

NDIS Service Needs in the City of Whittlesea

**A research report by the Access Team,
Whittlesea City Council**

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Acknowledgements

The City of Whittlesea would like to acknowledge the traditional custodians of the lands on which this report has been researched and written, the Wurundjeri Willum Clan. We pay our respects to their Elders past, present and future. This was, and always will be, Aboriginal land.

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Acronyms and abbreviations

Acronym	
CALD	Culturally and Linguistically Diverse
COVID-19	The pathogen, identified as a new (novel) coronavirus, SARS-CoV-2, causes the disease designated COVID-19.
CoW	City of Whittlesea
LAC	Local Area Coordinator
LGA	Local Government Area
NEMA	North East Melbourne Area (NDIS Service District)
WDN	Whittlesea Disability Network
WfV	Working for Victoria

1. Summary of key insights

The success of the NDIS depends on functional local service markets. Participants and their families should have access to a range of high-quality support options so that they can exercise choice and control over services.

Whittlesea City Council identified that many NDIS participants in the municipality face barriers to accessing the services they need. The Council's Access Team designed an extensive research project to determine the major service needs and challenges for local participants.

Spanning the period August 2020 to January 2021, the project comprised both quantitative and qualitative data collection methods. This included analysis of NDIS participant data to understand current and future service demand. It also included focus group discussions with Local Area Coordinators (LACs), who offered a unique perspective on service supply issues in the City of Whittlesea. Finally, the project captured the wide-ranging insights of participants and carers through in-depth interviews and an online survey.

The research found that there is significant unmet need for various NDIS services in the City of Whittlesea. With demand exceeding supply across a range of service types, participants face limited options and diminished service quality. The burden of poor access is unequally borne by Aboriginal participants, participants from Culturally and Linguistically Diverse communities, families who live in the growth areas and rural north, and participants with very complex disabilities.

Summary of the key insights:

- 1. Despite the impact of COVID-19 on people's movement and access to services, the number of NDIS participants in the City of Whittlesea grew substantially in the past year.** There were 3,826 NDIS participants in the municipality in September 2020, having increased by 730 participants since September 2019. Whittlesea City Council expects a similar annual increase in participants from 2021 to 2023, as an even greater share of the local population joins the Scheme. While most participants currently live in the established suburbs, an increasing proportion of new participants will be people who live in the growth areas.
- 2. The City of Whittlesea has among the largest number of youth NDIS participants in Victoria, with 58% of participants aged 0-18 years.** Affordable housing opportunities will continue to attract young families to the area, sustaining a high share of children and adolescent participants for years to come. Into the future, there will be a very high demand for NDIS services that are designed for young people.
- 3. The four most common primary disability types comprise 74% of all NDIS participants in the City of Whittlesea.** Of these, autism and developmental delay are expected to become increasingly prevalent. Growth in the number of participants with psychosocial disability is also forecast to accelerate in the coming years. By contrast, the share of NDIS participants

with intellectual disability, which is the second most prevalent primary disability type, is steadily decreasing across the City of Whittlesea and Victoria.

- 4. The demand for therapeutic support services far exceeds the supply.** This service gap is particularly evident in occupational therapy and speech therapy, but participants also face very limited options in physiotherapy, psychology and therapy assistance. Not only is the supply of therapy services insufficient, it is also not diverse enough; there is a need for therapy options that cater to participants of different ages, cultural backgrounds or very complex disabilities.
- 5. There is a shortage of services catered to the adolescent and young adult age groups.** Age is a crucial factor that determines the way disability services are designed and delivered. Whereas the early childhood age groups are well-supplied with supports, participants aged 12-25 years have difficulty accessing age-specific therapy supports, individual skill development and group social activities. Given the very large share of NDIS participants aged 0-14, pressure on this service gap will increase substantially in the next 5-10 years.
- 6. There is significant unmet need for behavioural support and specialist behavioural intervention services.** Given their highly specialised nature, these services are in high demand in the City of Whittlesea, especially among adolescent and young adult participants. With many organisations unable to take on new participants, families are travelling outside Whittlesea LGA to access providers.
- 7. Market insufficiencies are particularly pronounced in the growth areas and rural north, where demand is expected to increase rapidly in the near future.** Participants who live outside of the City's established suburbs face lengthy travel times and restricted choices, while those who live in Whittlesea Township have the most limited NDIS service options of all. Locational disadvantage is a major access barrier throughout the City of Whittlesea, with many families travelling far outside the LGA to reach the supports they need.
- 8. Aboriginal and Torres Strait Islander participants are excluded from NDIS services and experience poorer outcomes than non-Aboriginal participants.** This is largely due to the very limited supply of services that are culturally appropriate and safe for Aboriginal people in the City of Whittlesea. To address this, there is an urgent need to build the cultural competence of NDIS service providers. Within the broader network of Aboriginal organisations in Melbourne's north, there are also opportunities to build the capacity of organisations to deliver NDIS services for the first time.
- 9. There are significant and complex barriers to service access for participants from some CALD communities.** Many participants do not access services due to different cultural understandings about disability. In some cases, feelings of shame and stigma cause participants to engage with services far away from their community. To improve outcomes

for participants from CALD backgrounds, information about NDIS services must be communicated more effectively, including in a format that is culturally sensitive.

- 10. COVID-19 has reduced in-person supports and increased the pressure on psychosocial services, but physical distancing restrictions have also revealed the potential benefits of telehealth and online service delivery.** By harnessing this opportunity, and building therapists' capacity to effectively deliver online services, it will be possible to offer participants more flexible service options and reduce travel and transport barriers.
- 11. Many services are too general and do not cater to people with specific complex needs or more than one disability type.** Participants face challenges finding therapists who have the specialist skills required to build the capacity of people with uncommon disability types. Similarly, there is a shortage of support workers who are trained in working with participants who have complex behaviours. This service gap stifles participants' progress, places pressure on informal supports or leads to unutilised funding.
- 12. Informal support people play an instrumental role in ensuring participants gain maximum benefit from NDIS services.** Many participants depend on carers and family members to manage administrative issues and navigate the complex service market, or simply accompany them to therapy sessions. Without effective and consistent informal supports, the care of participants, and the success of the NDIS, are seriously compromised.
- 13. The quality of services delivered by Allied Health providers and support workers varies greatly, leading some participants to change providers frequently or receive care that is not appropriate for them.** Participants and LACs depend on therapists' reports to assess the need for more support. Often these reports do not offer meaningful insights, thereby hindering participants' progress or delaying the provision of additional funding.
- 14. Participants in the City of Whittlesea lack other employment and social opportunities that would further support the funded care they receive through the NDIS.** There are very few social group options for Aboriginal children with disability, and school leavers have difficulties finding employment and training opportunities. People in Whittlesea Township are isolated from accessible services. NDIS participants would like access to mainstream activities that are inclusive of people with disability.

2. Background

The introduction of the National Disability Insurance Scheme (NDIS) heralded a transformation in the way people with disability access supports in Australia. Emphasising an individualised model of support, the Scheme offers people with a ‘permanent or significant’ disability the chance to exercise choice and control in the service market.¹

When the NDIS was first rolled out in Victoria in 2015, residents of the City of Whittlesea were among the earliest recipients of the Scheme. In early 2021, there are now close to 4,000 NDIS participants in Whittlesea Local Government Area (LGA). These individuals, their carers and families, depend on the NDIS, and the existence of a functional disability service market, to access the supports they need.

Still in a process of implementation, the NDIS continues to attract scrutiny from participants, government and other observers who are interested in seeing the Scheme ultimately deliver on its promise. Prominent among these are reports that explore the concept of ‘thin markets’ and the capacity of the service sector to effectively meet demand from participants².

The issues of market insufficiencies in the NDIS are well-documented at the state and national level³. Recognising this, Whittlesea City Council identifies the need for a more localised understanding of service supply challenges and access barriers.

Previously, Council has relied on conversations with NDIS participants and disability organisations to signpost potential service gaps. Participants have asked for more options, while NDIS service providers are seeking guidance to plan for increasing demand. These conversations indicate significant opportunities to develop the NDIS service market and improve outcomes for participants.

Responding to the outbreak of COVID-19, the Victorian Government instituted the Working for Victoria (WfV) initiative, an economic survival measure designed to create employment and help local government authorities manage the impact of the pandemic⁴.

With funding from this initiative, the Council’s Access Team developed a research project to investigate the service needs and access barriers for NDIS participants in the City of Whittlesea. The findings of that research are discussed in this report.

Purpose of the project

The purpose of the NDIS Service Needs Research Project is to identify the barriers that NDIS participants in the City of Whittlesea face to accessing the services they need. The project aims to indicate potential thin markets where there is an undersupply of services. It also sets out to explore other service-related issues that prevent participants from achieving their goals through the NDIS.

¹ National Disability Insurance Scheme, What is the NDIS?, 20th November 2020 (cited 25th January 2020). Available from: <https://www.ndis.gov.au/understanding/what-ndis#find-out-more-about-the-ndis>

² Reiders, D., Carey, G., Malbon, E., Dickinson, H, Gilchrist, D., Duff G., Chand., S., Kavanagh, A. & Alexander, D. (2019). *Market Capacity Framework*. Centre for Social Impact: Sydney.

³ Mathys, Z & Randall, K 2019, *NDIS Market Dynamics Study*, National Disability Services, Melbourne.

⁴ Premier of Victoria – The Hon. Daniel Andrews, Economic Survival Package To Support Businesses And Jobs [Media Release]. 21 March 2020 (cited 07 October 2020). Available from: <https://www.premier.vic.gov.au/economic-survival-package-support-businesses-and-jobs>

The research project was designed to answer the following key questions:

1. Who makes up our community of NDIS participants, and how does this inform service needs now and in the future?
2. Within which areas in the local service system is the supply of disability services not sufficient nor diverse enough to meet the demand?
3. Besides service supply issues, what other barriers do NDIS participants face to accessing services and achieving their goals?
4. How does access to disability services differ for NDIS participants who live in different parts of the municipality?
5. How has COVID-19 impacted NDIS participants' use of services in the City of Whittlesea?

By designing and implementing a research plan in response to these questions, the project aims to develop an evidence base to inform further research, policy development, or advocacy for changes to NDIS service provision in the City of Whittlesea.

The ultimate purpose is to increase the capacity of participants to exercise choice and control in the delivery of their disability supports.

3. Research design

The NDIS Service Needs Research Project was designed and delivered by the Access Team at the City of Whittlesea. A mixed methods approach was taken, using quantitative and qualitative data sources to answer the key questions. The project, which commenced in August 2020, included the following research methods:

- 1. Analysis of NDIS participant data** – use of quantitative NDIS data to generate insights about the potential demand for NDIS services in the City of Whittlesea. This included:
 - a. a profile of participants in September 2020, with analysis of age structure and disability types. The data was obtained through direct download from the NDIS website, and through an External Data Request submitted to the NDIA.
 - b. a forecast of participants in June 2023, informed by assumptions about future trends. The data from the participant profile was used as the base for the forecast.
- 2. Focus group discussions** – five focus groups discussions with teams of Local Area Coordinators (LACs) at the Brotherhood of St Laurence. Engaging directly with participants in Whittlesea LGA, the role of the LACs is to prepare NDIS plans and connect participants with service providers.

Each discussion ran for approximately one hour and 15 minutes, facilitated by a member of the Access Team, and focused on the major services gaps and access barriers for participants. The results were synthesised across the five groups and are discussed in the findings below.

- 3. Online survey** – The Access Team developed an online survey for NDIS participants and carers who live in the City of Whittlesea. Open for responses for approximately five weeks, the survey was promoted to several local disability organisations and the Brotherhood of St Laurence. It was also promoted to members of the Whittlesea Disability Network (WDN), both at the monthly forums and via email.

Expert advice on the survey design was provided by a member of the Council’s Research and Engagement Team, who also built the survey on the Survey Manager Platform. The survey was tested by members of the Access Team.

- 4. Interviews** – Eight one-to-one interviews were undertaken with City of Whittlesea residents (two NDIS participants and six carers of participants). Interviewees were sourced through an Expression of Interest that was promoted to the WDN and other local disability organisations. The same member of the Access Team undertook each Interview, which ran for between 45 minutes and one hour.

The interviews were semi-structured and conversational in style. They focused on the participant or carer’s experience of taking part in the NDIS, the benefits they have gained, and any challenges they have faced in accessing the services that they need. The results were synthesised across the eight interviews and are discussed in the findings below. Two case studies were also compiled using these findings.

4. City of Whittlesea NDIS participant profile

Key findings:

- There are 3,826 NDIS participants in the City of Whittlesea, having increased by 730 participants in the past 12 months at an average growth of 6% per quarter.
 - The most prevalent primary disability type is autism (31% of participants), followed by intellectual disability (21%), developmental delay (14%) and psychosocial disability (8%).
 - The age profile of participants in Whittlesea is young, with 58% of participants aged 0-18 compared to 49% across Victoria.
 - Although the established areas of Whittlesea LGA are home to two-thirds of NDIS participants, demand for services is rapidly increasing in the growth areas and Whittlesea Township.
-

This section uses NDIS data to provide insights into recent trends in NDIS participation in the City of Whittlesea. This evidence can be used to inform policy, advocacy, and understand demand for NDIS services.

➤ NDIS participation continues to grow in the City of Whittlesea

In September 2020, there were 3,826 active NDIS participants residing in the City of Whittlesea. This represents approximately 1.6% of the total population of the local government area, slightly higher than the Victoria average of 1.5%.⁵

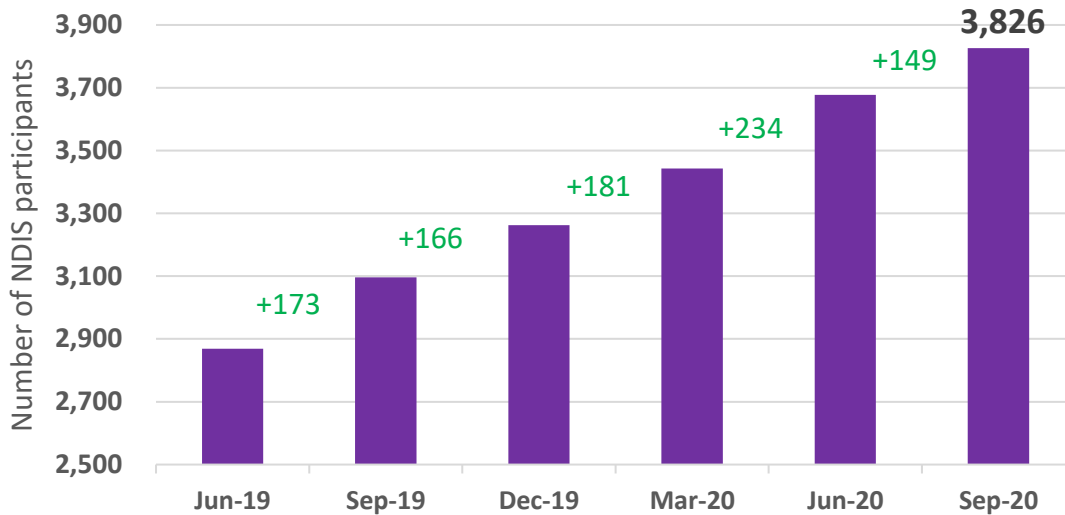
NDIS participation in Whittlesea LGA has continued to grow over the past year, increasing by 730 active participants from a total of 3,096 in September 2019. Rates of growth have varied in each quarter. For example, from June to September 2020, the number of participants rose by just 149, or 4%, compared to an increase of 234, or 7%, in the March to June period.⁶

The sudden decline in growth rate in the most recent quarter indicates the significant impact of Victoria's Stage 4 COVID-19 measures. This trend is also evident across the North East Melbourne Area (NEMA) and Victoria (see Chart 2). Physical distancing restrictions, including a reduction in the operating capacities of service providers, prevented some potential new participants from engaging with the NDIS during this period. It is likely that the number of new participants will increase in early 2021, partially driven by a backlog of people waiting to enter the Scheme.

