



**SPECTRUM
LABOR**

SUBMISSION

to

**THE SELECT COMMITTEE
ON AUTISM**

**Inquiry into the services, support
and life outcomes of the Autistic
community**

Contents

Introduction - 3
Terms of Reference
Part A - 4
Part B - 5
Part C - 6
Part D - 7
Part E - 8
Part F - 9
Part G - 13
Part H - 15
Part I - 17
Part J - 18
Part K - 19
Part L - 20
Part M - 21
Part N - 22
Appendix 1 - 23
Appendix 2 - 40
Appendix 3 - 44

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

INTRODUCTION

Spectrum Labor is a group within the Australian Labor Party that is focused on the promotion, support and protection of the Autistic Community across Australia. Founded in October 2017, the group has put out several press releases condemning the actions of various individuals to the detriment of the Autistic Community. We have also made policy submissions and given speeches about the *History of Autism* and *Migrants on the Autism Spectrum*. We have a Spectrum Labor Facebook page as well as a private group and we also have a website; <https://spectrumlabor.home.blog>

Those who are Autistic and their families and carers have over a long period of time been subject to much aversive conduct both within the mental health system and by the hand of society at large. Autism is seen as a disability that renders the individual unable to function in society and should therefore not be a part of it. This is far from correct. Equally, Autistics are seen as unintelligent and inherently socially inept with no redeeming qualities whatsoever. This is also far from correct.

Spectrum Labor asserts that Autism is genetic in origin and a different way of being. We reject the notion of a cure and believe that people on the Spectrum have a great deal to offer society, but community misunderstandings and lack of appropriate accommodations and services are preventing many Autistics from contributing fully to communities and workplaces and enjoying quality of life. We are currently preparing to launch an online petition asking for an inquiry into anti-Autism hate speech (of the kind currently being directed towards Autistic climate activist Greta Thunberg for example). We believe that Autistics need positive media portrayals to overcome prevailing bullying and discrimination.

Spectrum Labor consists of a growing number of self-identified members of the ALP on the Autism Spectrum. Autistics are known to have a strong social conscience and contribute greatly to political and community life. As there is still a great deal of confusion and stigma surrounding the Autism Spectrum, we expect our organisation to continue to grow as more adults undergo diagnosis and find the strength to share their diagnosis and become vocal about the issues that affect them. We are a multicultural group and currently have members from several states, including both men and women of all ages, people with experience teaching, counselling and bringing up children on the Spectrum. Our members either work or are looking for work, study or have additional issues that make it difficult to find a job.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART A

The current approaches and barriers to consistent, timely and best practice Autism diagnosis

For a long period of time, diagnosis has been difficult and traumatic. There are many reasons for this and some can not be fixed. The diagnosis of Autism is not simply a case of just ticking boxes. That can lead to what are called designer diagnosis results, which have been used in the past by anxious parents who want a quick diagnosis to excuse their child's poor behaviour and thereby avoid their own issues.

Best practice at the coal face has several steps. The first step is the family doctor/GP – not in diagnostics but rather in the more general position of referrals. Some GPs do not have adequate up-to-date ideas or information about Autism and some project negative views about disability and differences. The distorted views of some medical professionals can be absorbed by patients, or their families, and cause them to avoid going through with diagnosis.

In most instances, psychologists who do bulk bill under Medicare require a referral as part of that claim. Many psychiatrists require the same. This is partly why general practitioners need to be aware of the general signs of Autism. This presents a problem, especially in the area of early intervention which is considered crucial in the whole process and not just in diagnostics.

Even in getting past that point, the next step needs to be proper diagnosis that is done thoroughly. As stated, this can not be a case of ticking boxes. The psychiatrist or psychologist needs to get to know the Autistic first, and if the Autistic is not communicating as is sometimes the case that can be time consuming by default. It can't be rushed. It is not being suggested that it should be perfect because that is not possible, but it has to be as close as possible for the sake of the Autistic.

The final step is to confirm said diagnosis. The reaction to it plays a role in this, given (and this will be expanded on later in this submission) that adjustment to the condition of Autism is crucial in all respects.

