AHCCCS
Arizona Health Care Cost Containment System

Autism Spectrum Disorder Advisory Committee

Recommendations to the Office of the Arizona Governor Policy Advisor for Health and Human Services

February 9, 2016

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ASD Advisory Committee Report of Recommendations

Background

The Autism Spectrum Disorder (ASD) Advisory Committee was appointed in Spring 2015 by Christina Corieri, Policy Advisor for Health and Human Services, Office of the Arizona Governor. Dr. Sara Salek, Arizona Health Care Cost Containment System (AHCCCS) Chief Medical Officer and a child psychiatrist, served as point of contact between Ms. Corieri and the Committee.

The Committee was charged with articulating a series of recommendations to the State for strengthening the health care system's ability to respond to the needs of AHCCCS members with or at risk for ASD, including those with comorbid diagnoses. The charge included focusing on individuals with varying levels of needs across the spectrum, including those who are able to live on their own and those who may require institutional levels of care, and addressing both the early identification of ASD and the development of person-centered care plans.

Executive Summary

The Committee's recommendations include both systems-level changes that will take time to implement and are expected to ameliorate the root causes of many of the current problems, as well as short-term activities that could more quickly enhance an understanding of the current system by the full range of stakeholders and improve access for AHCCCS members with ASD. The systems-level changes include integration of physical and behavioral health care; delivering all Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services through acute health plans, with multiple plans available to ensure consumer choice; access to care coordination; and value-based purchasing.

This two-pronged approach is needed because many individuals with ASD are experiencing challenges that prevent timely diagnosis and the delivery of medically necessary services; their needs must be met immediately. In addition to tools to help people understand and use the current systems of care, specific recommendations are offered to make services through the public behavioral health system more accessible to AHCCCS members with ASD who are not enrolled in the Department of Economic Security (DES) Division of Developmental Disabilities (DDD) Arizona Long Term Care System (ALTCS) program.

There are currently long delays in accessing an appointment for ASD evaluation. The Committee recommends expanding the types of providers from whom DDD accepts an ASD diagnosis to include developmental pediatricians and pediatric neurologists (for children) and neurologists (for adults) in Arizona Administrative Code R6-6-302. In addition, AHCCCS should increase availability and access to licensed psychologists with expertise in ASD diagnosis for all AHCCCS clients at risk for ASD.

Web access should be improved and include comprehensive links to information needed by families and adults with ASD, primary care providers, providers of ASD diagnoses and services, and state agencies. Print copies of resources should be available for those without easy access to the Internet.

Recommendations include offering additional education and resources to all providers who work with individuals with ASD. This is urgently needed to enable providers to successfully guide individuals and families and provide cost-effective, high quality services. The Committee developed specific recommendations to address oral health care needs due to the difficulties individuals with ASD experience in accessing dental and oral health care services.

In response to the need for clarity about evidence-based treatment modalities, a Committee member and the Evidence-Based Treatment Work Group undertook a project that resulted in a major contribution to the field: an analysis of four large systematic review studies of ASD treatments. This analysis and the accompanying intervention descriptions will allow Arizona providers and families to better understand the range of modalities that may be effective for a given individual.

The Committee recommended use of an evidence-based practice definition that focuses on a Person-Centered Plan, starts with the best available scientifically rigorous research, and integrates clinical expertise, the individual's characteristics, and the goal of building family/caregiver capacity. Evidence-based practice is an approach to treatment rather than a specific treatment and incorporates culturally sensitive intervention strategies.

The Adults with ASD Work Group, in collaboration with ASU's Autism/Asperger's Research Program, conducted an online survey of 150 adults with ASD and their parents. Survey findings and the experiences of the group led to five major recommendations to advance quality of life and engage adults with ASD, their family members, and service providers in the design, delivery, and evaluation of services.

Finally, in recognition of the severe shortages of professionals and staff needed to serve individuals with ASD, the Committee recommends that the Governor's Office create an ASD Workforce Development Consortium. In addition to being a partner in serving individuals with ASD, the Department of Education should be enlisted as a partner in recruiting people to ASD-related career opportunities.

Process

The Committee met monthly for two-hour meetings from June through December 2015. In addition, five Work Groups held monthly two-hour meetings on the following topics:

- Early Identification and Diagnosis
- Evidence-Based Treatment
- Reducing System Complexity
- Increasing Network Capacity
- Adults with ASD

An independent consultant, Sharon Flanagan-Hyde, MA, Senior Partner, Flanagan-Hyde Associates, facilitated the meetings. All meeting agendas, materials, notes, and updates for the full Committee and Work Groups were posted online.

The Work Groups included Committee members and other interested individuals. The rosters of the full Committee and the Work Groups are included in Appendix A.

The Committee developed the following Guiding Principles:

- Work toward action items in a positive way.
- Keep recommendations as simple as possible.
- Include members at risk for ASD as well as those with a diagnosis.
- Keep discussions and recommendations:
  - Person- and family-focused
  - Culturally sensitive and competent
  - Evidence-based
  - Data-informed
  - Informed by best practice
  - Cognizant of network sufficiency considerations
  - Focused on building capacity
  - Cognizant of AHCCCS merging physical and behavioral health.
- Ensure compliance with the Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) requirements.
- Focus on optimizing outcomes (when possible, measurable outcomes).
- Seek innovative, system-level change with optimism, recognizing that Arizona's Medicaid waiver allows flexibility and that barriers and systems can be changed.
- Work toward collaboration among all entities and stakeholders, including other provider networks.
- Each Work Group is tasked with incorporating outcome measures in their recommendations.

The Committee developed the following Group Norms:

- Help create an environment that allows all to speak freely and without concern:
  - Listen with an open mind and a collaborative mindset.
  - Speak concisely and respectfully.
  - One person speaks at a time, as called upon by the facilitator.
- The full Committee will focus on the overall goals—Work Groups will handle details and tactics.
- Stay focused on the topic at hand and self-monitor to avoid tangents.
- When expressing agreement with other speakers, don't use up time repeating what has been said.
- Work towards consensus on recommendations.

Each Work Group used the following template to structure early discussions:

1. What are the areas of focus of this Work Group?
2. What do we collectively know about each area of focus?
3. What data do we have?
4. What data do we need?
5. What insights do we have that flow from our collective knowledge and the data?
6. What draft recommendations related to our areas of focus do we want to bring to the full Committees that would strengthen the health care system's ability to respond to the needs of AHCCCS members with or at risk for ASD, including those with comorbid diagnoses?
7. How is each recommendation consistent with our Guiding Principles?
8. What outcomes measures do we suggest for each recommendation?

Some Work Groups looked at literature from other states and spoke with key informants to learn what has worked well and gather input for the recommendations.

The Committee made requests to AHCCCS and DDD for data to support the discussions (see Appendix B).

Committee members asked adults with ASD to review a draft version of these recommendations. One person responded and his verbatim comments are included in Appendix C.

Many Committee and Work Group members have said that the information shared and relationships developed during this process have already had a positive impact on improving services for individuals with ASD.

Some Committee members have expressed a desire to continue meeting quarterly to support the implementation of recommendations and address any challenges that might arise.

Systems-Level Recommendations

The Committee recommends developing a service-delivery architecture that changes some of the responsibilities of AHCCCS-contracted health plans and preserves most, but not all, of the current DES DDD responsibilities.

AHCCCS Integrated Care

- AHCCCS should create an integrated system of physical and behavioral care that considers the whole health of an individual with ASD. In an integrated system, choice is essential, therefore more than one health plan would have contracts (the number of plans would be determined by AHCCCS). Each acute health plan would develop an integrated network specific for the needs of AHCCCS members with ASD. Although it is outside the scope of this Committee's charge, the Committee supports an integrated system of care for all AHCCCS members.

- The rationale for an integrated model in which the acute health plan serves as the "cocoon" for services is the high risk of comorbidities for individuals with ASD. Acute health plans have a higher level of expertise in dealing with medically complex members. In general, an individual's medical home would be a primary care provider contracted by the acute health plan, however, plans could implement other models.

  Since the ASD population may be new to the acute health plans, it is also recommended that they include the specialty behavioral health and social service expertise needed in managing members with ASD. An existing example is found in the new integrated Regional Behavioral Health Authority (RBHA) contracts that include staff and providers with experience and expertise in medical, behavioral health, and non-clinical, social areas like peer supports, housing, and employment. It is also recommended that considerations be given to alternative medical and health home models wherein the primary provider is the provider who is engaged and interacts most with the member. Often, members feel more comfortable and "at home" with these providers and are more willing to take their guidance with respect to other aspects of their care and services provided by others. An example is the SMI integrated RBHA, where the primary provider and team leader may be a psychiatrist, case manager, or peer with whom the member and family feel most comfortable. The primary care physician is definitely a part of the team but not necessarily the team leader.

- All Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services for individuals aged 0-21 would be provided by the health plan. This would address problems reported by families related to ALTCS eligibility and "aging out" of Arizona Early Intervention Program (AzEIP) services. The Committee recognizes that early brain and childhood development research unequivocally demonstrates that diagnosis and intervention must take place as early in a child's life as possible, preferably before a child's second birthday. (The average age of ASD diagnosis in Arizona is 4 years, 10 months.) A comprehensive range of service options and primary care and specialty providers would be available to provide all medically necessary services, including diagnostic evaluations, intensive behavioral therapies such as Applied Behavior Analysis (ABA) and other therapies that prove effective for a given individual and are consistent with Centers for Medicare & Medicaid Services (CMS) guidelines, occupational therapy (OT), physical therapy (PT), speech therapy (ST), and nutrition and feeding therapy. These therapies should include building the capacity of the parent/guardian/caregiver(s) to extend interventions beyond sessions into day-to-day life. Health plans should provide parenting classes, support groups, and/or home visiting programs for parents as needed to encourage a high level of engagement and leverage existing resources across state agencies.

