



## SUBCOMMITTEE RECOMMENDATION REPORT TO OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

**Subcommittee: COMMUNITY SERVICES FOR CHILDREN & FAMILIES**

**Report Date: JUNE 2010**

*ISSUE: There is currently not a consistent process for the identification of ASD throughout the state of Oregon, resulting in conflicting diagnostic results, frustration and confusion for families, and additional allocation of resources to address the inconsistencies.*

### **RECOMMENDATION: #1 IDENTIFICATION**

**The use of a single criterion (DSM) and agreed upon process for identification of ASD will be accepted in Oregon as a part of eligibility determination for publicly funded social services for children.**



**1A:** The Department of Human Services, the Oregon Department of Education, and the Oregon Health Authority will accept the DSM criteria and the agreed upon identification process for purposes of ASD determination.

*ISSUE: Families are not provided with adequate information and the proactive support needed to effectively navigate the service delivery system and link with others to create networks of community support.*

### **RECOMMENDATION: #2 NAVIGATION / FAMILY EMPOWERMENT**

**Information, navigation support and trainings are readily available and automatically offered to families upon a child's identification of ASD, at each phase of development from birth to age 18 (adolescence, adult transition, etc.) and any time a family requests. Families are participants in the design, implementation and evaluation of supports and services.**



**2A:** Every family in Oregon will automatically receive a standardized service delivery system navigation map/document at the time ASD is identified.

**2B:** Upon identification of ASD each family will be offered the opportunity to connect with an independent resource navigator of the families' choice.

**2C:** An updated and easy to use centralized statewide clearinghouse/web-based directory of information, trainings and services is available.

**2D:** Interactive, online service navigation / planning tool will be available for families, navigators and service coordinators to identify appropriate support services. The site will feature an overview of support service options; eligibility criteria survey; direct links to online applications/referrals; access to budget based service plan selector if applicable; and provider links. The visual service planning tool promotes person-centered planning, self-advocacy and empowerment. Budget based planning increases awareness of the value/cost of services and helps families prioritize supports and reduces service coordinator workload. Picture based and translated versions to increase accessibility. Those without computer access to gain access through their public library system or DD office. Samples: [www.dshs.wa.gov/esa/tec/](http://www.dshs.wa.gov/esa/tec/) | [www.peelregion.ca/ow/applying/allowance.htm](http://www.peelregion.ca/ow/applying/allowance.htm) | [www.ritzcarlton.com/en/Events/Weddings/Calculator.htm](http://www.ritzcarlton.com/en/Events/Weddings/Calculator.htm) | [www.servicemagic.com/](http://www.servicemagic.com/)

**2E:** Oregon ASD policy development and quality assurance advisory groups throughout the state are comprised of at least 25% self-advocate / family member representation.



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**2F:** A statewide community education and positive public awareness campaign informs the general public about ASD each April for National Autism Awareness Month; Press releases are initiated quarterly to direct families to a centralized state ASD resource guide. Television/social networking sites/newspaper media provide free public service opportunities.

**ISSUE:** *Children across the Autism Spectrum and their families frequently lack access to adequate, appropriate supports, services, and technical assistance.*

### **RECOMMENDATION: #3 SUPPORT SERVICES**

**Children and youth across the spectrum and their families can access a full continuum of proactive support services through public and private sectors.**



**3A:** Family Support funding is available to families eligible for DD services | Family support services are based on tiered levels of need rather than date of eligibility resulting in waiting lists (previous) and uniform support allocations (current).

**3B:** Eligibility criteria for publicly funded programs / services consider an expanded definition to meet the functional support needs of individuals across the ASD spectrum. *Note: Many children on the spectrum are not currently eligible for direct services, yet may have very specific needs. Eligibility criteria should be revisited based on expanding understanding of ASD.*

**3C:** Every child with ASD and their family in Oregon will have access to family centered, family driven, family support services when needed. *Essential support services to children and families include information; navigation; training; family to family connections; and respite. Support services may also include in-home care; community inclusion; social recreation opportunities; social skills development; early person-centered planning/self-advocacy training.*

**3D:** Families, children and youth will have opportunities participate in person centered planning/self-advocacy.

**3E:** Appropriate levels of direct therapeutic services and supports will be available and facilitated upon identification of ASD. *Note: Therapeutic services and supports may include behavioral therapy, physical, occupational and communication therapy; specialized equipment/supplies.*

**3F:** Families will have access to readily available respite services which includes stipends when needed and trained providers.

**3G:** In-home technical assistance, including environmental modification consultation and positive behavior support trainings, are readily available to family members whenever families indicate a need or it is recommended. Reference: 4C

**3H:** Adjust Children's Intensive In-home Supports (CIIS) assessment scoring to expand eligibility criteria so more children with intense behaviors receive vital pre-crisis services. Reference: 7B

**3I:** Children with intensive behaviors that do not meet CIIS eligibility are prioritized to receive a minimum level of additional supports to address their behavioral needs.

