

# TRAAC- Transition Resource and Adult Autism Clinic

A Joint Endeavor between Seattle Children's Autism  
Center and The University of Washington Medical Center

Crystal Kong-Wong MD  
University of Washington-  
Family Medicine Residency  
Chief Resident

# Background

- The University of Washington Neurosciences Institute identified a population of patients with neurological disorders having difficulty navigating the medical system.
- A panel of multidisciplinary providers came together to discuss these issues.
- From this discussion, the idea to start a new clinic focused on transition care arose.
- Based on available resources and expertise, the TRAAC clinic was formed as the arena to start these services.

**UW Medicine**  

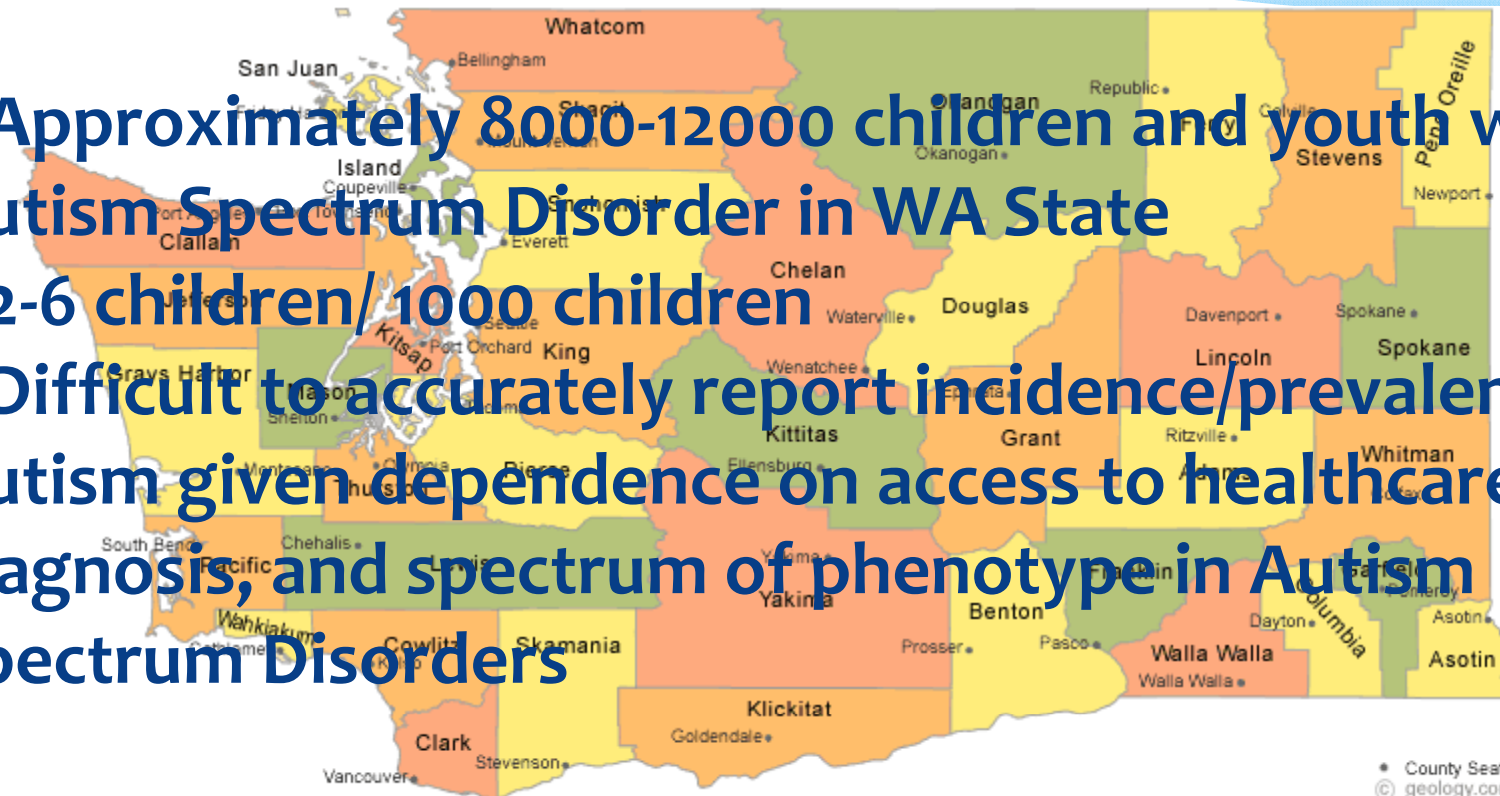
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**HEALTH SYSTEM**



