

Autism Advisory & Support Service Annual Report 2011/12



“Empowering children with Autism and their families
through knowledge & support”

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Above: Children enjoying the AASS drumming circle.

Incorporation

Autism Advisory and Support Service Inc ABN 63 073 684 085 is a not for profit incorporated association. Its members are the current Committee. Its registered office is located at 88 Memorial Ave Liverpool NSW 2170.

Charitable status, tax concessions and fundraising

Autism Advisory and Support Service is a Health Promotion Charity (HPC). It is endorsed as an Income Tax Exempt Charity and receives certain other tax concessions and exemptions consistent with its status as a HPC which relate to Goods and Services and Fringe Benefits taxes. Autism Advisory and Support Service has been endorsed by the Australian Taxation Office as a Deductible Gift Recipient (DGR). Autism Advisory and Support Service is registered under applicable fundraising legislation as required in NSW where it raises funds as follows: New South Wales: Registration number CFN 21161



Above: Students from the Cecil Hills High School Support Unit Choir who performed at the Foundation of Hope Charity Ball.

Presidents Report

Looking back over the past financial year, it is quite satisfying to reflect on the amazing accomplishments of the AASS team. We are still without recurrent Government funding, yet, word on our valuable service is spreading far and wide. It is encouraging to have countless Members of Parliament, both State and Federal, speak of our achievements in Parliament. It would be nicer to have a dollar value placed on our contribution to the Autism and Disability community, in particular when we have paid service providers and Government agencies come to us for advice and assistance. The AASS team have worked hard to organise the various fundraising activities which has seen an increase in our bottom line. This has allowed us to continue and extend our programs to include:

- A successful disability expo.
- An arts and craft group for children with Autism aged 7-15 years
- A social skills therapy group which took 40 children aged 7-15 off therapy waiting lists.
- The social group for young adults with Autism partnering them with neuro typical peers/mentors
- The worldwide launch of In My World, the AASS song and DVD for raising Autism awareness.
- Our inclusion to the Department of Education Student Services Advisory Committee for South West Sydney Region.
- The erection of a shade structure for our therapy play area
- The 1st annual concert for Autism
- Our partnership with UWS Campbelltown School of Medicine
- Australia's only 24 Hour Autism Hotline
- The Music 4 Health program with members of the Sydney Symphony Orchestra who played to 400 excited children with additional needs and their carers
- The 4th annual Foundation of Hope Charity Ball
- Support groups in various languages
- The expansion of our on line toy store

We also continued to meet with Government officials and politicians, provide individual advocacy and provide telephone and face to face guidance and advice to families needing support after their diagnosis. This was all achieved with no recurrent Government funding and while we ran our own events and fundraisers. One can only imagine what AASS can achieve with recurrent Government funding and support.

And the journey continues. We thank you for sharing it with us.

Yours sincerely

Grace Fava
President

The AASS Executive Committee



Grace Fava CLO, JP
Founder and President

Certificate IV Frontline Management, Adjunct Fellow Faculty of Health Sciences at University of Western Sydney, Board Member with Catholic Cemeteries Trust
Grace has worked in many diverse fields including Pharmacy, Office Administration and Accounts receivable for various organisations. Her passion for Autism was ignited when searching for services for her two boys who both regressed with Autism and Global Developmental Delay.
Grace is responsible for the day to day running of AASS and overseeing all aspects of the organisation.



Fiona Zammit B Ed
Vice President, Secretary

Fiona has a Bachelor of Education and has worked for the past 17 years as a Primary School Teacher.
Fiona is a founding member of AASS.
Fiona is responsible for all banking aspects of AASS and is an integral part of all AASS fundraisers.



