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Chairperson,

Inquiry into services for people with Autism Spectrum Disorder

Family and Community Development Committee

Joint Investigatory Committees

Parliament House

Spring Street

EAST MELBOURNE VIC 3002

To the Joint Investigatory Committee addressing the

Inquiry into services for people with Autism Spectrum Disorder

To provide a context for this submission, the following information is provided.

- This submission is from the State Executive of Key Word Sign Australia –Victoria (Formerly Makaton Australia – Victoria);
- Key Word Sign Victoria is a volunteer run organisation, with not for profit status;
- Our committee represents 69 trained and highly experienced Key Word Sign (formerly Makaton) Presenters. Their backgrounds are Speech Pathologists, teachers and parents;
- Key Word Sign Victoria is affiliated with Key Word Sign Australia. There are branches of Key Word Sign in all states and territories of Australia;

- Key Word Sign Victoria Presenters ran 5 central workshops, and 34 other workshops around the state for parents, support workers, other speech pathologists, teachers etc in 2014/2015 (Presidents report, 2015). Average workshop size is 15 people; approx. 585 individuals had the opportunity to learn about how to use and implement Key Word Sign in their own environment;
- Key Word Sign Presenters are active in maintaining their Presenter status by attendance at 1 of 3 Sign Updates/per year, access to regular newsletter and current research;
- Bi-annually, Key Word Sign Victoria provides opportunities for new individuals to be trained as Key Word Sign Presenters. Up to 20 people are provided with this opportunity to learn about Evidence Based Practice (EBP) in Sign and Gesture, and in particular EBP of Key Word Sign for clients with Autism Spectrum Disorder (ASD);
- Key Word Sign Victoria has a website at <https://keywordsignvictoria.org> Information for families, carers and other professionals is available from here. In addition, we provide a social media platform via <https://Facebook.com/keywordsignvictoria> .

Key Word Sign

Key Word Sign (formerly Makaton) is the use of manual signs and natural gesture to support communication. Key Word Sign is used to support language development in children and adults with communication difficulties. It can be used as an adjunct, alternative, or until speech develops. It assists people with their understanding of their world as well as their expressive communication.

Providing individuals with ASD and their community, with access to communication opportunities via Key Word Sign, assists the Choice and Control an individual has. This is essential for participation and inclusion across the person's lifespan, and also a primary premise of the National Disability Insurance Scheme (NDIS).

Key Word Sign uses a core vocabulary of selected words that comprises concepts and ideas considered to be the most appropriate for children and adults with communication and language difficulties. Key Word Sign uses signs from the Auslan community of signs. Auslan, is the native language of the Australian Deaf community.

Key Word Sign has been in use in Australia since the early 1980's

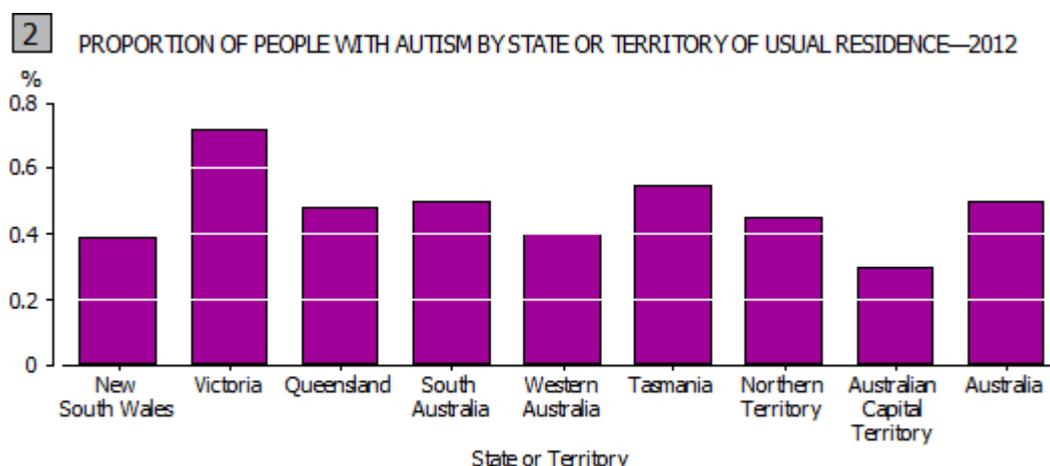
The committees' submission addresses, in particular,

