



Guide to Living with Autism Spectrum Disorder Birth to 19 years

Families Achieving Life Satisfaction

This booklet may assist you and your family to identify possible solutions and services to support young people with Autism within the Wairarapa/Hutt Valley regions.

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Purpose of this information

This information has been developed by staff at Wairarapa and Hutt Valley District Health Boards (DHB) for families of children who suspect or have had a diagnosis of Autism Spectrum (ASD).

While information is available elsewhere we wanted to have a single document for families in our areas which provided some easy go to information about ASD.

We have had families and agencies that support young people and their families with ASD review this information.

An update is planned in 2017. Please forward updated information and feedback to FOCUS@wairarapa.dhb.org.nz or RES-ChildDevSvc@huttvalleydhb.org.nz

A list of acronyms is provided on page 21 of this document.

What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a developmental condition characterised by challenges in social communication, challenges with thinking and being inflexible in ways others are flexible. This may be evident with restrictive, repetitive or obsessional activities. This is a clinical diagnosis and clinicians will use clinical criteria when determining a diagnosis.

ASD is truly a spectrum and covers a range of abilities. Some terms that are also used for people on the spectrum include Autistic Disorder, Autism and Asperger's Syndrome. The most common current way to talk about a child diagnosed with ASD is to talk about their level of function in different areas.

Children diagnosed with ASD may have other developmental delays, intellectual disability, learning and emotional difficulties, specific syndromes and medical conditions such as epilepsy for example

What does ASD look like?

http://www.health.govt.nz/publication/what-does-asd-look-quickcard-english (and available in Maori and Pacifica languages)

Does this person have ASD?

http://health.govt.nz/publication/does-person-have-asd-quickcard

Autism Spectrum Disorder Guidelines

http://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline

Perspectives for Others

http://www.inmyshoes.co.nz/index.html (DVD about ASD)

Make use of the Health Passport to take with you to different appointments:

http://www.hdc.org.nz/about-us/disability/health-passport

Who are the ASD Coordinators?

The ASD coordinators follow up with families who have a child that has a *new diagnosis* of ASD and/or can support families through the diagnostic process. Your local ASD Coordinator is:

Jasmine Gray ASD Coordinator c/- FOCUS Wairarapa Hospital

P O Box 96 Masterton

Ph: 0800 900 001 or 06 946 9813 Ext: 4085 Email: jasmine.gray@wairarapa.dhb.org.nz

Heather Drysdale

Developmental Services Coordinator

C/- Child Development Service

Hutt Valley DHB Private Bag 31-907

Lower Hutt Ph: 04 570 9993

Email: heather.drysdale@huttvalleydhb.org.nz

What do I do if I think my child has ASD?

Talk to someone else who knows your child:

- Family Doctor
- Other medical specialist
- Teacher at Early Childhood or School

Or someone who checks your child's development:

- Tamariki Ora
- Plunket
- B4 School Check Nurse

If they also think ASD is a possibility, ask them to refer your child for a team assessment with your local Child Development Service.

Diagnosis

The ASD Guidelines recommend a team assessment. This team normally comprises 2 or more of the following:

- Paediatrician
- Occupational Therapist
- Speech-Language Therapist
- Psychologist
- Psychiatrist

Sometimes this team assessment is referred to as a Multi-Disciplinary Team (MDT) or Child Development Service team assessment.

The team assessment might involve (but doesn't always):

- A developmental interview
- Physical examination
- Follow up blood tests
- Play assessment
- Formal assessment tools
- Observation at early childhood or school
- Information from early childhood or school or other professionals

It is recommended in the ASD Guideline that children under six years old see a paediatrician and have an audiology assessment.

A feedback session is usually organised to discuss the results of all parts of the assessment and possible diagnosis and next steps.

In some circumstances some individual practitioners may diagnose ASD e.g. a Psychologist, Paediatrician or Psychiatrist.

Communication & Social Needs

Children on the spectrum have a broad range of communication abilities from being non-verbal to speaking with correct grammar, but with subtle issues such as their accent and intonation. A focus for communication includes how he/she communicates with others. Communication also involves how much your child follows the language being used with them.

Some children learn to communicate using other means – pictures, signs, devices known as Augmentative and Alternative Communication (AAC).

Children may also have difficulty interacting with others and following social rules, particularly with their peers. Sometimes it may appear that they don't want to interact with others, while some children may be keen to be involved but don't know how to go about this. There can be difficulty with the subtle social cues.