June Young OAM JP
Treasurer

Business Owner – Stage Struck (NSW) Pty Ltd for 23 years.
Member of Quota International of Liverpool, Rotary Club of Liverpool Greenway, NSW Justices Association, National Council of Women, Fairfield RSL Women’s Auxiliary President
Past South Pacific Area Director of Quota International in Washington DC, USA
Business Person of the Year for Liverpool, Liverpool Australian of the Year.
Awarded the Federal Centenary Medal for Service to Liverpool Community
Awarded the Order of Australia Medal for “Service to the community through a range of Women’s, local government, business and ex-service organizations”



Bassema Ghaznavi

Certificate IV in Community Services (Employment Services) with a focus on Disabilities, Diploma in Disability, and Diploma in Case Management
Bassema is a founding member of AASS.
Bassema currently coordinates and mans the AASS 24 Hour Autism Hotline



Craig Kelly MP

Craig Kelly became the 1077th Member of the House of Representatives in August 2010, representing the seat of Hughes.
Craig entered Parliament with a unique set of experiences and who, along with his wife Vicky, care for his son Trent, who was born with Downs Syndrome and later diagnosed with Autism. Craig carries a drive and determination to make a real difference in the disability sector.
Craig said in his maiden speech that caring for Trent “has made me a better person. It has made me fully appreciate that each individual has a real value of their own, and the dignity of every individual must be respected. But most importantly it has awakened me to the fact that as a nation we need to do more, much more, for children with a disability and their carers.”

Summary

Autism Advisory and Support Service (AASS) was established in 2007 by a group of parents from South Western Sydney to fill the void in the health care sector encountered by families of children with Autism.

AASS was established as a support and network/advisory service to empower children with Autism and their families through knowledge and support, and to positively impact and influence their children's social and emotional development.

It is run by volunteers and has the legal status as a not for profit incorporated charity. AASS relies on funding grants, donations and sponsorships to meet its operational costs. Despite these financial obstacles AASS has grown in size and been able to expand its range of service delivery.

Since its inception AASS has:

- opened the AASS Community house/drop in centre, located in Memorial Avenue, Liverpool;
- established, coordinated and hosted support groups in a range of languages;
- established, coordinated and hosted social group for young adults with ASD and mentors;
- established, coordinated and hosted an art group, drumming circle and social skills therapy group.
- run a resource library, toy library, and toy and resource shop
- established, coordinated and facilitated Australia's only 24 hour Autism hotline.
- established and expanded their Autism friendly therapy play ground and sensory garden.

AASS continues to provide these services free of charge or for a nominal fee to the parents, carers and service providers of children with Autism.

The service began by supporting families in South West Sydney and now has grown as a support service to families in Western Sydney and in every state of Australia. It handles approximately 250 enquiries/cases per month.



Our Mission:

- To empower children with Autism and their families through knowledge and support
- To positively impact and influence their social and emotional development

Our Objectives:

- To advise and assist children with Autism and their families.
- To provide support and information to parents of children with Autism.
- To do this at a free or nominal price for families affected by Autism.
- To engage relevant stakeholders that can make a valid contribution to the development of service and facilities for children with Autism and their families.
- To be a source of information of Autism services.
- To seek funding to sustain development of Autism Advisory and Support Service



Above: Fiona Zammit and Janine Power accept a cheque from Renee Bebb from one of two Facebook fundraisers Renee ran for AASS.

Services

AASS does not currently receive any regular government funding, instead relying on donations, fundraising and grants to operate their service.

Today, AASS is still run by mostly unpaid volunteer parents who all have children with Autism. These parents have a diverse set of skills and come from varied professional backgrounds, offering unique expertise to AASS. Those professions include; education, business management and politics.

In addition to the professional skill set the Executive Committee members bring to AASS, as parents of children with Autism, they understand the right of the family and the individual with Autism Spectrum Disorder (ASD), to make decisions based on what they feel is best for their situation. Individuals on the spectrum should enjoy the same rights and opportunities as their neurotypical peers.

AASS fills the gap in service provision that exists, and does so at no charge to families affected. This is important, as studies have shown that raising a child with a disability cost at least three times more than raising a child without a disability.¹ Government funding focuses on early intervention, so families of children above the age of 6 need to find the money to pay for private services. This costs on average \$150 to \$200 per child per week for forty five minutes of speech therapy and forty five minutes of occupational therapy.

The main benefit that AASS provides is that we do can personally identify with the issues faced by parents accessing our service. We have all experienced the isolation and grief that a diagnosis brings; the frustration of searching for affordable and appropriate services; the battle to find a suitable educational environment for our children; the guilt connected with focusing on the child with the disability and not enough attention on other children; the burden of wondering what will become of our children when they are older.

