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A qualitative study of autism services and supports in Singapore: Perspectives of service providers, autistic adults and caregivers

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and Helena Legido-Quigley¹

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Abstract

The lifelong and complex nature of autism necessitates an array of services and supports spanning across different sectors and providers at different life stages of an autistic individual. However, research has shown that autistic individuals and their families often experience barriers accessing the autism-related services and supports that they need. This is the first qualitative study to explore the provision and coordination of autism services and supports in Singapore from the perspectives of service providers, autistic adults and caregivers. Semi-structured interviews with 21 participants revealed three main themes: (1) improving access to autism-specific services, (2) creating flexible supports in an inclusive environment and (3) addressing stigma and changing societal attitudes. Our findings suggest that Singapore may have achieved rapid growth in autism services, but broader social structures may be slower to change. To better support autistic individuals in society, autistic voices need to be amplified and a collective effort is needed to achieve a paradigm shift from impairment to capability.

Lay abstract

Because autism is a lifelong and complex condition, autistic people may need a range of supports cutting across different sectors (e.g. health, education and social care) at different stages of their lives. Studies in some countries have shown that autistic people and their families face difficulties accessing the services they need, but no research has been done on this topic in Singapore. To start addressing this gap, we interviewed 21 service providers, autistic adults and caregivers/parents of autistic children to find out their perceptions and experiences of autism services and supports in Singapore. Our participants told us that beyond improving access to autism-specific services, they also hoped to see more flexible supports in an inclusive environment and a broader change in societal attitudes. This study highlights that autism service provision should be informed by autistic voices and not only focus on impairment but also recognise the strengths of autistic people alongside their very real needs. The whole of society – including policymakers, professionals, employers, educators, families and autistic people themselves – needs to work together to fight autism stigma and discrimination.

Keywords

autism services and supports, autistic adults, caregivers, qualitative research, service providers, Singapore

Introduction

The lifelong and complex nature of autism necessitates an array of services and supports spanning across different sectors and providers at different life stages of an autistic individual. However, research has shown that autistic individuals and their families often experience barriers accessing the autism-related services and supports that they need.

Challenges in the autism care-seeking pathway begin at seeking a diagnosis. It is consistently reported in the literature that parents of autistic children in many countries find the diagnostic process stressful and experience

long waiting periods between initial assessments, referrals and a formal diagnosis (Crane et al., 2016; Eggleston et al., 2019; Lappé et al., 2018). Autistic adults also

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express varying levels of dissatisfaction with diagnostic services, influenced by factors such as the extent of delays, professional knowledge and attitudes, as well as the availability of appropriate post-diagnostic support (Crane et al., 2018; Jones et al., 2014; Lewis, 2017; Raymond-Barker et al., 2016).

Navigating the complex service landscape for post-diagnostic support is another challenge autistic individuals and their families face. A mixed methods study in Wales exploring care pathways for autistic children found that while health professionals described structured pathways, education professionals and parents described more confusing pathways, with parents bearing the responsibility of coordinating services across the disconnected healthcare and educational systems (Hurt et al., 2019). A qualitative study in China also found that healthcare services were predominantly provided by the government while education services were predominantly provided by parents of autistic children, with little cooperation between government-run and parent-run services (Sun et al., 2013). In a Canadian study, parents, policymakers and researchers agreed on the need to have more comprehensive services across the spectrum and throughout the lifespan, as well as to increase investment in children's mental health and development more generally (Shepherd & Waddell, 2015).

There is a growing body of literature showing that autistic individuals experience a drastic decline in services after they graduate from secondary education. This problem of a 'services cliff' is well-documented in the United States, where many families report that existing services are unsuitable for adults and have restrictive eligibility criteria as well as limited funding (Anderson & Butt, 2018; Milen & Nicholas, 2017; Shattuck et al., 2012). As a result, many autistic adults and their families have to bear the burden of advocating for services, managing self-directed services or paying for private services at high costs (Anderson et al., 2018). Thus, the transition to adulthood can be a period fraught with fear, frustration and uncertainty for autistic youths and their parents, with parents being particularly worried about who will look after their child when they are no longer able to (Cheak-Zamora et al., 2015; McMinn et al., 2018). In order to achieve better long-term outcomes for autistic people, recent research has highlighted the need for more attention and resources to be directed towards developing adult services such as employment support and residential care (Crompton et al., 2020; Hedley et al., 2016; Meiring et al., 2016).

Study context

Singapore is a multi-racial and multi-lingual country with a total population of 5.7 million people, of which 76% are Chinese, 15% are Malays, 7.5% are Indians and 1.5% are of other ethnicities (Strategy Group, Prime Minister's Office, 2019). English is the main working language in

Singapore, with Mandarin Chinese, Malay and Tamil being the other three commonly used languages. An estimated 1 in 150 children in Singapore are on the autism spectrum (3rd Enabling Masterplan Steering Committee, 2016), a slightly higher rate than the World Health Organization's global incidence of 1 in 160 children (World Health Organization [WHO], 2019).

