



Improving the Journey Before, During and After Diagnosis of a Neurodevelopmental Condition: Suggestions from a Sample of Australian Consumers and Professionals

Kiah Evans^{1,2} · Bahareh Afsharnejad^{1,3} · Amy Finlay-Jones^{1,2} · Jenny Downs¹ · Elissa Strumpher¹ · Jacinta Freeman¹ · John Wray² · Andrew J. O. Whitehouse^{1,2} · Narelle Mullan¹

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Abstract

Objectives The current study used a transdiagnostic approach to explore experiences of consumers and professionals on how the process of assessing and diagnosing neurodevelopmental conditions can be improved.

Methods Individuals with personal and/or professional experience of this clinical pathway were invited to complete an online survey. A convenience sample of 117 Australian participants provided qualitative data describing how to improve this clinical pathway, including 71 consumers and 53 professionals (seven participants held both roles). Descriptive statistics were used to summarize the characteristics of the participants and two researchers analyzed the qualitative responses using a template approach.

Results Participants described a five-stage “[journey](#)” spanning before, during and after diagnosis of a neurodevelopmental condition. They progressed through “[searching](#)” for an explanation, “[waiting](#)” for the diagnostic evaluation, “[investigating](#)” the signs and symptoms, “[knowing](#)” that their child has a neurodevelopmental condition and “[accessing](#)” support. Participants also suggested nine key improvements to this process that were named “[awareness](#)” through professional training and empathy, “[clearer pathways](#)” through professional checklists and plans, “[acceptable timeframes](#)” through reduced local waitlists, “[more holistic](#)” through assessment and supports, “[more collaboration](#)” through communication with key parties, “[stability and consistency](#)” through continuous and coordinated services, “[generic community programs](#)” through early needs-based support, “[understanding](#)” through meaningful diagnostic disclosure and “[addressing their needs](#)” through further targeted supports.

Conclusions The findings from this study provide a foundation for future work to improve the diagnostic journey for neurodevelopmental conditions through a collaborative effort between consumers, professionals, researchers and policy makers. These findings highlight the importance of a transdiagnostic and comprehensive clinical pathway that spans the entire journey, where supports are readily available to consumers before, during and after diagnosis. Further research is required to explore the experience of consumers and professionals from more diverse backgrounds, as a limitation of this study was that almost all participants were females and very few identified as belonging to a specific cultural group.

Keywords Assessment · Diagnosis · Neurodevelopmental Disorders · Quality Improvement · Support Needs · Transdiagnostic

✉ Kiah Evans
kiah.evans@uwa.edu.au

¹ Telethon Kids Institute, Northern Entrance - Perth Children’s Hospital, 15 Hospital Ave, Nedlands, WA 6009, Australia

² University of Western Australia, 35 Stirling Hwy, Crawley, WA 6009, Australia

³ Curtin University, Kent St, Bentley, WA 6102, Australia

Neurodevelopmental conditions (NDCs) include a diverse range of diagnoses that typically emerge in early childhood, affect the brain and impact functioning in a variety of domains (American Psychiatric Association, 2013; Morris-Rosendahl & Crocq, 2020; World Health Organization, 2018). NDCs are usually diagnosed using established criteria, with the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and *International Classification of Diseases for Mortality and Morbidity*

Statistics (ICD-11) diagnostic labels summarized in Table 1 for the categories of autism, attention, communication, intellectual, learning, motor and prenatal alcohol (American Psychiatric Association, 2013; World Health Organization, 2018). Diagnosis is mostly based on behavioural signs, many of which are present across NDCs, and NDCs frequently co-occur so that symptoms often overlap (American Psychiatric Association, 2013; Licari et al., 2019; Morris-Rosendahl & Crocq, 2020; World Health Organization, 2018). Because of this, the diagnostic experience is often associated with challenges for consumers and professionals. Consumers are defined in this study as individuals who are diagnosed with an NDC and their caregivers. Professionals are defined in this study as allied health or medical clinicians, educators and other paid persons who deliver services related to NDCs.

Challenges experienced by consumers and professionals include difficult or disappointing encounters, inaccessible information, insufficient expertise, delays, deficit focused language, stigma and inadequate supports. These challenges have resulted in feelings such as confusion, fear, frustration, helplessness, grief, guilt, stress and dissatisfaction (Alonso Soriano et al., 2015; Boshoff et al., 2019; Corcoran et al., 2017; Domeij et al., 2018; Elangkovan & Shorey, 2020; Green et al., 2013). Increasingly, a transdiagnostic approach is being advocated within clinical and research practice to encourage early identification and intervention, ensure differential and co-occurring diagnoses are considered, promote holistic support needs being identified and addressed, minimize

stigma, enhance adherence with clinical guideline recommendations and share clinical knowledge and resources (Bell et al., 2016; Bower & Elliott, 2020; Dadds & Frick, 2019; Finlay-Jones et al., 2019; Green et al., 2013; Licari et al., 2019; National Health & Medical Research Council, 2012; Whitehouse et al., 2018).

