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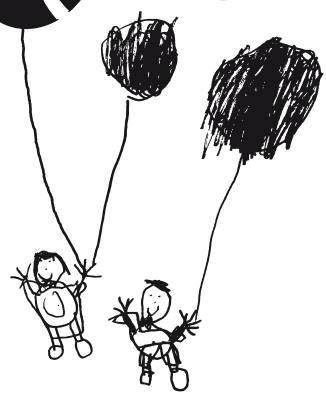
Information Sheet 36



Autism spectrum disorders

In May 2005 we were privileged to welcome Dr Jacqueline Roberts* to our Annual General Meeting. Dr Roberts presented an address on Autism Spectrum Disorders to our staff, members, parents, teachers and health professionals. With Dr Roberts' kind permission, we have reprinted her address.

It's a great privilege to be asked to talk to a group of people gathered for an important meeting such as this and I think probably indicates the growing interest and awareness of Autism Spectrum Disorders right throughout the special education community.

What I am going to do tonight is talk to you a little bit about Autism in general.

There are some interesting facts, figures and ideas about the increase in the numbers of children with Autism who are presenting for services and possible causes. I will first give a very quick overview – all you ever wanted to know about Autism but were afraid to ask in an hour – and then talk a little bit more about the treatment and management options that are available for children with Autism.

This information is based on a review I did for the Department of Ageing, Disability & Home Care which was completed at the beginning of last year looking at the various treatment and management options for Autism.

Seeing the world

"If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music he hears, however measured or far away."

Henry David Thoreau 1854

I thought that this was a nice quotation to start with.

I think it's really useful to remind ourselves that there are many different ways of being in the world and certainly being on the Autism Spectrum is an important way of being in the world.

I also think that we should sometimes question the assumptions we make about what is normal and what is not.

Working with children with Autism and their families is one of the most complex, frustrating and yet rewarding experiences one can have and it really makes you question very profoundly what it is that makes us human and makes us want to congregate together in groups.

Definition of Autism

This definition is quite a useful one. It was developed by the National Autistic Society in the U.K. (NAS) and clearly sets out some of the key things that we know are important when we are thinking about Autism.

"Autism is a complex developmental disability in which there is dysfunction of some parts of the brain and central nervous system. This affects how a person learns to understand and use communication and to interact with people and the environment (NAS 1998)."

We know for example that Autism is developmental disability.

This is important because when it was originally described in the 1940's by Leo Kanner, it was thought to be a mental illness.

In fact it was described as childhood schizophrenia and the treatment of choice at that time was psychoanalysis, which in many ways probably compounded the problems for families living with Autism Spectrum Disorders.

It was important that it was described and Kanner's descriptions are uncannily accurate even today.

The treatment at the time was heavily influenced by Freudian psychoanalysts. It was the era of the "refrigerator mother" – mums were thought to be responsible for the failure of the emotional attachment with their child.

I think one of the other really important things we know is that Autism affects the central nervous system. It affects the way the brain functions and as a result people with Autism have great difficulty making sense of the world around them.

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Learning Links is a non-profit charity assisting children who have difficulty learning and their families.

We raise funds to help children from birth to 18 years by offering a range of services including the following.

Early Childhood Services for children from birth to six years.

- Early childhood intervention and support for very young children.
- An inclusive preschool for children with and without special needs.
- An assessment and consultancy service for families who are concerned about their young child's development.
- Specialist early childhood teaching and therapy.

School Age Services for children from Kindergarten to Year 12 who have low support needs.

- Comprehensive assessments.
- Small group tuition and therapy.
- Occupational and speech therapy programs combining specialist education services and therapy.
- Outreach programs.
- The Ronald McDonald Learning Program for seriously ill children and the Reading for Life Program for children falling behind in their reading.

Family Services helping and supporting families and health professionals.

- Centre and home-based family counselling.
- Parenting Programs and groups for families.
- Case Management Services.

Professional Development for teachers and health professionals.

Presentations, workshops and advice on identifying and helping children with learning difficulties, learning disabilities and developmental delays.

Learning Links has branches in six Sydney locations at Peakhurst, Penshurst, Fairfield, Miller, Dee Why and Randwick. We also offer some services to children in country NSW, the ACT, Victoria and New Zealand. A complete list of branch locations and contact numbers is on the back cover.