- Integrated physical and behavioral health care services for individuals with ASD who are DDD targeted (in DDD but not qualified for ALTCS) would be covered by the AHCCCS acute health plan.
- Health plans should continually evaluate prior authorization requirements and avoid undue burdens on the provider and/or member.
- The Committee recognizes that a thoughtful approach is necessary to successfully operationalize an integrated care system for individuals with ASD. AHCCCS members would become eligible upon identification as at-risk for ASD or a diagnosis of ASD. Additional discussion is needed regarding identification of members with ASD through claims and/or referrals.
- To ensure smooth implementation, AHCCCS should streamline credentialing and offer online portals so that providers can easily contract with the acute health plans.
- All providers should utilize Arizona's Health Information Exchange (HIE) and electronic medical records (EMR) to integrate data and improve communication among the care coordinator and providers.
- AHCCCS is in the process of implementing person-centered planning[1] and this should move forward as quickly as possible.
- AHCCCS is the payor of last resort. Codes used by commercial payors should be adopted by AHCCCS and DDD whenever possible, or when universally accepted codes are available, to ensure that services covered by commercial payors are appropriately coded and billed.

Care Coordination

- Given the complexity of service needs, comorbidities, and multiple providers, consistent care coordination is essential. Every AHCCCS member with ASD should have access to a care coordinator through the acute health plan. The care coordinator should facilitate communication among health care providers so that an interdisciplinary team provides integrated treatment.
- The care coordinator could be based at the health plan, a multi-specialty clinic, or at the individual's medical home, e.g., at the office of the pediatrician or primary care

[1] Person-centered planning (Kincaid, 1996; O'Brien, Mount, & Obrien, 1991; Smull & Harrison, 1992; Vandercook, York, & Forest, 1989) is a process for identifying goals and implementing intervention plans. It stands in sharp contrast to traditional program-centered planning, in which individuals with disabilities are provided with those preexisting services that a particular agency or institution has available. In person-centered planning, the specific needs and goals of the individual drive the creation of new service matrices that are carefully tailored to address the unique characteristics of the individual. Specific individual needs are considered within the context of normalization and inclusion…to produce an intervention plan that emphasizes community participation, meaningful social relationships, enhanced opportunities for choice, creation of roles that engender respect from others, and continued development of personal competencies. (Carr, Edward G., et al. Positive Behavior Support: Evolution of an Applied Science. *Journal of Positive Behavior Interventions*, Vol. 4, No. 1, Winter 2002, pp. 4-16, 20.)

physician (PCP). Acute health plans should explore models to encourage PCPs to hire an office-based care coordinator and to recruit PCPs who have a care coordinator on staff.

- The care coordinator should have relevant experience and training and be responsible for ensuring access to all medically necessary services for members with ASD, including:
  - Interdisciplinary ASD treatment and ongoing evaluation of effectiveness of services
  - Medical and behavioral health services, with attention to the high risk for comorbid conditions
  - Coordination of prior authorizations
  - Coordination with schools
  - For DES DD ALTCS and DD targeted members, collaboration with the DDD support coordinator
- Acute health plans should put incentives in place to ensure that all entities work effectively with the care coordinator to deliver timely and high quality coordinated care, with consistent communication across all agencies, providers, and the health plan.
- AHCCCS should monitor the quality of care provided through care coordination. Policies and procedures should include ensuring quality regarding the qualifications, continued training, and accountability of care coordinators.

DES DDD ALTCS

- DES DDD should continue to be the managed care organization (MCO) for children and adults enrolled in ALTCS. The model should be as follows:
  - DDD would continue to provide a support coordinator and Home & Community Based Services (HCBS) to ALTCS enrollees.
  - DDD would subcontract with acute health plans for integrated physical and behavioral health services for ALTCS enrollees, including EPSDT services and care coordination. As was mentioned in the AHCCCS section above, consumer choice is essential. Therefore more than one acute health plan would have a DDD subcontract (the number of plans would be determined by DDD). (Note that the Committee is not recommending a model with a single acute plan such as Arizona's Children's Rehabilitative Services for either ALTCS or non-ALTCS eligible individuals with ASD.)
- Ensuring network sufficiency and the continuation of uninterrupted services will be an important consideration as current DDD EPSDT providers shift from participating in the DDD provider network, where service provision rates are set according to a schedule, to participating in the acute care network, which, per the recommendation below, will determine rates through value-based purchasing.
- DDD, AHCCCS, AHCCCS acute health plans, and DDD-subcontracted acute health plans should convene a work group to clarify and if necessary, streamline mechanisms for communication about members moving between AHCCCS acute health plans and DDD-subcontracted acute health plans. This work group should also address communication issues related to the status of referrals to DDD.

- DDD-subcontracted acute health plans and AHCCCS acute health plans should align provider networks, whenever possible, for two purposes: 1) If DDD and health plans contract with the same providers, it could simplify authorization for services, and 2) If an individual loses ALTCS eligibility, the providers could remain the same when services are provided by the health plan.

Value-Based Purchasing

- Implement value-based purchasing (VBP). Linking provider payments to improved performance holds providers accountable for both the cost and the quality of care they provide. VBP reduces inappropriate care and identifies and rewards the best-performing providers. Funding for care coordination should be included in VBP contracts.
- Outcomes measures and incentives for providers caring for individuals with ASD in a VBP model should focus on standards of care (such as comprehensive evaluations, screening for comorbidities, and timely access to care), quality of life indicators, use of best practices identified by professional organizations, individual/family satisfaction, and family-centered care.[2] It is important to recognize that because ASD is a spectrum, a "good" outcome varies widely from individual to individual.
- Maintain choice and the right to switch health plans once per year.
- When setting capitation rates for health plans, AHCCCS should distinguish the population with disabilities, including ASD, from the general AHCCCS population, since individuals with disabilities have more complex needs.
- AHCCCS should:
  - Align incentives across providers to avoid the shifting of risks and costs from one provider type to another.
  - Prioritize increasing providers in underserved areas including greater use of telemedicine and other ways to extend the use of providers in urban locations to rural areas.

[2] According to The Institute for Patient- and Family-Centered Care, "Patient- and family-Centered Care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.
Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them.
Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction." (http://www.ipfcc.org/faq.html)

- Set adequate reimbursement rates for comprehensive evaluations and services in order to attract competent service providers and reduce the provider shortages that currently exist. Rates should be competitive with commercial insurers.
- Provide specific reimbursement codes for travel. This is essential to make services available in rural areas.

Timely Access to Care

- AHCCCS measurements should include ongoing data collection and analysis to monitor utilization of covered services by AHCCCS members with ASD for the purpose of ensuring that individuals identified as at risk receive an evaluation within 45 days, and that upon diagnosis, there are no delays in receiving medically necessary services.

Understanding the Current System

The Committee recognizes that implementing systems-level changes will take time. There is an urgent need to help all stakeholders understand the current system. This is not a small task; Committee and Work Group members spent countless hours talking and studying documents to try to understand the services provided by different agencies and entities in Arizona. Key areas include:

- Families have difficulty learning about the full range of services available to them.
- Most PCPs don't know how the system works for children and adults with ASD and are not aware that there are multiple eligibility categories. Many assume that if they make a referral to AzEIP, no follow-up is needed to ensure that the child receives a diagnostic evaluation for ASD.
- AHCCCS should create and implement a Communications Plan with components for all stakeholders (including families, PCPs, ASD service providers, provider professional organizations, state agencies, schools, municipalities, the legislature, and the Governor's Office) with information about ASD screening, diagnosis, treatment, support services, and other resources. A draft Communications Plan Template is included in Appendix D.
- Members of the Reducing System Complexity Work Group created a simple flow chart designed for families (Appendix E) and a more detailed flow chart designed for providers to illustrate the screening and diagnosis process (Appendix F). Both these flow charts are examples of ways in which AHCCCS and DDD began to act on recommendations from this Committee prior to completion of this report. ***Rather than representing processes used in the past, the information in the flow charts illustrates operational changes now being implemented that should be fully functional within a few months.*** AHCCCS should add the provider flow chart to the AHCCCS Medical Policy Manual (AMPM).
- To the extent possible given federal regulations, all state agencies should use consistent terminology definitions. To assist in reducing confusion, Reducing System Complexity Work Group members developed a "crosswalk" of terminology currently used by different agencies (see Appendix G).
- Ensure that the term for ASD used by all agencies is the same as the current American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM). At this time, per the DSM 5, "Autistic Disorder" should be changed to "Autism Spectrum Disorder" in all policies, rules, and codes.

