OREGON COMMISSION ON AUTISM SPECTRUM DISORDER
LONG-TERM VISION
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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, some 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 families' and autistic individuals' self-identification preferences. 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 is the administrative rule terms used for special education eligibility, which also incorporates the scientific criteria for autism spectrum disorder (ASD) set forth in the Diagnostic and Statistical Manual, 5th Edition published by the American Psychiatric Association. 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 uses the 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.

I. INTRODUCTION:

OCASD. The Oregon Commission on Autism Spectrum Disorder (OCASD) was established by Executive Order to help improve services, supports, and other conditions for individuals and their families in Oregon. Its ultimate goal is to help all autistic individuals in Oregon experience rich lives through physical and mental wellness, opportunities for authentic personal relationships, lifelong learning, self-determination, and meaningful work.

ASD. ASD is a complex neurodevelopmental condition that affects many areas of functioning. It is no longer considered a single biological condition because of the genetic and behavioral diversity among the ASD population. What unifies the population is that their biological differences disrupt the course of social emotional development at or near birth. Current estimated prevalence is on the order of two per 100. In addition, the overwhelming majority of individuals with ASD have more than one condition. Many have four or more conditions, which can be physical, mental health, or both. Thus, individuals and their families usually require services and supports that span many public and private agencies throughout their lives. This makes ASD one of the more common neurodevelopmental conditions and one of the costlier for individuals, families, and society at large. It also requires effective coordination across service providers from health care, education, and social services, each of which can have different eligibility requirements, governing law, service models, and payment models.

The efficiency and effectiveness of services provided to individuals and families are key to both better life outcomes and to lowering the fiscal impact of ASD. Adults who were identified only as adults report long and painful struggles. Historically, outcomes for adults who were identified as children have also been discouraging. The fact that this is gradually changing with more research, more accurate identification, and better interventions provides the most powerful reason to continue to improve.

The fiscal burden of inadequate and uncoordinated services for autism falls on individuals and families in several ways. First, families need to pay more for services and supports for their child. Second, many parents must give up work hours or jobs to arrange care for their children and deal with multiple providers offering conflicting approaches. Third, individuals who did not receive adequate services as children may earn less by falling short of their potential as wage earners and may be less independent in their daily lives, thereby requiring more services. Finally, inefficient and uncoordinated services simply waste money.

Less apparent but equally important, most of the changes needed to provide better services and supports for individuals and their families will enhance the effectiveness of services for a broad swath of individuals, including those with and without identifiable mental health conditions.

Role of services in the lives of individuals and their families. This Long-Term Vision focuses on services and supports not as ends in themselves, but as a means to ensure that individuals and their families can have rich and flourishing lives as parts of their broader communities.

The behavior and characteristics of individuals vary widely. Because there is so much diversity within the autistic population, there is a broad range of views about what autism is and how best to serve those who experience it. Some rightly emphasizes that many autistics (especially those who are now adults) have not had the benefit of a formal diagnosis or special education eligibility determination. In addition, there is active debate within both the autism community and the broader disability community about the role of terms such as disorder, normality, and typicality. At present, our health, education, and social service systems require a formal identification of autism spectrum disorder or other qualifying disorder in order to provide services, and proof of greater dysfunctionality to get a higher level of services and supports. This sets up an unhelpful and sometimes disempowering tension between the need to prove dysfunctionality in order to enlist professional support and the need to foreground the strengths, potential, and commonalities autistic individuals share with non-autistic individuals. In addition, both within and outside the autism parent community, there has been strong advocacy for views and services that many others believe are either unhelpful or harmful for them or their children. Notwithstanding this diversity of views, several things seem clear.

Parents raising an autistic child have the same basic goals as those raising a non-autistic child: to help the child develop their strengths, work around their weaknesses, and become as self-sufficient and happy as they can be. As the understanding and acceptance of autism have grown and as services have improved, it is realistic to expect that, with the right services and supports from childhood, most adults can have, loving relationships with family and partners, friends, meaningful work, and active participation in their communities.