Whilst previous research has examined the diagnostic experiences of specific NDC categories (Alonso Soriano et al., 2015; Boshoff et al., 2019; Corcoran et al., 2017; Domeij et al., 2018; Elangkovan & Shorey, 2020), examining this topic through a transdiagnostic framework would assist to integrate this body of knowledge. An important scientific method to do this is qualitative research, which provides the advantage of allowing consumers and professionals to voice their own experiences of navigating the healthcare system and understanding of how clinical service delivery models for NDCs can be improved (Portney & Watkins, 2015). Although qualitative research is suitable for exploratory designs that aim to describe experiences and find relationships, it is limited to forming a foundation for future quantitative research using an experimental design that aims to determine cause and effect (Portney & Watkins, 2015). Therefore, this study aimed to explore suggestions from a convenience sample of Australian consumers and professionals with NDC experience or expertise on how the process of assessing and diagnosing NDCs can be improved. This research is important as it is an important first step towards further research and innovations in clinical service delivery through a transdiagnostic framework.

Table 1 Neurodevelopmental conditions (NDC)—categories and associated conditions

NDC category	DSM-5 ^a diagnostic labels	ICD-11 ^b diagnostic labels
Autism	Autism spectrum disorder	Autism spectrum disorder
Attention	Attention-deficit/hyperactivity disorder	Attention deficit hyperactivity disorder
Communication	Communication disorders	Developmental speech or language disorders
Intellectual	Intellectual disabilities	Disorders of intellectual development
Learning	Specific learning disorder	Developmental learning disorder
Motor	Motor disorders	Developmental motor coordination disorder Stereotyped movement disorder Cerebral palsy ^c Primary tics or tic disorders
Prenatal alcohol	Other neurodevelopmental disorders (including associated with prenatal alcohol exposure)	Other specified neurodevelopmental disorders (including Neurodevelopmental syndrome due to prenatal alcohol exposure) Fetal alcohol syndrome Fetus or newborn affected by maternal use of alcohol

^aDSM-5 refers to the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (American Psychiatric Association, 2013)

^bICD-11 refers to the *International Classification of Diseases for Mortality and Morbidity Statistics*, 11th edition (World Health Organization, 2018)

^cCerebral palsy is listed under the *Diseases of the nervous system* chapter of the ICD-11, but is listed with conditions from the *Mental, behavioural or neurodevelopmental disorders* chapter for this study

Methods

Participants

English-speaking individuals living in Australia, with personal or professional experience of the NDC diagnostic clinical pathway, were invited to complete a survey that was distributed through social and research networks of the researchers and their organization. A convenience sample of

117 participants provided qualitative data in the survey. The sample included 71 consumers (Table 2) and 53 professionals (Table 3), including seven participants who were both a consumer and professional.

Procedures

This study employed a descriptive cross-sectional survey research design (Portney & Watkins, 2015). Data were

Table 2 Consumer demographics and neurodevelopmental conditions (NDC)-related expertise ($n = 71$)

Variable		<i>n</i>	%
Cultural and linguistic diversity of consumer ^a	Specified culture	6	8.5
	No specified culture	65	91.5
	Language other than English at home	9	12.7
Gender of consumer	Female	69	97.2
	Male	2	2.8
	Other	0	0.0
Relationship to individual with an NDC ^b	Self	3	4.3
	Parent	62	87.3
	Other	9	12.7
Age of consumer	Up to 39 years	28	39.4
	40–49 years	27	38.0
	50 years or above	15	21.1
Age of individual at NDC diagnosis ^c	0 < 2 years	24	24.7
	2 < 4 years	16	19.8
	4 < 6 years	16	19.8
	6 < 12 years	16	19.8
	12 < 18 years	4	4.9
Diagnosed with NDC category ^d	18 years or older	5	6.2
	Autism	29	40.8
	Attention	11	15.5
	Communication	16	22.5
	Intellectual	20	28.2
	Learning	12	16.9
Satisfaction with NDC diagnostic process ^e	Motor	35	49.3
	Prenatal alcohol	6	8.5
	Very unsatisfied	8	13.1
	Unsatisfied	14	23.0
	Neither satisfied or unsatisfied	7	11.5
	Satisfied	20	32.8
	Very satisfied	12	19.7

^aCultures specified included $n = 1$ each of Aboriginal Australian-Noongar, Anglo Saxon, Australian, Greek, Māori New Zealander and Muslim, whilst languages included $n = 1$ each of Dutch, Filipino/Tagalog, German, Italian, Macedonian, Noongar, Spanish and Te Reo Māori (multiple free text responses possible, $n = 4$ did not specify language)

^bOther consumers included foster carers, step-parent, grandparent and aunt (multiple selections and/or free text responses possible)

^cAlthough most consumers ($n = 63$) reported just one age of NDC diagnosis, diagnostic ages for multiple people and/or events were reported by six consumers, resulting in a total of 81 ages

^dMultiple selections possible

^eOnly participants who recalled the diagnostic process well or very well were included for this calculation ($n = 61$)