⁵ National Disability Insurance Scheme – External Data Request for the City of Whittlesea (December 2020)

⁶ National Disability Insurance Scheme, 'Data downloads', 2nd December 2020 (Cited 6th of January 2021). Available from <https://data.ndis.gov.au/data-downloads>.

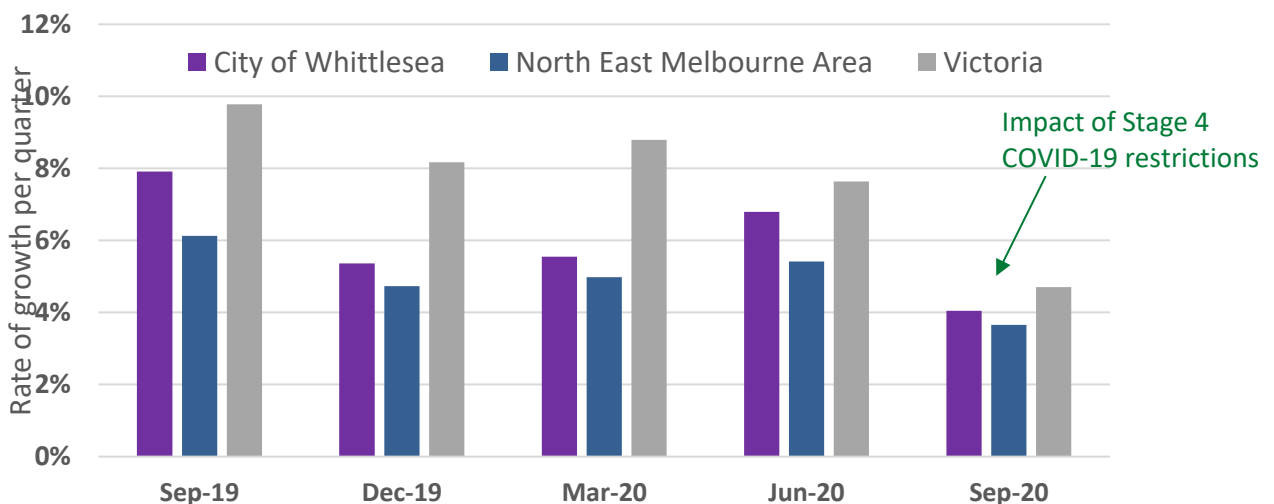
Chart 1. Number of active NDIS participants in the City of Whittlesea, June 2019 – Sept 2020



➤ Whittlesea is driving growth in the North East Melbourne region

Chart 2 also illustrates that although the City of Whittlesea is driving growth in the North East Melbourne Area, both the region and the LGA are growing more slowly than the Victorian average. Since Melbourne’s northern metropolitan region was among the earliest recipients of the NDIS, it has a more mature market, which is reflected in slower rates of growth. By contrast, a faster average growth rate across Victoria is the result of a more rapid uptake of the NDIS in areas where the Scheme is still emerging.

Chart 2. Number of active NDIS participants, growth rates per quarter, City of Whittlesea, September 2019 to September 2020



- Prevalence of autism and developmental delay reflects the City’s young population

The four most common primary disability types comprise 74% of all NDIS participants in the City of Whittlesea. There are 1,180 participants with autism, making up 31% of total participants. This is higher than the Victorian average of 29%. Participants with developmental delay also make up a greater share of participants in the City of Whittlesea, 14% compared to 10% across Victoria (see Table 1).

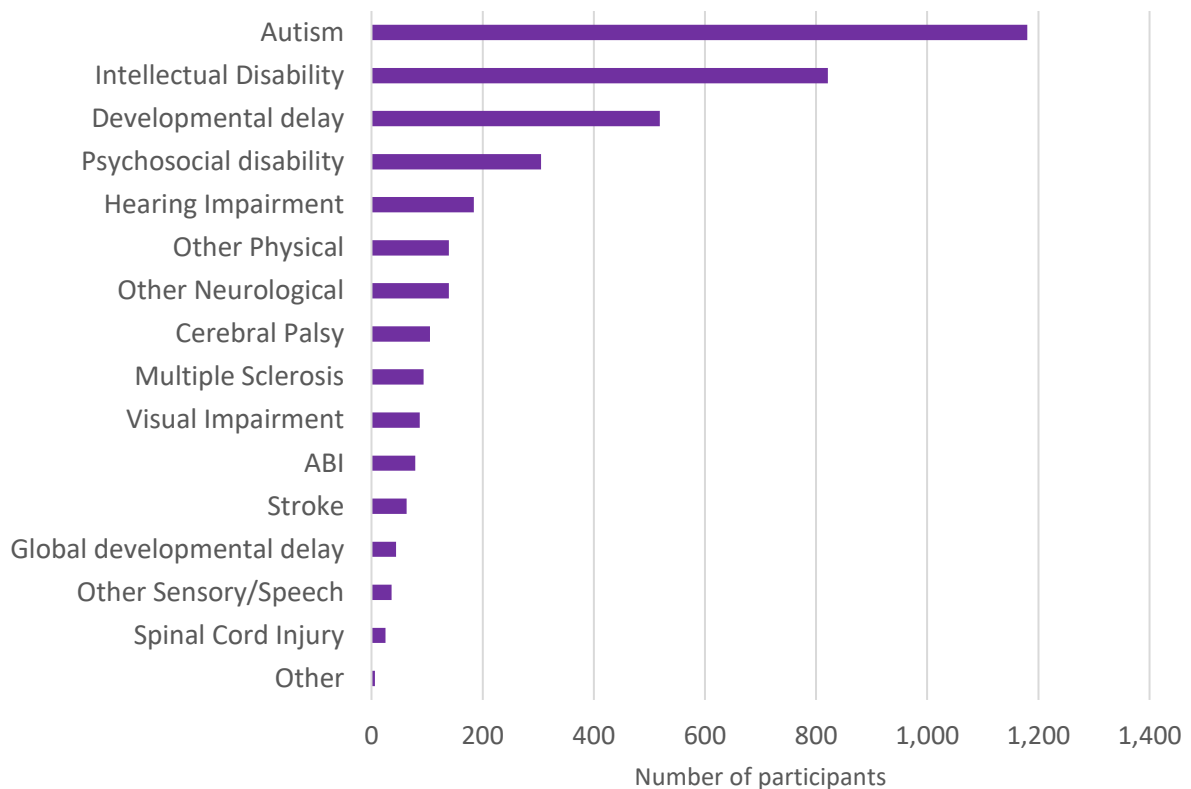
Given that participants with autism and developmental delay are almost exclusively aged 0-18, their greater prevalence in the City of Whittlesea is explained by the younger age profile of the LGA’s population. Psychosocial disability, which is predominantly diagnosed in people aged 35 and older, makes up 8% of City of Whittlesea participants. This is markedly lower than the Victorian average of 13%. Intellectual disability is relatively prevalent in all age groups, comprising an equal share (21%) of NDIS participants in both the City of Whittlesea and Victoria.

Table 1. Headline figures for NDIS participants – City of Whittlesea, September 2020

	City of Whittlesea	% of total	Victoria
Number of NDIS participants	3,826	1.6% (of pop)	1.5% (of pop)
Participants aged 0-18	2,206	58%	49%
Participants with autism	1,180	31%	29%
Participants with intellectual disability	821	21%	21%
Participants with developmental delay	519	14%	10%
Participants with psychosocial disability	305	8%	13%

Source: National Disability Insurance Scheme – External Data Request for the City of Whittlesea (December 2020). National Disability Insurance Scheme, 'Data downloads', 2nd December 2020 (Cited 4th of January 2021).

Chart 3. NDIS participants by primary disability type – City of Whittlesea, September 2020

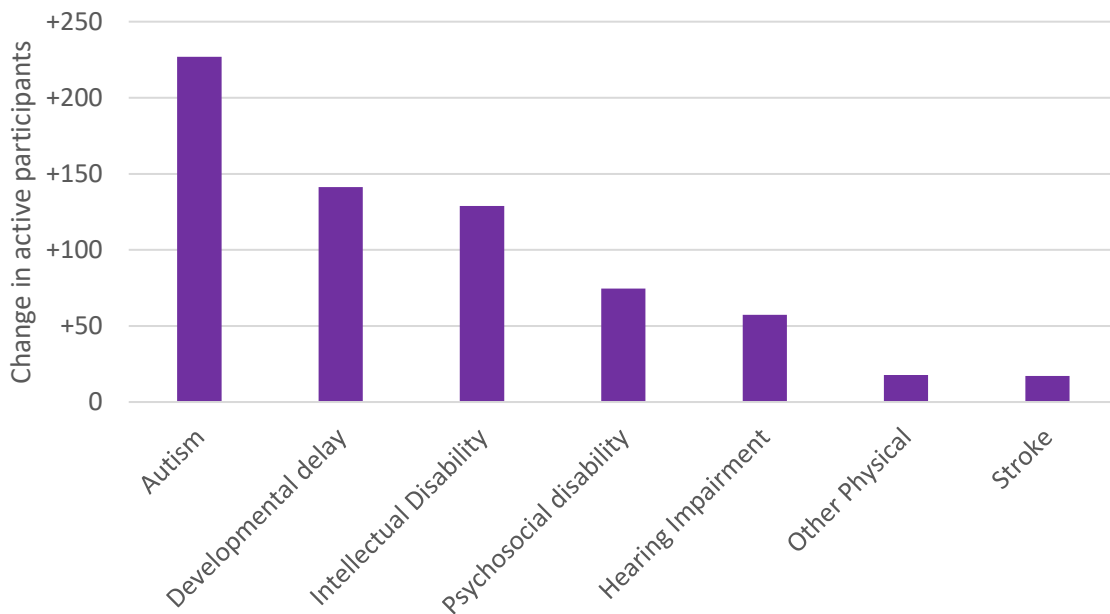


As shown in chart 4, the most prevalent NDIS disability types in the City of Whittlesea were also those that recorded the greatest increases in active participants in the past 12 months. However, of the additional participants, there were more people with developmental delay (+141) than there were people with intellectual disability (+129).

This indicates an increase in the share of overall participants with developmental delay, from 12% in 2019 to 14% in 2020. Meanwhile, there are 227 additional people with autism accessing the NDIS in Whittlesea since September 2019.⁷

⁷ National Disability Insurance Scheme, 'Data downloads', 2nd December 2020 (Cited 4th of January 2021). Available from <https://data.ndis.gov.au/data-downloads>.

Chart 4. Change in active participants by primary disability type, September 2019 - September 2020
- City of Whittlesea



➤ **Affordable family housing options sustain high shares of children and adolescent participants**

The age structure of NDIS participants in the City of Whittlesea reflects a greater share of young participants compared to the Victorian average. In September 2020, there were 2,206 participants aged 0-18, comprising 58% of total participants. This is a significantly larger share than the same age group across the North East Melbourne Area, 47%, and Victoria, 49%.

As discussed, the high rate of youth NDIS participation in Whittlesea is attributed to the young age profile of the City's population. The City of Whittlesea provides significant new housing opportunities that are attractive to young families, thereby sustaining a very large population of children and adolescents. Couples with children comprise 42% of all households in Whittlesea LGA, compared to just 31% across Victoria⁸.

With substantial residential development potential still existing in the LGA's greenfield areas, population forecasts indicate that young families will be the predominant household type in the LGA for years to come⁹. As a result, the larger than average share of youth participants will remain a feature of the NDIS in Whittlesea well in the future.

