Concern is raised that a child may have Autistic Spectrum Disorder

Symptoms and Risk Factors for ASD

Screening Tools and When to Use them

Referrer:
Are there Urgent Concerns?

Yes

No

Send referral to Paediatric Outpatient Clinic

What to include in referral letter

Triage:
Does referral letter indicate ASD?

Symptoms and risk factors for ASD

Yes/ Possible
(Including referrals made outside of WDHB)

No/ Unlikely

Incomplete information in referral

Triage clinician contacts GP and/or family for more info.

What to include in referral letter

Yes/ uncertain

Proceed to assessment

- Developmental Coordination Service (DCS) Coordinator initiates contact with family, discusses consent for process, and collects information. Letter is sent to GP and family. (link to letter)
- Patient is booked for review in General Paediatric Clinic. Triage guidelines

No

- Referral is triaged to appropriate destination.
- Exit ASD pathway.

Assessment/management (page 2)
ASD ASSESSMENT AND MANAGEMENT

● Paediatric Outpatient Clinic appointment within 8 weeks of referral. Medical/Developmental Assessment ASD Diagnostic and Assessment Tools (at discretion of clinician)
● DCS Coordinator collects additional information if needed from parents, MOE, Early Childhood Education, educational psychologist

Assessment Outcome

ASD diagnosis
(Meets diagnostic criteria)

Does not meet ASD diagnostic criteria

Uncertain
(Only progress to this branch of pathway once.)

MEDICAL
Ensure appropriate medical assessment has been done.

REFERRALS
● Ministry of Education-Special Education for Speech Language Therapy and Early Intervention.
● Taikura Trust for
  – Needs assessment and coordination of disability supports
  – Safety issues
  – Behaviour support
  – Respite for families.
● WINZ supports (such as Child Disability Allowance).

As appropriate:
● Occupational therapy (via CDS) for sensory profile when sensory issues significantly impact on function.
● Marinoto if Mental Health comorbidities.
● Social work (via CDS).

CAREGIVER EDUCATION
DCS coordinator provides information re: community supports and education, websites, pamphlets.

FOLLOW UP:
Clinical review within 6 months.

DCS coordinator may remain involved to support family for up to 2 years.

Referrals to other services as appropriate:
● Family Works
● Paediatric clinic
● Social Work
● MOE-SE
● Marinoto.

Ensure appropriate interim measures are in place:
● SLT
● Hearing assessment
● Parenting support
● etc.

Discuss at next MDT meeting, if necessary.

Refer for further assessment, if necessary:
● ADOS
● Play assessment (through Marinoto),
● Second opinion

Paediatric clinic review within 6 months.

EXIT ASD PATHWAY
● Ensure clinic letter is copied to family, GP, referrer (if not GP), and DCS Coordinator.
● Clinician may:
  – determine need for ongoing care under specialist services. Guidelines for paediatric/mental health follow up
  – discharge to primary care, with GP review within 6 months. Guidelines for GP to re-refer to Paediatric Clinic.

Further information:
CeDSS page about Autism
More information about ASD assessment
ASD differential diagnosis

CeDSS page about Autism
More information about ASD assessment
ASD differential diagnosis

Uncertain
(Only progress to this branch of pathway once.)

Back to referral/triage, page 1
ASD MULTI-DISCIPLINARY TEAM MEETING

The ASD MDT meeting will consist of:
- Paediatrician
- Paediatric registrar
- Representative from Marinoto
- Developmental Coordination Service coordinator
- Occupational therapist *may be included at later date*
- Speech language therapist (from Ministry of Education) *may be included at later date*

The roles of the MDT meeting will be:
- Review and discuss diagnosis of children who have been assessed in clinic.
- Determine need for further assessment of children with uncertain diagnosis.
- Discuss patients with potential ASD who have been reviewed in Paediatric or Marinoto clinics for other reasons.
- Review children who have been referred with a previous diagnosis of ASD.
Symptoms and Risk Factors for Autism

**SYMPTOMS OF AUTISM**

**GENERAL SYMPTOMS OF AUTISM**
- Developmental milestones (language and motor)
- Unusual social interactions or behaviours
- General health
- Eating and sleeping patterns,
- Potential familial or environmental effects on development