- 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 health, education, disability, housing, sport and employment services;
- c) the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS);
- d) evidence of the social and economic cost of failing to provide adequate services; and,
- e) the projected demand for services in Victoria.

A) The prevalence of Autism Spectrum Disorder in Victoria;

The Australian Bureau of Statistics in 2012 stated “The number of Australians with disability remained steady at 18.5 per cent of the population or 4.2 million people. Of these, 1.4 million Australians had a profound or severe limitation affecting their mobility, self-care or communication.” www.abs.gov.au #4430 Speech Pathology Australia states approximately 1 in 88 children have ASD. www.speechpathologyaustralia.org.au

The Australian Bureau of Statistics, also in 2012 (Published in 2014) completed an “Autism in Australia”, study. It concluded “an estimated 115,400 Australians (0.5%) had autism”. ABS #4428, 2012. The graph below, shows the prevalence of ASD across all states. Victoria is recorded as having the highest prevalence, at 0.72% of our population. We are unable to provide you with more up to date data. Considering the impact of Early Intervention ASD in South Australia, since the implementation of the NDIS, (incidence of children diagnosed with ASD and requesting NDIS services has risen substantially compared with predicted figures), these percentages are concerning. It could be assumed that, as the percentage of people with ASD in SA has become clearer, as NDIS services have come available, similar patterns could occur in Victoria.



Source: ABS Survey of Disability, Ageing and Carers, 2012

With these statistics, the needs of people with ASD, are particularly vulnerable as communication difficulties, and complex communication difficulties needs to be addressed. People with ASD are some of the most vulnerable in our community, many requiring particular advocacy to assist them to speak up, or be supported in speaking up for themselves and develop their social-pragmatic skills. Others again have specific language difficulties or developmental delay. Their Rights need to be addressed.

B) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;

Some people with ASD can learn to communicate effectively using speech alone. However, significant numbers of people with ASD use pointing to images, words or phrases to communicate; others use signing or Key Word Sign. www.keywordsignvictoria.org Others again use less formal means of communication such as their behaviour and people knowing them well to communicate. Irrespective of the person's means of communication, their messages need to be heard. These people must be considered and included in all aspects of local government services, health, education, disability, housing, sport and employment services

Barriers can be subtle, but many times the barriers to access communication are obvious. Subtle barriers can include:

- Not allowing time for the person to communicate;
- Teachers, workers, parents, support staff being unaware of how to communicate with someone who has ASD;
- Dismissing changes in behaviour as being insignificant;
- Dismissing communication unless it is done using speech.

Less subtle barriers can include:

- Lack of staff, including specialist Speech Pathologists, who can adequately resource teachers in classrooms, parents, families and the general community;
- Lack of knowledge by staff of how to communicate and effectively interact and educate individuals with ASD;
- Lack of training by all staff involved in how to communicate with people with little or no speech;
- Not acknowledging and not using the person's communication system.

Recent research in the area of ASD highlight many issues for people with ASD in accessing local government, health, education, disability, housing, sport and employment services.

Key Word Sign Presenters are well versed in the current and emerging field of the use of Key Word Sign for people with ASD. Some recent and emerging findings include from Capone & McGregor, 2004 and Hubbard et al (2012):-

- The gesture development of children with autism deviates from normal;
- Some have difficulties with pointing due to the social-emotional load associated with it;

But

- Like other children with language impairment, children with autism can use easily recognisable (or iconic) gestures to assist or augment their communication during conversations;
- Instruction in manual (sign) modality may be a useful clinical and education strategy.