⁸ Australian Bureau of Statistics, Census of Population and Housing 2011 and 2016. Compiled and presented by .id (informed decisions), (Cited 7th January 2021). Available from <https://profile.id.com.au/whittlesea/households>

⁹ Population and household forecasts, 2016 to 2041, prepared by .id (informed decisions), May 2019 (cited 8th January 2021). Available from <https://forecast.id.com.au/whittlesea/population-age-structure>

Chart 5. Age structure of NDIS participants in the City of Whittlesea, September 2020

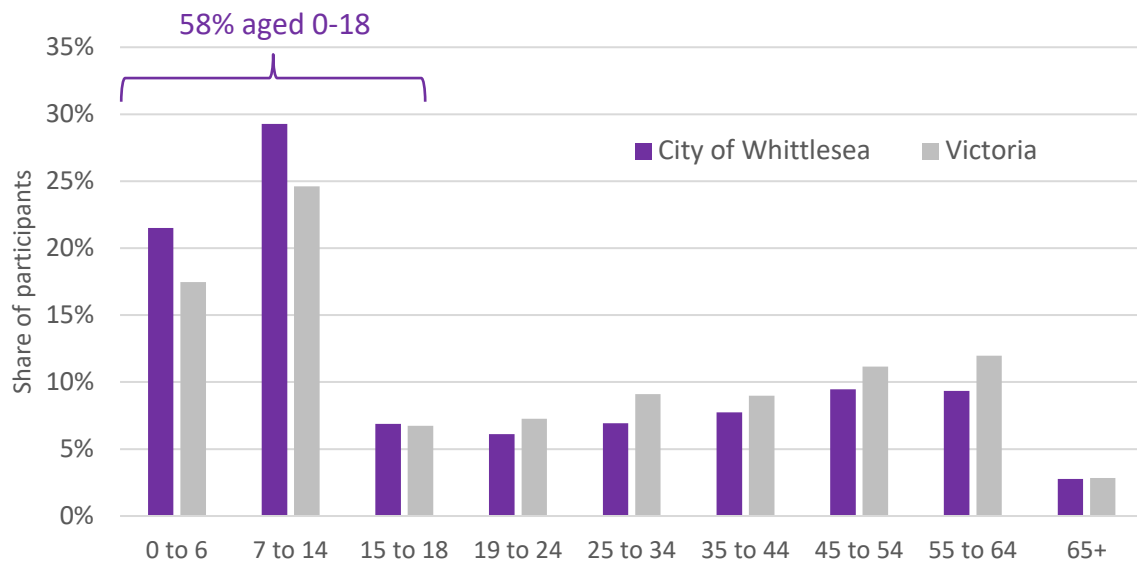
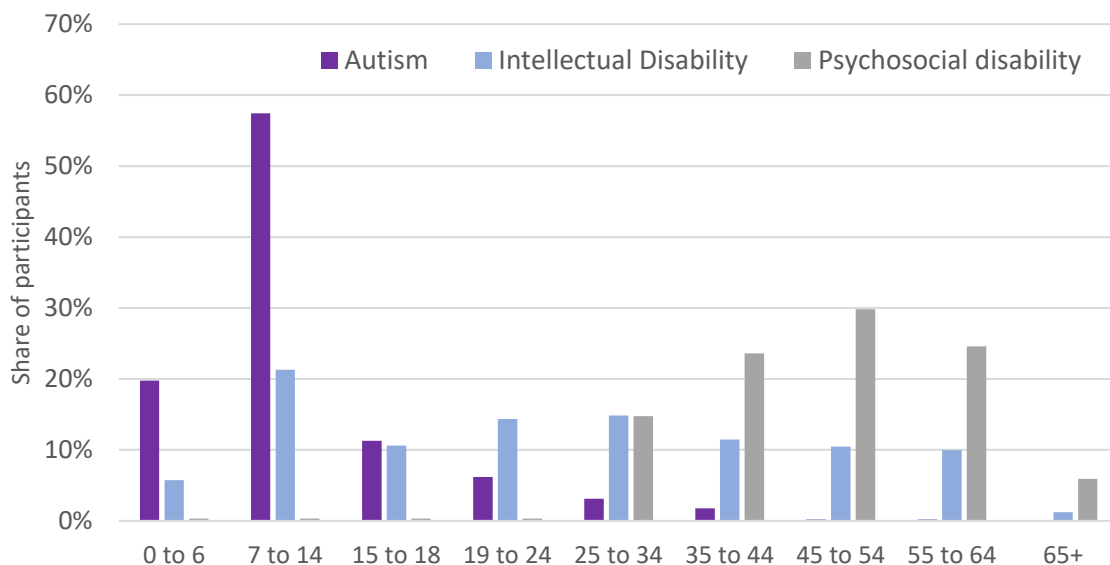


Chart 6 below clearly demonstrates that the age profile of NDIS participants varies greatly across different disability types. For example, 89% of participants with autism are aged under 19, while 60% of participants with psychosocial disability are aged 45 and older. This has clear implications for the design and delivery of disability services in the City of Whittlesea.

Chart 6. Age structure of NDIS participants, selected disability types, City of Whittlesea, September 2020

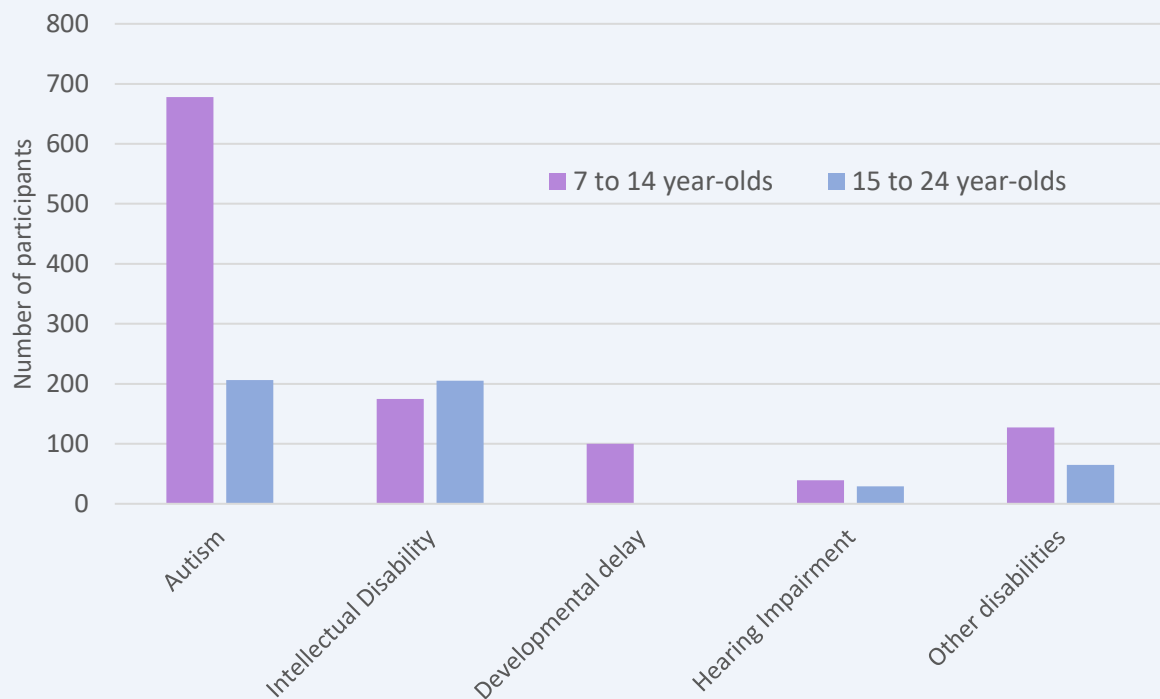


A closer look: youth NDIS participants in the City of Whittlesea

Approximately one in every four NDIS participants in the City of Whittlesea is aged 7 to 14 years old. Of the 1,120 participants in this age group, which encompasses the late childhood to early adolescent stages of life, 61% have autism as their primary disability, while 16% have intellectual disability and 9% have developmental delay.

A further 497 NDIS participants are aged 15 to 24 years old, in the older adolescent and young adult stages of life. Once again, the two dominant primary disability types among people in this age group are autism and intellectual disability. However, in contrast to the 7 to 14 age group, these two disabilities comprise equal shares of participants (41%), as shown in chart 8 below.

Chart 8. NDIS participants by major disability types, selected age groups, City of Whittlesea



Source: National Disability Insurance Scheme, 'Data downloads', 2nd December 2020 (Cited 6th of January 2021).

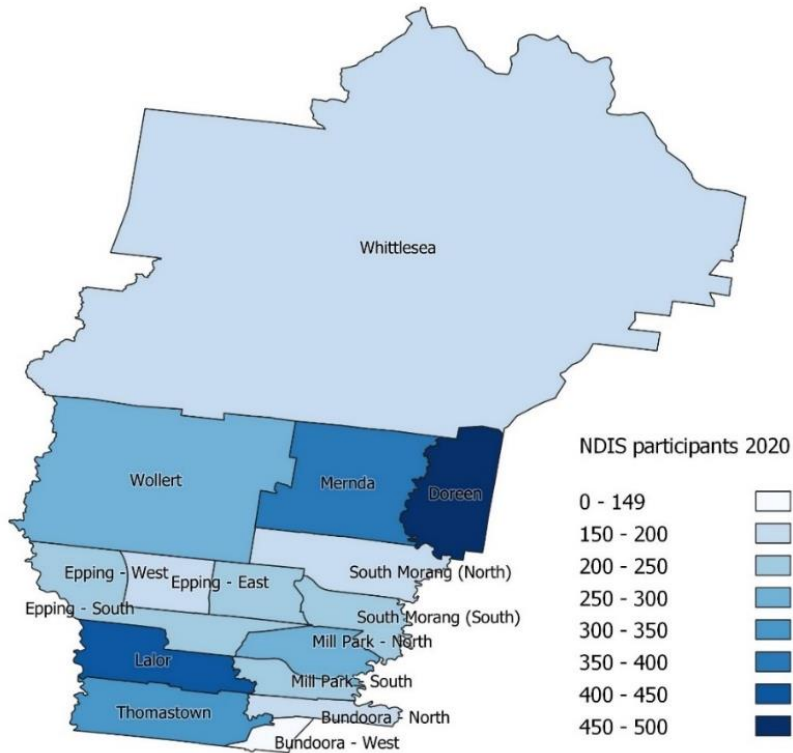
- Two-thirds of participants live in the established suburbs, but demand for services is increasing rapidly in the growth areas and rural north

While NDIS participants live in all parts of the City of Whittlesea, overall demand for NDIS services is higher in some suburbs than it is in others (as shown in Map 1). With 484 participants, or 13% of all participants in the LGA, Doreen was the suburb with the highest number of NDIS participants in the City of Whittlesea in September 2020. It was followed by Lalor, with 418 participants (11%), Mernda, with 370 participants (10%), and Thomastown, with 347 participants (9%).

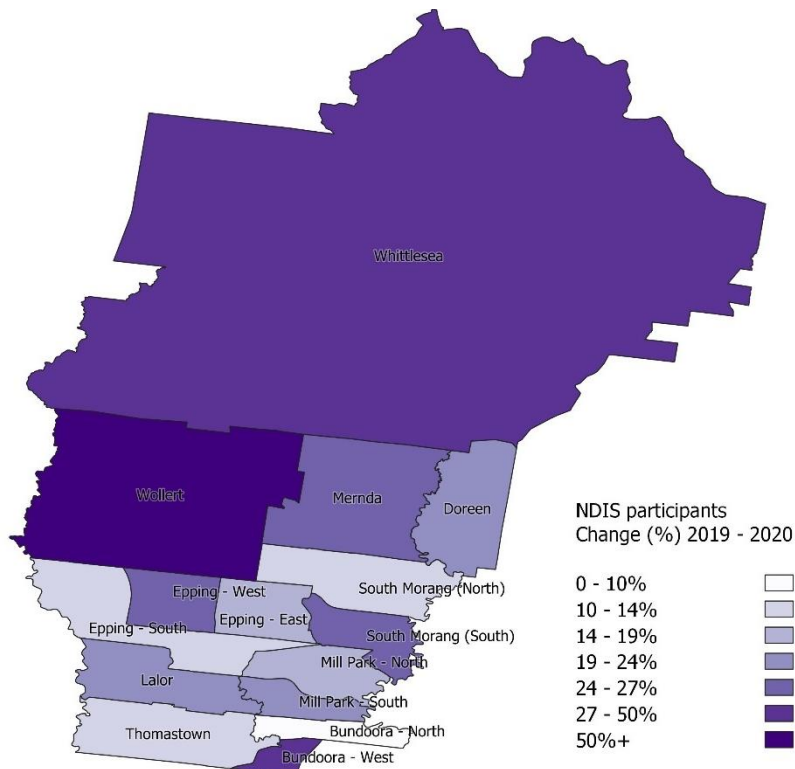
The high number of participants in Doreen and Mernda reflects recent population growth in these suburbs that is driven by rapid greenfield housing development. As Map 2 indicates, there were 93 new participants in Doreen and 76 new participants in Mernda since September 2019.¹⁰ Many of these participants will be young children whose parents have migrated to the area in the past ten years, either from the established suburbs of the municipality, from neighbouring LGAs or from overseas.

¹⁰ National Disability Insurance Scheme, 'Data downloads', 2nd December 2020 (Cited 6th of January 2021). Available from <https://data.ndis.gov.au/data-downloads>.

Map 1. Number of NDIS participants by suburb (SA2), September 2020



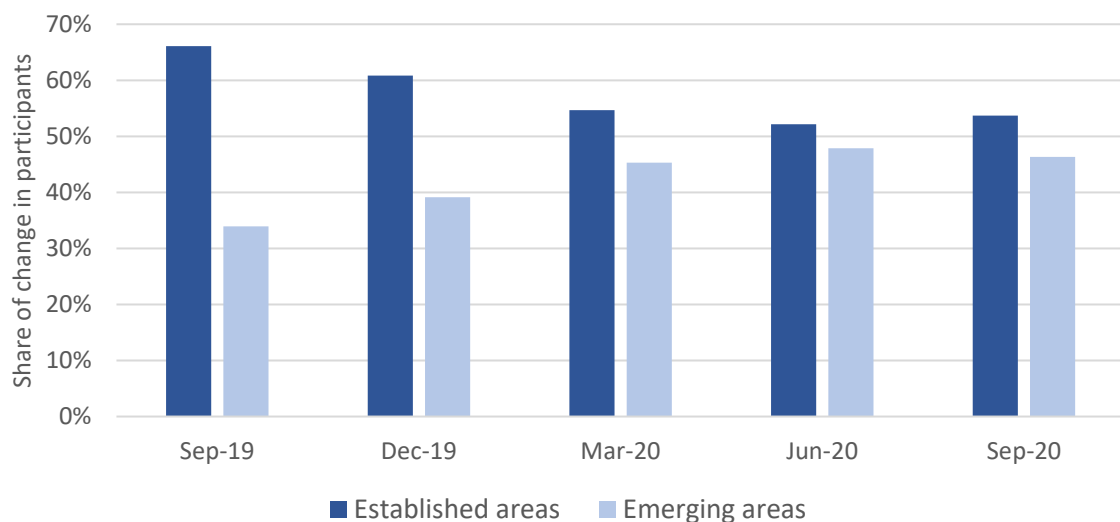
Map 2. Change (%) in NDIS participants by suburb (SA2), Sept 2019 - Sept 2020



What Map 2 also reveals is that, for similar reasons, Wollert emerged as the most prominent growth area for new NDIS participants in the past 12 months. With just 148 participants in September 2019, Wollert gained an additional 115 participants in the subsequent year. This represented 16% of the total change in participants in the City of Whittlesea from 2019 to 2020.

Notwithstanding a substantial increase of 80 participants in Lalor since September 2019, growth in many of the LGA's established suburbs has been modest relative to the existing base of NDIS participants in those areas. Bundoora and Thomastown, for example, recorded increases of just 36 and 39 participants, respectively.

Chart 9. Share of change in NDIS participants in the City of Whittlesea, established vs. emerging areas, 2019-2020



The key insight here is that the epicentre of demand for NDIS services in the City of Whittlesea is shifting in a northward direction. Although the established areas of Whittlesea LGA are home to two-thirds of NDIS participants, chart 9 illustrates that these areas account for a decreasing proportion of additional participants in the LGA.

Conversely, the share of total change in participants in the emerging areas, which include Doreen, Mernda, Wollert and the rural north, rose sharply from 34% in September 2019 to 48% in June 2020. Chart 9 shows that the upward trajectory of growth in the emerging areas was curbed slightly in the most recent quarter. This underlines the disproportionate negative impact of Stage 4 COVID-19 restrictions on people who live furthest from established service centres.