All parents draw on the help of others to raise their children, whether professionals such as pediatricians, or natural supports (family, friends, schools, child care and babysitters, faith communities, sports teams, music teachers, and the numerous others who help parents and their children create a meaningful life). Thus, for both parents and children, development is always a social process. Although disability is a natural part of the human experience, almost no parent comes to their child's autism armed with the knowledge or skills needed to understand and respond in a way to achieve their basic goals for the child. For that they need more expert help than parents of non-autistic children, not only for their child, but sometimes also for themselves.

Foundational social and cognitive development occurs within the context of the family. And while development increasingly shifts away from the family thereafter, most parents continue to play a supportive role throughout their child's lifetime. In addition to loving and encouraging their children as most parents do, the multiple roles of parents include: (a) learning about ASD and any other condition their child may have, (b) learning about their own child's strengths, differences, and needs, (c) learning how to coordinate, make decisions, and advocate for their child's care, (d) helping their child's social emotional development and meeting their child's other daily needs, (f) sharing with their child a vision for their future that includes high hopes, dreams and expectations, (g) helping their child understand that having a disability does not define someone's worth or potential, (h) maintaining their own physical and mental health, and (i) doing everything else that parents of non-autistic children do to work, maintain the family, and participate in their community. This is a tall order, and no parent plays all these roles equally well, all of the time, or without the paid and unpaid support of others.

Quality services for children can make a big difference in allowing them to achieve full lives. As with non-autistic children, it is usually difficult to predict how much a given child can achieve or how well integrated into their communities they will be as adults. Many children become much more functional over time, while others face increasing challenges during adolescence as they experience anxiety, depression, or other later-developing conditions. For many, physical or social aspects of life in the world of the non-autistic is stressful, for others not as much. Expectations need to be high but realistic, constantly toggling between the long-term goals of good relationships, meaningful work, community participation, and maximum independence and self-determination, on the one hand, and, on the other, the short-term goals of emotional well-being, safety, health, opportunities for growth, and problem-solving to lower barriers – all while respecting both the unique abilities and the unique limitations of the individual in question.

For autistic adults, growth does not stop, and for most, neither does the need for effective services and supports. The majority of individuals will at some point need affordable housing options with either environmental modifications, the availability of adult assistance or both; support in finding and maintaining jobs commensurate with their abilities; and a variety of other supports. For those who need them, quality services can help individuals stay safe and healthy, connect with others, and engage with the world in the ways they desire.

Purpose of this document. This document is designed to outline the state of the world that individuals and their families need in order to secure their health, safety, and ability to function as full members of society. It contains the goals towards which the work of the Commission will be directed over the years to come. The vision of the Commission is ambitious, but we are confident that we can achieve these goals over time in collaboration with the many wonderful people in the autism community, those in other disability communities, and those without disabilities who wish to create better health, education, and social services.

The Long-term Vision is intended to be a living document that is updated from time to time to reflect current scientific knowledge, feedback from stakeholders, and developments in the broader landscape of governmental and private organizations serving individuals and their families.

Assumptions. Following are the basic "ingredients" for providing adequate services and supports for individuals and families. These are goals towards which the elements of this Long-Term Vision are aimed. Although they are framed in terms of service providers, the primary responsibility for ensuring the existence of these items lies with the organizations and administrators that fund and employ the service providers and organize their work.

1. Service providers who have received adequate professional training in general and training on ASD specifically to competently provide the services needed by individuals and families.
2. Service providers who are culturally competent and have adequate linguistic competence or translation services relative to the individuals and families they serve.
3. Service providers who understand the specific characteristics of the individual/family and how that should affect the services provided.
4. Access to an adequate number of service professionals to perform the tasks that need to be performed, in all areas of the state.

