

INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

SUBMISSION FROM BROAD INSIGHT GROUP, DIANELLA COMMUNITY HEALTH

APRIL 2016

ABOUT BROAD INSIGHT GROUP

Broad Insight Group (BIG) is an Early Childhood Intervention Service and a program of Dianella Community Health (DCH) in Melbourne's northern suburbs. Broad Insight Group was established in the early 1970s by a group of local parents seeking services for their young children. Broad Insight Group provides a co-ordinated range of specialist education, therapy and support services to families with pre-school age children (0-6 years of age) who have a developmental delay or disability living in the northern suburbs, primarily in the City of Hume and Moreland local government areas.

In compiling this submission, DCH has drawn upon the set of key questions in the guide to submissions and public meetings made available by the Family and Community Development Committee of the Parliament of Victoria. Consultations have been undertaken with parents of children with Autism Spectrum Disorder (ASD) who access the service as well as specialist BIG staff (therapists, teachers and parent support workers). Staff at Broad Insight Group have considerable expertise in delivering services to children with ASD and with many years of collective experience in assessing the needs and gaps in service for children with ASD and their families. The lived experience of families and the staff that support them allows for clear identification of both unmet needs and aspects of current service provision that demonstrate good practice and contribute to attaining positive benefits for children and families involved.

Accessing services and quality of service

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

Enablers

- Amaze (a service of Autism Victoria) effectively delivers advice and information to families with a recent diagnosis of ASD. Amaze provides information and assistance to individuals with ASD, their parents, carers and families, support groups, ASD professionals, schools and other community groups on the subject of ASD.
- MyTime groups provide invaluable parent support and information to families. They are very well attended within BIG. MyTime groups provide facilitated peer support to parents and carers raising children with complex needs. Information is provided about local services and resources. A play leader looks after pre-school-age children whilst adults have time to connect with others who share similar experiences. The facilitator sources research-based parenting information and supports parents and carers to build relationships with other parents and carers. MyTime groups are free to attend and are available to anyone caring for a child under 16 years with complex needs. The groups are not disability specific.

Challenges

- Access to in-home respite care for families where carers have identified that they are experiencing severe carer stress is very limited. Some families are unable to receive respite where HACC services are already fully extended or where children are excluded due to their behaviours of concern. Other respite services provide short-term programs only. Council respite services can, at times, be inflexible and may not provide families with the hours of support required or at the times desired by the family. For example, Hume City Council has announced that from May 2016 the Council are planning to withdraw weekend respite services. Some families also experience judgemental attitudes towards their requests for service where the provider deems they are requiring too little or too much support. For example, a family within our service requested 6 hours of respite care for their child so that they could attend a family wedding, however the coordinating agency questioned the value of using up so many hours on an episode deemed non-urgent. For this family, attendance at the wedding had extremely high cultural and emotional value in terms of connection with family, culture and community. The family indicated that they felt uncomfortable with the implied judgement that they should not be requesting respite for a social event.
- Respite workers working with children with ASD do not always have an understanding of ASD, impacting on the quality of care they can provide and family confidence in the service.
- Some useful programs have ceased. Northern Autism Spectrum Disorders Network once provided training for early years providers and families. Another of their initiatives provided support to families on waiting lists for early intervention services.

- The current service system is stretched, making it difficult for families to access services. Community programs such as MyTime, where parents can access informal support from others, can be at capacity. Interested families are often referred to waiting lists to attend. This is of particular concern given recent research that identifies the positive value of playgroups and parent support.
- Families report that the amount of information they receive immediately post-diagnosis is overwhelming and the service system difficult to navigate. Parents report that gaining information about ASD and ASD services is 'like learning a foreign language'. The marketing of local services for children with ASD within a specific geographic area is poor. For most families, the main source of information about ASD-specific programs and services is often by word of mouth only, through attendance at early years community hubs based within primary schools. There are no central information hubs for local services for families with preschool-age children. The service provision model for children with ASD and their families assumes that parents do not work full-time. It also assumes that the mother is the primary caregiver and does not always take into account the support needs of fathers. Families report fathers often feel they have a lack of connection to and a poor understanding of the services their children are receiving.