Table 3 Professional demographics and neurodevelopmental conditions (NDC)-related expertise ($n = 53$)

Variable		<i>n</i>	%
Cultural and linguistic diversity ^a	Specified culture	3	5.7
	No specified culture	50	94.3
	Language other than English at home	4	7.5
Gender	Female	50	94.3
	Male	3	5.7
	Other	0	0.0
Practice setting ^b	Hospital	8	15.1
	Community based clinic	10	18.9
	School	9	17.0
	Private practice	13	24.5
	Other	13	24.5
	Practice location ^c	Major city	33
Practice location ^c	Regional	19	35.8
	Remote	21	39.6
	Professional discipline ^d	Occupational therapist	5
Pediatrician		9	17.0
Physiotherapist		5	9.4
Psychologist		12	22.6
Speech pathologist		8	15.1
Teacher		7	13.2
Other		7	13.2
Duration of professional NDC experience	Less than 2 years	2	3.8
	2–10 years	17	32.1
	11–20 years	13	25.0
	More than 20 years	20	38.5
Professional NDC experience by category ^c	Autism	46	86.8
	Attention	42	79.2
	Communication	39	73.6
	Intellectual	50	94.3
	Learning	39	73.6
	Motor	41	77.4
	Prenatal alcohol	36	67.9

^aCultures included $n = 1$ each of Aboriginal Australian-Noongar, Italian and Malaysian, whilst languages included German ($n = 1$), Mandarin ($n = 2$) and unspecified ($n = 1$)

^bOther practice settings included funding provider, government agency, not-for-profit organization, university/research institution and home based

^cMultiple selections possible

^dOther professional disciplines included nurse, administrator, carer/support worker, interpreter and foster carer

collected through an anonymous online survey administered via REDCap. A copy of the Participant Information Form was available on the landing page, and a statement was included that undertaking the survey was an indication of informed consent. The survey was open between June 2018 and February 2020, coinciding with the National Disability Insurance Scheme (NDIS) roll-out in Australia (Australian Government, 2018). This transition from multiple state/territory disability systems to a single national disability system

heralded substantial changes to eligibility assessments, support plans and service provision of disability supports.

Measures

The survey (Supplementary File 1) asked participants to provide demographic details (including cultural and linguistic diversity and gender) and describe their NDC experience and expertise. Consumers were asked to provide their

age and relationship to the individual with an NDC, along with details of their NDC experiences, such as the age of individual at NDC diagnosis, the NDC category and their satisfaction with the NDC diagnostic process. Professionals were asked about their NDC experience and expertise, such as their practice setting and location, along with their discipline, duration of NDC experience and specific NDC categories with which they are experienced. The survey concluded with an open-ended textbox for the participant to share suggestions on how to improve the NDC diagnostic clinical pathway (Fig. 1).

Data Analysis

Responses to the demographic and NDC experience and expertise questions were analyzed in SPSS Statistics software (version 26) using descriptive statistics, including median, interquartile range (*IQR*) and frequency (*n* and %) (Portney & Watkins, 2015). De-identified qualitative responses were analyzed in QSR NVivo software (version 12) by two researchers using a template approach, a type of thematic analysis where a coding template is developed, applied and refined (Brooks et al., 2014). Both researchers became familiar with and coded the data against an initial template, which was refined in an iterative manner to identify themes. Although consideration was given to if a response was from a consumer and/or professional during this phase, other demographic characteristics of the participants was not utilized during the thematic analysis. One exception was that the full responses from any participants who identified as belonging to a specific culture and/or spoke a language other than English at home were reviewed once the final

thematic framework was established, and it was confirmed that no diversity-related themes were present. These initial themes were refined and described by the first author prior to confirmation by the second researcher to establish credibility. Other strategies to enhance trustworthiness included reporting on participant demographics to allow readers to determine similarities and differences to their local context, dense descriptions of themes with illustrative quotes from numerous participants and establishing the researchers' expertise and potential influence on the data (Krefting, 1991). Both researchers were proficient in qualitative data analysis, had clinical backgrounds in occupational therapy or psychology and had experience in researching experiences associated with NDCs. The second researcher also had lived experience of the NDC diagnostic clinical pathway as a neurodiverse individual diagnosed during adulthood and a mother of two individuals diagnosed with an NDC. The remaining authors engaged in peer examination of the results with their collective multidisciplinary clinical and research expertise related to NDCs (Krefting, 1991).

Results

Most consumers (Table 2) were mothers of an individual diagnosed with an NDC, whilst six were foster carers and three reported having an NCD diagnosis themselves (median = 42 years of age, *IQR* = 12). Only six consumers identified as belonging to a specific cultural group and only nine consumers spoke a language other than English at home. The median age at the time of NDC diagnosis was 4 years (*IQR* = 5.5) and multiple diagnostic categories were reported (median = 2, *IQR* = 1, most commonly motor and autism categories). At least a half of the consumers expressed satisfaction with the NDC diagnostic clinical pathway. Professionals (Table 3) were also predominantly females and they worked in a range of practice settings and locations. Only three professionals identified as belonging to a specific cultural group and only four professionals spoke a language other than English at home. Professionals were from a variety of allied health, medical and other disciplines, with approximately two-thirds reporting at least eleven years of experience working across a broad range NDC categories. Participants described a five-stage diagnostic “[journey](#)” and suggested nine key improvements to this process (Fig. 2).