# Autism in Washington State

- Approximately 8000-12000 children and youth with Autism Spectrum Disorder in WA State
- 2-6 children/ 1000 children
- Difficult to accurately report incidence/prevalence of Autism given dependence on access to healthcare for diagnosis, and spectrum of phenotype in Autism Spectrum Disorders



# Transition Issues

The transition from pediatric to adult medical care and social services can be a difficult and confusing time for patients, families, and providers.

- \*Complexity of medical problems
- \*Difficulty facilitating referrals to appropriate specialists
- \*Limited time for visits
- \*Lack of knowledge of, and difficulty coordinating resources
- \*Difficulty accessing mental healthcare
- \*Lack of structured activities once out of high school transition program

# Functional Capacity

- \* Def: “The capability of performing tasks and activities that people find necessary or desirable in their lives.”
- \* Work
- \* Living Independently
- \* Self Care
- \* Safety
- \* Financial Security
- \* Health Insurance
- \* Legal Guardianship

# Quality of Life

- \* Def: “Reflective of subjective wellbeing, quality of life reflects the difference, the gap, between hopes and expectations of a person and their present experience.”
- \* Social Relationships
- \* Pursuing interests
- \* Productivity
- \* Managing maladaptive behaviors
- \* Family Function

# Cost to Society

- \* Can be measured as direct and indirect costs.
  - \* Direct costs- ex. Medical and non medical costs
  - \* Indirect costs- losses in productivity
- \* Ganz, ML: 2007 Study
  - \* Direct Medical Costs: \$305,956
  - \* Direct Non Medical Costs: \$978,761
  - \* Indirect Costs: \$1,875,667
  - \* Total Lifetime Costs: \$3,160,384

# TRAAC

## Mission/Vision:

- \*To provide excellent coordination of medical, psychological, and social services to the Autism population, making the transition from Pediatric to Adult care as seamless as possible.
- \*To continue to provide care to this Adult population throughout the lifespan, providing support to individuals and families.
- \*To improve quality of care and quality of life for this population through research, education, and innovation in care.

# Our Team



Crystal Wong MD (Family Medicine), Katrina Davis (Family Services Coordinator), Gary Stobbe MD (Neurology), Therese Vafaezadeh ARNP (Family Medicine), Lindsay Miller ARNP (Psychiatry), Mendy Minjarez PhD (Psychology)

# Primary Care Survey

- \* Submitted to the King County Academy of Family Physicians Members
- \* Goal was to solicit input from Primary Care Providers on common barriers to caring for special needs populations, gauge interest in utility of specific services, gauge interest in CME/Education opportunities, compile a list of providers with a special interest in providing Primary Care for our patients.
- \* Based on results, can target services at the greatest needs in our community.

# Survey Results

- \* 70 responses

1. Barriers/Difficulties in Caring for Special Needs Adults

- \* Lack of knowledge of resources: 67%
- \* Lack of adequate time for visits: 55%
- \* Lack of physician training: 55%
- \* Difficulty communicating with patient/caretaker: 47%
- \* Difficulty managing resources: 44%

# Survey Results- continued

## 2. What services would be helpful?

- \* Complex psychotropic medication consultations: 51%
- \* Mental Health services: 47%
- \* Annual medical reviews: 38%

## 3. What CME opportunities would you be interested in?

- \* Autism Screening Tools: 74%
- \* Resident/Medical Student Training: 65%
- \* Seminars on specific topics: 56%
- \* Online Education: 37%

# Survey Results- continued

- \* Referral list- 11/70 submissions wished to be included on a PCP referral list.
- \* 36% wanted to be kept informed about CME opportunities.
- \* One physician who is involved with another residency training program wanted to discuss ways to start a similar program at their institution.
- \* Received several inquiries about referrals for specific patients.

