SERVING AND SUPPORTING PEOPLE WITH AUTISM SPECTRUM DISORDER AND THEIR FAMILIES

Summary of Preliminary Findings and Recommendations

(Sept 2008)

Introduction

Focus of Report:

This report summarizes issues, findings and recommendations relative to six key areas that impact services and support to individuals experiencing Autism Spectrum Disorder (ASD) and their families in Oregon. The focus of this work addresses those issues from birth through adulthood that have direct impact on safety, well being and success of individuals with ASD.

Committee Purpose and Membership:

The Autism Spectrum Disorder Workgroup was created as an ad hoc committee by the Chairs of the House Education and Health Care Committees in response to the issues of the rapidly growing population of children and adults identified with ASD in Oregon. The Workgroup was chaired by Rep. Chris Edwards. The charge of the group included:

- Review the current status of services to children / adults with ASD in Oregon.
- Review recommendations and proposals from state agencies, families and advocates for addressing the needs of children / adults with ASD in Oregon.
- Develop a set of recommendations for addressing the needs of children/ adults with ASD in Oregon.
- Engage the ASD community and families in providing input on recommendations.
- Create a prioritized list of possible legislative initiatives and other short term and long term activities.
- Present legislative proposals to appropriate Interim Committees.

The Workgroup supported the following vision for individuals experiencing ASD and their families:

- Appropriate, effective and research based treatments, supports and services are available through the lifespan.
- Families and individuals with ASD must be involved in all aspects of service design and delivery. “Nothing about us without us.”

- Early identification and effective research based treatments and services for children are provided by skilled professionals.
- Integrated, coordinated wrap-around services are available to support the child and their family in the family home.
- Systems collaborate to avoid duplication and enhance effectiveness of supports and services.
- Children and adults with ASD are included and contributing members of their schools and communities.
- Recommendations made by this Workgroup will seek a healthy balance between quality of services and number of individuals served in order to produce the best societal outcomes given funding limitations.

Workgroup activities included:

- Review of services currently provided by state agencies.
- Review of a summary of task force reports from 13 other states.
- Discussion of proposals from state agencies.
- Development of report on findings and recommendations.

Committee Members:

Rep. Chris Edwards, Chair
Rep. Peter Buckley, Chair of House Committee on Education
Rep. Linda Flores
Rep. Sara Gelser
Rep. Ron Maurer
Sen. Alan Bates
Nancy Latini, Oregon Department of Education
Morgan Allen, Oregon Department of Education
Mary Lee Fay, Oregon Department of Human Services
Janel Salazar, Parent and Oregon Autism Alliance
Kathryn Weit, Parent, Oregon Council on Developmental Disabilities

Infrastructure for a Collaborative Approach to Autism Spectrum Disorder

Issue: Oregon currently lacks a coordinated approach to providing information, supports and services to individuals experiencing Autism Spectrum Disorder and their families.

Key Findings:

- The rapid increase in the numbers of individuals being identified with ASD, the complexity / diversity of their needs, limited resources and the pressure on the existing education and social service systems requires a more thoughtful, coordinated approach to funding and service development.
    - The needs of individuals with ASD and their families are often very complex. They receive services from a number of programs and agencies.
    - Greater awareness and coordination among agencies and stakeholders will result in more appropriate and cost effective services.
- Oregon is not taking full advantage of the wealth of knowledge, best practice, and skill currently available in the state and elsewhere.
- There are a number of initiatives being developed to serve individuals with ASD in Oregon.
    - A single entity charged with tracking what is needed and what is happening in the state will reduce any unnecessary redundancy and increase the chances of addressing all relevant issues.
- Oregon lacks a means to provide accurate, up-to-date information to parents and caregivers relative to interventions, services, supports and expected outcomes.
- There is no accountability to make sure changes actually occur.
- There is a need for leadership that is consistent and includes all portions of the community.

Recommendations: Create an ongoing Oregon Commission on Autism Spectrum Disorder to provide leadership and serve as a forum to establish priorities, set direction, ensure support, and monitor outcomes.

