

Submission S077

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Family and Community Development Committee



Submission to the Inquiry into Autism Services and Support

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About the submission

The submission is a joint initiative prepared on behalf of Distinctive Options, The Lab Network and Smart Communities. All three organisations are Not for Profit based and all have a priority focus on supporting either/and children, young people and adults with Autism and challenging behaviours.

The author of the submission, Murray Dawson-Smith has been employed in the Community sector for over 35 years and employed in the Disability sector for the past 15 years. The roles he has held include Executive Officer of VICRAID, the peak body that represented Disability Residential Service providers of Community Residential Units until merging with NDS. During this period Murray was one of the authors of the Disability Services Standards which were the precursor to the current Department of Human Services Standards.

Murray has also held a number of other senior positions in the sector including Executive Officer of Active Property Services Management (APSM) now known as Active Community Housing which is a specialist provider of accommodation to individuals with a disability. The organisation achieved registration as a Housing Provider during the period of employment by Murray.

More recently Murray held the position of Chief Executive Officer of Amaze (formerly Autism Victoria) for 6 years from 2008 until 2014. During this period Murray oversaw the organisation become a Registered Training Provider (RTO) specialising in training to the sector (both government and not for profit) in the areas of Autism Spectrum Disorder (Autism), Managing Individuals with Behaviours of Concern (Autism) and Developing Communication Strategies (Autism).

During this period Amaze also entered into an agreement with DEECD for the provision of services and support to enhance the outcomes of students with Autism in schools. This support included the development of specialist Autism standards for education providers, developing and delivering a broad range of training and development modules and establishing an Autism content online learning tool to support teachers better assist the learning outcomes of students with Autism.

Murray also oversaw the organisation develop and offer specialist certification for organisations wishing to demonstrate competency in supporting individuals with Autism including early childhood services and adult services (the adult standards were authored by Murray). This certification model was further developed and Amaze achieved accreditation through JAS-ANZ as a registered certifying/auditing body for the current Department of Human Services Standards.

The author currently holds a number of critical leadership positions including the position of Chief Executive Officer of Distinctive Options, a service providing Day Service programs, after school programs in Special School settings, outreach services and supports with a focus particularly on individuals with Autism and more challenging behaviours. The author also holds the position of Chair of The Lab Network board which provides oversight and administrative support to local Labs providing opportunities for young people with Autism to actively engage in social skills development built around their interest in programming and computers.

Murray also holds the position of Executive Director of Smart Communities, a Not for Profit organisation providing Arts based programs for young people and children with Autism as a vehicle for social skill development.

This submission would not have been possible without the input and support from a number of other people including Mr. Paul Staubli, Ms. Melissa Webster and Ms. Sandra Martin who all contributed information and advice to enhance the quality and content of the submission.

Executive Summary

Autism Spectrum Disorder (ASD) is a developmental condition which affects individuals in two main areas. They will have impaired communication and social interaction skills and may have restricted, repetitive patterns of behaviour, interest or activities. As a result individuals with Autism may have difficulties interacting with others and may find the world to be a confusing place. The difficulty in communicating can result in 'melt downs'.

The term Autism Spectrum Disorder (ASD) reflects the fact that no two people with ASD are alike. Even though each individual with ASD has difficulties in the areas of communication, socialisation and flexibility of thought, each has a unique combination of characteristics and so may seem quite different.

Over the past 15 years there has been a significant increase in the number of individuals being diagnosed with Autism. Current rates are stated as approximately 1:100, although more recently there is an emerging view the rates are more in line with 1:50 and even this is being disputed by many experts who suggest current assessment tools have a gender bias and the rate is more likely 1:30 and the gender mix closer to 2:1 male to female than the current ratio of 4:1 male to female. This rate (1:30) is also supported by much of the data being collected through the "Helping Children With Autism" package.

In this submission there are a number of suggestions as to why this rate of diagnosis has come about and whatever argument, whether it be better diagnostic tools or reclassifying disabilities that one subscribes to, the end result is more and more individuals are presenting with Autism and seeking both direct and indirect support.

The support demand includes advocacy, provision of training to professionals, access to early diagnosis, support to attend an appropriately skilled and supportive school, to transition into employment and higher education and/or to access appropriate disability support services who are capable of meeting the supports needs to achieve quality of life outcomes. More generally there is also the ongoing demand for appropriate and specific housing options beyond the current shared accommodation model of 4-5 residents in large group homes.

There are major challenges facing Government at both State and Federal levels if the quality of life outcomes aspired to can be met.

Expensive and/or hard to access diagnostic services limit the capacity of families to determine a clear diagnosis and then to access early intervention services even though it has been evidenced based that early intervention will save significant support costs over the life of the individual.

Likewise when children enter the school system there are enormous barriers to successful outcomes both within the context of academic success but also within the context of social integration. Families consistently report children being bullied, socially isolated from their peers, frustrated with academic learning models, disengaging from school, parent disconnection from the broader school community and in some cases lack of empathy and understanding from school staff and senior school leaders.

The failure of the State education system to demand more extensive teaching training in teaching individuals with a disability and in particular Autism, or to require a minimum of one student placement in a special school adds to the challenges for teachers in being able to meet the expectation of students and families leading many students to disengage or families to change schools or undertake in-home schooling.

The challenges facing this group of individuals continues beyond school with transitioning from school to higher education and/or employment sector often lacking the understanding or capacity to meet the support needs of the ASD individual. The ongoing inability of the system to meet these demands is compounded by a lack of training or understanding of staff in the employment arena that could have a major beneficial impact on the engagement of individuals on the spectrum with successful outcomes in paid employment.

Not only does this have an economic impact through loss of wages and the capacity of industry to perform at the optimum level but also directly impacts on the self-respect, esteem, financial independence and life choices of people with Autism and in many instances their families.

A significant number of adults in the support service system whether in one to one support or the group models including Shared Supported Accommodation and Day Services are not able to access appropriately targeted support to achieve quality of life outcomes. Again the training of staff does not, in most certificate courses, include Autism as a core unit and as a result successful outcomes for this group of individuals is by accident or simply through the experiential learning of staff rather than by design.

In effect, as a result of poor skills and practices by staff, service users are often experiencing distress, anxiety, sensitivity overloads and in response may exhibit inappropriate behaviours including aggression, absconding or other unacceptable responses. These behaviours may lead to influencing other service users to also exhibit difficult behaviours, increasing staff work cover claims and increased costs to service providers. Likewise staff may become disillusioned with the industry and/or have negative experiences and due to this lack of training, knowledge and skills staff are unnecessarily lost to the sector or worst still develop poor practice models that simply compound and continue the distress for service users.

The demand, therefore, for quality practices to be implemented and monitored on a continuous basis, are critical if services are going to effectively meet the needs of service users.

Raising a child on the spectrum can be a significant challenge for families and can place enormous pressure on the family unit and in particular the relationship between parents. This is often compounded by the experience families have of the support system from early intervention services through to the school experience then attempting to locate an appropriate adult support model for their child. Adding additional levels of stress many families become isolated from the extended family and lack even the most rudimentary of support networks.

The result can lead to many families disintegrating in response to the pressures they experience. The need to ensure family support in all its forms from respite through to advocacy and ongoing training of support staff are critical to maintaining the family unit.

It is certainly anticipated by participants and families the NDIA will deliver on the promises made to individuals and families however there will be an ongoing need for some support and actions to be implemented by the State Government if outcomes for individuals with Autism are going to result in enhanced quality of life outcomes. The recommendations below have been developed with a clear understanding of both the economic and political costs of this enhanced support submission

In total there are 32 recommendations the bulk of which are either cost neutral or have no up-front cost to Government but rather require political will only for implementation. Where costings for recommendations can be calculated is estimated these recommendations would cost the State \$5.56 Mil. in year 1 and reduce to \$2.25 Mil. in future years. A very small number have not been costed and these will require additional work to determine the financial implication of adoption. It should be stressed these figures are estimates only and although the writer believes they are reasonably accurate they should not be taken as givens without a due diligence process.