Recommendations:

1. That the service model be reviewed to ensure holistic and family-centred approaches are undertaken.
2. That programs, such as Northern Autism Spectrum Disorders Network that provide ASD training for early years providers and families be funded.
3. That community information hubs be established to provide local ASD resources and programs.
4. That respite services provide a flexible and family-centred service which is sensitive to the needs of children with ASD and directed by the family.
5. That support be provided for parents who work full-time hours, as most programs are conducted during work hours. This could include father support groups.

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?

Enablers

- Paediatricians are an excellent source of information for families during a child's preschool years and facilitate referrals to Early Childhood Intervention Service (ECIS) and allied health professionals.

Challenges

- Referral pathways for assessment for ASD diagnosis:
 - There are long waiting times for publicly funded multidisciplinary (MD) assessments. Furthermore, access to the MD stream at the Royal Children's Hospital (known as the Travancore Clinic), is limited to complex cases where another sensory impairment or neuro-disability exists. When children do not receive a MD assessment at the time of diagnosis, this presents a problem at school transition as further assessments must urgently be sought in order to apply for funding under the Program for Students with a Disability (PSD), which requires an MD diagnosis. In some cases, the family is required to pay for the services of a psychologist to 'sign off' on the diagnosis, causing financial hardship.
 - There has been a reduction in the number of diagnostic services available in the northern suburbs of Melbourne. The Early Diagnostic Clinic for Autism Spectrum Disorders at La Trobe University, for example, is now closed.
 - Parents presenting to primary practitioners querying ASD are not always referred on for further assessment.
 - There are long waiting lists for publicly funded paediatricians.
 - Paediatricians can be hesitant to diagnose ASD, especially in those children younger than 4 years of age. A wait-and-watch approach can delay access to early intervention in some cases.

The cost of private assessments is also a barrier, particularly for families with multiple children requiring assessment.

- Knowledge of ASD amongst health professionals
 - There is a general lack of in-depth understanding of ASD amongst medical professionals and GPs. For example, there is not enough awareness of and support for sleep issues in children with ASD, which often severely impact child and family functioning.
- Financial:
 - The cost of some private therapies is a barrier to accessing treatment (e.g. Applied Behavioural Analysis therapy is extremely intensive and expensive).
 - Children who are not permanent residents of Australia or from a New Zealand background do not receive Helping Children with Autism program (HCWA) funding, limiting their access to early intervention supports.
- Access:
 - There are long waiting lists for private therapists via HCWA funding.

Recommendations:

- 1. That accessibility to publicly funded paediatricians and multidisciplinary ASD assessments be improved.**
- 2. That education and awareness-raising occur to improve knowledge and understanding of ASD amongst GPs and other health professionals.**

Integration across governments and services

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

Enablers

- In our experience there is effective communication between ECIS services, kindergartens and schools.

Challenges

- ECIS services do not always communicate very effectively with other ECIS services. This will increasingly become an issue as the National Disability Insurance Scheme (NDIS) rolls out, with a market-driven, competitive approach being adopted. This may potentially impede inter-agency sharing of information relevant to the care of individual children.
- Communication between ECIS services and private therapists delivering HCWA therapy is not always good, despite it being important to share knowledge of goals being worked on at a given point in time for individual children.

Recommendations:

- 1. That initiatives be put in place to facilitate sharing of information between service providers to enhance continuity of care for children with ASD.**

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?

Enablers

- ECIS services work towards a family-centred, strengths-based approach to providing support to families.
- Therapists and teachers at BIG have specialist training and extensive experience in working with children with ASD.

- Families and BIG therapists/teachers work together to set and regularly review goals via Family Service Support Plans, nurturing strong partnerships with families.
- Having ECIS staff trained in the administration of assessment tools (such as the ADOS) is valuable as they contribute knowledge to parents and non-trained ECIS staff regarding early signs of ASD and approaches to intervention.