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There is a lot of confusion around what Autism actually is and you will hear it described in a variety of different ways.

When people talk about Autism they are usually talking about Autism Spectrum Disorders – a range of disorders fitting into the Autism Spectrum. The three disorders in this spectrum are Autistic Disorder, Atypical Autism and Asperger's Syndrome (or Asperger's Disorder).

Probably the best known of these is Autistic Disorder, also known as Classical Autism or Kanner's Autism. Atypical Autism and Asperger's Syndrome are often confused as children and adults with Atypical Autism don't meet the full criteria for a diagnosis of Autistic Disorder or Asperger's Syndrome but have some characteristics. Atypical Autism is often described as Pervasive Developmental Disability not otherwise specified (PDD-NOS) or Semantic Pragmatic Disorder.

The variety of labels can be confusing.

Autism Spectrum Disorders fit into a bigger bucket called Pervasive Developmental Disorders (PDD) and are the biggest group of these disorders.

These disorders also include Rett Syndrome – a fairly rare condition that only affects girls. It is different from Autism Spectrum Disorders in that respect, but similar in that the behaviours look very much like an Autism Spectrum Disorder, which is probably how it ended up in that diagnostic bucket.

PDD also includes the rare Childhood Disintegrative Disorder.

I have never actually seen a child with this, but they are reported in research literature. This is a condition where you have typical development for the first three to four years of life and then a marked deterioration of skills. Their development has characteristics of Autism.

The Asperger's group is by far the biggest and because it has only relatively recently been described, it has only recently become a formal diagnostic category.

A person with Asperger's has a typical IQ, but there is no associated intellectual disability and no obvious developmental delay in language. This is what distinguishes Asperger's Disorder from Autistic Disorder.

Just to confuse you, however, there are some people with autism who have a significant language delay and disorder but who test in the typical IQ range. While they are diagnosed as having Autistic Disorder, they are generally referred to as High Functioning Autism.

The proportion of people with Autistic Disorder who have intellectual disability is close to 80%. There is no intellectual disability associated with Asperger's, however those with Asperger's have problems with the function of language and conversational skills.

What are the characteristics of Autism?

Autism is a behavioural diagnosis and is based on the observation of behaviour rather than a blood or chromosome test.

Autism is a developmental disability and is characterised by three clusters of characteristics and some signs of each of those clusters are essential for a diagnosis to be made. The three clusters are communication, social skills and repetitive behaviour and/or restricted interests. (As a Speech Pathologist I always find it a little bit artificial to distinguish between communication and social skills as they're very much related.)

As Autism is a developmental disability, a diagnostic criterion is onset prior to 30 months.

There are no differences across backgrounds – ethnic, cultural or socio-economic. Autism is pretty even handed and pops up about the same ratio internationally in all groups.

Autism is much more common in boys than girls, particularly Asperger's Syndrome.

In the Autistic Disorder group, the average is about four boys to one girl and the Asperger's group, it is nine boys to one girl.

We know that some people with Autism have exceptional skills in certain areas.

Has anybody seen 'Rain Man'? Dustin Hoffman did a really good job there – he spent a lot of time with one young man in particular with Autism and he really captured the flavour of Autism to a great degree.

Tom Cruise said it was one of the most difficult roles he has ever played because he was playing opposite someone who wasn't giving him anything back emotionally – this would be typical of people with Autism.

The exceptional skill (gambling) that Dustin Hoffman displayed in that movie has yet to be found. However, it is not unusual to find children with Autism having very well developed exceptional skills in a certain area – often in maths and some kind of calculation ability.

We know one boy who can go from 2010 right through all of last century and can tell you straightaway what day of the week any date in that time was or will be. I have no idea how he does it, but I saw a film pitting a mathematician with an applied formula and a calculator against him and the person with Autism could do it straightaway, while the mathematician took maybe two minutes for each one.

There are some extraordinary skills that make people with Autism a very interesting group to work with – those are the things that we can help develop to compensate for some of the deficit areas.

The increased demand for services – an epidemic?

There has been a lot of talk lately of an epidemic of Autism and the incredible increase in demand for services, particularly in the early intervention area.