POSSIBLE SOLUTIONS

If a Speech-language therapist (SLT) is involved, talk with them about different approaches and interventions to support communication skills. Also discuss options with teachers and others about increasing communication opportunities.

Your child may be busy listening to what is said, thinking about what is being asked and how they will respond, so they may find it difficult to hold eye contact while they concentrate on this. Communication happens across the whole day, so think of times during the day when your child:

- Can share/show items
- Can let you know that he/she doesn't want something
- Can make requests for items and activities
- Can join in activities taking turns, e.g. hiding, tickling, more formal games, etc

Encourage social activities such as play dates with another child. Keep the time of the visit short and have a plan to support this. It is often best to start with the visits to your home.

Find local activities that your children might be part of such as Cubs or Brownies, swimming lessons, science clubs and Harriers.

At secondary school level, ask about buddy systems that the school runs or programmes such as the Duke of Edinburgh awards.

- Hanen Programme
 http://www.hanen.org/programs/for-parents/more-than-words.aspx
- Private SLTs Yellow Pages, NZSTA website
- The communication service run by IDEA services can work with families where a child has mild-moderate social-communication difficulties. Referrals are currently made by the ASD coordinators, health professionals, Life Unlimited and Focus
- Gesture dictionary/communication dictionary allows you to record your child's specific communication behaviours so that other people understand what they mean http://www.steppingstonesres.org/augmentandalt/004-comm.htm
- Vanderbilt Autism Resource Line. Email: autismresources@vanderbilt.edu http://kc.vanderbilt.edu/kennedy_files/VisualSupports-March2011.pdf
- Social Stories
 http://www.autism.org.uk/living-with-autism/strategies-and-approaches/social-stories-and-comic-strips.aspx
- Talklink is an organisation that helps with assistive technology including Augmentative and Alternative Communication (AAC): http://www.talklink.org.nz/
- Apps for Autism http://www.autismtoday.com/appsforautism.html
- Communication passports Person-centred booklet for those who cannot easily speak http://www.communicationpassports.org.uk/Creating-Passports/Templates/
- Cloud 9 run social clubs for pre-teens and teens as well as a mine-craft group in Tawa, Wellington. People from outside the area are welcome: http://withyoueverystepoftheway.com/about-us-2/

Behaviour

Some behaviour can be challenging. Problem behaviours normally happen for a reason and can be the child or young person trying to communicate – they are telling us something. Some behaviours might actually be developmentally appropriate for where your child is at right now.

Sometimes behaviour is a safety concern, e.g. a child running on the road. If other things aren't working, you could discuss safety concerns with any staff involved in your child's care or your Needs Assessment and Service Coordination agency to see if any assistance is available.

POSSIBLE SOLUTIONS

- Try using visual strategies such as visual schedules, Now and Then Cards, calendars, etc to support understanding
- Try using a timer to let your child know how much time they have on an activity
- Plan transition time if moving from one activity to another
- Some families find the Incredible Years Programme very useful
- Choose and prioritise which behaviour you will concentrate on
- Remember to have lots of positive play and activity time at other times with your child, this is often called 'time in'
- Try reducing the amount of language you are using so that they can focus on the key points
- Increase the amount of time your child has to process what is said
- You can use gesture or key sign, pictures and written information to support understanding
- Think about how you will use a strategy consistently throughout the day and talk to others who will also be with your child
- Think about what happens before and after the challenging behaviour occurs to identify triggers. The latter are called consequences and may be actually reinforcing the behaviour
- Think about what strategies help calm your child. Consider creating an individualised tool kit. One example of this may include:
 - MP3 player with music
 - Ear muff/plugs
 - Stress ball or equivalent
 - Note book and colour pencils
 - Hand sanitiser
 - Sunblock
 - Books
- Once your child is calm, you may be able to talk about what behaviour is okay and what is not okay. Talk about how others are feeling and how they are feeling. Use of comic strip conversations can be helpful with this.