- Develop and monitor implementation of a detailed, goal and outcome oriented state plan for ASD; that develops and aligns performance measures with appropriate agencies.
    - Provide regular updates on the status of plan goals and outcomes to the Governor, Legislative Assembly, and public.
    - Engage key stakeholders in developing, promoting, and implementing state plan goals and outcomes.
- Develop implementation strategies that utilize education, social services, Higher Education, health care, insurance, and community resources.

- Promote interagency agreements and other processes necessary to assure collaboration and coordination of services;
    - Promote universal screening, timely diagnosis and appropriate referral.
    - Create strategies for accessing and promoting best practice / research based information;
    - Promote regional coordination and collaboration of services and supports across agencies;
    - Define data needs and refine current data tracking systems;
- Develop strategies for braiding funding sources to ensure coordination and collaborative supports to individuals experiencing ASD and their families;
- Promote the development of an easily accessible clearinghouse / web based directory of services and information on Autism Spectrum Disorder;
    - Facilitate a communication network among stakeholders to keep apprised of initiatives and activities related to ASD in Oregon;
- Promote increased training opportunities on ASD for individuals with ASD; families, educators, health care and social service professionals, service providers, child care providers, law enforcement, and others;
    - Support certification and licensure activities related to ASD;
- Membership:
    - The Interagency ASD Committee should include representatives from the Department of Human Services, Oregon Department of Education, Institutes of Higher Education, Health Resources Commission, Title V of Maternal and Child Health, medical community, insurance providers, family members that represent different stages of life, individuals with Autism Spectrum Disorder and other key stakeholders.

Early Identification and Referral

<u>Issue:</u> Oregon lacks a coordinated system for early identification and referral for young children. Early identification and referral for services is important for the success of young children with ASD.

Key Findings:

- Not every young child in Oregon receives a wellness screening.
- Physicians may not do the recommended screenings at 18 months.
    - There have been several significant efforts to provide physicians with ASD screening materials in Oregon.
    - Most children are identified as having ASD by school programs
- There is a difference between a medical diagnosis of ASD and an education eligibility determination for ASD services. This disparity **may** result in inappropriate services or failure to recognize important medical conditions.
- The Oregon Pediatric Society has sponsored a workgroup to look at the issues related to accurate assessment /identification with other stakeholders including education.

Recommendations:

- Oregon should have an agreed upon <u>established standard practice and procedure</u> for diagnosis / identification and referral.
    - Oregon children should receive a well baby check and be <u>screened</u> for ASD at 18 months as recommended by American Pediatric Association.
    - All children suspected of ASD should be <u>referred immediately</u> for a more thorough multidisciplinary diagnostic evaluation that reflects a medical diagnosis and an educational eligibility assessment.
    - Children identified with ASD and their families should be <u>referred</u> immediately to the local Early Intervention / Early Childhood Special Education Program.
- As soon as possible, any child identified with ASD will begin an individually designed <u>program that reflects the needs of the child and family and uses research based best practice strategies.</u>

Education Services

Issue: Access to quality ASD services is not consistent across the state.

Key Findings:

- High quality services to children / youth with ASD do exist in many places throughout the state.
- The numbers and needs of children / youth with ASD have outgrown the current capacity of educational personnel.
  - Current ASD Specialists carry a high caseload, focus a significant amount of their time on assessments and do not have time to provide the needed assistance to classroom teachers.
  - Rural areas of the state experience an even greater challenge in finding and retaining staff trained to work with children and youth with ASD.
- Access to trainings, specialized services and technical assistance varies.
  - There is frequently not sufficient utilization of current best practice information or model programs.
    - Services and access to personnel training and support may be different depending on the capacity, role and expectation of Regional ASD Services, the ESD, and local school districts.
- The current model of Regional ASD Services no longer meets the needs of school districts that have a rapidly growing population of children and youth with ASD.

Recommendations:

- Create statewide service standards for research based best practice educational services for children and youth with ASD.
- Create service /support options that reflect the spectrum nature of Autism Spectrum Disorder.
- Recognize and address co-morbid mental health conditions.
- Reorganize the existing ASD Regional Program and funding strategies to better align services with the needs of students with ASD and school districts serving these students.
- Make better strategic use of existing resources.
- Increase accountability for use of research based best practice and student outcomes.
- Specify the definition of “engagement time.”
- Increase the funding for ASD services to expand the number of highly trained staff available to work with children / youth and support classroom teachers and paraprofessionals birth to 21 years of age.
- Create a system of family support and training relative to educational opportunities and expectations.
- Increase family access to trainings that will help them support instruction in the home setting.

