laxatives or enemas, strenuous exercise). Although binge eating disorder is often associated with weight gain and obesity, these features are not a requirement and the disorder can be present in normal weight individuals.

The addition of binge eating disorder in the ICD-11 is based on extensive research that has emerged during the last 20 years supporting its validity and clinical utility^{45,46}. Individuals who report episodes of binge eating without inappropriate compensatory behaviours represent the most common group among those who receive ICD-10 diagnoses of other specified or unspecified eating disorder, so that it is expected that the inclusion of binge eating disorder will reduce these diagnoses⁴⁷.

Avoidant/restrictive food intake disorder

Avoidant/restrictive food intake disorder (ARFID) is characterized by abnormal eating or feeding behaviours that result in the intake of an insufficient quantity or variety of food to meet adequate energy or nutritional requirements. This results in significant weight loss, failure to gain weight as expected in childhood or pregnancy, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding, or otherwise negatively affects the health of the individual or results in significant functional impairment.

ARFID is distinguished from anorexia nervosa by the absence of concerns about body weight or shape. Its inclusion in the ICD-11 can be considered to be an expansion of the ICD-10 category "feeding disorder of infancy and childhood", and is likely to improve clinical utility across the lifespan (i.e., unlike its ICD-10 counterpart, ARFID applies to children, adolescents and adults) as well as maintaining consistency with DSM-5^{45,47}.

Body integrity dysphoria

Body integrity dysphoria is a rare disorder characterized by the persistent desire to have a specific physical disability (e.g., amputation, paraplegia, blindness, deafness) beginning in childhood or early adolescence⁴⁸. The desire can be manifested

in a number of ways, including fantasizing about having the desired physical disability, engaging in "pretending" behaviour (e.g., spending hours in a wheelchair or using leg braces to simulate having leg weakness), and spending time searching for ways to achieve the desired disability.

The preoccupation with the desire to have the physical disability (including time spent pretending) significantly interferes with productivity, leisure activities, or social functioning (e.g., the person is unwilling to have close relationships because it would make it difficult to pretend). Moreover, for a significant minority of individuals with this desire, their preoccupation goes beyond fantasy, and they pursue actualization of the desire through surgical means (i.e., by procuring an elective amputation of an otherwise healthy limb) or by self-damaging a limb to a degree in which amputation is the only therapeutic option (e.g., freezing a limb in dry ice).

Gaming disorder

As online gaming has greatly increased in popularity in recent years, problems have been observed related to excessive involvement in gaming. Gaming disorder has been included in a newly added diagnostic grouping called "disorders due to addictive behaviours" (which also contains gambling disorder) in response to global concerns about the impact of problematic gaming, especially the online form⁴⁹.

Gaming disorder is characterized by a pattern of persistent or recurrent Internet-based or offline gaming behaviour ("digital gaming" or "video-gaming") that is manifested by impaired control over the behaviour (e.g., inability to limit the amount of time spent gaming), giving increasing priority to gaming to the extent that it takes precedence over other life interests and daily activities; and continuing or escalating gaming despite its negative consequences (e.g., being repeatedly fired from jobs because of excessive absences due to gaming). It is differentiated from non-pathological gaming behaviour by the clinically significant distress or impairment in functioning it produces.

Compulsive sexual behaviour disorder

Compulsive sexual behaviour disorder is characterized by a persistent pattern of failure to control intense repetitive sexual impulses or urges, resulting in repetitive sexual behaviour over an extended period (e.g., six months or more) that causes marked distress or impairment in personal, family, social, educational, occupational or other important areas of functioning.

Possible manifestations of the persistent pattern include: repetitive sexual activities becoming a central focus of the individual's life to the point of neglecting health and personal care or other interests, activities and responsibilities; the individual making numerous unsuccessful efforts to control or significantly reduce the repetitive sexual behaviour; the individual continuing to engage in repetitive sexual behaviour despite adverse

consequences such as repeated relationship disruption; and the individual continuing to engage in repetitive sexual behaviour even when he or she no longer derives any satisfaction from it.

Although this category phenomenologically resembles substance dependence, it is included in the ICD-11 impulse control disorders section in recognition of the lack of definitive information on whether the processes involved in the development and maintenance of the disorder are equivalent to those observed in substance use disorders and behavioural addictions. Its inclusion in the ICD-11 will help to address unmet needs of treatment seeking patients as well as possibly reducing shame and guilt associated with help seeking among distressed individuals⁵⁰.

Intermittent explosive disorder

Intermittent explosive disorder is characterized by repeated brief episodes of verbal or physical aggression or destruction of property that represent a failure to control aggressive impulses, with the intensity of the outburst or degree of aggressiveness being grossly out of proportion to the provocation or precipitating psychosocial stressors.

Because such episodes can occur in a variety of other conditions (e.g., oppositional defiant disorder, conduct disorder, bipolar disorder), the diagnosis is not given if the episodes are better explained by another mental, behavioural or neurodevelopmental disorder.

Although intermittent explosive disorder was introduced in the DSM-III-R, it appeared in the ICD-10 only as an inclusion term under "other habit and impulse disorders". It is included in the ICD-11 impulse control disorders section in recognition of the substantial evidence of its validity and utility in clinical settings⁵¹.

Premenstrual dysphoric disorder

Premenstrual dysphoric disorder (PMDD) is characterized by a variety of severe mood, somatic or cognitive symptoms that begin several days before the onset of menses, start to improve within a few days, and become minimal or absent within approximately one week following the onset of menses.

More specifically, the diagnosis requires a pattern of mood symptoms (depressed mood, irritability), somatic symptoms (lethargy, joint pain, overeating), or cognitive symptoms (concentration difficulties, forgetfulness) that have occurred during a majority of menstrual cycles within the past year. The symptoms are severe enough to cause significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning, and do not represent the exacerbation of another mental disorder.

In the ICD-11, PMDD is differentiated from the far more common premenstrual tension syndrome by the severity of the

symptoms and the requirement that they cause significant distress or impairment⁵². The inclusion of PMDD in the research appendices of the DSM-III-R and DSM-IV stimulated a great deal of research that has established its validity and reliability^{52,53}, leading to its inclusion in both the ICD-11 and DSM-5. Although its primary location in the ICD-11 is in the chapter on diseases of the genitourinary system, PMDD is cross-listed in the subgrouping of depressive disorders due to the prominence of mood symptomatology.

SUMMARY OF CHANGES BY ICD-11 DISORDER GROUPING

The following sections summarize the changes introduced in each of the main disorder groupings of the ICD-11 chapter on mental, behavioural and neurodevelopmental disorders in addition to the new categories described in the previous section.

These changes have been made on the basis of a review of available scientific evidence by ICD-11 Working Groups and expert consultants, consideration of clinical utility and global applicability, and, where possible, the results of field testing.

Neurodevelopmental disorders

Neurodevelopmental disorders are those that involve significant difficulties in the acquisition and execution of specific intellectual, motor, language or social functions with onset during the developmental period. ICD-11 neurodevelopmental disorders encompass the ICD-10 groupings of mental retardation and disorders of psychological development, with the addition of attention deficit hyperactivity disorder (ADHD).

Major changes in the ICD-11 include the renaming of disorders of intellectual development from ICD-10 mental retardation, which was an obsolete and stigmatizing term that did not adequately capture the range of forms and etiologies associated with this condition⁵⁴. Disorders of intellectual development continue to be defined on the basis of significant limitations in intellectual functioning and adaptive behaviour, ideally determined by standardized, appropriately normed and individually administered measures. In recognition of the lack of access to locally appropriate standardized measures or trained personnel to administer them in many parts of the world, and because of the importance of determining severity for treatment planning, the ICD-11 CDDG also provide a comprehensive set of behavioural indicator tables⁵⁵.

Separate tables for intellectual functioning and adaptive behaviour functioning domains (conceptual, social, practical) are organized according to three age groups (early childhood, childhood/adolescence and adulthood) and four levels of severity (mild, moderate, severe, profound). Behavioural indicators describe those skills and abilities that would be typically observed within each of these categories and are expected to improve the reliability of the characterization of severity and to

improve public health data related to the burden of disorders of intellectual development.

Autism spectrum disorder in the ICD-11 incorporates both childhood autism and Asperger's syndrome from the ICD-10 under a single category characterized by social communication deficits and restricted, repetitive and inflexible patterns of behaviour, interests or activities. Guidelines for autism spectrum disorder have been substantially updated to reflect the current literature, including presentations throughout the lifespan. Qualifiers are provided for the extent of impairment in intellectual functioning and functional language abilities to capture the full range of presentations of autism spectrum disorder in a more dimensional manner.

ADHD has replaced ICD-10 hyperkinetic disorders and has been moved to the grouping of neurodevelopmental disorders because of its developmental onset, characteristic disturbances in intellectual, motor and social functions, and common co-occurrence with other neurodevelopmental disorders. This move also addresses the conceptual weakness of viewing ADHD as more closely related to disruptive behaviour and dissocial disorders, given that individuals with ADHD are typically not intentionally disruptive.

