OCASD STRATEGIC PLAN 2021-2024
April 10, 2021 Draft

This Strategic Plan is designed to be read in conjunction with the OCASD Long-Term Vision.

Terminology. Different constituencies within the autism community have adopted different terms to designate individuals with this condition. Many self-advocates prefer the term "autistics" to describe themselves and include in that term the significant number of individuals who either have not had the benefit of a formal diagnosis or who were misidentified with another condition as children. Moreover, many self-advocates, parents, and others in the community dislike the use of "disorder" to describe autism.   Some parents use the term "individuals experiencing autism." Others use the term, "individual with ASD" or "individual with autism." The Oregon Commission on Autism Spectrum Disorder ("OCASD" or "the Commission") supports autistic individuals' and family members' self-identification preference\s. Currently, however, some health care services and all developmental disability services require a formal diagnosis of autism spectrum disorder (or other qualifying condition), and autism/autism spectrum disorder are the administrative rule terms used for special education eligibility. In the context of services requiring a formal diagnosis or eligibility determination, which are the focus of most of the Commission's work, therefore, this document follows the convention of "_____ with ASD." "*Adult*" means an adult with autism spectrum disorder (ASD). "*Child*" means a child with ASD. "*Family*" means the family or other caregiver(s) responsible for arranging care and services for the individual. "*Identification*" means "diagnosis" in health care contexts and "determination of eligibility category" in special education contexts. "*Individual*" means an individual with ASD, regardless of age. "*Health literacy principles*" applies to oral and written communications in health care, education, and social services. It means that when communicating with members of the public, the communicator uses language that is readily understandable to people at a 5th grade reading level. "*Parent*" means a legally recognized parent or other adult who has assumed the responsibilities ordinarily borne by a parent and who has a close personal relationship with the individual. "*Self-advocate*" means an individual who has been diagnosed with ASD or, in the absence of a formal diagnosis, believes that they have autism.

Committees. All committees and work groups are responsible for implementing a portion of this Strategic Plan. They will receive a list of online resources and a list of other stakeholders and community organizations with whom to explore collaboration on work of mutual concern. Committees and work groups will be asked to review their charges and recommend changes to the full Commission if they deem it appropriate, and to identify additional stakeholders and community organizations with whom to collaborate. Commission staff will be available to assist with scheduling and posting of meeting materials, creating and conducting surveys, and some types of research. In addition, the Commission's Zoom account will be available for conducting meetings and work management tools will be available to support operations and coordination with the committee's Commission liaison.

Scope of work. The scope of work assigned to each committee is ambitious and may not be achievable in three years. Committee chairs will work with their Commission liaisons to develop realistic time estimates as the work proceeds.

Numbering. For easy cross-reference, the numbering in this Strategic Plan follows the numbering in the Long-Term Vision.

I. FIRST ROUND OF COMMITTEE LAUNCHING: 2021

1. PROFESSIONAL TRAINING

1.1 Degree and certification program training. The Professional Training Subommittee identifies specific curriculum elements for the human behavior basics and ASD general trainings, as described in the Long-Term Vision. It specifies the level of detail appropriate for different professional roles. It identifies gaps between desired and existing degree program training in Oregon programs for relevant professionals. It identifies and/or prepares curriculum materials for students in degree programs in biological disciplines (speech language pathology, medicine, nursing, occupational therapy). It identifies barriers to implementation of desired training. Time permitting, it develops strategies to overcome barriers.

1.1.6 Differential identification. The Differential Identification Work Group continues to prepare internet-based training modules on the differential identification of ASD.

3. RESOURCES FOR NAVIGATING LIFE WITH ASD.

3.1 Service navigation. The Subcommittee on Navigating Life with ASD identifies which agencies and providers currently offer service navigation to families and adults with ASD and the scope of navigation services offered. It identifies the training currently received by service navigators in Oregon. It determines the service navigation needs of families. It researches models for the provision of comprehensive service navigation in other states, e.g., California Regional Centers, and for other conditions, e.g., diabetes and cancer. Time permitting, it develops standards for comprehensive service navigation and service navigator training.

3.8 Planning for the Lifespan. The Committee on Navigating Life with ASD researches currently available materials to assist families and adults understand their service options and plan for lifetime needs. It determines (a) whether these materials meet the information needs of families and adults in the 12 domains specified in the Long-Term Vision, (b) whether they are easily understood by families, and (c) how widely available they are. It establishes standards for planning materials and either identifies existing materials meeting these standards or determines how to create and distribute them.