# Services

Where we are at right now:

- \*Comprehensive Medical Review
- \*Complex psychotropic medication consultation
- \*Psychological Testing
- \*Facilitation of Medical Referrals (specialty care, lab draws, procedures, etc)
- \*Family Services Coordinator
- \*Resource Guide for community providers
- \*Autism Blog (<http://theautismblog.seattlechildrens.org>)
- \*Education for our team

# Example Transition Assessment

## OUTPATIENT NOTE

XXXXXX

DOB: XXXXXX

CLINIC: AUTISM CENTER

DATE OF SERVICE: 05/24/2011

CHIEF COMPLAINT: Follow-up Autism Center.

**HISTORY OF PRESENT ILLNESS:** XXXXX is a 23-year-old man with diagnosis of autism spectrum disorder as well as impulsive and disruptive behaviors. He comes in accompanied by his mother for routine Autism Center for follow-up. We last saw XXXXX in December 2009. At that point, he had just recently graduated from the Roosevelt High School transition program at the age of 21. Since we last saw XXXXX he continues to do a number of different activities including continuing to work at Safeway as well as going to classes at Highline Community College.

**MEDICATIONS:** None.

**ALLERGIES:** None.

**IMMUNIZATIONS:** Up to date.

**PAST MEDICAL HISTORY:** Autism.

**SOCIAL HISTORY:** XXXXX lives with his mother and father. He is an only child.

**CURRENT THERAPIES:** XXXXX is getting 1 hour of counseling at UW Care Clinic once a week. He has been doing this for the past 5 months. His referral stemmed from an episode where he assaulted his mother on the bus because he got upset with her and grabbed her head and pulled her hair. Since starting therapy, he has not repeated any outbursts or aggression towards other people. XXXX seems to enjoy therapy; however, his mother does not know if it is useful or not. She states that he typically just goes there and plays video games.

**CURRENT TRANSITION PROGRAM:** As stated before, XXXXX graduated From the Roosevelt transition program in 2009.

**LONG-TERM VISION OF PATIENT AND FAMILY:** Per XXXXX mom, ideally, she would like XXXXX to have a functional job as well as activities to fill his day so he does not get bored or frustrated. She would like to look into options for living independently although has had difficulties doing this- she states that "because of privacy issues I was not allowed to visit any group homes".

**HEALTHCARE AWARENESS:** XXXXX is only able to answer basic questions and is not able to comprehend his medical problems or medication. His mother does not have confidence that XXXXX would be able to navigate his own medical care.

**INSURANCE:** XXXXX is currently on Medicaid.

**EDUCATION:** XXXXX lives in Seattle with his family. He attended Roosevelt High School through age 21 in their transition program. He currently takes 2 courses at Highline Community College, although his mother states that he has been having some problems with skipping class and she thinks that this is because he does not have enough supervision at the community college. He is currently taking a math class and a reading class. He is not currently enrolled in the Highline Community College life skills track. Mother states that she does have an appointment next Monday with Peter's counselor at Highline Community College. She says that she has not specifically met with their Disability Services office.

**VOCATION AND WORK:** XXXX has been employed for the past 4 years at Safeway. He works there 3 days a week for 3 hours at a time. His mother shows me a letter today that outlines XXXX exemplary performance at work. She would like it if he could get more hours and has discussed this with XXXXX job coach through PROVAİL. However, she states that given XXXX autism, his options are limited. Ideally XXXX mom would like XXXX to gain some more skills so he can expand of the scope and breadth of this work.