Autism diagnosis for children involves long waiting lists. There are also waiting lists on accessing early intervention services and very few respite and sibling support services. This means that many Autistic children miss out on early intervention during the most important formative years and are not as school ready or do not get adequate support at school.

One other barrier in diagnosis – and this will also be detailed later in this submission – is the fear of said diagnosis as previously alluded to. It should be promoted as positively as possible. It is not the end of the world for the Autistic or their family. Dealt with appropriately, the rewards can be high and in some cases quite exciting. In the case of low functioning Autistics, on the face of it things may look bleak – but with early intervention great results can come. Don't fear Autism. That's a bad way to think and can have an adverse effect on the Autistic.

There are also barriers to Autism diagnosis for adults, including the same lack of information about Autism characteristics or the fact that Autism occurs on a Spectrum, negative perceptions of Autism and real fears that an Autism diagnosis could result in workplace discrimination. This prevents adults from properly understanding their differences and gaining the correct support services.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART B

The prevalence of Autism in Australia

This is a vexed issue historically. There are those in the community that claim that Autism has come from nowhere and refuse to believe the correct assertions that improved diagnosis through the DSM-IV in 1994 has played a major role in the statistics of prevalence. The proof of this comes in the form of many diagnostic results coming in adults who were previously not diagnosed as the criteria did not fit them. The part of the Autistic spectrum that is known as Asperger Syndrome is behind this – and the lack of knowledge of the work of Hans Asperger that remained hidden for decades.

The true prevalence of Autism is revealed in three factors.

The first – although not about Australia but nevertheless relevant – is the promotion of prominent figures in history as high functioning Autistic. The most prominent of these is Albert Einstein, but many other recognised genius' including one female (Marie Curie) have been promoted in the same way. Spectrum Labor believes these promotions are correct and factual.

The second relates to the assertion that many of the children regarded by their peers as eccentric, or the 1980's term of "nerd", could well have been Autistic. Adults diagnosed late would be an appropriate guide to this factor.

The third relates to the changing work place – a factor detailed later in this submission – from a stable specialised environment in which an Autistic could hide and not be noticed as different, to an unstable multi tasking environment pushing the Autistic out into the open.

These factors contribute to the assertion that Autism has been in society a lot longer in its current diagnostic form than some who seek to treat Autism badly are willing to admit.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART C

The misdiagnosis and under representation of females in Autism data, and gender bias in Autism assessment and support services

While earlier research indicated that there were four times as many Autistic males as there were Autistic females, more recent research suggests that there are in fact only twice as many Autistic males as there are Autistic females.

Girls and women on the Autism Spectrum typically teach themselves social skills and are often more outwardly sociable, despite their inborn differences. They may also adopt more typically feminine special interests that are not usually associated with Autism. The gender bias in diagnosis is partly due to the fact that medical professionals are overly dependent upon the early work of Hans Asperger and Leo Kanner who studied Autistic boys, and partly due to wider medical and social gender biases. Girls on the Spectrum are also less likely to engage in challenging behaviours that would prompt teachers or parents to seek diagnosis.

Girls and women on the Spectrum often feel compelled to mask their social differences and this can lead to mental health challenges. Correct and timely Autism diagnoses can allow women on the Spectrum to self-advocate, seek accommodations or support services and enhance their quality of life.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART D

International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity.

Australia is one of the worst performers in the OECD for disability employment. A study commissioned by Autism peak body Amaze, released in March 2019 (see Appendix 1), found that the unemployment rate for autistic people was 31.6%, which was three times the rate of people with disability and almost six times the rate of people without disability. This points to a great need for improvements in education and support services as a means of enhancing work readiness.

In order to respond correctly, best practice must be applied in all respects. The diagnosis must be full with all factors taken into account in order for the Autistic to have the maximum chance to adjust – even for adults who are diagnosed later in life. Full support consequent to diagnosis should be at the very least available, and this has to include all educational tools to the appropriate intensity if required. This will vary greatly so a one size fits all model should be avoided.