5. Adequate supports for individuals and families to ensure that they can make appropriate choices regarding care and services for which they are eligible, access those services, participate effectively in their or their child's development and care, and lead fulfilling lives.
6. Service providers who collaborate with each other on a regular basis to (a) ensure that all needed services are being provided, (b) communicate important information, (c) problem-solve, and (d) expand their own professional knowledge.
7. Adequate funding and institutional support for needed services and collaboration with other professionals.

II. LONG TERM GOALS

Note on OCASD's collaboration with other organizations. Most of what is needed by individuals and families with ASD is also needed by individuals and families of those with other conditions. Most of what service providers need to know in order to appropriately serve individuals and their families will help them better serve non-autistic individuals as well. Thus, every area of the Commission's work will involve extensive collaboration with stakeholders and organizations that have similar goals.

Note on rationale for certain goals. In order to make this Long-Term Vision easier to read, the rationale for some of the goals has been placed in footnotes.

1. PROFESIONAL TRAINING

1.1 Degree and Certification Programs:

1.1.1 Human behavior basics: biology and psychology. All training programs for educational, social service, and physical and mental health care professionals will include training in the current biology and psychology of behavior that includes the social emotional aspects of human behavior and the interplay between social, emotional, cognitive, sensory, and motor functioning. The training will be at a level appropriate to the scientific level of the professional discipline.[1]

1.1.2 Human behavior basics: early development. All training programs for educational, social service, and physical and mental health care professionals will include training in birth to five developmental psychology and its impact on subsequent behavior.[2]

1.1.3 Communicating with others outside of one's profession. All professionals will receive training on communicating their professional concepts and conclusions in terms that are accessible to those at an eighth-grade reading level (referred to in the literature as principles of health literacy).[3]

1.1.4 Childcare workers. Licensed family day care and center-based childcare workers will receive suitable training in the biology and developmental psychology of human behavior (including the social emotional aspects of behavior) and the interplay between social emotional, cognitive, sensory, and motor functioning. The training will also include ASD indicators.

1.1.5 ASD general. All training programs for K-12 educators, social service professionals working with individuals, and mental and physical health care professionals will include basic training in ASD. Basic training will include (but not be limited to) ASD indicators and what they mean; how to apply the outcomes research on ASD interventions to individuals; professionals: how to collaborate with families/individuals, as appropriate to the profession; families/individuals: how to collaborate with professionals; the health care, educational, and social service programs and agencies serving individuals and families.

1.1.6 Differential identification of ASD. All health and education professionals who are involved in the formal diagnosis or identification of ASD will receive training in the differential identification of ASD appropriate to their role in the identification process. This training will include both didactic and supervised practice, meeting minimum standards.

1.1.7 Public safety officers and correctional personnel. As part of their initial certification, public safety officers and correctional personnel who interact with inmates will receive human behavior basics and ASD-specific training suitable to their roles.

1.1.8 Licensed health professionals. Licensed health professionals who submit information to third party payers to obtain coverage for goods or services will be trained on the information needed to support medical necessity. See Goal 6.7 below.

1.2 Continuing education:

1.2.1 Professionals who did not receive all the training specified in Goal 1.1. Health, education, social service, and criminal justice professionals, and other emergency first responders, who have not already received the training described in Goal 1.1 will complete continuing education to obtain an equivalent level of understanding within a specified period of time after beginning work in the field. Professionals will receive updated trainings on a predetermined schedule.

1.2.1.1 Social service professionals. The elements of training will include everything in Goal 1.1 except the training for childcare workers and formal and informal diagnosis and identification.

1.2.1.2. Criminal justice professionals. All criminal justice professionals will receive ASD basic training. Prison guards and criminal justice professionals who have responsibility for charging and prosecuting decisions will receive training in behavior basics (biology, psychology, and developmental psychology) suitable for their roles.

1.2.1.3 ASD General training for ancillary staff who may interact with individuals. Public and private agency staff members who may interact with individuals, e.g. school secretaries and bus drivers, will receive training in how to communicate with individuals.