SUMMARY AND COSTINGS OF RECOMMENDATIONS

Recommendation 1: That government provide research funds to support an empirical data search to determine an accurate diagnostic rate.

Cost: \$60,000

Recommendation 2: That all hospitals undertake a review of current practice and consider the development of specific treatment areas that can be developed and designed, recognising and accommodating the needs of individuals with Autism when requiring hospitalisation.

Cost: \$1.5 Mil to create autism sensitive wards for 2 patients in 15 Metropolitan Hospitals. Hospitals include The Alfred, Austin, Box Hill, Dental, Royal Melbourne, Mercy, Monash, PANCH, Frankston, Peter Mac, Queen Elizabeth, Royal Children's, Royal Women's, Royal Victorian Eye and Ear and Western Hospitals.

Cost: \$1.5 Mil to create autism sensitive wards for 2 patients in 15 Regional Hospitals - locations to be determined.

Recommendation 3: That health education courses including for medicine, nursing and allied health provide specific and specialist training and support to staff in how to support individuals with Autism when attending hospital for treatments.

Cost: No cost. Incorporate the criteria for employment and thus an obligation on the educational organisation to meet

Recommendation 4: That certification for hospitals to include a core standard that requires hospitals to develop and demonstrate appropriate support regimes for individuals with Autism and other disabilities both in terms of the built environment and demonstrated health care practice.

Cost: No Cost. Include in certification/audit tool

Recommendation 5: That government increase funding for assessment and diagnosis to ensure access to assessment and diagnostic teams is a maximum of 3 months wait time.

Cost: To be determined on the basis of the outcome of Recommendation 1 above. Anticipating approximately \$250,000 per annum

Recommendation 6: That the Education Department include criteria for employment in the State system all new graduates must have a minimum of 120 hours of formal instruction in the teaching of students with a disability including Autism.

Cost: No cost. Include as criteria for employment and obligation on educational organisation to support employment of students upon graduation.

Recommendation 7: That criteria for employment in the State school system should also include a minimum of one teaching round being within the special school setting..

Cost: No cost. Include as criteria for employment and potentially this may provide greater resources for all special schools when hosting teaching rounds.

Recommendation 8: That a key performance indicator for the annual performance appraisal of school principals to be a demonstrated commitment to the ongoing development of an inclusive school community.

Cost: No cost. Include requirement in the annual KPI as one more indicator for performance based bonus payment

Recommendation 9: That a minimum of one school based professional development day per year focus on the development of teacher practice in supporting and teaching students with a disability (including autism).

Cost: No cost. A directive by the Department to insist on the training day only is required.

Recommendation 10: That all schools, as part of an annual reporting framework, to provide a report documenting actions taken during the reporting period to support a continuous improvement strategy highlighting initiatives and inclusive education outcomes. (These actions may include professional development, curriculum initiatives, specialist support etc.)

Cost: No cost. To form a key part of the Principal KPI reporting process

Recommendation 11: That Government undertake a review of the current guidelines for eligibility to the Program for students with a disability and ensure the guidelines do not discriminate against students with Autism.

Cost: To be determined.

Recommendation 12: That funding under the PSD criteria be expanded to allow students to access PSD funding to utilise the teacher's aide during recess periods to address issues of bullying.

Cost: No cost. Funding package to remain but use to be varied.

Recommendation 13: That all Certified courses in disability studies must include compulsory units in supporting individuals with Autism Spectrum Disorders, strength based practices and managing challenging behaviours.

Cost: No cost. This requires only agreement with ASQA to include Autism in the course as essential.

Recommendation 14: That DHHS review and amend standards to ensure in excess of 50% of the audit and certification process is based on practice.

Cost: No cost. This requires only a change in emphasis on certification process and a simple rewrite of standards.

Recommendation 15: That all members of the auditing team to have formal qualifications and/or industry knowledge to identify best practice support models for individuals with Autism.

Cost: No cost. This demand becomes a standard part of the qualifications for certifiers and contracts are dependent on compliance.

Recommendation 16: That DHHS review the current standards and ensure a core component relates to demonstrating practice competence in supporting individuals with Autism.

Cost: No cost. This requires only a revision of the standards to include Autism as a key reportable standard. (This has already been developed by Amaze)

Recommendation 17: That State Government transfer ownership of public housing to the community housing sector to support the capacity of the sector to access development loans to undertake residential/public housing developments.

Cost: The cost to Government is primarily to the State balance sheet as the housing assets are transferred to the housing sector. It should be noted however this will potentially lead to significant growth in accessible public housing and reduce pressure on the State to meet this funding need

Recommendation 18: That Government legislate for all large housing developments to include a component of public housing including housing for individuals with a disability.

Cost: No cost. This is a legislative action only

Recommendation 19: That Government establish a loan facility to provide loan funds to individuals with a disability and/or their families to enable the purchase of property to house individuals with a disability.

Cost: This would be based on determining need and undertaking a cost analysis. It may be possible to mirror the proposed NDIA scheme at a smaller scale for Victoria only. It should also be noted this is a loan model and as such is expected to be cost neutral

Recommendation 20: That Government policy with regards placement of individuals with a disability in SSA be modified to support a more dynamic mix of residents in every home.

Cost: No cost. This requires a change in practice only.

Recommendation 21: That Government require service providers to consider a range of options for residents during the week to support more stimulating relationships within the group home model as alternatives to the Day Service or group support model.

Cost: No cost. Rethink on the use of ISP funding to support an in home community connections staff person rather than residents attending at an external day support provider

Recommendation 22: That coach accreditation training to include a core component in supporting and engaging individuals with Autism in sport.

Cost: No cost. To be built into current curriculum content

Recommendation 23: That Government fund a campaign to encourage individuals with Autism to become more active in the arts and sporting participation (include highlighting current individuals in the arts and sport).

Cost: An annual cost of \$500,000, it is anticipated this initiative would be run in conjunction with the coach accreditation training and include a range of media strategies.

Recommendation 24: That Government support the transition to employment through the funding of Autism specific employment readiness training.

Cost: No cost. The training of staff and the ability to demonstrate staff competent in supporting individuals with Autism to be part of the certification process for employment services.

Recommendation 25: That Certification of employment services to include demonstrated knowledge of and ability to support candidates with Autism to access employment.

Cost: See recommendation 23 above

Recommendation 26: That Government provide small scale funding grants to employers to support the transition and ongoing engagement of employees with Autism. Funding to support employer organisations recruit and retain mentors and to educate existing staff.

Cost: No cost. Costs would be based on a per employee basis and capped at \$3,000 per employee. It should be noted this could/should be a cost met by the Commonwealth as they have responsibility for employment.

Recommendation 27: That Government provide funding for 3 years to support the establishment of alternative employment models to support and encourage the engagement of individuals with Autism in the workforce.

Cost: \$1.5Mil. per year for 3 years

Recommendation 28: That State government undertake a need's based study to determine the support needs in terms of staff for a fully functioning NDIA support system.

Cost: \$250,000

Recommendation 29: That the State retain and oversee the auditing and certification role of organisations providing service and support in Victoria.

Cost: No additional costs as organisations are currently certified by DHHS

Recommendation 30: That the State monitor the funding models implemented by the NDIA to support the current funding levels and to ensure where possible service users are not disadvantaged.