Issue: Current levels of service for young children are significantly lower than the National Research Council recommendation of 20-25 hours of engagement per week.

Key Findings:

- Services and strategies must be appropriate to the individual child with ASD.
    - Not every child will require 20-25 hours per week.
    - Instructional strategies that use such as Applied Behavioral Analysis are often effective with many students.
- Some providers report service averages of 8-12 hours per week for a child with ASD. Many children receive as little as 1-3 hours of service.
- The current birth – 3 program (EI) is not designed or funded to respond to the needs of children / families identified with ASD under the age of three.

Recommendations:

- Seek additional funding to increase the engagement time and intensive services for young children experiencing ASD based on individual need.

Issue: There are not enough skilled ASD Specialists, behavior specialists and teachers of children with ASD to meet the demand.

Key Findings:

- Best practice in the field of ASD is changing rapidly. Some ASD Specialists and teachers lack the most current information and ability to apply appropriate strategies.
- The lack of stable funding to increase statewide capacity to meet the need for skilled ASD specialists, behavior specialists, and teachers.
- Oregon does not have Board Certification for Behavioral Analysts

Recommendations:

- Work with higher education and Teacher's Standards and Practices to create an endorsement and a competency based certification process for ASD specialists.
- Increase the opportunities for professional development for teachers of children and youth with ASD.
- Increase the opportunities for professional development for districts who select not to participate in the current Regional Program system.
- Increase funding to meet increased capacity needed for skilled staff.
- Provide incentives to increase number of skilled professionals to work in more remote, rural areas of state.

Issue: Many children and youth with ASD are a part of the regular school programs. All educational staff must understand the potential impacts of ASD on students.

Key Findings:

- Many children and youth with ASD are fully capable of participating in the regular school program.
    - Teachers and other education personnel interacting with students with ASD must understand how ASD may affect the

student’s learning and behavior and how to adjust educational strategies and activities.

- Students with Asperger’s frequently do not receive the appropriate support they need in school, particularly in the area of social skills.

Recommendation:
- Provide training on ASD for all teachers and school staff within and outside of the current Regional structure.
- Improve the support available for children and youth experiencing Asperger’s and high functioning autism.

Issue: Many individuals with ASD do not make a successful transition to permanent employment or continuing education.

Key Findings:
- Successful transition from secondary school to employment or continuing education requires strategies that recognize the unique needs of individuals with ASD.
    - Many post secondary educational and social service programs are uncertain how to support an individual with ASD.

Recommendations:
- HS Transition programs must work with DHS / DD / VR, continuing and higher education programs to develop and implement appropriate transition services for individuals w ASD.
    - Build on the current interagency model of collaboration utilized in HS Transition that is not readily accessible for students with ASD. This will require specially trained staff dedicated to this model.

Social Services

Issue: DHS currently lacks the capacity to respond to the significantly growing population of individuals with ASD and their families who may require support and services from DHS.

Key findings:

- Services that were designed for individuals with physical or cognitive disabilities often fail to address the unique environmental, behavioral, communication, or sensory considerations that make ASD a distinct condition.

Recommendations:

- Add ASD Specialists within the Office of Developmental and Disabilities Program of Seniors and People with Disabilities with the following responsibilities:.
    - Represent DHS on a state level workgroup
    - Create a plan for addressing training and service issues within the Department.
    - Develop policy strategies, monitor / facilitate/ implement trainings to a variety of audiences and direct training and technical assistance contracts to support children and families.
    - Coordinate DHS services with other state agencies, higher education and stakeholders.
    - Provide or facilitate technical assistance to other program areas of DHS.
    - Promote the use of evidence based practices.
    - Provide staff support for the Oregon Commission on Autism Spectrum Disorder.

Issue: Staff and administrators in the Department of Human Services lack current accurate information about Autism Spectrum Disorders and understanding the impact of ASD on the individual / family and their ability to be successful. There is an expressed desire for access to information that is useable, current and reliable.

