



# Caring for Washington Individuals with Autism Task Force Report



# Autism Statistics

- ASD characteristics - lifelong
- U.S. prevalence ASD: 1 in 166 births
  - Type 1 Diabetes Mellitus: 1 in 400
  - Cancer: 1 in 2000
  - Cystic Fibrosis: 1 in 3500
- Private funding for research – ASD \$10.5M
  - JDRF \$118M
  - Childhood Cancer \$175M
  - CFF \$68M
- NIH funding FY04 - \$100M
  - Type 1 Diabetes Mellitus approx \$800M
  - Childhood Leukemia \$62M
  - Cystic Fibrosis \$128M



# Mandates for ATF

- Make recommendations to legislature – incidence of ASD, ways to improve delivery and coordination of services
- Review literature/talk to experts on cause and incidence of ASD
- Assess availability of current services for screening, diagnosis and treatment



# More Mandates

- Assess availability of services to families
- Review effectiveness of existing programs and services
- Review other issues and concerns
- Complete review and submit recommendations to legislature and Governor by December 1, 2006



# The Beginning

- Public cry for better services
- Strain on education/service systems
- Conflicting information to legislators
- ATF created in 2005 – SB 5311
- ATF members met for 10 months
- Listened/reviewed info
- Created emerging themes of concern



# Barriers identified

- Lack of access to early screening
- Lack of understanding for adults with ASD and Asperger's Syndrome
- Lack of ongoing ASD training for parents, educators and other professionals
- Inadequate links between screening, diagnosis and appropriate intervention



# More Barriers

- Inadequate parent and family supports across the lifespan
- Inadequate culturally competent interventions and services for diverse cultural and geographic communities
- Inadequate financing strategies for individuals to access appropriate care throughout the lifespan



# Racial Disparities

- Significant disparities based on race and ethnicity : African American children diagnosed 1.5 years later and require 3x # of visits (Mandell et al., JAACAP, 2002)

	White	African-Am	Latino
Age Diagnosed	6.3	7.9	7.4
Number of visits until diagnosed	4.1	13	8.3

(Philadelphia County, Medicaid Data – 1999)



# Beginning the Process

- Facilitator needed
- Topic driven panels convened
- Identified four areas for change
  1. Infrastructure
  2. Treatment
  3. Training
  4. Funding



## Continuing On...

- Professional presentations:  
University of WA Autism Center, Dept. of Health, OSPI, NW Autism Center, Autism Outreach Project, ESD 112
- Panels provided perspective:  
Educators, physicians, adults with ASD and parents
- ATF formed writing sub-committee



# Essential Groundwork

- Create/enhance coordinated system of regional autism centers
- Increase capacity to identify/track
- Screen all children before 3 years of age, preferably by 18 months
- A trained autism technical assistance specialist in each ESD
- Staff training for all state agencies who provide services and supports
- Create Autism Services Guidebook



# Infrastructure Recommendations (IN)

1. Create regional autism centers
2. Ensure all individuals get comprehensive health services and coverage
3. Contact by a service provider within 15 days of diagnosis
4. Increase capacity to identify and track people with ASD and their services across the lifespan



# Treatment Recommendations (TT)

1. Screen all children by age 3, ideally by 18 months
2. Screening, diagnosis, intervention across lifespan for ASD and AS
3. Minimum 25 hours appropriate intervention services up to age 5
4. Minimum 30 hours appropriate education services for K-12 (through age 21)



# More Treatment Recommendations (TT)

5. A trained autism technical assistance specialist in each ESD
6. Adults with ASD receive supports, therapies, vocational assistance to maintain life skills and employment
7. Develop and implement support for all graduating students with ASD before leaving high school
8. All adults provided appropriate, publicly funded services for WAAP



## More Treatment Recommendations (TT)

9. Develop Autism Services Guidebook, birth through lifespan
10. Increase availability of child/adult care providers to serve those with ASD
11. Provide appropriate wrap around services – trained respite/personal care
12. Provide family preservation services and strategies
13. Provide variety of options for out-of-home placement with ASD trained staff



# Training Recommendations (TG)

1. Create statewide training program for educators and other professionals
2. ASD training for medical students and medical practitioners
3. ASD training for educators and health and human service professionals
4. ASD training for first responders
5. Include ASD awareness in state emergency preparedness plans and training



# Funding Recommendations (F)

1. Complete financing plans to initiate these recommendations
2. Fund and enhance Regional Autism Centers in targeted areas of the state
3. Legislate required health insurance coverage of evidence-based interventions and services
4. Fund community-based organizations that provide culturally effective parent and family support



## More Funding Recommendations (F)

5. Create and fully fund a Medicaid home and community based waiver for ASD
6. Fully fund regular education and revise cost accounting method for SPED safety net funding
7. Create a student loan forgiveness program and other incentives to attract medical/dental and other health professionals
8. Create an Autism Awareness license plate
9. Create tax incentives for employers to provide meaningful employment for those with ASD



## Wrapping Up – What Works

- ATF members worked well together
- Panels on specific topics helpful
- Good access to many professionals
- Parent and self advocate input valuable
- Varied avenues of public input
- TVW access for meetings



# Lessons Learned

- Facilitator helps keep on track (funded)
- Need final writer assigned (funded)
- Assign to agency with resources available
- Evaluate regional needs
- Panels offer wide variety of perspectives
- Need more diverse input
- TVW great for sharing with public and legislators



# Next Steps

- Continue the task force with added members
- Change focus toward implementation
- Gather fiscal info on recommendations
- Have members update info to legislature
- Monitor Combating Autism Act
- ATF get federal updates



# New Members for ATF

- Person with ASD
- Representative from WA Learns
- Expert on transition/residential/employment for adults
- Representatives of regional hubs of autism activity from Tacoma/Seattle, Spokane, Yakima, Tri-Cities and Vancouver
- Representatives from diverse racial and ethnic groups



# Thank You!

## Members of the Task Force:

- Senator Marilyn Rasmussen
- Senator Pam Roach
- Lou Colwell
- Maxine Hayes
- Felice Orlich
- Ilene Schwartz
- Diana Stadden
- Ron Yauchzee
- Representative Maureen Walsh
- Representative Brendan Williams
- Geraldine Dawson
- Monica Meyer
- Linda Rolfe
- Dawn Sidell
- Carolyn Taylor

### Department of Health Staff:

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Reported to the  
Legislature  
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