Additionally research from Watson et al (2013), Wendt et al (2009) and Wong et al (2010) concludes, amongst other findings on Key Word Sign and Gesture:-

- Using signs can provide effective communication options for students with autism;
- Signing does not impact negatively on speech production and generally has a positive though modest impact on speech production;
- It is becoming clear that individual differences among children with autism may mean a preference for, and greater success with, one type of communication compared with another.

Consequently, individual differences should be taken into account when choosing and designing communication systems. This can only be achieved when Speech Pathologists have adequate experience, skills and knowledge in the area of ASD. Key Word Sign is one of a number of Augmentative and Alternative Communication (AAC) strategies that all Speech Pathologists must have available to them. Currently this is not the situation.

Research has also shown that “Creating a Sign Environment” ensures adequacy of interaction for people with ASD. This involves the people in the persons’ environment learning signs and using them in all communication. This includes at home, school, community, government services, healthcare setting, employment and leisure, etc.

“Sign teaching needs to be embedded in a creative approach to communication which encourages peer interaction and incorporates functional goals.”(Grove & McDougall 1991)

It also requires support from management, centre wide policies and practise on the use of Key Word Sign to be effective. Currently this approach is not available nor is it adequate for people with ASD.

David Trembath et al ,2016 in *What do speech-language pathologists think parents expect when treating their children with autism spectrum disorder?* identified there are various issues for Speech Pathologists working with families in how they best explain information and potential treatment options and interventions. In particular, access to information which may or may not be Evidence Based Practice (EBP) is easily available via the internet was highlighted as an ongoing discussion with parents. Speech Pathologists discussed the need to assist parents in developing EBP literacy.

“Given the plethora of intervention options, it is imperative that Speech Language Pathologists (SLPs) foster relationships that enable parents to become informed consumers of the wide range of options available (Auert et al., 2012;Simpson, 2005). In Australia, the need for parents to become informed consumers has been reinforced by the fact that, under the soon to be implemented National Disability Insurance Scheme (2014), parents will take primary responsibility for determining which interventions and supports their children with ASD receive (Purcal, Fisher, & Laragy, 2014).”

What must co-occur with this is a hub of skilled and knowledgeable Speech Pathologists who are aware of and know the wide variety of both EBP, including Key Word Sign and non-EBP interventions. This can only occur when Speech Pathologists with expert skills and knowledge in ASD are readily available to families and individuals seeking treatment and intervention for ASD. These Speech Pathologists need the opportunity to work in conjunction with other therapists to learn and develop their own skills. Every person with ASD is an individual and it is important Speech Pathologists have access to the best Evidence Based Practice to make decisions with families, for the benefit of the individual, but also the family and the community in which that person lives.

The alternative is situations which occurred in the 1980’s when Facilitated Communication was introduced. Suddenly previously unskilled communicators, many with ASD, were able to generate messages which the practitioners professed came from the person. It has been shown time and again since then, that, Facilitated Communication has been discredited by evidence based research. *Scott et al, 2014: The persistence of fad interventions in the face of negative scientific evidence: Facilitated communication for autism as a case example* and MUSEC Briefing Issue #9 *Facilitated Communication*.

It is also being seen currently when well–marketed programs are introduced to all students with ASD, eg: “PECS” is introduced as a whole of school program, irrespective of the student with ASD’s current skill attainment, their needs and their family needs. *Observation by*

author, 2014, 2015. Key Word Sign is rarely seen or used as an option for ASD students, even though the EBP has shown it does have success for some students.

In *Barriers to healthcare for people on the autism spectrum*, 2016 it found consideration of the issues for people with ASD improved the experience with the Health Care Provider. Areas such as “making appointments,” the “waiting area,” “communication” and “examination” need to be considered and modified. They hypothesised that improving access to first level healthcare situations would also assist in secondary or other health care diagnosis, such as mental health issues and other medical issues. They also hypothesised that better consideration of the needs of the sensory and social-pragmatic needs of people with ASD could also be a model for better education and employment inclusion.