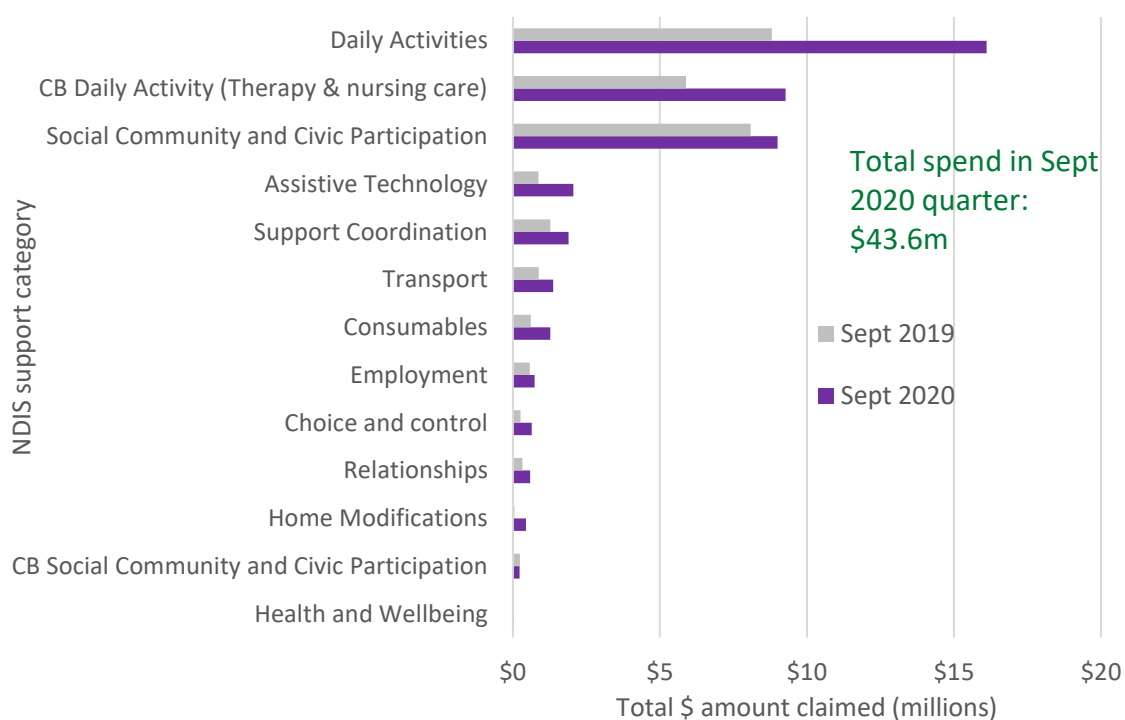
- More than half of claimed NDIS funding is spent on support workers and staff to assist with daily life

Analysis of NDIS participant budget expenditure reveals a predominance of several support areas for participants in the City of Whittlesea. In the July-September 2020 quarter, participants collectively spent more than \$16m on services in the NDIS support category 'Daily Activities'. This includes staff to assist with personal care, household cleaning, yard maintenance and other everyday needs. A further \$8m was spent on services classified under 'Social Community and Civic Participation', which includes support workers to assist participants to take part in activities in the community.

Given the sheer volume of labour required to support these everyday needs, it is not surprising that these categories attract such a large share of NDIS funding. What is interesting, however, is the dramatic rise in expenditure in 'Daily Activities' in September 2020, compared to the previous year. This represents an increase of 83% since September 2019.

In contrast to the more modest growth (58%) in 'Social Community and Civic Participation' (11%) and 'CB Daily Activity', which includes most therapy services, the sudden growth in 'Daily Activities' spending appears to signify the impact of COVID-19 on participant budget utilisation. When physical movement was restricted and many therapists suspended their services, participants spent more funding on services to support them at home. As more data becomes available throughout 2021, it will be possible to determine with more certainty if this is an ongoing trend.

Chart 10. Total participant spend (\$) by NDIS support category, City of Whittlesea, Sept 2019 and Sept 2020 quarters



5. NDIS demand forecast – 2020-2023

Looking to the future – a forecast scenario for the NDIS in June 2023 – City of Whittlesea

This section presents a forecast of NDIS participants in the LGA in June 2023. Produced by Whittlesea City Council, the forecast reflects assumptions about future growth in overall participation, as well as trends in age and disability types.

NDIS participant forecast methodology:

- **Base data:** The forecast uses current (September 2020) NDIS data as a base.
- **Population forecast:** Population forecasts are used to determine the number of people who will live in the City of Whittlesea, by age group, in June 2023.¹¹
- **NDIS prevalence rates:** Rates of prevalence, by age group and primary disability type, are adjusted to reflect evidence-based assumptions about likely future trends in NDIS participation in 2023.
- **Assumptions:** Assumptions about future trends are informed by current available evidence, including:
 1. Analysis of local demographic and residential development trends.
 2. Analysis of historical NDIS data for Whittlesea LGA and across Victoria.
 3. Insights from Department of Social Services NDIS Demand Map forecasts.¹²
 4. Research on rates of prevalence and NDIS eligibility by disability type.

Council forecasts that 6,088 NDIS participants will live in Whittlesea LGA in June 2023. This represents an increase of 2,262 participants from September 2020.

Key forecast assumptions:

- **In June 2023, one in every 42 people in the City of Whittlesea will be an NDIS participant.** The rate of NDIS participation will increase between 2020 and 2023, from 1.6% to 2.4% of the LGA population.
- **The number of NDIS participants will grow at an average of 201 additional participants per quarter,** slightly faster than 191 per quarter from September 2019 to September 2020.
- **The share of youth participants will increase further,** driven by the continued in-migration of young families to the municipality.
- **Significant growth in participants with autism, developmental delay and psychosocial disability,** with these three groups comprising larger shares of all participants in 2023.
- **Participants with intellectual disability will grow at a slower rate,** decreasing its share of all participants over the next three years.

¹¹ Population and household forecasts, 2016 to 2041, prepared by .id (informed decisions), May 2019 (cited 8th January 2021). Available from <https://forecast.id.com.au/whittlesea>.

¹² Department of Social Services, 'NDIS Demand Map', 2020 (Cited 16th of October 2020). Available from <https://blcw.dss.gov.au/ndis-demand-map/>.

Table 2. Forecast summary – NDIS participants in the City of Whittlesea, 2020-2023

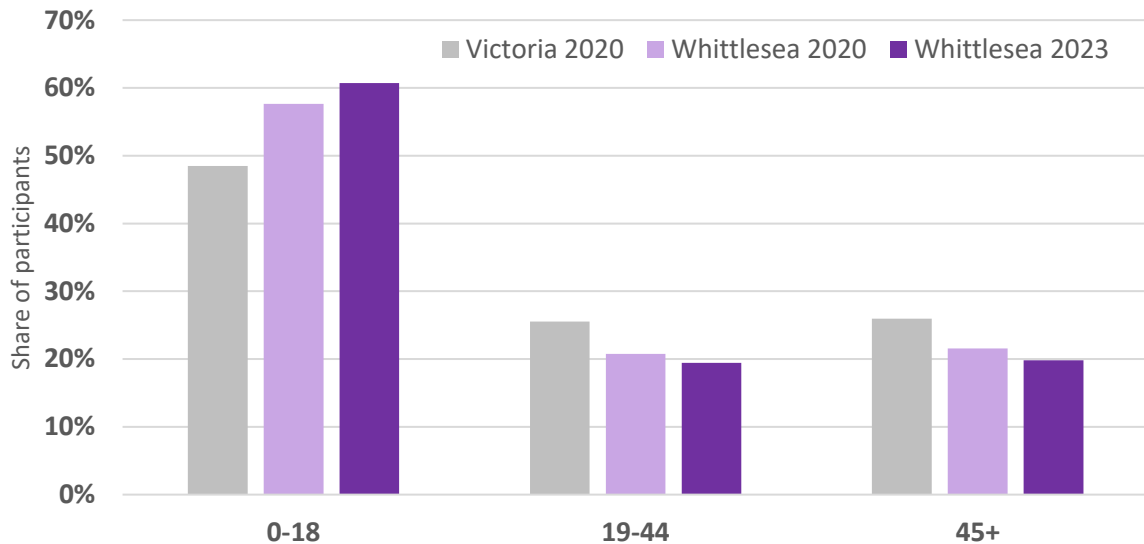
	Current - September 2020	% of total	Forecast - June 2023	% of total	Change 2020-23
Number of NDIS participants	3,826	1.6% (of LGA pop)	6,088	2.4% (of LGA pop)	+2,262
Participants aged 0-18	2,206	58%	3,696	61% ▲	+1,490
Participants with autism	1,180	31%	2,031	33% ▲	+851
Participants with intellectual disability	821	21%	1,028	17% ▼	+207
Participants with developmental delay	519	14%	948	16% ▲	+429
Participants with psychosocial disability	305	8%	579	10% ▲	+274

➤ **Forecast:** the young age profile of NDIS participants in the City of Whittlesea is a trend that is set to continue

The proportion of participants aged 0-18 is forecast to increase from 58% to 61% of all participants by June 2023. Forecasts of residential development indicate that there is potential for up to 5,000 new dwellings to be constructed in Doreen, Mernda, Epping, Wollert and Donnybrook in the period 2021 to 2023¹³. These housing opportunities will predominantly attract young families, thereby maintaining a large population of children and adolescents who access the NDIS.

¹³ Population and household forecasts, 2016 to 2041, prepared by .id (informed decisions), May 2019 (cited 8th January 2021). Available from <https://forecast.id.com.au/whittlesea/residential-development>

Chart 9. Current and forecast age profile of NDIS participants – City of Whittlesea, 2020-2023



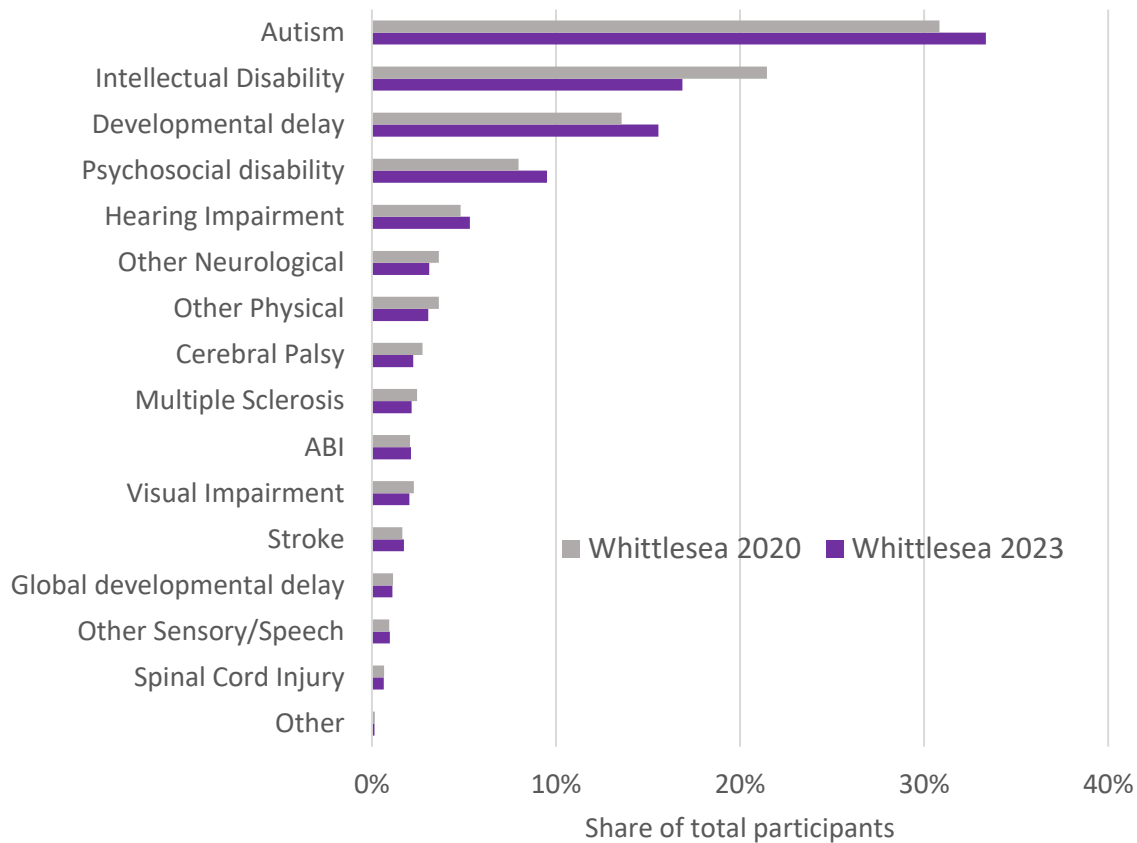
- **Forecast:** significant increase in demand for services related to autism, and developmental delay

As discussed, the age structure and disability profile of NDIS participants are intimately linked. The number of participants with developmental delay is forecast to reach 948 by 2023, an increase of 429 people, or 83%. The increasing participation of young children in the NDIS in the City of Whittlesea is the major factor underpinning the rapid growth in this disability type.

Similarly, the City’s young age structure is playing a significant role in the increasing predominance of autism. However, the forecast growth in this disability type is also supported by evidence that the rate of diagnosis of autism is rising substantially¹⁴. In other words, not only will many more children live in the City of Whittlesea by 2023, but a larger share of those children will be diagnosed with autism and access the NDIS as a result.

¹⁴ Centre for Disease Control and Prevention, ‘Data & Statistics on Autism Spectrum Disorder’, 25th of September 2020 (Cited 8th of January 2020). Available from <https://www.cdc.gov/ncbddd/autism/data.html>.

