

**SUBMISSION FOR THE PARLIAMENTARY INQUIRY INTO SERVICES FOR PEOPLE
WITH AUTISM SPECTRUM DISORDER**

Summary:

The following views and opinions were taken from formal and informal discussions with families as well as professionals at Irabina Autism Services - a disability organisation currently with services offered at its main branch in Bayswater North, Victoria and at its community hub in Pakenham, Victoria.

The views given primarily reflect individuals' opinions and perceptions with regards to the following terms of references:

- *ACCESSING SERVICES & QUALITY OF SERVICES*
- *HEALTH SERVICES*
- *SERVICES IN RURAL AND REGIONAL VICTORIA*
- *INTEGRATION ACROSS GOVERNMENTS AND SERVICES*
- *DISABILITY SERVICE PROVIDERS*
- *EDUCATION, EMPLOYMENT & HOUSING*
- *IMPACT OF NDIS*
- *COMMUNITY PARTICIPATION*

ACCESSING SERVICES & QUALITY OF SERVICES:

- What is **the experience** of people with ASD, their families and carers in accessing services, information, advice & support?
- What is **the quality** of these services, standard of advice and reliability of information given on ASD and the support provided?

In general, families that have had the opportunity to access Early Childhood Intervention Services (ECIS) funded through the Victorian State Government indicate that they felt supported and had an avenue to access information and advice as needed. There are some

discrepancies as to the level of support available, depending on which organisation families had accessed their ECIS and the experience level of the key workers or professionals they worked with. But generally, most families that have been linked into ECIS providers felt that they had experienced sufficient supports and services. A parent expressed that her ECIS provider assisted with significant guidance and support, and never assumed that as a parent she had the answers - but instead would communicate with her frequently and ensure she had the information she needed to support her child, herself and her family. When this family transitioned into the school system, there was a feeling of loss as the schools were less family-centred in their approach to working with families and expected parents to have the answers or find the answers in relation to helping their child deal with the additional supports they may need. Many families express that once they leave the support system of ECIS they need to learn to advocate for their child independently and for some families, this poses a great challenge and increased stress levels in their lives.

The professionals who work with children with ASD and their families indicate that there is a need for key workers working in ECIS to have some degree of clinical experience before being engaged as key workers. The role of the key worker requires professionals to work in a transdisciplinary and family-centred model. This requires these professionals to have a good overall understanding of the needs of the child and family, which then enables them to address various issues related to the child and the family as a whole and not just within their disciplines' area of concern. These professionals also need to recognise when needs are beyond their expertise and be able to seek immediate consultation with their colleagues, but then be able to support families to continue to implement any strategies or supports put in place through these team consultations.

As families transition away from ECI Services, there is a stronger need for parents/ families to self-network, gain knowledge and information about services and supports that can assist their child and/or family. Several parents acknowledged the undeniable value of being part of parent support groups e.g. MyTime groups, which provided them with the opportunity to share emotional support, practical advice and information on services/ activities that could benefit their child. Schools that were able to provide similar types of parent support groups were also another source of support for parents with school-aged children with ASD. Once again, families consistently indicate that they have to work much harder to keep up with the information around services/ programs for individuals with ASD, latest research information or new supports available as they can no longer just rely on ECIS professionals to keep them in the loop.

There have also been comments from families who perceive that as organisations that provide services grow and expand, there can be a drop in quality of the services. Comments were shared about big organisations that have begun to roll out hubs or satellite services in areas further out offer only “token services” and keep raising their prices for services. This was particularly noted when the Helping Children With Autism funding was put in place and there is a fear that this will be the case when NDIS rolls out in these regions. The feeling was that in areas such as Casey and Cardinia, where there are many more migrant families and families from lower socio-economic backgrounds, the price increases became a big deterrent to being able to seek ongoing services (after funding ceased) and with the added travel cost associated with it this made access to services unaffordable.

Concerns were also voiced by a parent about the costs of some services and/or equipment providers as soon as the word ‘autism’ or ‘disability’ becomes known or part of the parent request or conversation. There is a tendency for providers or suppliers to in some instances to charge more for services or resources on the basis of the label especially when they know that there is funding for the type of disability the child has e.g. HCWA or Better Start. There is added concern that this will happen too when the NDIS rolls out.