Additionally, Povey, 2015, in *What should services for people with autism look like?* states as people move through their life stages, services and community engagement needs to be considered at all these stages. Irrespective of whether a person has a high functioning IQ or not, social-pragmatic communication is difficult. Povey states

“..... The ability of staff to communicate, clearly and unambiguously, will also ensure that people using the service are able to participate fully in their own support. All people with autism benefit from unambiguous language, since language may be understood literally, irrespective of context....”

Key Word Sign is an easy, portable and inexpensive way for all support staff, families and individuals in the community to be able to think carefully about the language they use, simplify it and use language in a concrete way, to ensure greater participation for the person with ASD.

C) The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS)

Based on the experience in South Australia following the roll out of the NDIS, services for people with ASD will not be adequate in Victoria. When you compare the demographic data from the ABS Autism in Australia, #4428, 2012 survey, it would appear the current services for people with ASD will be significantly under resourced in Victoria when the NDIS is fully functioning.

Additionally, one of the premises of the NDIS is engagement with community and community sector services. People in the community and mainstream sector are not adequately prepared for welcoming people with ASD. Communities need training from specialist staff who know about ASD, and the sorts of things that can be done to make a community more welcoming to people with ASD. This requires resources and time to provide.

Observation by skilled and experienced Key Word Sign practitioners in Victorian schools, kindergartens, early intervention services, day services, accommodation services, supported employment situations and family interactions have reported time and time again the lack of awareness by all individuals of the needs of the person with ASD regarding their communication, including gesture and Key Word Sign. It appears communication needs are not considered. Even though the person may have some form of communication delay, including social-pragmatic, with or without intellectual disability, additional supports including formal and informal communication supports are not provided to the individual.

Consequently, people with ASD are left floundering and not able to make meaningful choices or participate in their day in meaningful ways. Nor are their Rights observed. They have no Choice and Control. Often a significant behaviour support plan is put in place without the support and co-assistance of a communication specialist, being the Speech Pathologist.

Support workers and integration aids now need to complete a Certificate IV in Disability Studies to get employment in the disability and support sector. This is admirable. However, Key Word Sign practitioners usually find that support workers have had no or inadequate training in communication strategies, Augmentative and Alternative Communication (AAC) strategies, and in particular no knowledge or skills in Key Word Sign. This is extremely detrimental to all people with ASD.

There are few expert and skilled Speech Pathologists who work with people with ASD. There are some who specialise in working with people with ASD, and then there are a few more who will see people with ASD but this is not part of their substantive caseload. Speech Pathologists, like other allied health professionals, need support to build capacity of their workforce to be able to deliver adequate services to people with ASD. This includes ongoing mentoring, and training support to therapists, and funded research to build on the sector knowledge on EBP. In particular, Key Word Sign Victoria, would recommend further research in the use of Key Word Sign for this population of people.

Without quality, skilled and experienced therapists in place, people with ASD will not be able to access the best options and services for them. Parents and families will continue to “go looking” for the best marketed, but not necessarily evidence based intervention.

D) evidence of the social and economic cost of failing to provide adequate services.

People with Autism Spectrum Disorder have the Right to access services for the

“...full and effective participation and inclusion in society.”

Article 3, UNCRPD (2006). The United Nations Convention on the Rights of Persons with a Disability (2006), which Australia is a signatory to, identifies this again and again across all the Articles of this Convention. Articles 2, 3, 4, 5, 6, 8, 9 and 24 are just a few examples of particular statements regarding this, such as

“taking all appropriate measures “

Article 4, General Obligations; UNCRPD, 2006 and

“training of professionals to adequately support people with disabilities”

Article 24, Education: UNCRPD, 2006, including people with ASD. The Convention states

“access to communication,.... including appropriate use of sign language”

is one of the Rights in Accessibility Article 9, UNCRPD, 2006. Article 6 builds on the concepts of awareness for the community of people with disability, Article 5 talks about Equality and non discrimination, including equal and non discriminatory access to the community, education, health and well being. If services are not available to people with ASD the government is **not** meeting its obligations under the Convention.