Chart 9. Current and forecast NDIS participants by disability group – City of Whittlesea, 2020-2023



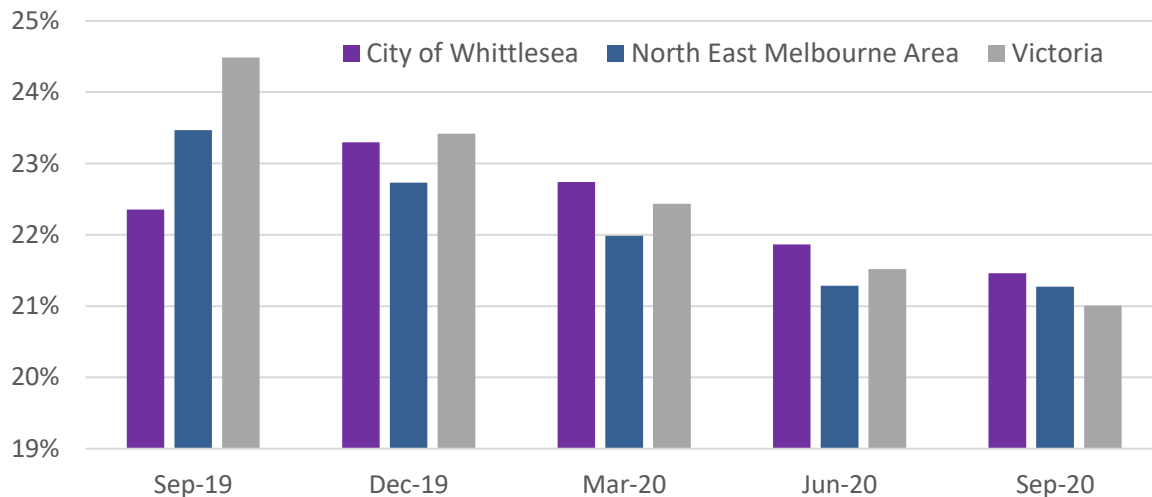
➤ **Forecast:** steady decrease in prevalence of intellectual disability

The relative significance of intellectual disability as a primary disability type is declining in the City of Whittlesea. While the absolute number of people with intellectual disability is, like all disability types, growing, the share of total NDIS participants in this disability group is steadily decreasing in Whittlesea LGA, the North East Melbourne region, and Victoria (as shown in chart 10).

This is influenced by the decreasing rate of eligibility for the NDIS of people with intellectual disability. According to the NDIA, as more people approach the Scheme who did not receive disability services prior to the NDIS, the impact of NDIS phasing arrangements will be diminished. As a result, fewer people with intellectual disability will be deemed eligible to access the Scheme.¹⁵ By June 2023, it is assumed that the share of total participants with intellectual disability will fall to 17%.

¹⁵ National Disability Insurance Scheme 2019, *People with an intellectual disability and the NDIS*, NDIS, Canberra.

Chart 10. Share of NDIS participants with intellectual disability – City of Whittlesea, North East Melbourne and Victoria



➤ **Forecast:** faster growth in participants with psychosocial disability

The other major change that is forecast is the increasing uptake of NDIS plans by people with psychosocial disability. Indeed, in the past year the share of participants with primary psychosocial disability in Whittlesea LGA has grown slowly, but surely, from 7.4% in September 2019 to 8% in September 2020. It is forecast to reach 10% by June 2023.

The reasons for this trend are twofold. First, there is evidence to suggest that psychosocial disability is afflicting an increasing number of people in Australia. Just as with autism, rates of prevalence of psychosocial disability grew between 2015 and 2018.¹⁶

Second, rates of eligibility for the NDIS for people with psychosocial disability are also on the rise¹⁷. While these rates are still reflective of NDIS phasing arrangements, it is assumed that the growth in psychosocial disability will be less affected by declining eligibility compared to other disability types.

This assumption is supported by NDIS demand forecasts produced by the Department of Social Services¹⁸. The forecasts indicate an acceleration of growth in the number of participants with mental health related disabilities across postcodes in the City of Whittlesea, in the next three years. Furthermore, it seems likely that the mental health effects of COVID-19 will increase demand for psychosocial disability services into the future, although the lasting impact of the pandemic remains to be seen.

¹⁶ Australian Bureau of Statistics, 'Psychosocial disability', 25th of September 2020 (Cited 8th of January 2020). Available from <https://www.abs.gov.au/articles/psychosocial-disability>.

¹⁷ National Disability Insurance Scheme 2019, *People with an psychosocial disability and the NDIS*, NDIS, Canberra

¹⁸ Department of Social Services, 'NDIS Demand Map', 2020 (Cited 16th of October 2020). Available from <https://blcw.dss.gov.au/ndis-demand-map/>.

Besides the growth or decline in the rates of participation among the four most prevalent disability types, only very modest changes to the NDIS profile of Whittlesea LGA are forecast (as shown in chart 9 above). These assumptions are informed by NDIS demand forecasts, analysis of historic trends and a comparison to regional and state benchmarks.

A note on the forecast:

This forecast represents Whittlesea City Council's assumption about the most likely future direction for the NDIS in Whittlesea LGA. This is based on the evidence available at the present time and may be subject to change as more up-to-date evidence becomes available. The purpose of the forecast is to support evidence-based advocacy and NDIS service planning.

Whittlesea City Council accepts no responsibility for decisions made based on this forecast. If you have further questions about the forecast, please contact the Council's Access Team.

6. Consultation findings

This section presents the findings of the qualitative research and is organised into the following sections:

- Participant and Carer Survey
- Choice and availability of services
- Age-specific service needs
- Quality of services
- Service needs of Aboriginal and Torres Strait Islander participants
- Supply in growth areas and the rural north
- Barriers faced by participants from Culturally and Linguistically Diverse backgrounds
- Impact of COVID-19 on participants' access to services
- Other findings about the experience of participants and carers

These findings are the result of consultations that were undertaken through the following methods:

- Focus group discussions with Local Area Coordinators
- Interviews with NDIS participants and carers
- Online survey for NDIS participant and carers

In discussing the consultation findings, this report privileges the quotes from research participants in order to maintain their direct voices.

NDIS Participant and Carer Survey

Introduction to the survey

The NDIS Participant and Carer Survey was open for a period of six weeks and received 34 responses from City of Whittlesea residents. Two of the respondents were participants themselves, while the remaining 32 respondents were carers who gave responses on behalf of the participants they care for.

Although a range of disability types were represented in the survey, the most common disabilities were intellectual disability, with 19 responses, and autism, with 17 responses. The results indicated that many of the participants have two or more disabilities.

Regarding the age of participants, the responses reflected a strong weighting towards the older age groups. With only two responses given for participants aged 0-18, one limitation of the survey is that it does not accurately represent the age profile of NDIS participants in the City of Whittlesea.

Top disability types of survey participants

Intellectual disability	19
Autism	17
Other physical disability	7
Developmental delay	6
Global developmental delay	6
Other	5
Cerebral palsy	4

Age of survey participants

0 to 18	2
19 to 24	1
25 to 44	9
45 to 64	9
65+	8
N/A	5

Survey participants lived throughout Whittlesea LGA. Mill Park was selected more than any other suburb, six times, while five participants lived in Doreen-Mernda, four lived in Epping and four lived in Whittlesea Township and Surrounds. There were no respondents from Thomastown or Wollert. One of the participants is an Aboriginal person, while two participants indicated that they speak a language other than English at home.

➤ 'Before COVID-19, how easy was it to access all the services funded in your NDIS plan?'

When asked how easy it was to access services before COVID-19, overall participants gave a very balanced response. It is notable that no respondents found it either 'very difficult' or 'very easy' to access the services funded in their NDIS plans. That being said, more than half of all respondents indicated either that it was 'difficult' (32%), or 'neither easy nor difficult' (24%).

This suggests that a large portion of NDIS participants in the City of Whittlesea face significant barriers to accessing the services they are funded to receive.

Response	No.	%
Very difficult	0	0%
Difficult	11	32%
Neither	8	24%
Easy	15	44%
Very easy	0	0%
Total	34	100%

'As there is far more demand than supply, they have no reason to need to attract and retain consumers'

[Survey respondent]

The remaining survey results are presented in the following sections, alongside findings from the focus groups and interviews.

Choice and availability of services

Key findings:

- Demand exceeds supply among a range of NDIS service types in the City of Whittlesea.
- With limited choice and availability of services, NDIS many participants will face long waiting times to access services, or they will access a service that does not meet their needs. In too many cases, participants cannot access services altogether.
- The most evident thin markets are in the therapeutic support services. Participants face limited options in the areas of occupational therapy and speech therapy, as well as psychology, physiotherapy and therapy assistance.
- There is a shortage of behavioural support and specialist behavioural intervention services.
- There is unmet demand for services that cater to specific complex needs or more than one disability type.

Throughout the research, it became clear that difficulties finding or accessing services in the City of Whittlesea is a major factor preventing NDIS participants from achieving their goals. Even for those participants who reported a positive experience on the NDIS, most people had at some stage faced challenges related to the choice and availability of services.

In particular, the consultations identified service supply gaps across the major therapeutic supports, as well as in behavioural intervention services and services that cater to participants with specific complex needs or more than one type of disability. These issues are explored below.

Survey result:

When asked about challenges people have faced to accessing services, the most common issues respondents selected were:

- | | |
|---|----------|
| • Lack of choice of services in my area | 14 (54%) |
| • Long delays and waiting times | 13 (50%) |
| • Lack of Information about services | 9 (35%) |
| • Poor quality of services | 8 (31%) |

Survey respondents said:

'As there is far more demand than supply, they have no reason to need to attract and retain consumers'

'Staff changes and shortages caused many problems. Hard to find an accurate local directory. Not easy to find providers and get to them when you have 3 NDIS plans in the household and balance other day to day tasks'

Therapeutic support services

A consistent theme highlighted in the consultations was the shortage of NDIS service options in key therapeutic support categories in the City of Whittlesea. Overall, the services that the participants have most trouble accessing are occupational therapy and speech therapy, although they also face limited choice in the fields of physiotherapy, psychology and therapy assistance. As one LAC remarked:

'it is in the allied health space that we are lacking supply'.

These therapeutic supports were repeatedly highlighted by participants, carers and LACs as services with busy schedules, long wait lists and a high turnover of staff.

➤ **Long waitlists for therapists**

The LACs in every focus group reported persistent challenges in finding local therapy providers who could take on new participants. Generally, participants would face a wait of between three and six months for a first session with a therapist, although during COVID-19 it was not uncommon to experience waiting times up to 12 months. One LAC gave an example of this challenge:

'There are long waiting lists for those who have to wait for a psychologist. I had one [participant] who had to wait for 11 months'.

The following comment, from a carer who lives in Whittlesea Township, reinforces this point, illustrating the perspective of several of the interviewees:

'I've been looking for a new speech therapist for almost 12 months and I just can't get into one'.

Far from having a range of options to choose from, some participants are left to try every service provider and hope for the best. As one carer put it:

'When there's absolutely no availability we look elsewhere to see if there is any other option. They generally all have waitlists, so often it's about being on numerous waitlists and then seeing who offers a place first'.

Failing this, one LAC suggests that people will be forced to travel further afield to find these key therapy supports.

'With a lot of OT and speech, and psychology services, because there are waiting lists, out of desperation parents are willing to go to other suburbs so that the needs are met'.

'You need a relationship with a therapist. It's not the same as buying something from a retail outlet'

[Carer]

Survey result:

Of the 27 survey respondents who have NDIS funding for therapy, behavioural management support, or services providing group and centre-based activities, respondents indicated that they had trouble accessing the following service types:

- Occupational therapy 12 (44%)
- Speech therapy 12 (44%)
- Psychology 7 (22%)
- Physiotherapy 6 (19%)

Survey respondents said:

'Staff shortages and staff not working full time. Lack of suitable after school hours appointments. Staff not reading existing notes before asking basic questions.'

'Waiting lists of convenient services for speech therapy, not accessed any over a 2-year period.'

'Waiting Lists for therapists that see older teenagers.'

➤ **Staff turnover and a lack of consistent care**

A high turnover of therapy staff was also highlighted as a significant challenge preventing participants from making meaningful progress on the NDIS. The following comment was typical of the experiences expressed by several of the interviewees.

'It's been a bit tricky getting psychologists in our area...there's a lot of movement in the sector, people moving in, moving out, going on leave, maternity leave, people will only work in a certain location on a certain day of the week.'

Even when occupational therapists, speech therapists or psychologists are available, there is no guarantee that these providers can offer the right standard of continuous care for participants. As one LAC pointed out:

'there's always people leaving organisations, there's not a continuation of service with the same therapist. So people don't like that obviously, they've got to start over again'.

A carer explained why a lack of continuity with the same therapy provider is a huge barrier for participants.

'You need a relationship with a therapist. It's not the same as buying something from a retail outlet. You're spending time with someone and they're working on helping you help yourself with building skills. That's something that requires building rapport'.

➤ **Limited access to therapy stifles participants' progress**

Access to limited service options clearly has a significant negative impact on NDIS participants. According to several participants and carers, inability to engage with occupational therapy, psychology and speech therapy services meant they had seen little or no change in their capacity to lead an independent and fulfilling life.

Another concern expressed by interviewees was that their inability to utilise their plan funding would result in a reduction of their budgets. This frustration is reflected in the following comment.

'When it's time for the plan to be renewed again, it's always a reflection on us that we're not doing what we should be doing for our child because there's still an abundance of money there. But if you can't engage with services, you can't spend the funds.'

Behavioural support and specialist behavioural intervention services

It was clear from the focus groups that the LACs observed significant issues engaging participants with providers who deliver behavioural support and specialist behavioural interventions services. Given the highly specialised nature of specialist behavioural intervention services, which need to be provided by a specific psychologist, this service is in particularly high demand in Whittlesea LGA.

The LACs consistently stated that accessing these specialists is an ongoing challenge in their work, and often resulted in waiting times for participants of more than six months. One LAC summed this issue up:

'the immediate availability of service providers of that service in the Whittlesea region is too small'.

Another LAC commented on the perceived service gaps in the field of behavioural supports:

'I had a participant who I had great difficulty engaging with behavioural supports because there are very limited services available in the LGA. When I contacted the service provider, they straight away said that they don't have any capacity and they cannot take any further [participants] so I had to engage that participant to a different LGA'.

For one carer who responded to the survey, the options people face in the area of behavioural support may depend on their age.

'It was difficult to find a behaviour therapist due to my son's age. He requires his Behaviour Support plan to be properly written and updated and requires support. Again the behaviour therapist only wanted to work with young children'.

Survey result:

Of the 27 survey respondents who have NDIS funding for therapy, behavioural management support, or services providing group and centre-based activities, respondents indicated that they had trouble accessing the following service types:

- Group activities in the community 13 (48%)
- Group activities in a centre 9 (33%)
- Specialist behavioural intervention support 6 (22%)
- Training in behaviour management 5 (19%)
- Training for carers/parents 3 (11%)

Survey respondents said:

‘My son was not accepted into any day group activities in [local organisations] because he requires 1:1 support and has funding for it but all places didnt have the resources to provide 1:1.’

‘There is a lack of group activities for teenagers. There is a couple of groups out there, but they are so in demand and booked out, we always miss out.’

Services for participants with specific complex needs or more than one disability type

Another issue related to the supply of NDIS services in the City of Whittlesea is the availability of highly specialised services that cater to participants with specific complex needs.