ADHD can be characterized in the ICD-11 using qualifiers for predominantly inattentive, predominantly hyperactive-impulsive, or combined type, and is described across the lifespan.

Finally, chronic tic disorders, including Tourette syndrome, are classified in the ICD-11 chapter on diseases of the nervous system, but are cross-listed in the grouping of neurodevelopmental disorders because of their high co-occurrence (e.g., with ADHD) and typical onset during the developmental period.

Schizophrenia and other primary psychotic disorders

The ICD-11 grouping of schizophrenia and other primary psychotic disorders replaces the ICD-10 grouping of schizophrenia, schizotypal and delusional disorders. The term "primary" indicates that psychotic processes are a core feature, in contrast to psychotic symptoms that may occur as an aspect of other forms of psychopathology (e.g., mood disorders)¹⁸.

In the ICD-11, schizophrenia symptoms have largely remained unchanged from the ICD-10, though the importance of Schneiderian first-rank symptoms has been de-emphasized. The most significant change is the elimination of all subtypes of schizophrenia (e.g., paranoid, hebephrenic, catatonic), due to their lack of predictive validity or utility in treatment selection. In lieu of the subtypes, a set of dimensional descriptors has been introduced¹⁸. These include: positive symptoms (delusions, hallucinations, disorganized thinking and behaviour, experiences of passivity and control); negative symptoms (constricted, blunted or flat affect, avolition, anhedonia); depressive mood symptoms; manic mood symptoms; psychomotor symptoms (psychomotor agitation, psychomotor retardation, catatonic symptoms); and cognitive symptoms (particularly deficits in speed of processing,

attention/concentration, orientation, judgment, abstraction, verbal or visual learning, and working memory). These same symptom ratings can also be applied to other categories in the grouping (schizoaffective disorder, acute and transient psychotic disorder, delusional disorder).

ICD-11 schizoaffective disorder still requires the near simultaneous presence of both the schizophrenia syndrome and a mood episode. The diagnosis is meant to reflect the current episode of illness and is not conceptualized as longitudinally stable.

ICD-11 acute and transient psychotic disorder is characterized by a sudden onset of positive psychotic symptoms that fluctuate rapidly in nature and intensity over a short period of time and persist no longer than three months. This corresponds only to the "polymorphic" form of acute psychotic disorder in the ICD-10, which is the most common presentation and one that is not indicative of schizophrenia^{56,57}. Non-polymorphic subtypes of acute psychotic disorder in the ICD-10 have been eliminated and would instead be classified in the ICD-11 as "other primary psychotic disorder".

As in the ICD-10, schizotypal disorder is classified in this grouping and is not considered a personality disorder.

Mood disorders

Unlike in the ICD-10, ICD-11 mood episodes are not independently diagnosable conditions, but rather their pattern over time is used as a basis for determining which mood disorder best fits the clinical presentation.

Mood disorders are subdivided into depressive disorders (which include single episode depressive disorder, recurrent depressive disorder, dysthymic disorder, and mixed depressive and anxiety disorder) and bipolar disorders (which include bipolar type I disorder, bipolar type II disorder, and cyclothymia). The ICD-11 subdivides ICD-10 bipolar affective disorder into bipolar type I and type II disorders. The separate ICD-10 sub-grouping of persistent mood disorders, consisting of dysthymia and cyclothymia, has been eliminated⁵⁸.

The diagnostic guidelines for depressive episode are one of the few places in the ICD-11 where a minimal symptom count is required. This is due to the longstanding research and clinical tradition of conceptualizing depression in this manner. A minimum of five of ten symptoms is required rather than the four of nine possible symptoms stipulated in ICD-10, thus increasing consistency with the DSM-5. The ICD-11 CDDG organize depressive symptoms into three clusters – affective, cognitive and neurovegetative – to assist clinicians in conceptualizing and recalling the full spectrum of depressive symptomatology. Fatigue is part of the neurovegetative symptom cluster but is no longer considered sufficient as an entry-level symptom; rather, either almost daily depressed mood or diminished interest in activities lasting at least two weeks is required. Hopelessness has been added as an additional cognitive symptom because of strong evidence of its predictive value for diagnoses of depressive disorders⁵⁹. The ICD-11 CDDG provide clear guidance on

the differentiation between culturally normative grief reactions and symptoms that warrant consideration as a depressive episode in the context of bereavement⁶⁰.

For manic episodes, the ICD-11 requires the presence of the entry level symptom of increased activity or subjective experience of increased energy, in addition to euphoria, irritability or expansiveness. This is meant to guard against false positive cases that might be better characterized as normative fluctuations in mood. ICD-11 hypomanic episodes are conceptualized as an attenuated form of manic episodes in the absence of significant functional impairment.

Mixed episodes are defined in the ICD-11 in a way that is conceptually equivalent to the ICD-10, based on evidence for the validity of this approach⁶¹. Guidance is provided regarding the typical contrapolar symptoms observed when either manic or depressive symptoms predominate. The presence of a mixed episode indicates a bipolar type I diagnosis.

The ICD-11 provides various qualifiers to describe the current mood episode or remission status (i.e., in partial or in full remission). Depressive, manic and mixed episodes can be described as with or without psychotic symptoms. Current depressive episodes in the context of depressive or bipolar disorders can be further characterized by severity (mild, moderate or severe); by a melancholic features qualifier that bears a direct relationship with the concept of the somatic syndrome in ICD-10; and by a qualifier to identify persistent episodes of more than two years' duration. All mood episodes in the context of depressive or bipolar disorders can be further described using a prominent anxiety symptoms qualifier; a qualifier indicating the presence of panic attacks; and a qualifier to identify seasonal pattern. A qualifier for rapid cycling is also available for bipolar disorder diagnoses.

The ICD-11 includes the category of mixed depressive and anxiety disorder because of its importance in primary care settings^{62,63}. This category has been moved from anxiety disorders in the ICD-10 to depressive disorders in the ICD-11 because of evidence of its overlap with mood symptomatology⁶⁴.

Anxiety and fear-related disorders

The ICD-11 brings together disorders with anxiety or fear as the primary clinical feature in this new grouping⁶⁵. Consistent with ICD-11's lifespan approach, this grouping also includes separation anxiety disorder and selective mutism, which were placed among the childhood disorders in the ICD-10. The ICD-10 distinction between phobic anxiety disorders and other anxiety disorders has been eliminated in the ICD-11 in favor of the more clinically useful method of characterizing each anxiety and fear-related disorder according to its focus of apprehension⁶⁶; that is, the stimulus reported by the individual as triggering his or her anxiety, excessive physiological arousal and maladaptive behavioural responses. Generalized anxiety disorder (GAD) is characterized by general apprehensiveness or worry that is not restricted to any particular stimulus.

In the ICD-11, GAD has a more elaborated set of essential features, reflecting advances in the understanding of its unique phenomenology; in particular, worry is added to general apprehension as a core feature of the disorder. Contrary to ICD-10, the ICD-11 CDDG specify that GAD can co-occur with depressive disorders as long as symptoms are present independent of mood episodes. Similarly, other ICD-10 hierarchical exclusion rules (e.g., GAD cannot be diagnosed together with phobic anxiety disorder or obsessive-compulsive disorder) are also eliminated, due to the better delineation of disorder phenomenology in the ICD-11 and the evidence that those rules interfere with detection and treatment of conditions requiring separate specific clinical attention.

In the ICD-11, agoraphobia is conceptualized as marked and excessive fear or anxiety that occurs in, or in anticipation of, multiple situations where escape might be difficult or help not available. The focus of apprehension is fear of specific negative outcomes that would be incapacitating or embarrassing in those situations, which is distinct from the narrower concept in the ICD-10 of fear of open spaces and related situations, such as crowds, where an escape to a safe place may be difficult.

Panic disorder is defined in the ICD-11 by recurrent unexpected panic attacks that are not restricted to particular stimuli or situations. The ICD-11 CDDG indicate that panic attacks which occur entirely in response to exposure or anticipation of the feared stimulus in a given disorder (e.g., public speaking in social anxiety disorder) do not warrant an additional diagnosis of panic disorder. Rather, a "with panic attacks" qualifier can be applied to the other anxiety disorder diagnosis. The "with panic attacks" qualifier can also be applied in the context of other disorders where anxiety is a prominent though not defining feature (e.g., in some individuals during a depressive episode).

ICD-11 social anxiety disorder, defined on the basis of fear of negative evaluation by others, replaces ICD-10 social phobias.

The ICD-11 CDDG specifically describe separation anxiety disorder in adults, where it is most commonly focused on a romantic partner or a child.