This is one of the reasons the NSW Department of Ageing, Disability and Home Care commissioned a review. They were very keen to find out what empirical evidence there was about the effectiveness of different treatments for children with Autism.

One of the questions in the minds of many people is this – has there been an increase? We can certainly say 'yes' there has.

We used to think that Autistic Disorder was prevalent in about four per 10,000 people, which makes it pretty rare. Now the most conservative studies will say 23 or 24 per 10,000. For the Asperger's population, conservative surveys are 36 per 10,000, so if we add those together, we are getting well up in to the 60's per 10,000. If you then add those with Atypical Autism and some characteristics but not the full-blown syndrome, you can add in another 30.

We are now up around the 90 per 10,000, a figure that is well-supported in good solid research. It certainly is a lot more common than we thought it was.

Is it an epidemic? Maybe we are just more likely to pick those kids up now, whereas they weren't diagnosed before. Children are also being identified much earlier than they were.

We really don't know if that's enough to explain the increase. There is a lot of work happening trying to get some information on that.

There are also a lot of wacky theories out there about the cause of Autism – everything from changelings to aliens from outer space.

People are looking for environmental reasons and we can't discount the possibility that reasons such as vaccinations exist, but all the theories (including the vaccination theory) proposed to date have been tested and very soundly disproved.

Unfortunately until research is done media coverage of possible reasons can lead to panic.

We were inundated with calls at the Association about vaccinations when I was working there. It is very difficult for parents and really important that we keep ensuring that there is good solid research.

The diet issues seem to be pretty big with children with disabilities. There is research now to demonstrate that there is no empirical evidence for most of those but there is still work going on in this area. I think what will happen is that they will find there is a small sub-group of children on the spectrum who do have gut problems and may respond to a gluten and casein free diet.

Asperger's and Autism – are they separate?

There is a lot of controversy about whether people with Asperger's should be considered separate.

There is no clear research to really support the idea that Asperger's is different from High Functioning Autistic Disorder. It is a diagnostic dilemma for practitioners and it is also a big issue for governments wanting to fund a program – the NSW Department of Education particularly.

Assuming that Asperger's represents the top end of the spectrum I think it's safe to say that people with Asperger's live in our world but in their way, whereas children with Autistic Disorders tend to live in their own world.

Variability in people with Autism

There is a lot of variability between people with Autism.

There are people with very severe communication problems and social skills problems, but do not show much repetitive behaviour – enough to have a diagnosis but not very marked.

Sensory issues used to be a diagnostic criterion as they are really common with Autism. This was dropped but there is talk now that they will be re-included. By sensory issues, I mean mainly hypersensitivity to certain kinds of input from senses or hyposensivity – 'hypo' is not very much and 'hyper' is too much.

You might have one child who is very hypersensitive to a certain sound – a certain frequency – so you get ear blocking. The same child might appear to not hear other frequencies.

Sensory issues are a very important factor when we are looking at and understanding people with Autism and developing treatment and management programs.

Information on Autism

Learning Links has two information sheets on Autism on its website at www.learninglinks.org.au

The information sheets are 'Asperger's Syndrome – Educational Placements' and 'Strategies for teaching students with Autism Spectrum Disorder'. Both information sheets can be downloaded from the Publications section of the website.

These issues are very difficult to assess because people with Autism can't tell us very easily what is happening to them. One good source of information is people at the top end of the spectrum telling us what it is like to have sensory problems.

We also know that Autism can be quite confusing because some children with Autism have excellent motor skills. If anyone knows children who can walk across the apex of the roof of the school building three storeys up and come down safely, or who walk around the top of the school fence or across a clothesline, then they know what I mean.

There are children with Autism who have extremely well developed motor skills and then there are children, particularly at the top end of the spectrum, who may be very clumsy.

I work with a little boy who has got a lot of sensory problems. He has severe Autism and an intellectual disability. He also has gravitational insecurity so the system that tells him where his body is in space and gives him a sense of balance is all out of whack. The place that he feels most comfortable is sitting on the floor – this is where he feels most secure.

Autism is a very heterogenous condition. There is lots of difference between children with Autism and even within one child you can have a variation in the way the characteristics are exhibited.

It is unlikely that one program can fit all kids, let alone when we bring into the equation the family's philosophy, resources and resilience.