So when a family comes to AASS for assistance, our empathy and understanding is real. We have learnt about ASD from life, not a textbook. We understand that ASD should not be approached with a “one size fits all” attitude. This unique approach brings families coming back to volunteer when they are more comfortable with their situation. We do not need to advertise our service, as word of mouth in particular from other service providers, keeps us very busy.

For parents and carers waiting for a formal assessment and diagnosis, looking for the right intervention and joining the long waiting lists can be extremely overwhelming, confusing and frustrating. AASS provides unbiased advice, encouragement, guidance and support.

¹ <http://www.jrf.org.uk/publications/paying-care-cost-childhood-disability>

Support Groups

These are held on a monthly basis (excluding school holidays) at the AASS House at Liverpool. We also have an Arabic Support Group which has filled a gap in service provision in the area.

Families can often feel overwhelmed and alone when faced with questions that Autism brings. Our support groups are designed so we may come together to support one another and share our experiences.

Our support groups also host a number of varied service providers and professionals who provide valuable information to families. These guest speakers prove to be popular with families desperate to learn as much as they can to assist their loved ones.



Social Group

The social group, attended by adolescents and adults affected by ASD, neurotypical peers/mentors and AASS volunteers, is held once a month in various social settings. Young adults with ASD learn much craved for social skills from their peers/mentors. The peers are university students studying in the fields of Medicine, Occupational and Speech Therapies, Psychology and Teaching.

The young adults with ASD gain skills and self esteem while the mentors gain experience in dealing with youths and the uniqueness that is Autism, while taking their invaluable experience with them in their future careers. We sincerely thank the Cecilia Kilkeary Foundation for their grant that allowed us to start this program.



Social Skills Therapy Group

AASS hear from families on a daily basis whose children were diagnosed after the age of 6, therefore missing out on important early intervention and the funding that it attracts; families who cannot afford the (average) \$120 per hour for therapists; whose children do not qualify for State Government assistance because they do not have an intellectual delay; families whose children have been waiting on the back of a waiting list for an average of eight years for ADHC therapies and assistance.

With the generosity of a Cecilia Kilkeary Foundation grant, we established a pilot program which took 40 children off the ADHC waiting list and gave assistance to children who were not eligible for their assistance. The Social Skills Therapy Group is run by an Occupational Therapist and a Speech Therapist together.

The higher functioning children completed a ten week program that has seen children from the group make friends and go on to have play dates outside the group. Other children are no longer continually discussing their current obsession and are becoming aware of social rules and norms. We are all extremely excited with these outcomes and the parents are in awe that their children have learnt so many skills in a short time. The parents were all given homework to complete outside of the groups and were extremely grateful for the opportunity to feel like they were contributing to their child's progress.

The most challenging group were the most exciting to work with- the children who are non verbal and have severe behaviours. They were screened by the therapists and the parents will be interviewed so group strategies can be decided.

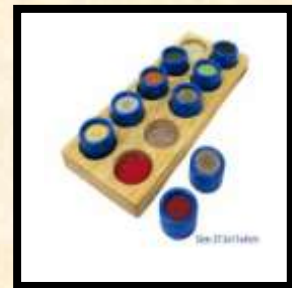
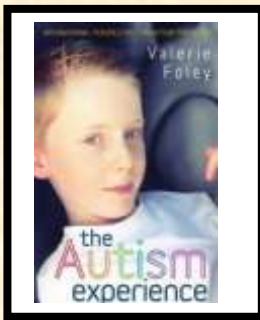
We are all working towards finding the funding to extend the program to 2013 and assisting many more children who have fallen through the cracks.



Resource and Toy Library and Shop

In response to the outcry from parents for more affordable resources and toys, AASS have established an extensive range of books, magazines and DVD's on Autism in a variety of language for loan. The range of books include information on therapies, diets, educational settings and requirements, teaching of social skills and how families can support each other. There are many books in the library that have been written by individuals on the spectrum.

The AASS shop has expanded greatly over the past year. It now runs online and in person, with AASS often taking a range to expos, information days and schools on request. Our range includes resources and sensory toys that assist with affordable therapy for individuals with ASD. These items provide a source of income for AASS to assist with our overheads while offering affordable prices to families and service providers.