4. SYSTEM INTEGRATION.

4.2 Universal consent forms. The Screening, Identification and Assessment Subcommittee (SIA) reviews the universal consent form developed by the Oregon Department of Human Services and the Oregon Department of Education to determine whether it needs modification for use in all health care, education, and social service contexts. SIA develops language for consent forms so that parents need to sign only one consent to authorize evaluation for all potential disabilities (education) and conditions (health care) and to facilitate communication across health care, education, and social services, while remaining in control of who is allowed to communicate with whom and for what purposes.

4.5 Standards for comprehensive information sharing tools. In coordination with SIA, the Interventions Subcommittee identifies or develops one or more instruments designed to capture the results of formal assessments and informal observations in order to assemble a complete, current, and detailed picture of the individual's specific characteristics, preferences, challenges, and needs. The instrument should capture types of functioning and developmental steps that are significant for social behavior, emotional functioning, sensory functioning, cognitive functioning, and adaptive functioning, as well as any other physical or mental conditions the individual experiences. The work group develops standards for the data elements so as to enhance (a) the usefulness of the information for recipients who do not share the originator's discipline and (b) the privacy of sensitive information.

4.6 Comprehensive intervention standards and planning tool. The Committee on Interventions establishes standards identifying a comprehensive package of ASD interventions that should be available and funded for all individuals and families. The work group creates a comprehensive checklist of common service and support needs for individuals with ASD and their families. The checklist will address both individual traits and the environmental supports an individual may need to be healthy and safe. The checklist will clearly identify (a) categories of intervention that should be provided to all individuals with ASD according to their developmental level (e.g., for social emotional development), (b) coaching and interventions provided by parents, siblings, or other relatives, (c) areas of assessment or inquiry across the range of functioning and needs that are frequently impaired in individuals, whether or not the characteristic is one of the DSM criteria (e.g., sleep, diet, executive functioning, co-occurring conditions), (d) blank spaces for service and support needs that are not listed but that may be required because of co-occurring conditions or other factors unique to the individual, (e) family support needs, and (f) spaces to identify which agency or provider will be responsible for the service or support. The data elements should address service needs in relation to the individual's level of development and support needs.

4.7 Identification team competencies.

> **Review and revise minimum team competencies.** A work group of SIA composed of professionals regularly engaged in identification of ASD and senior program

administrators reviews and revises OCASD's previously identified team competencies as necessary.

Engage licensing agencies to react to/promote competencies. OCASD leadership works with the governor's office to elicit licensing agency participation. SIA collaborates with licensing agencies in further review and tailoring of competencies for their licensees. SIA also helps licensing boards to craft guidance and/or administrative rules for their licensees.

Explore mechanisms to ensure that identification teams possess competencies. SIA works with state agencies to determine how to increase availability of psychologists (clinical, school) and other professionals in short supply in various locations within the state, e.g., through telemedicine, Oregon Department of Education/Oregon Health Authority psychologist pool, or a "dating service" that matches community professionals with agencies and institutional providers needing additional expertise. The work group explores potential mechanisms to ensure that identification teams possess required competencies.

4.7 Whole picture identification.

Research existing models. SIA researches existing models for comprehensive evaluations, for example, Regional Autism Centers in California and combined education and medical identification in Ohio.

Stakeholder engagement. Commission leadership and SIA members engage with potential collaborators for a whole picture identification process and pilot programs. These include representatives of the governor's office, legislators, the Systems of Care Advisory Council, the Oregon Department of Education, the Oregon Health Authority, private insurers, the Oregon School Boards Association, the Coalition of Oregon School Administrators, and the Oregon Education Association.

Comprehensive list of data needed for eligibility. SIA creates a comprehensive list of data needed to establish eligibility for (a) all state agency or state-funded services, and (b) privately funded services, if practicable. It develops a comprehensive tool to record the data.

Barriers and potential strategies to address them. SIA identifies legal requirements (e.g., confidentiality, consent, IDEA timelines) that evaluations for ASD must meet. It identifies barriers to whole picture identification arising from service model differences across systems (e.g., time availability of professionals and funding) and strategies to address them. It identifies system/organizational culture and internal political barriers and steps that can be taken to mitigate them.

Research partner for whole picture ID pilot. In order to demonstrate the value of a whole picture model for the state as a whole and to make improvements to a piloted model, Commission leadership and SIA seek out a long-term research partner to develop both short-term and long-term qualitative and quantitative outcomes data.

5. EDUCATION SERVICES.

5.2 Range of settings: student placement standards. The Education Committee surveys schools and families to determine in what types of classrooms children are currently placed and the factors that currently determine placement (e.g., types and location of classrooms that are available, parental preference, sensory issues, behavioral issues, co-occurring conditions such as intellectual disability or anxiety). The Education Committee develops guidance to support placement decisions by identifying factors that should be considered in determining the least restrictive environment. The guidance identifies the potential benefits and downsides of different settings as they relate to various child characteristics.

