

**Washington State Autism Diagnostic Teams
Survey of Service Models**

*Sponsored by the Washington State Combating Autism Advisory Council
Training Subcommittee*

Name of Center/Clinic: Mary Bridge Children's Hospital

Three clinics that diagnose autism:

- **Neurodevelopmental Program** – contact – Betsy Walters RN, nurse navigator
- **Neurology** – Betsy Walters, RN
- **Birth to Three Program** – Brenda Geyer RN, nurse coordinator

Location: Tacoma, Pierce County

Clinic Director: Glenn Tripp MD, Developmental Pediatrician

Intake Contact: Betsy Walters RN and Brenda Geyer RN

Phone:

Email: glenn.tripp@multicare.org

Website:

Phone interview with Dr. Tripp on May 15, 2009

Liaison for your clinic for interview: Glenn Tripp and Betsy Walters

Schedule & Capacity

What days and times does your clinic meet?

Don't have specific days and clinics. If have ASD in referral – go to either the navigator for Birth to Three or for navigator for over 3 and sort who/what clinic the referral goes to.

- 0-3 meets – 4 half days per week – mostly referrals from NDCs on kids who need medical evals (about 30% referred for ASDs)
- ND/Behav – meets every day – Glenn and Brad Hood are the developmental pediatricians;
 - This clinic will schedule SLP for neurologists, if not done in SLP services;
 - Sometimes refer to psychology for additional testing –
 - 3 neuropsychologists at MBCH (do some ASD, mostly TBI) – maybe see 1 child per month with ASD r/o
 - 2 other PhD psychologists – (don't participate in autism.)
 - Cross over model with ADOS when Glenn and Brad see the patients
 - ASD does not get a single evaluation format – it is individualized by person with all ages and all ranges of functioning;
 - kids with mildest condition/more difficult to sort out – try to have seen by psych/interdisciplinary;
 - more straight forward are seen in multidisciplinary fashion/spliced together; occasionally unidisciplinary by DBP or Neurology
 - Upper end/most complete evaluation –half day with SLP, neuropsychologist, OT, SW, - and DBP on another day for medical
 - Numbers: Referrals for autism (over 3 yo) – about 50 per month
 - Of 253 referrals (last 6 months) – 184 to DBP; 69 to neurology
 - Triage is based on way referral comes in from PCP (family cannot self-refer, depends on PCP); neurology more often sees kids who have a neuro assessment also desired – lots of referrals directly to Glenn; sometimes ask directly for neurology

- Nurse navigator – to make most appropriate initial triage decision; occasionally send to psychology department; [Nurse navigator position created in August '08.– Multicare under budget constraints, but this position is OK!!!]
- Five pediatric neurologists also see kids in clinic - (Tension about what is an evaluation – re: single doctor as point of contact for diagnostic opinion; now requiring some data collection around autism for everyone who sees these patients – hammering out the details)

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

- DBP – Brad Hood and Glenn Tripp –
 - have slots for 24 new kids per week (3/day with 10 f/u patients on same day; seen in 2 hour blocks for new patients – 90 minutes spent with family)
 - But if need to have ADOS, etc – will call back to DBPeds clinic after that is done.
- Neurology –
 - 1 hour new pt appt with call back if further testing needed – potential for 15/week among the 5 pediatric neurologists
 - actually see 10- 15 new patients per month;
 - Try to have MCHAT before appointment; but not very often done in the PCP office/ MCHAT not used correctly; for example, used on 4.5 yo.
- 0-3 program : Brad and Glenn – 6-8 kids per week. Appointments are for 1 hour each; screening with MCHAT before arrival; If need further assessment, come back. Increased number of providers are using MCHAT - but still get more from FRCs; In addition, Glenn is also using the MCHAT half of the time as a semi-structured interview at clinic; REFERRALS from anyone, not just PCP;
 - Everyone in this clinic has MCHAT done. Hope is to have nurse or SW do a follow-up MCHAT interview with referrals prior to seeing DBPs.

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

- DBPeds Clinic - Limiting new pts. See mid-teens and below; primarily <13 years old
- Psychology sees up to teenage and neurology to 18 years old.

Active Autism Group at MBCH –

- Formed to look at developing program at MBCH – meeting monthly with 4 monthly meetings so far.
- Topics: e.g. how to structure diagnostic process**;
- Members: Glenn, representative from each of following: pediatric neurology, psychology, nurses, SW, OT, and SLP and (Multicare/Good Samaritan Puyallup merged) a Children's Therapy Unit liaison

What is the typical age of clients you evaluate?

- 0-3 : up to 3 but still capturing most kids at 30-36 months; but getting closer to 24 months; a few at 12-18 months
- 4-9 for the older kids, but there are surprising number of 10-11 yo with trouble in school or regressing.

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

Outliers from Bellingham and Moses Lake; most Kitsap peninsula to ocean and down to Vancouver; south KC – Kent, Covington; few from Yakima because served by Seattle.

Do you have a waiting list? If yes, how long is the wait for families to obtain an appointment?

Yes, but down now. With Brad – down to 2-3 months in DBP, quicker in neurology – DBP requires a lot of pre-information before appt – telephone intake, packet sent and returned – upon return of packet until appointment about 2 months; if delay on packet return, can take much longer.

For neurology – family can call for appointment and will be given first available, usually 2-4 weeks depending on physician; Betsy (nurse navigator) does do some more extensive intake after the appointment is made

Personnel

List the disciplines represented on your diagnostic team?