Accessing the Current System

Until such time as the recommended integration of physical and behavioral health is in place for AHCCCS members with ASD, measures are needed to assist people in accessing and navigating the current system. AHCCCS should:

- Conduct a comprehensive study of the services that currently exist in Arizona for diagnosis and treatment of ASD for children and adults and a gap analysis based on demographic information.
- Document existing services in a database and update annually. The basis of this database can be a chart developed by members of the Committee and Work Groups.
    - Priority: Identify the providers with contracts through the public behavioral health system[3] who are qualified and comfortable conducting an ASD evaluation.
- Ensure that health plans help families navigate the systems and connect individuals with services.
- Provide clear, accurate information to the offices of primary care physicians and specialists about the steps needed to access services for different categories of AHCCCS members. Include:
    - The AHCCCS health plan is often the actual payer/funding source, even if another agency is involved in the processing of a request.
    - The documentation needed for AHCCCS to make a determination about eligibility for ALTCS services.
    - Different actions may be needed based on whether the patient is:
        - Referred to DDD and acute, still in process

[3] Background on Arizona's Public Behavioral Health System: Created in 1986, the Arizona Department of Health Services/Division of Behavioral Health Services (ADHS/DBHS) serves as the single state authority to provide coordination, planning, administration, regulation and monitoring of all facets of the state public behavioral health system. The Division contracts with community-based organizations, known as Regional Behavioral Health Authorities (RBHAs), to administer behavioral health services. Arizona is divided into three geographical areas served by the RBHAs. Mercy Maricopa Integrated Care (MMIC) serves Maricopa County. Health Choice Integrated Care (HCIC) serves Mohave, Coconino, Apache, Navajo, and Yavapai Counties. Cenpatico Integrated Care (C-IC) serves Pima, La Paz, Yuma, Greenlee, Graham, Cochise, Santa Cruz, Gila, and Pinal Counties. In addition to RBHAs, the state has agreements with five of Arizona's American Indian Tribes to deliver behavioral health services to persons living on the reservation. Gila River Indian Community, Navajo Nation, Pascua Yaqui Tribe and the White Mountain Apache Tribe of Arizona each have an agreement for both Medicaid and state subsidized services. Colorado River Indian Tribes has an agreement for state subsidized services. Services to other American Indian Tribes are provided and covered by the RBHA serving the geographic area. Also, tribal members will continue to have the choice of receiving their care through their Tribal Regional Behavioral Health Authority (TRBHA), tribally operated behavioral health program or Indian Health Services. To simplify the administration of programs and facilitate integration of behavioral and physical health services, DBHS will be moving under AHCCCS in 2016. (http://www.azdhs.gov/bhs/aboutbhs.htm)

  - Acute, not eligible for ALTCS
  - DDD targeted (in DDD but not qualified for ALTCS, so covered by the acute health plan)
  - DDD/ALTCS with Children's Rehabilitative Services (CRS)
  - DDD/ALTCS without CRS
  - ALTCS Elderly and Physically Disabled (EPD)
  - Dual eligible (Medicaid and Medicare)
  - CRS fully integrated or CRS partially integrated health plan types, which have behavioral health integrated into the health care benefits
- Engage in outreach and education for providers about how to access the public behavioral health system (RBHAs) for ASD diagnosis and treatment. It is important to emphasize that if an individual is not eligible for services through ALTCS, services are available through the acute health plan and RBHA.
- Eliminate the distinction between habilitation and rehabilitation services and the need for prior authorization. Each individual should have access to all medically necessary services, including intensive behavioral therapy.
- Expand use of telemedicine for diagnosis, treatment, and training to improve care in rural areas of the state. Treatment could include a range of services, for example speech therapy, among others.

Until systems-level integration is in place, the public behavioral health system should be more accessible and easier to navigate for individuals with ASD. Immediate changes should include:

- Amending AHCCCS RBHA contracts to require RBHAs to develop and implement a self-assessment survey to determine whether contracted professionals are comfortable diagnosing ASD, and if not, what professional development is needed and how it should be implemented. Anecdotal information suggests that many providers whose licensed scope of practice includes diagnosing ASD are not comfortable doing so. Given the workforce shortage and long delays in obtaining an appointment for diagnosis, it is essential that contracted professionals are providing this service. The results of this assessment should be reported to the AHCCCS Chief Medical Officer.
- Contracting with and encouraging utilization of developmental pediatricians.
- Contracting with clinical psychologists for ASD diagnoses. For example, there are at least 26 clinical psychologists in the Phoenix metropolitan area who are trained on the Autism Diagnostic Observation Schedule™ (ADOS) and who can complete a thorough battery of tests to diagnose ASD (e.g., Psychiatric Diagnostic Interview, Autism-DSM/ICD10 specific interviews, Autism questionnaires, and the ADOS-2, Adaptive Behavior and verbal/nonverbal cognitive skills).
- Ensuring that intensive behavioral services are readily available.
- Using current RBHA codes (below) and adding codes for clinical direction. Note that additional codes may be added over time. Travel codes should be specified in addition to the service codes.

Service Code	Service Description
H0002	Behavioral Health Screening
H004 HR	Individual Behavioral Health Counseling and Therapy
H004 HS	Family Counseling and Therapy
H004 HQ	Group Therapy
H0025	Behavioral Health Prevention education
H0031	Assessment by non-physician
H0034	Health Promotion - Medication training and support
H0038	Self-help/peer services (peer support)
H2014	Skills Training and Development
H2014 HQ	Skills Training and Development - Group
H2015	Comprehensive Community Support Services per 15 min
H2016	Comprehensive Community Support Services, per diem
H2017	Psychosocial Rehab
S5110	Home Care Training, Family (Family Support)
S5150	Respite, per 15 min
S5151	Respite, per diem
T1016	Case Management

DDD should finalize the data review, including the fiscal impact data, and implement the Habilitation Consultation service if the data support it.

Information about Resources

- Improve web access with comprehensive links to information needed by:
  - Families and adults with ASD
  - Primary care providers
  - Providers of ASD diagnoses and services
  - State agencies
- Because not all families have easy access to the Internet, printed copies of resources should be available. Computers for Internet access with printing capabilities could be made available at selected provider locations.
- AHCCCS should provide an electronic resource book to all contracted behavioral health clinics listing protocols and providers of services for individuals with ASD.

Provider Education

All providers who treat individuals with ASD would benefit from increased education and information about the range of needs and available services. AHCCCS should:

- Distribute a checklist for pediatricians/primary care providers to ensure that they check for comorbid conditions that are common in individuals with ASD. (A checklist is available in the American Academy of Pediatrics' resource *Autism: Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians*.)
- Work closely with professional associations (e.g., Arizona Academy of Family Physicians, Arizona Chapter of the American Academy of Child and Adolescent Psychiatry, Arizona

Chapter of the American Academy of Pediatrics, Arizona Medical Association) and with health plans on provider outreach and education.

- Encourage use of the article "Autism: Clinical pearls for primary care" in Contemporary Pediatrics (Nov. 1, 2010)[4] and two American Academy of Pediatrics (AAP) clinical reports: "Identification and Evaluation of Children With ASD" and "Management of Children with ASD," both reaffirmed by the AAP Council on Children with Disabilities in 2014. An addition resource is the AAP's *Autism: Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians.*
- Request that the Arizona Dental Association, perhaps in collaboration with A.T. Still University School of Dentistry & Oral Health and Midwestern University College of Dental Medicine–Arizona[5]:
  - Create and disseminate online training for dentists to help them provide appropriate oral health care for individuals with ASD.
  - Conduct an environmental scan and disseminate a list of dentists who have experience and willingness to provide care for individuals with ASD.
  - Provide each dental office with instructions and encouragement to create an office-specific storyboard to help prepare an individual with ASD for a dental visit: what to expect in the parking lot, office building, office, etc.
- Request that providers review their policies and capacity to provide oral health treatment for individuals with ASD. Individuals with serious comorbidities may require anesthesia and access to emergency assistance during dental procedures. Issues such as hospital privileges for dentists, the capacity of the operating room to accommodate dental equipment, and coordinating care in the hospital setting are significant challenges.
- Encourage all communities to develop resources similar to the Developmental Screening and Surveillance Yuma County Referral Roadmap.
- AHCCCS should designate a subset of PCPs for adults who specialize in care for individuals with ASD, similar to developmental pediatricians for children.

ASD Diagnosis

- The DDD Eligibility Manual, Policy 200-G, Autism (A) says "Acceptable documentation of autism must include a statement by, or evaluation from, a psychiatrist, a licensed psychologist, or developmental pediatrician with experience in the area of autism identifying a diagnosis of Autistic Disorder."
  - Make several changes to Arizona Administrative Code R6-6-302. Guidelines for Determining Developmental Disabilities "A. Autism, cerebral palsy, epilepsy, and mental retardation are determined as follows: 1. Autism — by a licensed psychiatrist or psychologist whose expertise in diagnosing autism is determined by

[4] http://contemporarypediatrics.modernmedicine.com/contemporary-pediatrics/news/modernmedicine/modern-medicine-feature-articles/autism-clinical-pearls-?page=full

[5] Autism Speaks has a toolkit for children with ASD: https://www.autismspeaks.org/family-services/tool-kits/dental-tool-kit

the Division." Change the term "mental retardation" to "intellectual disability (per the 2010 federal "Rosa's Law") and add "developmental pediatrician" and "pediatric neurologist." The new language would read: "A. Autism, cerebral palsy, epilepsy, and intellectual disability are determined as follows: 1. Autism — by a licensed psychologist, psychiatrist, developmental pediatrician or pediatric neurologist (for children)/neurologist (for adults) whose expertise in diagnosing autism is determined by the Division."
    - Change "autism" and "Autistic Disorder" to "Autism Spectrum Disorder."
- AHCCCS should increase availability and access to licensed psychologists with expertise in ASD diagnosis for all AHCCCS clients at risk for ASD.
- DDD should ensure that diagnosis is made using current DSM criteria. The clinical diagnosis of ASD should be made through a multidisciplinary evaluation[6] involving multiple informants and settings and should include a parent interview along with direct observation of the child. Further psychological testing may be indicated to evaluate cognitive skills, language skills, adaptive function, and academic function.
- This would provide a comprehensive profile of the individual's and family's strengths and needs in multiple domains and inform a comprehensive treatment plan. The assessment should not hinder or delay the initiation of services. The assessment should include:
    - Medical assessment, including screening for comorbidities and genetic testing as per current recommendations by organizations such as the American Academy of Pediatrics (AAP), American Academy of Child and Adolescent Psychiatry (AACAP), and American Academy of Neurology (AAN).
    - Speech and language assessment.
    - Psychological assessment (as outlined above).
    - When judged appropriate by the diagnosing clinician, use of the Autism Diagnostic Observation Schedule™ (ADOS) 2nd Edition (ADOS-2), or the current version, as a diagnostic instrument and a tool for treatment planning, outcome measurement, and measurement of change over time.
- AHCCCS should include as a best practice in the AHCCCS Medical Policy Manual (AMPM) and educate providers as follows:
    - The Centers for Disease Control and Prevention (CDC) has very comprehensive recommendations for screening and diagnosis of ASD for health providers.[7]
    - Screening for ASD should be accompanied by screening for medical and psychiatric comorbidities, including screening for ADHD and intellectual disability.
- AHCCCS should encourage the development of efficacious services, programs, and products that expand statewide capacity to accelerate early identification and diagnosis of ASD. These practices should include collaboration with organizations such as the Arizona Chapter of the American Academy of Pediatrics (AzAAP), Arizona Chapter of

[6] It is not necessary for all multidisciplinary evaluations to take place at the same time or at the same location.
[7] The CDC link is http://www.cdc.gov/ncbddd/autism/screening.html.

the American Academy of Child and Adolescent Psychiatry (AACAP), Arizona Medical Association (ArMA), and the Arizona Academy of Family Physicians (AzAFP).