➤ Challenges finding therapists with specialist knowledge and expertise

Although the local market may appear to offer a range of therapy options, the interviews indicated that many participants will try multiple therapists in search of one with the specialist skills to meet their needs. For one participant, while it has been relatively easy to access occupational therapists, engaging with therapists who understand their specific disability type has been a significant challenge.

‘Some OTs would be well versed with what my needs are, most wouldn’t. I found OTs more difficult to get’.

As the above comment suggests, the lack of specific knowledge and expertise among therapists was raised as an important concern by participants and carers. A carer described the difficulties they have experienced in finding a speech therapist with the appropriate level of skill to support their child, who is non-verbal.

'I had a speech therapist but she just wasn't meeting our needs. So I guess that's the other concern, a lot of the speech therapists have training in working with children with autism who speak. What I'm finding a lot these speech therapists don't have training in working with children who are non-verbal at this age'.

➤ **Services to support people with more than one type of disability**

Similarly, the consultations identified a shortage of local organisations that can effectively provide care to people who have more than one type of disability.

In one focus group, the LACs highlighted the lack of speech therapy and behavioural psychology services that are specialised enough to support children who have both autism and intellectual disabilities. Similarly, an LAC in another group pointed out:

'there are hardly any services that accommodate adults with autism and psychosocial disabilities...they can cater to one, not the other.'

The service options are very scarce for participants with complex care needs related to having two or more disabilities. Further, many NDIS services are too generalised and do not focus on the particular needs and experiences of different groups of people with disability. One LAC remarked:

'trying to find therapists, for example speech therapist who are trained to support participants who have hearing loss...I've had participants who have had to travel outside Whittlesea to find a specialised speech therapist to help them'

In addition, the focus groups found that there is unmet demand for specialised psychology services for children, for people with hearing impairments, for people with autism, or for people from Culturally and Linguistically Diverse backgrounds.

Survey result:

Of the 20 survey respondents who have NDIS funding to purchase assistive technology or personal care products, respondents indicated that they had trouble accessing the following service types:

- | | |
|--|---------|
| • Personal mobility equipment | 7 (35%) |
| • Personal care, bathing and bed equipment | 5 (25%) |
| • Continence items | 3 (15%) |

Survey respondents said:

'It took ages to find out what the best hearing devices were for me and how to get a local supplier.'

'Every Occupational Therapist contacted is unable to measure/fit wheelchairs for children/teenagers.'

'I wanted to learn how to lip read from a person rather than a computer program but no-one could tell me where to find this type of training'.

Age-specific service needs

Key findings:

- The age of participants is a crucial factor that informs the way NDIS services are designed. Participants in the adolescent and young adult stage of life (12-25) require services that are designed specifically for their needs.
 - Adolescent and young adult participants face limited options for age-specific therapy supports, individual skill development and group social activities.
 - Given the very large share of NDIS participants aged 0-14, pressure on this service gap will increase substantially in the next 5-10 years.
-

A consistent finding throughout the research is that there is an undersupply of services for adolescent and young adult participants in the City of Whittlesea. The point was repeatedly made that participants in these age groups face limited options across therapy supports, individual skill development and group social activities.

One of the causes of this service gap is that service providers tend to target the early childhood age groups (0-6) where there is more NDIS funding. The following comment is one of many from the survey and interviews that highlight this area of unmet need.

'There are services in the area, but the majority are all very in-house services and very focused on early intervention and young children. I have 2 teenagers on the Autism spectrum. To be able to get them into local services with qualified staff is not easy.'

The research also found that the lack of flexibility of therapy service providers further constrains the supply of services for older children and adolescents, which is a dominant market in the City of Whittlesea. While adolescent and young adult participants often require sessions in the evenings and on weekends, many therapists are unavailable during these times. This increases competition for appointments, as one carer suggested:

'Once [my daughters] were school age, we wanted sessions outside of school time, and of course everyone wants that as well, so it was tricky getting a regular fortnightly appointment'.

On top of this, the LACs commented that

The significance of this issue is further emphasised in the following comments from LACs.

'According to my experience this age group is very crucial where we are finding it very difficult to engage them, starting from teens to mid-20s or 30s'.

'Adolescent kids especially, whenever I am doing a review meeting, if they have funding for skills development in a group, that area of funding has not been utilised, because I hear from parents that it is impossible to find group skill development sessions that are catered for adolescent kids,

'I hear from parents that it is impossible to find group skill development sessions that are catered for adolescent kids'

[LAC]

from 10-19. So we hear frustration from the parents because they can't find those services in their area'.

'Demand is much higher than supply. You can clearly see that in things like high school children with Autism and other disabilities. Supports for that age range, I guess, that adolescent age, there's not much supports around especially here in Whittlesea. It's a really big gap.'

'Age 12-17 I have felt that there is a gap when it comes to social participation for that age group and a lot of other services, like specialised psychology.'

Case study: a long and complex journey

Janet* lives in Lalor with her husband and two daughters, Sarah* and Courtney*, both of whom access disability services through the NDIS.

Back in 2016, Sarah and Courtney were among the first City of Whittlesea residents to enter the Scheme. Janet remembers how relieved she felt to have access to support workers and therapy to support her daughters, who are now in secondary school. Given that her husband is the sole income earner in their household, this funding lifted a huge financial burden on their family.

Challenges with the NDIS planning process and accessing services

Despite the benefits, Janet and her family's journey on the NDIS has rarely been easy. From the beginning, it was difficult to understand the complex planning process and manage the paperwork. When her daughters' support worker funding was reduced on the second plan, Janet struggled to get reports from therapists to demonstrate the need for additional support. She believes that participants deserve more transparency when funded supports are changed.

In the past, Janet has also been frustrated by the shortage of therapy service options in the Whittlesea area. *'There are long waiting lists for both occupational therapists and psychologists, and possibly for speech therapists. Even though there are more of them around now, they seem to be mostly helping the younger kids.'* Janet added that a high staff turnover and a lack of flexibility among service providers have made it more difficult to access therapists.

'It's been a long journey'

After a lot of effort, Janet found a therapy clinic near their house that met Sarah and Courtney's needs. She also managed to advocate for more support worker funding to take the pressure off her and her husband. *'It has taken to plan number five before we have been given enough funding to have a support worker there a lot of the time...now we've finally got a good plan'*.

Now on their fifth NDIS plans, Sarah and Courtney are making good progress towards their goals. With support from a speech therapist and psychologist, the daughters have developed their organisational and communication skills. An occupational therapist is helping them to better understand their joints and flexibility. During COVID-19, Sarah and Courtney have maintained their therapy by taking part in online appointments.

Alongside consistent therapy, having access to skilled support workers has made a huge difference to Sarah and Courtney's lives. *'The girls like going out places with support workers rather than their parents. They're watching out for safety and care, but they also act as a friend'*.

Families need more support to understand the system

Although the NDIS is finally working well for Janet's family, it has taken a lot of patience to reach this point. She is concerned that not all families have the capacity to navigate the Scheme like she has. Janet believes the NDIA needs to listen to carers and support them earlier in the process, to help other participants enjoy the opportunities that Sarah and Courtney now have.

*names have been changed

Quality of services

Key findings:

- The quality of NDIS services varies greatly in Whittlesea LGA. It is difficult for participants to know which providers are delivering a high standard of care.
 - Participants and LACs depend on therapists' reports to assess the need for more support. Often these reports do not offer meaningful insights, thereby delaying participants' progress.
 - Many support workers are not trained to support people with complex needs, or they simply provide a low standard of care. This is particularly true in the case of staff from agencies.
 - Service quality issues are closely linked to thin markets and a lack of competition or consumer choice.
-

In addition to issues with the availability of NDIS services, a prominent theme raised in the consultations was the variability in the quality of services in the City of Whittlesea. Even when a participant can access the supports that are funded in their plan, there is evidence to suggest that many service providers are not delivering a high enough standard of care to meet participants' needs.

Of course, the issues of choice and quality of services are closely linked. The LACs agreed that a greater number of providers will lead to a more competitive NDIS market, in turn engendering higher quality services.

'We can send someone to, let's say, a speech pathologist, but do we know that is a quality person? We don't. We need more people, more providers in the region, so we can provide people with more choices'.

'We need more people, more providers in the region, so we can provide people with more choices'

[LAC]

➤ **Poor quality of therapists' reports**

The focus groups and interviews revealed a lack of professional rigour and insight in the reports provided by therapists. According to two of the carers interviewed, in some cases therapists' reports are not of sufficient quality to demonstrate the need for more support, thereby delaying the provision of additional funding to NDIS participants.

'I've historically tried to access different services and had a lot of therapists who didn't know what to do with [my daughter]. I got a bit sick of dealing with people who would just come to me all the time and basically write up a report based on what I told them'.

The LACs rely on therapists' reports about participants to gain insight into the quality of the service being provided. In some cases, these reports offer limited evidence of functional impact or opportunities for meaningful progress. According to the LACs, this is particularly true in the area of occupational therapy.

'They might actually provide a detailed report but it's still not realistic and it sets unrealistic expectations for participants and their families'.

'When the recommendations of funded supports are quite excessive, it demonstrates their inability to be meeting their needs in a timely manner'.

➤ **Skill and standard of care provided by support workers**

An issue that arose repeatedly throughout the research is the quality of service provided by support workers. Even in areas where this service is well-supplied, a challenge for participants is knowing how to find support workers who offer a high standard of care. One survey respondent, who has experience working in this sector, said the following:

'I have worked in disability support for 24 years. Quality is not a priority. We have good supports because of contacts I made during my working life. It shouldn't be this way. There is not quality checks by a totally independent authority'.

Research participants also highlighted a shortage of one-to-one support workers who are skilled enough to support people with complex needs. As one carer indicated:

'Complex behaviour is really difficult to manage and there doesn't seem to be a lot of support workers out there who have knowledge around how to support people with complex behaviours in a positive way. So I think that's a bit of a gap'.

Unfortunately, a lack of specialist skill was not the only issue raised when interviewees recalled their experience of accessing support work. Two carers suggested that staff from agencies, in particular, could be unreliable, poor at communicating and provide a low standard of care. One stated:

'We've had some horrors in terms of agency staff'.

Survey result:

Of the 24 survey respondents who have NDIS funding for support worker or nursing care services, respondents indicated that they had trouble accessing the following service types:

- | | |
|---|----------|
| • Access to community social and recreational activities | 11 (46%) |
| • One-to-one assistance with daily personal activities | 6 (25%) |
| • Activity based transport | 6 (25%) |
| • Household tasks incl. house cleaning and yard maintenance | 4 (17%) |

Survey respondents said:

'Live in non-urban area of Whittlesea. Struggle to find suitable support workers that are assertive, provide adequate personal care and engagement and who are regularly available when we need them and who are willing to travel to rural area.'

'Service providers unable to fill shifts, shifts being cancelled at the last minute, staff not willing to support multiple family members at the same time, staff not wanting to do one off shifts, support workers not receiving enough training and background information on clients.'

Service needs of Aboriginal and Torres Strait Islander participants

Key findings:

- Aboriginal and Torres Strait Islander people experience poorer outcomes on the NDIS than non-Aboriginal people do.
- There is a severe shortage of NDIS service providers who are culturally competent and safe to work with Aboriginal people.
- There is potential to develop Aboriginal support coordination services. These services can play a crucial role in connecting Aboriginal participants with culturally appropriate providers.
- Within the wider network of Aboriginal service providers in Melbourne's northern suburbs, there are opportunities to build the capacity of organisations to deliver NDIS services.

Aboriginal and Torres Strait Islander people face barriers to accessing NDIS services in a manner that is culturally appropriate and safe. One of the Local Area Coordinator focus group discussions examined the unique service needs and access barriers experienced by Aboriginal and Torres Strait Islander participants in the City of Whittlesea.

➤ **Unmet demand for service providers that are culturally competent to work with Aboriginal people**

The issue that was emphasised most strongly in the discussion was the scarcity of NDIS service providers that are culturally safe and culturally competent to engage with Aboriginal participants. According to the LACs, cultural competency means understanding Aboriginal lore and respecting that the way Aboriginal people do things may be different to the non-Aboriginal community. As one LAC put it:

'It's about the participant feeling safe to divulge their story, their needs, their family and be open with people in a cultural and a personal sense'.

In an NDIS service environment with very clinical professional systems, it is critical that service providers demonstrate the cultural knowledge and respect necessary to work effectively with Aboriginal people. Although many participants will request Aboriginal service providers, such as therapists or support workers, unfortunately the availability of these services is very limited in the City of Whittlesea. According to the LACs, it is also very difficult to find organisations that offer NDIS services and have any sort of experience working with Aboriginal community members.

This gap in services compromises Aboriginal participants' capacity to exercise choice and control over services. It also creates a risk, the LACs argue, that participants are left to engage with organisations that do not support them in a culturally appropriate way.

'We don't want to further isolate people from a scheme that can be really beneficial to them'.

There are 97 NDIS participants who are Aboriginal and/or Torres Strait Islander in the City of Whittlesea, or 2.5% of all participants (Sept 2020). This share has remained constant since September 2019, when there were 71 Aboriginal or Torres Strait Islander participants in the LGA.

Increasing the availability of Aboriginal service providers in the City of Whittlesea will also help to build confidence in a system that many Aboriginal people do not trust.

'There's already hesitation coming into engaging with service providers for a lot of mob, in the sense that the funding that they're utilising is coming from the government, and so there's a lot of distrust.'

As this comment from an LAC implies, many Aboriginal people associate the NDIS with negative experiences of government services. Recognising the systemic discrimination and racism that government authorities inflict on Aboriginal people, the lack of trust in the Scheme is completely justified.

➤ **Shortage of support coordination services and group programs for Aboriginal people**

The focus group discussion also highlighted specific service gaps for Aboriginal participants in the City of Whittlesea. Given the cultural barriers that Aboriginal people face to accessing NDIS services, the LACs stressed that there is a crucial role for Support Coordinators to play in connecting participants with culturally appropriate organisations.

Aboriginal participants who have gained most benefit through the Scheme are those who have established a relationship with a Support Coordinator who understands their needs. This service provider is well placed to help the person manage the range of different services in their life, as the LAC's comment below indicates. With only one local organisation providing appropriate support coordination services for Aboriginal people, this potential remains unrealised in Whittlesea LGA.

'The NDIS is not built for vulnerable people. It's not built for Aboriginal people, it's not built for people of colour'

[LAC]

'That person coordinates the stakeholders involved in [the participant's] pathway, so things are coming together between the NDIS funded supports, the mainstream supports like housing, and Community as well. That's when it works well'.

Further, there is unmet need for group programs for young Aboriginal people with disability in the City of Whittlesea. The LACs pointed out that Aboriginal children and school leavers with NDIS plans face very limited options for supported social groups that are designed specifically for them.