Journey

The first stage was “searching” for an explanation for their early concerns through professional recognition and referral for a diagnostic evaluation. The second stage was “waiting” for the diagnostic evaluation to commence, a process that was typically longer when accessing the

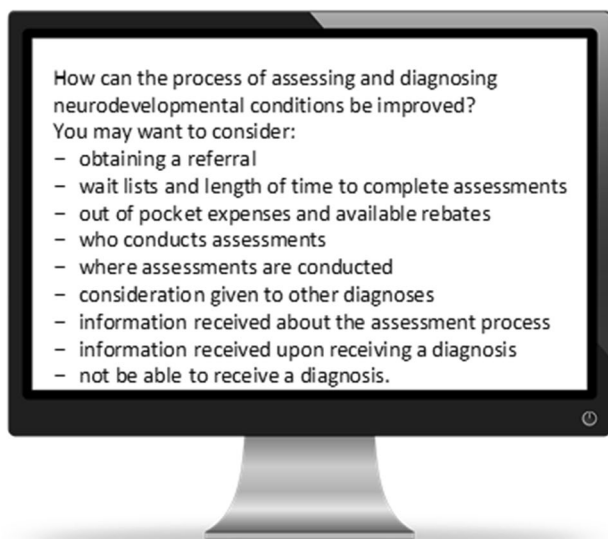


Fig. 1 Open-ended survey question and prompts. Note. Image of screen by mmi9 from Pixabay

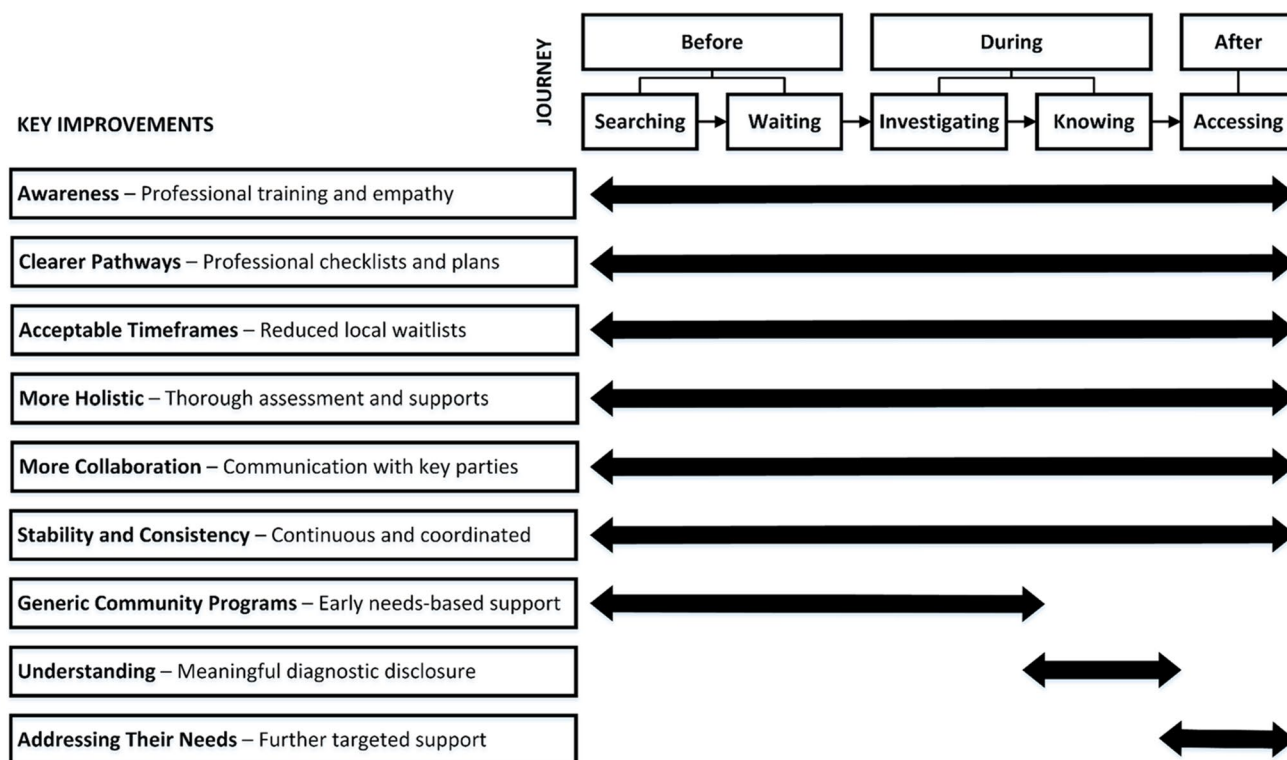


Fig. 2 The neurodevelopmental conditions (NDC) diagnostic journey and suggested areas of improvement

public health system. The third stage was “investigating” the signs and symptoms through a formal diagnostic evaluation. The fourth stage was “knowing” that their child has an NDC following disclosure of diagnostic outcome. The fifth stage was “accessing” support through securing funding and linkage with networks and services. Although these stages are described within a linear process, there is potential for stages to overlap or occur in alternative sequences.

