



**RESEARCH** 

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MARIE HUSKA (D)
ALEXANDRA DEVINE (D)
LUCIO NACCARELLA (D)

\*Author affiliations can be found in the back matter of this article

#### **ABSTRACT**

**Introduction:** Difficulty accessing services and supports during critical life transitions are recognised as contributing to unacceptably poor life outcomes for Autistic Australians. The National Disability Insurance Scheme (NDIS) provides funding for eligible individuals with permanent and significant disability to purchase services and supports to meet their needs and aspirations, holding the potential to improve transition support for the third of all NDIS participants with a primary diagnosis of autism.

**Aim:** This paper reports on research to better understand the NDIS policy and practice environment supporting Autistic youth during transition to life-after-school.

**Methodology:** Using a qualitative approach, individual interviews were completed with four Autistic NDIS participants aged 18–21 in 2019. Separate interviews were conducted with four family members nominated by each of the youth interview participants. Thematic analysis explored how Autistic youth and those who support them, experienced NDIS facilitated transition to life-after-school.

**Results:** Two key themes emerged: 1) Transition journeys: aspirations and experiences, and 2) Navigating the NDIS in pursuit of better transition experiences.

**Conclusion:** The research highlights a cross-sector, person and family-centred approach is needed to address barriers and build systems literacy for the NDIS to better meet the transition requirements of Autistic Australian youth.

## **CORRESPONDING AUTHOR:**

### Marie Huska

University of Melbourne, Australia

marie.huska@unimelb.edu.au

#### **KEYWORDS:**

National Disability Insurance Scheme (NDIS); autism; youth; family; transition to life-afterschool; lived experience

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### **INTRODUCTION**

In Australia, the National Disability Insurance Scheme (NDIS) represents an unprecedented shift in how eligible people with disability access disability services and supports. Supporting Australia's commitments under the Convention on the Rights of Persons with Disabilities [CRPD], (2006) and governed by the NDIS Act, 2013 (Cth), it provides services and supports considered reasonable and necessary, i.e., relate to a participant's disability; represent value for money that aren't day-to-day living costs; considered likely to be effective in participants' pursuit of goals and aspirations. Additionally considered are participants' access to other supports: informal (family, friends, community) and other formal supports through systems such as health, education and employment. Included within the NDIS are transition to life-after-school services and supports for Autistic youth, i.e., supports to move in a gradual and planned way from the Autistic youth's role as a school student through to their next stage of life as a young adult. This multi-layered environment in which Autistic youth NDIS participants are interacting, is directly or indirectly influencing their transition to life-after-school outcomes.

As of 2018, of the 4,400,000 Australians living with disability, 205,200 had a formal diagnosis of autism, the majority of whom were aged 5–24 years (ABS, 2018a). Over 73% required support with cognitive and emotional tasks, while 42% required support in communication and social engagement (ABS, 2018b). Though not all will gain access, for those that do, the NDIS has the potential to support Autistic Australian youth navigate the challenges of school to life-after-school transition. The limited understanding of how Autistic youth NDIS participants are currently being supported, however, undermines efforts to inform NDIS policy and practice to optimise supports for their successful transition.

To address this gap, research was undertaken in Victoria – Australia's second most populous state, to understand the school to life-after-school transition aspirations and experiences of Autistic youth NDIS participants, and how the NDIS may influence these experiences. We start with a synthesis of the relevant literature on key life transitions for Autistic youth within the context of the NDIS. We consider how the ecological models described by Bronfenbrenner and Ceci (1994) and Danforth (2021), can facilitate an understanding of the multi-layered environment influencing Autistic youth NDIS participants' transition to life-after-school. Following a brief methodological overview, we present results reflective of two overarching themes: 1) Transition journeys: aspirations and experiences, and 2) Navigating the NDIS in pursuit of better transition experiences. We conclude that NDIS policy and practice needs to consider this life transition phase as requiring its own approach, incorporating research evidence into practice, sensitive to the person and family-centred needs of Autistic participants, and working collaboratively across sectors to deliver positive outcomes for Autistic youth transitioning to life-after-school.

