

Autism 206:

Arzu Forough, President & CEO,
Washington Autism Alliance

September 16, 2021



Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION



WAACADEMY!

ACCESS TO CARE & SERVICES AT ANY AGE
IN HOMES, SCHOOLS AND COMMUNITIES

ARZU FOROUGH

WASHINGTON AUTISM ALLIANCE (WAA)

CLASS SCHEDULE I

HISTORY

SCIENCE/DEBATE CLUB

THE TEACHERS' LOUNGE

STUDENT COUNCIL/PROM COMMITTEE

AFTER SCHOOL CLUBS





HISTORY

HOW WE GOT HERE...

WAA was founded in 2007 by Arzu Forough through the personal experience of insufficient medical insurance and special education coverage for Autism Spectrum Disorder (ASD)

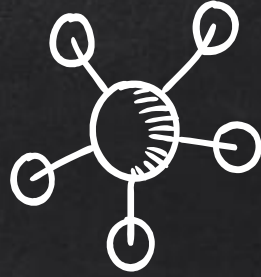
Started as a volunteer run, grassroots campaign

Became a 501c3 in 2012

Serves all of Washington State, with a physical presence in Puget Sound (King, Pierce and Snohomish Counties) and Clark County

Mission: To expand access to healthcare, education and services for people with autism and other intellectual & developmental disabilities (IDDs) in Washington State

We believe all families in Washington State should have the resources they need to support the well-being of loved ones with autism and other neurological disorders



SCIENCE/DEBATE CLUB

FACTS ABOUT ASD –

Prevalence is about 1 in 54 children; when WAA was founded, it was 1 in 100

WA is home to 51,096 children & adolescents under 21, as well as 91,768 adults 21 and older

ASD is diagnosed 4 times more among boys than among girls

2/3 of children with ASD have average or above average intellectual ability

About 10% of children with autism are also identified as having Down syndrome, fragile X syndrome, tuberous sclerosis or other genetic and chromosomal disorders

The co-occurrence of one or more psychiatric diagnoses is 70%

There are no medications that can “cure” ASD

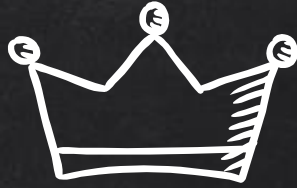
Sources: [CDC](#), [Washington State Health Care Authority](#), [DSM-V](#)



TEACHERS' LOUNGE

PROGRAM STAFF – RESPONSIBLE FOR

- Alice Kim - Access to Care Attorney (Special Education, Health Law)
- Arzu Forough - Government Relations
- Aspen White - Data and Technology
- Kathy Sheppard - Senior Legal Assistant, Special Education
- Leah Winter - Individual and Family Navigation
- Pam Kil - Director of Legal Services
- Rajakumari Chellappa - Administrative and Operations
- Romina De Coronel - Legal Assistant, Intake Screener



STUDENT COUNCIL/PROM!

OUR EVENTS

Blueprints to Special Education(BP), 3rd week of March & September (Coming up on Sept. 18th)

Presented by 4 special education attorneys, capped at 80 attendees

Day out for Autism (DoA),

Usually takes place in April (Autism Acceptance Month)

Is a family resource fair, 50 vendors, fun day out and peer to peer friendraising

Night Out For a Cause (NOFC),

Biggest fundraiser of the year

Gala and friendraising (Coming up on Oct. 23rd, Rainier Club)

It Takes A Village (ITV),

Conference/resource fair with service providers, panelists, speakers and fun activities (Announcement on our website)



AFTER SCHOOL CLUBS

SOCIAL AND SUPPORT CLUBS

SPA (Supporting Parents of Autism):

Structured bi-weekly 90 minute classes to support parents of autism. There are two separate groups based on the age of the individual with Autism (0-11; 12+) and capped at 10 participants per cohort. This is to group parents experiencing similar developmental life challenges and promote meaningful connection within the groups. The sessions combine psychoeducation, discussion, interactive activities and skills practice. Each week features a different topic or theme relevant to parenting and autism. The group is facilitated by a **licensed mental health counselor** and will provide a safe space for parents to access mental health support. WAA's Family Navigator is available following the classes to provide support in connecting with resources if needed.