In order for the best results to be achieved a large cost is involved and cannot be avoided if the Committee is serious about this subject.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART E

The demand for and adequacy of Commonwealth, state and local government services to meet the needs of Autistic people at all life stages

As stated previously, there are long waiting lists for early intervention services. Early intervention cuts out at school age and this does not give young children enough support. Access to school integration help is restrictive, so too is access to special help at after school and recreational programs. Autistic children can be excluded from play dates such as birthday party invitations. This can prevent Autistic children developing confidence in social situations. It is important that local government steps in with all-abilities social activities where Autistic children can experience out of hours socialising.

The Victorian Autism Plan has pledged to expand the peer support services offered by the ICAN Network in Victorian schools. This is especially important for Autistics to cope with the two most important transitions at school age – the transfer from primary school to secondary school, and the effects of puberty. We believe this should be done nationally and that similar Autistic peer support programs should also be encouraged in all tertiary educational institutions and workplaces.

Some sensory friendly quiet hour sessions are being introduced at movie theatres, shops and libraries, and some public places offer sensory accessible play areas and Autism Quiet Rooms, but this is on an ad hoc basis. To really make a difference to the lives of Autistics in the community, especially those with multiple disability and high care needs, local and state building codes should mandate accessible facilities and Autism Quiet Rooms in all public areas. All government subsidised facilities such as libraries and pools should provide accessible features and sensory friendly sessions as a condition of being funded. Government funded services and businesses that tender for government contracts should also be required to employ Autistics in at least 2.5% of all company positions, to mirror the actual incidence of Autism in the community - the best place to start this transformation being the public service, politicians' offices and municipal workforces.

Spectrum Labor calls for the support and expansion of initiatives such as The Lab, which is a growing network of technology clubs for young people diagnosed with High Functioning Autism who enjoy working with computers. The Lab offers mentoring by technology professionals in areas such as programming, 3D, digital design and gaming. While The Lab is not NDIS registered, many Lab participants use their NDIS plans to pay for Lab sessions. As almost all the branches are in Melbourne and very few in other states, we call for the funding and support of similar clubs nationwide, which prepare kids for well paying jobs. We also call for more support for other clubs based on typical autistic special interests such as historical re-enactments, train spotting and scientific interests, where the clubs celebrate and foster Autistics' special interests as a pathway to socialising, learning and jobs, encouraging Autistics to enrich themselves and society through their interests instead of labelling these as obsessions.

Social support and social skills services are also provided on an ad hoc basis and often concentrated in wealthier capital city suburbs. These tend to target younger people and rarely cater to the older person with a recent diagnosis who has struggled with socialising. These services should be provided in every area, on the same basis as Maternal and Child Health, Senior Citizens' Clubs etc – these should be services that anyone can access.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART F

The interaction between services provided by the Commonwealth, state and local governments

i. Health and mental health

As the Committee would be aware, the state government of Victoria is in the middle of a Royal Commission into Victoria's Mental Health Services. Unfortunately, Autism has not rated that much of a mention so far which is disappointing. This would be an opportunity for this discrepancy to be resolved federally.

As many people on the Autism Spectrum are unemployed or under-employed, low income limits their access to vital services. During freezes to Medicare rebates, people on the Spectrum may have to pay gap fees they cannot afford for health and mental health services. One study, published in the American Journal of Public Health in April 2017, finds the life expectancy in the United States of those with ASD subjected to injury to be 36 years old as compared to 72 years old for the general population (see appendix 2 – only the abstract is available to Spectrum Labor). Spectrum Labor believes this statistic may be related to fatal injuries suffered by Autistic children who wander.

Wandering is an important issue to tackle. Invariably this happens when the child is feeling trapped or scared and is unable to communicate this fact. When wandering occurs some parents fall into the idea of locks on doors and windows – when in fact this only worsens the prevailing situation. A child who wanders needs the space that is usually absent at the time to the extent required. This could in fact be related to the tendency by land developers to build apartments instead of proper homes with backyards. Space is an important mental health factor for Autistics.