Sydney Symphony Orchestra

It has been our honour and sincere pleasure to again host the annual toy orchestra in partnership with the Sydney Symphony Orchestra. Most children with Autism have a natural affinity to music, and this is captured during this event. Held at Mt Pritchard Community Club, 400 special needs children and their carers attended this years concert and were mesmerised by the heavenly sounds of the music. They were then invited to pick up their instruments provided by AASS. Conductor Stan then encouraged the children to join in. Children who were usually introverted let their hair down singing and conducting to the classics. The children were also encouraged to feel the vibrations from the music on the stage and on the instruments. They were treated to a show bag that was generously donated by Liverpool Quota and AASS.

NSW State Member for Cabramatta, Nick Lalich MP was present at this years concert. He was so moved by the event that he spoke of it in Parliament. This is an excerpt from his speech:

“...There was a wonderful atmosphere in the auditorium that day. The space was filled with the fun and enthusiasm... I will never forget the sight of one little boy singing an impromptu performance of a modern song I had never heard, yet all the children around him instinctively started to clap along and sing with him... The Sydney Symphony has performed for children aided by the Autism Advisory and Support Service several times in recent years and knows the benefits that music can bring to them... It was fantastic to see how their musical talents could bring smiles to so many children's faces. It was an inspiring day and I thank all those involved...”



Advocacy

One of the many services Autism Advisory and Support Service provide is individual advocacy, in particular for school related issues such as students being suspended and expelled from schools.

One of our many success stories is Jazs. Jazs is 15 years old, has Aspergers and was attending his local mainstream highschool. As is common with many students with additional needs, Jazs was a victim of bullying and was not in an environment appropriate for his needs. Jazs wanted to fit in; find a place where he could learn and make friends, however it was difficult when he had to face bulling on a daily basis. *“My Mum tells me all the time that my disability is not an excuse, merely a challenge.”*

Jazs’s Mum Helene contacted AASS to see what we could do to help. AASS opened discussions with regional staff from the Department of Education, who found a support unit in a mainstream school for Jazs to attend. With much trepidation, Jazs attended his new school at Macquarie Fields High School. The initial plan was to transition Jazs in slowly for a few hours a day until he was comfortable enough to stay for the full school day. Within a short time, Jazs was attending school for the full day. One term later Jazs became part of the school’s Students Representative Council (SRC) and loves attending school. In Jazs’s own words:

My whole life I have always been known as the kid that is different or the kid that is weird, but what most people forget is that I am a boy who has a name a boy that has feelings and boy that just wants to fit in. For me school has been a nightmare from day one. The kids never accepted me and the teachers never understood me. I have been bullied as far back as I can remember and don’t think I ever had a day at school where I was happy, where I felt like I fitted in or where I felt like it was actually ok for me to be me. There were many days I just didn’t want to wake up and face the world because the world was so cruel. School got so bad for me my Mum had to take me out of school and spent many months trying to find somewhere for me to go. We spoke to Craig Kelly MP and Melanie Gibbons MP and for the first time I actually felt like someone cared, it felt like someone wanted to listen and someone wanted to help

With AASS’s help, I have found my place in the world where I belong. I am now going to a school where it is totally ok to be me. The kids accept me and the teachers understand me. I am no longer the kid that is different or weird. I am for the first time Jazs and it is finally amazing for it to be ok to be me. It’s an awesome feeling to be excited to go to school every day. I have finally found my home.



Left: The inspirational Jazs.

The Concert for Autism

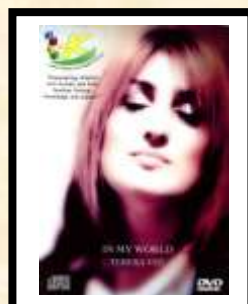
AASS were blessed to have a song written to help in our endeavour to raise awareness about Autism. Penned by John St Peeters and Michael Yule, and sung by the heavenly voice of Teresa Vee, “In My World” had its’ world release in May at The Concert for Autism. The film clip was shot at various locations including the AASS office and featured children with Autism and their siblings. The clip was unscripted yet the children were natural talents.

“In My World” was officially launched by Federal Leader of the Opposition, Tony Abbott MP during the concert which was held at Mounties. The line up of entertainment included John St Peeters, Daryl Braithwaite, Royalty Crew Dance Crew, Maria Venuti, Bruno Lucia, Alfredo Malabello, Donnie Sutherland, Declan Sykes and was compared by John Deeks.