**AGE UP TO 12 MONTHS**
**Failure to**
- look at faces,
- smile at others,
- coo/vocalise with pleasure
- respond to name,
- Babble,
- play social games,
- display “bright affect” (big smiles, warm joyful expressions)

**AGES 12-18 MONTHS**
**Failure to**
- Follow a point
- Point to request
- Point to indicate interest
- Use gestures
- Imitate
- Show interest in peers

**AGES 1-3 YEARS**
- Minimal showing/sharing of attention No babbling, pointing to or showing of objects or other gesture by 12 m
- No meaningful single words by 18m
- No two-word spontaneous (not echoed or imitated) phrases by 24mo
- ANY loss of any language or social skills at ANY age
- Link to NZ ASD Guideline for other symptoms
- Decreased attention to face/eyes
- Limited response to name
- Limited shared affect

**AGES 4-8 YEARS**
- Communication impairments
- Social impairments
- Impairment of interests, activities, behaviours
- Link to NZ ASD Guideline for symptoms

**AGE OVER 8 YEARS**
- Symptom changes and diagnostic dilemmas
- Social deficits
- Difficulty meeting academic expectations
- Considerations such as family, cultural, community, or other demographic factors that mediate the dysfunctional quality of behaviours

**SOME TYPICAL BEHAVIOUR FOR INFANTS/ TODDLERS**
- Echolalia (until 18-24 months)
- Repetitive movements (until 6-9 months)
- Insistence on sameness (3 years)
- Lack of pretend play (until 18 months)
- Jargoning (until 18 months)

**RISK FACTORS FOR AUTISM**
- Sibling with ASD
- Concern from parents or other caregiver
- Paediatrician concern
- Known conditions associated with ASD
  - Fragile X
  - Trisomy 21
  - Rett Syndrome
  - Global Developmental Delays
  - Neurologic conditions
  - Tuberous Sclerosis

Follow links to: SCREENING AND REFERRAL  ASSESSMENT AND MANAGEMENT  ASD PATHWAY Development Team

Back to referral/triage (page 1)  Back to assessment/management (page 2)
WHEN TO SCREEN FOR AUTISTIC SPECTRUM DISORDERS

Routine developmental surveillance at 18 months and 24 months
- Open-ended questions about concerns re: child’s development and behaviour
- Ascertainment of social and language milestones
- Child observations

Parental concerns
- Typically language delay
- First concerns arise around 15-18 months and are reported to clinicians several months later

Siblings of children with ASD
- Recurrence risk of 18-25% (20x greater than general population)
- Siblings also at greater risk of other difficulties

Children with conditions known to be associated with ASD
- Trisomy 21
- Fragile X
- Tuberous Sclerosis
- Rett Syndrome
- Global developmental delay
- Neurologic conditions

ASD SCREENING TOOLS

CHAT Checklist for Autism in Toddlers, ages 18-36 months

MCHAT-R, ages 16-30 months
20 questions

<table>
<thead>
<tr>
<th>Interpretation:</th>
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<tbody>
<tr>
<td>0-2 Low risk Passed, no action required. If &lt;24 months, rescreen after 2nd birthday</td>
</tr>
<tr>
<td>3-7 Medium risk Administer f/u interview (failed items) 0-1= pass 2+ = fail--&gt; refer for diagnostic evaluation</td>
</tr>
<tr>
<td>8-20 High risk Refer for diagnostic evaluation</td>
</tr>
</tbody>
</table>

CARS Childhood Autism Rating Scale, checklist for children 24 months and older
Scores over 25.5 indicate ASD

Communication and Symbolic Behaviour Scale—DP Infant Toddler Checklist
6-24 months
CONSIDER OTHER DIAGNOSES AND REFER FOR APPROPRIATE SUPPORT

- **Behaviour problems**: refer to Family Works for support 835-1288
- **Educational difficulties**: address through educational system
- **Developmental delays**: refer to outpatient paediatric clinic
- **Care and protection concerns**: refer to Child Youth and Family 0508-FAMILY (0508-326 459)
- **Intellectual disability**
- **Hearing impairment**: refer for hearing assessment for all children (<6?) with concern about language development
## INDICATORS FOR URGENT ACTION