1.2.2 Online training modules. There will be approved online trainings available at nominal cost for the didactic content in Goal 1.1

2. TRAINING FOR BUSINESSES AND OTHER ORGANIZATIONS.

2.1 Businesses and other organizations serving individuals. There will be trainings available for businesses and other organizations on how to provide autism-friendly services to the public.

2.2 Businesses and other organizations employing individuals. There will be trainings available for businesses and other organizations on how to recruit and provide support for autistic employees.

3. RESOURCES FOR FAMILIES AND INDIVIDUALS TO NAVIGATE LIFE WITH AUTISM.[4]

3.1 Autism awareness. OCASD and the websites of other state agencies will provide links to vetted ASD information.

3.2 Service navigators. Across the lifespan, every family and adult will have access to service navigators who are knowledgeable about evaluation, services, and supports for individuals with ASD and their families relevant to the individual’s age. Autism navigators will help families and individuals identify and understand how to access those resources. Autism navigation will start immediately upon referral of a child for an ASD evaluation.[5]

3.3 Evaluation support. See Goal 4.1.

3.4 Educational resources. Every parent of a newly diagnosed/identified child and every newly diagnosed adult will have access to curricula employing health literacy principles that include at least the elements listed below. These elements will be available as options for parents to choose in places and formats that are readily accessible to them (e.g., written resources, in person trainings outside of their work hours, e-learning opportunities).

3.4.1 Basics of ASD for parents and individuals. The DSM criteria for ASD, what the criteria actually mean, the diversity of the population (biological, gender, psychological, co-occurring conditions, cultural), and the current state of the research on the causes of ASD.

3.4.2 Generally recommended services for individuals and characteristics they are best suited to address. Information on interventions with the best available evidence and how to select appropriate services for an individual. There will be separate tracks covering early childhood, middle childhood/adolescence, and adulthood.

3.4.3 Availability of services and supports in the community. Information on peer supports, available services, and opportunities for inclusion. Note that this curriculum element will provide general information on the types of services available in communities throughout Oregon; care navigators will possess information specific to a given parent's community. There will be separate materials covering services for individuals 0-21 and adulthood.

3.4.4 Where to obtain reliable information and how to avoid claims without scientific basis. How to fact check for reliable information on interventions and services. How incorrect information can waste money and harm children.

3.4.5 Parenting an autistic child. Skills to engage and support the social emotional and cognitive development of autistic children and to deal with problematic behaviors. How to pace interventions and activities so as to avoid either family or child burnout. The importance of sleep, nutrition, and exercise for both the child and the family. Signs that additional medical or behavioral interventions may be advisable. Parenting teens and adults.

3.5 Parent coaching. See Goal 4.8

3.6 Counseling. Affordable and accessible counseling will be available to support the individual's and family members' emotional health and resilience. Counseling will be provided by licensed professionals with specific training in ASD.

3.7 Support groups. Parent and peer support groups will be available at either no or nominal cost. An OCASD work group will determine quality standards and sources of funding.

3.8 Planning for the Lifespan. Easily understood materials will be available to encourage parents and individuals to plan for needs across the lifespan in the following major domains: (1) relationships and social skills, (2) health, (3) activities of daily living, (4) leisure and recreation, (5) education and vocational training; (6) transportation and mobility; (7) transition to age of majority; (8) employment; (9) income management; (10) financial resources; (11) independent or supported living, and (12) community participation.

4. INTEGRATION ACROSS HEALTH CARE, EDUCATION, AND SOCIAL SERVICES[6]

4.1 Evaluation support. Parents and individuals will receive an explanation of the evaluation process and be given the opportunity to ask questions about it both in advance and during the evaluation. Communications with individuals and families will employ health literacy standards. Evaluators will continuously obtain feedback from parents and individual and take steps to improve the evaluation experience for families and individuals.