Medicare funded Health Care Plans for five visits per year will not cover the extra health and mental health services needed by many people on the Autism Spectrum.

ii. Education

We are stating the obvious when we point out that tertiary education is a Federal responsibility while other levels are in the domain of state governments. That of course doesn't mean that the Federal government doesn't contribute funding to primary and secondary schools.

Access to Integration/teacher aide help in schools is too restrictive for many children on the Autism Spectrum, with restricted access affecting children who have a learning disability as opposed to an intellectual disability, differences between what is available through private and public systems, access to special schools within a reasonable travel distance, children being forced out of special schools where they are happy and comfortable because they show signs of progress, and lack of access to extra services if a child has mild physical and intellectual impairment, especially in combination with English as a Second Language, but doesn't qualify for extra assistance under any one category.

Both teachers and teachers' aides need ongoing training to better understand and cater to Autistic students. Teachers' aides' positions are underpaid and undervalued as stereotypically female occupations. Teachers' aides should be considered skilled rather than unskilled and be paid at a

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

higher rate, with job security, to ensure Autistic children get the best quality assistance including the stability that is related to the Autistic need for routine.

Similarly many TAFE and university students on the Spectrum need properly qualified academic assistants and note takers. This role should be treated as a career path and not as a part time job for other students, some of whom quit the job when their own exams come up, leaving the Autistic student without support.

The UNCRPD calls for teaching staff with disability to be employed to assist children with communication, eg deaf staff to communicate in sign language and blind staff to use Braille. Spectrum Labor further advocates that teachers and teachers aides on the Autism Spectrum should be employed to promote understanding and acceptance of Autistic students and provide positive role models.

Many schools have not been designed with the sensory needs of children on the Autism Spectrum in mind. Anti-bullying programs need to be strengthened to ensure that children on the Autism Spectrum feel safe and accepted at school. As the recently released Victorian Autism Plan points out, people on the Autism Spectrum are more likely to be trans or gender diverse than the general population. This makes Victoria's Safe Schools Program very relevant for this vulnerable minority of children, yet this program is under attack from some religious groups and is not available nationally.

Physical Education is not a welcoming experience for many children on the Autism Spectrum, many of whom have some form of dyspraxia or low muscle tone. There is rarely any accommodation for these children and after hours sporting activities for such children are rarely available or collapse when they don't make a profit.

Schools often do not cater to the gifted or talented student on the Autism Spectrum, do not adequately develop a child's special interests or allow the Autistic child to develop and learn through exploring his/her special interest. Such children can be made to feel like failures when they don't fit in with conventional expectations or teaching methods or don't fit in socially. Children can then drop out or under-achieve at school, representing a huge waste of potential.

All of this needs to be made compulsory in all public schools and pressed also for all private schools. The offensive idea presented by Senator Pauline Hanson that separate schools for Autistics should be created is counter productive and also excuses poor conduct by mainstream schools, especially the one depicted in the example the Senator gave on the floor of the Senate. The child concerned should have got the support he needed at the public school he left, and should not have needed to change schools, especially into a private school, in order to access the needed support. Having said that, there are the odd situations where the school environment just isn't compatible with the Autistic – in which case another option needs to be made available.

iii. Employment

It is a fact that unemployment within the Autistic community is unacceptably high at 31.6% as perviously mentioned. The Amaze report (see Appendix 1) also provides other statistics that are either too high or reflect poorly in the current community attitude. All levels of government need to

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

get serious about overcoming unemployment and under-employment amongst people on the Autism Spectrum, by promoting employment programs and quotas. Demands for high level social skills in jobs where these skills aren't needed are clearly discriminatory. Autistics should have alternative ways to prove their credentials during the interview process. Perceptions that female employees should be more chatty or conform to uncomfortable dress standards, as an inherent part of teamwork, discriminate against women on the Spectrum.

Multi-skilling also threatens the jobs of people with disability including Autistics. Government incentives could help ensure that people on the Autism Spectrum gain and retain employment. A sustained public education campaign can help improve the employment prospects of people on the Autism Spectrum.

People with disability who go to work should be guaranteed a minimum wage. They should not be expected to subsist on sheltered workshop wages. Low wages on the basis of disability should become a thing of the past.