- AHCCCS can significantly improve access to critical early intervention services and programs through ongoing review and assessment of emerging practices by the AHCCCS Chief Medical Officer. This might include:
  - Based on an assessment of peer-reviewed data on efficacy and validity, consider reimbursement for use of the Naturalistic Observation Diagnostic Assessment (NODA), a technology product and service developed, researched, and validated in Arizona that uses smart phones to connect families with licensed, highly trained diagnosing psychologists. This has the potential to improve access to diagnosing psychologists, especially in rural areas of the state.
  - Reviewing the efficacy of the Early Access to Care-Arizona (EAC-AZ) program that provides a six-month intensive, specialized evidence-based diagnostic training to PCPs. This particular emerging practice has the goal of expanding the field of diagnosticians and providers of medical home care to children with ASD, to lower the age of diagnosis, and to lower the age of entry into intervention.
  - Exploring acceptance of ASD diagnoses from other doctoral-level professionals with documented, specialized training and expertise in diagnostics for ASD.

Evidence-Based Treatment Modalities

- AHCCCS should distribute and encourage use of the intervention descriptions and analysis of the following four large systematic review studies of ASD treatments developed as part of the Evidence-Based Treatment Work Group's activities (see Appendix H):
  1. (**NPDC**) National Professional Development Center/Autism Evidence-Based Practice Review Group at UNC Chapel Hill: Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., Schultz, T. R. (2014). *Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder.* Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.
  2. (**CMS**) The Centers for Medicaid & Medicare Services commissioned a review of existing services for ASD: U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. (2010). *Autism Spectrum Disorders Services (ASDs): Final report on environmental scan.* Baltimore, MD: Young, J., Corea, C., Kimani, J., & Mandell, D.
  3. (**NSP2**) National Standards Project – Phase 2: National Autism Center, A Center of May Institute: National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Randolph, MA.
  4. (**DHHS/AHRQ**) The Department of Health and Human Services and the Agency for Healthcare Research and Quality commissioned Vanderbilt University to complete a systematic review of the ASD research: Weitlauf A.S., McPheeters M.L., Peters B., Sathe N., Travis R., Aiello R., Williamson E., Veenstra-VanderWeele J., Krishnaswami S., Jerome R., Warren Z. *Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137.*

(Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2012-00009-I.) AHRQ Publication No. 14-EHC036-EF. Rockville, MD: Agency for Healthcare Research and Quality; August 2014. www.effectivehealthcare.ahrq.gov/reports/final.cfm.

The intervention descriptions and analysis are intended to serve as a guide regarding categorization of treatments (i.e., established evidence and emerging evidence) and are not intended endorse or exclude any specific treatment. The Committee recognizes that there is not a "one size fits all" ASD treatment approach. A Person-Centered Treatment Plan should be developed using an evidence-based approach: the intersection of research, clinical expertise, the individual's characteristics, and a focus on building family/caregiver capacity. Evaluations and treatments are developmentally appropriate. Ongoing screening for comorbidities is essential to ensure that the needs of the whole person are addressed.

- The AHCCCS Chief Medical Officer should appoint a multidisciplinary committee of licensed professionals and a few family members and individuals with ASD to update the "Analysis of Large Systematic Review Studies of ASD Treatments Tool" included in Appendix H annually. AHCCCS should distribute updates to all ASD stakeholders and post the update on the AHCCCS website.
- AHCCCS should design and implement a consistent process for ongoing evaluation of whether a treatment results in improvement for the individual. The care coordinator is responsible for ensuring that the evaluation takes place on a quarterly basis

Evidence-Based Practice

AHCCCS should use the following definition: Evidence-based practice means a decision-making process that starts with the best available scientifically rigorous research and integrates clinical expertise, the individual's characteristics, and the goal of building family/caregiver capacity. Evidence-based practice is an approach to treatment rather than a specific treatment and incorporates culturally sensitive intervention strategies. It focuses

on developing an individualized Person-Centered Plan. Evidence-based practice promotes the collection, interpretation, integration, and continuous evaluation of valid, important, and applicable individual- or family-reported, clinically-observed, and research-supported evidence. The best available evidence, matched to the individual's circumstances and preferences and a focus on building family and caregiver capacity, is applied to ensure the quality of clinical judgments and facilitate the most cost-effective care. (*Adapted from CA Trailer Bill*)

Adults with ASD

Arizona has a HCBS strategy that often rests on the ability of the family to provide care and support over the lifespan of individuals with ASD. However, not all individuals with ASD have family members. In addition, Arizona does not have the needed infrastructure to support the ever-increasing number of individuals with ASD now transitioning from high school to adult life. In addressing the needs of adults, it is important to acknowledge and strengthen the role of families to ensure their support continues and that Arizona's low rates of institutional care be sustained in the future.

Arizona needs to explore new territory in providing services for adults with ASD to increase quality of life, maximize independence to the greatest degree possible and reduce the cost associated with lifelong support and care of this burgeoning new population of adults. Innovation and flexibility are essential. AHCCCS and other State agencies must be fortified with a variety of practical, cost-effective strategies and begin building the system infrastructure to support adults with ASD over their lifetimes, and in the absence of a surviving parent or family member.

Engaging adults with ASD, families, and stakeholders is essential in the creation of member-directed services, ensuring appropriate health care options and strong provider networks, and incentivizing the development of an array of integrated and outcome-oriented community services and employment opportunities.

All individuals, regardless of ability, have the right to access the basic elements that make up a good life, beginning with: family, independence, personal responsibility, and freedom of choice. The Committee supports the principles of Self-Determination, which include:

- Freedom to exercise the same rights as all citizens; to establish, with freely chosen supports, family and friends, where they want to live, with whom they want to live, how their time will be occupied, and who supports them;
- Authority to control a budget in order to purchase services and supports of their choosing;
- Support, including the ability to arrange resources and personnel, which allows flexibility to live in the community of their choice;

- Responsibility, including the opportunity to take responsibility for making decisions; and
- Confirmation, in making decisions by designing and operating the services on which they rely.[8]

The Adults with ASD Work Group, in collaboration with the ASU Autism/Asperger's Research Program, conducted an online survey of 150 adults with ASD and their parents. Some major findings include: 44% unemployed, 35% employed without supports, 12% working with supports, 4% in center-based employment, 5% in group-based employment; average salaries, $3/hour in center-based and group-based employment. The full report is included as Appendix I.

The Adults with ASD Work Group urges AHCCCS to collect and analyze data on the major recommendations included in this report, identifying course corrections along the way and ensuring successful outcomes for more adults and their families living with ASD. We understand this requires AHCCCS to devise methods to ensure effective implementation and quality monitoring of the person-centered plan and reporting systems, which address a diverse population:

- The person transitioning to adult living
- The person living at home
- The adult living in a home of their own or another option
- The person who does not have a supportive family

The Adults with ASD Work Group has five major recommendations.

1. AHCCCS should support the ability of Arizona families to stay strong while they work to advance the quality of life for their adult sons/daughters with ASD.
    - Recognize the critical importance of the family in designing and implementing person-centered planning. Arizona's 5-year transition compliance plan for CMS devotes needed attention to person-centered planning and self-advocacy. In reality, family members most often implement these plans. Many adults with ASD need employment, community life engagement and 6-8 hours of community-based supports each day. Their families need to be able to rely on the person with ASD having 6-8 hours of community-based services with transportation provided each day.
    - Plan and develop a system for direct service provider support to address the social and emotional impact of long-term caregiving, with interventions to prevent emergency residential placements. Services should include behavioral health referrals, emergency respite, temporary out-of-home residential options and a provider network for peer support services.
    - Ensure a broad range of residential options that provide a continuum of services and long-term supports. At some point, many adults with ASD need residential services. Reliable forecasts of future residential needs and trends for this population are increasingly important.

[8] California Department of Developmental Services, https://www.dds.ca.gov/SDP/

- Confront the issue that many adults with ASD are not eligible for ALTCS and lack access to the services and supports they need for a good quality of life. Many adults with ASD who are not "at risk" of institutional care lack ALTCS eligibility. As they transition out of high school special education services, they will represent a significant population with an increased risk for poor health outcomes. These adults often experience significant skill regression, increased social isolation, lack of employment, and untreated depression and anxiety. Ensure that adults with ASD and their families have information and targeted service interventions to know how to access treatment and services through their health plans, and specifically how to address the area of behavioral health needs. While many adults with ASD can perform activities of daily living (ADL), they will continue to rely heavily on the financial and caregiving support of family members throughout their lives.