The highlight of the evening was when Teresa Vee called one of the stars of the video clip, Mitchell Zammino, on stage. Mitchell has Autism and a range of co morbidities, yet he stole the show when he told Teresa he wanted to marry her. The concert was a success and led AASS to a range of important connections and supporters. We look forward to holding the concert again in 2013.



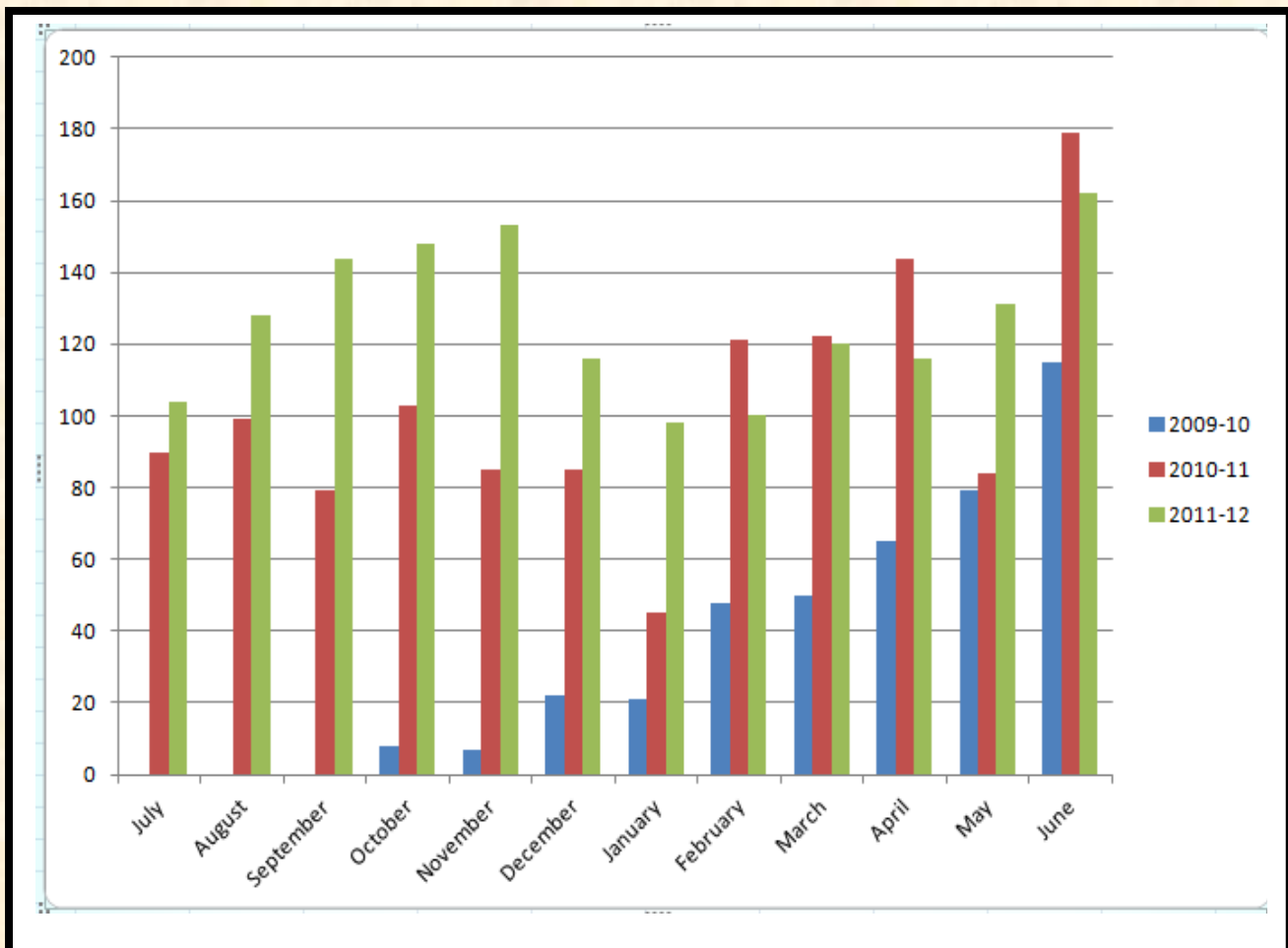
Clockwise from top left: Royalty Crew, The Concert for Autism poster, Tony Abbott MP, Teresa Vee and Mitch, Bruno Lucia, “In My World” DVD, John St Peeters and Tommy Emanuel and Daryl Braithwaite.



