Submission form

How to have your say

Please take the time to make a submission. The final pages of this consultation document explain how to make a submission and how to make sure it reaches the Ministry in time. There are also questions that might help you to write your submission. Your feedback is important: it will help shape the Fetal Alcohol Spectrum Disorder Action Plan.

All submissions are due with the Ministry by **5 pm** on **Friday, 26 February 2016**.

The Ministry of Health must have your submission by this date and time. Any submissions received after this time will not be included in the analysis of submissions. In making your submission, please include or cite relevant supporting evidence if you are able to do so.

There are two ways you can make a submission:

- fill out this submission form and email it to:
  FASD_Plan@moh.govt.nz

or

- mail your comments to:
  FASD Action Plan
  Ministry of Health
  PO Box 5013
  WELLINGTON 6145

The following questions are intended to help you to focus your submission. It will help us analyse the feedback we receive on the plan if you can use this format. You are welcome to answer some or all of the questions and you can tell us about other ideas or concerns you may have as well.

You do not have to answer all the questions or provide personal information if you do not want to.

This submission was completed by:	*(name)*	Sally Kedge
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Organisation (if applicable):		Joint submission on behalf of the New Zealand Speech-language Therapists' Association (NZSTA) and Talking Trouble Aotearoa NZ Ltd (TTANZ)
Position (if applicable):		NZSTA: Expert Advisor on Vulnerable Children/Youth TTANZ: Coordinator

Are you submitting this as *(tick one box only in this section)*:

- ☐ an individual or individuals (not on behalf of an organisation)
- ☑ on behalf of a group or organisation(s)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission and your name(s) will not be listed in the published summary of submissions, if you check the following box:

- ☐ I do not give permission for my personal details to be released.

Please indicate which sector(s) your submission reflects
(you may tick more than one box in this section):

- ☐ Māori
- ☐ Pacific
- ☐ Asian
- ☐ Consumers/families/whānau
- ☑ Service provider
- ☑ Non-government organisation
- ☐ Public health organisation
- ☐ Primary health organisation
- ☐ District health board
- ☑ Professional association
- ☐ Justice sector
- ☐ Education sector
- ☐ Social sector
- ☑ Academic/research
- ☐ Local government
- ☐ Industry
- ☐ Other *(please specify)*:

Questions

General

1. From your experience and perspective, what would you like the Government to take into account when developing the Action Plan?

Please note that throughout this submission some abbreviations have been used:
SLT = speech-language therapist(s)
SLCN = speech, language and communication needs

Current access to SLT services
The Government must address the current severe lack of access to speech-language therapy services generally, and in particular for children, youth and adults with FASD. New Zealand is missing many opportunities to address oral language competency in vulnerable populations, including those with FASD. Speech, language and communication needs (SLCN) are extremely common in people affected by FASD, yet most do not have these needs accurately identified or managed with intervention by a SLT.

Children/youth/adults affected by FASD and their whanau/carers and the professionals involved with them in NZ require access to appropriately skilled and experienced SLT services which can employ models of practice designed for the unique linguistic and cultural context of Aotearoa NZ.

Currently, those who can access SLT services generally receive very limited input for a short amount of time e.g. MOE services for those children who are at school.

Also, SLT services that exist currently are not equipped for the multiagency work required. Children's SLCN cut across all aspects of their lives. SLTs need to be able to work in an inter-sectoral way, with sufficient time and resources, to support children across the various contexts they communicate in so they can engage in interventions by other professionals (understand what is being said and can participate) e.g. in education at any stage of childhood, social work interventions, counselling, anger management, youth mentoring, drug and alcohol services, psychology interventions, relationship and social skill development, legal contexts such as understanding their care arrangements or any legal proceedings they might be involved with and expressing their views about these. SLTs also need to be able to support children as they transition into adulthood. SLT services that identify and support adults with FASD are also very limited. This is particularly important as they may go on to be parents themselves.