2. AHCCCS should actively engage adults with ASD, their family members and service providers in the design, delivery, and evaluation of services.
   - Establish an AASD Advisory Council (Adults with ASD) representing the participation of self-advocates (individuals with ASD), family members, providers and professionals. Adults with ASD and others can provide authentic, member-specific perspectives on what barriers exist and can assist in developing or evaluating proposed solutions. AHCCCS can demonstrate a commitment to transparency and accountability by engaging in regular dialogue and discussion with stakeholders ensuring the needs of this population are met.
   - Expand the system's capacity for youth-to-adult transition services and options for learning independent living skills. Strategies that support a successful transition to adult life maximize individual potential and minimize the dependence on state services. Resources invested at this juncture will have long-term benefits for both the individual with autism and for AHCCCS.
   - Determine the most cost-effective means of providing employment support services through inter-agency collaboration. Develop an improved system of employment support services to address needs over the lifespan. Employment support services will need to be designed with requirements to incentivize flexibility and responsiveness to the individual needs of the adult with ASD. Job development, the availability of worksite mentors, job coaching and transportation services are issues that will need to be revisited many times for each individual. See Appendix J for other cross-cutting issues.
3. AHCCS should support individuals with ASD to live a high quality life that includes housing, work, health care, continuing education and recreation.
   - Remove the barrier of transportation as a major impediment. Change the language of the AZ Medicaid Waiver to make transportation a stand-alone HCBS. Transportation represents a major problem for adults and AHCCCS currently limits Medicaid transportation reimbursement to accessing an ALTCS service. Reimbursement is not currently available to access employment.
   - Assess, address and remove environmental deterrents to increase community integration. Support AHCCCS providers such as occupational therapists to conduct environmental scans/assessments empowering them to modify and produce

environments where individuals with sensory and processing sensitivities can be more successful (i.e., homes, places of work, health care, learning). Support models where others may learn to create the same.

- Increase the availability of residential options by supporting existing and new/innovative options. Collaborate with the AZ Department of Housing and AHCCCS providers to demonstrate supportive housing in a broad range of environments and locations. Enhance the training and skills of in-home direct support service providers, focusing on the safety, security and comforts of "home," while increasing independence. Encourage social interactions and meaningful friendships through community development (small-large group gatherings) in residential settings, addressing the loneliness, isolation, and depression many adults face.
- Improve access to a supportive community and increase the number of successful outcomes. Allow AHCCCS billing for best and promising practices, including social support services to ensure adults with ASD benefit from HCBS community integration goals and requirements. Social organizing services for adults with ASD will help achieve CMS's goals for community integration and engagement activities. Ensuring age-appropriate community integration requires planning and expertise, and many adults with ASD lack the ability to initiate and navigate the range of social environments.
- Develop a system of long-term employment supports to address evolving needs over the lifespan, starting in high school, and expanding participation in individual supported employment.
- Employment programs must be designed with requirements that incentivize transition towards employment with increased salaries in the community, and flexibility and responsiveness to the individual needs of the adult with ASD. Job development, placement, job coaching and other services must be continually evaluated to support self-determination and achieve increased capacity and independence.
- Coordinate with DES to effectuate the benefits of the new federal Workforce Innovation and Opportunity Act (WIOA) signed into law on July 22, 2014. WIOA benefits begin at age 14 with pre-vocational transition planning. DDD is responsible for coordinating with other DES agencies to ensure access for all DDD members who are eligible for WIOA services.
- DDD center- and group-based employment staff should receive enhanced training to: 1) "fade" supports and increase the independence of clients so they can transition to more independent work; 2) ensure that each provider agency allocates appropriate staff resources to find suitable work for clients to do; and 3) rotate clients between/among different jobs to expand their skills. They should be incentivized to find higher-paid work for clients.
- Increase opportunities for greater independence and quality of living through compilation of respected resources and with Internet accessibility for use by individuals, families, and providers. Provide a current and reliable roster of all agencies/case managers/direct support service providers who understand and have

formal training; covered services/classes that addresses social communications/interpersonal relations, nutrition counseling and career-readiness; and life skills and training for direct support service providers.

4. AHCCS should support healthy living for adults with ASD, programmatically, systematically and with the evidence of positive outcomes.
    - Integration of care should address physical, behavioral, core symptoms, comorbidity issues, communications, and social and life skills development. AHCCCS should require targeted and personalized health screenings in preventive and well-care visits, with specific treatment plans to address comorbidities such as gastrointestinal (GI) symptoms, sleep disorders, epilepsy, and behavioral health issues prevalent in adults with autism, which for many individuals and families are "equally or more challenging than the core symptoms of ASD," according to the National Institute of Mental Health Interagency Autism Coordinating Committee (NIH IACC). In addition, services need to effectively address the core issues of autism, such as a speech therapy benefit that includes a class in social communication taught by an experienced speech pathologist or similar expert. AHCCCS providers of behavioral health benefits should provide cost-effective individual and/or group counseling for adults with ASD to address issues such as social isolation, anxiety, and depression.
    - Adults should have access to Board Certified Behavior Analyst (BCBA) services, if needed.
    - Align access to care with networks, people, information, and coding. Include on the website referenced previously in this report a roster of all providers/case managers throughout the state who understand how to effectively work with individuals with ASD. Require AHCCCS providers to use appropriate web-based tools and resources for adult assessment that have been developed and adapted for use across the lifespan. Continue to support the creation and maintenance of electronic health records. Effectuate meaningful assessments for adults on the autism spectrum.
    - Establish guidelines and requirements for continuity of care with case managers and direct support service providers who understand ASD. As recommended previously in this report, align health plan provider networks for adults with ASD covered by AHCCCS and/or ALTCS so as individuals leave or enter eligibility, health plans and providers have access to critical healthcare information.
5. AHCCCS should identify and publicize the metrics used to evaluate the quality of services provided for adults with ASD.
    - In consultation with stakeholders, establish outcome measures of effectiveness in health care, employment supports, residential services, and community integration. Annually report outcomes via an Adults with Autism Outcomes Dashboard, set target goals for improvement each year, determine what type of incentives are needed to improve quality, and obtain external validation and verification of results.

Workforce Development

- The Committee recommends state-supported:

  - Recruitment of underrepresented medical sub-specialists who care for children and adults with ASD (e.g., rural specialists, developmental pediatricians, child psychiatrists).
  - Therapist training/scholarships (e.g., speech, occupational, physical therapists).
  - ABA/BCBA training/scholarships for specialists in treatment expertise (e.g., BCBA-B, BCBA-M, BCBA-D).
  - Special educator training/scholarships (e.g., special educators of all levels, including preschool through college).
  - Internships with provider agencies that specialize in working with individuals with ASD.

- To address the shortage of professionals and non-professional staff needed to serve individuals with ASD, the Governor's Office should create an ASD Workforce Development Consortium. This might include the Presidents of the state universities, community colleges, and private higher education institutions (e.g., Grand Canyon University, A.T. Still University), the Department of Education, representatives from the community and businesses, veterans organizations, AARP Arizona, and AHCCCS. The Consortium would be tasked with monitoring and developing the workforce needed to provide the full range of services to individuals with ASD.
  - College students should be recruited for part-time habilitation and respite positions, which might foster professional interest in the field.
  - Veterans are a potential workforce pool due to high rates of unemployment. Veterans' participation would be especially useful in early intervention programs.
  - Retired individuals are also a potential workforce pool.
- The Department of Education should review and expand current opportunities for high school students to engage in learning activities with individuals with ASD. This might include students working with their schools with peers and job training programs such as Job Corps.
- AHCCCS and health plans should increase the use of online training for individuals entering the ASD workforce and for continuing education for the full range of providers.

Conclusion

The ASD Advisory Committee and Work Group members appreciate this opportunity to provide recommendations to improve the health care system's ability to respond to the needs of AHCCCS members with or at risk for ASD. We are eager to participate in a continuing dialogue to support implementation of these recommendations.

Appendix A: ASD Advisory Committee and Work Groups

Individuals (or their replacements due to position changes) appointed to the ASD Advisory Committee by Christine Corieri, Policy Advisor for Health and Human Services, Office of the Arizona Governor. All meetings were facilitated by Sharon Flanagan-Hyde, MA, Senior Partner, Flanagan-Hyde Associates. St. Luke's Health Initiatives and AHCCCS provided support for third-party professional facilitation.

Providers

- Karla Birkholz, MD, Arizona Academy of Family Physicians, HonorHealth Medical Group
- Robin K. Blitz, MD, FAAP, Chief, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children's Hospital
- Bryan Davey, PhD, BCBA-D, Chief Executive Officer, HOPE Group, LLC; President, Highland Behavioral
- Danny Kessler, MD, FAAP, Medical Director, Children's Developmental Center, Southwest Human Development
- Terry Matteo, PhD, Clinical Child Psychologist
- Brian van Meerten, MEd, BCBA, LBA, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)
- Daniel Openden, PhD, BCBA-D, President and CEO, Southwest Autism Research & Resource Center (SARRC)
- Jared Perkins, MPA, Director of Operations, Children's Clinics; Vice President, Autism Society of Southern Arizona
- Sydney Rice, MD, MSd, Board-certified Developmental Pediatrician; Associate Professor, Pediatrics, The University of Arizona College of Medicine in Tucson
- Anne Stafford, Executive Director, Arizona Chapter American Academy of Pediatrics' [did not participate]
- Ginger Ward, MAEd, Chief Executive Officer, Southwest Human Development

Family Member Advocates

- Albert Acuña, Chapter Chair, Autism Society of Southern Arizona – Santa Cruz
- Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition
- Erika Johnson, Chapter Vice Chair, Autism Society of Southern Arizona
- Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix
- Jon Meyers, Executive Director, The Arc of Arizona
- Joyce Millard Hoie, MPA, Executive Director, Raising Special Kids
- Ann Monahan, Board President, Arizona Autism Coalition; Vice President, State and Governmental Affairs, H.O.P.E. Group, LLC
- Denise Resnik, Co-Founder and Emeritus Board Member, Southwest Autism Research & Resource Center (SARRC); and Founder, First Place

Health Plans/RBHAs

- Rene Bartos, MD, MPH, FAAP, Medical Director, Mercy Care Plan

- Don J. Fowls, MD, Medical Strategies (formerly Chief Medical Officer), Mercy Maricopa Integrated Care (MMIC), RBHA
- Jennie McMillian, MA, LPC, Health Choice Integrated Care (HCIC), RBHA
- Leslie Paulus, MD, PhD, FACP, Medical Director, UnitedHealthcare Community Plan
- Terry Stevens, MA, LPC, Chief Executive Officer, Cenpatico Integrated Care (C-IC), RBHA

State Agencies

- Paul Gladys, MBA, Assistant Director, Division of Behavioral Health Services (DBHS), Arizona Department of Health Services (ADHS)
- Joanna Kowalik, MD, DES/DDD Acting Chief Medical Officer
- Laura Love, PhD, DES/DDD Assistant Director
- Sara Salek, MD, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)
- Karie Taylor, MA, Executive Director, Arizona Department of Economic Security—Arizona Early Intervention Program (AzEIP)

Early Identification & Referrals Work Group

Members of the ASD Advisory Committee are shown in bold.