Cost: No cost. State government to establish a small monitoring group including service providers (2), government representatives (2) and individuals or families (2) to monitor NDIA outcomes.

Recommendation 31: That the State to encourage the NDIA to fund at appropriate levels the full range of secondary supports including:

- Advocacy (All forms)
- Training
- Community Education
- Episodic support

Cost: Further to Recommendation 30 above the working party to provide advice and monitoring of the system to identify gaps in service delivery and recommend to NDIA possible options for consideration and adoption.

Recommendation 32: That the State support the NDIA to recognise the proposed insurance principles be viewed within a whole of life model and with a sequential and developmental model based on a life-long and pervasive disability that may change over time but will always be present.

Cost: No cost. This requires only the State to advocate to the NDIA to recognise and acknowledge the importance of understanding as part of the funding and developmental goals.

The prevalence of Autism Spectrum Disorders in Victoria.

Over the past 15 years there has been an acknowledged and reported increase in the number of people diagnosed with Autism. In 2002 a Latrobe University study reported the incidence of Autism was 27 individuals per 10,000 (1:370). By 2008 the international rate was presented as 63 individuals per 10,000 (1:160) and by 2015 in an article in The Australian newspaper Professor Cheryl Dissanayake of the Latrobe University Olga Tennyson Autism research Centre is quoted as stating the rate was now 200 individuals per 10,000 (1:50).

The growth of these figures has been put down to a number of factors including better diagnostic skills and tools, greater awareness and understanding of the characteristics of Autism by professionals and the belief that as awareness of Autism has grown so has the tendency to reclassify intellectual and development disabilities as Autism. The trend to re-classify has been supported by a Penn State University research project showing as Autism diagnostic rates increased the diagnostic rates of other disabilities declined.

Whether these studies do show rates increasing through greater awareness, better diagnostic skills and tools and/or the tendency to reclassify there are some figures that cannot be disputed within the context of planning for service delivery.

There is now a wealth of data related to diagnostic rates of Autism in children aged 0-6 years as a result of the Commonwealth funded "Helping Children with Autism" initiative. Rates of diagnosis in Victoria up to 2014 were in the order of 2,400 children per year with a birth rate of approximately 81,000 per annum. Given this was the rate for a number of years it suggests the rates of diagnosis as presented by Prof. Dissanayake of Latrobe University as 1:50 individuals may well be an under representative number and a rate of Autism in the range of 1:33 is more accurate.

Likewise data from the NDIA indicates approximately 31% of all packages are for individuals with a primary diagnosis of Autism. A further cohort of approximately 18% of all packages are for Intellectual Disability with up to 50% of this cohort having a dual diagnosis of Intellectual Disability and Autism and it therefore suggests the real rate to be in the order of 40% of all NDIA packages are supporting individuals with either a primary or secondary diagnosis of Autism.

During the author's tenure at Amaze there were also a significant number of requests from Mental Health providers and the Out of Home care sector to assist with training and raising awareness of Autism as they were reporting anecdotally many individuals seeking mental health support and/or accessing the Out of Home system were also presenting with behaviours associated with Autism but without any formal diagnosis.

Further compounding the challenge of service provision and the challenge of determining accurate prevalence rates is the belief among many researchers the male to female ration of 4 male to 1 female is not a true reflection of the female rates of Autism. A number of research projects have concluded current assessment tools have a gender bias and the subtle nature of Autism in girls is not being recognised through the assessment process. Professor Tony Atwood, a world acknowledged expert in Autism, is quoted as saying he believed a more accurate rate of male to female diagnosis was in the order of 2.5 male to 1 female.

A further study in Sweden has suggested the real rates are more in line with a 1:1 ratio.

Whether the rates of Autism are 2:1 or greater what is indisputable is the enormous increase in diagnostic rates over the past 15 years and the challenge this raises and presents for the ability of governments and service providers to meet the needs of this complex and challenging cohort of individuals.

Although this inquiry is looking specifically at the needs of the Autism community it is also certainly true to say many of the recommendations in this submission could/would be equally relevant and appropriate in providing support to individuals with cognitive and intellectual disabilities. To this end then the need for appropriately qualified and competent staff and an aware and knowledgeable support system to be effective for individuals with Autism is equally critical in supporting a range of other individuals with complex and challenging support needs.

Recommendation 1: That government provide research funds to support an empirical data search to determine an accurate diagnostic rate.

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

With the introduction of the NDIA it is anticipated the number of individuals eligible for support in Victoria will be in the order of 110,000 individuals. This is very significant increase on the current number of people seeking access to a support structure either in the form of direct one to one support, through group supports such as the Day Service models or with the acquisition of aids and equipment.

Whatever form the request for support takes it will be essential the system has sufficient skilled and competent people to not only ensure the support needs of individuals is met in pure “hands on” terms but will also see the need for the sector to employ sufficient people with appropriate skills.

In the Victoria context a number of facts are known.

We know that:

1. approximately 40% of all NDIA packages are going to support individuals with Autism in response to a primary or secondary diagnosis of Autism.
2. in total, approximately 110,000 will be eligible for some level of support
3. given 40% of all packages will need specialist Autism support if they are to achieve their potential this suggests up to approximately 44,000 individuals will need some level of support and/or advice from staff knowledgeable in Autism
4. a significant number of individuals with Autism (high functioning) will not meet the eligibility criteria for NDIA individual packages but will nevertheless need some level of engagement with the support system
5. The mental health, out of home care and justice (prisons) system have all requested professional development support to effectively manage high numbers of undiagnosed ASD individuals.
6. a significant cohort of Autism individuals will need episodic support at various times throughout their lives (examples of episodic support could include simple work place advocacy through to periods of respite or one to one support to manage “one-off” events)
7. the risk of family breakdown among families with and without children on the spectrum are similar until children reach adolescence and is then considerably higher for families with one or more family members with Autism thus the need for extended family support to this cohort will need to be developed and provided.
8. if work options and outcomes for individuals on the spectrum are to be optimised then additional resourcing will need to be committed to practical skill development while workplaces will need support to ensure placements achieve long term employment success.

9. relationship support and guidance where one or more parents are on the spectrum is critical to ensuring families not only remain intact but that healthy relationships are developed and maintained.

The question then is if the level of support demand is in line with the figures and “knowns” above “Does the current support system across the various branches of government have the capacity to adequately support individuals and families?”

Health Services.

Experience of the Health system suggests it is lacking the necessary knowledge, skills, structures and support to be able to meet the needs of the Autism community. The author is regularly advised of failings by the health system to understand many of the practice issues that could better support the Autism community.

“A woman in her mid-thirties was admitted to hospital for treatment for a medical condition that required a 3 week stay in hospital. The patient had behaviours of concern and in response the hospital took the decision to restrain the patient by the use of physical restraints for the period of her stay in hospital. As a result the individual returned to the disability support system with extreme levels of behaviour due to this hospital experience”.

There are a number of lessons that can be taken from this experience and to learn from in this story, including clear failures by the support staff in the disability service in that they failed to transition and inform the individual with regards the processes they would experience in attending Hospital. There was also a critical failure by the health system to understand autism and the impact the restraint would have on the patient and a further failure by the health system to ensure this individual had the level of support in hospital that may have made the hospital stay less traumatic and reduced the need for any form of restraint.

This example is not intended as an opportunity to attack the system but rather to highlight the inadequacy of the current system to meet the needs of complex individuals.

Recommendation 2: That all hospitals undertake a review of current practice and consider the development of specific treatment areas that can be developed and designed, recognising and accommodating the needs of individuals with Autism when requiring hospitalisation.

Recommendation 3: That health education courses including for medicine, nursing and allied health provide specific and specialist training and support to staff in how to support individuals with Autism when attending hospital for treatments.