Friendship Matters (Social Club):

Run by social skills coach and behavior technicians. Intended to prepare community to include our loved ones and to teach our peeps to learn to be in the world as they transition into adulthood, focus is on team building, collaborative problem solving, looking out for one another in the community, enhancing awareness of surroundings

Recent activities include: bowling, karaoke, mall - guitar center, pottery painting, dining out

CLASS SCHEDULE II

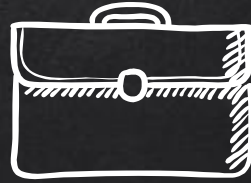
LATIN

GEOGRAPHY

SCHOLARSHIP PROGRAM

SPELLING BEE





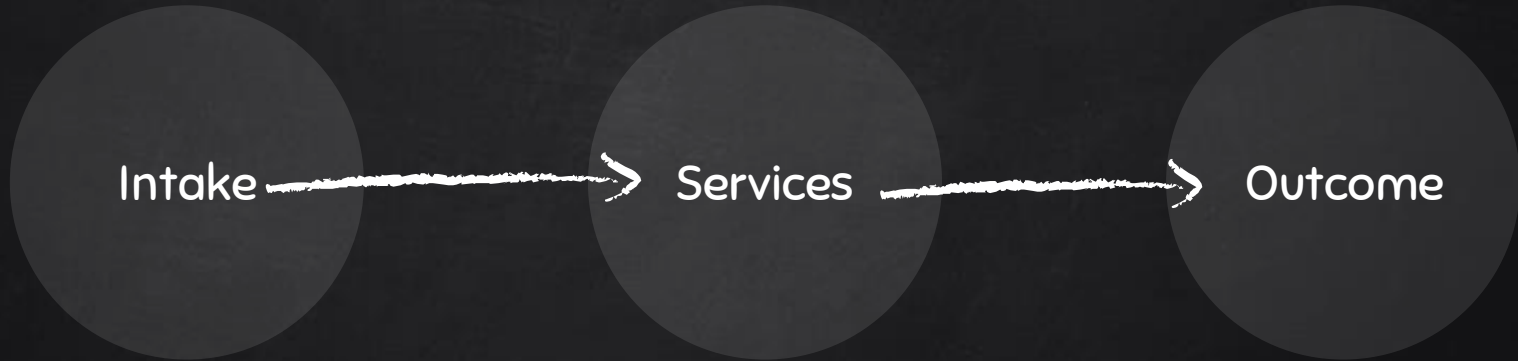
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OUR LEGAL WORK

- Individual Sases/Class Action “systemic change”
- Special Education
- Health Law
- Flexible Fee Structure
- Amicus Curiae ("Friend of the Court")
- Paralegal
- Civil Legal Aid



OUR PROCESS IS EASY



NOTABLE LANDMARK CASES ...

DF v WHCA (2010, settlement 2011)

1. Arzu's children named plaintiffs
2. ABA for all dependents of Public Employees (PEBB Benefits)
3. Shayan's settlement, coverage of all medically necessary screening, diagnosis and treatment, including ABA.

WAAA v. WHCA (2011, settlement 2012)

1. WAAA as named plaintiff, all our medicaid eligible members covered
2. ABA for all Apple Health - Final benefit

O.S.T. v. Regence Blueshield (2012, Settlement 2014)

1. NDT covered under MHP, covered in par with medical & surgical benefits

JC and HS (adults) v. WHCA (2020, settlement 2020)



EDUCATION BEST PRACTICE GUIDELINES (AUTISM IEP SUPPLEMENT)*

Education Best Practice Guidelines (Autism IEP Supplement)

1: Extended Educational Programming

Extended Day and Extended School Year (NOTE – these are distinct and need to be clearly defined.)

1. Duration and programming to be based on individual needs
2. Extended day needs to be different from In-Home Training
3. Determine eligibility criteria based not solely on likely regression, but also on a needs assessment of the following areas: behavior, social skills, communication, academics, and self help skills
4. Needs to be available to all eligible students; not to be determined by district availability funds / staff
5. To include variety of structural programs / settings
6. Services should be linked to IEP objectives and goals

2: Daily schedules reflecting minimal unstructured time

Individualized daily schedule reflecting minimal unstructured time and active engagement in learning activities to the maximum extent possible

1. Flexibility within routines to adapt to individual skill level
2. Learning activities are to be based on IEP goals and objectives and related educational activities
3. Engagement time may include lunch, snack, and recess
4. Consideration needs to be given to aiding students with changes in routine schedules such as, field trips, substitute teachers, and pep rallies

3: In-Home and Community-Based training

Include training and IEP goals and objectives to assist in acquisition and generalization to the home and community setting (appropriate social interaction skills including social and behavioral skills) based on needs assessment

Strategies to facilitate maintenance and generalization (home to school, home to community, school to home, school to community)

Consideration needs to be given to guidelines for the qualifications of the In-Home trainer

(NOTE-Define In-Home and Community-Based training)

4: Positive Behavior Support Strategies

Positive Behavior Supports include Functional Behavior Assessment, antecedent manipulation, teaching replacement behaviors, reinforcement strategies, data based decisions.