#### TRANSITIONING FROM SCHOOL TO LIFE-AFTER-SCHOOL

Successful transition from school to life-after-school is critical to economic and social participation in adulthood. Evidence indicates that insufficient supports during this period exacerbate the unique developmental, health and mental health challenges often experienced by Autistic youth (Bennett et al., 2018; Commonwealth of Australia [CoA] 2022; Davignon et al., 2018; Hatfield et al., 2018; Wehman et al., 2014; Wisner-Carlson et al., 2020). Within this, growing evidence identifies an increased prevalence of co-occurring mental health concerns such as anxiety and depression, with associated elevated risks for self-harming and suicidal behaviours (Bennett et al., 2018; Cassidy et al., 2018; Culpin et al., 2018; Lai et al., 2019; Mandell, 2018; Veenstra-VanderWeele, 2018). Underlying discrimination and 'the soft bigotry of low expectations' (CoA, 2022, p.212) compounds 'a culture of low expectations for students with disability in Australian schools' (Parliament of Victoria, 2018, p.xvi), denying Autistic youth the required resources and supports to actively participate in transition planning and pursue their post-school aspirations (Parliament of Victoria, 2018; US Government Accountability Office [USGAO], 2016).

Indeed, research highlights many Autistic students change schools because their school is unable to resource their needs (Jones et al., 2018; Jones et al., 2019; Jones et al., 2021). This limited capacity and willingness to adequately support Autistic students continues within post-secondary education and training, with studies highlighting Autistic youth are often denied reasonable academic adjustments (e.g., extended test-taking time, assistance with note-taking) (Jones et al., 2018; Hastwell et al., 2013; Lucas & James, 2017; Siew et al., 2017; Ward

et al., 2018). As such, the ABS (2018b) reported 32% of young Autistic Australians had not completed year 10, with only 26% completing post-secondary education, well below those with other disability (46%) and neurotypical peers (59%). Lower educational achievements compound limited support available to address barriers to work, such as recruitment anxiety and limited employer understanding of autism. Subsequently, the unemployment rate for Autistic Australians is almost eight times higher than for Australians without disability (ABS, 2018b). Ultimately, poor transition experiences negatively impact on broader life outcomes such as independent living, economic autonomy and social inclusion (Children with Disability Australia, 2015; Richdale et al., 2022; Roberts et al., 2022; Victorian Government, 2017).

Practical supports such as to develop organisational and social skills can promote more positive life transitions (Thompson et al., 2018; USGAO, 2016). In their discussion of policy and services Thompson et al. (2018) suggest participation of Autistic youth in higher education, employment and independent living will be achieved through a focus on individual strengths within person-centred approaches to the transition from school to adulthood. Other research suggests specific strategies to facilitate the participation of Autistic youth in transition planning are required (AMAZE et al., 2022; Chandroo et al., 2020; Hagner et al., 2014; Poirier et al., 2020). Relevant transition resources include those developed through the Australian Government National Disability Coordination Officer program (NDCO Resources), which aim to assist Autistic youth and their families in planning journeys post school, including potential NDIS supports, as described in the following section.

### **AUSTRALIA'S NATIONAL DISABILITY INSURANCE SCHEME**

The purpose of the NDIS is to enable the inclusion of people with disabilities in the social and economic life of our community (NDIS Act, 2013). Though one third of all NDIS participants have a primary diagnosis of autism (NDIA, 2022a), the NDIS does not include a specific autism and neurodevelopment participant pathway to provide targeted support to this considerable cohort (CoA, 2022). Nor does the NDIS have a specific strategy to support transition from school to life-after-school. However, in 2019 the NDIA released a participant employment strategy, followed by a 2021/22 Action Plan (NDIA, 2021a) and a report on research exploring employment barriers and enablers for specific participant cohorts, including Autistic participants (NDIA, 2021b).

NDIS School Leaver Employment Support (SLES) is available to participants who wish to pursue employment in their final years of school or directly after leaving school. SLES aims to enable transition through building skills, confidence, and capacity for work. However, several issues to the effectiveness of SLES have been identified such as: 'nobody explained the purpose of funding' (NDIA, 2022b, p.6).

#### THE VOICE OF AUTISTIC YOUTH

A position statement from AMAZE (2018) (peak-body representing Autistic people in Victoria) recommended further research to inform improving transition support. Similar recommendations by the Government committee on autism, emphasised the need for such research to draw on participatory approaches (CoA, 2022). This echo's broader calls for NDIS research to include the voice of NDIS participants to better 'critique and inform policy' that impact on their NDIS experiences (Olney & Dickinson, 2019, p.280). Accessing the valuable insights Autistic youth have into the type of supports they need for a successful transition to adulthood (Richdale et al., 2022) is important in building a better understanding of their needs and priorities.