4.2 Universal consent forms. There will be a comprehensive, universally accepted consent form meeting HIPAA and FERPA requirements. The form will cover evaluation for ASD and other potential conditions, as well as release of information. Individuals and parents will receive counseling about consent that meets minimum quality standards.

4.3 Standards for information control within organizations. Parent/individual consent will govern information sharing between organizations. In addition, there will be standards within organizations that limit sensitive information to those who need to know it in order to do their jobs.

4.4 Information systems. Computer-based information systems will support secure information sharing across disciplines and services at the discretion of the parents or individual (e.g., Evault) and follow principles of health literacy.

4.5 Tool for building a comprehensive picture of individual/family (information sharing tool). There will be a standardized tool for information sharing across systems and providers. The tool will capture data on the functioning, unique characteristics, and preferences of the individual with ASD and their family/caregivers. The tool will capture the results of both formal assessments and informal observations (including those by parents and caregivers). There will be 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. There will be standards identifying a comprehensive package of ASD interventions that should be available and funded for all individuals and families based on assessed need. There will be 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 for parents provided or supervised by licensed professionals, (c) 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, and (d) spaces to identify which agency or provider will be responsible for the service or support. Use of the planning tool will be initiated upon diagnosis/identification and updated regularly.

4.7 Whole picture identification and initial service planning. For purposes of this Long-Term Vision, Whole Picture Identification means a single coordinated, cross-system process whereby an individual is evaluated for ASD, made eligible for all public and private services for which they qualify, and comprehensively assessed for service needs. Pre-evaluation steps will be taken (e.g., screening for ASD and adverse childhood experiences) to ensure that there is a reasonable basis to believe an evaluation for ASD is appropriate. All ASD evaluations will meet the minimum quality standards identified by OCASD, incorporate sufficient parental consent to evaluate for all suspected conditions, and gather information needed for eligibility and service planning for all health care and state and local agency purposes (including education). Initial service planning standards will include individualized service recommendations and parent counseling based on the specific characteristics of the child and the family. Use of the information sharing and planning tools will be initiated as part of the identification process.

4.8 Parent interventions and coaching to support children's social emotional development. All parents will have access to interventions to develop their ability to engage with their children and to foster their children's social emotional development. In this context, interventions are programs delivered by or under the supervision of licensed professionals who have been trained in a parent-mediated program based on published developmental psychology and biological research, preferably with outcomes research demonstrating effectiveness. Affordable and accessible parent coaching will be available for problem-solving and to improve parents' ability to engage with and support their child's development throughout the lifespan. In this context, parent coaching is provided by a licensed professional with both training and experience in working with the families of individuals with ASD.

4.9 Coordination of care across systems and providers. To the extent permitted by the family/individual, there will be ongoing communication among service professionals (health care, education, social service agency staff, personal service workers, and home care workers) to ensure consistency, answer questions, address issues or challenges, and report progress.

4.10 Transition processes. There will be standards for the transition process from ECSE to K-12 education that will be met for all children. Existing standards for the transition process to adult life & services will be evaluated, revised as necessary, and met for all youth from age 14 or earlier through age 21 within the education system and within health care.

5. STANDARDS FOR EDUCATION SERVICES.

5.1 Universal design for learning. The principles of universal design for learning (UDL), as they apply to students with ASD, will be employed in all educational settings.[7]

5.2 Range of settings.

5.2.1. Range of settings available. Every school district will offer a range of classroom settings that are accessible to students with ASD and meet the diverse needs of the ASD student population. Inclusive classrooms will be available for all students with ASD.

5.2.2 Standards for inclusive classrooms. There will be standards for inclusive classrooms that address the needs of students with ASD. Standards might include such things as location of classrooms, physical layout and other environmental characteristics, number of students in the classroom, and training for teachers and paraprofessionals.