Behavior Intervention Plan developed and maintained based on a Functional Behavioral Assessment using current data collection of target behaviors.

1. Considerations and guidelines needs to be written for the person who is performing the functional behavior assessment (FBA). (Please see Yell and Drasgow 2000)
2. Behavioral programming across school, home and community-based settings

Education Best Practice Guidelines (Autism IEP Supplement)

5: Futures Planning for Integrated Living, Work, Community and Educational Environments

*Considered for all students with ASD, at any age

1. Consider skills necessary to function in all environments post graduation
2. Consider skills necessary to function in all environments 3 years hence
3. Consider skills necessary to function in all environments for current year

6: Parent/family education, training, and support

Parent/family education, training, and support is designed to provide the parent/family with skills/techniques needed in order to help their child become successful in the home/community setting. Parent training is provided by qualified personnel with experience in autism and may include but is not limited to information regarding parent support groups, workshops, videos, conferences, direct consultation, materials, all of which are separate and distinct from in-home training. The focus of the service is to increase the parent's knowledge of specific teaching and management techniques, curriculum information, provide information related to the child's disability and available resources, and facilitate parental carryover of in-home training. Strategies for behavior management, setting a structured home environment, or communication training may be considered. The intent is that parents are active participants in promoting the continuity of intervention across all settings based on IEP.

7: Staff-to-Student ratio

Staff-to-student ratio appropriate to identified activities and as needed to achieve progress on social, behavioral, and/or academic IEP goals and objectives.

The IEP team may determine ratios based on the following considerations:

- Level of learning (acquisition, fluency, maintenance, generalization)
- Priority given to work towards individual independence by fading dependence on 1:1 ratios
- Developmental level of the student (in the case of young children [developmental level 0-8 years]) no more than 2 children with autism spectrum disorder per adult as determined by results of adaptive behavior evaluations) (NOTE-Add in Best Practice Manual)
- Behavior needs
- Accommodations across all settings
- Transitions within the school day
- Teaching activities

8: Teaching Strategies

Teaching strategies shall be based on peer reviewed and empirically validated evidence-based practices/methodologies for students with autism. At this time the science heavily favors, but is not limited to those based on the science of applied behavior analysis, defined as the application of behavioral principles for the benefit of the learner and includes simultaneous evaluation of the effect of these applications.

The following instructional strategies should be considered:

- Pivotal Response Training (Naturalistic Approach)
- Discrete Trial Training (Structured Approach)
- Visual supports
- Structured learning
- Augmentative and Alternative Communication
- Social skills training

Education Best Practice Guidelines (Autism IEP Supplement)

Implementation of the instructional strategies should be reflected in the IEP. The following will be considered:

- How will this strategy be implemented?
- When?
- By Whom?

9: Communication

Communication intervention, which considers language forms and functions that enhance effective performance across settings. Strategies may include, but are not limited to:

- Augmentative and Alternative Communication
- Milieu, incidental, or naturalistic teaching
- Verbal Behavior
- Pragmatics
- Conversation skills

10: Social Skills Support

Consideration will be given to the following areas:

- a. Appropriate social skills assessment and curriculum
- b. Instruction provided by highly qualified service providers
- c. Use of trained peer facilitators such as, but not limited to, circle of friends
- d. Strategies may include but are not limited to video modeling, Scripts training, social stories, and role playing
- e. Support to be provided across all settings

11: Professional Educator/Staff Support

Professional development will be provided for all personnel who work with the student to assure the correct implementation of the techniques and strategies as determined by the IEP.

SUCCESS STORIES – UNREASONABLE CAPS AND DENIALS OF MEDICALLY NECESSARY SERVICES

“Washington Autism Alliance (& Advocacy) hailed a federal court ruling that a Washington health plan’s refusal to cover Applied Behavior Analysis (ABA), speech, occupational, physical and other neurodevelopmental therapies after age six violated the state’s Mental Health Parity Act. The therapies are commonly used to treat the developmentally disabled, including persons with autism.

In his ruling, Judge Lasnik said, “the Court ORDERS Defendants to cease their application of any treatment limitations [for mental health services] that are not generally imposed on coverage of medical and surgical services. The Court will not look kindly on failures to immediately implement its directive.”