### Urgent clinical concerns
- Loss of developmental milestones
- Deteriorating neurological signs or symptoms

### Child safety or protection concerns
- Child at risk to him/herself or others
- Care and protection concerns

### Urgent mental health concerns
- Safety issues with harm to self or others
- Severe anxiety

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GUIDELINES FOR REFERRAL LETTERS

Please include the following information in a referral letter:

- Specify concerns (including urgent concerns), duration of symptoms, whether there has been regression
- Past medical history
- Developmental history
- Examination and laboratory findings
- Significant family history (autism, developmental disorders, neurologic disease)
- Relevant social history
### TRIAGING REFERRAL TO PAEDIATRIC CLINIC

#### New Referrals
- **Age 0-15 years**: to be seen in General Paediatric Clinic.
- **Age 15+ years**: seen in Marinoto Clinic.

#### Re-referrals
- Patients who have been seen previously will be triaged to see the clinician who saw them previously, whenever possible.
- Medical problems (developmental regression, medication concerns, neurologic signs) will be seen by a medical doctor.
- Behaviour or mental health issues (aggression, anxiety, school phobias, etc.) will be reviewed by the DCS coordinator and/or discussed at the next MDT meeting.
Dear Family

Your child has been referred to the Paediatric Department at Waitemata District Health Board due to concerns over development or behaviour. You can expect a clinic appointment within 8 weeks, where your child’s behaviour and development will be assessed as well as a medical examination. You may also be contacted by one of our team members to learn more information about your child.

Regards,

The Paediatric Department
MULTIDISCIPLINARY TEAM

- Paediatrician
- Marinoto Mental Health representative
- DCS coordinator
- As appropriate:
  - Ministry of Education service coordinator
  - Child Development Service OT or team leader
**MEDICAL AND DEVELOPMENTAL ASSESSMENT**

**History:**
- Pregnancy and delivery (including alcohol and drug exposure)
- Medical problems,
- Medications,
- Family history (ASD, neurologic diseases, seizures, developmental disorders)

**Developmental assessment** for all children <6 years: early milestones, loss of milestones,

**Physical exam**
- Growth including Head circumference
- Dysmorphism (e.g. syndromic features, Foetal Alcohol Syndrome, etc.)
- Neurologic exam
- Neurocutaneous markers (e.g. Tuberous Sclerosis or Neurofibromatosis)

**Labs/ x-rays (as indicated)**
- TFT
- LFT
- CK
- As clinically indicated:
  - Fragile X
  - Chromosomal karyotype
  - Chromosomal Microarray [Link to LabPlus information](#)
  - MECP2 (Rett) probe

**Hearing assessment** in all children with concern about language development

**Other investigations** EEG if clinically appropriate
### ASD Screening Tools

- **CHAT** Checklist for Autism in Toddlers, ages 18-36 months
- **MCHAT-R**, ages 16-30 months
- **CARS** Child Autism Rating Scale, ages over 24 months, scores over 25.5 indicates possible ASD.

### ASD Diagnostic and Assessment Tool

- **DSM-IV**
- **DSM-V**
- **ICD-10**
- **CARS** Child Autism Rating Scale, ages over 24 months, scores above 25.5 indicate diagnosis of ASD
- **ADOS** (Autism Diagnostic Observation Schedule), if diagnostic uncertainty
- **Autism Mental Status Exam**

Less frequently used assessment tools:
- **ADI-R** (Autism Diagnostic Interview)
- Asperger Syndrome Diagnostic Interview
DSM-IV AUTISTIC SPECTRUM DISORDERS

[The following is from Diagnostic and Statistical Manual of Mental Disorders: DSM IV]

(I) A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) qualitative impairment in social interaction, as manifested by at least two of the following:
1. marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

(B) qualitative impairments in communication as manifested by at least one of the following:
1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. stereotyped and repetitive use of language or idiosyncratic language
4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following:
1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, non-functional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

