

Have Mental Health Services Met the Expectations of People With Neurodevelopmental Disabilities? 'Yes, No or I Don't Know'

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Dear Sir,

People with neurodevelopmental disabilities (NDD), such as intellectual disability and autism, often present with challenging and complex mental health problems. These can be inconspicuous at bedside and accompanied by exhaustive lists of complaints from carers. Understanding the broader picture and providing effective intervention demand extensive resources, involving the coordination of family, legal guardian, disability support and multidisciplinary health services. As clinicians attempt to navigate through these systems and due processes, however, the patient is often left unheard.

Among the many facets of patient-doctor relationship, there lies a consumer and service provider. This interaction, which places less emphasis on diagnoses and more on service experience, can be formatively measured through a consumer survey. In 2015, the Your Experience of Service (YES) survey, funded by the Australian

Government, was developed for mental health services. The recovery-oriented instrument measures how the service made a difference to consumer, provided information and support, valued individuality, supported active participation, and ensured safety, respect and fairness.¹ With growing demand for expanding mental health services, the survey is obtained routinely to substantiate care planning and funding decisions from the local clinical to federal governance. The recent Disability Royal Commission has also reiterated the importance of collecting and analysing data on health care and needs for the development of sound health policy.² Despite this, consumers with NDD have no comparable means of appraising the quality of their care.

Implementing a survey for people with NDD is often received with resistance due to the communication barrier. However, capturing the consumer perspectives can be reliable and meaningful. Questions can be modified to match the intellectual level, which can be ascertained from prior records or a brief cognitive screen. Rank-based response (a rating out of 10) can be substituted with closed-ended questions (i.e. 'yes, no, I don't know') followed by open-ended enquiry.³ Language level can be set at basic proficiency. The formative process should also be complemented with assistance of the carer, sufficient time, suitable environment and communication aid (e.g. visual analogue scale).

At present, people with NDD are passive recipients of generic mental health service, which is frequently inadequate for their complex needs.

The resultant consumer experiences probably resonate with these shortcomings and are frequently ensued by echoes of frustrated clinicians. Having the appropriate survey and systematic process (see Figure) to express these views are critical for refining the service quality, bridging the relationship among stakeholders and, ultimately, meeting the expectations of people with NDD.

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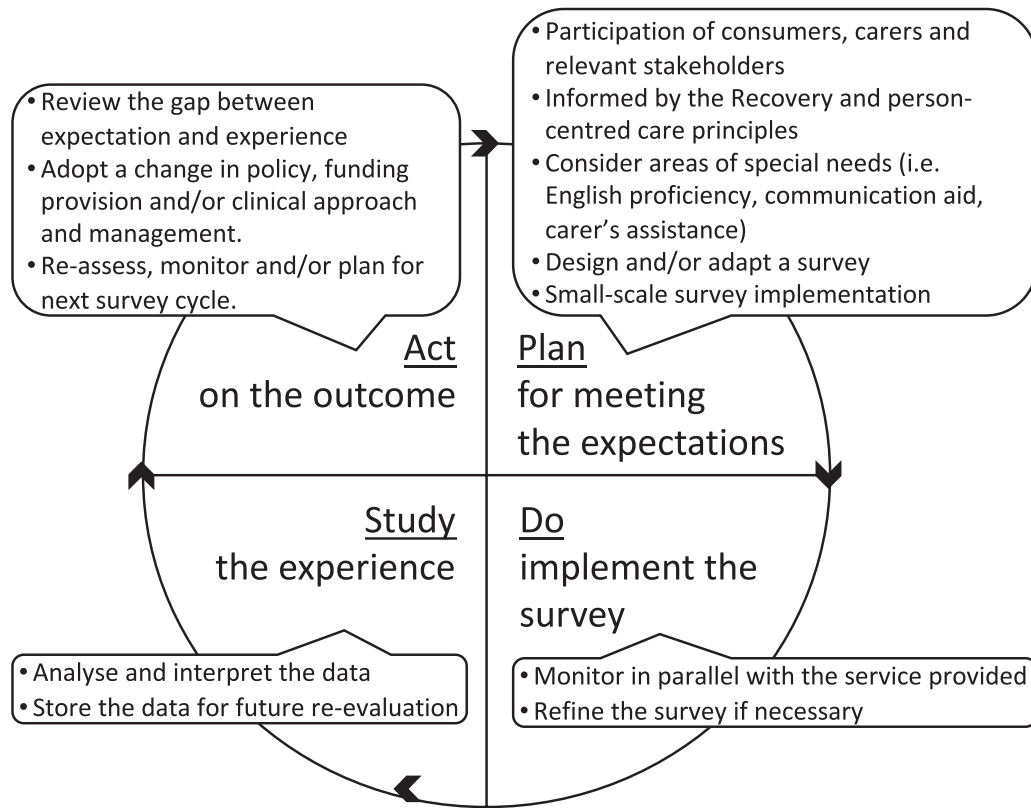


Figure. Adaptation of the Plan-Do-Study-Act quality improvement model⁴ for developing and implementing a consumer experience survey for people with neurodevelopmental disabilities.