As many people on the Autism Spectrum are solitary and highly motivated with their special interests, they should be given more support, financial assistance as required and if appropriate training to turn the interest into a self employment situation and start their own businesses. However this will require a permanent support structure in place given that customer service is generally not a strong point of an Autistic because of its inherent unpredictability.

iv. Justice

Sadly, it is well known that people with disability, including intellectual disability, are over-represented in prisons. This is a systemic failure on the part of schools, mental health services and support to vulnerable families, mainly caused by government under-funding and poverty, including low wages, insecure work and the inadequacy of welfare support payments.

In addition, some people with disability sometimes appear "suspicious" to law enforcement officers, they often do not know how to respond during contact with law enforcement personnel and may also lack the resources to seek legal help throughout the court processes. All levels of government must develop pathways to keep vulnerable people out of criminal justice, protect and rehabilitate vulnerable individuals within the prison system and re-integrate former prisoners back into society. We applaud the Victoria Police initiative in the Brimbank council area "Have a coffee with a cop" and feel that all police officers should get to know local people on the Autism Spectrum, especially those with intellectual disability, so that they build up a good rapport with them and can keep an eye out for their safety.

Autistics who feel wronged outside of the criminal system are generally unable to seek appropriate remedies due to a number of factors. This is not only due to a lack of appropriate information, there is also the issue of poor funding in legal aid services – which is keyed to the criminal system. A good example of this is legal representation in a matter of human rights. State funded legal aid services do not fund this, although there are other options. A harder area in civil law is defamation, a very complex area that is better handled by a qualified lawyer. In some cases for Autistics this is a variant on the human rights issue. Funding here needs to be increased and more resources made available.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

v. Housing

Supported accommodation is often difficult to access as there is insufficient stock and insufficient choice of lifestyles. Sadly, some people on the Autism Spectrum can be abused by their care-givers or other residents within this accommodation. It is better for the Autistic to have space that supported accommodation in its present form does not provide.

Choosing independent living arrangements can be incredibly difficult for unemployed and under-employed Autistics. Affordable, secure government housing and social housing options, in areas where there are adequate employment opportunities and public transport, need to be drastically increased as a matter of urgency. The need for space presses for options outside the capital cities where regular public transport is available. This brings up another issue of the lack of public transport around certainly Adelaide and Perth and to a lesser extent Brisbane. Sydney and Melbourne do better with services through regional areas to Newcastle and the Hunter Valley, the Blue Mountains, Moss Vale, Wollongong and Nowra, Geelong, Ballarat, Bendigo, Seymour and the Latrobe Valley. As a general rule, Autistics enjoy train travel and provision of housing not just for Autistics but for the wider community can take advantage of these existing services. The higher level of solitude smaller communities provide Autistics would also be beneficial in other ways.

Options further afield from Adelaide and Perth should be provided, especially Adelaide. The Federal government has recently asked for the states to suggest infrastructure projects. Restoration of rail services to the Barossa Valley, the Adelaide Hills and Murray Bridge as well as more frequent services to Northam and Bunbury would be ideal for this purpose – again not just for Autistics but for the general population where housing is a general issue.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART G

The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of Autistic people

Many studies have concluded that there is a higher prevalence of Autism amongst scientific (STEM) occupations and amongst child prodigies. By failing to properly support Autistics throughout their lifetimes, society misses out on the insights and innovations that Autistics have to offer.

Autistics with intellectual disability could become more productive and lead more satisfying lives if properly supported to engage in education, recreation and the workplace. This would ultimately reduce their dependence on welfare later on in life.