- **Albert Acuna,** Chapter Chair, Autism Society of Southern Arizona – Santa Cruz
- **Rene Bartos, MD, MPH, FAAP**, Medical Director, Mercy Care Plan
- **Don Fowls, MD**, Chief Medical Officer, Mercy Maricopa Integrated Care (MMIC, RBHA)
- **Joanna Kowalik**, **MD**, DES/DDD Acting Chief Medical Officer
- **Terry Matteo, PhD**, Clinical Child Psychologist
- **Sydney Rice, MD, MS**, Board-certified Developmental Pediatrician; Associate Professor, Pediatrics, The University of Arizona College of Medicine in Tucson
- **Karie Taylor, MA**, Executive Director, Arizona Department of Economic Security—Arizona Early Intervention Program (AzEIP)
- Jennifer Andrews, MBA, Researcher, University of Arizona, Department of Pediatrics
- Kim M. Elliott, PhD, CPHQ, Administrator, Clinical Quality Management, AHCCCS
- Janna Murrell, Director of Family Support and Education, Raising Special Kids

Reducing System Complexity Work Group

Members of the ASD Advisory Committee are shown in bold.

- **Rene Bartos, MD, MPH, FAAP**, Medical Director, Mercy Care Plan
- **Robin Blitz, MD, FAAP**, Chief, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children's Hospital
- **Diedra Freedman, JD**, Board Secretary/Treasurer, Arizona Autism Coalition
- **Paul Gladys, MBA**, Assistant Director, Division of Behavioral Health Services (DBHS), Arizona Department of Health Services (ADHS)
- **Erika Johnson,** Chapter Vice Chair, Autism Society of Southern Arizona
- **Jennie McMillian, MA, LPC**, Health Choice Integrated Care (HCIC), RBHA

- **Brian van Meerten, MEd, BCBA, LBA**, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)
- **Cynthia Macluskie**, Vice President, Board of Directors, Autism Society of Greater Phoenix
- **Ann Monahan**, Board President, Arizona Autism Coalition; Vice President, State and Governmental Affairs, H.O.P.E. Group, LLC
- **Jared Perkins, MPA**, Director of Operations, Children's Clinics; Vice President, Autism Society of Southern Arizona
- **Sara Salek, MD**, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)
- **Karie Taylor, MA**, Executive Director, Arizona Department of Economic Security—Arizona Early Intervention Program (AzEIP)
- **Ginger Ward, MAEd**, Chief Executive Officer, Southwest Human Development
- Monica Coury, JD, Assistant Director, Office of Intergovernmental Relations, AHCCCS
- Diana Davis-Wilson, MEd, BCBA, Clinical Executive Director, Hope Group
- Steve Sparks, Children's System Administrator, Division of Behavioral Health Services (DBHS), Arizona Department of Health Services (ADHS)
- Christopher Tiffany, MAEd, Director of Family Support and Education, Raising Special Kids
- Sherri Wince, DES/DDD ALTCS Administrator

Evidence-Based Treatment Work Group

Members of the ASD Advisory Committee are shown in bold.

- **Bryan Davey, PhD, BCBA-D**, Chief Executive Officer, HOPE Group, LLC; President, Highland Behavioral
- **Joanna Kowalik, MD**, DES/DDD Acting Chief Medical Officer
- **Cynthia Macluskie**, Vice President, Board of Directors, Autism Society of Greater Phoenix
- **Terry Matteo, PhD**, Clinical Child Psychologist
- **Daniel Openden, PhD, BCBA-D**, President and CEO, Southwest Autism Research & Resource Center (SARRC)
- **Leslie Paulus, MD, PhD, FACP**, Medical Director, UnitedHealthcare Community Plan
- Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United
- Maureen Casey, DES—AzEIP Professional Development Coordinator
- Diana Davis-Wilson, MEd, BCBA, Clinical Director, Hope Group, LLC
- Maureen Mills, Communications Coordinator, Raising Special Kids
- Karrie Steving, Children's System of Care Administrator, Mercy Maricopa Integrated Care (MMIC), RBHA
- Jacob Venter, MD, CPE, FAPA, Division Chief of Psychiatry, Barrow Neurological Institute at Phoenix Children's Hospital
- Megan Woods, MEd, BCBA, LBA, DES/DDD Behavior Analyst

Building Network Capacity Work Group

Members of the ASD Advisory Committee are shown in bold.

- **Bryan Davey, PhD, BCBA-D**, Chief Executive Officer, HOPE Group, LLC; President, Highland Behavioral
- **Don J. Fowls, MD**, Medical Strategies (formerly Chief Medical Officer), Mercy Maricopa Integrated Care (MMIC), RBHA
- **Danny Kessler, MD, FAAP**, Medical Director, Children's Developmental Center, Southwest Human Development
- **Jennie McMillian, MA, LPC**, Health Choice Integrated Care, RBHA
- **Brian van Meerten, MEd, BCBA, LBA**, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)
- **Ann Monahan**, Board President, Arizona Autism Coalition; Vice President, State and Governmental Affairs, HOPE Group, LLC
- **Terry Stevens, MA, LPC**, Chief Executive Officer, Cenpatico Integrated Care (C-IC), RBHA
- Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United
- Gary Brennan, FACHE, CHC, President and CEO, Touchstone Behavioral Health
- Arnetta DeCamp, ME, Cenpatico Integrated Care (C-IC), RBHA
- Maria Dixon, Clinical Associate Professor, Dept. of Speech & Hearing Science, College of Health Solutions, Arizona State University
- Vickie French, Assistant Executive Director, Raising Special Kids
- Tyrone Peterson (DES/DDD Behavioral Health Manager)

Adults with ASD Work Group

Members of the ASD Advisory Committee are shown in bold.

- **Karla Birkholz, MD**, Arizona Academy of Family Physicians, HonorHealth Medical Group
- **Jon Meyers**, Executive Director, The Arc of Arizona
- **Joyce Millard Hoie**, MPA, Executive Director, Raising Special Kids
- **Daniel Openden, PhD, BCBA-D**, President and CEO, Southwest Autism Research & Resource Center (SARRC)
- **Denise Resnik**, Southwest Autism Research & Resource Center—SARRC and First Place
- James Adams, President, Autism Society of Greater Phoenix; Director, Autism/Asperger's Research Program, President's Professor, Arizona State University
- Elanie Estrada (DES/DDD Administrative Coordinator)
- Christopher Tiffany, Director of Family Support and Education, Raising Special Kids
- Nancy L. White (Parent)

Appendix B: AHCCCS and DDD Data

AHCCCS
Arizona Health Care Cost Containment System

Douglas A. Ducey, Governor
Thomas J. Betlach, Director

ASD Advisory Committee Meeting - August, 12 2015

AHCCCS ASD Prevalence

Objective: Identify the current ASD prevalence in the AHCCCS system

- 2014 Prevalence Aged 0-20: 10,097/762,110 = 1.3%
  - ASD Aged 0-20 Distinct Member Count: 10,097
  - 2014 AHCCCS Member Enrollment 0-20 Years Old on 12/1/2014: 762,110
- Methodology
  - Timeframe: 1/1/2014 – 12/31/2014
  - Members equal or less than 20 years of age on Date of Service
  - Member had to have 2 or more paid claims or encounters with ASD in the primary diagnosis position
    - Claims are submitted with ICD-9 diagnosis code
    - ASD ICD-9 Diagnosis Codes
      - 29900/29901 – Autistic disorder
      - 29910/29911 – Childhood disintegration disorder
      - 29980/29981 – Other specified pervasive developmental disorders
      - 29990/29991 – Unspecified pervasive developmental disorder

Developmental Screenings

Objective: Understand the current utilization of developmental screening during the 9, 18 and 24 month EPSDT visits in the AHCCCS system

- Procedure Code 96110 - Developmental Screening, with interpretation and report, per standardized instrument
  - AHCCCS approved developmental screening tools are:
    - The Parent's Evaluation of Developmental Status (PEDS)
    - Ages and Stages Questionnaire (ASQ)
    - The Modified Checklist for Autism in Toddlers (MCHAT)
  - Policy updated in April 2014 allowing expanded reimbursement to incentivize providers to perform developmental screenings during an EPSDT visits for members under the age of two*
- Methodology
  - Paid Claims and Encounters
  - Timeframe: 10/1/2013 – 12/31/2014

Distinct Member Counts for Members Who Received Developmental Screening by Quarter

Age	CAL2013-Q4	CAL2014-Q1	CAL2014-Q2*	CAL2014-Q3	CAL2014-Q4
<1	1,414	1,486	1,716	2,234	2,278
1	1,280	1,454	1,784	2,165	2,187
2	727	794	1,084	1,650	1,756
Total	**3,421**	**3,734**	**4,485**	**6,049**	**6,221**
% Change		+9.1%	**+22.8%**	**+32.0%**	+2.8%

- Percentage of members who received Developmental Screening compared to the total EPSDT Visits performed for ages 0-2 years old from 10/1/2013 – 9/30/2014
  - Members aged <1: 6,850/36,486 = 18.8%
  - Members aged 1-2: 10,938/71,362 = 15.3%

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Eligibility of Individuals with Autism

- Early Periodic Screening Diagnosis Treatment (EPSDT) – Children qualified for Medicaid and eligible for EPSDT coverage to age 21.
- 9,160 Individuals with Autism Served by DDD (27% 0f Total DDD population)
- **DDD state funded** (DD only) – Meets the eligibility requirements for enrollment in the Division per R6-6-302[9] The person does not qualify for any Medicaid services – neither acute nor long term care.
- **Targeted Support Coordination** (TSC) – Meets the eligibility requirements for enrollment in the Division per R6-6-302. The person qualifies for Medicaid acute services - not long term care. AHCCCS reviews functional needs and financial eligibility.
- **Arizona Long Term Care System** (ALTCS) – Meets the eligibility requirements for enrollment in the Division per R6-6-302. The person is considered at risk for institutionalization and eligible for HCBS.