Importance of oral language communication skills for life
Being able to communicate well in all contexts in life sets children and young people up for success. Successful relationships depend on being able to communicate well with others, whether these are relationships within families, between peers in the playground or with adults. Good language skills are protective for children, enabling a level of resilience against other risk factors that they may experience. Strong oral language skills are vital foundation skills for building literacy at school as well as skills in managing emotions and behaviour. Education and employment success depends on language and communication skills that are usually taken for granted. Skills such as being able to tell a good story or account, giving a clear explanation, negotiating an argument or persuading someone else to change their mind on an issue all depend on oral language skills.

Oral language competence is central to nearly everything we need to do in life yet it does not receive a high profile and this is a missed opportunity. Those who do not easily develop strong oral language skills are vulnerable, this is particularly the case for children with FASD as many do not have their oral language needs properly identified and addressed.

Most people never have to spend time thinking about how to speak or whether they can understand what someone else is saying because these skills mostly develop without difficulty in childhood for about 90% of the population. However, there is strong evidence that a focus on oral language competence could provide an opportunity for developing vital protective skills for vulnerable children in our society, as well as ways around difficulties for those who have needs in these areas.

SLT approach with vulnerable families

Speech-language therapists are ideally placed to develop rapport with vulnerable families. The caseloads of SLTs provide an easy way to identify vulnerable children, although many children who require support for oral language are currently missing out on these vital services. Speech-language therapists' work supports the key adults in children's lives to recognise opportunities and learn strategies to build children's language skills. This work builds relationships as well as supports learning. When adults, whether parents or other professionals who need to use 'talk' in their work with children, understand how to recognise children's oral language profiles and are skilled in using strategies to communicate more successfully, frustration levels decrease resulting in less emotional and behavioural breakdowns. Families engage well with communication assessment and intervention, as it is easily understood, non-blaming or threatening, functional and positive. They often have high levels of rapport and trust and make disclosures to SLTs. A holistic strength-based approach is employed. The core skills of SLTs are in providing practical interventions for children within whatever context they need to communicate in e.g. within everyday family life, within their education settings, etc. The specialised skills of SLTs have untapped potential currently in NZ with populations like those children with FASD who might be included in populations who access care and protection, child and adolescent mental health, forensic and justice services. There is strong evidence that undiagnosed and untreated language difficulties are widespread across these populations. Well-established international research findings have settled on a conservative 50% prevalence of significant oral language competence issues in these vulnerable populations.

Timing of SLT involvement
Oral language competence starts building from birth. Babies who have developed secure attachments with supportive and responsive adults have the best context for building their listening and speaking skills, no matter what language they are learning. Speech-language therapists are ideally placed to provide support for teenage parents to enable them to build strong relationships with their babies and to learn about how to set up their children for success with talking and understanding language. Although early intervention is currently considered as a key factor for current distribution of SLT funding, many children do not get adequately identified early and have their needs met. They may surface later with other needs e.g. literacy difficulties, behavioural problems, involvement in youth justice. Many vulnerable children and adults need assessment and therapy throughout their life at different times as they develop. Key points where speech, language and communication need to be carefully considered but are currently missed opportunities are Gateway Assessments, Children's Teams and Youth Justice assessments. Adults who have contact with young children need strong skills in building language within the context of play and learning environments. A much stronger focus on oral language is required within the initial training and later professional development of early childhood and school education staff, social workers, health staff (e.g. nurses), psychologists and other professionals who work with children.

Professionals' needs for oral language awareness and strategies that support communication development
Adults who have contact with young children need strong skills in building language within the context of play and learning environments. A much stronger focus on oral language is required within the initial training and later professional development of early childhood and school education staff, social workers, health staff (e.g. nurses), psychologists and other professionals who work with children.

2. a. What is your community or organisation already doing to prevent or respond to FASD?

The needs of vulnerable children and youth are high on the agenda for speech-language therapists. This includes children affected by alcohol.

AWARENESS: NZSTA and TTANZ have provided a range of submissions (parliamentary and other) relating to the speech, language and communication needs of vulnerable children and youth in NZ. Some of these have related to specific groups of children and youth that would include those affected by alcohol e.g. those receiving special education services in education.