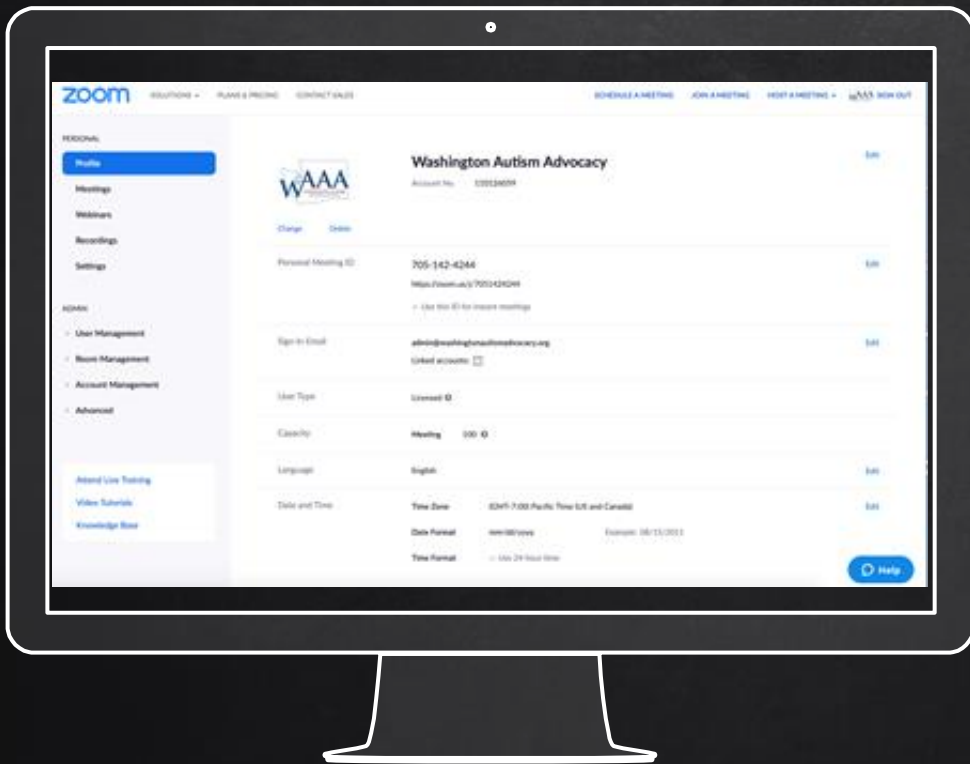
SUCCESS STORIES – REGULATING SECLUSION AND RESTRAINTS OF STUDENTS IN PUBLIC SCHOOLS

HB 1240 led to *responsible reform that helps teachers and students*

- *Prohibits the planned use of restraint or isolation as part of an individual student's program.*
- *Continues to allow the use of restraint or seclusion to guarantee safety—when there is imminent risk of serious harm to students, staff, or property.*
- *Promotes staff training and instructional methods that actually work.*



GEOGRAPHY

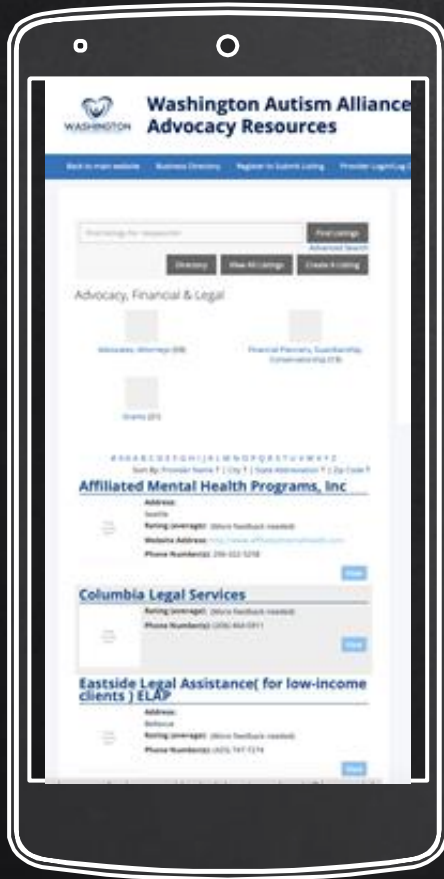


GEOGRAPHIC BARRIERS ARE NO LONGER A PROBLEM!