Recommendation 4: That certification for hospitals to include a core standard that requires hospitals to develop and demonstrate appropriate support regimes for individuals with Autism and other disabilities both in terms of the built environment and demonstrated health care practice.

Assessment and Diagnostic Services

It is the experience of the author of this submission it is obvious to most parent's when their child has a developmental disability. While many other parents inherently know or will suspect that something is perhaps not behaviourally quite appropriate with their child at a very early age. This knowledge or suspicion may be reinforced by the local childcare service, maternal and child health provider or perhaps in the early years of schooling.

In all cases there is a desire to have the questions answered but this is too often tempered by the lack of accessible assessment services (both locational and time) and/or the high cost of assessment for families.

Current data clearly demonstrates families who wish to access government funded services can wait for unacceptably long periods (particularly in rural and regional locations) and/or are facing considerable costs if choosing to fund assessments from private sector providers.

There is a raft of evidence and many anecdotal stories of families waiting up to 12 months and longer to be able to access formal assessment. The length of wait can have a major impact on the health and well-being of families as they seek and wait for an assessment to be undertaken.

Given current research clearly demonstrates best practice interventions recognise the earlier intervention can begin the greater the outcomes for the individual and by extension the less funded supports are required into the future it can be very strongly argued an investment in resourcing additional assessment and diagnostic teams will have a long term benefit to the individual, their family and the support system.

These benefits include skills development of the individual, enhancing quality of life outcomes for the individual and their family and reducing the long term support costs to the individual.

Recommendation 5: That government increase funding for assessment and diagnosis to ensure access to assessment and diagnostic teams is a maximum of 3 months wait time.

Education Services.

There have been a number of inquiries by various State and Commonwealth Departments and agencies including a NSW Parliamentary Inquiry in 2010, Senate Inquiry in 2015 and a comprehensive inquiry by the Victorian Equal Opportunity and Human Rights Commission in 2013 all of which focused on the experience of children with a disability and the education system.

The Victorian Government also announced a review of the Program for Students with a Disability in 2015.

In all instances the input by parents and students with Autism paints a fairly depressing picture for many of these students.

It should be noted from the outset the author acknowledges there are schools in Victoria performing well and have enthusiastically and positively embraced the need to support the Autism student community and are achieving some exceptional outcomes. The Education Department should also be commended for undertaking a number of initiatives to address the concerns of families including the development of on-line learning opportunities, funding teachers to attend a range of professional development courses, funding Amaze to undertake a partnership with a small number of schools to review current practice and to develop a more professional approach to support of students with Autism.

The Department also funded and conducted a pilot program for schools to develop inclusive practices for the Autism school community and the results in a number of schools was very impressive and could well prove to be a good model for long term support.

Having said that it should also be acknowledged a large number of schools are not achieving the outcomes that families and individuals would expect. There are many stories of students being inappropriately restrained both in purpose built settings and by the use of physical restraint.

“Parents of a primary aged student reported their child had been restrained by the Deputy Principal of their school and forced to remain in a locked room for approximately 5 hours. When the parents attended at school their child had soiled their clothes and refused to return to the school environment. The parents made the decision to home school their child to avoid further stress on their child”

Likewise many parents have reported their child was not supported appropriately and they were forced to leave the local school either as a result of conscious or sub-conscious acts by senior school staff.

In many instances parents report these schools had clearly made the decision they were unable to provide the appropriate level of support and thus advised and requested parents remove their child from the school. Whilst in other instances parents report the school received the Program for Students with a Disability (PSD) funding on the basis of their child’s support needs only to see the school use the funds for more generic purposes and their child not receive the direct support they required for a successful school experience.

During the period the author was CEO of Amaze there were many requests from schools across Victoria seeking professional development for staff and in many instances more focused advice with regards a particular student/teacher requesting specific advice. Clearly, there is enormous goodwill and willingness by many teachers to understand Autism and a real willingness to develop the knowledge and skills to more effectively support this group of students. This presents a great opportunity to enhance outcomes for students with Autism in the State school system.

During this same period and as part of the inquiry by the Victorian Equal Opportunity and Human Rights Commission, Amaze was also asked to review approximately 110 Individual Education Plans prepared by various schools.

The author of this submission undertook the review and in all but 3 plans the engagement of students in both the preparation and planning process was missing and the expectation by schools of parent engagement and active home based strategies was also missing. In effect the schools were often holding meetings without any real engagement of the very people who had the most stake in the planning process – the students and their parents. This approach flies in the face of the need to engage students and families to support choice, control and empowerment.

Further compounding the issues confronting students with Autism has been the implementation of the Program for Students with a Disability (PSD) and the narrow criteria for access to the funding supports provided by the program.

A key criteria for access to support funding is the assessment of students in both receptive and expressive language skills. This requires potential students undertaking language testing measuring both expressive and receptive language skills and then averaging the outcome. This has led to many students who require support being ineligible due to their high rating for expressive language skills comparative to their poor receptive language skills. In essence students with Autism may have an extensive vocabulary and can demonstrate high level oral competency but lack the receptive language skills necessary to function well in a learning environment.

Further impacting on the experience of students with Autism in mainstream schools is the high level of bullying they often encounter. Autistic students can exhibit behaviours that are different from the mainstream school population and this can result in students with Autism experiencing high levels of bullying by other students. These differences range from obsessive interests in a narrow range of topics through to a lack of understanding of the social rules of the school.

“A 12 year old student was interviewed by the police after a parent complained their child had been sexually assaulted by the student with Autism. The child explained that other boys in the class had encouraged the behaviour and he had no insight or understanding the behaviour would be considered sexual”

“A 15 year female student was told by her school friends when you like a boy it is acceptable to send sexualised texts including explicit photos to an older student if you like them. She was subject to ridicule after sending messages to a student in year 12 because she didn’t understand that these actions happen once a relationship was established rather than simply because a boy had said hello. There was a complete lack of understanding by the 15 year old student of the rules and expectations of female/male relationships.”

The result of these experiences has seen a large number of students with Autism disengage from the school experience and either leave school and become housebound or as critically, engage in behaviours to achieve peer acceptance that will often result in these individuals entering into the justice system either through the courts or into the “Out of Home Care” system as parents struggle to manage the young person’s behaviours.

Clearly the impact of this situation is the total disengagement of young people in employment in one set of circumstances and/or alternatively engagement with the justice system and the consequent long term costs of incarceration. In both instances this has a major cost implication for State Government.

The experience then for teachers, parents, students and the broader school community have varied enormously from school to school. Schools with the most encouraging outcomes are those schools with a real commitment to ensuring the whole school community is part of the solution. In effect the schools doing best are those where the lead is being driven by the school principal, staff, school council, parents and students.

It is important to also note Governments of both political persuasions have had a long standing commitment to creating inclusive schools and a policy position endorsing this approach. Internal documents prepared by Government include “The Blueprint for Government Schools” and more recently “Inclusive Schools are Effective Schools”. This policy position has been supported by a number of programs and other initiatives funded by the department of Education and Early Childhood Development as cited earlier.

However it is fair to say success has been piecemeal to say the least and is very much dependent on the commitment by the school and in particular the principal as the driving force for practice and culture change.

Where the principal and school community have been supportive through pro-active actions including professional development support for staff, reported outcomes have, in many cases, been remarkable. On the other hand where the commitment of the principal has been less than 100% and where the school community has not been brought into the journey students with Autism have had far more negative outcomes.

It is the contention of this submission that if schools are to achieve the goal of inclusion and it should be noted the research shows all students including neuro-typical students benefit from a diverse school population then cost effective strategies should/could be adopted.