In terms of quality of information – when people are new to autism services i.e. during the early intervention years, the information provided appears to be up-to-date, relevant and very much needed by the families. As the family moves on, they become more discerning about the information they are given, the quality and accuracy of it, and how best to advocate for their family member. This is something to bear in mind as those families who are proactive and self-advocating will need support to get to the information that is relevant to their current needs as opposed to “one size fits all” type of information. The support required may not be as much around finding the relevant information but perhaps to provide a sounding board when parents/ families are trying to explore what may be next steps in their journey to support their child or family member with ASD.

HEALTH SERVICES

- Does the health system provide **adequate access, information** and support to people with ASD and their families in Victoria?
- What is the **accessibility and availability of quality assessments** and diagnoses of people presenting with ASD?

For professionals at Irabina, having the opportunity to service families in two different areas of Victoria has shown that there is a significant difference in

the information that families receive through the health system. For instance, the information that families in the southern region receive in terms of where to get further assessments if they want to pursue a diagnosis, what services to access once a diagnosis is confirmed and even when there is no diagnosis, but definite developmental delays, (this information) is fragmented and lacks detail. It appears that families that have access to more inner city or more experienced health practitioners, will be directed more quickly to the services they need.

According to the families in the southern region, there seems to also be a lack of knowledge from their first point of call when they start to notice developmental differences in their children. The GPs although supportive and caring in many ways, do not have the depth of knowledge particularly about services, funding availability and where or how to access these funding tiers. Once referrals are made to paediatricians, once again it depends on the paediatrician's knowledge and experience as to whether families get the information on where to get more assessments or to access services and supports. Those paediatricians who do have in depth knowledge and experience usually have very long wait lists and charge considerably more, which often restricts many families for financial reasons or for the wellbeing of all members of the family, they simply do not feel they can wait that long.

Both professionals and families mention that access to quality assessments particularly for diagnostic purposes is limited, with long waitlists in most places particularly community-based services. While private practises or organisations that offer diagnostic assessments can be very expensive, Medicare offers very limited rebates to assist with these diagnosis assessments. There are also discrepancies as to what assessments are required to get a confirmed diagnosis of ASD. Some families obtain a diagnosis purely through a paediatrician while others are sent by their paediatricians to obtain further assessments from a multidisciplinary team of professionals before a diagnosis can be confirmed. The cost therefore will vary for the family.

It must be noted that there are (still) many families who have a child with ASD who do not access services when the child is young as they have not been informed that their child is presenting with needs, differences or possible ASD.

Therefore they greatly miss out on information and often, when challenges present itself more significantly in transitions stages (e.g. moving into school environment), these family's initially rely on their local primary school to professionally guide them through those early days, the process of seeking a diagnosis and gathering information about services, funding entitlements and other supports. It is thus likely that many families do not receive advice, nor have full knowledge of all they are entitled to as the education sector themselves do not necessarily have the information needed.

SERVICES IN RURAL AND REGIONAL VICTORIA

- Are there particular issues with services **access and quality** of service in rural and regional areas of Victoria?
- What is the accessibility and availability of services that are **age appropriate**?

There are families that live in regions which are still considered metro regions and not rural, but have to travel a significant distance to access services – whether they are specifically autism based or that provide supports for families who live with a disability in general. A mother of three children with ASD who lives in Lang Lang, shared that for her family and several other families in that area, access to services has always been challenging because of the travel factor and in some instances, services being restricted based on which side of the border/which city council you fall under and not just based on how close a family is to the service.

The travel to access suitable services is a limiting factor for some and although more disability organisations and ECIS are expanding by setting up hubs or satellite services, these services are limited in what they offer. The distance factor also adds to the cost of accessing services or the cost of getting supports to come out to service them in their own community.

INTEGRATION ACROSS GOVERNMENTS AND SERVICES

- How well are services **across the different levels** of government integrated?
- Is there a **collaboration and appropriate linking up** between service providers, particularly in relation to **transitions** from one area of the sector to another?

Most families have experienced the challenges that can happen when their child moves into the early childhood education setting, and then the school age setting. With families that have ECIS in place, the liaising between the early education system and ECIS is present but the quality of this collaboration can vary - again depending on the key worker experience, the organisations' experience as a whole and the education setting the child is in.

More often than not, families feel that if they have a reliable and experienced ECIS provider they are supported to advocate for better collaboration and communication between services and sectors. If they do not have the support, they have to rely on themselves as parents to continue to ensure cross-communication occurs between all services and sectors that relate to their child and the family as a whole. This becomes more of a challenge when children transition into the school setting as the education sector has its own guidelines as to what falls within the child's educational goals and what are considered outside of those goals. Parents then need to

understand what these guidelines are and navigate the terminology that comes with this sector to be able to advocate effectively for their child.

