



**Lived
Experience**
AUSTRALIA

Initial Assessment and Referral (IAR) for Mental Healthcare – Older Adults (Consultation Draft)

10 June 2022

Submitted to:

National Project Manager

Ms Jenni Campbell

Jenni.a.campbell@outlook.com

Table of Contents

Table of Contents	2
Background.....	3
Our Response.....	3
Contact.....	7

Background

Lived Experience Australia Ltd (hereafter LEA) is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. Our core business is to advocate for systemic change and empowerment of consumers in their own care. This advocacy involves promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion.

Our Response

Thank you for the opportunity to provide our thoughts on this important work. Timely, accurate and effective person-centred assessment and referral to appropriate supports for older adults experiencing mental ill-health is essential for the person and their family and carers. This IAR tool is an important step in supporting GPs, other specialists and health professionals and referrers to do that more holistically to ensure the person receives high quality care and support.

We note that 2 individuals associated with LEA have provided their lived experience perspective to this detailed process, Ms Susan Adam and Mr Norm Wotherspoon).

We note and acknowledge the enormous effort, skill and time that has clearly gone into the formulation of this draft IAR Guidance and the accompanying Decision Support Tool. This includes the many stages of development of the broader IAR tool's development and implementation planning. It is very timely and satisfying that you have now focused on how the tool needs to be formulated for older adults.

Overall, the Guidance is laid out very clearly and comprehensively. It is important that mental health care professionals (clinical and non-clinical) access this document and use it effectively in their practice. We think you have the balance of detail and succinctness right in this document. We note that the domains focus on problems and the assessment tool is focused on how much the various issues are problems. We note that there is little or no opportunity to identify the strengths that the person brings to their situation and wonder if something about this could be flagged somehow in the document, for example, where you remind and emphasise the importance of the health care professional using their clinical judgment and knowledge of the person. We believe this is particularly important for older adults who may have accumulated vast experience over their life-course which could be mobilised as part of addressing mental health concerns.

We commend you for the very accessible layout of the detail of each domain, with dot points, practice points and rating information clearly described and accessible.

Likewise, the Decision Support Tool preamble is laid out well and its information is very accessible, providing a quick and clear summary of the overall guidance. The Logic Diagram is initially 'busy' but no doubt you will undertake more fine-tuning to improve the overall layout. We commend you on capturing what is clearly a layered set of processes and assessment information.

Below we have listed more specific comments which we hope are useful:

p.6 | 2nd paragraph where you talk about assessment being undertaken in partnership – we suggest that you include reference to the family. They are often invisible in the assessment and care process and are often excluded from involvement by health professionals. Our national research with mental health consumers and carers confirms this situation remains very common across all level of the healthcare system, even though consumers tell us they want their family carers involved.

p.6 final dot point where you make reference to 'recovery needs' – we suggest that this concept is clarified. In the context in which it is used here (as additional to clinical needs), we believe you are talking more specifically about personal recover. If you were to expand on this concept a little to explain what it means more from the person's perspective, it would help set the tone of the

document as more inclusive of the person's perspective. Mike Slade and others with lived experience have written extensively on personal recovery. Personal recovery relates more to 'a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness.'¹ Leamy, Bird et al.² propose that personal recovery is built on the five processes of Connectedness, Hope and optimism, Identity, Meaning and Purpose, and Empowerment, which they refer to as the CHIME framework.

p.7 Expectations and final paragraph – it is good to see these explicitly stated here to ensure those who use the guidance and tool continue to draw on their local knowledge, local needs, flexibility and the nuance required to truly provide individualised assessment to each older adult according to their specific set of circumstances. Our only concern here is with PHN performance variations that may then result in potential inequalities the services and resources available to individuals and communities.

p.12 The information provided here on supported decision-making could include a clearer definition so that health professionals are clear about truly walking alongside the person to enhance their capacity to make informed decisions, ensuring their legal rights, whatever their situation is. From a lived experience perspective, seeking help and receiving services can be disempowering for a range of 'system' reasons. Finding every opportunity to preserve and enhance the person's preferences is vital. A person may be detained under a mental health act, for example, but they may still know what they want to eat, wear, etc. Supported decision making is about the everyday things as much as the big issues.

p.13 regarding Guiding Principle – Response and flexible – timely communication should also include the consumer and family/carer!

p.14 regarding the points made about non-clinical staff – In relation to peer workers, we refer you to the National Peer Workforce Guidelines³ which provide good guidance about preferred supervision arrangements, by senior peers or by clinicians.