It is important to also note that Inclusive Schooling comes with a range of other challenges and a recent paper *“Inclusive Education in Australia: rhetoric, reality and the road ahead”* authored by Johanna Anderson and Christopher Boyle (April 2015) provides a good overview of not only the current status of inclusive schooling but also highlights the potential risks and provides a guide for future action.

Recommendation 6: That the Education Department include criteria for employment in the State system all new graduates must have a minimum of 120 hours of formal instruction in the teaching of students with a disability including Autism.

- Recommendation 7:** That criteria for employment in the State school system should also include a minimum of one teaching round being within the special school setting.
- Recommendation 8:** That a key performance indicator for the annual performance appraisal of school principals to be a demonstrated commitment to the ongoing development of an inclusive school community.
- Recommendation 9:** That a minimum of one school based professional development day per year focus on the development of teacher practice in supporting and teaching students with a disability (including autism).
- Recommendation 10:** That all schools, as part of an annual reporting framework, to provide a report documenting actions taken during the reporting period to support a continuous improvement strategy highlighting initiatives and inclusive education outcomes. (These actions may include professional development, curriculum initiatives, specialist support etc.)
- Recommendation 11:** That Government undertake a review of the current guidelines for eligibility to the Program for students with a disability and ensure the guidelines do not discriminate against students with Autism.
- Recommendation 12:** That funding under the PSD criteria be expanded to allow students to access PSD funding to utilise the teacher's aide during recess periods to address issues of bullying..

Disability Services

Much has been written about the Disability sector over the past few years with a number of inquiries and research projects being undertaken to take a closer look at the capacity of the disability sector to manage the level and complexity of individuals seeking support.

Additional inquiries have been held into the experience of individuals accessing support and the levels of abuse and neglect these individuals may experience. This is the first inquiry looking specifically at the issues of service and supports to a cohort of individuals with either a primary or secondary diagnosis of Autism and Government should be commended for undertaking this inquiry.

The historic change of policy by government to move from institutional care to community support and inclusion has obviously seen a massive shift of service provision from large institutional models to smaller and more discreet services through the Shared Support Accommodation model along with the growth in Day Services and more recently again with the introduction of Individualised packages of support leading to a major increase in the number of one to one support packages.

The goals of de-institutionalisation were to create opportunities for individuals with a disability to access their community through the provision of local housing stock and through this localisation of living it was anticipated individuals with a disability would become part of their local community.

In reality many of these “community housing options” have led to the creation of mini institutions with staff determining who and when residents can leave the house, who and when visitors can attend and household decisions made by support staff rather than residents. Rather than creating homes in which support people come in to provide services in response to requests by residents the reality is these are structured work places in which staff needs dominate and take priority whilst residents needs run a poor second.

The notion of more individualised service supports will be accelerated via the NDIA and this suggests the service system will need to be more conscious of and competent in the support of all individuals with a disability and particularly the ability to support individuals with Autism. This change to a stronger individualised funding model will hopefully see the service system become more accountable and market driven although to date the outcomes of the trial sites suggests in the main current service providers remain the primary provider of support with little demand to become more innovative with their service provision.

Given the statistics from the NDIA are clearly identifying some 31% of all packages are for individuals with a primary diagnosis of Autism and a further 9% may have a secondary diagnosis clearly then the sector will need to be highly competent and knowledgeable with regards the support needs of individuals with Autism.

The current key qualification for employment in the disability sector is the acquisition and achievement of Cert. 1V in Disability Studies and it is noted that under the NDIA this may be reduced to Cert. 11 for determining unit pricing.

In many cases these courses are not equipping emerging staff for the challenges they will face in the sector as very few have a compulsory unit on Autism Spectrum Disorders. Distinctive Options have made the decision that even when staff are employed with experience and the Cert. 1V qualification they will be required, as part of the induction process, to undertake an internal session on basic Autism knowledge as well as the need to undertake a session focusing on strength based practices.

It is the experience of Distinctive Options that without the basic skill sets specific to Autism many staff are ill equipped to work actively and positively with individuals with Autism.

Recommendation13: That all Certified courses in disability studies must include compulsory units in supporting individuals with Autism Spectrum Disorders, strength based practices and managing challenging behaviours.

Further challenging the sector at an organisational level is the current certification process including both ISO 9001 and the DHHS Standards.

The concerns with the certification process are two fold and relate to both the measurable standards and the capacity and knowledge of the certification teams to observe and determine good or poor practice.

The ISO 9001 standards are primarily concerned with documentation and do not in themselves have any bearing on the day to day practice of the service under review. The experience of Distinctive Options has been of a certification process that is driven by the quality of the organisation's policies, procedures and forms as well as the updating of records that demonstrate regular review and continuous improvement processes. It appears that somehow this is then taken as a demonstration of good practice.

It could be strongly argued this has little bearing on the capacity or more importantly the competency of an organisation to provide quality support and rather is more concerned with risk management than service provision. It is recognised that risk management is important but this should not be at the expense of diverting resources from practice to remain certified.

In 2014 a Latrobe University study by Jade McEwen, Prof. Chris Bigby and Jacinta Douglas examined the DHHS standards and concluded that 81% required a written response or supporting document whilst 19% required interviews of staff, service users and families and observation of practice.

Given ISO 9001 is primarily concerned with the production of policies etc. and the DHHS standards are also more concerned with documentation than active consideration of practice it is hardly surprising that no service to the knowledge of the author has lost its funding due to their practices not meeting the standards.

It is equally of concern that even where certification auditors do observe practice it is highly questionable if they possess the necessary competence to make a judgement on whether a service is of sufficient quality to meet the standards and in particular to assess competence in Autism practice.

It should also be noted current DHHS standards do not specifically require services to demonstrate either a knowledge surrounding Autism or practices that support best outcomes for this cohort even though the bulk of individuals in most services will have a diagnosis of Autism.

It is the experience of Distinctive Options that generally the process of certification whether ISO 9001 or the DHHS standards requires both Senior Management and in many cases staff to devote enormous time, energy and resources to demonstrate compliance via the production of documents when it is argued this resourcing would be better spent focusing on practice and demonstrating this to the certification team.

It is the contention of the author the certification process has resulted in the tail (policies and procedures) currently wagging the dog (practice) rather than the reverse which is not as it should be.

Recommendation 14: That DHHS review and amend standards to ensure in excess of 50% of the audit and certification process is based on practice.

Recommendation 15: That all members of the auditing team to have formal qualifications and/or industry knowledge to identify best practice support models for individuals with Autism.

Recommendation 16: That DHHS review the current standards and ensure a core component relates to demonstrating practice competence in supporting individuals with Autism.

Housing Options

The lack of housing options for individuals with a disability is a critical issue that has been identified and commented on for a number of years and appears to be occupying significant time in the NDIA with recent announcements suggesting some options may be opening up for people to achieve housing independence.

Much has also been written about the challenges of providing sufficient housing at an affordable price to support the notion of choice and independence. This research includes the "Inquiry into the Adequacy and Future Directions of Public Housing in Victoria" in 2010 and more recently the paper titled "A place I can proudly call home" produced by Every Australian Counts in 2015.

The development of a range of housing types and styles is going to be critical in meeting the specific needs of individuals with a disability including individuals with autism.

Current research has identified the optimum model for successful housing outcomes occurs when individuals live in one/two bedroom units either in a cluster setting or as part of a larger unit development. This model allows residents a high degree of independence and choice with regards both utilisation of the home and the opportunity to connect with other residents and the local community.

This model also enables residents to have visitors, guests who can stay overnight and/or longer and the option of having a pet for additional company. It also acknowledges the notion of home ownership/occupancy is intrinsically linked to an individual's sense of community and belonging and thus where ownership is vague or appears to be the domain of the service provider the sense of ownership and inclusion in the community by residents is diminished or more concerning non-existent.