The Singapore government issues every child born in Singapore with a health booklet that records their developmental progress from 0 to 6 years old and facilitates screening for developmental concerns, including autism. The Child Development Programme located in two leading public hospitals is responsible for diagnosing the majority of autistic children and serving as the point of entry into the post-diagnostic support system (Ho, 2007). Sung et al. (2020) have provided an overview of the current autism services provided in Singapore, including diagnostic and clinical services, early intervention, educational provisions for school-going children and support services for adults. Singapore's first autism-specific programme within special education was available in 1989, and three autism-specific special schools were established between 2004 and 2006. As of 2020, Singapore had a total of 19 special schools serving approximately 6000 students (Sung et al., 2020). We have summarised the main types of services in Figure 1, and the key bodies involved in service provision in Table 1. In general, Singapore adopts a 'Three Ps Model' of service provision that entails a collaboration of the public, private and people sectors to provide disability services (Poon, 2015).

The blueprint for disability services in Singapore is the Enabling Masterplan, which is developed by a committee comprising representatives from government agencies, professionals in the disability field, social service agencies (SSAs), disabled persons and their caregivers. In the third and most recent Enabling Masterplan, the committee identified the growing number of individuals diagnosed with autism as a key trend in Singapore's disability landscape and called for more research to study the service needs of specific disability groups (3rd Enabling Masterplan Steering Committee, 2016).

With regard to diagnostic services in Singapore, a survey conducted 20 years ago reported that 60% of autistic children were diagnosed before the age of 3 years (Bernard-Opitz et al., 2001), and this percentage is likely to have increased with greater professional and public awareness of autism. Another survey reported that parental satisfaction with the diagnostic process of autistic children varied depending on the level of perceived collaboration with professionals, perceived helpfulness of received information and severity of the child's autism (Moh & Magiati, 2012). While the post-diagnostic support needs of autistic individuals in Singapore have not been explicitly researched, a study on autistic adolescents documented that they had greater problems with domestic life, major life areas and

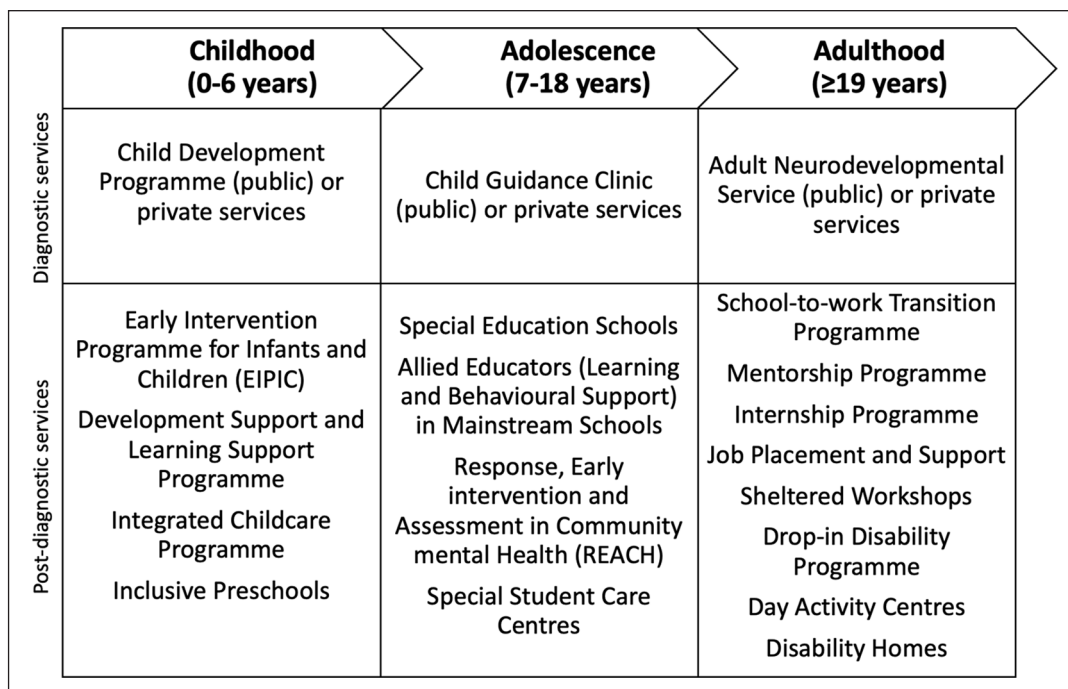


Figure 1. Autism services provided in Singapore across the lifespan.