INFORMATION/ASSISTANCE

 Your local NASC can refer you through to a Behaviour Service if this is appropriate. Contact your local NASC or your ASD Coordinator to assist you with this.

http://www.healthcarenz.co.nz/clients-families/behaviour-support-services/

• IDEA Services Behaviour/Communications programmes http://www.ihc.org.nz/our-services/specialist-services/autism-programmes/asd-communication-and-behaviour/

Tips for Getting the Most from Behaviour Support Services.
 http://www.altogetherautism.org.nz/file/Documents/2010-Documents/10-tips-for-getting-the-most-from-behaviour-support-services.pdf

• Incredible Years is a parent training course for managing behaviour. This is free and run at different times throughout the year:

http://www.incrediblefamilies.com/parenting-programmes/

 Resources Available from Autism Wairarapa Charitable Trust Email: autismwairarapa@gmail.com

 Tips for Autism is a course run by the Ministry of Education (MOE) with some MOH funding and is for educating staff and families around an individual child's needs http://www.tipsforautism.org.nz/

Visual strategies including social stories and comic strip conversations

www.usevisualstrategies.com

http://www.do2learn.com/picturecards/howtouse/schedule.htm

http://passthrough.fw-

notify.net/download/162332/http://kc.vanderbilt.edu/kennedy_files/VisualSupports-Nov2011.pdf

http://autismdigest.com/visual-strategies-valuable-support-at-any-age/

http://vkc.mc.vanderbilt.edu/assets/files/tipsheets/socialstoriestips.pdf

http://www.autism.org.uk/living-with-autism/strategies-and-approaches/social-stories-and-comic-

strips/how-to-use-comic-strips.aspx

http://www.autism.org.uk/living-with-autism/strategies-and-approaches/social-stories-and-comic-

strips/how-to-write.aspx

http://carolgraysocialstories.com/social-stories/

http://usevisualstrategies.com/about-linda-hodgdon/

• Tactics: An assessment, therapy and training service for behaviour issues.

(Private provider: see page 18).

Contact: 04 2330164 email: karenbaddiley@tautoko.org.nz.

www.tautoko.org.nz

CHALLENGES

Eating & Drinking

Selective eating is common. Sometimes there will be a pattern to the foods he/she likes and dislikes. This can be related to the colour, smell, and texture of the food.

POSSIBLE SOLUTIONS

- Be careful not to make food and family mealtimes a battle ground
- Think about the different food groups such as protein, carbohydrates, fruit and vegetables etc. and think about whether your child has something in their diet from each group
- Some children prefer the different foods on a plate not to be touching or mixed up
- Have a routine for mealtimes including washing hands, setting out the plates etc.
- If your child refuses to have certain food on a plate then give them a second plate to put the food on
- Encourage family mealtimes where everyone eats together and you sit at the table
- Get your child to help with food preparation
- Talk about food in a positive way
- Play with food make faces, feel the textures etc
- If your child likes science, you can bring in scientific concepts e.g. which food floats/sinks, which food remains hard or melts, which nutrients and vitamins each food contains etc.
- For a dish with many elements, e.g. pizza, start with one element they like and, once they get used to it, then add in extra elements one at a time
- Encourage the 5+ a day for fruit and vegetables. Look at the updated food pyramid together. (There is a new lay out, see link mentioned further below.)
- Encourage your child to touch the food initially and gradually work towards it being near their face, nose, lips and mouth. For some children, putting the food in their mouth can be very stressful so allow them to take their time
- Do not force your child to eat foods

- Talk to your GP or Paediatrician about a referral for a dietician and/or feeding assessment if your child has less than 30 foods in their diet. This is only offered through some DHBs
- Talk to your MOE speech-language therapist who might also have additional advice
- Sensory Processing Disorder Foundation website http://spdfoundation.net
- Visual Food Guide
 http://www.heartfoundation.org.nz/healthy-living/healthy-eating/healthy-heart-visual-food-guide
- 5+ a Day Education Resources
 http://www.5aday.co.nz/education/education-resources.aspx

Bowel & Bladder

Some children with ASD may take longer and be harder to toilet train. Other children have on-going difficulties with bowel and bladder function.

POSSIBLE SOLUTIONS

- Take your child to the toilet at regular intervals. Initially the goal is sitting on the toilet, so praise them for this. For bowel motions this is best half an hour after they have eaten. Don't make them stay there until something happens
- Encourage them to pull their pants up and down, wipe themselves, flush the toilet and wash their hands to support the routine
- With a bowel motion in a nappy, show the child you tipping it into the toilet and then encourage them to flush the toilet
- Talk with your child's teacher and other staff involved with your child about establishing a routine you can all do
- Keep fluids up and encourage a healthy diet
- Talk to your GP, paediatrician or other health practitioner about obtaining continence support if your child is over 4 years of age and in nappies through the day, this may be provided by your District Health Board (DHB)
- Having a visual schedule or social story can support toilet use
- Some children at school who have ongoing issues may be eligible for MOE high health funding so talk with the teacher and school
- Some families find a reward system works well when they are toilet training

- Continence NZ Helping kids young and old http://www.continence.org.nz

Physical Movement & Needs

For some children with a diagnosis of ASD, there may be some difficulty with movement skills. This may look like the child has coordination difficulties, struggles with sports (particularly team sports) and as a consequence they may be choosing to opt out of physical activities.