Awareness

Participants explained that professional “awareness needs to be raised evenly across the state” about “what they might ‘see’ for each [NDC]”, diagnostic evaluation processes, post-diagnostic supports and funding options, such as “Medicare line items”. Awareness about empathetic communication was also needed, including “active listening to parents—not dismissing concerns or attributing them to parental inexperience or worry” and being “a little nicer” when asking questions. Awareness could be raised through making “affordable” professional training available.

Clearer Pathways

There was a suggestion that consumers receive “information ... about the assessment process”, ideally as “a list of the process in checklist form” at the time of referral. This would ensure consumers understood “what the process was and who to see”. Professionals involved in conducting diagnostic evaluations require “a ‘gold standard’ process that is consistently applied throughout the state” and “monitored”. It should “clearly outlin[e] which professionals have what responsibilities” and include an “approach [for] providing the information about diagnosis” and developing a “funding plan” after the diagnosis.

Acceptable Timeframes

Efforts to “reduc[e] the waitlist time” were recommended so that consumers have “the ability to see a [clinician] in an acceptable timeframe” to “allow timely diagnosis and access to services”, particularly “important early intervention”. Suggestions for improved timeframes include minimizing the “wait and see” approach, streamlining the wait periods for each specialist and assessment, “better funding of health professionals to complete assessments”, overcoming “patchy

availability of developmental services”, increasing access to “local providers” who possess the required “contextual and cultural understandings”, decreasing community paediatric caseloads and finding “some way of helping fund the cost of [private] assessments” to alleviate burden on the public system without it being “extremely costly” for consumers.

More Holistic

A “more holistic” assessment was encouraged, with “consideration given to other diagnoses” and psychosocial factors (such as “trauma”). Consumers should then be referred to “professionals trained in the relevant areas” for further specialist assessment if required to prevent “non-diagnosis” without a comprehensive transdiagnostic evaluation. Some participants advocated for “an integrated framework setting out broad pathways across community setting, based on functional needs assessments ... within a neurodevelopmental model”. Hence, all clinicians require “essential training” in the assessment and intervention options for all NDCs and relevant psychosocial factors.

More Collaboration

A need was described for “more collaboration between disciplines”, as “interdisciplinary communication and information sharing could be improved” to “work better together” and reach a “very high quality” level within teams and between “individual therapists”. Collaborative examples include “multiple professionals assessing your child together”, “each assessment should inform the others” and “we give the families an overall picture”. Greater collaboration “would help to make the process a little less stressful for the parents”, facilitate professionals “being effective and doing the best we can do” and allow the “workforce ... to expand and skilled practitioners can coach the new practitioners”. Clinicians also need to collaborate with key stakeholders across the “health, education and disability sectors”, ideally through an “agreed framework for data sharing ensuring assessment information is shared across assessment sites and that assessments are not duplicated unnecessarily”.

Stability and Consistency

It was identified that consumers need “continuous support” and a “coordinated approach” during “each difficult step” of the NDC diagnostic journey. A strategy to maintain “some stability and consistency” involved “assessments being completed in conjunction with primary therapist[s]” through eliciting their input because they “know the case well and are better able to notice changes”. Similarly, “ongoing therapeutic involvement with [the] assessing team” provides continuity where families can “realize [the] full benefit of

[the] relationships established in [the] assessment process”. Finally, “better coordination of care” through “a single point of reference for parents who are within the assessment/therapy process to guide them to services available” was suggested.

Generic Community Programs

A consumer need for “support availab[ility] in the community” through “generic community ... programs” whilst awaiting a diagnostic evaluation was raised. These programs may “alleviate need for further assessment in some cases, as well as identifying high priority cases” for “assessment and [specialist] referral”. There is optimism that the transition to NDIS will facilitate such programs, expressed with “Overall I feel with such great demand, we should be assessing less kids but providing therapy for more. Hopefully with NDIS, urgency for diagnosis will fade, as its association with funding becomes less significant”. However, further reform in education settings is required through shifting towards “more acknowledgement of ‘needs’ rather than diagnoses”.

Understanding

Diagnostic disclosure of NDCs was noted to require improvement so that consumers have an “understanding of what [it] means”. The feedback session at the end of the diagnostic evaluation needs to be delivered in a safe and “comforting” manner in-person, “assume a person knows nothing about how these things are diagnosed and they should explain every step”, allow enough time to help consumers “understand [the] diagnosis”, answer questions surrounding how the diagnosis may “affect the child’s future schooling / jobs / quality of life” and “explore ... options” for “where to go next”. Reports need to be written “objectively [and] accurately”, be “readable by families and still meaningful for other professionals who may become involved in providing services down the track” and be “more respectful of the differences and strengths of the individual”. Furthermore, “it is not enough to just explain a diagnosis” or provide a “non-diagnosis”, instead “families need strategies that they can apply immediately, even if it is just one thing that would have the biggest impact” to “better cope with the problems that they are facing”. Finally, diagnostic disclosure should “assist them in adapting to the new diagnosis and future interventions” and facilitate optimism, illustrated with “of course it’s going to be challenging but a bit of hope given can be a good thing”.