Table 1. Key bodies and their roles in autism service provision in Singapore.

Body	Role
Standing Committee on Disability	Coordinates inter-ministerial and inter-agency efforts on disability issues at the government level, comprising members from the ministries of health, education, social and family development, as well as National Council of Social Services and SG Enable
Ministry of Health (MOH)	The Child Development Programme under MOH provides diagnostic services as well as brief interventions and supports for developmental conditions
Ministry of Education (MOE)	The Special Educational Needs Division in MOE oversees policies and programmes for students with special needs in special education schools and mainstream schools
Ministry of Family and Social Development (MSF)	The Disability Office in MSF serves as the national focal point for disability policies
National Council of Social Services (NCSS)	National coordinating body for social service agencies, including disability agencies
SG Enable	Provides information and referral for disability services, administers grants and support to disabled persons and their caregivers, and enhances employability and employment options for disabled persons
Autism Network Singapore	Alliance of the five leading social service agencies providing autism services, three of which run special education schools dedicated to autistic children

interpersonal interactions, than mobility, self-care, and general tasks and demands (Poon, 2011). A study on parents of autistic adolescents in Singapore also found that many of them expected their children to work in sheltered workshops or be unemployed, and none expected their children to participate independently in community (Poon, 2013). This study highlighted the need for interventions that develop the skills of autistic youths and empower their family members, formal support services for autistic adults and programmes to raise public awareness of autism.

As very little research has been conducted on autism services and supports in Singapore, this qualitative study sought to conduct a preliminary exploration of the topic in order to guide future studies and service improvements. The specific research objectives were to:

1. describe the provision of autism services across the lifespan and coordination of autism services across different systems as experienced by service providers and users, and

2. identify barriers to accessing services or gaps in service coordination from the perspectives of service providers and users.

Shattuck et al. (2020) have emphasised the importance of taking a life course, systems approach to autism services research. A life course approach recognises the changes autistic people may experience in the availability and quality of services over their lifetime, while a systems approach can provide greater insight into how the complex range of autism service systems functions, interacts and can be improved. Thus, this study adopted a life course, systems approach to understand the current provision and coordination of autism services in Singapore, as well as to identify areas of improvement towards achieving a comprehensive and integrated service landscape that is able to meet the needs of autistic individuals and their families. Furthermore, Shattuck et al. (2020) also called for greater involvement of different stakeholders, including service providers and users, in the improvement of autism service systems. While this study focuses more on the perspectives of service providers, efforts were made to include the views of some autistic adults and caregivers/parents of autistic children to gain a more holistic understanding of the topic at hand.

Methods

Participants and recruitment

Purposive and snowball sampling was used to recruit key informants with professional experience or lived experience of autism services in Singapore. To capture a diversity of perspectives, we recruited a range of experts from different backgrounds, including healthcare, education and social service providers, professionals from the government and non-government sectors, as well as caregivers/parents of autistic children and autistic adults. Participants were recruited via email or in person at an autism-related conference. Interviewees were also asked to recommend other potential candidates at the end of each interview. Participants were only asked to provide names of these potential candidates and not their contact details unless they received permission to do so. The contact details of all participants were obtained from publicly available information and/or the research team's existing personal contacts.

Data collection

Forty people were approached in total and ten did not respond. Six further people declined to participate in the study and three people dropped out of the study due to lack of time or perceived lack of expertise. In total, twenty-one participants were interviewed in this study, comprising

twelve service providers and nine service users (five autistic adults and four parents of autistic children). All participants were of Chinese ethnicity except one who was of Malay ethnicity. Thirteen participants were female and eight were male. Of the twelve service providers, three worked in health services, three in education services, three in social services, and three in non-profit disability organisations. Three worked exclusively with children while the rest had experience in services for both children and adults. Of the five autistic adults, two were in their twenties, two were in their thirties and one was in their fifties. All of the autistic adults were able to share information about their perspectives and experiences verbally, and four out of five of them were employed. Among the parents, three had autistic children aged 7–14 years old while one had an adult child in her twenties. Two of their children were verbal and did not have accompanying intellectual disability, while the other two were minimally verbal and had accompanying intellectual disability. Specific data on socioeconomic status and educational attainment levels were not recorded.

Semi-structured, in-depth interviews with an average duration of 1 h were conducted in English between June 2019 and January 2020. Ethical approval was obtained from the National University of Singapore Institutional Review Board (LS-19-147). Informed consent for participation, audio recording and publication were obtained from all participants via a Participant Information Sheet and Consent Form. Interviews were conducted in mutually agreed locations such as participants' homes or workplaces to ensure participant comfort and confidentiality. Given the sensitive nature of the research topic, interviewees were reminded that they could decline to answer any questions or withdraw from the study at any time.