Awareness Raising is discussed in Article 8. This includes aspects such as

“promote awareness of the capabilities and contributions of persons with disabilities.” Measures to this end include: “...to promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;”

Key Word Sign Presenters observe the social and economic cost of (in)appropriate and ongoing services not being adequately provided to people with ASD, their families' education and support staff. These are examples many experienced Key Word Sign Presenters see or hear of on a regular basis.

Example 1:

A young person is now on 1:1 supported program in their educational program. There was no support/funding for social skills/communication skills training within the education system when he was younger.

Example 2:

Teaching staff are unclear about how to interact with, and develop individualised and appropriate communication strategies for each student. Key Word Sign Presenters and Speech Pathologists skilled in this area are not available to the teacher (either not at all or on an irregular basis). The teacher is unsure what to introduce, and often may select a communication program that has been highly promoted or marketed, rather than communication strategies that is the best fit, based on Evidence Based Practice for each student. Student learning is compromised on a daily basis. Educational attainment and future employment or community interactions are also compromised.

Example 3:

Adult requires more support, often 1:1 as the person has been unable to develop functional skills without formal communication or appropriate AAC. The staff in the environment have little understanding of this persons communication skills (both formal and informal). He uses increasingly complex and dangerous Behaviours of Concern (BOC), which lead to increased individual support and the costs that occur with this.

Example 4:

A young adult living in a Community Residential Unit uses challenging behaviours or Behaviours of Concern (BOC), is self harming and harming others. It is decided it is safest for everyone, if this young person is moved into a unit by himself, supported by 1:1 support at all times. The staff have little understanding of this persons communication skills. Interactions then develop into reactionary responses by staff, rather than observing and engaging in positive communication interactions. Other costs include, few staff want to work in this environment, so it becomes

increasingly difficult to locate the most appropriate support. Staff have a high stress load, and have many incidents they need to report due to damage to building, property or themselves. Other secondary costs include the person is unable to access the community for their leisure or social inclusion, and critically access to appropriate primary and secondary healthcare is jeopardised.

The social and economic costs of inadequate services for people with ASD are enormous.

E) the projected demand for services in Victoria.

Key Word Sign Victoria is unable to project what the demand is for services for people with ASD. However, based on current services and expertise in this area, it is significantly below what will be needed in the future.

Future improvements

1. People with ASD require access to more skilled and knowledgeable Speech Pathologists with particular skills and knowledge in AAC, and Key Word Sign;
2. Behaviour intervention strategies developed for people with ASD must have input from a skilled Speech Pathology practitioner;
3. Research into Evidence Based Practice (EBP), including use of Key word Sign for people with ASD is needed;
4. Implementation of “Communication Awareness Training”, including how to use Key Word Sign for all local government services including community, health, employment services, educational sectors, disability, housing and sport;
5. Support workers completing Certificate IV in Disability Studies must have appropriate modules on EBP Communication strategies, including AAC and KWS. These must be developed by appropriately trained and experienced people in the sector, preferably Speech Pathologists and/or Key Word Sign Presenters;
6. Key Word Sign Australia - Victoria is run by a small group of volunteers. Opportunities are needed for funding to support people with ASD and their families to know more about Key Word Sign, including developing further research in this area.

Key Word Sign Australia-Victoria thanks you for the opportunity to present this submission. We would be pleased to expand on any of the issues raised via further submissions or discussion with the committee.



Cathy Basterfield

Vice President

On behalf of Key Word Sign Australia – Victoria Committee

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Speech Pathology Australia Fact Sheet - What is Autism Spectrum Disorder

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Speech Pathology Australia Position Statement – Augmentative and Alternative

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