Having previously identified the multi-layered environment in which Autistic youth NDIS participants are interacting, we consider the essential elements of the ecological model (Bronfenbrenner & Ceci, 1994; Danforth, 2021) to further inform our understanding of their experiences. Both Bronfenbrenner and Ceci (1994) and Danforth (2021) conceptualise the context influencing individual development as having many levels/systems. For our Autistic youth this considers how their individual characteristics, such as developmental age, gender identity and individual expression of autism are directly interacting with those in their immediate environment i.e., their microsystem (includes e.g., family, teachers, peers, community), who are reciprocally interacting with Autistic youth and each other (i.e., the mesosystem). Beyond this direct two-way interaction, the ecological model assists our consideration of how Autistic youth and those in their microsystem are directly or indirectly experiencing reciprocal interactions with

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the broader exosystem (e.g., education, health, and employment systems) and macrosystem – the policy and cultural context of the society in which they are transitioning to adulthood.

Showcasing research conducted with Autistic youth NDIS participants and those who support them on their school to life-after-school transition journey, this paper aims to address the research gap in their lived experiences of transition supports within the context of the NDIS. In reporting our findings, considering the ecological model and synthesising key literature, this paper contributes to an understanding of whether Autistic youth receive the NDIS transition supports they need. This knowledge is essential to informing future NDIS policy and practice for the provision of best possible transition support of Autistic youth and their families.

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### **METHODS**

The study was positioned within a constructivist paradigm, reflecting a belief participants would 'describe the meaning and significance of experiences' as they experienced them (Tong et al., 2007, p.351). To provide understanding and knowledge of the meaning and significance our participants ascribed to their lived experience, phenomenological methodology was utilised i.e., individual semi-structured in-depth interviews with Autistic youth who were accessing NDIS support during their school to life-after-school transition. Reflecting the key role family frequently play in navigating NDIS supports during this period (Flower et al., 2019), we thought it valuable to understand if and how the aspirations and experiences discussed by Autistic youth differed from those expressed by key support people. Hence, separate interviews were conducted with a support person nominated by each youth participant.

Through consultation with a MetroAccess Community Development Officer (CDO) working closely with Autistic youth, the lead author was introduced to the Executive Officer (EO)/co-founder of different journeys: a community social group providing opportunities for Autistic youth and Autistic adults and their families to connect. MetroAccess – a partnership initiative between the Victorian State and Local governments, aims to build the capacity of local communities across metropolitan Victoria so they are more welcoming and inclusive of people with disabilities. Both the CDO and EO acted as community advisors for the study.

The study was undertaken by the first author to partially fulfil the requirements of the degree of Master of Public Health. Being aware of the subjectivities, bias and preconceptions derived from professional and personal experiences, the first author used reflexive practice throughout the research (Liamputtong, 2013). Reflexive strategies employed by the first author included critical self-reflection, and discussions with supervisors and community advisors.

Ethical approval was granted by the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee (ID: 1953724).

## **RECRUITMENT**

With permission from the EO of different journeys, information flyers were distributed to Autistic youth and their families. The lead researcher was subsequently invited to attend a social event to provide additional information about the study. All study participants were recruited through different journeys. Each Autistic youth recruited was asked to select a support person whom the lead researcher could approach to also be a participant. Plain Language Statements and Consent forms were prepared in accessible formats and emailed to participants. Participants were offered a choice of settings for the interviews (e.g., own home, library, MetroAccess office). All participants chose to be interviewed in a shared space within their home. All participants were offered communication preferences, such as a communication partner (two participants chose this). Consent and understanding of what participation involved was re-confirmed at time of interview.

Four Autistic youth and their four chosen support persons (identified hereafter referred to as – circle of support participants) participated in the individual semi-structured interviews. At the time of interview, each youth was a NDIS participant. Table 1. presents Autistic youth participant demographics. Most identified as male, became NDIS participants whilst at school and report current post-school education engagement, with only one youth currently in partime paid employment. Most circle of support participants were their mother.

**CHARACTERISTICS AUTISTIC YOUTH PARTICIPANTS** Age range 18-21years Gender identity 1 female 3 males Education/training status 1 in final year of school (Victorian Certificate of Education) 1 in NDIS SLES program 1 in bridging course at Tertiary and Further Education (TAFE) 1 completed school – no current post-secondary education. 1 part-time Employment status 1 seeking employment 2 not seeking employment Place of residence All family home (1 grandmother's home) Time as NDIS participant range 1-3yrs Relationship to circle of support participant 3 mothers 1 grandmother Support frequency by circle of support participant All daily

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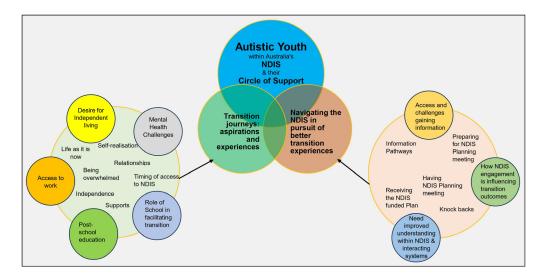
**Table 1** Autistic youth participant demographics.

