

Every child thrives, belongs, achieves

THE GREEN PAPER ON VULNERABLE CHILDREN

Submission from



Autism New Zealand Inc.
Including Asperger Syndrome and Related Disorders



1st February 2012

Introduction

Autism New Zealand Incorporated (CC21220) is a national, not-for-profit organisation with fifteen branches and over 6,000 members.

The New Zealand Autism Spectrum Disorder Guideline notes that in New Zealand there are approximately 40,000 people with an Autism Spectrum Disorder (ASD)¹. While there are no prevalence figures specifically relating to children and young people in this area, the majority of our members are family members with children with an ASD. The proposed recommendations in this Green Paper therefore have potential to have a major impact on our membership.

Autism New Zealand provides information, advice and support to those with an ASD and their families and whanau. Autism New Zealand also provides parent education programmes and other services and training – some of which are funded by the Ministries of Health, Education and Social Development.

This submission has been prepared by the Chief Executive on behalf of the National Board and branches who have contributed to the views contained in this document. The National Board is as follows:

Glenys Fry – President and parent of a teenager with an ASD

Wendy Duff – parent of a teenager with an ASD

Martin Wylie – parent of a young child with an ASD

John McKeown – principal of a special needs school

Heather Clay – parent of a child with an ASD

George Kingi – Maori Board member

Angela Arnold-Saritepe – Psychologist

Jen Birch – person with Asperger's Syndrome

Lachlan Mackay – person with Asperger's Syndrome

Summary

Autism New Zealand welcomes the opportunity to comment on this very important Green Paper on Vulnerable Children. The New Zealand Autism Spectrum Disorder Guideline notes that in New Zealand there are approximately 40,000 people with an Autism Spectrum Disorder (ASD). This response focuses particularly on young people with an ASD and their families however we are strongly of the view that the principles of care and community that need to be applied to families of children with special needs should apply to all families with children.

Autism New Zealand is also of the view that improving the lives of vulnerable children is dependent on providing proper support, training and respite for their parents and whanau as much as protecting children who are at risk. A shift in thinking to “strengthening” rather than “protection” will enable some of the cultural change that is so difficult to implement.

¹ New Zealand Autism Spectrum Disorder Guideline, Ministries of Health and Education 2008 p 17

Our view on the Government's vision.

We agree with the Government's vision that "Every Child Thrives, Belongs and Achieves." Autism New Zealand seeks to ensure every day both through service and programme delivery as well as advocacy that this vision is achieved for children and young adults with ASD and their families.

It is our experience that an important aspect to children and young people and their families thriving and achieving is that they feel they belong and are valued members of their communities and the wider society. This requires a level of acceptance and understanding of ASD that is not currently widely held.

While Government has taken a strong first step in developing the New Zealand ASD Guideline with the Autism community, Autism New Zealand still hears too often of children who because of lack of early intervention or lack of schooling support, do not achieve and thrive as much as they could.

In order for the Government's vision to be fully realised, Autism New Zealand believes that all children need to feel a sense of belonging. Specific needs of children and young people with ASD include increased and sustained early intervention, early support for families/whanau of people with ASD, and a supportive school environment. But also part of this sense of belonging is the sense that it "takes a community to raise a child." This is not a common experience for many families as the child with ASD is often perceived as being "difficult" or the result of "bad parenting" which further isolates them from their communities.

Autism New Zealand is of the view that supporting parents and the wider whanau is a fundamental requirement to ensure vulnerable children thrive, belong and achieve. Taking a strengths based, rather than punitive, approach to this will be the most effective and cost efficient way to reduce the violence and neglect that many vulnerable children experience. We observe many families who are remarkably resilient when faced with their particular challenges. Children become more vulnerable when this resilience is not supported in practical and community based ways.

Specific Issues and Questions.

We have only responded to some of the questions asked as there are many other organisations that will be better able to respond to other questions asked in the Green Paper. Our responses are as follows:

Sharing Responsibility.

Have Government agencies got the balance right in supporting parents, caregivers, family and whanau, to meet their responsibilities, while also protecting the needs of vulnerable children.

Autism New Zealand does not believe so. Our field workers have considerable experience of parents and families experiencing extremely high levels of stress, anxiety and dislocation because of lack of initial support and knowledge from a number of agencies including government agencies. In the area of ASD, Government still seems to us to be taking an “ambulance at the bottom of the cliff” approach.