[9] A person must have a developmental disability before the age of 18, attributable to a cognitive/intellectual disability, cerebral palsy, epilepsy or autism with substantial functional limitations in three or more of the following:

- Self-care: needing help with eating, hygiene, etc.;
- Receptive and expressive language: needing help with communicating with others;
- Learning: needing help with acquiring and processing new information;
- Mobility: needing help with moving from place to place;
- Self-direction: needing help with managing personal finances or making decisions;
- Capacity for independent living: needing supervision or assistance on a daily basis; and/or
- Economic self-sufficiency: not being financially independent.

ALTCS Members by Autism Diagnosis and Age as of 6/30/15

Age Range	Autism Diagnosis Count (ALTCS)
00 - 02.9	32
03 - 05.9	581
06 - 17.9	5,536
18 - 21.9	872
22 - 44.9	1,153
45+	129
Total	**8,303**

Non-ALTCS Members by Autism Diagnosis as of 6/30/15 (Total Autism N= 857)

Primary Diagnosis	Targeted Case Management	DDD State-only
Autism	403	454
DDD Non ALTCS Totals	**4,281**	**3,220**

Non-ALTCS by Autism and Age

Age Range	Autism Diagnosis Count (Non-ALTCS)
00 - 02.9	40
03 - 05.9	169
06 - 17.9	520
18 - 21.9	132
22 - 44.9	122
45+	13
Total	**996**

Appendix C: Review by Adult with ASD

Committee members asked adults with ASD to review a draft version of these recommendations. One person responded. The Committee appreciates his time and willingness to share his perspectives. The comments of Andrew Robinson are as follows:

1. No mention was made of ADDPC (Arizona Developmental Disabilities Planning Council) in the report. Why is this important? Because many of the goals and recommendations in the report, overlap what ADDPC is involved with. The successes that ADDPC has had, can contribute to the success of many of the goals set forth in the report.
2. First paragraph of the Executive Summary. No evidence has been provided that the root cause many individuals are experiencing that prevent timely diagnosis will be addressed by systems-level changes. I received my diagnosis in under two months but I know a mother whose daughter was not diagnosed until she was 15. The timeliness of the diagnosis was not due to any system-level implementations, but with the individual's attitude, approach, and cooperation with the system as is. This needs to be clarified: if the parents are unwilling to have their children diagnosed with ASD, they will do anything within their power to prevent it, and if a process or goal is unpopular with the parents, the system will side with them by refusing to wholeheartedly engage in it. It is currently very unpopular to have a child diagnosed with ASD, with some parents calling it a disastrous, heart-breaking diagnosis.
3. Section on AHCCCS Integrated Care and early diagnosis and intervention. It is not a coincidence that most children are not diagnosed, on average, until they are about five years old — that is the age at which parents have to be prepared to send their children off to Kindergarten and therefore can no longer be in denial of their child's unique behaviors. Parents and their attitudes need to be the number one target for getting an early diagnosis, making everyone else's job all the easier. This will not be easy, as I have talked with a few parents who think they can help their child with ASD, far better than any institution could. An extremely small number can but most fail and give up, but only after they have run out of all options.
4. How exactly is any government institution going to identify who is at risk or not, based on the data or services utilized? It is not the place of AHCCCS, nor is AHCCCS qualified to monitor people at risk of ASD. It is up to the ASD individual or the parents of an ASD child to decide if they want to seek a diagnosis or not.

Appendix D: Draft Communication Plan Template

The starting point for developing a Communications Plan is identifying audiences and the messages to be communicated. Audiences might include all types of providers, health plans, DDD, AHCCCS, other state agencies, peer and family-run organizations, the legislature, the Governor's Office, counties and municipalities, schools, colleges and universities, places of worship, and other stakeholders.

Types of communication might include e-mail blasts, phone calls, face-to-face conversations, newsletters, websites, direct mail, and social media. A communication plan template might include these five categories:

Audience	Communication Type	Purpose	Responsible Party	Due Date/Status

Appendix E: Flowchart for Providers

Information for Primary Care Providers
Identification and Referrals for Autism Spectrum Disorder (ASD)

Note: The content of this flow chart is currently being implemented and will be fully functional within a few months.

AHCCCS covers medically necessary services for Medicaid beneficiaries diagnosed with ASD. Primary Care Providers (PCPs) play a critical role in early identification and referral to evaluation and treatment.

A diagnosis by a Specialized ASD Diagnosing Provider is a critical step in developing the member's care plan for the treatment of ASD.

Step 1: Screen for ASD

Conduct developmental screening at child's early and periodic screening, diagnostic, and treatment (EPSDT) visits to identify potential ASD according to the AHCCCS Medical Policy Manual, Policy 430- EPSDT Services. EPSDT/Well Child visits include the following:

- Comprehensive Developmental Screening
- Determine needs of the child from the developmental screening results
- Make appropriate referrals to evaluation

If services are needed prior to a diagnosis for ASD, or if ASD is not diagnosed, do not delay referrals for medically necessary services. For example, if you find a child needs speech therapy, do not wait for a diagnosis of ASD to refer the member for speech therapy services.

Step 2: Refer for Diagnosis

If you suspect or if screening results indicate a potential diagnosis of ASD:

- Contact the member's Acute Health Plan Behavioral Health Coordinator to initiate referral to the Regional Behavioral Health Authority (RBHA) Specialized ASD Diagnosing Provider. A Specialized ASD Diagnosing Provider is board certified or board eligible in:
    - Developmental Behavioral Pediatrics
    - Neurodevelopmental Pediatrics
    - Adult or Child Psychiatry
    - Licensed Clinical Psychology, doctoral level

Step 3: Services, Treatment, and Care Coordination

Once the member is diagnosed with ASD:

- The Acute Health Plan Behavioral Health Coordinator will provide you with a copy of the member's evaluation and treatment plan.
- Make appropriate referrals:
    1. Advise the member/caregiver to apply for eligibility with the Arizona Long Term Care System (ALTCS)/Division of Developmental Disability.
    2. *If under age 3*: Refer member to Arizona Early Intervention Program (AzEIP).
    3. *If over age 3*: Refer member to Division of Developmental Disabilities (DDD).
- Periodically review treatment plan with member/caregiver to ensure services are being provided and are effective.

A new referral and approval may be required periodically based on progress in treating the condition.

Appendix F: Flowchart for Families and Members

Information for Members and Families
4 Steps to Access Services for Autism Spectrum Disorder

Note: The content of this flow chart is currently being implemented and will be fully functional within a few months.

AHCCCS covers medically necessary services for all Medicaid beneficiaries diagnosed with autism spectrum disorder (ASD). **Follow the steps below to get started:**

Step 1: Visit Your Primary Care Provider

If you suspect your child has ASD, schedule an appointment with your primary care provider (specializing in family practice or pediatrics). If your primary care provider agrees with your concerns, a referral to a Specialized ASD Diagnosing Provider (listed in Step 2) will be made to confirm the ASD diagnosis.

Step 2: Get Diagnosed

Once a referral by your primary care provider has been made, schedule an appointment with the Specialized ASD Diagnosing Provider recommended by your primary care provider. A Specialized ASD Diagnosing Provider must be board certified or board eligible in:

- Developmental Behavioral Pediatrics
- Neurodevelopmental Pediatrics
- Adult or Child Psychiatry
- Licensed Clinical Psychology, doctoral level

Step 3: Get a Referral and Authorization

Once diagnosed, a Specialized ASD Diagnosing Provider and/or your primary care provider will discuss treatment options with you and request authorization for AHCCCS members to receive treatment through the medical and/or behavioral health plans.

- Once services are authorized, you and your Provider(s) will be notified that you can begin. See Step 4 below.
- For any services not authorized, you will receive a notice of action from your health plan that includes your appeal rights.

Step 4: Get Treatment

Schedule an appointment with the treating Provider(s). Your treating Provider(s) will:

- Develop an individual treatment plan
- Work one-on-one with you and your child
- Help parents and caregivers develop the skills to provide support and implement strategies
- Supervise services provided by assistant behavior analysts and behavior technicians
- Re-evaluate your child as needed

A new referral and approval may be required periodically based on progress in treating the condition.