5.1, 5.2 Range of settings: standards for inclusive classrooms. The Education Committee develops standards for general education classrooms that include autistic students. As part of this, the Education Committee tailors Universal Design for Learning principles to common characteristics of children with ASD.

5.3 Availability of professionals with competency in psychology. The Education Committee surveys schools to determine the number and types of mental health professionals available to support classroom teams, their training with respect to developmental psychology and neuroscience in general, and ASD specifically. The work group determines the current roles of mental health professionals with respect to children with ASD, the number of hours they generally devote to each child across different functions (evaluation, IEP planning, and learning and behavior support between IEP meetings). The Education Committee surveys special education directors, regional programs, and education service districts to determine (a) what efforts they have made to increase their access to mental health professionals who have training in ASD and are able to participate in evaluation, IEP planning, and learning and behavior supports between IEP meetings, (b)whether they anticipate any changes in the near term, and what barriers exist to their doing so.

II. SECOND ROUND OF COMMITTEE LAUNCHING (2022 and beyond)

6. PHYSICAL AND BEHAVIORAL HEALTH SERVICES.

6.1 Issues in accessing physical and behavioral health care. The Health Care Committee surveys families and adults to determine their level of satisfaction with and ease of access to basic and specialist health care (availability, effectiveness, affordability, environmental, and communication).

6.2 Programs for co-occurring mental and behavioral health issues. The Health Care Committee determines the availability of professionals and programs with the expertise to provide services to individuals with co-occurring mental/behavioral health conditions.

6.3 Standardized data elements and forms for establishing medical necessity. The Health Care Committee develops guidance for health professionals on establishing medical necessity for commonly needed services and equipment. It decides whether to seek new Insurance Division administrative rules to create standardized data elements for establishing the medical necessity of services and equipment commonly needed by individuals.

6.4 Nondiscrimination. The Health Care Committee determines whether discrimination against individuals creates a barrier to accessing adequate health care.

6.5 Emergency services. The Health Care Committee develops one or more mechanisms to ensure that emergency health professionals are rapidly oriented to an individual's autism and needs.

7. SOCIAL SERVICES AND SUPPORTS.

    7.1 Data gathering re needs and barriers. The Social Service Supports Committee gathers data on the number of adults and children with ASD in Oregon and their current living arrangements. It determines the types and adequacy of services they are receiving from governmental and private agencies (DD Services, Vocational Rehabilitation, brokerage services for adults, and others). It determines how easy it is for families and individuals to access services and supports; what barriers to doing so exist, if any; the nature of services actually being received; how well the services meet their needs; and needs that remain unmet.

    7.2 Analysis of barriers. Barriers to improvement and alternative service models are explored.

    7.3 Strategies to overcome barriers. The work group develops strategies for overcoming barriers.

III. OUTREACH BY COMMISSION LEADERSHIP AND DATA GATHERING BY COMMISSION STAFF (2021-2023)

8. SERVICE PROVIDER AVAILABILITY AND EFFECTIVENESS

    8.1 Oregon data. Commission staff determines the current availability of providers of different types in sample communities across Oregon and their training with respect to ASD.

8.2 Standards for workforce adequacy. Commission staff researches the existence, if any, of standards on work force needs per unit population for various professions serving individuals and families.

9. HOUSING.

9.1 Data gathering. Commission staff gathers data on the currently unmet and projected need for safe, supported, and subsidized housing for autistic adults.

9.2 Cross-disability coalition. Commission staff and leadership determines which existing organizations are best suited to increasing housing options for adults and how best to advocate for the needs of adults within those organizations.

10. CRIMINAL JUSTICE.

10.1 Data gathering. Commission staff gathers information on the experiences of individuals with ASD and their families with the criminal justice system.   It researches whether there is any existing Oregon data on (1) screening for possible mental or behavioral health issues in individuals who are arrested; (2) interrogation practices that may unduly influence individuals to confess to crimes or waive the right to counsel or, in the case of juveniles, to have a parent or other trusted adult present during interrogation; (3) the types of crimes individuals are charged with; (4) the practices of jail and prison officials with respect to identifying whether an inmate has ASD; (5) the treatment of individuals with ASD in jails and prisons; and (6) the experiences of individuals after release. Commission staff determines whether there are any national groups working to change the insanity defense and sentencing guidelines for individuals with developmental disabilities and mental health disorders. Commission staff researches criminal justice advocacy and policy groups in Oregon.

10.2 Cross-disability coalition. Commission leadership engages with other disability and criminal justice policy and advocacy organizations to determine whether to join in the work of existing groups or to create an autism specific committee or work group within the Commission. The Commission determines which route to follow.   The System of Care Advisory Council may take the lead with respect to juveniles, in which case OCASD would participate as appropriate.