Too many families have had to disrupt their lives unnecessarily because of lack of support and understanding in the school system. The phenomenon of the “Kiwi Standdown” (where children with ASD and other special educational needs are sent home because of lack of teacher aide resourcing or inability of teachers to cope) is very well known to the families we deal with. We note that the Government has made attempts to address this situation in the “Success for All” initiative that seeks to have 80% of schools fully inclusive by 2014 and 20% “well on the way” to reaching this goal and we welcome this. However, we believe that there will be need to be a societal culture change for this to occur. Autism New Zealand is attempting to assist this by the development of a “Schools Toolkit” which will be used in every school to assist teachers, school leadership and students in working with diversity. It concerns us however that we had to receive assistance from other than government agencies to do this vital work.

While Autism New Zealand understands the need for fiscal restraint in this financial environment, we firmly believe that in the area of Autism, this is a false economy. If Government does not pay for good quality interventions and support now, we know that Government will pay later for less desirable social outcomes. The Knapp study, *The Economic Impact of Autism 2007*², indicates that costs to Government considerably rise depending on what life and social outcomes happen to adults with ASD (whether they live independently, in supported living, or residential care.) While it needs to be acknowledged that there will be some people with ASD who will always require high levels of state intervention and care, Autism New Zealand believes that there are too many people with ASD whose potential is being wasted because of lack

² Knapp, Martin; Romeo, Renee; Beecham, Jennifer, *The Economic Consequences of Autism in the United Kingdom*, Foundation for People with Learning Disabilities, 2007.

of support and effective early intervention. This is exemplified by the very high numbers of adults with Asperger's and Autism who are unemployed.

These outcomes are in spite of the fact that New Zealand's policy settings in relation to disability are actually very progressive and forward looking. We totally support the principles of the *New Zealand Disability Strategy* and the *United Nations Convention on the Rights of Persons with Disabilities* both of which aim to ensure that disabled people and their families have the best quality lives possible and are fully included in the wider community. It is essential in our view that Government fully plays its part in the successful implementation of these policy settings.

When should Government agencies step in and intervene with families and whanau?

It is Autism New Zealand's view that Government agencies should acknowledge the resiliency and autonomy of families as a good first principle. They should also acknowledge that families generally want the best for their family members. Our organisation has contact with many families who have spent thousands of dollars on interventions and support for their child with Autism. Family members attend conferences to seek to understand how their family member behaves and "what makes them tick." We believe that Government should seek to empower and support those families in an active way that may not necessarily require extra funding.

A good example of where that doesn't happen at present is in the area of respite for young people with ASD. Our organisation undertook a survey last year where we surveyed Autism New Zealand members. Of the 47.2% of respondents who stated that they had access to respite care, **ALL** of them stated that their access to respite care was inadequate. This is deeply disturbing to us given the essential nature of respite care. Of the 53.8% who were not accessing respite care only 18% indicated they weren't using respite because they didn't need it and more than 35% indicated that they had no information about what was available. Autism New Zealand is of the view that significantly more could be done to ensure that families knew what was available to them to support them to enable their children to thrive, belong and achieve.

How can Government encourage communities to take more responsibility for the wellbeing of their children?

One of the things which is most disturbing to Autism New Zealand are the levels of institutional and societal discrimination which families who have young people with ASD face. We believe this is because of a lack of understanding and awareness in the wider community about the needs of children with ASD and their families.

We welcome initiatives from Government such as the appointment of a specific Human Rights Commissioner for Disability Rights, an awareness campaign seeking to change attitudes and behaviours toward disabled people and their families, and the implementation of initiatives resulting from the New Zealand ASD Guideline.

However, we believe that further social change towards attitudes towards disabled people is required. We are aware of the successful “Like Minds, Like Mine” campaign and would welcome such a campaign focusing on the strengths and abilities of disabled children and young people and their families.

We agree that family and child wellbeing is not just a Government responsibility – it is a community one. Many NGOs have a primary focus in supporting and strengthening communities and the government should foster the relationship between itself and these NGOs to ensure the best benefit is achieved for all. We are aware that there is a significant amount of discussion about partnerships with NGOs in both government agencies and from politicians. This discussion needs to be turned into practical and effective relationships that make better use of limited funds and have clearly identified and more positive outcomes for children, their families and the communities they live in.

Show Leadership.

How can an action plan help outcomes for vulnerable children? What could be the priorities for children for the early years, for primary school- aged children and adolescents?

Ideally, Autism New Zealand would like to see a specific Autism Act (such as has been applied in England and some states of Australia) which would outline specific requirements on Government in terms of providing support to people with Autism and their families. This Act would also spell out clearly which Government agencies and departments have responsibility for ASD. It is Autism New Zealand’s view that Autism covers all areas of life, and this view is reinforced by the New Zealand ASD Guideline.