The treatment of Autism

In the 70s Autism was described objectively for the first time, mainly by the behaviourists who were coming from a learning theory perspective. These were the people who were conditioning dogs and things like that.

These professionals applied learning theory – the idea that if you reinforce a behaviour you will increase its likelihood of occurring and if you don't, you will decrease it. This was a great breakthrough for children with Autism, because for the first time someone was saying to parents that these children can learn.

Autism Interest Group

Are you a family with an interest in Autism?

If you are happy to have your contact details on a database with the intention of informing you, by post or email, of events/conferences/workshops and articles relevant to autism spectrum disorders, please give your details to Veronica Borham, Learning Links, 12-14 Pindari Rd Peakhurst NSW 2210, phone 9534 1710 (Tues/Wed/Fri) or mail@learninglinks.org.au

Parents at last had some hope instead of being told that they failed in their emotional attachment and must institutionalise their child and get on with their lives. At the same time, Autism Associations were being started all over the world (including the one here in New South Wales) with the aim of providing educational opportunities for their children.

In the 80s we had the inclusion of observations of behaviour – a very objective way of looking at behaviour – in the formal diagnostic systems. For the first time, Autistic Disorder was described in DSM III and diagnosed. Asperger's Disorder was included in the 90s.

What's happened since then?

Since then we have been looking at research into possible underlining causes of these characteristic observable behaviours.

There has been a lot of interest in things like sensory characteristics of Autism because they could explain things that we see and observe in children with Autism especially behaviour problems. There has also been interest in the way children think and learn and this explains a lot of characteristics and guides us in program development.

There is interest in the specific empathy disorder characteristic of autism, ie where someone has trouble conceiving that other people have thoughts and minds that are different from theirs. This has huge implications for social behaviour.

There is also a lot of work on information processing and attention issues.

We know for example, that we get information from our senses all the time. People here are sitting and listening and shutting out the rattle from the air conditioning, the lights around you and other things that are happening in the room.

Then, you have information coming in about your clothing, the feel of your clothes on your body and the chair you are sitting on. Even with all this, you are still listening. People with Autism have great difficulty doing that.

Neurologically, the research shows they just can't collectively attend so well.

All that information comes flooding in and it is screened and selected at a much higher level in the information processing process than is the case for people without autism.

We are finding out that the brains of people with Autism actually process information differently and the way they attend and respond is different.

We know also that there are specific problems with things like frontal lobe functions such as planning, organising, sequencing for people with Autism.

We know that they have some cerebellar abnormalities so they have problems with fine motor coordination and frequently a particular problem with the coordination of the fine motor movements required in speech (dyspraxia). There is information coming in now about what is underlining the observable behaviours of Autism. Because we understand it better, we are better able to program.

When I started working with Autism more than 20 years ago, the more traditional behavioural approaches were best practice – that's what everybody did and that was an improvement on the psychoanalytical approach which wasn't getting anywhere fast.

For example in my early years working in the area, I saw children who would block their ears a lot. We now know it was because they were sensitive to sound, but we didn't know that then.

Behavioural theory suggested that because the child was blocking his ears, he can't hear me so he is not learning. If that is the case, the thought was that we have to stop him blocking his ears.

The treatment in the extreme form when everything else failed was to put the child's arms in splints so he couldn't get his hands up to his ears. I heard of one particular child spending a lot of time attempting to get his shoulders up to block the sound from his ears.

Now we realise that that was absolutely the wrong way to treat that behaviour.

We have come a long way.

We now understand more about sensory sensitivities and the need to modify the environment. For that boy it means helping him deal better with whatever sounds that were triggering his sensitivities. Maybe we could use a Walkman or earphones, or look at reducing the amount of sound in the environment.

It is important that we do research to understand the underlying characteristics of Autism, because it directly informs the way we respond to and manage the right program for these children.

I think what we see happening now is an understanding of those characteristics of Autism that include the sensory, cognitive, communication and empathy areas. The high level of anxiety and fear we see in children with autism because of the characteristics of Autism and how they relate to the environment could really be the root cause of a lot of the behavioural problems in Autism.

Programs to help children with Autism

Biological & Psychodynamic

Firstly, there are the biological and psychodynamic approaches.