Being physically active is very important for everyone and finding activities that the child wants to participate in can sometimes be a challenge. Some children may be very active and seek a lot of physical movement

Below are some ideas that have been reported as more successful for children with ASD

POSSIBLE SOLUTIONS

- Try groups such as Scouts/Cubs and Guides/Brownies which give incentives like badges to complete activities
- Encourage a sport that is more individual rather than a team sport, e.g.
 martial arts, golf, fishing, tramping, archery, trampolining etc. These
 activities still allow being with peers but not necessarily the complex
 physical requirements of playing a team sport
- Talk to local gyms, sports clubs, ballet classes and swimming pools about how they adapt classes/encourage all participants e.g. for children with ASD
- A trampoline can be great for providing lots of physical movement

- Autism Intervention Trust has a weekly gym class in Wellington at Capital Gymnastics in Newtown (11 Hutchison Road, behind the NZ School of Dance), 9.30am to 11am on Sundays. It is organised into run in two groups - younger and older children. (School terms only). Cost is \$80 per term http://www.autisminterventiontrust.org.nz/wordpress/
- Ausome kids is for ages 3 10 years. Tuesdays 1pm 1.45pm. \$40.00 for the term.
 Contact Autism Wairarapa Charitable Trust on 06 370 4590
- Upper Hutt Special needs Indoor Sports: Thursday 3.30 4.30 (School term only).
 Contact Robyn Stokes (manager) 04 9767468 or 0210659872. email:robynls@clear.net.nz
- Some resources from dyspraxia websites can be useful for children with ASD http://www.dyspraxiadcdcork.ie/ http://dcd.canchild.ca/en/ www.dyspraxia.org.nz www.movementmattersuk.org/
- Youtube clips on how to do activities can be helpful e.g. riding a bike: https://www.youtube.com/watch?v=2eypxf5CzrA
- Riding for the Disabled: <u>www.rda.org.nz</u>

Sensory Needs

Sensory processing is a broad term that refers to the way in which we receive, organise and respond to information. We receive information through a number of senses including: tactile (touch), visual (sight), auditory (hearing), gustatory (taste) and olfactory (smell) senses. Additional senses relate to how we understand movement and how our limbs co-ordinate and relate to each other (proprioceptive and vestibular senses).

It is necessary for children to process information from a number of different sensory systems at the same time (modulate the information) in order to be able to attend to and react to information from different sources appropriately.

Children with autism may find it difficult to process sensory information. These difficulties may become a concern when they start impacting on the child's participation in functional activities (e.g. aversion to new clothes, not brushing teeth, not being able to sit at a place to complete a meal, getting scared of sitting on the toilet). Not all children have to have their sensory needs managed.

POSSIBLE SOLUTIONS

- Discuss any sensory issues with your paediatric Occupational Therapist if involved
- While there is a lot of information about weighted blankets there is not good evidence about these and they should be trialled with guidance from an Occupational Therapist
- For ONGOING RESOURCING SCHEME (ORS) funded children, ask your key MOE person about referring to the MOE Occupational Therapist if appropriate
- Use routines and visual schedules so that children can predict what will be happening and how long certain activities might last

- Sensory Processing Disorder Foundation http://spdfoundation.net
- Children's Therapy Clinic, run by private OT http://www.childrenstherapy.co.nz/index_files/Page1429.htm
- Sensory and motor therapy equipment http://www.sensorycorner.co.nz/catalog/

Sleeping

Lots of things seem harder when you and your child are missing out on a good night's sleep. Many children with ASD have issues with sleeping – including difficulty getting off to sleep, wakefulness during the night and disturbances through the night. Sleeping is a physical process but all children have to learn how to get to sleep.