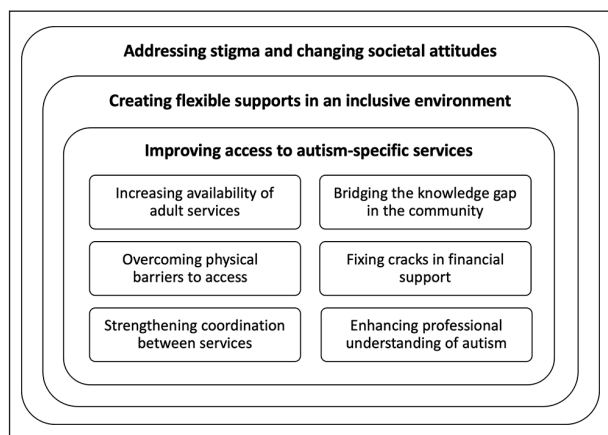
Trained qualitative researchers conducted the interviews following an interview guide. Developed based on existing literature on the topic, the guide included questions to explore perceptions of autism services from pre-diagnosis to post-diagnosis and from childhood to adulthood, as well as any gaps or barriers in service access and coordination (Supplementary Appendix 1). Data collection ceased when researchers agreed that data saturation had been reached.

Data analysis

Interviews were recorded in full, transcribed in verbatim, and coded using QSR NVivo 12 Software. A combination of deductive and inductive approaches from thematic analysis was used. The framework of service access developed by Penchansky and Thomas (1981) and enhanced by Saurman (2015) was first used to code the data deductively according to dimensions of access including availability, approachability, accessibility, affordability, adequacy and acceptability (Table 2). Themes and sub-themes generated

Table 2. Framework of service access.

Dimension of access	Definition
Availability	Volume and type of services in relation to demand for services
Approachability	Awareness of services through information and communication
Accessibility	Geographical location and ease of reaching services
Affordability	Ability of the population to pay for services
Adequacy	Organisation, coordination and integration of services
Acceptability	Attitudes of service providers and service users towards each other

**Figure 2.** Thematic framework of perspectives on autism services and supports in Singapore.

inductively from the data were then used to better inform the structure and content of our thematic framework.

One researcher performed initial coding of the interviews and a second researcher checked the analysis for reliability and validity. Keeping reflexive notes and participating in regular discussions were emphasised to ensure that interpretations were grounded in the data. Both researchers, who have a background in health systems and policy research, reached a consensus on the final themes. Data analysis ceased when the researchers agreed that thematic saturation had been achieved. All interview data were anonymised upon analysis. Due to the small size of the autism service sector in Singapore and concerns expressed by participants that they would be easily identifiable, characteristics such as their professions and roles are not reported. All quotes used are labelled by participant number so that those from the same participant can be linked.

Community involvement

Community engagement and participatory research have only just emerged in Singapore and they are not common practice. Consequently, community members were not involved in the design and conduct of this study, the interpretation of results or the writing of this article. We aim to include community consultation in all our future studies.

Results

Three main themes were identified from our data: (1) improving access to autism-specific services, (2) creating flexible supports in an inclusive environment and (3) addressing stigma and changing societal attitudes. Figure 2 shows our thematic framework and Supplementary Appendix 2 contains the full table of themes, sub-themes and supporting quotes.

Theme 1: improving access to autism-specific services

Increasing availability of adult services. There was consensus across those with professional and lived expertise that, 20 years ago, there were little to no autism services in Singapore, but rapid and substantial progress has since been achieved. Our participants indicated general satisfaction with the provision of services for autistic children such as early intervention and special education, although some had lingering concerns about the quantity and quality of services. More prominently, service providers and users highlighted a major gap in services for autistic adults and their caregivers/families:

I find the adults have very little avenues available in Singapore. It's not the same as the rich help that we have in place for the children . . . There is zero support for persons like myself. There's even zero support for young adults who have already been through the system and graduated. As soon as you hit 18 years old, sorry, it's all dried up, you know, we got nothing left for you. (Autistic adult, Participant 3)

Participants reported that demand for adult services exceeds supply, highlighting limited capacity and options in terms of respite care, residential care and employment support services. One caregiver explained how there could be a waiting time of up to 20 years to obtain a place at a day activity centre, as clients who enter are entitled to stay from 18 to 55 years old. Service providers and parents expressed concerns that when autistic adults drop out of services and are left at home for a prolonged period without meaningful engagement, they can lose the skills that they have acquired and start to exhibit behaviours that are challenging for their caregivers. Parents also expressed

fears about what would happen to their children in the future when they are no longer around:

I think the challenge right now for the entire sector is a lot of employment, residential living, because a lot of parents are saying ‘what happens to my child when I’m not around? Who is he going to stay with? How is he going to access community services and resources?’ So I think this to me is one of the biggest gaps right now, because parents are also aging and if we don’t find some of these solutions to empower some of our people with autism, they are adults right now, they will become old folks with autism, so it’s an aging autism population that we will also face in time to come. So things like healthcare, residential living, independent living, employment, will become very, very pressing issues. (Service provider, Participant 21)

Bridging the knowledge gap in the community. Despite the increased availability of services, participants highlighted a persisting lack of awareness of services offered by different service providers. There appeared to be some isolated services that autistic individuals and caregivers/families did not know about, which they attributed to insufficient marketing and publicity done for the general public. Service providers and users also opined that there is a knowledge disparity between families. They shared that while some parents are very knowledgeable and resourceful, other less-educated and non-English speaking parents may still struggle to understand what autism is, and find it difficult to understand the suite of services being offered or find a service provider that they can communicate with in their language:

I have met parents who, even at the parents-teacher meeting, they only speak Mandarin, so they need translation. And often many talks in the community, even for the special needs community, it might only be in English, so they may not have access to it. Yeah even the other ethnic groups too. Most of them can understand simple English, but what happens when it becomes more specialised field of say, estate planning, special needs trust funds, deputyship, leaving a will for your kids? These are a bit more specialised topics that they might need the language to help them understand. Not just the language to help them understand, but let’s say a Mandarin speaker, or not so educated, someone to explain to them, not only explain to them, but help them get into action. (Parent/caregiver, Participant 19)

Participants acknowledged that the government has made efforts to fill this knowledge gap. For example, a service provider shared that the Ministry of Health has a multi-lingual sign-posting programme to equip parents with a better understanding of their child, how to manage their behaviour and the services available to them. Another provider also shared that the Ministries of Health and Education also jointly organise an annual bi-lingual forum for parents of pre-school children with special needs to

help parents understand the various options available, help them to make informed decisions about their child’s educational placement and assist them with transition into mainstream or special education schools:

We partner parents. Because parents are important. And we try to do that throughout the journey . . . So which school for my child? Of course the psychologist, the medical practitioners, they give advice. But ultimately, it is the parent’s choice and we want parents to make informed decisions and we want to involve them in that decision. (Service provider, Participant 7)

Overcoming physical barriers to access. Service providers shared that Singapore has set up autism centres in different parts of the island and strived to move services from the hospital to the community, as close to the family as possible. SSAs also provide concessions and subsidies for the cost of travelling to services. However, some autistic individuals and caregivers in our sample still found services inaccessible because of distance, way-finding difficulties and environmental bombardment on public transport:

I know that there’s job support, but it’s quite far away, and quite inaccessible. I have problems getting to places the first time. And even after the fifth time . . . And then, it’s quite demoralising when you get lost . . . And a lot of us autistics, we are quite at home. Going out is quite hard. If someone came to get us, I mean I know we are not blind, but if someone came to get us, it would at least jump-start. (Autistic adult, Participant 20)

Fixing cracks in financial support. Service providers stated that from their standpoint, financial constraint is never a reason for which an individual does not access services. They explained that for services run by SSAs, fees are borne partly by the government and partly by the service user, with donations being raised to cover the remaining fees for families who are unable to pay. They added that for government services such as mainstream education and healthcare services, the standard funding mechanism applies whereby fees are means-tested and government subsidies are available for those who meet the criteria.

However, a few autistic adults pointed out that because eligibility criteria are based on household income, problems emerge when there is disagreement within the family over the decision to utilise services, due to stigma or other reasons. This was felt to result in a situation where autistic individuals who need financial assistance are neither able to receive parental support nor qualify for subsidies:

Because when you base it only on household income, the thing about the nature of disabilities like autism and other disabilities that are psychological or mental health, due to the stigma, there are a lot of parents out there who are in denial, or not willing to support, or they keep living in the mindset that no, my child doesn’t need treatment, doesn’t need to see

a psychiatrist, because they worry about the stigma. But what if the child really needs? So, with this kind of system, it's people like that, like me, who fall through the cracks because our parents are well-to-do. Our parents can afford it, but they don't want to support us. (Autistic adult, Participant 13)

Strengthening coordination between services. Service providers explained that hospitals in Singapore have a multi-disciplinary team of paediatricians, psychiatrists, psychologists, therapists and social workers who contribute to the short-term care of autistic children after diagnosis. However, in the longer term, most centres or organisations at the community level would not have all these services under one roof, which means that autistic individuals and their caregivers have to coordinate between different service providers. Both service users and providers acknowledged that fragmentation of services exist:

I mean this relates to my general experience working here as well that you know, although, services are aware of what other people are doing, there's still quite a lot of segregation and what I call my hospital, my castle, you know, this is what I do, I know what you do and you know what I do, but there's less of a coordinated and more interactive approach to services. It's more like, you know, you go there, if that finishes or doesn't work then you go maybe there, but we don't have an integrated model. I think that could be improved. (Service provider, Participant 10)

However, participants also recognised that mechanisms have been put in place to improve coordination of services. Service providers reported that within the government sector, coordination between the education system and health system has been enhanced by the Institute of Mental Health's Response, Early intervention and Assessment in Community Mental Health (REACH) teams who assist school personnel in supporting autistic students in the school setting and refer those who need more intensive help to the clinic setting. Within the non-government sector, collaboration has also reportedly increased with the establishment of the Autism Network Singapore (ANS) that currently links up the five leading SSAs providing autism services. Furthermore, the government and non-government sectors were felt to have developed a strong partnership, in which SSAs receive funding and training from the government but retain the flexibility to customise their own services to meet the needs of their specific client groups:

And we find this partnership actually very useful because the special school, what it means is they can do the kind of intervention and programming that they believe in, try out new things because you're not constrained by a set syllabus from the MOE, you have that flexibility but at the same time, you don't have to worry about money so much . . . so that is I think a very unique situation but a situation that has been helpful and that also gives us a close partnership. (Service provider, Participant 7)

Nonetheless, participants pointed back to a gap in the post-18 realm, explaining that while children aged 0–6 years old would be supported by a case manager in hospital, and children aged 7–18 years old would typically be guided by a case manager in school, no such care coordinator currently exists for autistic adults. Furthermore, even in the education setting, both service providers and users highlighted that autistic students who cope academically and struggle quietly might be overlooked:

But some schools are too overwhelmed, inundated with so many students with problems, so the most boisterous type will be identified. The quiet type and the parents who don't make noise will not be identified. So it really depends on the skills of the school personnel to tease them out. (Service provider, Participant 5)

Enhancing professional understanding of autism. From the perspective of service users, it appeared that service providers in Singapore still lack a nuanced understanding of the autism spectrum and the different kinds of needs among autistic individuals. Verbally and intellectually able autistic adults experienced difficulties obtaining a diagnosis and encountered professionals who prescribed medication for their behaviours without addressing the underlying cause:

Diagnosis can go wrong . . . Then you give us all the wrong drugs, you know, and I've experienced that . . . the attitude, 'Oh, you don't look autistic anymore. So you are cured. So you have no need because you can do [postgraduate studies]. You even topped your class. You have what needs?' But the real time understanding of autism and the lived experience is very lacking. (Autistic adult, Participant 3)

Post-diagnosis, these individuals also found that they were expected to cope without support. They pointed out the misconception that intelligent and vocal autistic persons are 'high-functioning' and therefore without support needs, when some of them in fact struggle with basic day-to-day living, sensory difficulties and social difficulties. Conversely, they explained how non-verbal autistic persons are labelled as 'low-functioning', when in fact they can have hidden talents and alternative modes of communication that have just not been discovered or are ignored. The need to enhance professional knowledge of autism was acknowledged by a few service providers as well:

Some clinical psychologists have knowledge of ASD, but many clinical psychologists are more attuned to looking at them from a mental health treatment perspective. Like oh, you are obsessive-compulsive. Oh, you have personality disorder . . . that's why adults with ASD are often medicated. But I have been training a group of clinical psychologists on how to have a differential diagnosis. The important thing is that the professionals must be equipped with understanding of developmental psychology, not just looking at the treatment

symptoms and then attacking the symptoms. (Service provider, Participant 5)

Theme 2: building flexible supports in an inclusive environment

Participants expressed that while some autistic individuals require intense, specialised care, many may only require some reasonable accommodations to thrive at school, work and life. Rather than creating more pockets of services, they felt that it would be more effective and economically efficient to build flexible supports in an inclusive environment that would benefit not just autistic people but everyone in general.