Below is a list of positive traits that people on the Autism Spectrum typically possess, which are invaluable for the wellbeing and productivity of society;

- are conscientious, reliable, honest and not likely to be bullies
- are intelligent, persistent and talented and have a propensity for obsessive research, thus developing a broad and deep base of knowledge in subjects of interest
- are free of prejudice, untainted by the judgments that people often make regarding one another's social position or social skills, are very accepting of the quirks and idiosyncrasies of others
- don't discriminate against anyone based on race, gender, age, or any other superficial criteria
- bring a highly original perspective to problem solving
- can listen to people's problems and provide a fresh perspective, offering objective assessments based on the information provided
- can recall fine details that others miss
- can speak their minds and be themselves without fearing social censure
- have a lot of passion when engaging in activities they like, which may translate into a talent for certain athletic, artistic, scientific, lobbying or charitable pursuits
- have a tendency to adhere to routines
- have exceptional memories
- have extreme endurance
- have high integrity
- have values that aren't shaped by financial, social, or political influences
- are highly motivated and able to work independently without supervision
- pay attention to detail
- stick to their positions, even in the face of intense social pressure
- tend to become proficient in the technological media required for lucrative employment in the "information age"
- have enormous reserves of personal strength, will not go along with the crowd if they know that something is wrong

To illustrate the loss to society of failing to properly support Autistics, we quote the example of the American child prodigy Jacob Barnett who, at the age of two, was diagnosed with Autism, Asperger Syndrome. Jacob's parents were crushed when they were told he may never talk or read. His parents never gave up and used a special treatment for children with Autism, where children are allowed to

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

play or focus on subjects that interested them. Jake showed a remarkable early interest in astronomy and would study books of stars over and over again. He is reputed to have an IQ higher than Einstein's and began university studies at the age of 12.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART H

The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for Autistic people

i. Autism understanding within the NDIS

When the Productivity Commission performed its initial examination of the proposal for a National Disability Insurance Scheme in 2010 and 2011, co-founder Philip Gluyas put in a submission and also made a presentation. Subsequent to that he presented the Commission office with a copy of a study done by AEIOU in 2007 showing the cost of Autism (see Appendix 3).

For some reason, this report was not published as part of the inquiry and consequently we believe was not taken in to proper account. This has in part we believe led to several errors by the NDIA leading to higher functioning Autistics getting no access whatsoever and at one point even mid functioning Autistics had their funding cut. This latter cut was consequently reversed. But given that it would appear that the report from AEIOU was ignored, and the Productivity Commission final report had a tendency at times to block Autism with conditions like acquired brain injuries, understanding of Autism was impeded from the start.

ii. The utility of the Early Childhood Early Intervention Pathway for Autistic children

This was an area covered extensively in the aforementioned Productivity Commission final report. Mention was made of the New South Wales Footprints Program although it would appear the Autism Behavioural Intervention Association has moved away from it now. One disconcerting remark in the Commission report was "Thus, it is not possible for the Commission to be prescriptive about the timing and duration of early intervention for particular types of disability". This remark can be seen on page 93 of Volume 2 of the final report which we assume the Committee already has possession of. It was also noted that participants requested more information and Autism Victoria (Amaze) was included as an example. The concern is that the Productivity Commission were seeking ways to save money through time and duration – a factor that in this case cannot be calculated and therefore needs to be exponential due to the wide variations in requirements of early intervention.

This concern is confirmed with an observation on page 104 of Volume 2 of the final report about the restricted number of economic analysis reports. On this basis it would appear that the NDIS needs more funding in early intervention in order to achieve the goals of successful early intervention.

iii. The ability of the NDIS to support Autistic people with complex needs, including those transitioning from prison settings

The NDIS presents potential users with a nightmare maze to find their way through before accessing appropriate services. This particularly affects Autistics with intersectional issues such as non-English speaking family background and people living in remote areas such as Indigenous people. The under-funding and red tape of the NDIS limits its accessibility and effectiveness in dealing with complex needs and people exiting the prison system. We fear that without affordable housing, adequate income support and sufficient job opportunities, these most disadvantaged Autistics will not have their basic needs met and will remain vulnerable.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

iv. The adequacy and appropriateness of supports to empower Autistic people to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services

Spectrum Labor was represented at the Shadow Minister's recent Disability Summit in Melbourne where leaders of peak bodies attested to the complexity of the NDIS in its current format. They further pointed out that some staff administering the NDIS are inexperienced. These matters need urgent attention to allow Autistics self-determination and control.