POSSIBLE SOLUTIONS

- A good routine leading up to bedtime can support good sleeping habits.
- It can help if the different steps in this routine are displayed pictorially, this is called a "visual schedule"
- Have a consistent time for being in bed
- Light keeps children awake so think about good dark curtains
- If your child is anxious about the dark, opt for a small night light
- Keep TVs and other media devices out of the bedroom, e.g. tablets, laptops, smart phones
- The blue light in media devices actually lowers the amount of sleep hormone created, so try and have a two hour gap from using these devices before bedtime
- Some families report that having a heavy blanket on the bed has made a difference to their child staying asleep
- You can also talk to a medical practitioner about any medication options for supporting sleep
- Avoid caffeinated drinks

INFORMATION/ASSISTANCE

 Raising awareness of sleep health http://www.sleephealthfoundation.org.au

Early Childhood, Education & Employment

Choosing the right Early Childhood Education (ECE) and/or school can feel daunting. Many families worry about how their children will manage at ECE or school. The Government funds 20 free hours for 3 and 4 year olds in ECE. There may also be the possibility of extra ECE hours or out of school care (OSCAR) if you are receiving the Child Disability Allowance through WINZ and meet the eligibility criteria.

POSSIBLE SOLUTIONS

- Plan a transition to the centre see if the centre will let you do visits before your child starts or if you can stay to settle them in
- Plan a transition at least six months prior to starting ECE or school
- Transitions are also important if changing school, moving on to intermediate and college and leaving school
- Consider having a meeting with ECE or school staff for yourself and others involved to discuss the transition
- If you are with an Early Intervention provider (MOE/Wellington Early Intervention Team) they can support you through the transition to school, plus determine whether any funding or resourcing is appropriate for your child
- Treat each new class and change as a transition you plan for
- Discuss with the school the sort of support your child will be able to receive
- At school important people for you to be involved with are the classroom teacher, the Special Education Needs Coordinator (SENCO) and often the school principal or assistant and deputy principal
- Individual planning meetings at ECE or school are useful to help you set specific goals for your child as well as how to support those goals. At school these are usually called Individual Education Plans (IEPs)
- Make use of transition books and 'survival' kits
- Consider the use of a home/school communication book

- Starting school and ECE http://www.education.govt.nz/
- NZ Education 0 through to 16+ http://www.education.govt.nz/home/our-new-website/
- Tips for Autism: http://www.tipsforautism.org.nz/
- Autism NZ Framework for Autism (FANZ course)
 <a href="http://www.autismnz.org.nz/training_programmes/fanz_programmes
- Supporting school age children on the autism spectrum http://www.positiveparterships.com/au
- Australian Education website for Parents and Teachers http://www.positivepartnerships.com.au/

Support Groups & Information

When families get a diagnosis of ASD, it can be quite overwhelming. Even if you thought ASD was likely, it can still be challenging. Take time to process this and don't feel that everything has to happen at once. Remember your child is still your child and they have their own personality and potential.

Contacts for organisations that offer support and information

ORGANISATION	WHAT THEY DO	HOW TO CONTACT THEM
Altogether Autism	Provide individualised information on autism and autism related issues. This can range from straightforward information on the services and supports in a particular region, to complex medical or psychological advice for specific problems.	0800 273 463 http://www.altogetherautism.org.nz/
Autism NZ Inc	Provide support, resources and information on autism spectrum disorders to those with these conditions, their family/whānau, caregivers and professionals working with them.	04 803 3504 Wellington 06 929 7004 Wairarapa 0800 288 476 http://www.autismnz.org.nz
Autism Wairarapa Charitable Trust	Autism Wairarapa Charitable Trust provides support, information and advocacy for people affected with ASD and other associated conditions. Support Group is each month and resources are available upon request.	Wendy Paterson Wendy Roesler 06 370 4590 autismwairarapa@gmail.com
Barnados	Children are the heart of what they do. They offer a range of support for children, parents, families and communities throughout Aotearoa New Zealand	0800 005 437
Birthright	Works with families to facilitate the growth of confidence, skills and resilience within the family unit and with individual members	04 567 7123 Hutt Valley 04 499 0055 Wellington
CCS Disability Action	Provide support and strengthen communities so people with disabilities are included in the life of the family and in their community.	0800 227 2255
CCS Disability Action Wairarapa CCS Disability Action Lower Hutt	Information on local activities for people with disabilities e.g. bocchia group, archery, ten pin bowling	06 378 2426 Wairarapa 04 567 891 Lower Hutt info@CCSDisabilityaction.org.nz
Cloud 9	Cloud 9 run regular social clubs and mine craft groups in Tawa, Wellington	http://withyoueverystepoftheway.co m/
Family Works	Want all children/tamariki to flourish, so they work to support them and their families/whanau and to champion their cause in our communities	04 439 4900 Wellington 04 528 4164 Hutt Valley 06 308 8028 Wairarapa
IDEA Services Hutt Val	IDEA services run a free programme for families of children before they start school called ASD Plus. They also have a programme for families of children 11-16 years old called Growing Up with Autism (GUWA) Ley and Wairarapa DHB: ASD Guide March 2016	0800 273 7587 14