Given the importance of this workforce in understanding, being trusted, and engaging with the person on holistic aspects of the person's circumstances from a lived experience and also the importance of the elements of personal recovery as mentioned earlier, it would be good for this Guidance document to link to the importance of this non-clinical workforce in this role. Currently, the statements read as if the assessment is primarily a clinical one and that non-clinical staff can only be trusted with some elements (largely social elements), and then only under strict supervision from clinical staff. The other concern with this approach is that it could potentially lessen the reader's sense of the importance of the social issues within the domains. Our experience is that these provide crucial context and can be core drivers to everything that is trying to be achieved 'clinically'.

Also, in the practice point on this page, we believe that trust and rapport are central practice skills and therefore use of the term 'may' seems to be an underestimation of what should be a core goal. More generally is the issue of language regarding use of the term 'reluctance' which places sole responsibility for engagement with the person. We stress that engagement is a 2-way process,

¹ Anthony (1993). "Recovery from mental illness: The guiding vision of the mental health service system in the 1990s." *Psychosocial Rehabilitation Journal* **16**(4): 11-23.

² Leamy, M., V. Bird, C. Le Boutillier, J. Williams and M. Slade (2011). "Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis." *Br J Psychiatry* **199**(6): 445-452.

³ Byrne, L., Wang, L., Roennfeldt, H., et al. (2021) National Lived Experience Workforce Guidelines. National Mental Health Commission. <https://www.mentalhealthcommission.gov.au/lived-experience/lived-experience-workforces/peer-experience-workforce-guidelines>

similar to health literacy; please consider revising to ensure that deficit language doesn't inadvertently impact the tone of the document.

p.15 Paragraphs stating 'Initial assessment should consider....' – When reading this section, we reflected on the potential impacts on the aging partner of the person (where this circumstance is relevant), and also where the 'patient' may be the carer of an aging partner. We recognise that this circumstance is briefly noted in some of the detail later regarding domain factors for consideration. We believe that this is a very importance consideration in the context of older adults.

p.16 Table 1 provides a useful capture of the domains and various factors to consider. We believe they would benefit from a small number of additional factors. Currently, the clinical elements stand out much more than the social elements and the table lacks a real 'feel' for older adults and their unique circumstances that may impact mental ill-health. For example:

Domain 2 – burden of carer responsibilities when they themselves are aging. Social role value and changes in social roles, sense of purpose in life, and so forth may be significant triggers to the development of depression for older adults and suicidality.

Domain 3 – basic functions could include financial and administrative management

Domain 4 – past trauma/PTSD which we know can take many years to reveal itself or be 'diagnosed' (e.g., war services, emergency service first responder service, past experiences of abuse). We also understand that receiving a serious physical health diagnosis is an important trigger to thoughts of suicide in older adults.

Domain 6 – the wording here implies that various circumstances are current one. However, given the focus population, many of the circumstances listed may be part of long and complex history that may go back decades.

Domain 8 - As a general comment here and across the document, there is virtually no mention of older adults from CALD, Aboriginal and Torres Strait Islander, refugee, or LGBTIQI populations. The issues of trauma experiences as part of their life-course are likely to be of particular importance for these populations. Problems with trust in systems is a well-known phenomenon in these populations, largely because of historical and current issues of stigma, discrimination, abuse and trauma perpetrated within these systems. Understanding this from a lived experience is incredibly important to us. It is one of the reasons why we have concern about the tone of the document and this domain seeming to be predominantly about 'reluctance' by the person.

p.17 In the Overarching rules section, 3rd dot point – You mention information collected from various people. Where you state 'other informants', we wonder if you could give examples here. Our experience is that, for many older adults with mental ill-health who may have experienced years of marginalisation or social isolation and have no family, neighbours or other community members, Meals on Wheels visitors, etc may be the only people they know and who know of them.

p.18 The last dot point on this page should be strengthened to clarify what you mean by 'personalised assessment'. We suspect that you are alluding to the importance of social factors and history for the individual, as per those comments we have made above re Table 1.

p.21 Domain 2 - The statement about 'context of information' regarding the other 7 Domains is such an importance point here. Should this be bolded? Given the strong links between particular factors pertinent to older adults (receiving a diagnosis of a serious physical health condition and loss of spouse/partner), we wonder if these should be flagged on this page too?

p.24 Domain 4 – We wonder if you also need to say something about the volume of physical health co-morbidities and their potential cumulative impacts? Regarding the ratings, we wonder if the person's sense of control and self-efficacy to manage these conditions should also be considered here?

p.26 Domain 5 – Based on our recent national research on engagement and disengagement (The Missing Middle Report⁴), we also think it is important for the assessment to consider reasons for disengagement from services.

p.27 Domain 6 – It is somewhat disappointing that this Domain which focuses on social and environmental stresses doesn't have any Practice point detail. The factors listed as dot points offer a rich source of ideas for practice points. We suggest 'Trauma' could be expanded to meet this need. Or perhaps an example scenario that captures the life-course, history, and contextual factors that have already been flagged. I can think of many and feel certainly that your committee has a wealth of expertise to identify examples. My own example is of a parent in his late 80s, former police officer, longstanding PTSD issues, recent widow, living alone in rural area with declining physical health with a number of 'new' physical health diagnoses, who is now experiencing nightmares again, largely recalling the 'bad' cases from his early police career. The history and context really helps to explain what is going on with his current mental health decline.