For example, one professional opined that compared to a few sessions of social skills intervention with an autistic child, which would have limited effect as the child changes and his or her social context changes, it may be preferable to engage the child's parents, teachers and friends to build a circle of support around the child that could continue throughout his or her life in a much more natural way:

I think services is one thing because it often implies like a particular place and group of people doing something, whereas I think supports . . . so lately, I do prefer that word as well because I think support is different. It can be formal and informal. It can be frequent or sessional, sporadic, as and when needed. It can be blended more in your everyday life. (Service provider, Participant 10)

An autistic adult echoed the same sentiment, as he recounted that being taken out of class for social skills interventions at a clinic only reinforced the idea that he was different from his peers and led to more peer bullying. The turning point for him was when a teacher engaged him in peer tutoring, and he naturally picked up social skills interacting with his classmates in a way that tapped on his strengths and interests:

I guess that was a time when I actually did pick up some meaningful social skills, and in a setting that I enjoyed because they had to ask me questions. I didn't need to force my way through, it was them who had to adapt to me. I felt quite happy, quite privileged . . . So when you talk about socialisation for folks with Asperger's, there is some tactic to it. Put them in a situation where they find it more comfortable. (Autistic adult, Participant 8)

Theme 3: addressing stigma and changing societal attitudes

Narratives revealed that Singapore may have high-quality services embedded within a broader social structure of discrimination. Both autistic adults and their caregivers/parents shared their experiences of stigma and called for greater public acceptance of autism:

Because sometimes people may think that this is just an excuse for the children to misbehave, or the caregiver is not taking good care of the kid. Because sometimes we do see articles or posts about missing children. They do not understand that some caregivers are trying to strike a balance between letting the children be independent and having some time for themselves. We have to face the child forever. So sometimes, we just want to let the child learn. But the public may not be so accepting of special needs children. (Parent/caregiver, Participant 17)

Participants perceived that attitudes in Singapore are still largely rooted in the traditional medical model, according to which autism is seen as a disease that needs to be cured, rather than a neurological difference to be accepted and accommodated. They conveyed that these attitudes are reflected in schools who only accept autistic students who are able to fit into their set expectations of behaviour and performance, employers who are reluctant to re-design their jobs so that they can hire autistic people, and some parents who expect service providers to cure their autistic children. In particular, autistic adults emphasised the need to shift away from focusing on the impairments and deficits of autistic people, to focusing on their value and potential:

Very importantly, we need to start aligning ourselves with the worldwide movement away from a purely medical model. So I'm not against the science. You know, we need science. I'm a scientist myself in a way, but we need to look at the humanity and not just refer to autistic people as a disease. And autism is not a disease. Now we know that. So Singapore needs to step out on that. (Autistic adult, Participant 3)

Participants agreed that changing mindsets and breaking the cycle of discrimination require collective effort from society, including policymakers, professionals, employers, educators, families and autistic people themselves:

It's a chicken and egg problem. If the autistics don't come out, if the 20% don't come out and say that, hey, autistics have potential, then the discrimination cannot be fixed. But if the discrimination is not fixed, they will not want to come out and become the shooting targets. (Autistic adult, Participant 11)

Discussion

Overall, both service providers and users in this study reported substantial growth in the availability of autism services in Singapore, although they also highlighted a gap in services for autistic adults and their caregivers/families. Disparities emerged between the views of service providers and users in terms of the perceived approachability, accessibility, affordability and adequacy of services, with some autistic adults and caregivers/parents of autistic children falling through the cracks despite considerable efforts

described by service providers to move services closer to home, improve coordination of services, as well as increase provision of information on and subsidies for services. In terms of the acceptability of services, some service users expressed that providers lack a nuanced understanding of the autism spectrum and the different kinds of needs of autistic individuals, and some providers also demonstrated awareness of this problem. Beyond the need for improvement in services, our participants also called for the development of more flexible supports embedded in an inclusive environment and for a broader change in societal attitudes. While this was mentioned by service providers and users alike, autistic adults in particular emphasised the need for a paradigm shift in the way disability is conceptualised and approached.

Our preliminary findings mirror the ‘services cliff’ phenomenon observed in the United States whereby autistic individuals lose access to services once they leave the school setting (Anderson & Butt, 2018; Milen & Nicholas, 2017; Shattuck et al., 2012). Our results also corroborate evidence in the United Kingdom that autistic adults without intellectual disability face significant challenges getting diagnosed and obtaining post-diagnostic support, and that this may be linked to a narrow professional view of the autism spectrum as a severe childhood disability (Crane et al., 2018; Jones et al., 2014; Raymond-Barker et al., 2016). In addition, this study suggests that while mechanisms have been established in Singapore to facilitate better coordination between the healthcare and education systems as well as government and non-government sectors, the older and more academically able autistic individuals might again be overlooked in these efforts to provide integrated support. A similar situation has been noted in England, where Education, Health and Care plans have been introduced in an attempt to provide holistic support for students with special needs, but it is reportedly difficult for those who are progressing academically to secure these plans (Boesley & Crane, 2018). This shows that an over-emphasis on education could overshadow other areas of needs such as social, emotional and mental health.