Obsessive-compulsive and related disorders

The introduction of the OCRD grouping in the ICD-11 represents a significant departure from the ICD-10. The rationale for creating an OCRD grouping distinct from anxiety and fear-related disorders, despite phenomenological overlap, is based on the clinical utility of collating disorders with shared symptoms of repetitive unwanted thoughts and related repetitive behaviours as the primary clinical feature. The diagnostic coherence of this grouping comes from emerging evidence of the shared validators among included disorders from imaging, genetic and neurochemical studies³⁵.

ICD-11 OCRD include obsessive-compulsive disorder, body dysmorphic disorder, olfactory reference disorder, hypochondriasis (illness anxiety disorder) and hoarding disorder.

Equivalent categories that exist in the ICD-10 are located in disparate groupings. Also included in OCRD is a subgrouping of body-focused repetitive behaviour disorders that includes trichotillomania (hair-pulling disorder) and excoriation (skin-picking) disorder, both sharing the core feature of repetitive behaviour without the cognitive aspect of other OCRDs. Tourette syndrome, a disease of the nervous system in ICD-11, is cross-listed in the OCRD grouping because of its frequent co-occurrence with obsessive-compulsive disorder.

The ICD-11 retains the core features of ICD-10 obsessive-compulsive disorder, that is, persistent obsessions and/or compulsions, but with some important revisions. The ICD-11 broadens the concept of obsessions beyond intrusive thoughts to include unwanted images and urges/impulses. Moreover, the concept of compulsions is expanded to include covert (e.g., repeated counting) as well as overt repetitive behaviours.

Although anxiety is the most common affective experience associated with obsessions, the ICD-11 explicitly mentions other phenomena reported by patients, such as disgust, shame, a sense of “incompleteness”, or uneasiness that things do not look or feel “right”. ICD-10 subtypes of OCD are eliminated, because the majority of patients report both obsessions and compulsions, and because they lack predictive validity for treatment response. The ICD-10 prohibition against diagnosing obsessive-compulsive disorder along with depressive disorders is removed in the ICD-11, reflecting the high rate of co-occurrence of these disorders and the need for distinct treatments.

Hypochondriasis (health anxiety disorder) is placed in OCRD rather than among anxiety and fear-related disorders, even though health preoccupations are often associated with anxiety and fear, because of shared phenomenology and patterns of familial aggregation with OCRD⁶⁷. However, hypochondriasis (health anxiety disorder) is cross-listed in the anxiety and fear-related disorders grouping, in recognition of some phenomenological overlap.

Body dysmorphic disorder, olfactory reference disorder, and hoarding disorder are new categories in ICD-11 that have been included in the OCRD grouping.

In OCRDs that have a cognitive component, beliefs may be held with such intensity or fixity that they appear to be delusional. When these fixed beliefs are entirely consistent with the phenomenology of the OCRD, in the absence of other psychotic symptoms, the qualifier “with poor to absent insight” should be used, and a diagnosis of delusional disorder should not be assigned. This is intended to help guard against inappropriate treatment for psychosis among individuals with OCRDs³⁵.

Disorders specifically associated with stress

The ICD-11 grouping of disorders specifically associated with stress replaces ICD-10 reactions to severe stress and adjustment disorders, to emphasize that these disorders share the necessary (but not sufficient) etiologic requirement for exposure to a stressful event, as well as to distinguish included

disorders from the various other mental disorders that arise as a reaction to stressors (e.g., depressive disorders)⁴¹. ICD-10 reactive attachment disorder of childhood and disinhibited attachment disorder of childhood are reclassified to this grouping owing to the lifespan approach of the ICD-11 and in recognition of the specific attachment-related stressors inherent to these disorders. The ICD-11 includes several important conceptual updates to the ICD-10 as well as the introduction of complex PTSD and prolonged grief disorder, which have no equivalent in the ICD-10.

PTSD is defined by three features that should be present in all cases and must cause significant impairment. They are: re-experiencing the traumatic event in the present; deliberate avoidance of reminders likely to produce re-experiencing; and persistent perceptions of heightened current threat. The inclusion of the requirement for re-experiencing the cognitive, affective or physiological aspects of the trauma in the here and now rather than just remembering the event is expected to address the low diagnostic threshold for PTSD in ICD-10⁴².

Adjustment disorder in the ICD-11 is defined on the basis of the core feature of preoccupation with a life stressor or its consequences, while in the ICD-10 the disorder was diagnosed if symptoms occurring in response to a life stressor did not meet definitional requirements of another disorder.

Finally, acute stress reaction is no longer considered to be a mental disorder in the ICD-11, but instead is understood to be a normal reaction to an extreme stressor. Thus, it is classified in the ICD-11 chapter on “factors influencing health status or contact with health services”, but cross-listed in the grouping of disorders specifically associated with stress to assist with differential diagnosis.

Dissociative disorders

The ICD-11 dissociative disorders grouping corresponds to ICD-10 dissociative (conversion) disorders, but has been significantly reorganized and simplified, to reflect recent empirical findings and to enhance clinical utility. Reference to the term “conversion” is eliminated from the grouping title⁶⁸. ICD-11 dissociative neurological symptom disorder is conceptually consistent with ICD-10 dissociative disorders of movement and sensation, but is presented as a single disorder with twelve subtypes defined on the basis of the predominant neurological symptom (e.g., visual disturbance, non-epileptic seizures, speech disturbance, paralysis or weakness). ICD-11 dissociative amnesia includes a qualifier to indicate whether dissociative fugue is present, a phenomenon that is classified as a separate disorder in ICD-10.

The ICD-11 divides ICD-10 possession trance disorder into the separate diagnoses of trance disorder and possession trance disorder. The separation reflects the distinctive feature in possession trance disorder wherein the customary sense of personal identity is replaced by an external “possessing” identity attributed to the influence of a spirit, power, deity or other spiritual

entity. In addition, a greater range of more complex behaviours may be exhibited in possession trance disorder, while trance disorder typically involves the repetition of a small repertoire of simpler behaviours.

ICD-11 dissociative identity disorder corresponds to the concept of ICD-10 multiple personality disorder and is renamed to be consistent with currently used nomenclature in clinical and research contexts. The ICD-11 also introduces partial dissociative identity disorder, reflecting the fact that the preponderance of ICD-10 unspecified dissociative disorders is accounted for by presentations in which non-dominant personality states do not recurrently take executive control of the individual's consciousness and functioning.

Depersonalization and derealization disorder, located in the other neurotic disorders grouping in the ICD-10, is moved to the dissociative disorders grouping in the ICD-11.

Feeding and eating disorders

The ICD-11 grouping of feeding and eating disorders integrates ICD-10 eating disorders and feeding disorders of childhood, in recognition of the interconnectedness of these disorders across the lifespan, as well as reflecting the evidence that these disorders can apply to individuals across a broader range of ages^{45,47}.

The ICD-11 provides updated conceptualizations of anorexia nervosa and bulimia nervosa to incorporate recent evidence, which eliminates the need for ICD-10 "atypical" categories. It also includes the new entities of binge eating disorder, which is introduced based on empirical support for its validity and clinical utility, and ARFID, which expands upon ICD-10 feeding disorder of infancy and childhood.

Anorexia nervosa in the ICD-11 eliminates the ICD-10 requirement for the presence of a widespread endocrine disorder, because evidence suggests that this does not occur in all cases and, even when present, is a consequence of low body weight rather than a distinct defining feature of the disorder. Furthermore, cases without endocrine disorder were largely responsible for atypical anorexia diagnoses. The threshold for low body weight in ICD-11 is raised from 17.5 kg/m² to 18 kg/m², but the guidelines accommodate situations in which the body mass index may not adequately reflect a worsening clinical picture (e.g., precipitous weight loss in the context of other features of the disorder). Anorexia nervosa does not require "fat phobia" as in the ICD-10, to allow for the full spectrum of culturally diverse rationales for food refusal and expressions of body preoccupation.

Qualifiers are provided to characterize the severity of underweight status, given that extremely low body mass index is associated with greater risk of morbidity and mortality. A qualifier describing the pattern of associated behaviours is included (i.e., restricting pattern, binge-purge pattern).

Bulimia nervosa in the ICD-11 can be diagnosed regardless of the current weight of the individual, as long as the body

mass index is not so low as to meet definitional requirements for anorexia nervosa. In lieu of specific minimal binge frequencies that are, in fact, not supported by evidence, the ICD-11 provides more flexible guidance. A bulimia nervosa diagnosis does not require "objective" binges and can be diagnosed on the basis of "subjective" binges, in which the individual eats more or differently than usual and experiences a loss of control over eating accompanied by distress, regardless of the amount of food actually eaten. This change is expected to reduce the number of unspecified feeding and eating disorder diagnoses.

Elimination disorders

The term "non-organic" is removed from the ICD-11 elimination disorders, which include enuresis and encopresis. These disorders are differentiated from those that can be better accounted for by another health condition or the physiological effects of a substance.

