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INC NO A0011648H ABN 97 470 256 857

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To whom it may concern,

**Re: Submission - Parliament of Victoria, Family and Community Development Committee,
Inquiry into services for people with Autism Spectrum Disorder.**

Introduction

Extended Families Australia is a not-for-profit community organisation that provides support, respite, significant social relationships and community participation for children with disabilities and their families in Melbourne and the Mornington Peninsula. Our vision is for a society where children and young people with a disability experience full community inclusion and participation and their families are strong, resilient and connected.

We support children and young people (0 to 30 years) with a disability to feel valued, develop their full potential and participate fully in our society by building skills and strengths and facilitating positive connections for the children and their families with supportive volunteers and their community.

Children and families who are supported by Extended Families have access to a number of flexible support options including individualised volunteer matching for social, recreational and respite support, supported play groups, friendship groups and social events.

Children with Autism Spectrum Disorder (ASD) and their families make up more than 60% of our client base. As such we have a responsibility to contribute our experience, observations and feedback from families within our organisation to the discussion regarding the provision of services for people with Autism now and into the future.

In this submission we will be addressing the following points within the terms of reference;

- a) the prevalence of autism spectrum disorder in Victoria
- b) the availability and adequacy of services provided by the Commonwealth, State and local governments across education, disability and sport
- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS)
- d) projected demand for services in Victoria

Autism Spectrum Disorder within Extended Families

Currently we have 190 children matched to a volunteer for community inclusion and friendship support. 101 (53%) of these children have ASD. Another 460 children and their families have requested a volunteer match, and whilst waiting are also invited to participate in other social and recreation events and activities. 308 (67%) of children waiting to receive a volunteer match have ASD.

In addition Extended Families provides three parent support / play groups and two Friendship Groups for the Vietnamese community, including one group focused specifically on pre-school children with ASD and

their parents. Each year approximately 129 families participate in these groups, the children in these groups are close to 80% ASD, suggesting a very significant occurrence in the Vietnamese community.

We also note that a significant number of the families we support have more than one child with ASD. We estimate this to be around 15%.

The other significant factor is that 78% of the children with ASD in our service are males.

In summary

- 101 children with ASD currently matched to volunteers (approx. 140 over a year)
- 308 children with ASD currently waiting for a volunteer match
- 86 Vietnamese children with ASD participate in groups (80% of total) (103 families, in some groups just parents attend)
- 15% (estimated) of families in our services have more than one child with ASD
- 78% of children with ASD in our services are male.

Many families who have a child/ren with ASD have provided feedback that our volunteer match program is an attractive model as it offers a range of potential roles that could support the child and family depending on their individual need. Our programs meet the documented needs of these children for consistency, social skills development and are tailored to meet these needs of children who have autism. In particular families have commented they value;

- The relationship / friendship / companionship formed between the volunteer, child and family;
- The consistency of having the same person involved with their child and family;
- Having someone else that will encourage and support their child to participate in community life; and
- Someone that can be a role model or mentor for their child,

While children with ASD are the largest proportion of disability type receiving a service through Extended Families, the data also highlights they form the largest percentage of disability type waiting to receive a service. At this point in time we don't have enough volunteers with the skills and commitment needed to meet the demand from families nor sufficient resources to manage that number of volunteers.

We are acutely aware that for many families (regardless whether they have a child with Autism) the length of time they are on our waiting list is frustrating and does not meet their expectations, despite our best efforts to ensure families are made aware of the situation.

We have observed parents becoming strong advocates for their child and family. However more often we observe parents struggling to survive and get the support they need for their child and family. Being an advocate is a constant role and all parents, regardless of their ability to be able to advocate for themselves, need support. We believe that peak organisations like Amaze, are essential for the support they provide individuals and families and their capacity to advocate for the needs of people with ASD at all levels.

Our programs have appealed to families who have a child with Autism from the Vietnamese and Chinese communities, in particular in the Outer South, Western and Eastern regions of metropolitan Melbourne. A high proportion of these parents have given feedback that they feel under-confident in managing their child, especially when out in the community. This means they don't go out on their own and are not in a position to support their child to be included in the community. Families have reported that having a volunteer helper or being involved in a culturally specific families group with support from a paid Coordinator gives them more confidence in being able to manage their child when out in the community. Families within these groups rely heavily on their Coordinators to provide them with essential information and direct support on a range of topics regarding support for their child e.g. funding that is available and how to apply for it, planning a holiday or outing, behaviour management strategies.

Many families from a culturally and linguistically diverse background will need re-assurance that the NDIS will be a positive service they can access and specialised support and assistance to do so.

Services

There is a strong need for more autism specific services. For example, Extended Families runs a preschool playgroup for Vietnamese families in the western region of Melbourne who have a children with Autism Spectrum Disorder. This group was established as a Play Connect group and previously received Play Connect funding, however funding was withdrawn in December 2012. Extended Families has tried to hobble together funding to continue this group as it is so vital and important to participants, but this remains a challenge and we are extremely disappointed that this vibrant culturally specific group was targeted when funding was cut.

The facilitators describe how important it is for parents to have the support to learn how to manage the behaviours of their child in a supportive, non-judgemental environment where all the children have a similar range of issues related to ASD. Information is provided about appropriate services; selecting a kindergarten and/or school; and there is an opportunity to socialise with other parents and share their experiences.

Given these programs have been so successful for the Vietnamese community we would postulate that there are other cultural groups where families with a child with autism feel isolated and unsupported and that programs that have catered to the Vietnamese community, such as supported playgroups and friendship groups, could well be replicated amongst other cultural groups where language and a knowledge of the service system are barriers to their receiving the support they require.