5.2.3 Guidelines to support placement decision-making. There will be written state guidelines that support sound decision-making with respect to student placements, addressing specific student characteristics (e.g., age, severity of ASD characteristics, cognitive ability, the presence of co-occurring conditions that cannot be accommodated in an inclusive setting, and parental preference for mastery of skills versus the child's exposure to a typical classroom setting). The guidelines will indicate considerations pointing toward or away from different placement options. They will be written employing health literacy standards.

5.2.4 Support for parents' decision-making. The decision-making guidelines will be provided to parents in advance of IFSP or IEP meetings. and parents will be offered the opportunity to raise any questions so that they understand the guidelines before the IFSP/IEP meeting. Parents will also be given the opportunity to meet the teachers and view any classroom settings in which their child might be placed.

5.3 Availability of professionals with competency in psychology Every educational agency serving students with ASD will ensure that a dedicated licensed professional with demonstrated competency in the biology and psychology of social emotional functioning, mental health disorders, and birth to five psychological development is available to consult with every school team in the development and fulfillment of a child's social communication goals, as well as other goals as appropriate.

5.4 Expanded core curriculum. Every child will receive specially designed instruction and related services with respect to an expanded core curriculum that addresses the common needs of students with ASD, based on assessed need. The expanded core curriculum will include social development, communication development, cognitive development, sensory and motor development, adaptive and life skills, executive function skills, and such other elements as may from time to time be established as part of the curriculum.

5.5 Implementation with fidelity. There will be a mechanism to ensure that educators providing interventions for ASD and the expanded core curriculum have received appropriate training in the intervention or curriculum element and have access to coaching from someone at a higher level of expertise. There will be a mechanism to determine whether educators are implementing interventions for ASD and the expanded core curriculum with fidelity.

5.6 Assessments of individual learning. In all educational settings, students with ASD will be assessed to determine whether they can use what they have been taught in a functional way in activities of daily living.

5.7 Systemic assessment data. There will be a statewide system for assessing the acquisition of essential skills by children that is sensitive to growth over time. Data will be aggregated to contribute to the evaluation and improvement of programs as well as for accountability.

5.8 Augmentative and alternative communication. Given developmental expectations for the student's age, any child who has limited or no speech (in some or all contexts) has timely access to augmentative and alternative communication (AAC). Qualified staff provides training on its use for the child, the teacher, and parents. There will be standards on the role of education professionals in helping to establish medical necessity for insurance coverage.

5.9 Integration into whole school. Students with ASD are valued members of their school communities. They are included in all before- and after-school activities and special education classrooms are viewed as an integral part of the school by principals. Special education classrooms are not moved from school to school without sufficient advance notice and explanation to permit families to respond or opportunity to give input into the decision-making process.

6. STANDARDS FOR HEALTH CARE, MENTAL HEALTH, AND BEHAVIORAL HEALTH SERVICES.

6.1 Screening. Every child will be screened for ASD by 24 months of age.

6.2 Environmental standards. Health care, mental health, and behavioral health providers will be able to provide services in physical environments that are appropriate for individuals with hypersensitivities and other needs arising from their ASD.

6.3 Communication. Health care, mental health, and behavioral health providers will have the training, policies, and tools to be able to communicate appropriately with individuals and families.

6.4 Nondiscrimination. Health care providers will not discriminate against individuals in the provision of scarce medical resources on the basis of their ASD.

6.5 Emergency services. First responders and emergency department staff will have protocols for determining whether an individual has ASD and communicating with individuals, families, guardians, and other caregivers.

6.6 Co-occurring mental health and substance abuse services. There will be programs available to address co-occurring mental health and substance abuse issues in the ASD population. Such services will be staffed by professionals who have training in how these issues manifest and are best treated in the ASD population.

6.7 Standardized data elements and forms for demonstrating medical necessity. There will be standardized forms and data elements to support medical necessity for services and equipment provided to individuals and families.

6.8 Other issues to be determined.

7. EFFECTIVENESS AND AVAILABILITY OF SOCIAL SERVICE SUPPORTS. Ease of access, availability, and effectiveness of supports will be improved. Service gaps will be remediated.