The proposed optimum model above also encourages and supports the ongoing development of independent living skills and encourages and supports residents to make connections with their local community organisations such as libraries, sporting groups and other interest areas.

On the negative side there is a risk to individuals connecting with people who may attempt to take advantage of the resident and exploit their vulnerability for personal advantage. There are also potential personal safety issues as a result of these more independent models and risks of homelessness if the property is not adequately maintained, is damaged or rent and other bills are not being paid in a timely fashion.

A 21 year female living in a one bedroom unit was subject to a sexual assault and exploitation by "friends" including financial demands. As a result she was forced to access foodbank support for food and ultimately lost her unit due to a failure to meet her rental obligations and complaints by neighbours due to the behaviour of the young people attending at her unit.

It should be noted this experience is not unique to young people with autism nor is it unique to individuals with a disability however it does highlight the need for a successful tenancy to incorporate a support component and to recognise the need for ongoing skill development for successful housing outcomes.

Equally importantly, for individuals with Autism, is the need to support the development of their social skills and their interpersonal relationships to ensure as much as possible the establishing of positive social relationships and as a defence against the potential exploitation of these relationships.

It is also relevant to this inquiry to discuss the current shared supported accommodation (SSA) model and to highlight the challenges of this model and the current strategy of housing individuals with similar support demands in the one house.

At present the primary housing option apart from residing with family is within the SSA system and is often characterised by the residents attending the same day service. In effect the result of this model is that residents wake to a house full of people with a disability, travel by communal transport to a day service with people with a disability and participate in programs with individuals with a disability. Then at the end of the day travel by communal transport back to the place of residence with the same group of individuals they reside with.

In effect there is little or no contact with anyone other than other individuals with a disability and the support staff. This clearly raises significant concerns both in terms of the capacity of these individuals to have contact with people other than individuals with a disability and equally the desirability of presenting examples of appropriate behaviour when all contact is with individuals with similar behavioural profiles.

The question of providing individuals with new experiences including meeting new people clearly creates challenges for the service system and for ensuring the service can provide a challenging and stimulating environment.

The challenge then is for Government in partnership with the community housing sector and where possible the “for profit” housing development sector to be able to create significant growth in accessible and affordable housing to meet the shortfall in current housing demand.

This may demand of government the need to further develop the capacity of the community housing sector to enter into housing development based on loans against existing housing stock via the transfer of ownership from the Department to housing associations and providers and building in to the “for profit” sector a legislated requirement for all new developments to have a component of public housing included.

Recommendation 17: That State Government transfer ownership of public housing to the community housing sector to support the capacity of the sector to access development loans to undertake residential/public housing developments.

Recommendation 18: That Government legislate for all large housing developments to include a component of public housing including housing for individuals with a disability.

Recommendation 19: That Government establish a loan facility to provide loan funds to individuals with a disability and/or their families to enable the purchase of property to house individuals with a disability.

Recommendation 20: That Government policy with regards placement of individuals with a disability in SSA be modified to support a more dynamic mix of residents in every home

Recommendation 21: That Government require service providers to consider a range of options for residents during the week to support more stimulating relationships within the group home model as alternatives to the Day Service or group support model.

Sporting and other Recreational Opportunities.

There has been a long standing view that many individuals with Autism do not have an interest in the performing and creative arts or playing sport or engaging in team activities. This appears to have been based on the misconception that individuals with autism prefer to focus on special interests only and that these interests are primarily interests that are not active or creative activities but rather individualised and topic specific.

It is certainly true many individuals with Autism do engage in special interest activities others would consider passive and show little interest in more overt or physical or team based activities but there are a range of reasons for this situation.

It is equally true however that many individuals with Autism would be keen to access the performing and creative arts and/or play team and individual sports but are often reluctant to do so given the unique challenges inherent in these activities.

As with almost all activities people engage in there are both written and unwritten rules associated with any activity and for individuals with Autism this can be a key reason for not engaging. A key characteristic is a fear of failure or not being able to perform certain skills at a satisfactory level and the arts arena and sport, like any activity, require practice and patience to achieve satisfactory levels of success. When these levels of skill do not happen quickly or levels of performance are not achieved immediately this may lead to the autistic individual not engaging at all or to leave the activity in frustration or from a fear of failure.

Additionally there are many written and unwritten rules in most of these activities and this can be a major barrier to participation given the often complex written rules and subtlety of the unwritten rules. For individuals with Autism the frustration when colleagues, team-mates or opposition players break the written rules and are “not punished” by the umpire or coach can seem unfair and frustrating. Along with this frustration is the failure by some to follow the unwritten rules such as shaking hands after the game, mixing with the opposition post-match or not making critical comments about team-mates all of which can all lead to a withdrawal of support for and of the autistic player.

Clearly, as with education or employment the critical challenge to support engagement of individuals in the arts or sport is the capacity of directors/producers, coaches and team-mates to understand the impact Autism can have on team members and to ensure appropriate supports etc are in place. Again this requires a re-think on how we engage and encourage participation if the aim is to engage autistic individuals in the full range of arts and sports activities.

Recommendation 22: That coach accreditation training to include a core component in supporting and engaging individuals with Autism in sport.

Recommendation 23: That Government fund a campaign to encourage individuals with Autism to become more active in the arts and sporting participation (include highlighting current individuals in the arts and sport).

Employment outcomes

Statistically, employment outcomes for individuals with Autism are quite poor. ABS census data indicates in the order of 34% of individuals with Autism are employed compared to 54% for all other disability groups.

There would appear to be many reasons for this however in saying that it is clear there is a critical need to change these employment outcomes.

Employment provides an individual with a range of positive outcomes including but not limited to independence, self-esteem, identity, choice and control and realising potential.

Equally, from a purely economic point of view there is this massive pool of highly talented people whose skills and competencies are not currently being used. These people could make excellent employees if employers were only willing to give them a chance.

Numerous research studies have found that adults with Autism experience challenges in securing and sustaining competitive employment.

People with Autism are more likely to be un-employed (without a job), under-employed (in jobs that underutilise their knowledge, skills and experience) or 'mal-employed' (in jobs for which they are expressly unsuited / that people do not enjoy) than the population at large. (Baldwin, Costley, Warren, 2012)

Securing the right position presents further challenges for this cohort of job seekers with many challenges being identified including a lack of employment service and employer knowledge about Autism, including the support needs of people on the spectrum, a lack of relevant pre-employment training, including workplace social and communication skills and a difficulty for people on the spectrum to perform in a traditional interview situation - having difficulty 'thinking on their feet' in an interview situation

“MW graduated with a Master’s Degree but is unable to gain employment as the recruitment process from interpreting a job advertisement through to interview is overwhelmingly daunting. MW is unable to access DSP and unable to actively pursue employment via the current employment process”

Further compounding the challenges for successful employment are the ongoing issues for people in the workplace including the need to adjust to new procedures and routines, remembering and following complex instructions, responding flexibly to unexpected situations, communicating with colleagues, interacting socially and managing potential sensory sensitivities.

“JB is a qualified CPA and was recently dismissed from their position due to the claim they were in conflict with their manager. When leaving a number of female staff expressed relief knowing the person was leaving as they expressed concerns regarding his behaviour believing on many occasions his actions bordered on or even crossed the line into stalking. JB was very confused with these comments and could not understand why they were made. The lack of support and guidance led him to lose his job when with the right support this behaviour could have been addressed and stopped”

These examples highlight the importance of providing both pre and in employment training and support to individuals with Autism. The pre-employment training should consist of a number of elements including:

- Support in understanding the process of recruitment including an understanding of job advertising.
- Developing good communication skills to assist people to work effectively, build solid relationship and prevent misunderstanding. This could include the purpose of communication in the workplace, the importance of social conversations and casual relationship building
- It is also recognised that for many employees with Autism the unwritten rules can be daunting and lead to misunderstanding and loss of employment.