Impact of NDIS

Based on conversations and feedback from families involved with our organisation, our experience is that many families have little or no understanding of the NDIS, what it means, what they will need to do and how it will impact their family. This is starting to be addressed in the North East Melbourne area who will be phased in first, as our organisation and many others have commenced information sessions. We are finding that families want and need extra support to help them be ready to transition into the NDIS.

Those parents who do have some understanding have expressed fear that with the introduction of the NDIS some children with Autism potentially may not be eligible to receive funding for services, in particular those who are verbal and on the surface appear to be 'managing'. Reaching this point of 'managing' is often due to much hard work from families in developing structure and routine to support the needs of their child. However when something unexpected or unplanned happens their child isn't able to cope and doesn't know what to do without some support and guidance. This is especially true when a child is trying to participate in the community. Parents report that when placed in community and social settings their child really struggles to be included in a meaningful way without assistance to navigate the many variables within the environment.

As an organisation that uses a volunteer based model to provide a service to families with a child with Autism we are concerned about what the introduction of the NDIS will mean for us and other organisations who uses the valuable time and skills of volunteers.

We will be introducing new services for families, however our volunteer match program offers a child and family a unique opportunity to develop a genuine friendship with the volunteer to a point that in many cases the volunteer becomes like a member of the family. Many families have said they really value the fact that there is someone out there in the community who cares about them and their child and who is willing to give up some of their own time to support them. While families find the volunteer model appealing, they are largely unaware of the time and money that is invested in recruiting, screening and

accrediting volunteers before they are matched with a family. These are essential processes that ensure, as much as possible, child safety and the recruitment of volunteers with the necessary skills to support children with complex needs. With the introduction of the NDIS we are unsure what this will mean for the long term future of our volunteer match programs.

The lack of clarity about where volunteer based services fit under the NDIS is a major concern for Extended Families and other organisations. With a significant gap before the ILC component of the NDIS is implemented, and the lack of opportunity to fit the extensive work of establishing volunteers into the individualized funding model, there is real danger of losing significant social capital. Urgent work is required in this area.

Education

The families in our program that opt to include their child in mainstream schools often speak of difficulties in getting funding to ensure their child is able to receive the support they need to learn and participate in the classroom.

Families report struggling to find an appropriate school setting for their child. We have observed a common pattern of families moving their child between schools to find a more appropriate environment. Parents often feel unsupported in trying to find information about the options and make those choices. They are often unsatisfied with what is on offer and many have said they have had to make compromises on what they believe the ideal education setting would be for their child due to a lack of options.

Community participation

Through our volunteer match program a primary focus of our work is promoting the inclusion of children with a disability in their local community and support their meaningful participation. We aim to empower individuals and break down barriers by changing social attitudes and creating positive opportunities for the individuals and families we support and our volunteers.

In speaking with families within our organisation we have found that many children with Autism find participating in the community extremely challenging. They struggle forming social relationships, making friends and reading other people's emotions. Many parents report their child has no real friends, has never been to a party or invited for sleep overs and really the only people they interact with are other family members.

While there are a range of programs to facilitate the participation of people with ASD in the community (e.g. our Family Match and Live Your Community Program, Inclusion Melbourne's Leisure Buddies etc...), it is not enough. In particular for teenagers, families tell us that there aren't enough supported opportunities for their child to form social relationships with peers while participating in the community. Many families have said their teenager needs a lot of encouragement and motivation to get out be active and form connections, otherwise they will happily spend long periods of time on their own at home using technology. Families do their best at getting their child/young person active and involved in the community but often say they just don't have enough time or energy to invest in getting this happening consistently.

Families have told us that having a volunteer is great. They can get the volunteer to focus on what their child needs to help them be able to participate in the community. In particular families like the volunteer to role model appropriate behaviours in the community and help develop the social skills the child needs to participate in the community such as;

- Taking turns
- Listening to others
- Responding to rules
- Interacting with other children
- Responding appropriately to the environment.

The range of sport and recreation options that are inclusive has increased over the years, however families with a child with Autism report varying experiences with how well their child has been included in community sport and recreation.

Families have given us feedback that their child/ren find participating in team sports incredibly difficult. Parents know the benefits of their child being involved in a team sport setting and the child loves the sport, however finds it hard to pick up and navigate social cues and understand interactions, which often leads to the child becoming frustrated and, if not managed appropriately, having a meltdown. This is an outcome that neither the child, family or sporting group want to see happen. Families suggest their child needs gradual progression in a group recreation activity and benefit a lot from having the support of another person they trust/feel comfortable with to help them facilitate/navigate social interactions with other children and coaches etc, when participating in sport and recreation.

Other issues reported by families regarding participating in sport and recreation;

- Limited knowledge, awareness of autism among volunteers facilitating community sport and recreation.
- Participation gap once the child gets a little older, they don't quite fit in with their age group but there is nothing else offered except options more suitable for adults. Important to have a pathway to maintain their interest otherwise they lose interest and drop out.
- Sport and recreation offered might be inclusive for adults but not for children and vice versa.

Conclusion

Autism is generally misunderstood in our community as it manifests in such a broad way across the Autism Spectrum. Each child on the spectrum is uniquely different, though many share similar features. Parents frequently report that others don't understand the complexities of this disorder e.g. people often tell them they just need to be stricter with their child and they will be all right. This exacerbates the stress and grief families struggle with on a day to day basis throughout their lives. Children with autism often look like any other child in the community, and many have considerable abilities and strengths, and thus other people often struggle to understand the impact of this very complex and challenging disability. Increased appropriate support and services would lead to improved outcomes for children and families and better community understanding of ASD in the long term.

Contact for questions re submission

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