Universities Australia response to the Commonwealth Department of Health and Aged Care's open consultation on the draft Intellectual Disability Health Capabilities - online survey

January 2023

1. Name: Policy Director Health and Workforce

2. Organisation: Universities Australia

3. Type of response: Organisational

4. If representing an organisation, which sector does your organisation belong to? University/Education/Research Institution

5. What health discipline or field of expertise does your organisation belong to/do you work in?

Education provision for pre-registration students and beyond in all of the discipline areas outlined, plus related research.

- 6. Do the six broad capability areas (see discussion paper and listed below) capture the important areas that health students should know about and be able to do? The six capability areas are:
 - i. Intellectual disability awareness
 - ii. Communication
 - iii. Quality evidence-based clinical care
 - iv. Coordination and collaboration
 - v. Decision-making and consent
 - vi. Responsible, safe and ethical practice.

Response:

There is in principle support for the capabilities noting that:

- capabilities ii to xi are already taught to pre-registration health professionals as they apply to all clients and aspects of health service delivery across all disciplines;
- suggested amendments/additions to the capabilities are provided under below under each specific capability.

It would also be useful to introduce these capabilities in the context of respectful, quality care that puts the client at the centre as the desired outcome. These capabilities help health professionals achieve this goal with *all* patients/clients.

A preamble would also be useful about the lifelong nature of capability development and the ongoing process of learning and reflection for health professionals about the care of persons with intellectual disabilities. That is, these capabilities are continuously developed over time. Some consideration about how these capabilities might grow beyond pre-registration curricula and into the role and continuing development of a registered health professional would also be helpful.

7. For the capability area 'Intellectual Disability Awareness', are the key capabilities captured?

Response

It is recommended that information about: disability type and prevalence by age group; and main health condition of people with disability is included in this section. This information can be found in the ABS 2019a, 2019b and table PREV12 at www.aihw.gov.au

The following are also suggested for consideration of inclusion in this section:

- an overview of intellectual disability for practitioners which illustrates that it occurs along a
 spectrum and is often comorbid with other disabilities/health conditions. This includes
 consideration of the spectrum of intellectual disabilities and where/how this may impact
 primary health care/social care (e.g. those who have hidden disability, who can easily be
 overlooked by health professionals and their disability is attributed to a behavioural choice)
- dispelling myths and biases about people with intellectual disability
- understanding the complex nuances of disability rights and respect
- what to do if you suspect someone might have an intellectual disability
- signs of intellectual disability (i.e in relation to expected developmental stages)

A further consideration for inclusion is also building practitioner understanding that any treatments suggested take into account patient lifestyle or other treatments/conditions. This is touched on in the section referencing polypharmacy but it is wider than this.

8. For the capability area 'Communication', are the key capabilities captured?

Response:

Generally supported but the following are also suggested for consideration of inclusion in this section:

- how to identify what support networks are in place for a client with intellectual disability
- understanding the client's access to and ability to use a range of communication tools and information technology to communicate
- how to assess a client's understanding of information provided by the health care professional
- use the wording "Communicate for safety" (instead of "Communicate about safety") to reflect communicating in ways that contribute to feeling safe as well as being (physically) safe
- communication to assess client strengths

9. For the capability area 'Quality Evidence-Based Clinical Care', are the key capabilities captured?

Response:

The following are suggested for consideration of inclusion in this section:

- The importance of interprofessional collaboration/use of multi-professional expertise, including the client/consumer's own knowledge
- Importance of practical examples a toolkit of evidence-based strategies
- Raising issues if a practitioner has concerns about sub-standard care
- Further unpacking the term "Diagnostic overshadowing and other reasons for misdiagnosis"
 (It seems complex in its current format.) This could be grouped with deterioration statements
 under banner of holistic or comprehensive assessment that considers physical, cognitive and
 psychosocial dimensions of the person and the need for ongoing assessment to address their
 changing needs.
- Include statements around supporting achievement of goals (e.g. maintaining independence, acquiring new skills etc.) Planning and goal setting currently appears absent
- Suggest refer to "partnership in care" rather than "Inclusion in care" to convey more equal and respectful involvement.
- Also under the "inclusion in care" section, consider care that reflects the person's values and beliefs, as well as their needs and preferences.
- Add wording to convey that "care" occurs in many ways and contexts and that evidence contributing to care includes, but is not limited to, clinical evidence.