24 Hour Autism Hotline

AASS developed Australia’s only 24 hour Autism hotline at the end of 2009. We took our idea to the Federal Government for funding and were refused. Understanding the lack of any similar service that operates 24 hours a day, 7 days a week, Autism specific, where the phone is answered first time or your call is returned within a few hours, AASS were determined to fundraise to make this necessity a reality.

Today the hotline takes an average of 125 calls per month from around Australia from families in crisis, Medical professionals and service providers asking for assistance for their patients and siblings and friends wanting more information on Autism so they can better understand the disorder. While some requests for assistance can be quickly resolved, many require days and sometimes months of follow up. The following graph shows the increase in calls to AASS from around Australia:



Awards 2011-12

As evidence of our outstanding work, AASS have been recognised over the past year with the following awards:

2011 Westpac International Women's Day Ruby Awards

2011 NSW Carers Awards - Team Award

2011 The Centre for Volunteering - South West Sydney Macarthur Team Award

2011 Liverpool Council - Hon Companion of the Order of Liverpool Award

2011/12 Liverpool Quota Citizen of the Year



Our sincere thanks go to everyone who gave their time and money in this last financial year to help AASS in our endeavours, in particular the following people and organisations that have supported AASS through their individual and collective fundraising efforts:

Country Link	Mounties	Canterbury Leagues Club
Australian Museum	Cabramatta Leagues Club	Darryl Melham MP
Penrith White Water	Bonnyrigg Heights Public School	Novotel Brighton Le Sands
Club Marconi	Liverpool Catholic Club	Monster Night
Chrisco	Vinnies Ristorante	Bridge Climb
Museum of Fire	Natural Beauty Clinic	Roses Only
David K Hair	Luna Park	Taronga Zoo
Featherdale Farm	Sydney Imax	Flight Centre Bonnyrigg
Ryde Parramatta Golf Club	GS and DC Rodham	Rydalmere East Public School
Quest Apartments Campbelltown	Sue Galvin	Beresford Community Centre
Paul Lynch MP	F and G Carbone	Gigi's Restaurant
Steves Automotive	Deem Hire	Western Plains Zoo Dubbo
Nick Lalich MP	Lina Nashmi	Greenfield Park Newsagency
The Hon Barry O'Farrell MP	R and V Carrozza	Jean Hunt
Dr Andrew McDonald MP	R and D Leonello	Ben Bath
Antonio Calipari	A and T Betts	Castar group
D and F Lopreato	M and C Plant Hire	Antonio Canto
George Dominello	Rick Quercigrossi	Frank Giampaolo
Marie Sly	Andrew McPartlane	Rick Grech
Paul Grech	Frances Nobilo	Pina Pisano
A Crestani	Rita Raiti	Rachella Lombardi
Fiducian Portfolio Services	JA Bourke	KISS Solutions
Michelle Pisano	Zamprognio Family	Laureti Family
Scundi Family	Agostino Family	Linda Fallon
Renee Bebb	Allison Gaskin	Vince Berardinelli
Daniel Berardinelli	Adriano Chiovo	Liverpool Glass
Bunnings Hoxton Park	Vartuli family	Rotary Greenway
Rotary Wetheril Park	Quota Liverpool	Jenny Lam
C and G Rositano	John Deeks	Harris Freedman Lawyers
Harrys Cafe De Wheels Liverpool	Vittoria Coffee	Imax Theatre
Pep's Autos	Kenmards Self Storage	Nerada Tea
Natural Beauty Clinic Casula	Bridge Climb	M and A Organisation
Studio Blaq	Hunts Comfort Inn Casula	Westpac Liverpool
Abati Family	Heather Barrett	G and T Carbone
Flaiban Family	Chris Hayes MP	Liverpool Rental Specialists
Lansvale Holden	Alfredo Malabello	M and A Chiovo
A and G Micali	Alan Spinks	Partick George
Smooth 95.3FM	Coates Hire	De Angelis Taylor

We thank you for sharing our vision of assisting individuals with Autism and their families, carers and service providers.