#### **DATA COLLECTION**

Data was collected between June and August 2019. Interviews with Autistic youth varied from 40–60 minutes, with circle of support interviews lasting from 60–90 minutes. Semi-structured interview guides were developed in consultation with MetroAccess CDO, but not provided to participants prior to interview. The guides facilitated discussion on the youth's aspirations, expectations and experiences e.g., what did you think would be achievable in your transition from school to life after school, alongside their perceptions on whether and how their NDIS supports helped them progress towards their aspirations or what could have been done differently. Utilisation of communication supports such as communication partners, participant choice in interview location, reframing questions participants found confusing or challenging, allowing time for responses and accepting self-regulation activities, enabled rich data to be gathered. Circle of support participants were asked about their Autistic youth's transition experiences, alongside their perspectives on the NDIS supports received e.g., what were the facilitators or barriers of utilising NDIS funded supports in achieving a successful transition, with similar communication accommodations applied as required.

### **ANALYSIS**

All interviews were audio recorded and de-identified transcripts prepared by the first author. This enabled data familiarisation and sharing, discussion of analysis and findings with supervisors (second and third authors). A thematic approach to analysis was applied by the first author (Liamputtong, 2013), looking to understand the meaning and significance study participants ascribed to their experiences. Following familiarisation during transcription, the first author re-read transcripts, identifying 38 initial codes. Looking for patterns of meaning and following discussion with supervisors, initial codes were condensed into 12 categories including e.g., for Autistic participants: Relationships i.e., with family, peers, support staff, educators; and for Circle of support participants: Information Pathways i.e., education providers, health/mental health providers, community groups. Further review of topic categories and discussion with supervisors facilitated identification of eight emerging themes. Discussion of themes with study supervisors and community advisors enabled further interpretation and refinement into the two central themes. Figure 1. visually presents the thematic coding process. Additionally, implications of the findings for consideration by the NDIS, specific to improving the transition outcomes for Autistic youth in life-after-school were identified.

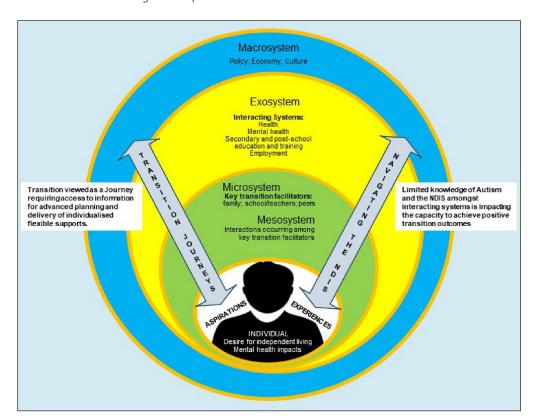


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**Figure 1** Thematic coding process.

## **RESULTS**

The heterogeneous expression of autism was reflected in the individual lived experiences of participants. Final analysis revealed challenges and opportunities interacting across two key themes: 1) Transition journeys: aspirations and experiences, and 2) Navigating the NDIS in pursuit of improved transition experiences. Drawing from the ecological model, the first author developed Figure 2. to illustrate the multi-layered context within which Autistic youth NDIS participants are experiencing their transition from school to life-after-school, i.e., the environment influencing their experiences and transition outcomes.



**Figure 2** Multi-layered environment influencing Autistic youth' transition to life-after-school.

#### TRANSITION JOURNEYS: ASPIRATIONS AND EXPERIENCES

Each youth spoke of their aspirations for life-after-school, relative to personal goals such as living independently, training and employment. Their stories described different strengths, needs and stages in their transition journey. Most spoke of the mental health challenges which emerged during this life stage. Summaries below reflect how the participants discussed moving through and adapting to the challenges in achieving post-school transition aspirations.

#### Role of school in facilitating transition

School experiences were diverse. From practical day-to-day support (e.g., sensory accommodations for school activities), to not receiving any tailored school supports, including poor experiences within vocational education and training (VET) based schools. Negative experiences left some participants feeling the need to lower employment aspirations. One youth participant expressed feeling totally unprepared for the challenges associated with losing the daily structure of school and interacting with potential employers and social services. Another stated: 'Through the end of school I didn't understand anything' (P3 [Autistic Youth]), having experienced family breakdown, homelessness and the emergence of ongoing mental health challenges. All youth described their family rather than school were the most supportive in preparing for and travelling the transition to life-after-school journey with them.