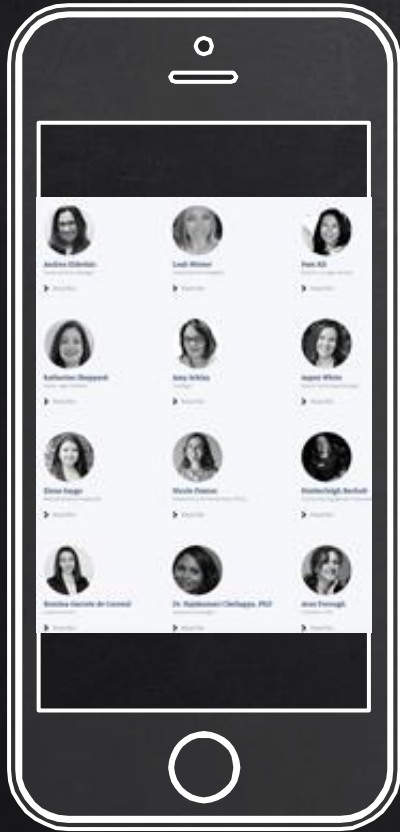
OUR FAMILY NAVIGATORS ARE AVAILABLE TO ANSWER YOUR QUESTIONS IN A HIPPA COMPLAINT AND CONFIDENTIAL PLATFORM VIA ZOOM.



Our self-advocacy tools are easily accessed on a tablet



RESOURCES ARE AT YOUR
FINGERTIPS FROM ANYWHERE IN
THE STATE



To reach us by phone dial
425.894.7231, our staff are
standing by!



SPELLING BEE

ABA

COE

DDA

HCA

EPSDT

MHP

MCO

PPP

IEP

OSPI

DSHS

OCR

NDT

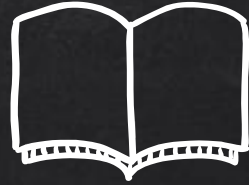
BPSPEd

SPA

DOH

NOFC

DoA



SCHOOL NEWSPAPER



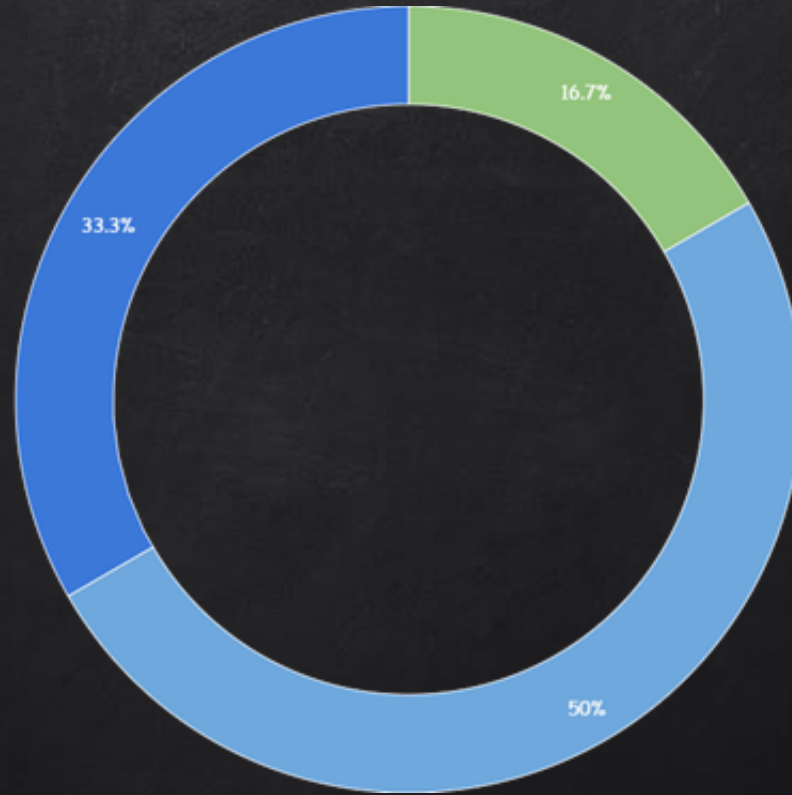
DRAMA CLUB

FACEBOOK, WEBSITE, TWITTER, NEWSLETTER



“WAA IS WORKING EVERY DAY TO CREATE EQUITY THROUGH CHANGING LAWS, PROVIDE RESOURCES FOR FAMILIES THAT DON'T KNOW WHERE TO TURN OR HAVE THEIR QUESTIONS ANSWERED, AND CREATING A COMMUNITY OF INCLUSION FOR THOSE ON THE AUTISM SPECTRUM OR ANY OTHER SPECIAL NEED THAT SOMEONE MAY HAVE.”

BARBARA LECHTANSKI'S: EVAN WONDERS OF THE WORLD TEAM IN THE DAY OUT FOR AUTISM



16.7% System Navigation, 33.3% Special Education, 50% Health Law



142,864

Whoa! That's a big number, aren't you proud?



Join Us!



**Make an
Investment**



**Share the
Story**



**Advocate for
Change**

www.WashingtonAutismAlliance.org

CLASS DISMISSED!



Any Questions?

Olivia



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