Addressing Their Needs

Participants felt that following an NDC diagnosis and “having established function and need, all children and their

carers should be entitled to services to assist in addressing their needs”. Examples of relevant and targeted supports included “funding”, “intervention”, “plans”, “books”, “counselling” or “parenting support”. It is important to schedule “another closely followed session to include support with ongoing referrals and paperwork required to access appropriate funding” and follow-up with funders and professionals for “confirmation of referral and then family engagement”.

Discussion

This qualitative survey explored suggestions from a convenience sample of 117 Australian consumers and/or professionals with NDC experience or expertise on how the process of assessing and diagnosing NDCs can be improved. Consistent with other international literature exploring the NDC diagnostic journey for specific NDCs (Alonso Soriano et al., 2015; Boshoff et al., 2019; Corcoran et al., 2017; Domeij et al., 2018; Elangkován & Shorey, 2020), participants sought a consistent and comprehensive clinical pathway that spans the entire diagnostic journey, from the time they are searching for answers until they have understood the diagnosis and are accessing help to address their needs. Whilst the five stages in this diagnostic journey were presented sequentially, many consumers experience multiple and overlapping diagnostic journeys. The developmental nature of these conditions, combined with variability in task demands faced across the life course, means that not all NDC diagnoses are evident in an individual at any one point in time. Consumers may find themselves at different stages in the diagnostic journey for different diagnoses, highlighting the importance of professionals conveying a sense of a shared diagnostic journey.

Congruent with this, it was suggested that the components along the clinical pathway be administered in a collaborative, coordinated, compassionate and informative manner. Importantly, participants felt the clinical pathway should be delivered holistically using a transdiagnostic model, with support tailored to individual needs rather than primary diagnosis. They felt that the clinical pathway also needs to be adequately resourced to ensure affordable assessment and support services with acceptable wait times. Transdiagnostic and community-based supports to address needs and guide consumers through the process were suggested during the earliest stages when concerns first emerged. Participants called for a paradigm shift within the clinical pathway, where consumers could access supports whilst awaiting a diagnostic evaluation, a scenario that has since become possible with the introduction of early intervention and supports for children and adults through the NDIS (Australian Government, 2018). Research within the broader mental health field provides encouraging support for transdiagnostic

interventions that can support consumers prior to diagnosis (Kennedy et al., 2019).

We identified perspectives that NDC assessment and diagnosis pathways need to be clearly articulated in diagnostic guidance documents and associated educational programs to raise awareness of the clinical pathway amongst consumers and professionals. Existing local and international clinical guidance documents cover assessing and diagnosing some NDCs in Australia (Blank et al., 2019; Bower & Elliott, 2020; National Health & Medical Research Council, 2012; Novak et al., 2017; Whitehouse et al., 2018) and work is currently planned to revise (attention and prenatal alcohol categories) or create (motor category, Licari et al., 2020) Australian guidelines. Whilst the Australian autism guideline (Whitehouse et al., 2018, p. 13) recognizes the importance of undertaking assessments “in the context of a broader neurodevelopmental and behavioural assessment”, other guidelines make more general recommendations such as undertaking a holistic assessment and considering differential diagnosis and co-occurring conditions (Blank et al., 2019; Bower & Elliott, 2020; National Health & Medical Research Council, 2012). The findings from this research highlighted the importance of NDC guideline developers clearly articulating a transdiagnostic approach where clinical guidance documents for other NDCs are considered.

Limitations and Future Research

A strength of this study was the transdiagnostic and consultative research design that allowed an exploration of the lived and professional experiences of the NDC diagnostic clinical pathway before and during the NDIS roll-out in Australia. These experiences spanned several diagnostic categories, practice settings and disciplines. However, sampling bias limited our ability to examine the diagnostic journey experienced in relation to specific NDCs, geographical regions, cultural and linguistic diversity, socioeconomic status or during discrete time periods. The findings are subsequently not representative of the diversity of populations in Australia or internationally, with the voice of minority populations, including First Nations people, underrepresented (amplified by the use of an English-language survey only).

This is particularly important, as First Nations people and other culturally and linguistically diverse groups are less able to access healthcare services to identify developmental concerns and receive early intervention (Garg et al., 2017; Overs et al., 2017). Although consumers and professionals who did not identify as female were eligible to participate, we had very few males ($n=5$) and no one who had another gender volunteer for the study. Hence, it is unknown if males and gender diverse individuals share a similar journey or suggestions to improve the clinical pathway. In addition, it was beyond the scope of this study to explore the

experiences of children with personal experience of the NDC diagnostic clinical pathway, or consumers who have experience of this phenomena but the outcome was not an NDC diagnosis.