A wide range of meetings/conferences with agencies/ key professionals have been attended by TTANZ SLTs to discuss how to support those vulnerable children and youth with SLCN to have their needs address e.g. Children's Commissioner, MPs, managers of organisations (both governmental and non-governmental)

TRAINING: TTANZ provides training for professionals working with vulnerable children and youth to support them to spot when children have speech, language and communication needs and learn strategies to address these. Training has now been provided to a wide range of organisations, professional groups and agencies e.g. youth court judges, social workers and youth justice coordinators, resource teachers of learning and behaviour, youth mentors etc.

TTANZ also coordinates a special interest group for speech-language therapists working with vulnerable children/youth to build professional networks and skills. TTANZ has also hosted international experts who have provided professional development for speech-language therapists and for other professionals working with vulnerable children/youth.

DEVELOPMENT OF EARLY INTERVENTION: TTANZ are part of a working group to develop early universal promotion across a wide range of agencies working with children and youth of oral language competence as a protective factor for all children to enable them to have the best start at school. This project is coordinated by COMET in Auckland.

WORKING GROUP with the YOUTH COURT: TTANZ SLTs sit on a working group chaired by Judge Fitzgerald to address the communication needs of youth involved with the justice system. This group has a range of projects underway that involve 1) SLT training so professionals recognise speech, language and communication needs of those in the youth justice system, 2) development of protocols to provide communication assistance for those who require in justice processes, 3) revision of tools and practices to create a 'communication friendly' environment to ensure all young people can participate in legal proceedings

RESEARCH: TTANZ is currently conducting academic research looking at the language and communication profiles of a range of vulnerable children and youth.

PUBLICATIONS: TTANZ SLTs were the authors of a chapter in a book addressing the SLCN of people with FASD in the legal system.
Fetal alcohol spectrum disorders in adults: ethical and legal perspectives: an overview on FASD for professionals. Monty Nelson editor.; Marguerite Trussler editor. Cham Switzerland : Springer. 2016

SLT SERVICE PROVISION: Although there are a handful of SLT services available as part of multidisciplinary non-private services e.g. Hawkes Bay Child Development Team have an SLT on staff who is involved in multi-agency diagnoses of FASD, this is very rare in NZ. For most children who do not qualify for the limited provision provided by MOE SLTs, Special School SLTs, or for ACC funded SLT, there is very little available, particularly for those over 8 years. Most children and youth with FASD do not receive SLT as part of their multiagency diagnostic team and they are highly unlikely to receive SLT intervention even if they have a diagnosis.

SLTs from TTANZ have provided assessment and some intervention services for a very small number of children and young people affected by FASD. These independent services have been contracted by a range of agencies e.g. CYF to provide SLT for individuals in both community and residential settings (both youth justice and care and protection), MOE (through High and Complex Needs funding or Intensive Wraparound), Youth Court, non-governmental agencies e.g. specialist care providers. These private services have been provided because there are not SLT services available for these children/youth within the current SLT governmental funding structures. To date, most children receiving these services have received assessment only because provision of SLT interventions to carry out recommendations is considered to be too expensive, despite the huge impact of unaddressed SLCN needs.

Providing private services in this ad-hoc manner for a select group of individuals is not ideal. Many miss out who need these services. It is not possible to effect systemic-level changes in practice that would benefit a much wider group of children/youth e.g. provide training and support for non-SLT staff to change their practices so that all receive communication-friendly interventions. Part of the reason for this is funding, but also because many children with SLCN have their needs unrecognised. These needs are very easily masked by other difficulties e.g. behavioural difficulties, other learning needs and professionals require specialised training to know how to detect SLCN, particularly in older children and youth. SLTs also require support and training to address the SLCN of children affected by FASD.

b. What is the best way for the Action Plan to support this?