Also, in the first paragraph, we suggest you add the word 'risk' to 'increased symptom severity....'

The dot point regarding victimisation or trauma could mention war and refugee experiences as examples? The dot point about socioeconomic disadvantage could give use and access to technology as an example?

p.28 Domain 7 – The information on this page feels 'under-developed'. For older adults, the role of family and other informal supports is very important, given it often involves intimate relationships that may have spanned decades. Death of primary carer or spouse, for example, is so significant for this population and has wide-reaching implications and impacts for the person re placement, support, community connections, etc. Again, it is disappointing that this important domain doesn't possess a Practice Point section.

p.29 Domain 8 – We note that technology is not mentioned in the information on this page. Time and time again, we hear from our members who are older adults that services like the NDIS and the Carer Gateway of inaccessible to them because they are not 'digital natives'. This is not an issue of 'motivation' as such; it is likely an access and literacy issue?

p.31 We note that resources and service options specific to CALD populations and older adults with complex communication needs are not mentioned in the list of dot points here?

p.32 Care appropriateness – should this list also flag primary supports/carers?

p.33 Regarding your description of self-management services, this seems to disproportionately focused on online services and examples. Given the above comments about older adults and technology, we wonder whether this section needs some revision?

We also note that the role of community pharmacists isn't mentioned in the document? Like GPs, they are often a primary source of information and advice about medications, self-management, etc.

We suggest the dot point about peer support could be expanded to include '(formal and informal groups and individual peer support)'. We know that there is a rich and diverse network of self-management support and exchange of self-care ideas happening as a result of peer interactions in the community! The established literature stresses the importance of groups and interpersonal peer exchange, in particular, for helping people to not feel alone and for sharing information about how to apply health professional advice to their daily lived circumstances.

p.35 Level 3 – We suggest that adding 'navigation support' may be of value here, particularly has this level signals in increase in the number of issues and their intensity, and a potential decline in the

⁴ Kaine, C. & Lawn, S. (2021) The 'Missing Middle' Lived Experience Perspectives Lived Experience Australia Ltd: Marden, South Australia, Australia. <https://www.livedexperienceaustralia.com.au/missingmiddlemedia> or https://www.livedexperienceaustralia.com.au/files/ugd/907260_8b2ad57fd3e8494080e609c7f82281d4.pdf

person's capacity to navigate or manage them. Navigation support is more than care coordination, and it may also include navigation support to ageing primary carers too.

p.36 Level 4 – the dot point about 'Support to minimise functional impairment' could be clearer regarding who might deliver this. Allied health professionals such as physiotherapists, exercise physiologists, dietitians, and occupational therapists could be mentioned here? Peer workers could also be mentioned, given an important aspect of their role is often to 'walk alongside' the person to help them operationalise their goals and the advice provided by health professionals.

Also, should allied health professionals also be listed alongside GPs regarding the 'comprehensive physical health assessment' dot point?

p.44 Section 3 Progress Monitoring – Regarding who should monitor progress, we note that you have not mentioned that the consumer also does this. In how the information is currently written, the consumer is merely a recipient of health professional expertise. Lived experience from the consumer perspective is also important 'expertise' that is important when evaluating progress of treatments and interventions; indeed, it is central to it!

p.45 Following on from the above comment, it would be good to expand the Practice Point about use of outcome and experience measures. We have recently completed research with mental health consumers about their positive experiences of these measures. This research was conducted with the Australian Mental Health Outcomes and Casemix Network (AMHOCN) and the results clearly identify how consumers use such measures actively as part of self-management too. The report on this research will be available shortly from <https://www.livedexperienceaustralia.com.au/research> .

Contact

We would be very pleased to provide further clarification around any of the points raised or further inform the discussion.

Please feel free to contact should you wish to discuss any points raised in this submission. We hope that the points raise here are of value to you in finalising this importance work ready for next steps in implementation.



Professor Sharon Lawn
Board Chair and Executive Director
Email: slawn@livedexperienceaustralia.com.au
Mobile: 0459 098 772