One biological approach is medication. There is good information about medication out there on the internet; I am not a medical practitioner so I don't feel very comfortable talking about medication.

The psychodynamic approaches are not very common in Australia. The idea of re-establishing an emotional attachment with the mother has never really taken hold in Australia, which is probably a good thing.

Educational & Behavioural

We know that the most effective programs for children with Autism are educational and behavioural programs.

Essentially these can be classified as primarily behavioural or developmental in orientation or somewhere in the middle – a more integrated approach.

It is important to look at what the program does, what makes it effective and what is available in NSW.

We can think of the educational programs in terms of a continuum – at one end of the continuum we have the traditional behavioural programs, for example in Sydney families can access C.A.R.D. (the Centre for Autism and Related Disorders).

The traditional behavioural approach to Autism was based on learning theory. This began in the late 60s and early 70s and was quite radical in suggesting that children with Autism could learn by using discrete trial training.

Traditional behavioural programs that are available today are 30-40 hours a week and very intensive.

Programs utilising Applied Behaviour Analysis (ABA) are where the most research has been done probably because those programs have been around a long time.

Programs like the Lovaas Program have made some fairly dramatic claims in terms of positive outcomes and generated a lot of controversy.

There is no doubt that ABA in the broad sense as a way of working with children with Autism is still one of the most effective tools we have. It is really looking at changing behaviour, developing skills through play and teaching appropriate behaviour.

Positive behaviour support is very much based on ABA. I think we have to differentiate between ABA as a tool and a method of working with children and ABA Programs, which are quite prescriptive and probably better described as intensive behavioural intervention (IBI).

There has been a lot of controversy generated in this area because of the pressure from families and professionals who want that intensive input.

Inclusive Behaviourist Programs

This is probably not so relevant here in Australia because we don't actually have an inclusive behavioural educational program. Suffice to say that one of the problems that children with Autism have is generalising the skills that they learn to other settings.

If you teach a child to do something like tie up their shoelaces in the classroom, they won't automatically be able to do that at home. You might have to teach it specifically at home as well.

One of the ideas was to teach children the skills they need in a regular setting so in, for example, the LEAP Program, you have 13 children in a preschool group, 3 of whom have Autism and 10 of whom don't – two staff, one aide and therapy support. It is a very traditional behavioural program but it is conducted in an inclusive setting.

Some Applied Behavioural Analysis programs have moved on from the traditional behavioural models to incorporate some of what we call the culture of Autism. I think probably the best known example here would be the Picture Exchange Communication System (PECS) program.

Family Services in Sydney's North & West

Learning Links receives limited funding for our Family Services in Sydney's western and northern suburbs. We have always tried hard to raise money to ensure that these services are free to parents.

Fundraising has proved more difficult in recent years and these areas lack the funding to cover the cost of the service. We will continue to support families with the current level of services in these areas, and if anyone can contribute to the cost of their service with a small donation, it would be much appreciated.

The PECS program uses behavioural technology to teach a child the skill. The skill that they are teaching is for the child to use a picture, for example a photograph or a line drawing, to request something because it is understood and acknowledged that children with Autism have much better visual than auditory skills.

The program is using behavioural technology but acknowledging the strengths of Autism that can be utilised to compensate for those deficit areas. It is unlike the traditional behavioural model which tends to move through typical developmental stages and would not have considered any alternative to training speech until the child was seven or eight years old.

Contemporary Behavioural programs are very popular and the PECS Program would be the most well known example in NSW.

Managing the environment

Moving into the middle of the continuum, we have programs that take account of the characteristics of Autism like visual support, good memory skills but also stress the importance of structure and routine for children with Autism. There is an emphasis on managing the environment as well helping children cope and function. There is also not the same promotion of the idea that the child will become normal.

These programs say that some of these characteristics are going to be with this child for life and we have to help them develop skills so that they can be independent and reach their maximum potential and we have to adjust the environment to help them function.

The TEACCH Program would be the best example of that and I would suggest that, although it hasn't been systematically researched, the ASPECT (was the Autism Association of NSW) program would be closest to the TEACCH Model here in NSW.

Developmentally-based programs

At the other end of the continuum, we have programs that are developmentally based that focus on following the child's lead. The idea is that you go into the child's world rather than trying to make the child come into ours – child-directed rather than adult-directed.