10. For the capability area 'Coordination and Collaboration', are the key capabilities captured?

Response:

In addition to the proposed points under this capability, the following are also suggested for consideration of inclusion in this section:

- the importance of interprofessional and intra-professional team communication and best practice examples of how to achieve that
- identifying the decision-maker at different points eg. The client, carer, medical practitioner, dentist, nurse, allied health professional
- managing interprofessional conflict (may fit better in the "communication" section)
- · managing conflict situations with the client and their family
- the importance of ensuring continuity of care across contexts and settings throughout the person's lifespan (this capability refers to "transitions" only rather than continuity)
- the need to consider carer supports
- NB The figures from the AIHW referenced above show that irrespective of the type of
 disability, the aspects of disability that dominate are loss of hearing, confusion/learning,
 chronic pain, mental/emotional problems and inability to participate in activities. These cross
 over many disability types and are so often misunderstood or misattributed, hence the need
 for an intra-professional team approach.

11. For the capability area 'Decision-Making and Consent', are the key capabilities captured?

Response:

In addition to the proposed points under this capability, the following are also suggested for consideration of inclusion in this section:

- how to assess client capacity for decision-making
- where to find information to support the person and/or family and the health professional about decision-making and consent
- how to manage personal interpersonal/professional conflict with regard to decision-making
- privacy and confidentiality understanding the person's right to privacy; considerations by the health professional regarding the information collected and ways in which it is collected, used and/or shared with others (Privacy Act, 1988).

12. For the capability area 'Responsible, Safe and Ethical Practice', are the key capabilities captured?

Response:

In addition to the proposed points under this capability, the following are also suggested for consideration of inclusion in this section:

- reference(s) to the guiding frameworks used.
- guidance on speaking up within the system to protect the rights of a person with an intellectual disability, especially if substandard care is suspected.
- under safeguarding consider including "evaluation and reporting of unsafe practices"
- emphasise the lifelong approach to continuous capability development for health professionals (views of responsible, safe and ethical practice of an experienced practitioner may be significantly more "layered" than that of a health professional student).

13. Please provide any other observations or advice that you have not had the opportunity to make on the capabilities.

Response¹

We support the overall goal of improving health for people with a disability however have reservations about the extent to which curriculum inclusion alone will have an impact. To be effective we recommend that this is also accompanied by policy support for clinical experience with intellectual disability health clients within services.

• Health course curricula are becoming increasingly full and there are many competing interests that must be considered across a 3-4 year (plus) pre-registration degree. Virtually all of the capabilities proposed in the framework are already covered broadly in all health professional curricula in a way that new entry professionals can apply them to a range of clients and situations. Content on the health of people with intellectual disability is also already included to varying extents in curricula across the disciplines. However, access to

clinical placements and experience with people with intellectual disability health issues is more limited.

- Adding yet more content to the curricula on a specific group is challenging. A better way to
 embed health students' skills and knowledge in working in partnership with this specific client
 group is to include a greater range of clinical experiences. Policy that unlocks extended
 experience and/or placement capacity in services where students can gain practical
 experience in working with people with intellectual disability is needed. Curricula change
 alone is insufficient.
- Certain issues that lead to poorer outcomes in people with intellectual disability relate more to
 the overall system (service coordination issues, lack of service access etc.) than to the skills
 and knowledge of the treating health professional. These systems issues will not be
 addressed through curricula additions. Enabling access to clinical experience/placement for
 students in services will help both students and the services themselves to gain a greater
 understanding of the health needs of intellectual disability health clients.
- As well as the generalist skills in intellectual disability health that the capabilities are designed
 to address, it is also worth looking at how to grow the specialist special needs workforce.
 Certain disciplines, for example dentistry and psychiatry report that there is a lack of such
 workforce in some places currently, leading to delays in access. This may be true for other
 disciplines too. A coordinated, needs-based approach is suggested.
- 14. Do you consent to components of your submission being de-identified and included in a publicly available summary of findings?

Yes