When NDIS funds are redirected to other budgetary areas it is these most vulnerable users who are disadvantaged the most by these changes. Spectrum Labor calls for the proper funding of the NDIS to ensure every user can access appropriate support. We believe the economy will benefit in the long run from encouraging people with disability and/or Autism to develop their potential and become more physically and psychologically healthy and productive.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART I

The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy

It is most important that people on the Autism Spectrum be central to the development of a National Autism strategy and that advocates, such as parents and professionals, can also have input but not the final say. Unfortunately, the rights of Autistics lag behind that of every other disability – we still have “experts” who are expected to speak for us, rather than in support of us. Part of the problem is that Autistics are so poorly understood and regarded that many Autistics fear “coming out”, leaving “experts” to fill the gap.

An Autism Strategy will differ from a Disability Strategy in that Autism encompasses people who are socially different, who may or may not show other signs of disability, and in fact can appear unusually highly capable. An Autism strategy will need to cater to a huge variety of people on a very broad spectrum. An Autism Strategy will need to be as much about better utilising Autistic talents as it would be about helping Autistics.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART J

The adequacy of funding for research into Autism

Spectrum Labor supports research into matters affecting Autistics' quality of life, education and general health. We especially support research into the needs of women, LGBTIQ people and ethnic minorities on the Spectrum. We do not support research into an Autism cure or any pre-natal Autism screening processes. We believe that Autism is a natural and vital variation of the human genome which allows creativity, individualism and strong leadership. It has been well said that Autistic genes allowed for the creation of the first axe and that, without Autistic genes, we would all still be sitting around the campfire socialising!

One research line that we believe should be pursued is that of confirming Autism's genetic base – thereby putting a stop to alternative theories based in the idea that Autism isn't natural. This we believe lies in the behaviours. In the Diagnostic Statistical Manual Version 4 (since superseded by the DSM-5) a diagnosis was confirmed with five of a set of six behavioural traits. However we believe that every single human being on Earth has at least one of the said traits. No human being has none of them. One can have four of them – and not be on the Autistic Spectrum. A confirmation of this as being a genetic factor would be beneficial to the understanding of Autism.

Equally, research should be done to understand sensory sensitivity and the consequent concept of sensory overload. This we believe is behind the regressions for those at the lower end of the Autistic Spectrum, and confirmation of this would also be beneficial especially in terms of early intervention techniques.

Research into frequently co-occurring conditions such as Irritable Bowel Syndrome and Dyspraxia could also be enormously helpful. This we believe is related to sensory issues. We recognise that some Autistic adults choose to use psychiatric medication with good reason, however we don't support research into medicating otherwise happy and healthy Autistic children simply because they are Autistic.

Spectrum Labor calls for social and psychological research to determine best practice for assisting the most vulnerable people on the Spectrum such as Indigenous Autistics, Autistics from immigrant backgrounds and Autistics members of the LGBTIQ community.

We further advocate psychological and educational research to assist with specific learning issues which occur more frequently amongst Autistics, such as dyslexia (reading disability), dyscalcula (difficulty with maths), dyspraxia (co-ordination required for sports, dancing etc), prosopagnosia (difficulty with facial recognition) and topographic agnosia (difficulty with sense of direction and recognising landmarks, which affects one of the authors of this submission). Technological solutions should also be developed to assist Autistics with difficulties such as facial recognition and recognising landmarks. Of course these solutions will only be of limited use if they are not made generally available to Autistics living in all parts of Australia, regardless of their financial status.

As indicated in the introduction and earlier in this part, we absolutely oppose any move towards research into a cure, which may be presented in some form to the Committee. Autism is a natural human variation that requires adjustment, not elimination.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART K

The social inclusion and participation of Autistic people within the economy and community

Spectrum Labor calls for a public education campaign to promote Autism Acceptance, as opposed to Autism Awareness, which has become synonymous with “bewareness”. Disability access, including Autism Quiet Areas and sensory features, are needed in all public spaces. Increases to pensions and Newstart are urgently needed to allow people on the Spectrum to live decently and buy what they need. Governments must address the educational and employment needs of people on the Spectrum as a matter of urgency.