All circle of support participants felt schools had done little or nothing to prepare them or their Autistic youth for the transition to life-after-school. Feeling naive and lacking confidence to advocate for more appropriate levels of support from the school, some described missing access to critical information about support services, including the NDIS. Others identified being offered some transition support at school, though in reality – too little too late.

Circle of support participants were concerned how decisions and supports provided during the school-to-post-school transition would impact the mental health of their youth. Worried the wrong decision post-school would increase the risk to Autistic youth mental health, one commented '...the mental health just diminishes and all of that compounds into a whole lot of other issues and I don't want that to happen.' (P2a) [a]-indicates quote from circle of support participant for Autistic youth participant.

### Post-school education and training

Youth participants varied in their aspiration for post-school education. One identified an immediate goal of attaining a higher education degree, drawing on their own self-efficacy and supported self-advocacy, they had worked with family to explore different universities and on and off-campus supports. Aware many Autistic students start but don't complete their post-secondary education, this participant found only one of the universities offering adequate individualised academic and social supports. Others were attending training courses anticipating this would ultimately see them gain mainstream employment. For those where capacity and readiness for employment training was unclear, participation in a NDIS funded SLES program could build skills towards enabling participation in a TAFE course.

TAFE was viewed as having highly supportive teachers, anticipating positive experiences would translate into success when seeking open employment. However, despite reflecting positively on the support provided throughout TAFE studies, the lack of translation to open employment had left one youth questioning its worth, saying: 'They [employers] do not care about the certificates ... You could have fifty certificates...' (P1).

#### Access to work

One youth was working part-time whilst studying. Two spoke positively of the work experience gained during current training, seeing this as an attribute when seeking future employment. For one youth, the three-year post-school journey of seeking employment had not only been unsuccessful but detrimental. Multiple unsuccessful employment applications were followed by access to government funded employment support, only to be told things such as: '...he's not allowed to have an autism tantrum because it would disturb other people' (P1a), resulting in him going '...from happy, happy, depressed, depressed, angry ...on the floor a dithering mess ... actually so angry and so depressed, suicidal' (P1). Reconnection to psychology services supported this youth, describing his mental health as: 'surfaced from the water, but still submerged. My nose is above water, but that's it' (P1). With employment aspirations disregarded by school and employment services, this youth was trying to gain work experience through non-competitive/ supported employment, hoping this would lead to future mainstream employment.

### Desire for independent living

All youth participants expressed a desire to eventually live independently. Most in vague language, viewing it more as a long-term goal, with one participant saying: '...it may look like I'm an adult, but

I'm a five-year-old inside'(P3). When spoken of as more a medium-term goal, informal supports were viewed as providing '...a bit, but not that much ...sometimes I can get home without anyone ...when I'm at [train] station' (P2), not the perception non-verbally communicated by their circle of support participant! Though all circle of support participants expressed support for their youth to live independently, expression of support was stronger when identified as a long-term goal.

All youth expressed the understanding that without paid employment, their dreams of living independently couldn't be realised. Equally, all viewed being able to drive as important for achieving independence, regardless of whether this aspiration was currently being pursued. All highlighted the ongoing need for support from family, mental health and NDIS services to mitigate the impact of their mental health on their journey to independence.

#### Mental health

Three youth participants discussed how mental health challenges impacted their transition journeys, requiring the need for support from family and a wide range of services and systems. This included experiences at *different journeys*, identified as particularly important in maintaining social connection. The opportunity to develop new social relationships was a valued mental health support:

'...and there's this really weird thing with Autistic kids, that when there's other Autistic kids there, they can cope ...and everyone just goes, well my mates are here, I can cope. They're coping. I'm coping.' (P1a).

All circle of support participants identified their youth's: 'Mental health risks are amplified during this transition phase ...' (P4a). The specific concern of high rates of suicide amongst Autistic youth was raised as further exacerbated by challenges experienced in accessing NDIS supports specific to mental health issues. These participants simply wanted their youth to have an everyday life: '... an independent member of community, on her level.' (P4a) and 'I need for [P2] to move forward independently. I want him to be able to get his license. I want him to be able to get a job.' (P2a). While another summed up the overall sentiment of the group, speaking about what she'd learnt through this transition phase: '...if there is a dream there, don't squash it!' (P1a).

