

Washington State Autism Diagnostic Teams Survey of Service Models

Sponsored by the Washington State Combating Autism Advisory Council

Background

Name of Center/Clinic: Seattle Children's Autism Center

Location: Seattle, King County

Clinic Director: Charles "Chuck" Cowan, MD- Medical Director of Autism Program

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Liaison for your clinic for interview: Jason Russo, RN

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Seattle Children's Autism Center opened in August of 2009. It is now the one place at Seattle Children's Hospital for families and community providers to contact for questions of diagnosis and treatment of Autism, regardless of age. The Seattle Children's Autism Center is a multidisciplinary Center, including:

- Developmental Pediatricians
- Psychiatrists
- Psychologists
- Speech and Language Pathologists
- Neurologists
- Behavioral Specialists
- Pediatric Nurse Practitioners
- Psychiatric Nurse Practitioners
- Nursing

Schedule & Capacity

What days and times does your clinic meet?

The Autism Center is open Monday through Friday.

How many diagnostic evaluation slots do you have per clinic day?

We don't currently do any complete evaluations all in the same day. With that being said, there is a plan rolling out later this month to do 1 day, multidisciplinary, complete evaluations later this month. Kids may have a variety of appointments along the way to diagnosis. First step is almost always with a Nurse Practitioner, who will do an intake and physical, and determine what needs to happen next.

This could be any of the following:

- An assessment through speech, including ADOS testing

- An assessment through psychology, including testing
- A direct referral to an MD for “confirmation of diagnosis”

What is the age range of clients you accept for diagnostic evaluations?

We will see children up to 21 for a diagnostic evaluation.

What is the typical age of clients you evaluate?

The bulk of our new evaluations are between 2 and 9 years old.

What geographic region do you serve (where do your families come from)?

We see children primarily from central Puget Sound and North, and East of the mountains (Tri-Cities, Yakima, and Wenatchee). This is the same as the general population seen at Seattle Children’s Hospital.

Do you have a waiting list? Yes

If yes, how long is the wait for families to obtain an appointment?

This is a moving target. However; the time from initial request to first visit at the Autism Center is probably currently 6-9 months. It is hard to know how long it takes from the initial request to the full completion of the evaluation process. There can be gaps of time in the process. The child may get first visit, but still take a while to get formally diagnosed. During this time the child is getting linked to services.

Can a family get on a waiting list if they are currently applying for Medicaid, or do they have to wait until they have received Medicaid?

Family can be on waiting list.

Personnel

List the disciplines represented on your diagnostic team?

The Monday autism clinic has:

- Developmental pediatrician (Chuck Cowan, Annie Leavitt, Gwen Glew)
- Psychologists
- Speech Language Pathologists
- (there is no OT as part of the team)
- Neurologists
- Psychometrist

How long has your diagnostic team been in place? Since August 2009

Are you able to offer bilingual administration of evaluation tools? Yes

- **Do you use an interpreter?** Yes- frequently use interpreters especially for Spanish speakers. Also for children who are deaf, children who speak Asian or African languages
- **Do you have bilingual professional conducting assessments?** Yes, we have one psychologist who is bilingual in Spanish.

Clinic Protocol

Intake

Briefly describe your intake process.

Pathway to autism diagnosis can be quite convoluted depending on presenting symptoms and the referral process. We're pretty good at identifying the chief complaint and where to triage. Seattle Children's Autism Center is open to all patients with presenting complaints of autism, rule out autism, or high speculation of autism. Each child will be funneled through a single entry point. The intake process will decide which of multiple teams are best to evaluate that specific child.)

Intake begins with a request for services from a Primary Medical Doctor (PMD). It has to be a PMD (a few exceptions). This starts the process. All requests go to a central intake at Children's. Then often ask the family to send school data and family history, but don't require they have it in **before** the visit. Families can bring these in at the time of visit. It depends on who sees the child as to whether they need the additional info (more experienced/trained need less).

Do you conduct a screening prior to child's appointment in the clinic?

Not for the Autism Clinic- children have typically had screening via parental and PMD concerns. Increasingly, PMDs are referring as a result of doing an MCHAT. The PMD's either tell the Autism Center that they did the MCHAT and child needs further evaluation, or they include actual numerical results of the MCHAT. (Chuck was not sure what percentage of children referred as result of MCHAT had autism except that more often than not the MCHAT findings are likely to be correct. The MCHAT sensitivity and specificity depends on age among other factors- the younger the age, the less reliable the screening tool is.)

However, if child does not get referred specifically for autism, then the screening function happens when the developmental pediatrician or ARNP in one of the other neurodevelopmental clinics sees the child and suspects autism and puts the child in the que to get the full assessment through the Autism Clinic.

Do you require a primary care provider referral to the clinic? Not required, but preferred.

Who typically makes referrals to your center?

- Primary health care providers- except for rare exceptions, require that referral comes from PCP (not parent referrals)
- Public health nurse, CHN coordinator, FRC
- School personnel
- Family
- Other _____

How do you prefer to receive records from families and providers?

(Check as many as apply)

- Families bring the reports to the initial meeting.
- Families collect and send reports to clinic in advance
- School/ medical personnel fax reports to clinic in advance.