Disorders of bodily distress and bodily experience

ICD-11 disorders of bodily distress and bodily experience encompass two disorders: bodily distress disorder and body integrity dysphoria. ICD-11 bodily distress disorder replaces ICD-10 somatoform disorders and also includes the concept of ICD-10 neurasthenia. ICD-10 hypochondriasis is not included and instead is reassigned to the OCRD grouping.

Bodily distress disorder is characterized by the presence of bodily symptoms that are distressing to the individual and an excessive attention directed toward the symptoms, which may be manifest by repeated contact with health care providers⁶⁹. The disorder is conceptualized as existing on a continuum of severity and can be qualified accordingly (mild, moderate or severe) depending on the impact on functioning. Importantly, bodily distress disorder is defined according to the presence of essential features, such as distress and excessive thoughts and behaviours, rather than on the basis of absent medical explanations for bothersome symptoms, as in ICD-10 somatoform disorders.

ICD-11 body integrity dysphoria is a newly introduced diagnosis that is incorporated into this grouping⁴⁸.

Disorders due to substance use and addictive behaviours

The ICD-11 grouping of disorders due to substance use and addictive behaviours encompasses disorders that develop as a result of the use of psychoactive substances, including medications, and disorders due to addictive behaviours that develop as a result of specific repetitive rewarding and reinforcing behaviours.

The organization of ICD-11 disorders due to substance use is consistent with the approach in the ICD-10, whereby clinical syndromes are classified according to substance classes⁷⁰.

However, the list of substances in the ICD-11 is expanded to reflect current availability and contemporary use patterns of substances. Each substance or substance class can be associated with mutually exclusive primary clinical syndromes: single episode of harmful substance use or harmful pattern of substance use, which represents a refinement of ICD-10 harmful use; and substance dependence. Substance intoxication and substance withdrawal can be diagnosed either together with primary clinical syndromes or independently as a reason for delivery of health services when the pattern of use or possibility of dependence is unknown.

Given the extremely high global disease burden of disorders due to substance use, the grouping has been revised to optimally enable the capture of health information that will be useful in multiple contexts, support accurate monitoring and reporting, and inform both prevention and treatment⁷⁰. The addition of ICD-11 single episode of harmful substance use provides an opportunity for early intervention and prevention of escalation of use and harm, whereas the diagnoses of harmful pattern of substance use and substance dependence suggest the need for increasingly intensive interventions.

The ICD-11 expands the concept of harm to health due to substance use to comprise harm to the health of other people, which can include either physical harm (e.g., due to driving while intoxicated) or psychological harm (e.g., development of PTSD following an automobile accident).

The ICD-11 includes substance-induced mental disorders as syndromes characterized by clinically significant mental or behavioural symptoms that are similar to those of other mental disorders but that develop due to psychoactive substance use. Substance-induced disorders can be related to substance intoxication or substance withdrawal, but the intensity or duration of symptoms are substantially in excess of those characteristic of intoxication or withdrawal due to the specified substances.

The ICD-11 also includes categories of hazardous substance use, which are not classified as mental disorders but rather are situated in the chapter on "factors influencing health status or contact with health services". These categories may be used when a pattern of substance use increases the risk of harmful physical or mental health consequences to the user or to others to an extent that warrants attention and advice from health professionals, but no overt harm has yet occurred. They are meant to signal opportunities for early and brief interventions, particularly in primary care settings.

ICD-11 disorders due to addictive behaviours include two diagnostic categories: gambling disorder (pathological gambling in ICD-10) and gaming disorder, which is newly introduced⁴⁹. In ICD-10, pathological gambling was classified as a habit and impulse disorder. However, recent evidence points to important phenomenological similarities between disorders due to addictive behaviours and substance use disorders, including their higher co-occurrence as well as the common feature of being initially pleasurable followed by progression to loss of hedonic value and need for increased use. Moreover,

disorders due to substance use and disorders due to addictive behaviours appear to share similar neurobiology, especially activation and neuroadaptation within the reward and motivation neural circuits⁷¹.

Impulse control disorders

ICD-11 impulse control disorders are characterized by the repeated failure to resist a strong impulse, drive or urge to perform an act that is rewarding to the person, at least in the short-term, despite longer-term harm either to the individual or to others.

This grouping includes pyromania and kleptomania, which are classified in the ICD-10 under habit and impulse disorders.

The ICD-11 introduces intermittent explosive disorder and reclassifies ICD-10 excessive sexual drive to this grouping as ICD-11 compulsive sexual behaviour disorder^{50,72,73}.

Disruptive behaviour and dissocial disorders

The ICD-11 grouping of disruptive behaviour and dissocial disorders replaces ICD-10 conduct disorders. The new term better reflects the full range of severity of behaviours and phenomenology observed in the two conditions included in this grouping: oppositional defiant disorder and conduct-dissocial disorder. An important change introduced in the ICD-11 is that both disorders can be diagnosed across the lifespan, whereas the ICD-10 construes them as disorders of childhood. Additionally, the ICD-11 introduces qualifiers that characterize subtypes of disruptive behaviour and dissocial disorders intended to improve clinical utility (e.g., prognostically).

ICD-11 oppositional defiant disorder is conceptually similar to its ICD-10 equivalent category. However, a "with chronic irritability and anger" qualifier is provided to characterize those presentations of the disorder with prevailing, persistent irritable mood or anger. This presentation is recognized to significantly increase the risk for subsequent depression and anxiety. The ICD-11 conceptualization of this presentation as a form of oppositional defiant disorder is concordant with current evidence and diverges from the DSM-5 approach of introducing a new disorder, disruptive mood dysregulation disorder⁷⁴⁻⁷⁶.

ICD-11 conduct disorder consolidates the three separate conduct disorder diagnoses classified in ICD-10 (i.e., confined to the family context, unsocialized, socialized). The ICD-11 acknowledges that disruptive behaviour and dissocial disorders are frequently associated with problematic psychosocial environments and psychosocial risk factors, such as peer rejection, deviant peer group influences, and parental mental disorder. A clinically meaningful distinction between childhood and adolescent onset of the disorder can be indicated with a qualifier, based on the evidence that earlier onset is associated with more severe pathology and a poorer course of the disorder.

A qualifier to indicate limited prosocial emotions can be assigned to both disruptive behaviour and dissocial disorders. In the context of an oppositional defiant disorder diagnosis, this presentation is associated with a more stable and extreme pattern of oppositional behaviours. In the context of conduct-dissocial disorder, it is associated with a tendency towards a more severe, aggressive and stable pattern of antisocial behaviour.

Personality disorders

Problems with the ICD-10 classification of ten specific personality disorders included substantial underdiagnosis relative to their prevalence among individuals with other mental disorders, the fact that only two of the specific personality disorders (emotionally unstable personality disorder, borderline type, and dissocial personality disorder) were recorded with any frequency in publicly available databases, and that rates of co-occurrence were extremely high, with most individuals with severe disorders meeting the requirements for multiple personality disorders^{16,17}.

The ICD-11 CDDG ask the clinician to first determine whether the individual's clinical presentation meets the general diagnostic requirements for personality disorder. The clinician then determines whether a diagnosis of mild, moderate or severe personality disorder is appropriate, based on: a) the degree and pervasiveness of disturbances in functioning of aspects of the self (e.g., stability and coherence of identity, self-worth, accuracy of self-view, capacity for self-direction); b) the degree and pervasiveness of interpersonal dysfunction (e.g., understanding others' perspectives, developing and maintaining close relationships, managing conflict) across various contexts and relationships; c) the pervasiveness, severity and chronicity of emotional, cognitive and behavioural manifestations of personality dysfunction; and d) the extent to which these patterns are associated with distress or psychosocial impairment.

Personality disorders are then further described by indicating the presence of characteristic maladaptive personality traits. Five trait domains are included: negative affectivity (the tendency to experience a broad range of negative emotions); detachment (the tendency to maintain social and interpersonal distance from others); dissociality (disregard for the rights and feelings of others, encompassing both self-centeredness and lack of empathy); disinhibition (the tendency to act impulsively in response to immediate internal or environmental stimuli without consideration of longer-term consequences); and anankastia (a narrow focus on one's rigid standard of perfection and of right and wrong and on controlling one's own and others' behaviour to ensure conformity to those standards). As many of these trait domains may be assigned as part of the diagnosis as are judged to be prominent and contributing to the personality disorder and its severity.

In addition, an optional qualifier is provided for "borderline pattern". This qualifier is intended to ensure continuity of

care during the transition from the ICD-10 to the ICD-11 and may enhance clinical utility by facilitating the identification of individuals who may respond to certain psychotherapeutic treatments. Additional research will be needed to determine whether it provides information that is distinct from that provided by the trait domains.