**3J:** Children and youth experiencing co-occurring conditions will receive appropriate supports and services. Reference: 3B and 3C



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*ISSUE: Access to and provision of quality ASD services is not consistent across the state; disparities exist in technical assistance resources and insufficient utilization of current best practice information or model programs.*

### **RECOMMENDATION: #4 TRAINING, CAPACITY BUILDING, PROFESSIONAL DEVELOPMENT**

**There is a collaborative statewide effort to increase the awareness, knowledge and skill of professionals and service providers in the public and private sector who support children and youth throughout the spectrum of ASD and their families.**



**4A:** Human service professionals, including those in mental health, developmental disabilities, child welfare, and health care receive ongoing ASD training and technical assistance.

**4B:** Individuals providing child care, respite and other services to children and youth with ASD and their families receive ongoing ASD training and technical assistance. Reference: 3G

**4C:** Individuals providing behavior support services will have skill, knowledge and ability to appropriately implement a variety of positive behavior support strategies.

**4D:** Evaluators and service providers demonstrate competency in identifying youth with mild ASD related concerns and awareness of local resources. | Ensure accurate identification of youth with ASD in juvenile justice system

**4E:** High school level peer tutors, youth leaders and self-advocates participate in ASD-related training with school personnel to maximize their involvement and shape future providers.

*ISSUE: Law enforcement often lack effective techniques for responding to a crisis involving an individual with ASD and may misinterpret communication issues and atypical behaviors.*

### **RECOMMENDATION: #5 FIRST RESPONDER AND LAW ENFORCEMENT**

**Law enforcement and first responders including paramedics, fire department and emergency room personnel receive training to increase their understanding of ASD and use of effective interaction strategies.**



**5A:** Trainings that increase awareness and effective interaction strategies are integrated in law enforcement and first responder curriculum.

**5B:** Families are aware of options to have their children and youth listed on local law enforcement community data base systems.

**5C:** Emergency Preparedness & Household/Local/State Emergency Plans reflect the needs of children with ASD



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*ISSUE: Service agencies often develop resources in isolation resulting in unnecessary expenditures of time and funding rather than streamlining and combining resources. Children and families get caught between the differing funding streams.*

### **RECOMMENDATION: #6 DELIVERY SYSTEM ADMINISTRATION / INTERAGENCY COLLABORATION**

**An interagency model of collaboration facilitates wrap-around service delivery for children with Autism Spectrum Disorder to ensure integrated educational, medical/mental-health, in-home and community supports and services.**



**6A:** A statewide data collection system for DHS/OHA provides ASD identification statistics and service delivery data for purposes of budget planning, service development and quality assurance. Specify number of individuals with ASD and identify the type/intensity/duration of support services provided. *Note: Information needed to evaluate distribution of resources, budget planning and ASD program development.* | Public agencies such as MH and Child Welfare also to include code for ASD on standard data forms.

**6B:** Interagency agreements and, when appropriate, braided funding between education, health care and social service agencies assure collaborative wraparound approaches for children, youth, and families.

**6C:** There is greater awareness of and access to developmental disability services for eligible children.

**6D:** Each local / regional DD office has a designated service coordinator staff to function as the primary ASD Resource Coordinator for the communities served by that office; and form a statewide Network of Oregon Resource Coordinators for Autism Services (ORCAS) who will participate in interagency trainings and statewide initiatives.

**6E:** Service coordinators, child welfare workers, mental health staff, and others assisting families are knowledgeable, efficient, and have the tools to assist families immediately access needed resources and support services.

**6F:** Each local/county Mental Health office will identify a professional who is knowledgeable about the array of MH and ASD supports in the community. | Expand to Child Welfare & Juvenile Justice

**6G:** Existing private and non-profit entities join with service providers, state agencies, and federal programs to form a coordinated statewide ASD consortium to share information and increase ASD resources throughout the state.



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*ISSUE: The State of Oregon is currently facing significant budget deficits which reinforces the need to implement innovative strategies such as interagency collaboration, proactive systems of community based supports and maximize federal matching fund opportunities.*

<b>RECOMMENDATION: #7 FUNDING</b>
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<b>Funding is available from state and federal initiatives/opportunities to sustain and enhance ASD service delivery systems.</b>
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<b>7A:</b> A share-of-cost funding partnership protocol should be developed between DHS, ODE, healthcare systems, and families (with support of community organizations). Each entity to have a designated role, share of cost, and responsibility for an integrated service plan outcome.
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<b>7B:</b> Fully fund existing CIIS (Children's Behavioral Intensive Services) waiver
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<b>7C:</b> DHS should submit applications for additional Medicaid waivers to support funding of home and community based family supports and services.
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<b>7D:</b> Monitor federal legislation targeted to Autism Spectrum Disorder and apply for federal initiatives as appropriate.
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