## NAVIGATING THE NDIS IN PURSUIT OF BETTER TRANSITION EXPERIENCES

Experiences navigating the NDIS varied considerably. From the process of access, through identifying appropriate and available services and supports, to interaction between the NDIS and other service systems, achieving desired transition outcomes proved challenging at different points in the journey. In particular, circle of support participants reported experiencing several barriers to optimally supporting their youth's transition aspirations. Summaries below reflect these challenges.

### Access and challenges gaining information

Access to the NDIS was automatic for the youth with existing disability program funding. For another, considerable advocacy by their circle of support was required to achieve an appropriate NDIS plan of supports. Initially denied access, two were only deemed eligible when reaching crisis point: 'Had to prove I was on my lowest low for them to accept me' (P1).

All circle of support participants described precarious access to information and support to understand the NDIS, would leave those with limited advocacy capacity disadvantaged. One circle of support participant commented: 'different journeys has been key in unpacking the NDIS puzzle ...meeting the transitional officer at [local government services] ...and support from a friend educated on the NDIS' (P3a). Each described their varied initial and ongoing capacity to undertake a sustained effort to be NDIS informed. The relentless challenge of knowing what information was required and gaining access to accurate, consistent information, highly frustrating.

For some, this was counterbalanced by the general support of family and friends: 'We have a great family network and supports within the family, so that's also been helpful ...there are a lot of people out there that don't have that' (P2a). It was universally acknowledged different journeys fulfilled a highly valued role in providing a social network for the sharing of information, knowledge and experiences of the NDIS. Capacity for information gathering and advocacy was viewed by circle of supports as an inequity strongly influencing transition outcomes.

#### How engagement with the NDIS is influencing transition outcomes

Viewing the NDIS as a complex bureaucratic system, difficult or near impossible to navigate, perceptions of NDIS supports impacting transition journeys varied. All circle of supports described a sense of ownership and responsibility for NDIS access, planning and reviewing processes. Conversely, youth perceptions appeared influenced by an apparent lack of ownership of their plan or knowledge of the NDIS and its processes: 'It's done little for me to date …but I can see it's helped reduce some of the stress experienced by my parents' (P1) or 'I don't know how hopeful I am of the NDIS being able to help …halfway happy' (P3). While circle of support's varied from: '…the NDIS is doing what it's meant to do …and keeping our family together' (P4a) to '…the NDIS did nothing in the first year' (P3a).

Both participant groups identified the standard of autism knowledge as poor amongst NDIS staff and services, creating barriers to transition planning and outcomes. Desired transition outcomes were only achieved when needs were accurately identified, enabling development and appropriate implementation of NDIS plans. Participants identified knowledge and understanding of autism essential to informing NDIS policy and practice, creating a safe environment for Autistic youth and those supporting them to interact with the NDIS.

### Need for improved understanding within NDIS and interacting systems

All participants discussed the importance of accessing supports and other service systems that could meet their individual need and provide a flexible response. Circle of support participants spoke of their challenges in understanding requirements of and navigating different service systems, such as education, health, mental health, community programs and the NDIS, as systems don't understand each other. This contributes to confusion when working to facilitate transition outcomes: '…cross sector communication is essential' (P4a). Systems working together to always keep the transition goals of the individual front of mind was viewed as essential to achieving desired outcomes.

### **DISCUSSION**

This research sought to generate evidence about the lived experiences of Autistic youth and their transition supports within the context of the NDIS. Key themes and sub-themes identified describe how participants are interacting within the context of their immediate and more distal environments (Bronfenbrenner & Ceci, 1994; Danforth, 2021). For Autistic youth, this context includes "...the wide range of system levels that influence individuals with autism, including the immediate responses of caregivers and family, school, local community, as well as broader cultural, economic, and political practices." (Danforth, 2021, p. 1595). Consistent with international research findings, participant experiences reflect poor transition outcomes across key life areas: access and completion of postsecondary education and training, employment, health and wellbeing, social connectedness and independent living (Anderson et al., 2018). Autistic youth find themselves in environments that do not understand or accommodate their needs (education, employment, social), that fail to recognise the critical support role families play and lack comprehensive supports through integrated service systems. Our study findings suggest the NDIS has an opportunity to partner with Autistic youth, the supports and systems influencing their transition environments, to set up empowering environments, tapping into individual strengths in pursuit of personal goals to achieve successful transition outcomes (Donaldson et al., 2017; Funnell & Rogers, 2011).