The ICD-11 also includes a category for personality difficulty, which is not considered a mental disorder, but rather is listed in the grouping of problems associated with interpersonal interactions in the chapter on "factors influencing health status or contact with health services". Personality difficulty refers to pronounced personality characteristics that may affect treatment or provision of health services but do not rise to the level of severity to warrant a diagnosis of personality disorder.

Paraphilic disorders

The ICD-11 grouping of paraphilic disorders replaces the ICD-10 grouping of disorders of sexual preference, consistent with contemporary terminology used in research and clinical contexts. The core feature of paraphilic disorders is that they involve sexual arousal patterns that focus on non-consenting others⁷⁷.

ICD-11 paraphilic disorders include exhibitionistic disorder, voyeuristic disorder, and pedophilic disorder. Newly introduced categories are coercive sexual sadism disorder, frotteuristic disorder, and other paraphilic disorder involving non-consenting individuals. A new category of other paraphilic disorder involving solitary behaviour or consenting individuals is also included, which can be assigned when sexual thoughts, fantasies, urges or behaviours are associated with substantial distress (but not as a consequence of rejection or feared rejection of the arousal pattern by others) or confer direct risk of injury or death (e.g., asphyxophilia).

The ICD-11 distinguishes between conditions that are relevant to public health and clinical psychopathology and those that merely reflect private behaviour, and for this reason the ICD-10 categories of sadomasochism, fetishism, and fetishistic transvestism have been eliminated²⁶.

Factitious disorders

The ICD-11 introduces a new grouping of factitious disorders that includes factitious disorder imposed on the self and factitious disorder imposed on another. This grouping is conceptually equivalent to the ICD-10 diagnosis of intentional production or feigning of symptoms or disabilities, either physical or psychological (factitious disorder), but extended to include the clinical situation where an individual feigns, falsifies, or intentionally induces or aggravates medical, psychological or behavioural signs and symptoms in another individual (usually a child).

The behaviours are not solely motivated by obvious external rewards or incentives, and are distinguished on this basis from

malingering, which is not classified as a mental, behavioural or neurodevelopmental disorder, but rather appears in the chapter on “factors influencing health status or contact with health services”.

Neurocognitive disorders

ICD-11 neurocognitive disorders are acquired conditions characterized by primary clinical deficits in cognitive functioning, and include most conditions that are classified among ICD-10 organic, including symptomatic, mental disorders. Thus, the grouping includes delirium, mild neurocognitive disorder (called mild cognitive disorder in ICD-10), amnesic disorder, and dementia. Delirium and amnesic disorder can be classified as due to a medical condition classified elsewhere, due to a substance or a medication, or due to multiple etiological factors. Dementia may be classified as mild, moderate or severe.

The syndromal characteristics of dementia associated with different etiologies (e.g., dementia due to Alzheimer disease, dementia due to human immunodeficiency virus) are classified and described within the chapter on mental, behavioural and neurodevelopmental disorders, whereas the underlying etiologies are classified using categories from the chapter on diseases of the nervous system or other sections of the ICD, as appropriate⁷⁸. Mild neurocognitive disorder can also be identified in conjunction with an etiological diagnosis, reflecting improved detection methods for early cognitive decline, which represents an opportunity to provide treatment in order to delay disease progression. The ICD-11 therefore clearly recognizes the cognitive, behavioural and emotional components of neurocognitive disorders as well as their underlying causes.

CONCLUSIONS

The development of the ICD-11 CDDG for mental, behavioural and neurodevelopmental disorders and their underlying statistical classification represents the first major revision of the world's foremost classification of mental disorders in nearly 30 years. It has involved an unprecedented level and range of global, multilingual and multidisciplinary participation. Substantial changes have been made to increase scientific validity in the light of current evidence and to enhance clinical utility and global applicability based on a systematic program of field testing.

Now, both the version of the ICD-11 chapter to be used by WHO member states for health statistics and the CDDG for use in clinical settings by mental health professionals are substantively complete. In order for the ICD-11 to achieve its potential in the world, the WHO's focus will shift to working with member states and with health professionals on implementation and training.

The implementation of a new classification system involves the interaction of the classification with each country's laws,

policies, health systems and information infrastructure. Multiple modalities must be developed for training a vast array of international health professionals. We look forward to continuing our very productive collaboration with the WPA and to working with member states, academic centers, professional and scientific organizations and with civil societies in this next phase of work.

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Adverse drug event-related hospitalisation in persons with neurodevelopmental disorders: a state-wide retrospective cohort study

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Abstract

Background Little is known about the sociodemographic and clinical characteristics of adverse drug events (ADEs) in patients with neurodevelopmental disorders (NDD).

Objective The objective of this study was to describe and compare the demographic details of people with and without NDD hospitalised due to ADEs.

Methods The all-inclusive New South Wales Admitted Patient Data Collection from 2001 to 2014 was employed to identify ADE-related hospitalisations in patients with NDD using the *International Classification of Diseases* 10th revision Australian modification codes. We derived case sets specific to different clinical groups and patient characteristics and compared proportional differences between patients with and without intellectual disability using chi squared tests.

Results A total of 2173 patients with NDD were admitted for acute care of ADEs, accounting for 0.7% of all ADE-related hospitalisations. Hospitalised ADEs among patients with NDD increased by two-fold over the 14-year study period. Psychotropic

medications and opioid analgesic medications were leading causes of ADE-related hospitalisations in patients with NDD. Compared with their counterparts, patients with NDD were younger, experienced more socio-economic disadvantage and less private insurance coverage, suffered with less severe but different co-morbid clinical conditions and incurred more challenges in the acute hospital care setting.

Conclusion Although the pattern of ADE-related hospitalisations in patients with NDD differed from that in patients without NDD, there is a lack of targeted healthcare programmes to meet their special needs. This study suggests the need for countermeasures in primary healthcare settings to reduce the burden of ADEs in this vulnerable group.

Keywords adverse drug events, hospital care, neurodevelopmental disorders, therapeutic medications

Introduction

Neurodevelopmental disorder (NDD) is a diagnostic group in the new version of the *International Classification of Diseases* (ICD-11) that includes the 'behavioural and cognitive disorders that arise during

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the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, or social functions' [World Health Organization (WHO) 2018a]. This group incorporates categories previously scattered in three different ICD-10 sections such as the *Disorders of Intellectual Development* or *Intellectual Disability* (ID) (F70–F79), *Autistic Spectrum Disorder* (ASD) (included in the group of Disorders of Psychological Development: F80–F89) and *Attention Deficit Hyperactivity Disorders* (ADHD) (part of the group of Behavioural and Emotional Disorders with onset usually occurring in childhood and adolescence: F90–F99) (WHO 2016). Multiple studies have reported substantial costs and high disease burden in persons with ID, ASD and ADHD, respectively (Gustavsson *et al.* 2011; Doran *et al.* 2012; Horlin *et al.* 2014), and demonstrated the need to improve healthcare for persons with these conditions. A comprehensive analysis of the resource utilisation and costs of ASD in Scotland (MacKay *et al.* 2017) has reiterated the association of autism to many co-occurring conditions such as ID, ADHD, Tourette's syndrome, challenging behaviours and other mental disorders. Of these co-occurring conditions, as the authors highlighted, 'the single most important moderator in terms of outcomes and their translation into economic implications is the presence or absence of intellectual disability' (MacKay *et al.* 2017, p. 17).

Despite high co-occurrence and co-causality of ID, ASD and ADHD (Guennewig *et al.* 2018; Williams *et al.* 2018), previous evidence has been established in separate categories, even in policy informative studies that grouped other major categories such as mood disorders, addiction or psychotic disorders (Gustavsson *et al.* 2011). Understanding health disparities in relation to these NDD conditions as a group is essential to inform healthcare policy and planning as well as improve outcomes in this vulnerable population.

Taking multiple medications is common in persons with NDD (PwNDD) (Croteau *et al.* 2017). For example, the rate of polypharmacy was higher in individuals with ID aged 50+ years than that in their counterparts without ID (39% vs. 18%) (Straetmans *et al.* 2017). High-risk prescribing of potentially inappropriate medications is also prevalent in persons with ID (Axmon *et al.* 2017), which could increase the risk for adverse drug events (ADEs). The term ADEs

used in this study includes unintended injuries resulting from medication use at usual therapeutic doses (Nebeker *et al.* 2004), excluding those due to overdose and medication errors. Previous studies reported higher incidence of ADEs in PwNDD compared with those without (McCracken 2005; Mahan *et al.* 2010; Aagaard & Hansen 2011; Fahourm *et al.* 2016; Scheifes *et al.* 2016b; Sheehan *et al.* 2017), with a variety of ADEs being reported during the use of psychotropic medications, e.g., cardiovascular complications (Vigod *et al.* 2016), cognitive and emotional disorders (Kovshoff *et al.* 2016) and metabolic disorders (Aagaard & Hansen 2011; Vigod *et al.* 2016). Despite this, epidemiological profile analysis regarding ADEs serious enough to warrant hospital acute care is scarce in the extended group of NDD.