Key Findings:

- Survey of DHS agencies indicated a perception that there is an increase in the number of individuals / families experiencing ASD receiving services from DHS.
- Individuals may “fail” in current services because DHS programs may not understand and / or have been unable to adequately respond to the issues presented by ASD.

Recommendations:

- DHS ASD Specialists will develop and/or identify publications to educate DHS staff and field about ASD.

- DHS ASD Specialists will <u>develop, promote or facilitate training opportunities</u> and best practice information on ASD for social service staff, direct care staff and others.
- DHS will identify and attempt to address those areas where individuals with ASD are "falling through the cracks."

<u>Issue:</u> There are an insufficient number of qualified behavioral consultants able to respond to the needs of both DHS and education programs serving children and adults with ASD.

Key Findings:

- It is difficult to find behavior consultants who have the skills to effectively work with children and adults in the family home.
- Some individuals who identify themselves as behavior consultants lack knowledge of effective, safe, appropriate, and approved interventions with individuals expressing significant challenging behavior.

Recommendations:

- ODE, DHS and Higher Education programs should work together to <u>develop strategies to increase the availability of qualified behavioral consultants.</u>
  - Explore incentives and recruitment strategies
  - Strengthen or develop training and certification programs
- ODE and DHS should consider a <u>teaming model of support</u> utilizing the strengths of personnel in both agencies.

<u>Issue:</u> There is a lack of coordinated intensive intervention /treatment and support for young children experiencing significant levels of ASD

Key Findings:

- Frequently the families of young children with autism are unaware that case management / service coordination services might be available to them. County developmental disability programs may tell families that they have nothing to offer them so families do not pursue enrollment.
- The eligibility standard for the current Medicaid Behavior waiver which provides intensive support is very high and only children who pose a risk to themselves or others are eligible. The waiver is not at capacity.
  - Technical assistance and support delivered to the family in the family home is sometimes highly successful.
  - Not every child / family experiencing ASD will require intensive wraparound services.
- Few children with ASD receive the intensive intervention recommended by the National Research Council.

Recommendations:

- ODE and DHS should work together to <u>develop integrated wrap around services</u> for children experiencing significant levels of ASD and their families
- DHS should explore <u>expanding the existing behavior Medicaid waiver or consider creation of another waiver</u> specific to ASD to provide time limited intensive interventions.

- DHS should provide comprehensive <u>wrap around service coordination</u> for young children with ASD and their families when needed.

<u>Issue:</u> There is a lack of adequate support for families / foster care families and providers experiencing challenges with an individual with ASD .

Key Findings:

- County DD Programs report an increase in numbers of families with youth with ASD requesting access to services.
    - Family support programs have been unable to assist the growing number of families requesting support.
    - Some families may need to seek out in home placement for their family member in order to get sufficient help.
    - Some families may not have enough resources to work and support their adult or child at home.
    - Children with ASD going into foster care are increasingly complex and there is insufficient training and support for providers.
- DD case manager case loads are too high to be able to provide the support families need.
- Throughout DHS, Family Support services for families caring for children and adults experiencing ASD are limited.
- Empowered families are an important key to long term success for a child with ASD.
- Families may have no one to connect to when they first receive a diagnosis of ASD and have no idea how to navigate the system.

Recommendations:

- DHS must <u>increase supportive services that help empower families / foster families</u>. These services may include information / referral, respite, behavior consultation and assistance, appropriate home modifications, and in-home staff support if necessary.
- Increase training for case managers, providers, and families to build appropriate plans to keep individual in the home setting.
- Access to support services must be available before they reach crisis.

<u>Issue:</u> Services to individuals with ASD must be available across the lifespan.

Key Findings:

- Individuals with ASD have the lowest employment rate of any disability category.
- Individuals with ASD frequently fail in continuing education and higher education settings.
- Families express concerns about their ability to continue to provide in-home support for their adult family member who experiences with significant ASD and challenging behaviors.
- Access to community resources like recreation and public transportation are important for a full and active life for many adults with ASD.