“HK was employed in a mid-sized organisation. He had booked the meeting room and at the booking time he went to the room and observed a meeting was being conducted. He asked the people in the ongoing meeting to please vacate as he had booked the room and it was time for his meeting. He also requested that they clean the room before leaving. After his meeting he was dismissed as he had interrupted the Board and “told them in no uncertain terms” that they should leave and take their rubbish”

Clearly the employee had no understanding that you do not interrupt your Board and tell them to stop their meeting and leave, making sure they remove all rubbish prior to vacating. From the employees perspective he had the right to ask the meeting to vacate as the room was booked for another meeting. However if he had been able to access a mentor or advisor before making his demands it is possible he would still be employed.

In both stories of **JB** and **HK** above it would be likely there was more than the one incident occurring in the workplace that led to their departure. In saying this it is equally true that had they been able to get good advice and support both leading up to and throughout their time in the workplace they may both have been able to transition effectively into employment and be gainfully employed still.

Further challenging the ongoing achievement of effective long term employment outcomes is the issue of work place bullying that many individuals on the spectrum both can experience or be accused of.

It is important to provide strategies for identifying bullying both as a victim but equally as a potential perpetrator of bullying. This requires employers to help people on the spectrum to recognise shouting and talking aggressively, spreading rumours, teasing, verbal abuse and physical abuse are all forms of bullying.

Workplace stress can impact on all employees at times during their employment and this is particularly true of employees with Autism. Again it is critical for successful employment outcomes that these employees are provided with the range of strategies and coping mechanisms to diminish the potential for stress to be an overwhelming experience.

Support in the pre-employment stage and then ongoing can create the right environment for success in the workplace. The support should be focusing on the strengths of the individual employee and these can best be described as potentially being high level academic skills, visual thinking, precise technical

competence, attention to detail and a range of personal strengths including honesty, efficiency, consistency, no interest in office politics and low absenteeism.

At the present time there is significant resistance to the employment of individuals with a disability and particularly the autistic workforce. This suggests the need to not only continue promoting the benefits of employing people with a disability including autism but equally it requires greater initiative and innovation in creating additional pathways into employment.

These alternative pathways should enable employees with Autism the opportunity to develop their understanding of the workplace, including the expectation of employers, the development of the social skills required for successful integration and the ongoing appreciation for the hidden rules of every workplace.

One such strategy may be the creation of an organisation that accepts work on an outsourcing model. The organisation is then able to employ individuals with Autism and to develop their workplace understandings whilst at the same time develop their skills and experience within a workplace that understands and supports their learning style.

The outsourcing model could then lead to the placement of autistic employee in mainstream positions once the employee had gained the necessary insight and understanding of the workplace to make the transition successful.

Recommendation 24: That Government support the transition to employment through the funding of Autism specific employment readiness training.

Recommendation 25: That Certification of employment services to include demonstrated knowledge of and ability to support candidates with Autism to access employment..

Recommendation 26: That Government provide small scale funding grants to employers to support the transition and ongoing engagement of employees with Autism. Funding to support employer organisations recruit and retain mentors and to educate existing staff.

Recommendation 27: That Government provide funding for 3 years to support the establishment of alternative employment models to support and encourage the engagement of individuals with Autism in the workforce.

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

The National Disability Insurance Scheme has been described by some as the greatest social change in the past 40 years. The introduction of the scheme promises to deliver a fundamental change to the way in which support is provided to people with a disability.

Not only is the aim to change the way service and support is provided but the scheme also proposes an enormous increase in the number of individuals able to access support services. These supports may be in the form of direct support through the engagement of staff and/or the purchase of aids and equipment or less obvious supports through the provision of advocacy, advice, training and community education etc.

Assuming the growth figures are accurate and the number of eligible participants with Autism will be in the vicinity of 40% of all recipients the question of sector capacity to support their needs is a critical question that to date has not been effectively answered by either the Commonwealth or the NDIA.

The current situation within Victoria recognises a major shortfall in support staff well trained and skilled in supporting individuals with more complex and difficult behaviours. The primary competency training of Cert IV, Disability Studies does not in the main have Autism as a core unit but rather as an elective and this will compound the challenges of the present and future for the meeting of support needs.

Perhaps of greater concern is the current funding envelope and the willingness of the NDIA to adequately fund the support needs of individuals with Autism. It appears from the outside the NDIA are keen to limit funding packages and although this may have benefits from a budget perspective it does raise concern regarding the capacity of services to provide the necessary support to achieve quality of life outcomes in the longer term.

Equally, the NDIA does not yet have a good sense of or response to the question of episodic support to individuals who can manage well most of the time but do need short term interventions at times.

It is also true that many individuals with Autism could be gainfully employed if the appropriate levels of support were provided to the individuals along with support and guidance to encourage employers to recruit these potential employees. How these types of initiatives may be funded is still not clear from a support provider perspective.

From a state service system position there is the risk of the Commonwealth abrogating its responsibility to support some individuals as they may argue they do not meet the funding criteria as set by the NDIA. This may result in many people needing a level of support outside of the parameters set by the Commonwealth but nevertheless cannot function effectively in the community without some support.

“During the author’s time with Amaze (Autism Victoria) both the Mental Health sector and the Out of Home Care sector accessed training from Amaze as they were recognising many of the individuals presenting for Mental Health or Out of Home Care support clearly presented with characteristics of Autism. Many of these clients did not have a diagnosis but nevertheless were presenting with support needs.”

Will these individuals be able to access funding through the NDIA and as importantly how and where will these “non-disability specific service” be able to access the training and support they need to operate effective services? Will the State Government be expected or required to step in to provide the support or will they simply direct concerns to the NDIA and the Commonwealth? At the end of the day it is important to ensure people with Autism are not placed in a position of disadvantage through lack of service and support.

Recent news reports also suggest the Commonwealth is keen to influence the composition of the Board of the NDIA and although this in itself is not cause for concern along with this development news reports have been suggesting the Commonwealth is taking this approach in an effort to influence the criteria for the application and approval process for support funding. Given the ongoing debate surrounding fiscal policy this may be cause for concern and may lead to underfunding and/or no funding of supports and this may in turn lead to pressure on the State to meet the unfunded areas of need.

Further concerns regarding the NDIA and the adequacy of service are related to the certification of services and how this will be undertaken in the future. The current model of certification via DHHS standards has been the focus of certification on policy and procedure rather than the quality of practice. It is of concern if this model of certification continues under the NDIA with little or no focus on the critical areas of quality of life and a focus on practice.

If the support system is to truly be able to meet the needs of service users then the certification process and more importantly the staff who undertake certification must have the relevant skill, knowledge and experience to be able to attend a service and by observation, discussion and review be able to make an informed assessment with regards the quality of practice.

“At a visit to a service one program was identified as Toast Making. On enquiring what the program was the service provider advised it was were participants attended the Supermarket, purchased bread and on their return to the service toasted 2 slices of bread. On further questioning it emerged that a number of service users had been on the program for some 5 years and had not progressed beyond putting the bread in the toaster. The service provider was unable to clearly describe what the program was aiming to achieve or how it would be measured.”

In this instance the service had recently undergone the formal audit process and was certified as meeting DHHHS standards. Given this was an example only of the programs being provided by the service it was clear the auditor did not understand what good practice was or how to undertake the appropriate steps to ensure the service was meeting its obligations to provide a meaningful and vibrant support service.