In 2017, WHO launched its third global patient safety challenge "Medication Without Harm" with the aim to halve the burden of severe preventable ADEs in the next 5 years. Safe and quality medicine use represents one of the key healthcare needs in PwNDD (Sullivan *et al.* 2018). The aim of this study is therefore to assess and compare the demographic details of people with and without NDD hospitalised due to ADEs. Because ADEs are largely preventable, this evidence is important to provide indication for setting priorities, developing ADE prevention strategies and improving healthcare in this vulnerable population with high disease burden.

Methods

Data sources

The New South Wales (NSW) Admitted Patient Data Collection (APDC) is a complete census of all admitted patient services maintained by the NSW Health Department (ABS 2007). It covers all public and private hospitals in NSW as well as multipurpose services and day procedure centres. Clinical information for hospital admission, including the principal cause of hospitalisation and the principal procedure during episodes of care, is coded at the time of discharge using the Australian modification of ICD-10 (ICD-10-AM) (WHO 2004). NSW Health Department conducts a range of regular data quality checks and utilises clinical coding software to improve coding accuracy. Based on the data use agreement

with NSW Health Department, we used de-identified APDC data from July 2001 to June 2014 without identifiable personal information on names and residential address and extracted the patient's age, sex, marital status, post codes of usual residence, urgency of admission, up to 53 medical diagnoses, principle procedure block numbers, date of admission, date of separation and separation mode. The Australian National University Science and Medical Delegated Ethics Review Committee approved this study (#2016/030).

Persons with/without neurodevelopmental disorders

In this retrospective cohort study, PwNDD were identified using ICD-10-AM codes (F70–79 ID, F80–89 disorders of psychological development and F90–98 behavioural and emotional disorders with onset usually occurring in childhood and adolescence) (WHO 2004), to reflect a set of clinically significant development disorders (Salvador-Carulla *et al.* 2018). Persons without NDD were treated as the control group in the following analysis.

Hospitalised adverse drug events

We selected the ADE-related hospitalisations using ICD-10-AM external cause codes (Y40–Y59) from the chapter 'External causes of morbidity and mortality' because these episodes of care were caused by the 'drugs, medicaments and biological substances in proper therapeutic use' (WHO 2004). We further selected cases having a diagnosis code describing specific clinical symptom due to medicine use, with the intention to fully capture all ADE-related hospitalisations (Du *et al.* 2017). There were multiple updates to the ICD-10-AM during the study periods, which did not affect these codes.

Clinical information

To investigate leading therapeutic groups as the potential causes of adverse events for hospitalisation, we categorised different medications into 20 therapeutic groups according to the ICD coded categories of external causes (Y40–Y59). We further categorised the primary diagnosis as the clinical condition that warranted a hospitalisation according to ICD coded body system groups, to investigate the

patterns of potential ADE-related clinical consequences. Similarly, we considered co-morbid conditions in terms of hospitalised major injury and disease groups widely reported as leading causes of death, i.e., coronary heart diseases (ICD-10 codes I20–I25), cancer and malignant tumours (C00–C97), dementia and Alzheimer's disease (F01, F03 and G30), chronic obstructive respiratory diseases (J40–J44), cerebrovascular diseases (I60–I69), unintentional injuries and poisoning (S, T, V01–X59 and Y85–Y86), self-harm and suicides (X60–X84 and Y87.0) and whether having other co-morbid mental disorders using ICD F-codes as yes or no. We used the Australian Classification for Health Interventions procedure block codes for primary procedures to identify leading intervention groups. We categorised severity of co-morbidity as mild (total score of 0), moderate (total score of 1 or 2) or severe (total score ≥ 2) using the Charlson index score (Charlson *et al.* 1987). Length of stay was categorised as 1, 2–6, 7–12 or >12 days. We also used the separation mode to identify persons who died in hospital, were discharged to home or were transferred at the end of acute hospital care.

Patient demographic characteristics

Because the APDC comprised de-identified episodes of care, we only considered urgent cases to reduce the impact of multiple counting. We treated financial year of separation as categorical and further categorised age group in years (i.e. <18 , 18–44, 45–64 and 65 years and over); sex as male or female; single status as yes or no; socio-economic status as 1st (most disadvantaged), 2nd, 3rd, 4th or 5th (least disadvantaged) quintile using the postcode-based Index of Relative Socio-Economic Disadvantage (ABS 2018); private insurance as yes or no; and rurality of residence as rural or urban using the postcode-based Accessibility/Remoteness Index of Australia Plus (AIHW 2004). A separate category for unclassifiable values was included in the analysis.

Statistical analysis

We carried out all analyses using SAS version 9.4. We derived ADE-specific case sets and calculated numbers and proportions of PwNDD across different clinical groups and patient characteristics.

Proportional differences between persons with and without NDD were evaluated by chi squared tests. Negative binomial models with population offsets were used to evaluate the incident rate ratio (RR) and associated 95% confidence interval (CI) for hospitalised ADEs in PwNDD (case group) comparing with their counterparts without NDD (control group), sequentially adjusting for potential confounders, firstly, age group and sex, then additional year in continuous form and interaction with year, single status and interaction with single status, private insurance, socio-economic status, rurality of residence and severity of co-

morbidities. We set P value < 0.05 as a statistically significant level.

Results

A total of 2173 PwNDD were admitted for acute care of ADEs, accounting for 0.7% of all ADE-related hospitalisations during the study period. Table 1 shows the descriptive demographic characteristics of the study population. Among NSW residents hospitalised for ADEs, PwNDD were relatively younger (18.4% aged 65+ years vs. 62.0%, $P < 0.001$) and living without a partner (89.0% vs. 49.9%,

Table 1 Number (and proportion %) of ADE-related hospitalisation in persons with/without NDD by patient characteristics

Characteristics	NDD		P-value
	With	Without	
Age group (years)			<0.0001
0–17	444 (20.4)	13 089 (4.2)	
18–44	732 (33.7)	39 991 (12.8)	
45–64	598 (27.5)	65 900 (21.1)	
65+	399 (18.4)	194 120 (62.0)	
Sex			<0.0001
Male	1237 (56.9)	140 591 (44.9)	
Female	936 (43.1)	172 509 (55.1)	
Rurality of residence [†]			0.002
Rural	87 (4.0)	17 360 (5.5)	
Urban	2055 (94.6)	293 051 (93.6)	
Unclassifiable	31 (1.4)	2689 (0.9)	
Private insurance			<0.0001
Yes	287 (13.2)	88 739 (28.3)	
No	1886 (86.8)	224 361 (71.7)	
Socio-economic status (quintile) [‡]			<0.0001
1st (most disadvantaged)	484 (22.3)	70 639 (22.6)	
2nd	462 (21.3)	66 511 (21.2)	
3rd	538 (24.8)	62 111 (19.8)	
4th	414 (19.1)	56 989 (18.2)	
5th (least disadvantaged)	243 (11.2)	54 098 (17.3)	
Unclassifiable	32 (1.3)	2752 (0.9)	
Single status			<0.0001
Yes	1933 (89.0)	156 138 (49.9)	
No	240 (11.0)	156 962 (50.1)	
Financial year [‡]			<0.0001
2001–2002	107 (4.9)	14 634 (4.7)	
2013–2014	214 (9.9)	37 441 (12.0)	
Total	2173 (100)	313 100 (100)	

[†]A separate category for unclassifiable values was included in the analysis.

[‡]Only the first year and last year data over the study period were presented. ADE, adverse drug event; NDD, neurodevelopmental disorders.

$P < 0.001$), compared with their counterparts without NDD (Table 1). About 56.9% of PwNDD in the study population were male, 94.6% resided in urban areas and 86.8% had no private insurance (Table 1). Over the study period, more hospitalised ADEs were consistently observed in both population groups (Table 1).

Table 2 presents the clinical characteristics of ADE-related hospitalisation in both groups. While severe co-morbidities were less common in PwNDD (9.5% vs. 19.7%, $P < 0.001$), they experienced longer acute hospital care with one-third length of stay greater than 12 days (35.6% vs. 22.1%, $P < 0.001$), compared with those without NDD. Of the PwNDD hospitalised for ADEs, the most common clinical reason for admission was mental disorders, which accounted for 49.9% in total (dementia and Alzheimer's disease 4.5% plus other mental disorders 44.4%). There was no statistically

significant proportional difference of dementia, Alzheimer's disease and cerebrovascular diseases between these two groups (Table 2), unlike the other ageing-related chronic diseases such as chronic obstructive respiratory diseases and cancers, where a significant lower proportion of such diseases was observed in PwNDD compared with their counterparts. Although the proportion of co-morbid self-harm and suicidal behaviours was low in both groups, these behaviours almost quadrupled in PwNDD (2.8% vs. 0.7%, $P < 0.001$) (Table 2). At the end of the acute episode of care, PwNDD were less likely to die in hospitals but more likely to be transferred to another care setting instead of home discharge (Table 2).