IHC Library	The IHC library has a great selection of books for children and adults, DVDs and other resources on ASD. It is free to register and borrow items although you will need to organise to return items and pay for postage or take back to the library in Wellington.	http://www.ihc.org.nz/rsources/our-library/ 0800 442 442
NZ ASD Guidelines	A guideline for ASD	http://www.health.govt.nz/publicatio n/new-zealand-autism-spectrum- disorder-guideline
Open Home Foundation	The Open Home Foundation of NZ has been helping families since 1977, providing secure and loving Christian social services for children, young people and their families throughout New Zealand.	04 566 3990 Hutt Valley 06 378 2195 Wairarapa
Parent to Parent	Have a regular e-newsletter: email them to receive this	04 569 9398 Wellington wellington@parent2parent.org.nz
Positive Partnerships is an Australian Education website.	Supporting school age children on the autism spectrum	http://www.positivepartnerships.co m.au/public/index.cfm?action=show PublicContent &assetCategoryId=686
Supergrans	SuperGrans is a free service open to everyone who wants practical assistance and support in learning the basics of home management and life skills to better provide for oneself or family.	06 377 3115 Wairarapa 04 566 9778 Hutt Valley
Supporting Families Wairarapa	SFW offers: support for family/whānau/friends who care for someone with a mental health or Resource addiction issue with education, information and advocacy, supports people with experience of mental illness or other disability into employment, further education and community participation, Reducing stigma around mental illness and disability through education and support	Centre open Mon – Fri 10am – 3pm 06 3773081 Wairarapa www.sfwai.org
Wairarapa STARS trust	Wairarapa STARS trust support people who are affected by a disability or a barrier to employment or any service related to employment. They help people to develop a CV or write cover letters to interview skills. They can assist people to find work experience to gain skills to enter the work force.	Contact Shane Haskell 06 377-3171 or 027 2679462 or shane@starstrust.org.nz
Wellington City Mission	The Wellington City Mission operates four community service programmes - Mission for Families, Mission for Youth, Mission for Independence and Mission for Seniors. Through two subsidiary organisations The Mission also runs Kemp Home & Hospital (Mission Residential Care Limited), and their Ezee Meals manufacturing business (Mission Foods Limited	04 389 2033 (Wellington)
Your local library may hold different books and resources you can borrow		

Government Agencies and Services

Various agencies provide support for your child. These may be funded by the Ministry of Health (MoH) or Ministry of Education (MoE). Not all children are eligible for all of the services listed.

Sometimes there is so much happening for a family that a referral to Strengthening Families will often be made. The purpose of this is to coordinate all the agencies you are involved with to work out how best to support your situation: http://www.strengtheningfamilies.govt.nz

HEALTH AND EDUCATION FUNDED SERVICES

- For a full list of General Practice's (G.P's) refer to your local DHB or White Pages
- DHB Paediatricians review and monitor children's development
- Child Mental Health teams at the DHBs will assess and see children who have issues with mental health over and above their diagnosis of ASD
- Other DHB staff who could be involved with your child include, for example, Public Health Nurses and Social Workers

Wairarapa DHB is developing a Child Development Service and currently employs Occupational Therapists, Physiotherapists, and visiting Child Developmental Therapists

Paediatrics Outpatients Department

Hutt Valley DHB Child Development Service employ Occupational Therapists, Physiotherapists, Speech-language Therapists (feeding), Psychologists, Visiting Child Developmental Therapists and a Therapy Assistant

Paediatrics Outpatients Department

Ministry Of Education Early Intervention Teams.