	Address the speech, language and communication needs that have been identified as affecting approximately 38,180 children with FASD (page 6 of the discussion document). Some action points suggested in the table below:		
1	Raise awareness across agencies on the importance of oral language competence for children and how to detect speech, language and communication needs.	• Increase focus across agencies working with children and youth on proactive universal interventions that support population level focus on the protective role of speech, language and communication and ways that all children can have their communication needs supported	e.g. Specialist training and support for a wide range of agencies: Midwives, Plunket, social workers, libraries, education (both pre-school and school level)
2	Tailored training that focuses on SLCN and FASD for agencies who work with the families/carers of vulnerable children and youth who may have been affected by alcohol	• Those babies who are known to have been affected by alcohol at the time of birth to have special monitoring and proactive services from birth to support whanau/carers to develop speech, language and communication skills. • Focus on how to detect SLCN in FASD for all the children they work with • Address needs with 'across life' strategies to support whanau and professionals to build communication skills • Build understanding of how SLCN may impact on their own professionals' interventions and how to address this • Ensure those children/ young people whose SLCN might be masked by other factors (e.g. behaviour, other diagnoses) can be accurately identified	e.g. Midwives, alcohol and other drug services, social workers, foster carers, GPs and practice nurses, educators, psychologists, legal professionals e.g. family lawyers, judges, criminal justice professionals e.g. probation services, prison staff working with parents
3	SLT tools/processes for identification and intervention of SLCN in FASD to be urgently developed for the NZ context	• Culturally safe tools and practices for the unique NZ linguistic and cultural context are required • Research to examine international models of SLT provision required to ensure best fit for NZ context is developed • Increase in SLT services to ensure children and whanau receive services in a timely manner (i.e. early and for long enough – these SLCN are likely to be on-going and will affect many aspects of children's lives over time. A short block of intervention is going to be insufficient.	e.g. Te Reo Maori tools developed, models of practice that address Te Tiriti O Waitangi principles, assessment protocols that fit with international best practice and current NZ context of how services are organised
4	SLT development of specialised skills and training to identify FASD and carry out evidence based assessments and interventions	• Workforce training required	

5	SLTs to be integral to multidisciplinary assessment and intervention teams	• Ensure that SLTs are accessible to provide speech, language and communication expertise into the teams requiring this across agencies working with children across childhood (from birth to 18) • This will require additional funding for SLT services, training for SLTs to carry out this role (see 4) • SLT provision needs to go beyond a role in diagnosis of FASD. SLCN affect whole of life and SLTs need to be able to provide support addressing these needs across education, health, whanau/family life contexts as well as working in partnership other professionals whose interventions are orally based.	
6	Specialised communication consideration required in certain contexts where SLCN will have an important impact on outcome e.g. legal situations where children/youth may be victims/witnesses/defendants e.g. court, family group conferences, police interviews	• Information provided in ways that children/youth can understand • Professionals structure proceedings in ways that children/youth can participate	e.g. professionals are supported with how to ask questions that are tailored to the level of the child; are aware of how to check the child understands what has been asked of them; know how to use visual strategies to support communication etc.

c. What does the Action Plan need to focus on, build on or take into account to ensure that it is responsive to Māori?

Regarding addressing the SLCN of children with FASD, the plan needs to support the development of SLT practices that honour the principles of Te Tiriti O Waitangi. In particular, this means that SLT services need to develop assessment/intervention methods, tools and practices that are culturally safe. One current gap for achieving this is the lack of SLTs who identify as Maori themselves and also a lack of SLTs who speak Te Reo Maori and have highly developed culturally competency. Supporting professional development and service development in these areas is urgently required.

Part Three: The Action Plan

Key principles

- Focus on empowering families/whānau.
- Collaborate to achieve a collective impact.
- Prevention is always possible.
- Build on strengths.
- Strive for sustained, systemic change.

(Pages 11–12)

3. Do you support these principles?

☑ Yes

☐ No

Please provide reasons and comments below.

• Focus on empowering families/whānau:	• Speech, language and communication development starts when children are still in-utero so ensuring that families/ whānau know how to best support their children to communicate needs to start then. There are many positive steps that can be taken to promote oral language. • Children learn to communicate in social contexts with those who are caring for them, so it is vital that those people are equipped with the skills to promote speech and language, particularly for those who have known vulnerabilities to difficulties in this area i.e. in this context, any baby affected by alcohol. For some generic advice might be sufficient, but for some, they will need to work directly with specialist SLTs who can support them to use specific strategies in the ways that they interact with their children.
• Collaborate to achieve a collective impact.	• A multiagency/multisectoral approach is required. SLTs cannot work in isolation on these issues. 'Talk' is the means by which most professionals do their work – therefore, their 'talk' needs to be at the right level for each child, whether the professional is a teacher, a social worker, a police officer, a judge.
• Prevention is always possible.	• Agreed, particularly important if a whanau has one affected child. Important to provide support for unborn children and support for any other undiagnosed siblings in case they are also at risk of FASD or other vulnerability.
• Build on strengths.	• Agreed, a future focussed, strengths-based approach is required where individual and collective motivations and resources are utilised.
• Strive for sustained, systemic change	• Systemic change is urgently required in terms of development of frameworks for identification, diagnosis and intervention, and in terms of ensuring SLT workforce is available and appropriately skilled for this work (additional training will be required for many.)