It is reported that some families need considerably more support than their local school provides and often feel intimidated about questioning the school and its provision for the child. Both within the education sector and in general, families may be aware of their right to complain and/or advocate for their child, (although many would not be aware) but often are not able to seek or take this proactive approach due to their own personality, cultural reasons, language / interpretation difficulties, the ethos presented by the service provider or their own lack of knowledge and understanding. These families then take the approach of resignation, that there is nothing they can do and/or they are unable to 'make a difference' for their family member. Some service organisations embrace the family's decisions and encourage them to follow their own hopes for their child. Others 'squash' or actively discourage the family's decisions – perhaps with valid reasons, but still without necessarily seeing the situation through parent eyes.

There are also concerns about what is funded under NDIS and what is the responsibility of the Education department for instance- particularly in relation to child's supports at school. As a service provider we also have our questions about when is the child's NDIS package going to fund for a service if it is a service that affects both educational and therapy-based goals. There will need to be very detailed communication and collaboration between all parties involved with the child for the best outcomes, but will NDIS funding assist in ensuring time is given for these discussion, collaborations and planning to occur?

DISABILITY SERVICE PROVIDERS

- Does the disability service sector provide **sufficient and quality tailored** services to people with ASD?
- What is the level of **unmet demand** for these services?
- How well do these services perform in **meeting the expectations** of their clients?

According to some families, there is a tendency for providers to sometimes go overboard with their assumptions on what is "safe" and appropriate for the individual with ASD. Families are sometimes discouraged from involving their child in certain activities as the service providers are concerned that parents have too high expectations of their child or that as service providers, they are not addressing "therapy-based goals" if they include a child in a program. On the other hand, parents feel that providers are not being flexible enough in seeing how the participation in itself is the goal and not the achievement of the goal of which the program is developed for. This highlights the point

that there needs to be more open and honest communication between families and service providers and at times, difficult conversations to determine what constitutes best outcomes for the child/ family- is it the achievement of the goals of the program or more about the successful and quality of participation?

Families feel that they need to advocate strongly for what they feel their child's needs are and what their family's needs are which inevitably impacts on their child, and what the successful participation for the child can look like. Their experience has been that they are not always listened to or there is not always the opportunity to have these collaborative and honest discussions.

Professionals on the other hand feel a sense of responsibility to always provide programs that address therapy goals and take on the responsibility of making sure that the child's developmental outcomes are being catered to, but losing sight at times of the whole families' needs and the quality of life aspect for each child and family.

Another area of support that families have raised as an unmet need is more supports for fathers and siblings of children with ASD. More often than not, support groups are held during the day which is not accessible for most fathers (and/or mothers who work full-time). The education and support of fathers can highly impact on the family dynamics and the supports each parent can give to each other, to their child with ASD and the family unit as a whole. Similarly, siblings of individuals with ASD often have significant difficulties understanding, accepting and supporting their sibling with ASD. The supports and coaching they receive can benefit them not only in their current family life, but also help contribute to preparing them for their life long support of their sibling with ASD.

EDUCATION, EMPLOYMENT & HOUSING

- What is the **accessibility to and quality of** education services being provided to people with autism?
- How **inclusive** is the education sector, at all levels, to people with ASD?
- What are the **resource limitations**?
- Are the **accommodation needs** of people with ASD being met?
- What **models of housing** represent best practice and how developed is the sector in providing sufficient and appropriate housing options?
- How well equipped is the workforce across the sector in providing **informed, compassionate and professional** service to people with ASD?
- What are the **training needs and qualifications** necessary to ensure a skilled workforce

The overall message from families when it comes to thinking about the education, employment and housing sector is about doing away with the "one size fits all" mentality. Being able to individualise goals and what is focused on, on a daily basis is where they feel services need to head more

toward and move away from the idea that all individuals with ASD have to follow the “pre-trodden path through society”. There should be less assumptions based on the fact that the path through life should look the same for each individual with ASD just because they share a diagnosis. Families have a fear that at times they are made to feel like they have to “fit-in” to the mould of each organisation you are trying to be a part of or otherwise, there is nothing more that can be done for their family member with ASD.

There is an urgent need for places of education to team with outside service providers to ensure effective education of children, where continuity and joint goals are in place between schools and outside services. When this is not in place, it leads to a disjointed approach and considerable confusion for the parents and also by school employees. School employees need to further their professional knowledge of working with individuals with autism / disability in a regular and ongoing manner.