(A) social interaction
(B) language as used in social communication
(C) symbolic or imaginative play

(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder
DSM-V AUTISTIC SPECTRUM DISORDERS

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. **Deficits in social-emotional reciprocity; ranging from abnormal social approach** and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,

2. **Deficits in nonverbal communicative behaviors used for social interaction**; ranging from poorly integrated-verbal and nonverbal communication, through abnormalities in eye contact and body language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

3. **Deficits in developing and maintaining relationships**, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases);

2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes);

3. Highly restricted, fixated interests that are abnormal in intensity or focus (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests);

4. **Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment** (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects); *(emphasis mine)*

**This is new

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.

*Back to diagnostic tools*
*Back to referral/triage (page 1)*
*Back to assessment/management (page 2)*
ICD-10 DIAGNOSTIC CRITERIA FOR AUTISM DISORDER (ICD-10) (WHO 1992)

A. Qualitative impairment in reciprocal social interaction, three from the following five areas
   1. failure to use eye gaze, body posture, facial expression and gesture to regulate interaction adequately;
   2. a failure to develop (in a manner appropriate to mental age, and despite ample opportunity) peer relationships that involve a mutual sharing of interests, activities and emotions;
   3. rarely seeking and using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness;
   4. a lack of shared enjoyment in terms of vicarious pleasures in other people’s happiness and/or a spontaneous seeking to share their own enjoyment through joint involvement with others;
   5. a lack of socio-emotional reciprocity, as shown by an impaired or deviant response to communicative behaviours;

B. Qualitative impairments in communication, two from the following five areas
   1. a delay in, or total lack of, spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication;
   2. a relative failure to initiate or sustain conversational interchange (at whatever level of language skills is present) in which there is a reciprocal to and fro responsiveness to the communication of the other person;
   3. stereotyped and repetitive use of language and/or idiosyncratic use of words or phrases;
   4. abnormalities of pitch, stress, rate, rhythm and intonation of speech;
   5. a lack of varied spontaneous make-believe play, or when young, social imitative play.

C. Restricted repetitive and stereotyped patterns of behaviour, interests and activities, two from the following six areas
   1. an encompassing preoccupation with stereotyped and restricted patterns of interest;
   2. specific attachments to unusual objects;
   3. apparently compulsive adherence to specific, non-functional routines and rituals;
   4. stereotyped and repetitive motor mannerisms that involve either hand/ finger flapping or twisting or complex whole body movements;
   5. preoccupation with part-objects or non-functional elements of play materials (such as odour, the feel of their surface, or the noise/vibration that they generate);
   6. distress over changes in small, non-functional details of their environment.

D. Developmental abnormalities must be present in the first three years for the diagnosis to be made

E. Clinical picture is not attributable to other varieties of pervasive developmental disorder, specific developmental disorders of receptive language with secondary socio-emotional problems; reactive attachment disorder or disinhibited attachment disorder, mental retardation with some associated emotional/behavioural disorder, schizophrenia of unusually early onset; and Rett syndrome.
REFERENCES

Autism Diagnostic Observation Schedule (ADOS)

Indications:
ADOS can be helpful if there is diagnostic uncertainty.
It is not needed if a child meets diagnostic criteria with DSM-V, ICD-10.

Patients determined to need ADOS will be allocated for an assessment at the Multidisciplinary Team Meeting.
Autism Mental Status Exam, link [www.autismmeentalstatusexam.com](http://www.autismmeentalstatusexam.com).

This gives you links to information about the Autism MSE including:
- Manual for how to use the tool
- “Get AMSE” link to download the tool
EDUCATION AND SUPPORT FOR FAMILIES

INFORMATION SHEETS FOR FAMILIES
Community Information Sheet North and Rodney - support and activity groups
Community Information Sheet West - support and activity groups

OTHER RESOURCES
• List of other ASD Patient Information Resources (Autism site on CEDSS)
• Private Behavioural Specialists
• Parenting supports

Follow links to: SCREENING AND REFERRAL ASSESSMENT AND MANAGEMENT ASD PATHWAY Development Team
INDICATIONS FOR ON-GOING FOLLOW UP WITH CHILD HEALTH SERVICES