➤ **Opportunity to build the capacity of Aboriginal organisations to deliver NDIS services**

To address the shortage of NDIS services that are appropriate for Aboriginal people, the LACs suggest that there is untapped potential within the broader network of Aboriginal-led organisations in Melbourne's north. If the process of registering to deliver NDIS services was less complex, it could substantially increase the service options available to Aboriginal participants. One of the LACs summed up this opportunity:

'To build up the capacity of Aboriginal organisations that aren't NDIS-registered in Whittlesea to be able to deliver these services. There are a lot of Aboriginal organisations in Whittlesea that aren't delivering NDIS supports.'

Adding to this challenge, the NDIS does not recognise the complexity of the relationship that exists between an Aboriginal service provider and an Aboriginal participant. As a result, organisations do not provide Aboriginal staff with the support they need to deliver services to other Aboriginal people. The lack of cultural understanding in the broader system leads to diminished service options for participants.

'A lot of the reasons that the market is insufficient is that the NDIS is not built for vulnerable people. It's not built for Aboriginal people, it's not built for people of colour.'

Service supply in growth areas and the rural north

Key findings:

- The majority of NDIS service providers are located in the LGA's established suburbs. Participants in the growth areas and rural north have access to more limited service options.
 - Participants in these areas face longer waiting times and diminished choice and control. Many will undergo lengthy, and expensive, trips to reach the disability services they need.
 - Service providers offer less flexible options to participants who live far away. This restricts how participants use their plan to access therapy, support workers or house cleaning staff.
 - The demand for services in the north will increase in the coming years, as rapid population growth drives up participant numbers in Mernda, Doreen and Wollert.
-

In each of the focus groups, the LACs reiterated that most service providers are located in the established suburbs of Thomastown, Mill Park, Lalor and Bundoora. By contrast, there is substantially diminished choice and availability of services in the newer growth suburbs and the rural northern part of the LGA. This was reinforced in the interviews with participants who live in Mernda and Whittlesea Township.

➤ Long travel times to reach services

Clearly, as a result of the shortage of service options outside the LGA's established suburbs, many NDIS participants are forced to undergo lengthy, and expensive, trips to reach the disability services they need. It is not uncommon for participants to travel outside of Whittlesea, to Melbourne's inner northern suburbs or the city centre, to increase their service options. One LAC described this locational disadvantage:

'Travel is an ongoing issue for residents of Whittlesea LGA because it's an expanding area. People who live in Mernda or Doreen have no choice pretty much. They will have to drive for at least half an hour or 45 minutes to access the nearest service provider. It's more of a concern for participants who live in Whittlesea Township. They either don't access services or they don't make the most of their plans.'

'I don't think our township has anything to offer for people with disability'

[Carer]

➤ **Restricted choice and control for participants**

Since many service providers will not send casual staff long distances for short shifts, participants who live far away have restricted choice in how they use their plan to access support workers, carers or house cleaning staff. As one LAC pointed out, the issue of travel also limits therapy options:

'For people living further north in the Whittlesea Township, Mernda, those sort of places, the conversation of travel and transport would happen in nearly every plan review meeting, I would have thought, and the logistics of how that works and finding providers...if [providers] are based in Mill Park are they going to drive out to Whittlesea Township for one hour of therapy?'

For the growing number of participants who live outside the established suburbs, the feeling of isolation from disability services is particularly acute. A carer who lives with their family in Whittlesea Township summed this up:

'I feel like we're in the country, we're too far away from anything. I don't think our township itself has anything to offer for people with disability'.

Similarly, another carer is despondent about the lack of options available in the LGA's growth suburbs and new housing estates.

'We are moving to Wollert, because I've found a cheaper house there...but there's no support there'.

Case study: living with disability in Whittlesea Township

Searching for the right disability services is a familiar challenge for most NDIS participants. However, for people who live in small towns or rural areas, finding service providers who meet their needs is particularly tough.

Monica* is nine years old and lives with her family in Whittlesea Township. Monica attends a local school, and in her spare time she loves to go horse riding and swimming. Since birth, Monica has lived with a complex disability that affects her communication skills and physical development. Monica's family has received funding through the NDIS for the last four years.

'If you can't engage with services you can't spend the funds'

According to Carol*, Monica's mum, Monica has not had the positive experience on the NDIS that their family had hoped for. Although Monica's plan has funding for speech therapy, occupational therapy and physiotherapy, a constant issue is the lack of therapy service options near their home. *'The biggest challenge for us living in the Whittlesea Township is getting engaged with therapists out this way. A lot of people just won't travel to Whittlesea'*.

In one example, Carol highlighted the difficulty she has faced in finding a therapist who could help to build Monica's communication skills. *'The ones I have tried really haven't met the needs for Monica and her being non-verbal'*. In the 12 months that Carol has spent searching for a new speech therapist, Monica's ability to communicate has improved very little. Carol recalled similar frustrations in accessing occupational therapists and physiotherapists; service providers either will not travel to the Township, or they do not have the skills to meet Monica's needs.

'The whole philosophy behind the NDIS doesn't seem to be working'

Carol also believes that Monica's NDIS budget is not enough for someone with her complex disability type. The main issue, she argues, is that plans are approved by the NDIA, rather than the Local Area Coordinator who understands the rare challenges that Monica faces. *'The process does an injustice to families, because you sit with the LAC who has come into your home and seen your child, but they're not the person who approves your plan'*.

Without access to therapists, Carol has asked for funding for support workers to help Monica practice physiotherapy exercises at home. *'I've been trying to get some community hours so that someone can come in and just take the pressure off. And I've been knocked back saying that she's not eligible, so I get no respite or funding for anyone to come in and do that'*.

Opportunities for improvement

Due to the NDIA's poor understanding of Monica's diagnosis and the shortage of service options in Whittlesea Township, Monica has never received the support that she needs. For Carol, a positive step is that Local Area Coordinators are now having a greater influence over approving NDIS plans than before. Determined to keep advocating for improvements to the Scheme, Carol is hopeful that this is a sign of a brighter future for Monica.

*names have been changed

Barriers faced by participants from Culturally and Linguistically Diverse backgrounds

Key findings:

- Participants from Culturally and Linguistically Diverse communities face complex barriers to accessing services and achieving their goals through the NDIS.
 - Different cultural groups have very different understandings of disability. This informs their approach to engaging with NDIS services, especially therapy and psychosocial supports.
 - Participants from some CALD communities associate disability with feelings of shame and stigma.
 - The NDIA and service providers do not support families by communicating in a culturally appropriate format, as well as in different languages, to enable participants to effectively engage with NDIS services.
-

In all the focus groups, the LACs were keen to emphasise that NDIS participants from Culturally and Linguistically Diverse (CALD) backgrounds face specific challenges related to accessing services. The following themes were most prominent.

➤ Differing understandings of disability among CALD communities

A key point that emerged from the research was that different cultural groups have very different understandings of disability, and this informs their experience of engaging with NDIS services. Recognising that the CALD population in Whittlesea LGA is itself incredibly diverse, these notions of disability are often not accommodated by the NDIS service system.

For example, several of the LACs remarked that some participants were reluctant to use therapeutic services, because they were unsure of the benefits of capacity building supports. One LAC suggested that a common view among adult participants is that therapy will not make a difference to a lifelong disability:

'They say "I can't understand that therapist, if he's not understanding what I'm trying to say he will never get me, I have this from childhood, it's not going away"...they are more interested in core supports'.

The LACs also observed that mental health-related disabilities are not always recognised as disability within some communities. In some cases, this prevents participants from accessing psychosocial services and leads to poorer mental health outcomes. An LAC gave an example of this issue:

'The Arabic-speaking community don't identify mental health or psychosocial disabilities. They will do anything not to stigmatise a person with a psychosocial disability. And to them disability is pretty much a physical disability, so someone sitting on a wheelchair or using equipment in the community.'

'The way that information is presented actually sometimes offended the families because it wasn't culturally sensitive'

[LAC]

➤ **Feelings of shame and stigma about disability**

Another barrier to accessing NDIS services for participants from some cultural groups is the experience of shame and stigma related to having a disability. One of the LACs gave the example of a family who took their son to access disability services far away from Whittlesea LGA because they did not want to be seen by members of their community.

'For cultural reasons the first plan was not utilised. The parents were hesitant. They thought if someone sees them going to OT or physiotherapist, mum thought that they will be recognised and they'll be frowned upon within their community and the kid will be laughed at for having a disability.'

This point was reinforced in another focus group:

'I have a few Arabic participants and they are not willing to engage in services because of the stigma around the disability.'

There are 641 NDIS participants from Culturally and Linguistically Diverse backgrounds in the City of Whittlesea (Sept 2020). This represents 16.8% of all participants, an increase from 15.7% in September 2019.

More broadly, Census data reveals that CALD communities comprise approximately 50% of the total population of the LGA. This indicates that there is likely to be many people with disability in these communities who are not receiving the supports there are entitled to.

➤ **Information not communicated effectively to CALD communities**

The LACs also stressed that the NDIS service market in the City of Whittlesea is not providing adequate support to participants from CALD communities. They argued that information is often not communicated in different languages, let alone in a culturally appropriate format, to enable participants from CALD backgrounds to understand and engage with NDIS services.

The following comments reflect the LACs' concern that there is a gap in support for CALD participants in the City of Whittlesea.

'Trying to connect families and getting to explain the NDIS and to get them to understand it takes a lot more support and effort. I think that there really isn't enough services to help them understand the NDIS and how it can help them and their families.'

'In Whittlesea we have a big growing middle eastern community and there's just not enough support to help them navigate the NDIS.'

The groups argued that emerging service providers offering support coordination within CALD communities were one way of fostering engagement of participants with services. The LACs also reiterated the point that increasing knowledge and understanding of cultural differences by service providers and the NDIA more broadly will be fundamental if participants from CALD backgrounds are to realise the potential of their NDIS plans.

As the following comments indicate, it is not enough simply to translate information. Rather, services need to consider how different perceptions of disability are grounded in culture.

'The way that information is presented actually sometimes offended the families because it wasn't culturally sensitive'.

'It's not so much a language barrier as it is a cultural barrier. It's about understanding the cultures and tailoring the NDIS process to their lifestyle'.

Survey result:

Of the 19 survey respondents who have NDIS funding for plan management and support coordination services, respondents indicated that they had trouble accessing the following service types:

- | | |
|----------------------------|---------|
| • Support coordination | 8 (42%) |
| • Financial administration | 2 (11%) |

Survey respondents said:

'Had various support coordinators but had issue with most of them due to lack of training and procedures not being followed and staff shortages. Also had trouble getting this funding in all of the plans.'

'It was difficult to find a support coordinator to help manage a big funding plan and expertise in finding appropriate services for my son.'

Impact of COVID-19 on participants' access to services

Key findings:

- Access to NDIS services reduced for many participants during COVID-19. This was due to providers reducing services to mitigate against the risk of virus transmission, or participants suspending their own supports out of concern for their safety.
 - Participants had mixed experiences of using telehealth services; some people struggled to engage effectively with therapists online, while others enjoyed the flexibility and flexibility of accessing services from home.
 - The psychosocial service system has coped well with the surge in demand for services during COVID-19. The social and economic implications of the pandemic could have a lasting impact on mental health.
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COVID-19 and restrictions have had a profound impact on people with disability. The consultations and survey highlighted the most significant ways in which the pandemic has affected access to services for NDIS participants in the City of Whittlesea. These are described below.

➤ Reduction of in-person supports

A major impact of COVID-19 on NDIS participants has been the reduction of in-person support types as a result of physical distancing restrictions. To lower the risk of virus transmission, many service providers have been forced to cease operation of certain services that include support workers, group social activities, housekeeping and in-person therapeutic supports.

Not only has the contraction of these services diminished the support received by existing participants, it has also resulted in fewer service options for people who are trying to access a service for the first time. As one LAC commented:

'I've noticed a lot of providers don't even have a list anymore, they've just sort of cut off their service for anyone new during COVID.'

'The minute I heard about COVID-19 we locked down. I did all the attendant care myself from March'

[Carer]

In addition, the LACs noted that participants themselves were choosing to reduce their supports due to a concern about the threat of COVID-19.

'The other thing we've seen with COVID is people not engaging with services for their own safety, so somebody that might have an hour a week of house cleaning or two hours a week of personal care, they've ceased that support out of fear or for their own safety. It's been a big barrier.'

This finding was supported in the interviews, with one carer recalling the challenge of caring for her daughter herself after cancelling their support work staff:

'The minute I heard about COVID-19 we locked down straight away. I did all the attendant care myself from March. In the beginning, it was a relief because I just felt as though we were safe. Then I started to get really tired, and by the time carers started to come back in, I was really exhausted.'

Survey result:

When asked about impact of COVID-19 on services, most respondents indicated that the services they access have reduced.

- | | |
|---|----------|
| • My services have reduced | 15 (48%) |
| • My services have stayed the same | 8 (26%) |
| • I have received/am receiving different services | 5 (16%) |
| • My services have increased | 3 (10%) |

➤ Impact on mental health and demand for psychosocial services

The interviews revealed that some participants and carers have experienced considerable negative mental health impacts as a result of physical distancing restrictions. For example, one NDIS

participant lost all of the shifts they work at a local leisure centre, which had been an important source of structure in their life.

'It's been really hard on my mental health in lockdown, the second time around... I had a routine and when you lose the routine it's really hard'.

Indeed, COVID-19 has resulted in a huge increase in demand for mental health services among NDIS participants in the City of Whittlesea. Despite observing that the psychosocial service system was already marked by long waitlists and a shortage of specialised service options even before the pandemic, the LACs agreed that this area of the market has coped relatively well this additional pressure.

However, the LACs also expect the mental health impacts of COVID-19 to continue for some time yet. One LAC suggested that the demand for psychosocial supports may be just as high during the recovery period of the pandemic.

'Once coronavirus ceases I just wonder whether we are going to get almost a second wave of impact once people are trying to get back to work, the trauma people have experienced through this period, I wonder whether we're going to see requests for even more support. During this lockdown I think people have tried to make do, but I actually suspect that the next six months could be just as bad'.

➤ **Mixed experiences of telehealth and online service delivery**

One of the most significant features of COVID-19 for NDIS participants has been the transition to telehealth and online modes of service delivery. The research suggests that participants have had mixed experiences of accessing services online, which have depended on the age of participants, their disability type and their previous experience of using virtual communication tools.

Survey result:

62% of respondents started accessing telehealth or online disability services for the first time during COVID-19. The remaining 38% did not access telehealth at all during the pandemic.