7.1 Developmental disability services for children. After hours crisis support will be available for families/individuals with ASD across the age range. Other issues will be identified through feedback from individuals and families and worked on by OCASD.

7.2 Vocational rehab. VR workers and job developers will be able to help those with higher cognitive functioning and/or executive functioning issues get and maintain employment commensurate with their capabilities. Other issues will be identified through feedback from individuals and families and worked on by OCASD.

7.3 Brokerage services. Challenges in finding and retaining personal service workers will be addressed. Other issues will be identified through feedback from individuals and families and worked on by OCASD.

7.4 Other issues to be determined.

8. AVAILABILITY OF SERVICE PROVIDERS ACROSS THE STATE.

8.1 Standards for workforce adequacy: number. There will be standards for the number of service providers of different types per unit ASD population to ensure that there are enough professionals to meet the needs of individuals with ASD.

8.2 Standards for workforce adequacy: accessibility. There will be standards for workforce accessibility through a combination of driving time limits and telehealth options.

8.3 Standards for workforce adequacy: applicability. Standards will be applicable to education and social service agencies and both public and private health insurers.

8.4 Phase-in of standards. There will be a 10-year phase in to adequate numbers and accessibility of professionals to meet the needs of individuals with ASD.

8.5 Methods of ensuring workforce adequacy. OCASD will work with key agencies to assist in developing strategies to ensure workforce adequacy.

8.6 Periodic updating of workforce standards. Workforce standards will be updated on a preset schedule to reflect changes in evidence-based ASD interventions.

9. HOUSING. Home modifications for safety will be supported through technical assistance and needs based financial assistance. There will be substantially greater availability and range of safe, supported, and low-income housing for individuals with disabilities, including ASD.

9.1 Financial assistance for modification of childhood housing. Sliding scale financial assistance will be available to families of children who need environmental modifications to keep their children safe and healthy.

9.2 Housing availability: types of units. There will be housing units with varying levels/types of support and environmental characteristics available to adults. In every county there will be options for such units to be integrated into community housing stock.

9.3 Housing availability: cost. Units for adults who need supported or environmentally altered units will be available on a sliding rental scale.

9.4 Housing availability: accessibility. Sufficient appropriate housing units will be available in all Oregon counties. Location of units will take into account public transportation and proximity to employment opportunities for those able to work.

9.5 Individual housing plans. At several predetermined points in time and at other times as necessary, individuals and their families will be offered the opportunity to work with a housing specialist to plan for the individual's short-term and long-term housing needs.

9.6 State and local planning for the development of housing. Individuals and family members will be invited to participate in state and local planning for the development of housing for autistics.

9.7 Collaboration with commissions and advocacy organizations. OCASD, other state commissions, the Oregon Housing Authority, and other advocacy organizations for individuals with developmental, physical, and mental health disabilities and disorders will collaborate to enhance housing opportunities for vulnerable Oregonians.

10. CRIMINAL JUSTICE. The criminal justice system will function more appropriately with respect to individuals with ASD and other mental and behavioral conditions in the following areas: (a) training for all personnel in the criminal justice system on how mental and behavioral health issues affect conduct, response to police/sheriff officers, and the behavior of incarcerated individuals; (b) initial police contact with individuals with mental and behavioral health issues; (c) screening for mental and behavioral health issues among arrested individuals; (d) appropriate standards for conviction, imprisonment, and alternatives to imprisonment for individuals with mental and behavioral health issues; (e) appropriate mental and behavioral health screening and services for those with mental and behavioral health issues in jails and prisons; (f) use of physical and chemical restraints and segregated housing/isolation for those in jails and prisons; and (g) appropriate transition services following release from jails and prisons.