The families that have children that are falling in between specialist and mainstream education systems are also faced with the added challenge of not finding the supports they need. A parent who has a child who has just transitioned this year into a mainstream high school struggles with the fact that the school has not been able to gain additional funding to help support this child’s social and emotional needs at school, but the child’s needs do not necessarily warrant a specialist setting. The options for this family is to continue to advocate and allocate whatever finances they can afford to help support their child at school, while also take on the challenge of making sure there is collaboration and team work between service providers and the school for best outcomes for their child. This highlights the gap is in the school system that exists particularly for children that have challenges that are not considered significant enough to be eligible for additional supports and the school has limited funds to then find individualized ways to support this child. For most families, the perception is that they are faced with school systems that focus on the teaching of their programs and not the teaching THE child.

IMPACT OF NDIS

- What will be the **impact of the roll-out of the NDIS** on services, and choice of service for people with ASD and their families?
- Are there likely to be **gaps** in service emerging as a result?
- How will the **different levels** of government service provision be changed or impacted?

The government’s message to the public overall is that NDIS will provide more individualisation and increase scope of services for all individuals with a disability. But is the government also providing the funding or supports in terms of infrastructure to help organisations that deliver the supports and services

be able to increase the scope of services they offer e.g. the information technology / systems that helps support work efficiencies and cross-sector communication, buildings to house different types of services for varying age groups, processes to support cross referrals and again, effective cross collaboration of services / organisations? Will the NDIS perhaps be able to build on a concept like a retirement village but for individuals with ASD/ disability- where there are central services that provide immediate supports/ services but then around these services will sit complimentary services that can be accessed quickly and seamlessly, and all this can be supported through the funds of the NDIS.

There is also continued confusion as voiced both from families and service providers as to what can be accessed under NDIS funding and what is not in scope. For instance, today some schools allow parents to pay for their own therapy for their child within school hours. Others probably do not. Some schools have their own therapists funded through the Education Department. And some schools are just better equipped or have more knowledge in how to gain more funds through the education system to support a child with ASD. However, who is responsible for payments for these additional services when the NDIS is in place? Will schools redirect their funding elsewhere if families are paying with their own / NDIS funds, and who will ensure a whole care team approach?

Service providers and especially early childhood intervention providers have also voiced concerns about whether NDIS will allocate part of child's individual funding to enable the carers/ parents to get the supports they need to advocate, support and educate themselves to be able to up skill their child with ASD/ disability. The family-centred approach needs to continue to be supported through the NDIS as evidence shows that this model ensures best outcomes for children with disability. So it would be remiss if funding did not cover parent/ carer access to education and even emotional supports and services.

COMMUNITY PARTICIPATION

- What **programs exist to facilitate the participation** of people with ASD in the community?
- What are the **opportunities for participation** in sports and recreation?

The supports to help individuals with ASD participate in community programs and activities are still limited. More needs to be done in respect to educating and coaching community organisations on how to support individuals with ASD which then enables individuals with ASD more opportunities to participate in these community activities and programs. All organizations that have activities and programs for children need to look outside the box about

what inclusion can look like and how inclusion can mean different things for different individuals and/or their families.

Families seeking more opportunities for their child to engage in community based programs have noted that different organisations have different programs which increase the participation of people with ASD. These tend to be focussed on supporting participation in holiday programs, recreational and camps. However, there is wide variation in how these same organisations provide for the needs of those with ASD and other disabilities. Some organisations claim they do not have enough staff to cater for higher needs individuals. Families have concerns about what this means for children with higher needs and when will sufficient government support be available to these organisations to cater for children requiring "more than usual" supports. Families feel that consideration must be given to increasing numbers that can be supported, and number of programs that can include children with ASD- remembering the wide spectrum that exist in this diagnosis. If a program is out there and a parent goes through the process of enrolling the child, only to be told there is a 12 to 18 month or more waiting list, just so their child can participate in a simple outing in the community- this is disheartening for the families concerned.

The information provided is the result of contributions from:

- Informal discussions with families and professionals at Irabina Autism Services- Bayswater and Cardinia branch
- Formal discussion with families, in particular the following two parents who are also interested to be contacted via Irabina to be give evidence at public hearings that will be organised following this submission:
 - Rachel Shambrook – Casey
 - Helen Wise- Cardinia

For further information please contact:

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