The emphasis is on playing with the child and developing the relationship with the child so the emphasis is on reaching the child. If the child is sitting there tapping, you sit there and tap until the child pays some attention to you.

Probably the best known example of this type of program here at the moment is the Relationship Development Intervention (RDI) program.

Assessing programs

I think it is helpful when you think about programs to know where they are coming from in terms of their philosophical basis because for some families a more behavioural approach is better and for others, the developmental approach is better.

There is probably more evidence supporting the behavioural approach but that doesn't mean to say that we can't look at the developmental approach as well. There has been research on the developmental approach but we just don't have the results because it hasn't been around quite so long. It is also harder to research. Behaviourally-based programs lend themselves very much to data collection.

There is a need to acknowledge the culture of Autism when developing programs.

A good example is the Hanen Program – It Takes Two to Talk. The Hanen Program was developed for children with Down syndrome and intellectual disabilities. The program is based on working with parents to help parents develop the skills to play and interact with their child and promote their child's development. Hanen uses a lot of video feedback and that kind of thing – it's very systematic.

Parents of children with Autism became interested in the Hanen Program and tried it. They found it wasn't as effective as it could be for children with Autism because they needed more visual input to help them utilise their visual spatial sphere and more structure and predictability.

The Hanen organisation, a Canadian based organisation of speech pathologists, came up with the Hanen Program – More Than Words. This program acknowledged the culture of Autism. I think this is a very good example of a program that was adapted to cater better for children with Autism.

From diagnosis to intervention

For those people who are involved in early intervention or who have young children with Autism, there is now an increasing recognition of the characteristics of Autism at a much younger age.

We now know what the first signs of Autism are. We have issues like social gaze difference, problems with joint attention and pre-verbal children who unlike their peers are unable engage their parents in a shared moment (such as attracting their attention to point to something or looking backwards and forwards between a parent and an object of interest).

As a result diagnosis is happening earlier and early intervention is increasingly important for these children and families. It is really important that as soon as the child is identified, there is some early intervention service that is going to meet that child's and family's needs.

Unfortunately that is not happening. One of the issues that keeps coming through is the fact that families have got a diagnosis but have to wait 12 months for intervention. That's devastating for someone who has a two-year-old to be told that there is nothing for them until the child is three.

They may be able to access other early intervention, but there are big waiting lists for programs tailored for children with Autism.

Autism is a multidisciplinary condition that affects a whole range of areas so we need to involve a range of professionals – educators, speech pathologists, occupational therapists, psychologists – making the assessment, diagnosis and intervention resource-intensive.

Family Support

Families are in there for the long haul with children – professionals move in and out of your life, but you're the ones that are there for the long haul, and really there is an increasing interest in how we can better support families through that process.

We are probably not doing it too badly in early intervention, but school can be a real issue for many families. They are often not very family friendly at school and that can be a real problem.

When parents were systematically surveyed, they said their partner was their main source of support and their extended family was second. Professionals came trailing along in third place.

This is what we need to focus on.

Research also tells us that we need to focus on the development of the social communicative process in children, preventing challenging behaviour and increasing independence and the ability to function independently in a normalised setting.

Programs in NSW

There are quite a few programs in NSW that are primarily behavioural, including a proposal for a school which is not actually up and running yet. The rest are primarily early intervention programs.

There are also integrated programs. Some of these such as the Aspect programs combine a developmental and behavioural approach and acknowledge the culture of Autism.

The Hanen Program – More Than Words is also available and this takes into account the culture of Autism.

Relationship Development Intervention is a very big in NSW at the moment. There is only one person trained to provide it here as yet, but there are families who are bringing people in from the States to do that program.

Giant Steps is difficult to classify because it was primarily a therapy based program for preschool and school age children with Autism, but it has now evolved into more of an educational program.

The NSW Department of Education hasn't yet formulated a theoretical framework for the work they do in the Autism Specific Support Classes of the Department.

For regional and rural areas, things are very difficult.

The Department of Education does have some support classes in regional NSW and ASPECT is expanding its regional reach quite significantly this year. ASPECT has opened up a program on the Far North Coast for early intervention and is opening school based and early intervention programs in Wagga Wagga and Albury.