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[1] **Rationale:** Modern health, education, and social service professions are largely based on scientific disciplines that are themselves siloed and narrowly focused. The last two decades have produced a tremendous amount of biological and psychological research on human behavior that is directly relevant to successful interventions and education, not only for individuals with ASD, but also for individuals with other disabilities/disorders. Among the most significant findings are the degree to which different types of functioning are integrated throughout development and in producing behavior at any point in time. Of particular relevance to ASD are relatively recent findings on the importance, biology, and psychology of social emotional interaction. Yet current child development textbooks, for example those published by Pearson, continue to review development in silos (physical development, cognitive development, and social development), without any indication of how these areas of functioning affect each other either developmentally or at any given moment in time. Nor do they address how the nervous system functions to produce behavior. A basic understanding of psychology and of the nervous system that integrates all of the major domains of functioning are keystones to understanding the human beings that health, education, and social service professionals deal with every day.

[2] **Rationale:** While humans and their brains develop throughout their lives, early experience not only affects subsequent brain development to a unique degree, but also lays the foundation for social, emotional, and cognitive functioning throughout life. Understanding these processes is critical to understanding all developmental disabilities, disorders arising from early childhood environmental disturbances, and the range of typical functioning both within a single culture and across cultures.

[3] **Rationale:** health literacy principles affect the degree to which families, individuals, and other professionals can understand and make practical use of the information they need in order to respond to their child's or their ASD.

[4] **Rationale:** A primary goal of all services aimed at individuals and their families is to support and develop their ability to navigate life with autism according to their own priorities. None of the existing service delivery silos (health care, education, social services) was created to focus on the full range of needs facing families and individuals trying to learn about ASD and how to get their needs met. Given that families and individuals are diverse in their starting points, informational and emotional needs, learning preferences, and time availability, in addition to cultural and linguistic diversity, there must be a range of high quality educational, service navigation, support, and coaching resources available.

[5] Care navigation services are now routinely provided to cancer patients. These services typically focus on health care alone. The need for such services is every bit as great for a complex neurodevelopmental disorder like ASD, which requires care coordination across multiple types of providers in multiple systems.

[6] **Rationale:** As stated in the introduction, several aspects of ASD require the effective integration of services across existing silos of care (health care, education, and social services). What is less obvious to professionals who work within each silo is the degree to which the very strength they bring to their work, namely their expertise, is also a limitation, making it difficult from them to understand the broader context in which individuals and families experience and respond to ASD. This is not a personal shortcoming of a given professional, but a result of the scientific method itself and of the institutions that have been established to provide care and education, all of which were established in the mid-19th to the mid-20th centuries, when our understanding of human development and behavior was substantially different from what it is now.

All of the current health professions are grounded in biological and psychological research that has, over the course of the last two centuries, become increasingly specialized and reliant on the experimental method. The experimental method requires that variables of interest be isolated from other potentially confounding factors. Yet individuals and families live in a complex ecosystem full of confounding factors. Even if the sciences of human development and behavior were much further advanced than they now are, no single discipline trains its

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professionals to understand all of the other disciplines that have important information bearing on the care and education of individuals and families. While teams of professionals are more common within silos, teams of professionals across silos is still extremely limited or nonexistent. It is only by working with other types of professionals on a regular basis that individuals within a given profession can improve their understanding and their own professional practice.

Finally, as a result of these discipline- and silo-specific constraints, it is difficult for most professionals to grasp the extraordinary burden families and individuals face in trying to get the full range of their needs met from multiple systems and professionals. All of the time, confusion, and stress engendered by the repetitive and inconsistent demands of each separate system and professional intervention can make each one less effective and add real suffering for those whom the professionals have devoted their lives to serving.

[7] UDL is an educational framework based on research in the learning sciences, including neuroscience. Its three main principles are: multiple means of representation, multiple means of action and expression, and multiple means of engagement. These principles apply to the physical aspects of the learning environment, as well as to the curriculum and equipment used. When properly applied, UDL principles create flexible learning environments that can accommodate individual learning differences.