An elevated number of Autistics experience Irritable Bowel Syndrome and seek modified foods such as gluten-free and lactose-free alternatives. Some families seek additive-free foods to help regulate their children’s behaviour – under guidance of qualified dieticians. The current high prices of these non-allergenic foods punishes many Autistics and their families who are already financially disadvantaged and makes going out to relax and socialise even harder. The expense of consulting dieticians – who are not always covered by Medicare – also presents a restriction.

These families should be able to easily access these foods in any canteen, shop or holiday spot without undue expense or the burden of having to organise their eating plans in advance to get around lack of availability. Legislation mandating the availability and prices of these foods is needed and councils could step in to ensure availability in sparsely populated areas.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART L

The capacity and sustainability of advocacy, self-advocacy and self-determination supports for Autistic people, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities

Spectrum Labor calls for the appointment of an Autism Equality Commissioner to ensure equal rights and dignity for Australia's 600,000 Autistics. We believe that governments should fund and support self advocacy and make public advocacy services freely available to people on the Autism Spectrum and their families. We are more than ready to do this. We believe that all efforts should be made to help Autistics with intellectual disability or speech impairment to self advocate. We also call for funding and support to organise Autistic Pride events.

While we welcome the good intentions of parents and experts in the Autism field, these voices should not substitute those of self-advocates. We oppose the tactics of large charities such as Autism Speaks with its depiction of Autism as a burden and tragedy. We ascribe to the social model rather than the medical model of disability – often, people on the Autism Spectrum are incredibly successful, focused and productive people when we can choose an appropriate environment to live, work and study in. Nothing about us without us! We are different, not less.

"We are different, not less" – "Nothing about us without us"

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART M

Any bill that relates to matters within the scope of this inquiry that is referred to this committee

The main existing legislation that comes under scrutiny in this part is the Disability Discrimination Act. Spectrum Labor will be re-launching a petition in late January 2020, calling for an inquiry into the issue of hate speech against the Autistic community either by the Human Rights Commission or by a Parliamentary Committee. This Committee could in fact take it into account. The ideal solution would be the insertion of a section to the DDA that is similar in function to that of Section 18C of the Racial Discrimination Act. Social media has at times been extremely nasty to the Autistic community – for instance the comments made about Greta Thunberg's Autism status by the likes of Andrew Bolt and more recently Rush Limbaugh. This cannot continue.

Spectrum Labor opposes provisions within the Religious Discrimination Bills which would allow colleagues, supervisors, medical or educational professionals to voice similar antiquated faith-based theories about Autism, eg that a child's Autism is a divine trial, a sin, a result of demon possession or a punishment for parents' sins. These views would shame and harass parents and may turn some parents away from early interventions and education in favour of faith healing, quack cures and exorcisms. We also oppose those provisions that would allow religious worshippers to shame Autistic women into stereotypically feminine behaviour, which is contrary to their inborn attributes. Spectrum Labor stands in solidarity with LGBTIQ Autistics who would be harmed by religious opposition to same sex marriage.

*Spectrum Labor: Submission to the Select Committee on Autism
Inquiry into the services, support and life outcomes of the Autistic community*

PART N
Any other related matters

Spectrum Labor advocates that Applied Behavioural Analysis (ABA) therapies be focused around meeting the actual needs of the child rather than making a child behave in a conformist way. Many ABA regimes are aversive in nature and there is no evidence to show that it is in any way beneficial. In fact it can be argued that it is actually detrimental and can worsen an Autistic's mental health. Such techniques should be discouraged at best and at worst banned altogether.

Also, the use of Miracle Mineral Solution (MMS) in Autistics has to be banned. MMS is nothing more than bleach which supposedly cures "Autism Worms." Doctors have repeatedly warned against this mistaken therapy and we regard feeding bleach to children as nothing short of child abuse which should be punishable by law. We are horrified that it took a sustained petitioning campaign to force Amazon to withdraw a best-selling book advocating this so-called treatment. We further fear that the Genesis II Church, which profits from MMS, could be given protections under any proposed Religious Discrimination Bills which would allow it to promote its products or dangerous interpretations of Autism as a religious right.