Both Wairarapa and Hutt Valley areas have Early Intervention teams who employ Early Intervention Teachers (EITs), Speech-Language Therapists (SLTs), Psychologists, Advisors on Deaf Children (AODC) and Kaitakawaenga (KTW)

Ministry Of Education School Teams

Children are eligible for MOE services when they are Ongoing Resourcing Scheme (ORS) funded, have significant communication and or behavioural needs. The Wellington Early Intervention Team (WEIT) is based in Lower Hutt and operates across the region. They employ a Physiotherapist, Speech-Language Therapist, Early Intervention Teachers and a Music Therapist. WEIT receives the same level of funding per child as both DHB & MOE services. It is run as a TRUST and does charge a top up donation:

04 567 4082 Wellington

or go to www.weit.org.nz

Ministry of Health (MoH)	http://www.health.govt.nz/search/results/autism
	and search under Autism Spectrum Disorder and/or special education
Ministry of Education (MoE)	http://www.education.govt.nz/
	and search under Autism Spectrum Disorder and/or special education
Needs Assessment Service Coordination Agencies (NASC)	Wairarapa DHB area, NASC = FOCUS Contact: 06 946 9813
There may be a discussion about referral to the Needs Assessment and Service Coordination (NASC) and there is a different NASC in each area. Your child is eligible and can be referred to this service if they have the diagnosis of ASD and have disability support needs. The NASC complete checks with you and your child to determine goals, needs and strengths. Supports such as carer support may be allocated as part of a support package.	Hutt Valley DHB area, NASC = Life Unlimited Contact: 04 569 3102
School	
Important people are your child's teacher or the Special Education Needs Coordinator (SENCO). Special supports for children at school are based on eligibility criteria. See school section.	
Work and Income	http://www.workandincome.govt.nz/individuals/a-z-
For disability allowance information	benefits/disability-allowance.html

Private and Alternative Services

Autism Intervention Trust:

Supports families to access behavioural interventions for their child as well as running a Wellington based holiday programme and gym http://www.autisminterventiontrust.org.nz/wordpress/

Victoria University:

Psychology clinic carries out Cognitive assessments and some interventions for a fee. Opening Hours: Monday to Thursday 9:00 am - 5:00 pm 04 463 6400 Email: psycholinic@vuw.ac.nz

Educational Psychology:

Programme which looks at programmes for children including use of Augmentative and Alternative Communication Systems and may be part of research programmes: The Educational Psychology Clinic 04 463 9772, Email: jeff.sigafoos@vuw.ac.nz

Private Psychologists:

See the Yellow Pages or the New Zealand College of Clinical Psychologists for details http://www.nzccp.co.nz/for-the-public/find-a-clinical-psychologist/ Or

The New Zealand Psychological Society http://www.psychology.org.nz/?

• Private Occupational Therapists:

See the Yellow Pages or New Zealand Association of Occupational Therapists (NZAOT) http://www.nzaot.com/

• Private Speech-Language Therapists Association (NZSTA):

For details: http://www.speechtherapy.org.nz/page/find-a-therapist/map-and-listings/

• Private Paediatricians:

See Yellow Pages or the Paediatric Society for details: http://www.paediatrics.org.nz/

• Private Psychiatrists:

See Yellow Pages or White Pages http://yellow.co.nz/

SPELD:

Can do an assessment to determine if your child has a specific learning disability such as dyslexia (written language) or dyscalculia (maths). They also provide follow up intervention: www.speld.org.nz

• Skylight Counselling and Support Services:

www.skylight.org.nz or 04 920 9967

Tactics:

An assessment, therapy and training service for behaviour issues. Contact: 04 2330164 email karenbaddiley@tautoko.org.nz. www.tautoko.org.nz