Challenges

- ECIS workers have had increasing case loads over the last few years. Face-to-face services provided by ECIS are not frequent enough to deliver optimal outcomes and relationships between ECIS services and families are weakened.
- Currently, families are allocated a Key Worker (KW)) in ECIS. ECIS services attempt to match a family with a KW that best meets the family's needs based on their skills and experience, however the fit may not always be ideal. Furthermore, parents prefer to be able to choose the discipline of their KW or to have the option of changing KW from time to time.
- Some parents see HCWA providers as 'money hungry' as therapy fees can be higher for families with HCWA funding compared to families seeking private therapy without HCWA funding.

Recommendations:

1. That State Government ECIS funding levels be increased to return case loads to reasonable levels of no more than 15 clients for a full-time employee.
2. That family preferences regarding allocation of individual KWs be taken into account when allocating KWs.
3. That HCWA providers be transparent about their fee schedules and explain to families how HCWA sessions are costed e.g. allowing for administrative time etc.

Education

What is the accessibility to, and quality of the education services provided to people with autism? How inclusive is the education sector, at all levels, to people with ASD? What are the resource limitations?

Enablers

ALL LEVELS

- A KW or case manager that can help navigate the system, provide key documentation and be with family at transition times is invaluable.
- There is a growing understanding of the needs of children with ASD within the education sector.
- HCWA funding can be used to fund Inclusion Support delivered by specialist teachers in early childhood services and schools.
- All registered teachers are now required to complete 20 hours of disability training.

CHILDCARE

Often, early childhood professionals initiate discussions with parents regarding developmental delays in children and recommend that parents follow up concerns by seeing their GP.

KINDERGARTEN

- Children with ASD who meet eligibility criteria for Kindergarten Inclusion Support (KIS) funding can receive extra support in the classroom, normally in the form of a KIS worker/aide.

SCHOOL

- Special schools are a good source of ASD-specific events and programs for parents.
- Some schools have an Autism Adviser (e.g. Wilmott Park Primary School in Craigieburn).

Challenges

ALL LEVELS

- Staff training at all levels is lacking (how to support children with ASD, sensory needs of children with ASD, social skills support, use of visual supports, etc).
- Educational facilities that have a reputation for good outcomes for children with ASD quickly become flooded with applications from children with ASD through word of mouth. The load is not spread evenly as a result.
- When only one staff member at an educational facility has knowledge of how to support a child with ASD, there are challenges when that staff member is absent.
- There is lack of inclusion for children with ASD across school programs (e.g. school excursions or out of hours school care are often not accessible to children with ASD).
- There is a general lack of willingness among staff to help children requiring support for toileting and hygiene.
- There is a lack of funding for specialised equipment, e.g. calming sensory equipment, for children in all educational settings.

CHILDCARE

- Childcare centres are under-resourced to meet the needs of children with ASD. This is both in terms of training and provision of specialist equipment.
- Inclusion Support Subsidy (ISS) funding is not being taken up frequently enough by childcare centres. Centres may not budget for inclusion support (a gap exists between the funding provided and the actual cost of service).

- Child care centres no longer have access to funding for professional development, leaving staff with a knowledge and skills gap when addressing the needs of children with ASD.

KINDERGARTEN

- Kindergarten Inclusion Support funding is deficit based (based on safety or medical issues, for example). Under this approach, children with support needs but who present with internalising behaviours (e.g. anxiety and withdrawal) are not prioritised in the same way as those with externalising behaviours.
- Some kindergartens suggest to parents reducing their child's hours of attendance at kindergarten due to difficulty in meeting their needs.

SCHOOL

- Parents have been discouraged from enrolling their children in some mainstream schools, the stated reason being that schools already have too many children with additional needs.
- Some specialist ASD schools are at capacity, removing parent choice in education.
- Some schools have suggested to parents reducing their child's hours of attendance at school due to difficulty in meeting their needs.
- Many children with ASD are missing out on Program for Students with Disability funding due to language scores being above the cut-off of 70 (low language skills being a necessary co-requisite for funding eligibility along with a diagnosis of autism). These 'higher-functioning' children still have substantial support needs. Children with ASD who do not receive any funding still require support to access the curriculum, for safety within and outside the school environment, addressing their sensory needs and for individual support from staff.
- Mainstream schools refusing enrolments for children with ASD:
 - There is pressure to withdraw children from school if behavioural issues arise, or pressure to reduce hours so that children are not attending school full-time. These pressures increase family stress levels.
 - Children in one family may attend various schools, increasing parent load and stresses on family life.
 - Not all children can access their preferred school (e.g. there is significantly less funding provided for children attending independent schools compared with government schools).
- Programs are conducted which are not appropriate or individualised to the learning needs of the child.
- There can be lack of communication between school and parent.
- Currently there are no Occupational Therapists within the mainstream school system. Sensory needs in children are not adequately supported within the school environment as a result.
- Often the Department of Education and Training only becomes directly involved when the school environment is clearly not working for individual children at a