Though describing very individual transition journeys, an opinion consistently expressed was NDIS supported processes need to start much earlier. The concept of transition planning starting early is discussed by Hatfield et al., (2018) as required to address the anxiety Autistic youth experience when thinking about their future and the individual timespan which may be required for the transition journey. An early start to transition planning for youth with diverse needs from school to adult-life is recognised internationally (HM Government, 2021), including evidence-based best practice transition guidelines (NZ Ministry of Education, 2019; Stewart et al., 2009) and the USA's, Individuals with Disabilities Education Act 1990, requiring transition planning be started by the age of sixteen (Bennett et al., 2018). This recommendation for earlier commencement of transition planning could importantly facilitate earlier recognition of need and access to timely mental health supports. Evidence from the USA also suggests that a comprehensive well-coordinated approach, in which regular communication between

the Autistic youth, their family or carers and service providers starts early, obtains a better understanding of individual needs and risks (USGAO, 2016; USGAO, 2017). When individual needs are not identified along the transition journey, the capacity to learn and practice life-skills is impacted. Individual autism expression characteristics influence the nature of support and the time it takes to acquire these skills. Life skill acquisition supports aspirations for independence in further education and employment, which then reduce the risk of social isolation, amplifying the need for individualised and flexible supports across the transition journey. Most importantly, timely individualised supports have the potential to reduce escalation of mental health issues and risks associated with suicide in this population (Hedley et al., 2018).

An unexpected finding of this study was only one youth participant discussed participation in the NDIS planning process. This could reflect adolescent indifference or the need to actively plan to support Autistic youth participation. Hagner et al. (2014) identified five potential strategies to facilitate participation: individualised meeting preparation; ensuring rapport exists between the youth and the meeting facilitator; employing a flexible meeting design; enabling the youth to attend at a distance either in the meeting space or via electronic means; and ensuring individual communication support is available when required. All participants identified the importance of an individualised and flexible approach to NDIS transition supports. Facilitating this from the first interactions with the NDIS could enable Autistic youth's voice to be heard. In turn, this would contribute to development of their individual identity, building capacity for self-determination and self-advocacy towards achievement of successful transition outcomes (Hatfield et al., 2018).

All youth participants identified their family member as the current key information gatherer and coordinator of their respective NDIS supports, confirming the critical role families play in the transition journey. However, circle of supports highlighted the challenges and inequities experienced in efforts to access essential NDIS information across all NDIS processes. The differing capacity for confident, assertive interactions with the NDIS was viewed by Olney and Dickinson (2019) as potentially raising "Questions of equity and fairness in the NDIS" (p.284), raising both practical and ethical concerns for the NDIS.

Identified as negatively influencing interactions with all NDIS processes and thus outcomes, was the poor standard of autism knowledge and understanding within NDIS practitioners, partners and interacting systems. This issue was highlighted in a submission to the inquiry on NDIS planning: "Our observation is that few, if any, NDIS planners have the experience, expertise and qualifications they need to deliver appropriate NDIS plans for Autistic NDIS participants" (A4, 2019, p.5). The submission suggests the history of autism diagnosis in Australia is why "...many senior staff, bureaucrats and planners regard autism as a type of intellectual disability" (A4, 2019, p.5). Further, the overall limited experience of service providers is adversely impacting their understanding of the individual needs of Autistic people. Most recently, the Government committee on autism report, identified the need for improved understanding of autism within the NDIS and across interacting systems (CoA, 2022).

Limited knowledge and experience are contributing factors to the delay in access to appropriate supports. The A4 (2019) submission suggests this overall lack of knowledge and experience stems from disability studies curricula inadequately addressing the needs of Autistic people and recommending professional development autism education for all planners. Additionally, the Government committee on autism report identifies a much wider need for this type of professional development across all NDIS practitioners, partners, service providers and systems with whom Autistic NDIS participants and their key advocates interact (CoA, 2022).

Youth participants viewed their neurodivergent characteristics as assets, but reflected the challenges of navigating neurotypical environments, such as education, employment, social services and the NDIS. Circle of support participants echoed these challenges and raised concerns for the mental health of Autistic youth. Aiming to support a successful transition, they identified the persistence required to effectively advocate in these environments. These challenges again point to the deficit in professionals' autism knowledge, but also a deficit of systems literacy for all those influencing an Autistic youth's transition environment. Participants identified successful transition requires a team approach. Building understanding of each system, individually and within the context of multiple systems, will facilitate interrelationships that positively influence transition outcomes. The capacity of the NDIS to support successful transition for Autistic youth is impeded by current policy, practice and distance between it and other service systems (Whitburn et al., 2017).