Local Agencies & Support

- Information/Assistance Hutt Valley/Wairarapa
 - Citizens Advice Bureau, 06 3770078, 0800 367 222 Wairarapa
 - Citizens Advice Bureau: Petone
 - http://www.cab.org.nz/acabnearyou/petone/Pages/home.aspx
 - 04 568 8877 and email: cab.ptone@xtra.co.nz
 - Citizens Advice Bureau Upper Hutt
 - http://www.cab.org.nz/acabnearyou/upperhutt/Pages/home.aspx
 - 04 528 9040 and email: cab.upperhutt@clear.net.nz
- Check your local paper and newsletters
 - Wairarapa Times Age
 - Community News
 - Wairarapa News
 - Carterton Crier
 - Greytown Grapevine
 - Martinborough Matters
 - Featherston Phoenix
 - The Hutt News: http://fairfaxmedia.newspaperdirect.com/epaper/viewer.aspx
 - Upper Hutt leader: http://fairfaxmedia.newspaperdirect.com/epaper/viewer.aspx
- (i-site) for general information on activities in the Wairarapa 06 3700900 www.wairarapanz.com
- King Street Art Works 16 Queen Street, Masterton is a creative space for those who have used mental health services, 06 378 9777, www.kingstreetartworks.co.nz
- Local gyms and exercise groups
 - Way Yoga, 06 377 1802
 - Body Mind Pilates, 06 370 1121
 - City Fitness, 06 377 7699
 - CLM Health and Fitness. 06 370 0060
 - Greytown Health and Fitness, 06 304 8656
- Local swimming pools
 - Genesis Recreation Centre, 06 378 7758
 - Carterton, 06 379 5067
 - Greytown (only open during summer), 06 306 9611
- List of supports, including foodbanks, gyms etc. through the Hutt Valley PHO Te Awakairangi Health: http://www.teawakairangihealth.org.nz/ourservicesandprogrammes
- Marae social and health programmes
 - Kokiri Marae, Seaview, Lower Hutt: 04 939 7111 web: https://www.kokiri.org.nz/
 - Orongomai Marae, Wallaceville, Upper Hutt: 04 527 8944 web:
 http://www.orongomaimarae.co.nz/ Email: orongomai.marae@paradise.net.nz:
 - Waiwhetu Marae: 04 5668214: http://www.atiawa.com/ Email: waimre@xtra.co.nz
 - Wainuiomata Marae: 04 5648395 http://www.wainuiomatamarae.org.nz/
 - Koraunui Marae, Stokes Valley: 04 939 6662
- Toy Libraries: for Wainuiomata, Eastern Harbour, Petone, Lower Hutt, Taita, Western Hills, Stokes valley, Upper Hutt http://www.huttkids.co.nz/toy-libraries-upper-hutt-valley

	Terms/Acronyms
AAC	Augmentative & Alternative Communication
AODC	Advisors on Deaf Children
ASD	Autism Spectrum Disorder
AWCT	Autism Wairarapa Charitable Trust
CCS	CCS Disability Action
DHB	District Health Board
ECE	Early Childhood Education
EIT	Early Intervention Team
FANZ	Framework for Autism in New Zealand
GP	General Practitioner (or Doctor)
GUWA	Growing Up With Autism
HDC	Health & Disability Commissioner
KTW (MLC)	Kaitakawaenga (Maori Liaison Coordinator)
IEP	Individual Education Plan
MDT	Multi Disciplinary Team
MOE	Ministry of Education
МОН	Ministry of Health
NASC	Needs Assessment & Service Coordination
NZAOT	New Zealand Association of Occupational Therapists
NZSTA	New Zealand Speech-Language Therapists Association
ORS	Ongoing Resourcing Scheme
OSCAR	Out of School Care and Recreation
ОТ	Occupational Therapist
RTLB	Resource Teacher Learning & Behaviour
SENCO	Special Education Needs Coordinator
SLT	Speech-Language Therapist
SPELD	Solutions for People Experiencing Learning Difficulties
WEIT	Wellington Early Intervention Team
WINZ	Work & Income New Zealand

Feedback, Advocacy and Complaints

YOUR RIGHTS AND RESPONSIBILITIES:

- You have the right to be treated with dignity and respect
- Your privacy and confidentiality will be respected at all times
- Your cultural and personal background, beliefs and values will be taken into account by our service
- You have the right to be involved in and informed at all stages of our service involving you
- You can refuse to have, or withdraw from our service at any time
- You have the right to decide who is with you during meetings we have with you
- You are entitled to receive information in a format or via a medium you can understand
- You have the right to access all the information we gather and hold about you at any time and to know how that information will be used
- You have the right to raise any concerns you have about our service with us at any time,
 and to have those concerns dealt with promptly by us
- You should provide all the information we ask for to ensure the best outcome

WAIRARAPA DHB FEEDBACK

In writing Complete a green Feedback form available in all areas of the hospital

Phone Call the Quality officer on 06 946 9800 (South Wairarapa residents 0800 946 9800)

Email <u>quality@wairarapa.dhb.org.nz</u>

HUTT VALLEY DHB FEEDBACK

In writing Hutt Valley DHB Quality Team, Hutt Valley DHB, Private Bag 31907, Lower Hutt

Phone 04 566 6999

Email feedback@huttvalleydhb.org.nz

You also have the right to involve a health advocate and/or the office of the Health and Disability Commissioner.

The Health and Disability Commissioner

PO Box 1791, Auckland

Telephone:

Auckland 09 373-1060 Wellington 04 494 7900 Email: hdc@hdc.org.nz The Nationwide Advocacy Service

Free phone: 0800 555 050 Email: advocacy@hdc.org.nz