We believe as a minimum it is essential that any action plan acknowledge that:

- This area of Government work is very challenging and requires long term solutions and not ones conditioned to electoral cycles.
- That a cross party and collaborative approach is essential
- There is a hugely diverse range of children who may be considered vulnerable.

Any action plan should also have:

- A realistic timeframe for implementation
- A level of funding which is joined up and not siloed and acknowledges the ongoing importance of successfully addressing issues for vulnerable children for the future wellbeing of New Zealand society.
- A robust and diverse evidence base.

Our organisation is clear that two areas which should receive priority in this action plan (and also funding) are Early Intervention and Transitions. These are often the two areas which can be most effective in terms of good outcomes for children with

ASD and their families but they are often the areas which can miss out most in terms of funding and focus.

Autism New Zealand supports evidence based early intervention for children on the spectrum. The effects of this early intervention can have lasting impacts for future positive outcomes for people on the spectrum. We are also aware of ensuring that the public get the best possible outcome from any early intervention. For young people with ASD early intervention needs to occur at varying stages of their development including, pre-5, 8 – 10 and puberty. We acknowledge the Green Paper recognises that areas of vulnerability occur most at early childhood and puberty and suggest that any interventions that work for children with ASD and their families are very likely to have success for all in the disability sector and potentially all those families who may have vulnerable children.

Another area where focused support is required is the area of transitions. Children and young people with Autism find change especially difficult and this can consequently cause additional stress for families. Success in this area may not come down to additional money being spent but rather a change in attitude which seeks to ensure that all players involved in a child's transition focus solely on the needs of the child and work towards that objective.

We are not convinced that legislation to achieve cultural and social change is necessarily sufficient, rather a Child Action Plan which has both short and long term objects and to which all political parties sign up to also requires comprehensive and regular reporting against the implementation actions specified in the plan.

One of the main issues we confront is a lack of statistics and hard data in the area of Autism. For example, there is no clear data about the number of people with ASD in New Zealand (the latest estimate is around 1:100 and comes from a 2005 English study). This lack of data has made it very difficult to get a sense of the size of the population and any issues which result from this. We acknowledge that one of the issues may be defining which children and families exactly are “vulnerable” – but we believe that it is important that a start is made in this important area. However if we assume that 1% of the population is on the autism spectrum then there is some logic in applying that statistic to all of the figures mentioned in the Green Paper.

Child-Centred Policy Changes

Do you think the Government should provide more targeted services for vulnerable children? If yes, from where should funding be taken? Should the Government reprioritise spending to provide more early intervention?

Autism New Zealand's views on this are clear. We believe it is absolutely essential that more funds be provided for Early Intervention and we take the view that a lack of focus on this does not provide good “value for money” for the New Zealand taxpayer. We are aware of a number of overseas studies on early intervention which clearly

show the economic future cost of not providing sufficient service at an early point in a person's life and believe that this must be factored into government budgeting processes which currently appear to be very short term.

We understand the emergencies which have occurred in New Zealand in the last eighteen months together with a global financial disaster however we believe that investing in early intervention is an absolute priority to avoid long term costs that could well become unsustainable. We find it difficult to believe that the Government would provide money for the fund-holders in South Canterbury Financial, but at the same time not consider early intervention services as an integral part of any funding plan. We are aware of a number of specific early intervention models operating in Australia including the "Helping Children with Autism" package which provides a small amount of funds and appears to be having significant benefit to families who have a child with ASD.

Funds for improved early intervention and other targeted services for vulnerable children and their families does require some re-prioritisation however we would also suggest that using the partnership model with NGOs would result in limited funds being spent much more effectively. Extending the age of eligibility for superannuation could well result in better funding in the early years without impacting significantly on those who are at the other end of their lives.

**How much monitoring of vulnerable children should the Government allow?
Who should monitor vulnerable children and under what circumstances?**

We believe there should be some care taken before implementing a compulsory monitoring regime for vulnerable children. It is important to acknowledge that parenting Autistic children is stressful and challenging. Indeed, many families have to "monitor" their children on a regular basis. Any monitoring of families of children with Autism needs to have as a first basis that:

- Parents of children with Autism want to parent their children well – they need support and not condemnation to do this.
- There will be parents who are also on the spectrum.
- Parenting of any child is a challenging job.

We are concerned that there continues to be a separate "pathway" for disabled children into the care of Child, Youth and Family. Often, complex parenting issues to do with a disabled child "turn" into care and protection issues when they may just be issues which are to do with the complexities of parenting a disabled child. We are particularly concerned that some parents are feeling that they have to turn parenting issues into "care and protection" issues because in that case they will receive services. Comprehensive support and understanding should be provided so that families do not get into the position of needing to be monitored. That will only happen when social attitudes to Autism change and there is comprehensive investment.