On one hand, many participants gained less benefit from taking part in therapy sessions online compared to seeing a therapist in person. This is particularly true in the case of school age participants, who may have difficulty focusing on a telehealth appointment or be experiencing 'screen fatigue' due to online schooling. The LACs also remarked that participants with certain disability types, such as autism or hearing impairment, were not as confident to engage with online services and were more likely to miss appointments altogether.

In an interview which illustrates this point, a carer explained that because her nine-year-old daughter had not been comfortable using telehealth, she attended very few therapy sessions in 2020.

'Telehealth was no good for her, it's a waste of time, she can't sit still for two seconds. And that's what most therapists have been doing through COVID, so obviously most of her plan won't have been spent'.

On a positive note, the focus groups and interviews also suggested that COVID-19 had revealed the potential benefits of online services for NDIS participants. Some participants have provided positive feedback on the experience of online service delivery, highlighting the efficiency and flexibility afforded by accessing services from home.

'It does provide that extra choice and control. For some participants, it saves time, it's more comfortable for them to engage in a session on their device rather than face to face so I think that's been really helpful for some, especially those who feel that facing up to someone in person is a bit overwhelming'.

One participant, a professional in his thirties who communicates online every day for work, argued that telehealth should become a much more commonly used tool by service providers.

'I'm actually accessing my OT more because of telehealth. Going to these appointments sometimes gets annoying. Because I'm accustomed to talking through issues online, it's been easy for me'.

Clearly a therapist who is highly skilled at using online tools can make a considerable difference, as indicated by the following comment.

'Our son engaged well with the telehealth medium, so our therapy sessions were able to continue. Our speech therapist did a fantastic job of using the technology options that were available to them and she was able to capture and engage him well for most of the sessions'.

‘What would you like to change about the NDIS in your area?’

Each interviewee was asked the question ‘What could change about the NDIS or disability service system that would benefit you, or the person you care for?’

The responses were wide-ranging, and included the following:

- **Increased flexibility of funding arrangements**

Three of the people interviewed would like to exercise more autonomy in the way they spend their funding. This included using funding to access sports and leisure centre facilities, home maintenance and housekeeping services. One carer, who has unspent funding due to a shortage of therapists in her area, would like to reallocate that funding to access support workers.

- **More transparency in the planning process**

For some participants and carers, the greatest challenges were experienced in navigating the complex NDIS planning process. Three carers expressed a desire for more transparency from the NDIA and LACs about why things are done the way they are, particularly when plans are changed.

One of the carers would like LACs to be responsible for approving the plans they prepare, rather than the NDIA, thereby giving the family confidence that the funded supports reflect their needs.

- **Better education of participants about service options**

A concern among interviewees related to their lack of knowledge about available services. Choosing between a range of providers can be an overwhelming experience, with limited information available about which NDIS services are out there, and which are most suitable.

The interviewees argued for improved access to high quality Support Coordinators, who can build the capacity of participants and carers to exercise choice and control in the service market.

- **Access to mainstream activities that are inclusive of people with disability**

One of the responses argued for a wider range of opportunities for people with a disability, beyond those that are funded through the NDIS. While this young participant’s experience of the Scheme has generally been positive, his mother has struggled to find mainstream activities, such as sporting clubs and organisations, that are inclusive of her son’s disabilities.

- **A more integrated service sector**

The success of the NDIS in the City of Whittlesea depends on the existence of a well-functioning marketplace. One participant, who also works in the disability sector, argued that participants would benefit most from a closer integration of services, whereby providers work together to support participants based on a common set of principles.

‘The local service sector needs to gel more and work in harmony to support the community. They need to have a strong referral system, and they need to be across who’s doing what in the sector’.

Other findings about the experience of participants and carers

Key findings:

- Participants and carers experience challenges in navigating the complex NDIS planning process, communicating with the NDIA, and understanding what supports are available.
 - Participants receive diverse benefits through the Scheme, including financial relief, more personalised supports, and the chance to envisage and seek new opportunities in life.
 - Informal support people play a crucial role in ensuring participants gain maximum benefit from the NDIS. Outcomes for participants are compromised if effective and consistent informal supports are absent.
-

Experience of the NDIA and planning process

It was clear from the interviews that the participants and carers have experienced significant challenges in navigating the NDIS planning system, managing the administrative aspects of joining the scheme, and understanding what a participant is entitled to receive.

➤ **Initial anxiety**

Almost all of the interviewees reflected on the confusion and uncertainty they felt when they initially came into contact with the NDIS. A common theme was that participants and carers were nervous about engaging in the process and were unsure about what was expected of them.

One participant recalled how they felt after transitioning to the NDIS:

'That was my first plan so I was really anxious to see how it will go'.

A carer pointed out that they were not clear what their role was in the first planning meeting:

'Reflecting on how I engaged in the process, the first year I prepared as much as I thought I could, but I didn't really know what we needed. I remember being so anxious and so worried about going to the planning meeting because I didn't know what to anticipate and I didn't feel like I was as well prepared as what I would have like to have been and I didn't have any more information to go by'.

➤ **Lack of confidence in the planning process**

Even once a plan has been prepared and approved, there is no guarantee that the funded supports will reflect what the participant actually needs. Several carers found that the quality of plans depended very much on the knowledge and experience of the Local Area Coordinator.

In some cases, there is a risk that plans are generic and do not provide the individualised model of support that is a core principal of the NDIS.

'It has taken to plan number five before we have been able to get a support worker there a lot of the time'

[Carer]

'Someone had cut and pasted a whole lot of stuff, they hadn't really written the plan up properly...they had actually cut and pasted from another client'.

Unfortunately, for some participants the challenges persisted beyond the first plan. Three of the carers interviewed argued that they had never received enough funding for therapeutic supports. In their view, a major cause of this disadvantage is that their child's disability is not well understood or recognised by the NDIS.

'If my daughter had a diagnosis of autism, I would know straight away my plan would be double what I'm getting'.

➤ **Knowledge about local service options**

Another source of anxiety expressed by participants and carers is a lack of clarity around what supports are available, and how to access them. In one way or another, every person interviewed expressed a need for more guidance about where to find NDIS services. For example, one carer pointed out that they would have benefited from receiving a starter pack, with useful information about services in their area. Another carer echoed this sentiment:

'One of the challenges is that you don't know what you don't know as a parent...you don't know what services are available or might be of benefit to your child'.

For most, but not all interviewees, their experience of the planning process improved over time, once they had grown accustomed to navigating the system and managing the administrative burden. One carer remarked that their daughter is now getting an appropriate level of support:

'It has taken to plan number five before we have been able to get a support worker there a lot of the time.'

Another carer has noticed an improvement in their interactions with the Local Area Coordinator.

'I feel like they've been monitoring and tracking things a little but more, asking us if we need help finding and accessing services to use the funds within our plan'.

Survey result:

One in every three (35%) survey respondents indicated that a **'lack of information about services'** was an issue they had faced when attempting to access services through the NDIS.

Benefits of participating in the NDIS

Despite the challenges raised above, the interviews also highlighted the significant positive impact that the NDIS can have on participants' lives.

➤ **Financial relief and respite for carers**

Among a diverse range of benefits cited by interviewees, a consistent message was that the NDIS provides huge financial support to families. As the following comment indicates, the goals-oriented

planning model has given one family funding for disability supports that they previously paid for themselves.

'Anything [our daughter] needed prior to NDIS coming in we needed to pay for and source ourselves. So it was a completely new experience for us in regards to looking at her goals and what she needed basically'.

Another parent's experience reinforced this:

'It would be difficult for us to facilitate the level of support that [our son] is receiving without the funds that are provided through the NDIS'.

For one parent, the funding they receive for a support worker has given them the resources to be able to take a break from their caring responsibilities.

'It helped us greatly. It was easier having someone else around. It just meant that I could do more things independently and know that she was being cared for that way. Before the NDIS we didn't have enough money ourselves to pay for that, we just had to do it ourselves, but that just caused more pressure on the family'.

➤ **Personalised model of care**

Interviewees indicated that building a relationship with a support worker who understands their needs has made a huge difference to their everyday life.

'It's getting out of the house, that's what I want to do. Having a support worker that understands me.'

Indeed, a prominent theme in the interviews was the idea that a more personalised model of care fosters improved outcomes for participants. This was demonstrated powerfully by one carer, who argued that the shift to an individualised funding model under the NDIS has completely transformed their daughter's life. In this example, specifically trained support workers and a tailored program of therapy has reaped enormous benefits.

'She's talking more, even her specialist has indicated that it's quite outstanding that given her degenerative condition she's actually speaking and making choices more every day, and that's because of the change of funding'.

Another parent also emphasised the benefits of having access to personalised therapy, indicating that their occupational therapist has built the capacity of the whole family to care for their daughters.

'We've discovered a lot of things about the girls both physically and emotionally through exploring stuff with the occupational therapist. My husband and I have learned a lot of useful things that we can use to help each girl that the therapist has discovered'.

➤ **Support with family life and accessing new opportunities**

Beyond fundamental services such as therapy and support work, the NDIS also enables some participants to envisage, plan and access opportunities they may previously not have thought possible. For example, one participant is considering the option of getting support to attend TAFE.

NDIS funding also has a positive impact on family life and relationships. For one participant, having a support worker to help them contribute to housework has enabled them to be the partner and father that they want to be.

'The NDIS enables me to be able to pull my weight to have a well-rounded and balanced relationship that is not just reliant on one person...I want a relationship where my sons get to see the man contribute equally so that they can contribute equally later on'.

Role of informal supports

A prominent theme that emerged in the interviews and focus groups was the substantial difference that carers and family members make in supporting participants to engage with services through the NDIS.

Informal support people can play an important role in managing administrative issues and navigating the complex service market, or simply accompanying participants to sessions. According to the interviewees and LACs, this support can enable a participant to gain much greater benefit from the NDIS than they otherwise might.

'There's always the question of what's going to happen when I can't do this anymore'
[Carer]

➤ **Handling the administrative burden of the NDIS**

Three of the carers interviewed emphasised that they spend considerable time and effort handling the administrative tasks related to the NDIS. One carer remarked:

'The administrative burden and work that I have to do has significantly increased under the NDIS'.

➤ **Navigating the system and advocating for participants**

The carers also pointed out that they have devoted themselves to learning about and researching the system to ensure they can advocate for a plan that meets each of their child's needs. It is apparent that participants without this degree of support may receive an NDIS package that is not necessarily suitable for them. As one explained:

'I feel like the outcome shouldn't really be driven by how many hours I put in. I spent probably the equivalent of a week's solid work planning and linking back to all these goals, which really is actually the NDIA's need, not mine'.

Another carer suggested it has taken them some time to understand the service market:

'Support workers have varying degrees of skill levels, so it is sometimes difficult to tell which provider has the right type of staff for you. It's been a long journey, but I'm better at that now'.

At times, the help of multiple family members is required to ensure that participants regularly attend services. The following comment is from a carer who does not have access to support workers where they live in Whittlesea Township.

'I rely on my mum to help me out on the days that I work to drop her off and pick her up, so those sort of services aren't around either'.

➤ **Managing stakeholders and engaging with services**

Given that many participants do not receive funding for support coordination, it is often left to families and carers to fill this gap. According to the LACs, when informal support is absent or not consistently available, it compromises the whole experience of the participant. In contrast to the comment above, another LAC described one young participant whose mother and sister also have disabilities that reduce their capacity to support him.

'It becomes really hard to engage this kid with services out there because we don't have the reliable informal support that we can work with'.

It is evident that some informal support people take such an active role in the process that they independently find and manage all of the supports received by the person they care for.

Two of the carers interviewed explained that they had effectively assembled a 'care team' of therapists and support workers who communicated about each of the participants' needs. The integration of services in this way allows them to collaborate, mutually learn and reinforce the strategies of the other therapists involved.

Without the care and attention of the carers in these scenarios, the benefits gained through this integrated approach would not be possible. One of the carers expressed their concern about the vulnerability of a system that depends so heavily on informal supports.

'There's always the question of what's going to happen when I can't do this anymore'.

7. Conclusion

The NDIS is premised on the idea that people with disability should exercise choice and control in the planning and delivery of their supports. While the objective of increasing participants' freedom should be strongly commended, its success depends on all participants having access to a range of high-quality support options near where they live.

Without robust local service markets, the NDIS will produce no better outcomes than Australia's existing system of disability care. That system, according to the 2011 Productivity Commission, was 'unfair, fragmented and inefficient', and gave people with disability 'little choice and no certainty of access to appropriate supports'¹⁹.

This report demonstrates that there are opportunities to develop NDIS services and provide participants in the City of Whittlesea with more choices, and more certainty. The report identifies the major service needs and access barriers for local participants, presenting an evidence base to inform advocacy and service planning.

Future direction and opportunities

The report has found, above all, that Whittlesea LGA has thin NDIS markets, where the supply of services is not sufficient to meet the demand. Limited availability is particularly evident in certain support types, for example, in occupational therapy, specialist behavioural intervention services, and services designed for adolescent participants.

Promoting service expansion in these 'gap' areas should be considered a priority. As many of the people consulted in this report have said, increasing the supply of services will create more options and more competition. This is a crucial step in the right direction.

However, growing the number of service providers will not, by itself, equate to better outcomes for all participants in the City of Whittlesea. Approaches to developing services must consider the needs of people who are disproportionately impacted by existing market insufficiencies.

There is an urgent need to build the capacity of the service sector to support Aboriginal participants. This will be achieved not only by increasing the supply of Aboriginal service providers in the area, but also by promoting cultural competency and education across mainstream NDIS providers.

An increasing share of NDIS participants live in the LGA's growth areas and rural north. These areas are already underserved across both NDIS and non-NDIS services. In the next five to ten years, most of the participants who live in Mernda, Wollert and beyond will be children. The planning and development of these emerging residential areas presents a challenge, but also an opportunity to establish an NDIS service network that provides more effective and timely support to participants.

The NDIS will not be delivering on its promise in the City of Whittlesea until it recognises the diverse needs of the City's Culturally and Linguistically Diverse communities. This report echoes other research²⁰ in calling for more culturally responsive, specialised disability services for migrant and

¹⁹ Parliament of Australia, 'The National Disability Insurance Scheme: a quick guide', 3rd of March 2017 (Cited 27th of January 2021). Available from

https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/NDIS.

²⁰ Ethnic Communities Council of Victoria, *Multicultural Community Perspectives on Disability and the NDIS*, Melbourne.

refugee participants. The design of these services must be guided by people from migrant communities.

This report has offered an overview of service needs and access barriers for NDIS participants in the City of Whittlesea. While the report has identified limitations in the service market, it has not explored the barriers that service providers themselves are facing. A priority for future research is to examine these challenges in greater depth.

Finally, the consultation methods engaged mainly with carers, but very few participants themselves took part in either the interviews or online survey. Subsequent research in this area should further highlight the perspective of NDIS participants.