Future research that proactively recruits a more diverse population, and subsequently explores these areas of diversity, is recommended. This could include more in-depth qualitative research studies using purposive sampling, where interviews or focus groups would allow the thematic framework to be investigated further through seeking more detailed experiences, testing the relationships between themes and applying a greater range of strategies to achieve trustworthiness (Krefting, 1991). Furthermore, although this research was informed by a consumer reference group and participants were consulted to share their experience, this study was limited in that it did not progress beyond mid-levels of consumer participation (Roper et al., 2018). Future research that is led or co-led by individuals diagnosed with NDCs is recommended to co-produce knowledge and recommend service improvements. Another limitation of this study was that the reliance on qualitative data allowed subjective experiences to be explored, but did not allow statistical relationships between experiences and outcomes to be examined. Future quantitative survey research is recommended to expand upon this study, eventually leading to experimental research designs to evaluate the effectiveness of innovations to service delivery (Portney & Watkins, 2015).

The findings from this study provide a foundation for further work to improve the NDC diagnostic journey through a collaborative effort between consumers, professionals, researchers and policy makers. Whilst this study occurred in Australia, the findings may be applicable to a broader audience. These findings highlight the importance of a transdiagnostic and comprehensive clinical pathway that spans the entire NDC diagnostic journey, where supports are readily available to consumers before, during and after a diagnostic evaluation.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s41252-022-00289-z>.

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Author Contribution KE: collaboratively designed the study, executed the study, analyzed the quantitative and qualitative data and wrote the paper. BA: analyzed the qualitative data and collaborated with writing of the study; AFJ: collaboratively designed the study, assisted with the data analyses and collaborated with editing of the final manuscript; JD: collaboratively designed the study, assisted with the data analyses and collaborated with editing of the final manuscript; ES: assisted to execute the study, assisted with the data analyses and collaborated with editing of the final manuscript; JF: collaboratively designed the study, assisted to execute the study, assisted with the data analyses and collaborated with

editing of the final manuscript; JW: collaborated with the design and editing of the final manuscript; AJOW: collaborated with the design and writing of the study; and NM: collaboratively designed the study, assisted with the data analyses and collaborated with editing of the final manuscript. All author approved the final version of the manuscript for submission.

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Declarations

Ethics Approval All procedures involving human participants were in accordance with the ethical standards of the institutional and national research committees and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethical approval was granted by the University of Western Australia (2019/RA/4/20/4314).

Informed Consent Online informed consent was obtained from all consumers and professionals involved in the study prior to commencing the survey. A statement was included upon accessing the survey link that undertaking the survey was an indication of informed consent and participants completed the survey anonymously. The Participant Information Form advised that information from this project may be published in summary reports, conference presentations, media and academic publications. Consent was not obtained to make the full dataset of individual participant data available.

Conflict of Interest The authors declare no competing interests.

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References

- Alonso Soriano, C., Hill, E. L., & Crane, L. (2015). Surveying parental experiences of receiving a diagnosis of developmental coordination disorder (DCD). *Research in Developmental Disabilities, 43–44*, 11–20. <https://doi.org/10.1016/j.ridd.2015.06.001>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. Arlington, VA: Author.
- Australian Government. (2018). *National Disability Insurance Scheme Act 2013*. Compilation No. 9. Retrieved from <https://www.legislation.gov.au/Details/C2018C00276>
- Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., Reynolds, J. N., & Racine, E. (2016). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics, 9*(1), 65–77. <https://doi.org/10.1093/phe/phv012>