The age-sex adjusted risk of hospitalised ADEs in PwNDD was elevated two times (RR: 2.19; 95% CI: 2.00–2.40) when compared with individuals without NDD (Table 3). After sequentially controlling for

Table 2 Number (and proportion %) of ADE-related hospitalisation in persons with/without NDD by clinical information

Characteristics	NDD		P-value
	With	Without	
Severity of co-morbidities			<0.0001
Minor	1491 (68.6)	166 005 (53.0)	
Moderate	476 (21.9)	85 519 (27.3)	
Severe	206 (9.5)	61 576 (19.7)	
Length of stay (days)			<0.0001
1	306 (14.1)	64 649 (20.7)	
2–6	693 (31.9)	114 627 (36.6)	
7–12	401 (18.5)	64 684 (20.7)	
>12	773 (35.6)	69 140 (22.1)	
Co-morbid conditions warrant hospitalisation			
Coronary heart diseases	56 (2.6)	29 341 (9.4)	<0.0001
Cancer and malignant tumours	102 (4.7)	42 260 (13.5)	<0.0001
Dementia and Alzheimer's disease	97 (4.5)	13 025 (4.2)	0.48
Chronic obstructive respiratory diseases	54 (2.5)	21 105 (6.7)	<0.0001
Cerebrovascular diseases	72 (3.3)	12 019 (3.8)	0.20
Unintentional injuries and poisoning	636 (29.3)	81 822 (26.1)	0.001
Self-harm and suicide	60 (2.8)	2214 (0.7)	<0.0001
Other mental disorders	965 (44.4)	58 449 (18.7)	<0.0001
Separation mode*			
Home discharge	1623 (74.7)	241 677 (77.2)	0.006
Being transferred	445 (20.5)	57 354 (18.3)	<0.0001
Death	34 (1.6)	10 329 (3.3)	0.01
Total	2173 (100)	313 100 (100)	

ADE, adverse drug event; NDD, neurodevelopmental disorders.

*A separate category for unclassifiable values was not included in the analysis.

Table 3 Incidence RR for hospitalised ADEs in persons with NDD in comparison with those without NDD

Model covariates [†]	RR (95% CI)
Model 1: Age group and sex	2.19 (2.00, 2.40)
Model 2: 1 plus year and interaction with year	3.09 (2.59, 3.69)
Model 3: 2 plus single status and interaction with being single	3.76 (3.13, 4.50)
Model 4: 3 plus private insurance	3.38 (2.82, 4.04)
Model 5: 4 plus socio-economic status	3.11 (2.62, 3.70)
Model 6: 5 plus rurality of residence	2.36 (2.03, 2.75)
Model 7: 6 plus severity of co-morbidities	1.89 (1.64, 2.18)

[†]Covariates were sequentially added to the previous model.

ADE, adverse drug event; CI, confidence interval; NDD, neurodevelopmental disorders; RR, rate ratio.

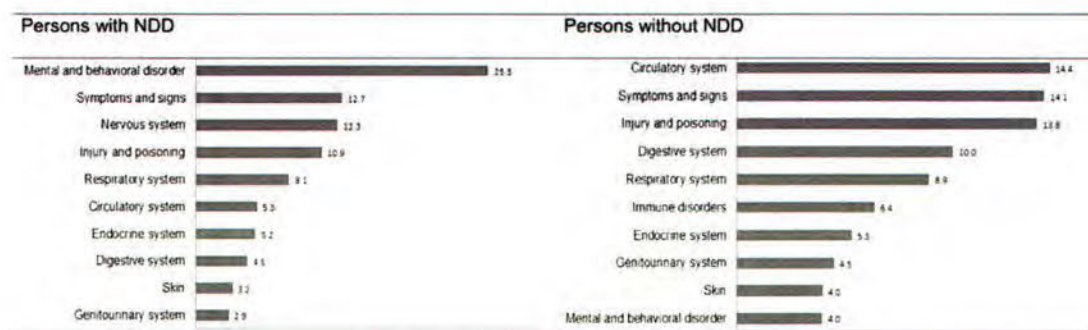


Figure 1 Top 10 leading primary diagnosis for hospitalised adverse drug event in persons with/without neurodevelopmental disorders (NDD). [Colour figure can be viewed at wileyonlinelibrary.com]

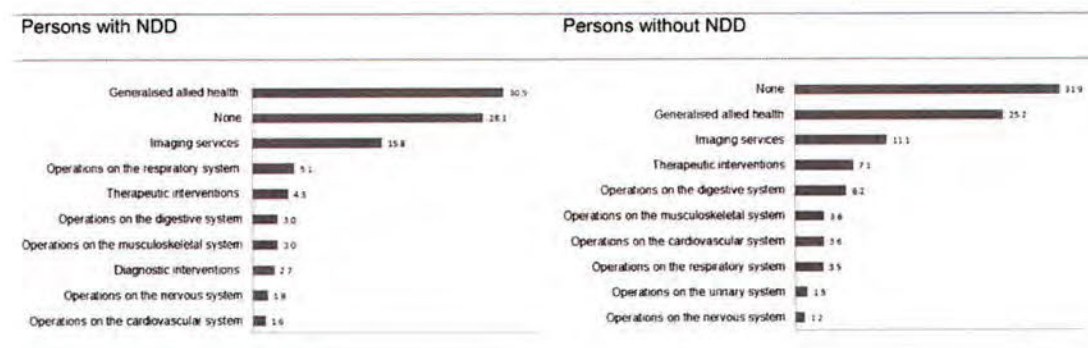


Figure 2 Top 10 leading primary procedures for hospitalised adverse drug event in persons with/without neurodevelopmental disorders (NDD). [Colour figure can be viewed at wileyonlinelibrary.com]

other potential confounders, hospitalised ADEs remain 89% more likely to occur in PwNDD than their counterparts without NDD (RR: 1.89; 95% CI: 1.64–2.18) (Table 3).

Figures 1 and 2 show the top 10 leading primary diagnosis and procedure groups for hospitalised ADEs. Among PwNDD, mental and behavioural disorder accounted for over one quarter (25.3%) of

clinical reasons warranting admissions, followed by symptoms and signs (12.7%) and nerve system conditions (12.3%). In contrast, the leading primary diagnosis for hospitalised ADEs in persons without NDD was circulatory conditions (14.4%), followed by symptoms and signs (14.1%) and injury and poisoning (13.8%) (Fig. 1). While the majority of primary interventional procedure groups were similar between persons with and without NDD, diagnostic interventions were more commonly carried out, accounting for 2.7% of all ADE-related hospitalisations in PwNDD.

Figure 3 presents the top 10 leading therapeutic groups for hospitalised ADEs in PwNDD and their counterparts. The majority of hospitalised ADEs in PwNDD were due to psychotropic medications, which are less commonly seen for hospitalised ADEs in their counterparts. Therapeutic use of medications commonly seen in the general population including opioids, anticoagulants and penicillin also demonstrated their leading contribution to acute hospital care for adverse events in PwNDD.

Discussion

In this study, we described the epidemiological profiles of hospitalised ADEs in PwNDD in comparison with those without NDD. It was clear that this vulnerable group, compared with those without NDD, experienced elevated risk of hospitalised ADEs, an apparent socio-demographical disparity, used a similar range of common medications, suffered less severe but different comorbid conditions and incurred more challenges in acute hospital care. These demographic and clinical

characteristics of ADE-related hospitalisation in PwNDD resonate with the global call to improve their health and care, particularly in relation to medication prescriptions in primary healthcare settings (Sullivan *et al.* 2018). ADE prevention in PwNDD is presumed to be complicated. Our findings reinforce the importance to provide specialised countermeasures to reduce ADE-related healthcare burden in PwNDD.