4. What changes would you make to these principles? Why?

Proposed outcomes

- Outcome 1: Women are supported to have alcohol-free pregnancies.
- Outcome 2: People with neurodevelopmental issues are identified early and receive timely assessments from FASD capable teams.
- Outcome 3: People and their families, whānau and caregivers receive timely, joined-up support tailored to their needs and strengths.
- Outcome 4: There is an improved evidence base so we can make good decisions and effective investments.

(Page 13)

5. Do you support these outcomes?

☑ Yes

☐ No

Please provide reasons and comments below.

Outcomes 2 and 3 are particularly relevant to the SLT profession for reasons outlined in previous answers.

6. What changes would you make to these outcomes? Why?

Part Four: What we can do differently

Outcome 1: Women are supported to have alcohol-free pregnancies

Building blocks for action:

- shifting New Zealand's drinking culture
- providing clear, unambiguous and consistent messages
- empowering women to make active, planned choices about pregnancy
- supporting a consistent primary health care response
- increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy.

(Pages 14–16)

7. Do you support these building blocks?

   ☐ Yes

   ☐ No

   Please provide reasons and comments below.

8. What changes would you make to these building blocks? Why?

9. a. What actions would support these building blocks?

b. How would you prioritise these actions?

10. a. What would we want to measure to make sure we were achieving this outcome?

b. What would be the best indicator of change in the short term? In the long term?

Outcome 2: People with neurodevelopmental issues are identified early and receive timely assessments from FASD capable teams

Building blocks for action:

- building family and community capacity to understand and identify FASD and other neurodevelopmental issues
- building evidence-based awareness and understanding among professionals
- ensuring clear referral pathways
- providing multidisciplinary assessment and the creation of an individualised profile
- increasing clinical capacity and capability.

(Pages 16–18)

11. Do you support these building blocks?

☐ Yes

☐ No

Please provide reasons and comments below.

12. What changes would you make to these building blocks? Why?

13. a. What actions would support these building blocks?

b. How would you prioritise these actions?

14. a. What would we want to measure to make sure we were achieving this outcome?

b. What would be the best indicator of change in the short term? In the long term?

Outcome 3: People and their families, whānau and caregivers receive timely, joined-up support tailored to their needs and strengths

Building blocks for action:

- improving community understanding
- universal approaches tailored to need
- support for parents, families and caregivers
- multidisciplinary care planning and coordination
- accessible care and support pathways
- support to navigate the system.

(Pages 18–21)

15. Do you support these building blocks?

☐ Yes

☐ No

Please provide reasons and comments below.

16. What changes would you make to these building blocks? Why?

17. a. What actions would support these building blocks?

b. How would you prioritise these actions?

18. a. What would we want to measure to make sure we were achieving this outcome?

b. What would be the best indicator of change in the short term? In the long term?

Outcome 4: There is an improved evidence base so we can make good decisions and effective investments

Building blocks for action:

- routinely collect and analyse key data
- evaluate the effectiveness of interventions
- encourage research.

(Pages 21–22)

19. Do you support these building blocks?

☐ Yes

☐ No

Please provide reasons and comments below.

20. What changes would you make to these building blocks? Why?

21. a. What actions would support these building blocks?

b. How would you prioritise these actions?

22. a. What would we want to measure to make sure we were achieving this outcome?

b. What would be the best indicator of change in the short term? In the long term?

Final comments

23. Is there anything else you want to tell us? If so, feel free to make any further comments here.

I would be very happy to discuss any aspect of this submission in person or in writing.