Our results point to an overarching need for greater understanding and acceptance of autistic individuals at all levels of society. At the professional level, service providers must be better trained to diagnose and support autistic individuals across the spectrum, across the lifespan and across different areas of needs. To enhance professional understanding of the lived experience of autism, autistic adults should be involved in the process of this training (Gillespie-Lynch et al., 2017). At the broader societal level, there is also a need for employers, colleagues, teachers, students and the general public to learn how to relate to, include and accommodate autistic people. A combination of both education interventions and contact interventions that provide opportunities for purposeful interaction

between autistic and neurotypical individuals may be required to improve lay knowledge, attitudes and behaviours (Corrigan et al., 2012; Dachez & Ndobu, 2018). Crucially, all these efforts should be grounded in a cohesive ideology that does not solely focus on impairment and deficits but recognises the strengths and potential of autistic individuals alongside the very real needs that they may have. While autism stigma is not a problem unique to Singapore (Liao et al., 2019; Yu et al., 2020), our participants’ responses suggest that Singapore may be lagging behind in the global movement away from a pure medical model of disability.

The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) offers a useful tool for service development based on an integrated biopsychosocial model of disability. In the ICF, disability is conceptualised as the product of interaction between health conditions (e.g. autism) and contextual factors, and disability is an umbrella term covering impairments, activity limitations and participation restrictions (WHO, 2001). A study using the ICF to describe the functioning of autistic adolescents in Singapore found relative strengths in carrying out activities (e.g. self-care) compared to challenges in participation (e.g. interpersonal relationships), and recommended that services focus on capitalising these strengths as much as supporting areas of need (Poon, 2011). Another model that has gained popularity in the disability field is the capability approach, whereby capability is determined by the interaction between individual ability, available resources and environmental factors, and capability can in turn translate into achievements in multiple domains of life functioning (Sen, 1985). This approach can also serve as a framework for autism service provision and policymaking, whereby the goal of services and policies would be to increase the capabilities of autistic individuals so that they can achieve improved functioning in areas including physical health, mental-wellbeing, social participation, education, employment and independent living (Shattuck et al., 2012). Fundamentally, this change in ideology must recognise autistic individuals as autism experts and empower autistic voices to shape the policies and services that are intended to support them (Gillespie-Lynch et al., 2017). This means that moving forward, autistic people should be increasingly engaged as equal partners in higher-level leadership and policy decision-making, in research and writing, as well as in giving talks and workshops to educate both professionals and the wider public.

This is the first qualitative study to explore how different stakeholders experience autism services and supports in Singapore, and much larger-scale research is needed to evaluate service provision and utilisation in the country, especially to examine inequalities in access and develop targeted solutions. Several quantitative studies in other countries have shown that sociodemographic factors such

as ethnicity, income level and education level affect the level of service utilisation in families with autistic children (Nguyen et al., 2016; Pickard & Ingersoll 2016). Qualitative studies have also documented the challenges that minority groups face in accessing autism services, including language barriers, lack of awareness and lack of empowerment (Fox et al., 2016; Jegatheesan et al., 2010; Khanlou et al., 2017; Zuckerman et al., 2014). While our data suggest that there are disparities in access, we are unable to draw specific conclusions due to the lack of ethnic and linguistic diversity among our participants and lack of data on their socioeconomic status and educational attainments. Future research should seek to study population groups that may require additional forms of outreach and assistance to ensure equitable access to information and services. Future policies should also re-evaluate the current criteria for subsidies that are based on household income, taking into account the stigma attached to neurodevelopmental and mental health conditions that can cause conflict within the family over care seeking.

A strength of this study is that it has not only presented the perspectives of service providers but also conducted an initial exploration of whether they seem to align with the experiences of service users. In fact, this is one of the few studies in Singapore that has included the voices of autistic people themselves. Nonetheless, we acknowledge that our sample size of autistic adults and parents/caregivers of autistic children was smaller than that of service providers, and we hope that this article will lead to more autism research in Singapore that incorporates the balanced input of both experts by profession and experts by lived experience. There is also the possibility of social desirability bias in this study, given that service providers may have presented more favourable views of their services. To minimise this as much as possible, participants were reminded that they were being interviewed in their individual capacity and not as representative of their organisation, and that their institutional affiliations would not be reported. Encouragingly, their accounts did include both the positive and negative aspects of autism service provision in Singapore.

Conclusion

This study has provided unique insight into the provision of autism services and supports in Singapore from the perspectives of service providers, autistic adults and caregivers of autistic children. Our findings shed light on three main themes: (1) improving access to autism-specific services, (2) creating flexible supports in an inclusive environment and (3) addressing stigma and changing societal attitudes. Results suggest that while Singapore may have achieved rapid growth in autism-specific services, broader social structures now need to follow. To better support autistic individuals in society, autistic voices need to be

amplified and a collective effort is needed to achieve a paradigm shift from impairment to capability.

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Supplemental material

Supplemental material for this article is available online.

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