Making Child- Centred Practice Changes.

What can be done to improve and promote collaboration between professionals and services?

Often one of the major complaints of families of children with Autism is that they feel like they have to tell their story to many different agencies and organisations in order to get the support they need. This is in common with other families who have disabled children and young people. One of the reasons for this is that there is no “one central place” for people to gain information and support.

As part of the ASD Guideline Implementation, ASD Coordinators were appointed in some DHB's. These coordinators had a focus specifically on children (under 18) and their families. While this initiative was welcomed by Autism New Zealand we were and remain concerned that this is not in all areas of the country. We also acknowledge the Ministry of Health's initiative to trial the introduction of Local Area Coordinators in some areas to provide support and information. Our concern perhaps lies in the number of different coordinators (including the above as well as Whanau Ora) compared to the relatively few services available to be coordinated.

In order for services to be best coordinated between the often very committed professionals working in the Autism field and services like Autism New Zealand we believe:

- Parents require comprehensive and early support at diagnosis of ASD and for professionals to acknowledge the expertise which exists in organisations like ours.
- The debate about whether Autism is a mental health condition or a disability be resolved and professionals and services be clearly aware of this.
- More “mainstream services” (for example Plunket) need to have a clear understanding of and training in the impacts of ASD on families and young children with ASD.

What principles, competencies or quality standards should be included in the minimum standards for a workforce for children? Who should be included in a workforce for children?

Autism New Zealand believes that a well trained and skilled workforce for children is absolutely essential. However, it is our experience that often the workforce which works with children with Autism are grossly undervalued, underpaid and underappreciated. For example, Early Intervention teachers in schools are the lowest paid teachers in the teaching workforce. People working in Needs Assessment and Service Coordination are sometimes untrained students who see working with disabled people (including children and young people) as a holiday job which does not require skills and training. Not only is this unreasonable, it is also dangerous.

We therefore welcome the move by the Ministry of Education to develop a Post Graduate Qualification and believe this should be extended further to ensure that all teachers have a more comprehensive element to their training. We also believe that more “mainstream” services such as Plunket and Schools should better acknowledge the skills their workforce needs to work with children with Autism and their families. While the Government’s move to increase exposure of all teachers to special education training is welcome, we still believe that it is not okay that a teacher is able to go through teachers’ training college for three years and only be exposed to an hour lecture on special education.

Our organisation therefore believes that any standards around a workforce for children need to acknowledge:

- The vast diversity of children (and consequently the vast diversity of their needs)
- The importance of proper and respectful engagement with families and whanau.
- Knowledge of technical skills regarding dealing with children (such as basic child development and knowledge of behaviour)

How can the Government’s frontline services better connect vulnerable children and their families and whanau with the services they need?

Autism New Zealand’s experience has been that sometimes Government frontline services either:

- Don’t acknowledge the expertise of organisations such as Autism New Zealand in dealing with families with ASD OR
- When they do so do not resource this appropriately (i.e. they ask NGOs like Autism New Zealand to undertake work which they could be doing without providing the financial resources to do so)

Concluding by “Thinking Differently.”

Autism New Zealand wishes to conclude this submission by “thinking differently” (this is our by – line). We suggest it is only in this way that this country will obtain lasting change for our children.

The Green Paper contains “real life stories” of children who are considered to be “vulnerable.” This response has been written by Autism New Zealand’s Research and Policy Analyst, Matt Frost. Matt is a 31 year old man with Autism. At many points as he was growing up, Matt was considered “vulnerable”.

What made Matt’s life reasonably successful in terms of negotiating being a “vulnerable child?”

- He had parents and whanau who loved him.

- Part of this love was them accessing comprehensive speech language therapy, paediatric support and doing intensive socialisation with him.
- Matt had two years at school where he had a mix of specialist provision and mainstream schooling.
- He was encouraged to have friends, explore his interests and be the person he needed to be.
- His parents and siblings walked a fine balance between allowing him to “be autistic” (including some challenging behaviour) and encouraging him to explore other socially appropriate ways of behaviour.
- Matt’s interest in reading and learning was encouraged at school and not rejected.
- When Matt was subject to bullying, that was not tolerated.

Matt discussed this submission with his parents and his mother said one thing which greatly worried him. She said that she was glad he wasn’t a child now due to the environment in which we are supporting (or not supporting) children with Autism.

This is greatly worrying. But it seems to Matt that the things he outlined above are not that hard to achieve – they just require community commitment and caring towards vulnerable children and their families. He believes it’s only when we make the change to this that we will really be in a position to take action on vulnerable children.