**GUARDIANSHIP:** XXXX mother is applying for guardianship. She does have an attorney and she has an appointment on 5/31/2011 to go to court.

**SUPPLEMENTAL SECURITY INCOME DIVISION OF DEVELOPMENTAL DISABILITIES:** Medicaid: XXXX does have Medicaid insurance. He also does have a Core waiver. Currently, his mother is getting financial compensation as his respite caretaker.

**HOUSING:** Currently, XXXX lives with his parents, although his mother is quite interested in pursuing independent housing, although she does not know where to start. She states that she has tried to go visit some home cares but has had difficulty getting in touch with people or getting permission to go visit because of "privacy issues" given the residents there.

**RECREATION, SOCIALIZATION, COMMUNITY INVOLVEMENT:** XXXXX is not doing many outside activities save for work and school. He predominantly enjoys computers. His mother would like to get him more involved with other activities, but she does not know where to start.

**TRANSPORTATION:** XXXX often goes by private vehicle to places, but he can take the bus. He has never been an elopement risk and his mother states that sometimes he says that he would like to go places by himself but he is inhibited and "afraid" to do this on his own.

**PHYSICAL EXAMINATION:** Height is 176.5 cm, weight is 73.9 kg. In general, this is a well-appearing, well-developed male with no apparent distress. For most of the visit, he is preoccupied with playing with iPad. He does follow simple commands. He does greet the examiner and say "What's your name?" He displays no repetitive or stereotyped behaviors. He displays some fixed staring at the examiner. He also has some scripted speech. His speech does have abnormal prosody and some abnormal pronunciation.

**ASSESSMENT AND PLAN:** XXXX is a 23-year-old man with a diagnosis of autism seen today for help with coordination of transition services and routine autism follow-up. Overall, his mother seems to be working very hard at getting activities scheduled for XXXX; however, she has had difficulty filling all of his days. She is concerned that he is getting frustrated and bored at home because he does not have enough things to do. XXXX seems to be doing well at work and does have a job coach. We wonder if this job coach through PROVAİL could help maximize services through PROVAİL as well. Additionally, it does not seem like XXXX family is utilizing their DDD

caseworker enough as this would be a good point person to direct the family to getting XXXX more activities such as other classes or volunteer experiences. Additionally XXXXX is attending Highline Community College, which we do know has a life skills program and we wonder if this would be appropriate for XXXX. It would be interesting to see what the mother learns from the counselor on Monday. XXXX would also benefit from some additional occupational therapy, specifically targeting life skills and adaptive skills so he can learn how to be more independent.

### RECOMMENDATIONS:

1. We would like to discuss XXXX case with our multidisciplinary transition team and then summarize our recommendations with the family at a future appointment.
2. We will place a referral to the University of Washington Department of Rehabilitation/ Occupational Therapy for XXXX to address life skills training.
3. We will look into placing a referral to speech therapy through Mosaic Speech Therapy, specifically to therapist Nola Marriner for adult speech therapy targeting XXXX communication disorder.
4. We would also encourage XXXX mother to look into services that the DDD caseworker can help the family with specifically regarding other activities for XXXX, as well as looking into future living environments.
5. We encouraged the family that they are doing the majority of the things that we recommend for transition, including transitioning to adult primary care doctor as well as transitioning XXXX over to adult services as well as obtaining legal guardianship.
6. XXXX will follow up in this clinic at the end of June to review plan for coordinating services.

# Expansion/Goals for the Future

- \* CME- didactics, online resources
- \* Medical Student and Resident Training
- \* Expansion to other DD and disabled populations
- \* Outside referrals
- \* Research
- \* Expansion of Mental Health Services (social skills groups, counseling, etc.)
- \* Integration of other Medical Specialties (Rehab Medicine, etc.)
- \* Community Help Line (phone consults)

# References

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# Questions???



## THANK YOU!!!

Micah likes sweet potatoes and the nice people in the LEND program!