- Blank, R., Barnett, A. L., Cairney, J., Green, D., Kirby, A., Polatajko, H., Rosenblum, S., Smit-Engelsman, B., Sugden, D., Wilson, P., & Vinçon, S. (2019). International clinical practice recommendations on the definition, diagnosis, assessment, intervention, and psychosocial aspects of developmental coordination disorder. *Developmental Medicine and Child Neurology*, *61*(3), 242–285. <https://doi.org/10.1111/dmcn.14132>
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2019). A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis. *Health & Social Care in the Community*, *27*(4), e143–e157. <https://doi.org/10.1111/hsc.12691>
- Bower, C., & Elliott, E. (2020). *Australian guide to the diagnosis of fetal alcohol spectrum disorder (FASD)*. Australian Government Department of Health.
- Brooks, J., McCluskey, S., Turley, E., & King, N. (2014). The utility of template analysis in qualitative psychology research. *Qualitative Research in Psychology*, *12*(2), 202–222. <https://doi.org/10.1080/14780887.2014.955224>
- Corcoran, J., Schildt, B., Hochbrueckner, R., & Abell, J. (2017). Parents of children with attention deficit/hyperactivity disorder: A meta-synthesis, part II. *Child & Adolescent Social Work Journal*, *34*(4), 337–348. <https://doi.org/10.1007/s10560-017-0497-1>
- Dadds, M. R., & Frick, P. J. (2019). Toward a transdiagnostic model of common and unique processes leading to the major disorders of childhood: The REAL model of attention, responsiveness and learning. *Behaviour Research and Therapy*, *119*, 103410. <https://doi.org/10.1016/j.brat.2019.103410>
- Domeij, H., Fahlström, G., Bertilsson, G., Hultcrantz, M., Munthe-Kaas, H., Gordh, C. N., & Helgesson, G. (2018). Experiences of living with fetal alcohol spectrum disorders: A systematic review and synthesis of qualitative data. *Developmental Medicine & Child Neurology*, *60*(8), 741–752. <https://doi.org/10.1111/dmcn.13696>
- Elangkovan, I. T., & Shorey, S. (2020). Experiences and needs of parents caring for children with cerebral palsy: A systematic review. *Journal of Developmental and Behavioral Pediatrics*, *41*(9), 730–739. <https://doi.org/10.1097/DBP.0000000000000880>
- Finlay-Jones, A., Varcin, K., Leonard, H., Bosco, A., Alvares, G., & Downs, J. (2019). Very early identification and intervention for infants at risk of neurodevelopmental disorders: A transdiagnostic approach. *Child Development Perspectives*, *13*(2), 97–103. <https://doi.org/10.1111/cdep.12319>
- Garg, P., Ha, M., Eastwood, J., Harvey, S., Woolfenden, S., Murphy, E., Dissanayake, C., Jalaludin, B., Williams, K., McKenzie, A., Einfeld, S., Silove, N., Short, K., & Eapen, V. (2017). Explaining culturally and linguistically diverse (CALD) parents' access of healthcare services for developmental surveillance and anticipatory guidance: Qualitative findings from the 'Watch Me Grow' study. *BMC Health Services Research*, *17*(1), 1–12.
- Green, S. E., Darling, R. B., & Wilbers, L. (2013). Has the parent experience changed over time? A meta-analysis of qualitative studies of parents of children with disabilities from 1960 to 2012. In S. N. Barnartt & B. M. Altman (Eds.), *Disability and intersecting statuses* (pp. 97–168). Emerald Group Publishing Limited.
- Kennedy, S. M., Bilek, E. L., & Ehrenreich-May, J. (2019). A randomized controlled pilot trial of the unified protocol for transdiagnostic treatment of emotional disorders in children. *Behavior Modification*, *43*(3), 330–360.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, *45*(3), 214–222.
- Licari, M., Finlay-Jones, A., Reynolds, J. E., Alvares, G. A., Spittle, A. J., Downs, J., Whitehouse, A., Leonard, H., Evans, K., & Varcin, K. (2019). The brain basis of comorbidity in neurodevelopmental disorders. *Current Developmental Disorders Reports*, *6*(1), 9–18. <https://doi.org/10.1007/s40474-019-0156-7>
- Licari, M., Williams, J., Impact for DCD Team. (2020). *National survey evaluating the impact of developmental coordination disorder in Australia: Summary of results*. Telethon Kids Institute.
- Morris-Rosendahl, D. J., & Crocq, M. (2020). Neurodevelopmental disorders: The history and future of a diagnostic concept. *Dialogues in Clinical Neuroscience*, *22*(1), 65–72. <https://doi.org/10.31887/DCNS.2020.22.1/macroqc>
- National Health and Medical Research Council. (2012). *Clinical practice points on the diagnosis, assessment and management of attention deficit hyperactivity disorder in children and adolescents*. Commonwealth of Australia.
- Novak, I., Morgan, C., Adde, L., Blackman, J., Boyd, R. N., Brunstrom-Hernandez, J., Cioni, G., Damiano, D., Darrach, J., Eliasson, A., de Vries, L., Einspieler, C., Fahey, M., Fehlings, D., Ferriero, D., Feters, L., Fiori, S., Forssberg, H., Gordon, A., . . . Badawi, N. (2017). Early, accurate diagnosis and early intervention in cerebral palsy: Advances in diagnosis and treatment. *JAMA Pediatrics*, *171*(9), 897–907. <https://doi.org/10.1001/jamapediatrics.2017.1689>
- Overs, B., Woolfenden, S., Williams, K., Jalaludin, B., Axelsson, E., Dissanayake, C., Descallar, J., Harvey, S., Beasley, D., Murphy, E., Eapen, V., and the 'Watch Me Grow' Study Group. (2017). Predictors of developmental surveillance completion at six months of age in south western Sydney. *Child: Care, Health and Development*, *43*(2), 307–315.
- Portney, L. G., & Watkins, M. P. (2015). *Foundations of clinical research: Applications to practice* (3rd ed.). F.A. Davis.
- Roper, C., Grey, F., & Cadogan, E. (2018). *Co-production: Putting principles into practice in mental health contexts*. University of Melbourne.
- Whitehouse, A., Evans, K., Eapen, V., & Wray, J. (2018). *A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia*. Cooperative Research Centre for Living with Autism.
- World Health Organization. (2018). *International classification of diseases for mortality and morbidity statistics (ICD-11)*. World Health Organization.

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