There are an emerging number of organisations that are presenting with Autism in their title. This is due in part to the emerging awareness of the prevalence of the disability but is also in response to the commercialisation of disability supports as a direct response to the NDIA. The question of competence with regards these emerging services should be a key focus of Government to ensure service users are receiving the appropriate level and quality of support necessary for quality of life outcomes.

The NDIA promises enormous change in the sector from the ability of individuals to select the types of service and support they want and need to the challenge of the service system to be capable of responding to these demands.

Equally the State can play a critical role in ensuring service and support is provided at a level and standard that brings quality outcomes for individuals accessing support. This will demand of the State the need to audit and monitor the service system with a focus on practice and when necessary to have the political will to remove/cancel the licence of services that fail to meet these standards.

This submission is not a comment on the NDIA however it should be noted within the context of service delivery and development the NDIA is prefaced on an Insurance model which demands outcomes leading to a reduction in service needs over time. The Transport Accident Commission (TAC) model has been able to accept some TAC fund recipients will, by the nature of their injuries/disability be life-long funded by the TAC with little or no likelihood of significant reductions in support.

This is also true for participants of the NDIA who have a lifelong pervasive disability such as autism. It is important the State advocate to the NDIA/Commonwealth that change will often be a long term goal and it is essential the NDIA set goals that recognise the nature of the disability and the need to link goals across development domains and long term (whole of Life) timelines.

Recommendation 28: That State government undertake a need's based study to determine the support needs in terms of staff for a fully functioning NDIA support system.

Recommendation 29: That the State retain and oversee the auditing and certification role of organisations providing service and support in Victoria.

Recommendation 30: That the State monitor the funding models implemented by the NDIA to support the current funding levels and to ensure where possible service users are not disadvantaged.

Recommendation 31: That the State to encourage the NDIA to fund at appropriate levels the full range of secondary supports including:

- Advocacy (All forms)
- Training
- Community Education
- Episodic support

Recommendation 32: The State support the NDIA to recognise the proposed insurance principles be viewed within a whole of life model and with a sequential and developmental model based on a life-long and pervasive disability that may change over time but will always be present.

Evidence of the social and economic cost of failing to provide adequate services

The social and economic costs of failing to provide adequate services will be difficult to quantify and this submission will not attempt to put a price on the costs.

In saying that this submission recommends effort be directed to evidence base the social and economic costs by considering the following:

Early Diagnosis: Consideration be given to the social and economic costs of the:

- a. Long term impact on missed diagnosis and the benefits of early intervention
- b. Distress caused to families not being able to understand or respond to a child's behaviours
- c. Misinterpretation of diagnosis leading to inappropriate treatment regimes
- d. Social isolation of children and families with an ASD child

Education: Consideration be given to the social and economic costs of:

- a. Poor academic outcomes for students with different learning styles not acknowledged and accommodated for within the school setting.
- b. Inability of schools to support ASD students leading families to home school and thus limit the ability of parents to enter the workforce and the potential economic impact on the family and impact on social development of the student.
- c. Students experiencing bullying and social isolation leading to early leaving and potentially entering the justice system or becoming isolated in the family home
- d. Impact on teachers and other student's academic outcomes due to behaviour management issues and lack of training for teachers in strategies to better manage this cohort.
- e. Health impacts for students not engaging in active sports or performance arts etc.
- f. Students engaging in inappropriate relationships built on poor understandings of social rules (inappropriate use of texting etc.)
- g. Loss of self-esteem by students through academic underachievement

Family Dynamics: Consideration be given to the social and economic costs of:

- a. Family breakdown, which is similar across all groups until adolescence when marriage breakdown for families with a child with Autism is significantly higher
- b. Inability of both parents entering the paid workforce due to care needs of child.
- c. Ongoing costs of support for majority of ASD individuals as they are unsuccessful in gaining employment
- d. Social isolation of families due to behaviours of the child at all ages
- e. Additional support costs for home modifications, home maintenance, medications and other in home support costs
- f. Children attending support services requiring additional monies for extra support costs.

Employment: Consideration be given to the social and economic costs of:

- a. Loss of productive outcomes for individuals often highly skilled and competent.
- b. Costs to the public purse through loss of income tax income and other indirect and direct taxes on expenditure (GST, Stamp Duty etc)
- c. Loss of self-esteem, increase in self-harming behaviours and ongoing contact with the justice system
- d. Cost of social payments (unemployment or disability supports)
- e. Increase in mental health demands on the service system
- f. Lack of independence and capacity to make life choices.

Housing: Consideration be given to the social and economic costs of

- a. Demand on the public purse for the provision of public housing
- b. Loss of revenue to the State through potential stamp duty and other costs in home ownership
- c. Social costs due to lack of community inclusion and engagement through home ownership/occupancy.
- d. Inability to engage in social practices including relationship building through friendship networks

Disability Services: Consideration be given to the social and economic costs of:

- a. Services failing to meet the developmental needs of individuals through lack of staff skills and knowledge
- b. Inadequate support models leading to increasing behaviours and potential for self-harm or harm to other service users and/or staff.
- c. Increasing costs to service providers through work cover claims, loss of staff and ongoing staff recruitment and training.
- d. Demand on the State for the provision of disability specific housing to meet the needs of individuals no longer able to live at home or in mainstream public housing.
- e. Exploitation of individuals living independently by community members taking advantage of housing circumstances.

The projected demand for services in Victoria.

The answer to the question of projected demand for services is simply “How long is a piece of string”.

The question for the State is simply what type of service system does the State wish to see in operation in Victoria.

Certainly at this stage it is, in the author’s opinion, too early yet to make a definitive statement about the effectiveness of the NDIA and how this will impact on individuals with Autism in Victoria. What can be said however is that given the current economic climate, the aim of the Commonwealth to increase influence at the NDIA Board level and the need to restrain cost growth in the scheme there is the real risk the system will not achieve all the goals it was originally presumed would be met.

There was clearly a belief within the disability community and the community more generally the scheme would be a deal maker with respect to support and outcomes for individuals with a disability. As the journey continues and greater awareness of the limitations of the scheme driven by cost management suggests it may lead to a two tiered model with the NDIA funding a “Target” service and families/individuals needing to provide additional funding if they seek a “David Jones” service.

It is also becoming apparent that as the scheme continues to roll-out there will be some individuals whose packages of support will be less than that funded through the State. This will be particularly true for some families who are currently receiving large funding packages in response to the “squeaky wheel” strategy. It is unlikely these families will receive the same levels of funding through the NDIA.

This may see a number of families make the heart wrenching decision to relinquish their child and thus place greater demands in terms of housing needs, funding and support requirements on the service system.

There will also be some areas of support that may not fall within the scheme frame and how these supports are funded and as importantly how to ensure these demands are kept to a limited number is going to be lead to a great demand on the State government going into the future of the scheme.

Although not truly a service demand there is nevertheless a need for the service system to be monitored and poor services be identified and remedial action undertaken to enhance service outcomes. This State has a history of being a leader in quality systems and although they have primarily focused on policy and procedure it is nevertheless an area in which the State should demand an ongoing role.

The only rider on this would be the desire for the State to take a much more active role in demanding and overseeing the role of certifying bodies to concentrate on practice rather than procedural matters such as policy development/proof of quality improvement which has little impact on service delivery. Proof of practice should be a far stronger element than is currently the case and services should be more rigorously and extensively assessed.

Likewise the State has the ability to address those areas in which the State has direct responsibility. In practice the State can address the issues in education and health with little to no cost. Likewise early diagnosis could be a key element for the state along with a range of training and professional development services aimed at Health, Emergency Services and Education professionals.