Recommendations:

- DHS and ODE must develop and implement <u>integrated transition services</u> for individuals with ASD
- DHS must work to <u>improve long term employment outcomes</u> for individuals with ASD
- DHS must <u>increase access to appropriate 24 hour comprehensive services</u> for individuals with ASD.
- DHS must collaborate with other agencies to <u>increase access to technology and appropriate, affordable housing.</u>
- DHS must <u>increase the capacity of providers</u> to serve individuals with ASD.

<u>Issue:</u> Rural and linguistic, cultural, or racial minorities

Key Findings:

- Individuals with ASD and families who live in rural areas or who are members of a linguistic, cultural, or racial minority <u>may experience even greater difficulty in accessing appropriate services.</u>

Recommendations:

- There must be an <u>increased effort to include strategies to address geographic, linguistic, cultural, and racial service disparities.</u>

<u>Issue:</u> Access to appropriate /timely crisis and law enforcement services

Key Findings:

- Law enforcement is often poorly trained on how to deal with an individual with ASD in crisis.
- Because of their inability to communicate well or unusual behaviors, individuals with ASD may not receive necessary support in crisis or protection from law enforcement.

Recommendation:

- <u>Provide training about ASD to law enforcement</u>.
- Identify options for appropriate crisis response.

Health Care

Issue: Many Physicians are not aware of the diagnostic characteristics of ASD.

Key Findings:

- The American Academy of Pediatrics has issued practice guidelines for the early identification and referral of children with ASD.
  See above "Early Identification and Referral"
- Internal Medicine and family practice physicians frequently provide care to individuals with ASD but may not receive the necessary training or information.

Recommendations:

- Provide information and technical assistance to all pediatric, internal medicine and primary care settings to implement the nationally recommended ASD screening and surveillance guideline.
- Provide accurate up-to-date information on diagnostic and support resources for individuals with ASD to all physicians.

Issue: Many individuals with ASD require additional or specialized interventions to access basic health care.

Key Findings:

- Many individuals with ASD may not receive appropriate basic health care because of the possible impacts of sensory differences, language and communication issues, and challenging behaviors.
- Many physicians are not aware of the possible associated medical and co-morbid mental health conditions related to ASD.

Recommendations:

- Provide information and technical assistance to all physicians.
- Provide comprehensive health services in a medical home knowledgeable about ASD and its associated medical and co-morbid mental health conditions.
- Physicians must be able to access additional or specialized interventions necessary to support basic health care.
- Physicians must be able to authorize treatments necessary to identify and address associated medical and co-morbid mental health conditions.

Issue: Currently public and private insurance in Oregon does not provide comprehensive integrated coverage for physician directed treatment plans for Autism Spectrum Disorders.

Key Findings:

- Many states have successfully passed insurance legislation that covers physician directed intensive treatments for ASD.

Recommendations:

- Review and analyze insurance initiatives in other states.

- Explore <u>specific health Insurance coverage</u> for physician directed, medically necessary ASD treatments, as part of a comprehensive strategy for braiding funding for services.

<u>Issue:</u> Children with developmental disabilities are sometimes unable to access treatment services if the condition is considered to be the result of their disability.

Key Findings:

- Despite passage of HB 2918, there are still children being denied access to therapy services.

Recommendations:

- Further legislation may be required to <u>protect children with disabilities</u> including ASD from being denied access to important medical treatments.
- <u>Track current insurance practice</u> related to children with disabilities.

Higher Education

Issue: Training, research, and programmatic resources available in higher education are often not well supported or linked to service delivery in education, social services, and health care.

Key Findings:

- Oregon has nationally recognized programs and individuals working in fields related to ASD.
    - Often the information from Oregon institutions of higher education is more widely recognized outside the state.

Recommendations:

- Participate in the Oregon Commission Autism Spectrum Disorder to identify needs in the areas of personnel preparation, research and training.
- Form a collaboration of higher education personnel to work on the issues related to ASD research and information dissemination.
- Assist Oregon agencies to develop a research based best practice approach to treatment interventions and service delivery
    - Assist in the identification and dissemination of information and research on ASD
    - Encourage funding and wider dissemination of proven best practices related to ASD
- Increase ASD specific training for physicians and other health related professions.
- Improve professional development in education, social service, direct care services, technical assistance professionals.
    - Create a statewide collaboration to develop certification and licensure for specialists in the area of ASD.