**MEDICAL FOLLOW UP**
- Patients with developmental issues,
- Wider health concerns,
- Requirement for medication management,

**MENTAL HEALTH FOLLOW UP**
- Patients with significant anxiety or aggression
- Extreme anxiety affecting child/young person across two domains
- Depression
- Self-harm
- Suicidal ideation
- Extreme behaviour problems
- ADHD
- Obsessive-Compulsive Disorder
- Psychosis

**OCCUPATIONAL THERAPY FOLLOW UP**
- Safety concerns
- < 5 years old with sensory issues impacting on occupational performance

**SOCIAL WORK FOLLOW UP**
- Family or social stressors affecting coping.
GUIDELINES FOR GP TO RE-REFER TO PAEDIATRIC SERVICE

- Patient demonstrates new symptoms suggestive of developmental disorder or autistic spectrum disorder.
- Patient has regression in developmental skills or failure to progress as expected.
- Patient has escalation in behavioural difficulties
- Parents are having difficulty coping.
- Difficulty with transition times (new school, home changes, relationship changes).
- Non-improvement in symptoms after a 6 month period of observation (e.g. persistence of symptoms despite provision of a stable home environment).
WINZ SUPPORTS FOR FAMILIES OF CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

Child Disability Allowance CDA
Conditions:
- Physical, sensory, psychiatric or intellectual disability
- Child and caregiver must be NZ citizen or permanent resident
- Not means-tested (eligibility does not depend on family’s income)
- At 16 years if child is independent, this converts to Supported Living Benefit
- Terminates at 18 years
- May be extended after review by case manager if child remains dependent, in school or tertiary care

Disability Allowance DA
Conditions:
- have a disability that is likely to last at least six months
- have regular, on-going costs because of your disability which are not fully covered by another agency
- are a New Zealand citizen or permanent resident
- normally live in New Zealand and intend to stay here
- Means tested (eligibility depends on family income)

Supported Living Payment
Conditions:
- You must also be 16 years or older
- Meet one of the following conditions:
  - permanently and severely restricted in your ability to work because of a health condition, injury or disability,
  - OR totally blind,
  - OR caring full-time for someone at home who would otherwise need hospital-level or residential care (or equivalent) who is not your husband, wife or partner.
- If you have a health condition, injury or disability, you must be permanently and severely restricted in your capacity to work because of a health condition, injury or disability. This means you:
  - have a condition affecting your capacity to work for more than two years, OR have a life expectancy of less than two years AND can’t regularly work 15 hours or more a week in open employment
  - OR are totally blind.

Transition to Work Assistance
If a person wants to work
MENTAL HEALTH REFERRALS

Refer to Marinoto for significant comorbidities which affect the daily functioning of the child or young person and/or family members.

- Extreme anxiety affecting child/young person across two domains
- Depression
- Self-harm
- Suicidal ideation
- Extreme behaviour problems
- ADHD
- Obsessive-Compulsive Disorder
- Psychosis
ASD PATHWAY DEVELOPMENT TEAM

Lead: Todd Warner, paediatrician, Waitakere Hospital
Ann-Marie Nottage, Developmental Coordination Service, North Shore Hospital
Bobby Tsang, paediatrician, North Shore Hospital
Danielle Fernandes, Developmental Coordination Service, Waitakere Hospital
Fiona Anderson, Team Manager, Marinoto Child and Youth, Waitakere Hospital
Fiona Ironside, Operations Manager Child and Youth, Waitakere Hospital
Julie Mitchell, ASD Developmental Coordination Service, North Shore Hospital
Maneesh Deva, paediatrician, Waitakere Hospital
Margaret Mitchell-Lowe, psychiatrist, Waitakere Hospital
Meia Schmidt-Uili, paediatrician, Waitakere Hospital
Mirsad Begic, psychiatrist, North Shore Hospital
Shirley Campbell, Team Leader Child Development Service, North Shore Hospital
Simon Baxter, psychiatrist, North Shore Hospital
Stephanie Doe, Operations Manager Child Health, Waitakere Hospital