mainstream school. At this point, they may be offered Severe Behaviour Disorder funding and a functional placement at a specialist school. However, this is usually in response to children with very challenging, externalising behaviours. When a child displays anxious, withdrawn (yet overtly compliant) behaviours the same flexibility does not exist.

- Children with ASD who miss out on PSD funding receive very little support within the school system, so cut-off of care and support from ECIS is keenly felt by the child and family.
- School enrolment is a prolonged process and often a stressful time for parents, waiting to see if their child's enrolment is successful.
- Despite schools being informed that a child with ASD requires PSD funding, often assessments (speech-and-language or cognitive assessments) are conducted late in the year preceding starting school. This provides limited time for parents to look for alternative school placements for their child should he/she not qualify for PSD funding.

Recommendations:

- 1. That education supports are funded for all children with ASD, not just those with low language or cognitive scores and that they can access specialist schools if they choose to.**
- 2. That more funding be provided to kindergartens to provide KIS aides and equipment for children with ASD.**
- 3. That childcare centres receive incentives for the uptake of ISS funding to support children with ASD.**
- 4. That schools, kindergartens and childcare centres receive more funding for training and equipment for ASD.**
- 5. That all children with ASD have access to an Occupational Therapist in the education system.**

That school enrolment patterns of children with ASD be scrutinised to identify why certain schools are attracting high numbers of children with ASD and why others have adopted a 'burden-shifting' approach.

Workforce issues

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?

Enablers

- There are many dedicated individuals within the sector who have significant experience and specialist training in working with people with ASD.
- Sometimes parents of children with ASD gain qualifications to work within the sector, bringing their own valuable lived experience to benefit other families.

Challenges

- The workforce has difficulty keeping up to date with latest Evidence Based Practice and research. There is little money available for ongoing professional development within large and small organisations.
- ASD assessments can be expensive to purchase, therefore not all organisations are equipped to conduct them and many don't have staff trained to administer them.

Recommendations:

- **That more time and funding be made available for professional development for the ASD workforce.**

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?

Challenges

- Parents would like more information about services available through the NDIS.
- There is a question mark as to whether NDIS/LAC/Access Partner planners will have a sufficiently in-depth understanding of ASD to collaborate towards providing appropriate plans.
- It is unlikely that there will be enough children's therapy services available to meet the predicted demand. This will result in long waiting lists for therapy.
- Children may find it difficult to receive NDIS-funded services at school if schools are unwilling to allow NDIS therapists to conduct sessions during school hours and on school premises. There may also be a lack of service providers willing to see families after school or on weekends to counter this.

Recommendations:

1. **That the NDIS increase efforts aimed at providing information to parents about services they can expect for their children under the new scheme.**
2. **That NDIS/LAC/Access Partners be carefully selected to have as in-depth knowledge as possible of ASD and that they receive training to stay up-to-date with new evidence in the area.**

3. That issues of capacity to deliver therapy services on the ground be looked at carefully with consideration of incentives to attract more providers.

CONCLUDING REMARKS

Broad Insight Group (BIG) has collaborated with families accessing our service to prepare this submission for the Parliament of Victoria's Inquiry Into Services for People with Autism Spectrum Disorder. Our focus has been on children as this is the sector of the ASD community that we directly serve. Our collective experience has identified both elements of current systems that are working well as well as notable gaps in service. We would like to thank our families and staff for formulating and sharing their insights. There are often difficult and long-term challenges for children with ASD and their families, but we also witness tremendous resilience, love and commitment in the families we work with. We commend the Victorian Government for inviting submissions to this inquiry, and hope that this process will result in greater support for members of our community living with autism.