8 RNs involved in getting this information! Want to support neurology equally.

0-3 yo: Usual – SE, OT, SLP and nursing; referred kids probably had testing in 0-3 program which comes in to the clinic; M-chat already done and clarified; Then to Developmental Behavioral Pediatrics after that; could be referred to interdisciplinary autism group with neuropsychology in addition to OT and SLP – but this is very rare, rate-limiting step.

Older kids –

- DBP Clinic – packet from home and school and rating scales; seen by DBP
 - Have available further assessment – (trickle of kids that can be seen because so few evaluators available) – SLP, psych, OT (rely on school psych, etc as much as possible, but if need it, will schedule before clinic visit);
 - Require – CBCL, Vanderbilt, Parent and teacher, GARS; If any private or school services, incl. mental health done – request those reports;
 - If no assessment – Vineland is done by SW.
- Neurology – asking for school records and behavior rating scales beforehand. (Vanderbilt, Australian scale for Aspergers), any other prior records. No other specialty above the nursing support

How long has your diagnostic team been in place?

- 0-3 – 20 years
- DBPeds – 16 years for Glenn; Brad joined in August 2008
- Neurology – 16 y with one or more neurologist

Are you able to offer bilingual administration of evaluation tools? Yes, with interpreter services.

Screening tools are all in English, also have availability of telephone interpretation.

- Do you use an interpreter? Y
- Do you have bilingual professional conducting assessments? - NO

Clinic Protocol

Intake

Briefly describe your intake process.

SEE ABOVE

Do you conduct a screening prior to child's appointment in the clinic? YES, see above

Who typically makes referrals to your center?

- XX Primary health care providers – unless in the birth to three clinic, which accepts referrals from anyone
- ___ Public health nurse, CHN coordinator, FRC
- ___ School personnel
- ___ Family
- ___ Other _____

Diagnostic Evaluation

What assessment tools do you use in your clinic?

A variety- struggles with rating scales – all imperfect

Tool

Discipline Administering

ADOS – but not every kid gets this.

Do have a training coming up in June – bought all the materials and have other certified; Will have about 10 ADOS savvy folks → ways to stratify evaluation; drift is the problem

How long does the multidisciplinary assessment process take? –

4 hours – morning, if get to that point on older kids – interdisciplinary pre-meeting; crossover; team meeting; decision and parent informing – 2 slots a month available – very few kids get that (OT, SLP, Psych, SW) – Not apportioned by referral to Psych; These kids are probably ones who have been on waiting list for a while – use these slots for kids who have not had anything done at all – live a long way away with lack of access.

The psychologist owns the diagnosis in the multidisciplinary assessments. This approach is of benefit for treatment planning; Kids have a better treatment protocol outlined at the end of the evaluation.

Does your diagnosis process include a medical evaluation?

Might not require that in the multidisciplinary team – but if goes through team and need this, it would be a second appointment. Realistically, nowadays this always happens

How do you share evaluation results with the family?

- in the half day clinic visit – psychologist leads a parent conference with closure at end of AM
- DBP – feedback to parent at end of appointment
- Neuro – either at end of the appointment or if sent for additional information will give feedback to parent at follow-up appointment

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

Report – written – forwarded to PCP

Follow-up

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

Varies: working on streamlining

- Want a common set of zip code or county sorted real resources that will be pulled down by smart phrases on the EPIC EMR. That is a challenge; Hard part is identification of what is in their locale.
- Referred to the schools for 504 or IEP;
- SW offers resources for community support, CSHCN, DD etc.;
- All of the web-based information in WA state –
- Further indicated service referrals; ABA – would help but not available

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?

Varies – similar but not as autism specific

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

YES , but don't have two scheduled follow-ups as presumably Seattle Children's does (a few weeks out and then a later appointment with specific tasks at f/u). We want to move to that; especially one to check on connection to services

When seen in DBP Clinic sent as a consultation from PCP, send report back;

- Primary does accept 10% back
- But for ongoing management - 90% are Brad's and Glenn's;
 - Management for life ;
 - Brad sees 3-4 new kids a day; Glenn limits to 2; with 8-10 half hour follow ups after (10 hour day);
 - There are more kids out there than are referred. A kid or parents in crisis – can get in within a week.
 - Regular f/u now is about 6 weeks to schedule.
 - In addition, the saturation of autism in the group has crept up. Rarely see ADHD any more, but 5-6 new Autism per week.

Neuro – asks for 3-4 month follow-up, unless there are diagnostic tests for which they see the child sooner.

Outcomes

Approximately what percentage of the clients referred to rule-in/rule-out autism receive an ASD diagnosis? 70% Medicaid at the MBCH; Will give this soon, they are collecting this information.....

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

DD, ID, Speech delay, code 783. – inadequate development; list autism, but sublist every impairment

Funding

How is your clinic funded?

No grants. Not for profit organization ; bill insurance; philanthropic help – via MBCH.

Which disciplines on your team bill for the diagnostic visit?

Physicians; psychologist; SLP, OT, SW if person to person contact, but not on phone,
Nurses and SW do not bill. But the amount returned/reimbursed is abysmal

How are the evaluations paid for: all of choices below

Private insurance

Medicaid- 70% in Glenn's clinic

Families pay some of fees out of pocket – Co-pays only

Families pay all of fees out of pocket – RARE, but could happen

Other: _____ On rare occasion - School district

Challenges

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

- Number of kids that are referred – unable to meet that need in timely fashion that they (the MBCH Providers) desire; working really hard to do this and cannot;
- Frustration with lack of access to an actual interdisciplinary team;
 - piecing together a multidisciplinary.
 - Interdisciplinary approach is cost ineffective and very difficult to pull off.
 - Transdisciplinary model is intriguing – opening up the diagnosis to other disciplines able to do this – see this as the future – SLP esp. - SLP could participate in the diagnosis but not OT