Persons with NDD showed a pattern of socio-demographical inequality in hospitalised ADEs, which are consistent with results from previous studies (ABS 2014; Balogh *et al.* 2010; Lewis *et al.* 2016; Arvio *et al.* 2017; Peklar *et al.* 2017). ADEs were commonly seen among relatively younger PwNDD, compared with those without. While ageing is associated with possible consumption of a disproportionately large amount of medications and thus leading to elevated risks of ADEs (Nissen 2006; Hubbard *et al.* 2013), this phenomenon was not observed in PwNDD. It is possible that they used more potentially inappropriate medications with excessive drug burden at an early stage, due in part to their high disease burden. Considering premature deaths in PwNDD as their life expectancy is on average 20 years shorter than those without (Barbarese *et al.* 2013; Hirvikoski *et al.* 2016; Arvio *et al.* 2017), there might be a potential overlook of appropriate healthcare needs in PwNDD. This could also be true especially when they live alone and experience high risks of adverse events (Lewis *et al.* 2016), which may partly indicate why single PwNDD suffered more ADE-related hospitalisations as observed in this study. Although PwNDD face the challenge of independent living and encounter multiple barriers to access necessary

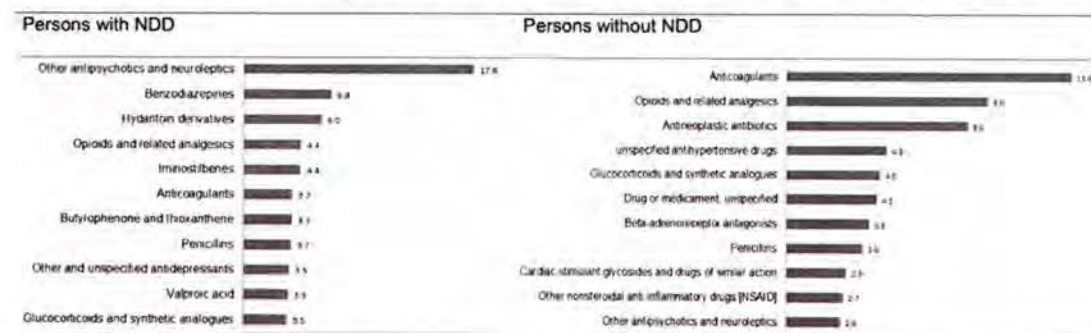


Figure 3 Top 10 leading medication agents for hospitalised adverse drug event in persons with/without neurodevelopmental disorders (NDD). [Colour figure can be viewed at wileyonlinelibrary.com]

healthcare services, they have the same rights as those without to have their complex healthcare needs addressed (WHO 2018b). However, many of these healthcare needs were socially and environmentally determined (Emerson *et al.* 2011; Duchan & Patel 2012; Fayyad *et al.* 2017), e.g., the observed overrepresentation of socio-economic disadvantage in PwNDD. Hence, improved healthcare services addressing the social and environmental determinants of their medication safety may have the potential to reduce the burden of ADEs.

Not surprisingly, hospitalised ADEs in PwNDD were primarily caused by psychotropic medications. This is consistent with findings in previous studies (Ji & Findling 2016; Paton *et al.* 2016; Scheifes *et al.* 2016a). It is also alarming that opioid-related ADEs were prevalent in PwNDD as well as the general population. This first-ever finding coincides with the global epidemic of inappropriate use of therapeutic opioids (Humphreys 2017) and highlights the necessity for development of multimodal pain management strategies including pharmacological, physical and psychosocial approaches in PwNDD (Bryson *et al.* 2003; Doody & Bailey 2017). Given the subjective nature of pain experience and the prevalent co-morbid mental disorders in PwNDD, it is particularly important for healthcare professionals to conduct effective pain assessment and identify high ADE risks associated with opioids prescriptions in PwNDD who would have difficulties expressing discomfort.

Medication safety advocates rely on few data sources to ascertain ADEs including the hospitalisation data we used in this study. Some variables employed in the ADE risk mitigation clinical tools are difficult to apply to PwNDD (Rozich *et al.* 2003). On the one hand, persons with cognitive impairment might lack the communication ability to recognise and interpret their experience (Valdovinos *et al.* 2005; Charlot *et al.* 2011); on the other hand, healthcare professionals may face various barriers in communicating with PwNDD so as to identify their unmet healthcare needs (Boardman *et al.* 2014; Waxegård & Thulesius 2016). Because reactions to therapeutic medications vary greatly from individual to individual, no clinical guidelines would fit all scenarios. Therefore, it is difficult to take precautionary countermeasures to prevent ADEs in this vulnerable population. Improving doctor–patient

communication and practitioner capacity building are critical especially in primary care settings (Gandhi *et al.* 2003; Sullivan *et al.* 2018). Collective efforts including provision of health education programmes and updates on clinical guidelines to improve medication safety in this vulnerable population are warranted; without which, it is likely that the ADE burden would continue to grow.

We found that PwNDD admitted for ADEs were diagnosed with less severe co-morbidities in comparison with those without. Chronic conditions like cancers, coronary heart diseases and chronic obstructive respiratory diseases were less common. Consistent with previous studies (Brown & Beail 2009; Hannon & Taylor 2013; Scheifes *et al.* 2013; Allely 2014; Ji & Findling 2016), mental disorders and self-harm were more prevalent in PwNDD. This increased the complexity of care, as we observed lengthy hospital stay, excessive use of diagnostic intervention and high likelihood of being transferred in PwNDD at the end of acute care for ADEs. Various programmes to improve quality of healthcare for this vulnerable group have taken place in many countries around the world (Baum *et al.* 2013; Salvador-Carulla *et al.* 2015). However, most of these programmes encourage PwNDD to use mainstream healthcare services with little effort to tailor service provisions to meet their complex needs (Schrevel 2015; Hepsı & Pike 2016). Many healthcare professionals do not have much experience to recognise special healthcare needs of this special group (Furst & Salvador-Carulla 2017). Recently, it has been recommended that healthcare providers designate at least one staff to develop expertise in meeting healthcare needs from PwNDD (NICE 2018; Sullivan *et al.* 2018). Continuing efforts are imperative to provide specialised and enhanced services to optimise their health and care (Salvador-Carulla *et al.* 2013; Solberg *et al.* 2015).

Many hospitalised ADEs are preventable (Thomsen *et al.* 2007). The results of this study further supported this in that most PwNDD involved in ADE-related hospitalisation coincided with less severe co-morbid conditions. However, the complexity facing the healthcare professionals to provide care for PwNDD did not diminish because these people were hospitalised longer than those without and more likely to be transferred after acute care. Clearly defined goals in clinical practice to

improve medication safety among this vulnerable group are urgently needed (US DHHS 2014). International guidelines to improve psychotropic medication in PwNDD have been proposed, including surveillance of ADEs (Deb *et al.* 2009). This is particularly fundamental to prevent unintentional injuries resulting from medication use (Bates *et al.* 1995; Krug 2004). A number of strategies, such as targeted training for clinicians, early identification of high-risk factors and effective safety guidelines for practitioners, have been suggested in prevention of ADEs (Ducoffe *et al.* 2016; Sullivan *et al.* 2018). These strategies could be highlighted and translated into the setting of primary healthcare for PwNDD, a population group at high risk of ADEs. Despite a focus on psychotropic medication use, the special medication safety needs in a wider context such as opioid use have been unfortunately somewhat overlooked. For example, the recently updated guidelines of primary healthcare for adults with ID did not specify recommendations to reduce the occurrence of ADEs in this high-risk population (Sullivan *et al.* 2018). Future policy initiatives could develop relevant clinical guidelines targeting this high-priority area, which may reduce the healthcare burden of preventable ADE-related hospitalisations among PwNDD.

Previous studies using separate NDD conditions have prevented an overall health disparity analysis, which may have influenced the low priority setting for some of these conditions such as ID (Salvador-Carulla & Symonds 2016). The analysis of these NDD conditions as a group in the current study may be particularly relevant to understanding of disparities in medication safety, and therefore, the findings may inform intervention strategies to improve outcomes in this group. Limitations of this study have to be acknowledged. First, the identification of NDD was based on the clinical diagnoses for persons admitted for ADEs. It is likely that only cases with severe impairment would be ascertained in this study. Therefore, the burden of ADEs in this vulnerable population would be underestimated. Second, we were unable to determine the causality of ADEs because the admitted inpatient data collections did not comprise details of any clinical chart review for us to identify mechanisms of ADE occurrences, for example, drug–drug interaction due to polypharmacy or inappropriate prescribing. Third, coding practice

might vary between different facilities, which could lead to an underestimate of the actual occurrence of ADEs serious enough for hospitalisation. Given that data quality checking procedures have been implemented at each hospital and the Department of Health, our results are likely to be robust but conservative. Furthermore, we have conducted sensitivity analysis by excluding study subjects with unclassifiable information on their rurality of residence and socio-economic status and noticed little change in the risk estimate when comparing hospitalised ADEs in PwNDD with their counterparts without NDD. Nevertheless, the use of routinely collected admission data enables the identification of hospitalised ADEs in PwNDD, which is particularly useful in gaining a comprehensive profile with clinical importance. Despite these limitations, this is the first available population-based profile for ADE-related hospitalisation in PwNDD. Further studies centred on ADE prevention in conjunction with mental health management specific to different conditions (e.g. non-affective psychotic disorders or mood disorders) in primary healthcare may have the potential to identify countermeasures for improving medication safety and reducing the burden of ADE-related hospitalisation among PwNDD.

In summary, PwNDD experienced a socio-economically disproportionate burden of hospitalised ADEs. Psychotropic medications and opioids analgesics were the leading medication agents. This basic description of sociodemographic and clinical characteristics of hospitalised ADEs in PwNDD provides fundamental evidence to inform further investigation and countermeasure development.

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Conflict of Interest

There are no known conflicts of interest to declare.