Is there other information or tests that are helpful to have before the clinic appointment?
Information from any prior evaluation that has been done through school or early intervention services is very helpful.

Diagnostic Evaluation

What assessment tools do you use in your clinic?

<u>Tool</u>	<u>Discipline Administering</u>
• ADOS	Psychology or SLP or Psychometrist
• Detailed but not stereotypical developmental history (not ADI-R but basically the same info)	
• A variety of speech tools, depending on age including Preschool Language Scale, Rosetti Infant Language Scale, CELF, etc.	
• we often do the ADI-R in addition to ADOS. Sometime Mullen or other cog measure	

How long does the multidisciplinary assessment process take?

This can take a long time from intake by ARNP to official diagnosis. It depends on other services that need to be involved (i.e. speech, psychology, audiology, etc)

Does your diagnosis process include a medical evaluation?

Yes. We do a basic medical history and a physical exam. Usually have recommendations to do genetic studies. Sometime referrals go to sleep specialists, GI, or neurology.

How do you share evaluation results with the family?

The SLP or Psychologist is usually the person who gives the results to the family and provides the family with additional info such as feedback messages to share with the school.

How do you share evaluation results with the primary health care provider?

Send a report.

How do you share evaluation results with the child's early intervention or program?

If the family agrees, by signing an exchange of information release form, we can send the evaluation report to them. Otherwise, the family is free to share their copy with whomever they choose.

Follow-up

If a diagnosis of ASD is confirmed, what referrals and resources do you give to families?

Have a packet of information- includes 100 Days kit from Autism Speaks, the schedule for Autism 101 and 200 classes, internet resources. Also, depending upon where they are in getting hooked up with services, information about services such as 0-3, school programs and other resources.

If a diagnosis of ASD is not confirmed, but there are developmental delays of a different etiology, what referrals or resources do you offer the family?

It depends on the issues. E.g. for ADHD, would refer to PCP, for learning disabilities to the school. The diagnosis depends on what information is shared.

Do you follow-up again with families after the diagnostic process? Y N

Dr Cowan usually tells the family he'd like to see them again in 3 months to 1 year, regardless of whether they have received an official diagnosis in the process. This helps the clinic ensure that kids get plugged into resources. This also helps with confirming the diagnosis if a child has the same symptoms/issues later in the year. Some children do change and outgrow their diagnosis and need to be reevaluated and follow up helps with that, too. Follow-up is offered to families, but the clinic does not make an immediate appointment and they don't call the family if they don't come back. The clinic used to call families a month or so before it was suggested they return which Dr Cowan felt was especially helpful for vulnerable families (economics, other primary language).

Outcomes

Approximately what percentage of the clients referred to rule-in/rule-out autism receives an ASD diagnosis?

Not sure. In general perhaps ~70% of patients who come in with concerns about autism have their concerns validated with a positive diagnosis. There are many reasons why there may be over diagnosis and under diagnosis in community settings. Our process tends to be highly accurate as we follow most patients to assess the stability of the diagnosis, but it is a clinical system not a research one so we cannot account for those patients who do not follow up with us. We as well change our mind about diagnoses as we follow children. Some children who appear on the border of a diagnosis are watched without applying an ASD diagnosis.

If ASD is ruled out, what other diagnoses are given?

Speech/language issues are most common such as dyspraxia of speech or some other speech issue. Other diagnoses included ADHD, intellectual disability/mental retardation, or some combination.

Funding

How is your clinic funded?

Patient revenues, Children's funding

Which disciplines on your team bill for the diagnostic visit?

All- dev peds, psych, speech, neuro, ARNP's

How are the evaluations paid for:

- Private insurance
- Medicaid (if no, skip the next 2 Medicaid questions)
 - "Open Medicaid" (Fee-for-Service)
 - Healthy Options-if yes, with which plans are you affiliated?
 - Molina
 - Community Health Plan of WA
 - Group Health
 - Clark United Providers
 - Regence Blue Shield

- Families pay some of fees out of pocket (whatever copays their insurance requires but no separate system for families coming to Autism clinic)
- Families pay all of fees out of pocket
- Other: _philanthropy and Children's.

If a family doesn't have insurance, do you offer a sliding fee? We offer to help them look into whether or not they qualify for Medicaid, or have them speak to financial specialist with Children's to see if they qualify for uncompensated care.

What general sources help financially subsidize your clinic?

- Fund Raisers/Guild
- Institutional support
- Government contracts
- Medicaid reimbursement
- Private insurance
- Private grants
- Other

Challenges

At this time, what are the key challenges your multidisciplinary diagnostic team faces.

- To define what is the optimal assessment strategy which would drive the resources you have. There is everything from the ATN model protocol where you do everything for everyone every time to a very limited clinical assessment by one specialist who knows autism but does no testing.
- Funding for parent education and case management which is a key element.
- Ongoing deficit funding from philanthropy. Autism diagnostic evaluation will never pay for itself.
- Optimistic on the one hand: With every problem Chuck can see a solution. Compared to 2001 we've made a lot of changes in a short time.