How can parents assess programs?

There is a lot of variability in the quality, quantity, and availability and the type of program. It is a very difficult minefield for parents to find their way through.

We know that programs often have long waiting lists and many are very expensive in term of both money and time.

We really need up-to-date information about what's available so that families can make an informed decision and service providers know what they are referring children to.

We need more research to evaluate outcomes so that we can say confidently a program has a certain effect and we need some coordination so that when a child is diagnosed and a need is evident, a program is available. This continues to be a big problem.

Children and families are all very different so we need to know what type of child a program works particularly well for. We need to find out about whether age and language and cognitive ability effects outcomes.

Some programs work better for younger children, some work better for older children. Some work better for children with a significant intellectual disability and Autism, some for more high functioning children.

Questions to ask

What are the long-term outcomes? Very few programs can give you that information and I would include the ASPECT programs in that because it is very difficult research to do. It is an important question to ask to at least get providers thinking about it.

What are the costs of the program in terms of time, money, the impact and stress on the family and how well does this program meet the criteria for an effective program?

When we look at the research across the board, it is evident that it doesn't matter really what orientation the program has in terms of its philosophical basis, there are key things that have been identified which make programs successful despite their philosophical basis.

There is a need for Autism specific curriculum content to take into account the characteristics of Autism. We need to cater for a child's learning strengths and weaknesses.

We need to provide a highly supportive teaching environment characterised by predictability and routine and taking into account the sensory issues that children with Autism may be dealing with like overwhelming responses to some sounds or light.

For example, it is a good idea to not have fluorescent lighting if there are children with Autism around. Many people with Autism can actually see the flickering effect of fluorescent lighting and we know how irritating that can be to anyone when a fluro goes on the blink.

We need a functional approach to problem behaviour that just means looking at the function of the behaviour for the child. Why is this child trashing the house? What's going on? What's triggering this behaviour? What can we do to avoid those triggers?

Transition support is also really important. Programs that actually support the movement of the child from one program to the next, for example from an early intervention program to a school placement.

One core characteristic of a successful program is family involvement. Family involvement is seen as a key factor and good programs involve families in more than a token way. We need programs that do not see families once or twice a year to keep them informed but those with real consultation and involvement with families in the team.

In relation to the issue of intensity, the recommendation is for a minimum of 15 hours a week of treatment, which is a lot more than we usually have the resources to be able to provide.

When you talk to families you probably find out that they are doing that number of hours anyway because they might be accessing private speech pathology or occupational therapy or the child is going to a supported preschool a couple of days a week.

We need to provide more resources for early intervention particularly. We think it is quite normal for a child to spend 30 hours a week in school, but when it comes to early intervention, there doesn't seem to be the same understanding of the importance of access to services.

The provision of occupational therapy services relates to the big sensory issues around Autism. It is important to get some professional support to help teachers and the child's family accommodate those sensory issues.

There is a lot of debate as to whether it is best to educate children with Autism in a segregated setting or in an inclusive setting, but philosophically there is general movement towards inclusion.

For some people with Autism inclusion can work – it really depends on the child and what stage they are at and how well it's managed and how well it's resourced. There needs to be an emphasis on child independence, initiative and choice making and augmentative communication in an inclusive setting.

It's about understanding that these children are very good visually, but they have great problems understanding auditory input, especially speech. We need to work out how can we show them what we want them to know and provide them with the means for them to show us. It is all about thinking visually and communicating with the child using visual systems rather than auditory systems.

**Dr Roberts is a consultant specialising in Autism Spectrum Disorders. She works with individual clients as an early intervention teacher with young children with Autism, a researcher, a post-graduate supervisor and a lecturer, an educator in Australia and overseas. Dr Roberts has worked for ASPECT (formerly the Autism Association of NSW) for 20 years and her experiences range from hands-on service delivery as a teacher and speech pathologist to overall responsibility for the provision of all professional services delivered by ASPECT. Dr Roberts has a Doctorate in Linguistics and is a Senior Lecturer at the University of Canberra. She holds Honorary positions in the Department of English and Linguistics and MUSEC at Macquarie University and is a Clinical Lecturer at the University of Sydney where she also teaches the Autism strand in the Post-graduate Program in Developmental Disability Studies.*

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