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Dear Eleni

Review of CHS Guideline for Managing Functional Neurological Disorders in Adults and Children

This letter has been prepared by the ACT Mental Health Consumer Network (the Network) in response to the invitation from the Canberra Health Services (CHS). It incorporates verbal and written feedback received from consumers¹ in relation to the CHS Guideline for Managing Functional Neurological Disorders in Adults and Children (the Guideline). The Network welcomes the invitation to provide feedback on the Guideline.

Consumers highlighted the following issues for consideration and review:

1. The Guideline is highly technical and may be difficult for consumers without clinical knowledge to review meaningfully. A plain-language supporting document should be provided alongside technical guidelines during consumer

¹ The Network uses the term 'consumer' because it is the established and widely understood descriptor across ACT legislation, policy frameworks and advisory structures, ensuring clarity and consistency in our systemic advocacy. At the same time, we recognise that people with lived experience do not all identify with the same language, and that terms such as 'people with lived experience' and 'peer' are increasingly used in contemporary contexts were relevant. Our approach is to retain 'consumer' where required for system engagement, while respecting individuals' right to self-identify in the way that best reflects their experience. This supports inclusion, aligns with national lived experience guidance, and maintains the Network's authority and effectiveness within the mental health system.

consultation to explain key terminology and context and enable informed feedback.

2. Consumer involvement should be clearly reflected throughout the assessment and information-gathering process. Section 1 – Positive diagnosis of FND (p. 4) states that a positive diagnosis should be communicated to the consumer at the time of diagnosis, while Section 2 – Multidisciplinary management of FND (p. 4) recognises the consumer as an active participant in multidisciplinary care. The principle of consumer-centred communication and active consumer participation should be applied consistently from the assessment stage onwards, with opportunities to understand the process, clarify information and contribute to how their experiences are understood.
3. Clear, appropriate and consistent communication is particularly important during history taking and assessment. Section 3 – History Taking (p. 6) appropriately emphasises allowing consumers time to describe their symptoms and feel heard. FND can include cognitive changes, fatigue, and speech or word-finding difficulties (Section 1 – Symptoms of FND, p. 3), which for some consumers may affect communication or participation in assessment. Consumers noted that clear, consistent and calm communication can support meaningful participation in the assessment process, whereas unclear or inconsistent communication may affect a consumer's ability to explain their experiences fully and accurately. Communication should therefore be adapted where needed, with information provided clearly, consistently and in a reassuring manner, recognising that consumers may be better able to describe their experiences and symptoms when they feel comfortable and supported during the assessment.
4. The emphasis on consistent language, documentation and handovers across the multidisciplinary team in Section 3 – Assessing for positive symptoms of FND (p. 6) is positive. However, it is unclear how this consistency will be achieved across different practitioners and disciplines. Specific FND training and/or common practice guidance for MDT members should be included. Greater transparency is also needed so that consumers understand the roles and approaches of different team members and, where appropriate, how relevant information is shared between them.
5. Section 3 – Assessing for positive symptoms of FND (p. 6) also directs clinicians to explain their actions and highlight normal findings to promote

transparency and build consumer confidence. The same principle should extend to abnormal, unexpected or other clinically significant findings, with clear explanations of what they mean and what will happen next. This is particularly important because the Guideline requires clinicians to assess for coexisting conditions even with a known FND diagnosis, and Section 4 – Differential diagnosis (p. 8) confirms that FND does not rule out other underlying disorders.

6. Finally, approaches focused on positive clinical signs, reinforcement, or directing attention towards or away from symptoms may affect consumers differently. Section 3 – Assessment of FND (pp. 5–6) identifies symptom-focused attention as a possible maintaining factor and refers to distraction techniques and demonstrating symptom reversibility. These approaches should remain individualised and responsive to the consumer's experience, with the approach reviewed or adapted where it increases distress or negatively affects engagement with care.

If you have any questions or require further clarification regarding this feedback, please do not hesitate to contact us on (02) 6230 5796 or executive@actmhc.org.au.

Thank you once again for the opportunity to provide feedback on the Procedure. We look forward to receiving further consultation requests in future. Consumers value being heard and look forward to seeing how their perspectives are reflected in the final approach.

Yours sincerely



Dalane Drexler
Chief Executive Officer