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**Transitions** 

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The most integral members of the transition team are the Autistic youth and the family or carers who provide informal support on a daily basis. When considering the Autistic youth and the multiple relationships within their transition environments, a person and family centred approach appears beneficial to the transition process. This approach supports the need to focus on individual strengths and what matters to the Autistic youth and their family. At the same time, it remains mindful of the need to support systems and builds opportunities to leverage knowledge held by others in supporting successful transition outcomes. As Hagner et al., (2014) suggest, this approach can be useful for producing individual changes and changes at systems levels. Echoing these recommendations and affirming prioritising a person and family centred approach, the Government committee on autism report sets development of a National Autism Strategy as "the centrepiece of efforts to improve outcomes for Autistic Australians' (CoA, 2022, p.x).

What matters to Autistic youth and their informal support is essential to achieving successful transition outcomes. Particular concern was expressed for the increased mental health risks for Autistic youth during this phase of life. It was clear informal supports play a critical role and need easy access to quality information and services to effectively support the transition journey. NDIS practitioners, partners and interacting services and systems need to hold appropriate standards of autism knowledge, and work together with Autistic youth as team members to support positive transitions outcomes. As the NDIS continues to develop its capabilities in effective engagement with Autistic youth, their informal supports and wider community, a whole government approach is required to achieve broad policy and social change.

### STRENGTHS AND LIMITATIONS

The study's strength lays in prioritising the voice of Autistic youth. Time proximity of interviews to phenomena of interest likely enhanced participant recall. The first author's professional knowledge and experience of working with Autistic youth and their families contributed to the context within which data was collected, enhancing participation through development of accessible documents, offering alternative communication support, responding ethically and sensitively to challenges during interviews, whilst being mindful of the potential for introduced bias during the research process.

This is a small-scale study with difficult to reach participants. Participant gender bias may reflect diagnosis gender imbalance, and mothers of Autistic youth' greater participation in related research (Thompson et al., 2018). Wider age inclusion, utilisation of focus groups and time for increased relationship building to enhance engagement with Autistic youth (Mitchell & Beresford, 2014), may enhance future research.

### **CONCLUSION**

The research findings, literature synthesis and consideration of the ecological model, indicate NDIS policy and practice needs to consider the unique features of Autistic youth's transition from school to life-after-school. The large cohort of Autistic NDIS participants that will enter this life stage over the next decade, requires greater evidence-based approaches to better support successful transition outcomes. For study participants, the experience of NDIS support during transition was characterised by key barriers. The autism community regards early planning and preparation, using co-designed person and family centred approaches, as urgently needed to address the transition challenges and interconnected barriers experienced. These individualised approaches recognise transition supports may be required over a longer period of time and must include a strong focus on mental health.

Urgent action is required to provide equitable access to NDIS information, a barrier impacting the crucial transition support role of family (Thompson et al., 2018). Concurrently, the standard of autism knowledge held by NDIS staff and interacting services and systems must be improved and sustained. This will build capacity for collaborative transition planning and delivery of supports. Alongside the development of a National Autism Strategy, a greater NDIS policy and practice focus on responding to the transition needs will hopefully improve the life outcomes of all Autistic Australians as they navigate life-after-school (Hagner et al., 2014). Building systems literacy for the NDIS to better meet the transition requirements of Autistic Australian youth is essential.

### DATA ACCESSIBILITY STATEMENT

Data has not been made accessible for this publication. Participants were not asked to give consent for their data to be made widely available.

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### **ETHICS AND CONSENT**

The research study was approved by the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee (ID: 1953724). Informed consent to participate in the study was obtained from all participants. Any data obtained from participants were anonymised.

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#### **COMPETING INTERESTS**

The authors have no competing interests to declare.

#### **AUTHOR CONTRIBUTIONS**

MH served as the PI on the project, led the research including conceptualization, design, data analysis and paper preparation.

AD co-supervised the PI of the project and provided invaluable support to preparation of the paper.

LN supervised the PI of the project and provided invaluable support to preparation of the paper.

# **EDITORIAL AND PEER REVIEW INFORMATION**

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## **AUTHOR AFFILIATIONS**

Marie Huska orcid.org/0000-0002-7021-0527

University of Melbourne, Australia

**Alexandra Devine** orcid.org/0000-0002-7549-9876

University of Melbourne, Australia

**Lucio Naccarella** orcid.org/0000-0001-7163-3022

University of Melbourne, Australia

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