Appendix G: Cross-walk of Terminology

ASD Early Identification and Referral Work Group – Crosswalk of Terms				
Activity	AHCCCS	Behavioral Health	AzEIP (Includes DDD under 3)	DDD over 3
Screening	Screening means regularly scheduled examinations and evaluations of the general physical and behavioral health, growth, development, and nutritional status of infants, children and adolescents, and the identification of those in need of more definitive evaluation.	Screening means examinations and evaluations and the identification of those in need of more definitive evaluation.	The activities carried out to identify, at the earliest possible age, children suspected of having a developmental delay or disability and in need of early intervention; and includes the administration of appropriate instruments by personnel trained to administer those instruments.	Typically screening refers to a process or tool used by a physician to determine the need for further action. Additionally, screening tools are referenced in relation to eligibility determinations.
Evaluation	A review performed by a provider to determine a definitive diagnosis and the medical necessity of a need for services.	A review performed by a behavioral health provider to determine a definitive diagnosis and the medical necessity of a need for services.	The procedures used by qualified personnel (Multi-Disciplinary Team [MDT]) to determine a child's initial and continuing eligibility for AzEIP.	A service performed by a professional to determine the need for services.
Assessment	The identification of risk factors through the use of a comprehensive assessment tool covering psychosocial, nutritional, medical and educational factors.	The ongoing collection and analysis of a person's medical, psychological, psychiatric and social conditions in order to initially determine if a health disorder exists, if there is a need for behavioral health services, and on	Ongoing procedures used by qualified personnel to identify the child's unique strengths and needs and the early intervention services appropriate to meet those needs throughout the period of the child's eligibility	The Individualized Support Plan (ISP) is the Division's assessment tool. A critical component of person centered planning, the assessment process involves the member and their family as appropriate in the identification of support needs and

ASD Early Identification and Referral Work Group – Crosswalk of Terms				
Activity	AHCCCS	Behavioral Health	AzEIP (Includes DDD under 3)	DDD over 3
		an ongoing basis ensure that the person's service plan is designed to meet the person's (and family's) current needs and long term goals.	and includes the assessment of the child; and the voluntary assessment of the child's family.	includes their participation in decision-making.
Services	The health and medical benefits provided to members enrolled in the AHCCCS program by an AHCCCS Contractor.	The behavioral health benefits provided to members enrolled in the AHCCCS program by a Regional Behavioral Health Authority (RBHA).	Services identified in IDEA, Part C, which assist families in providing learning opportunities that facilitate their child's successful engagement in relationships, activities, routines, and events of everyday life. Services are provided in the context of the family's typical routines and activities so that information is meaningful and directly relevant to supporting the child to fully participate in his or her environment.	Those covered services provided by qualified service providers within the scope of their practice to prevent disease, disability and other adverse health conditions or their progression or to prolong life.
Care Coordination	Services that assist members and their families in receiving care and services that allow each member to achieve treatment and quality of life goals.	Care coordination encompasses a variety of activities for coordinating services and providers to assist a member in achieving his or her recovery goals	Service Coordination services to assist and enable a child and the child's family to receive services and rights, including procedural	Coordination of Care is a component of Support Coordination and assists members in obtaining acute, behavioral health, and educational

ASD Early Identification and Referral Work Group – Crosswalk of Terms				
Activity	AHCCCS	Behavioral Health	AzEIP (Includes DDD under 3)	DDD over 3
		described in the Individual Recovery Plan. These activities, which can occur both at a clinical and system level, are performed by Treatment Team members depending on a member's needs, goals, and functional status.	safeguards, required by IDEA, Part C. The AzEIP Team-based early intervention contractor appoints an AzEIP service coordinator upon referral who shall serve as the single point of contact for the family to coordinate all services required under IDEA, Part C across agency lines. Service coordination is an active, ongoing process.	services.

Appendix H: Systematic Review Studies

Appendix H includes Intervention Descriptions and analysis of the following four Systematic Review Studies:

1. (**NPDC**) National Professional Development Center/Autism Evidence-Based Practice Review Group at UNC Chapel Hill: Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., Schultz, T. R. (2014). *Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder.* Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.
2. (**CMS**) The Centers for Medicaid & Medicare Services commissioned a review of existing services for ASD: U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. (2010). *Autism Spectrum Disorders Services (ASDs): Final report on environmental scan.* Baltimore, MD: Young, J., Corea, C., Kimani, J., & Mandell, D.
3. (**NSP2**) National Standards Project – Phase 2: National Autism Center, A Center of May Institute: National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Randolph, MA.
4. (**DHHS/AHRQ**) The Department of Health and Human Services and the Agency for Healthcare Research and Quality commissioned Vanderbilt University to complete a systematic review of the ASD research: Weitlauf A.S., McPheeters M.L., Peters B., Sathe N., Travis R., Aiello R., Williamson E., Veenstra-VanderWeele J., Krishnaswami S., Jerome R., Warren Z. *Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137.* (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2012-00009-I.) AHRQ Publication No. 14-EHC036-EF. Rockville, MD: Agency for Healthcare Research and Quality; August 2014. www.effectivehealthcare.ahrq.gov/reports/final.cfm.

ASD Committee member Terry Matteo, PhD and his colleague Cindy Hoard, EdD developed this analysis of the four systematic reviews in November 2015. Members of the ASD Evidence-Based Treatment Work Group provided guidance and feedback.

INTERVENTION DESCRIPTIONS

COMPREHENSIVE INTERVENTIONS

Comprehensive Interventions utilize multiple focused interventions that are organized around a central theoretical or conceptual framework, target multiple domains, and are typically longer in duration.

Comprehensive Behavioral Intervention Programs for Young Children: Interventions involving a combination of instructional and behavior change strategies and a curriculum that addresses core and ancillary symptoms and behaviors of ASD. (CMS) Examples include: Life Skills and Education for Students with Autism and Other Pervasive Behavioral Challenges (LEAP), Early Start Denver Model, UCLA Young Autism Project.

Structured Teaching: This intervention involves a combination of procedures that rely on the physical organization of a setting, predictable schedules, and individualized use of teaching methods. These teaching methods may be used in comprehensive interventions such as Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) and LEAP.

FOCUSED INTERVENTIONS

Focused interventions refer to treatments that are typically shorter term in duration and target discrete skills.

Academic Interventions: Interventions involving the use of traditional teaching *methods to improve academic performance. (CMS)*

- **Direct Instruction:** Instructional package involving student choral responses, explicit signal to cue student responses, correction procedures for incorrect or non-responses, modeling correct responses, independent student responses. *(NPDC)*
- **Collaborative Coaching:** Systematic consultation across years to promote achievement of IEP goals. *(NPDC)*
- **Collaborative Learning:** Academic learning organized around joint activities and goals. *(NPDC)*
- **Handwriting Without Tears:** Multisensory activities promoting fine motor and writing skills. (NPDC)
- **Sentence Combining Technique**: Instructional package including teacher modeling, student practice, and worksheet to increase adjective use in writing. *(NPDC)*
- **Test Taking Strategy Instruction:** Instructional package including modeling, mnemonic devices, verbal practice sessions, controlled practice sessions, advanced practice sessions. *(NPDC)*

INTERVENTION DESCRIPTIONS
Antecedent Intervention/Package: Interventions involving the modifications of events that typically precede the occurrence of a target behavior. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. (CMS). Prompting, Time Delay and Stimulus Control/Environmental Modification are included within this category.
• **Prompting**: Verbal, gestural, or physical assistance given to learners to assist them in acquiring or engaging in a targeted behavior or skill. Prompts are generally given by an adult or peer before or as a learner attempts to use a skill. (NPDC)
Stimulus Control/ Environmental Modification: Term used by NPDC interchangeably with Antecedent-based Interventions. Interventions in which environmental modifications are used to change the conditions in the setting that prompts a learner to engage in an interfering behavior. The goal is to identify factors that are reinforcing the interfering behavior and then modify the environment or activity so that the factor no longer elicits the interfering behavior. (NPDC)
Auditory Integration Training: Intervention involving the presentation of modulated sounds through headphones in an attempt to retain an individual's auditory system with the goal of improving distortions in hearing or sensitivities to sound. (CMS)
Behavioral Package: Interventions designed to reduce problem behavior and teach functional alternative behaviors or skills through the application of basic principles of behavior change. (CMS) NPDC lists nine separate interventions that fit within this category as well as Behavior Momentum Intervention. NSP2 & CMS include Reductive Package within this category.
• **Differential Reinforcement**: Provision of positive/desirable consequences for behaviors or their absence that reduce the occurrence of an undesirable behavior. Reinforcement provided: a) when the learner is engaging in a specific desired behavior other than the inappropriate behavior; b) when the learner is engaging in a behavior that is physically impossible to do while exhibiting the inappropriate behavior; or c) when the learning is not engaging in the interfering behavior. (NPDC) This term is used by NPDC and in overall category of Positive Behavior Support Strategies or in Behavioral Package (NSP2 & CMS)
• **Exposure:** Interventions involving gradually increasing exposure to anxiety-provoking situations while preventing the use of maladaptive strategies used in the past under these conditions. (CMS) Also defined as the increasing or decreasing of the stimulus intensity or conditions to promote the occurrence of the desired response. (NPDC)
• **Extinction:** Withdrawal or removal of reinforcers of interfering behavior in order to reduce the occurrence of that behavior. Although sometimes used as a single intervention, extinction often occurs in combination with functional behavior assessment, functional communication training, and differential reinforcement. (NPDC)

INTERVENTION DESCRIPTIONS
• **Functional Behavior Assessment (FBA):** Systematic collection of information about an interfering behavior designed to identify functional contingencies that support the behavior. FBA consists of describing the interfering or problem behavior, identifying antecedent or consequent events that control the behavior, developing a hypothesis of the function of the behavior, and/or testing the hypothesis. (NPDC) The term is used by NPDC and in overall category of Positive Behavior Support Strategies and also used by NSP2 and CMS in the Behavioral Package.
• **Functional Communication Training (FCT):** Replacement of interfering behavior that has a communication function with more appropriate communication that accomplishes the same function. (NPDC) This term is used by NPDC and in overall category of Positive Behavior Support Strategies and is also used by NSP2 and CMS in the Behavioral Package.
• **Reinforcement**: An event, activity, or other circumstance occurring after a learner engages in a desired behavior that leads to the increased occurrence of the behavior in the future. (NPDC) Included in Behavioral strategies category & Behavioral Package (NSP2 & CMS)
• **Removal of Restraints:** Gradual removal of restraints involving application of pressure to arm, shadowing. (NPDC) Included in Behavioral Strategies category
• **Response Interruption/Redirecting:** Introduction of a prompt, comment, or other distracter when an interfering behavior is occurring that is designed to divert the learner's attention away from the interfering behavior and results in its reduction. (NPDC) Included in overall category of Positive Behavior Support Strategies; Behavioral Package (NSP2 & CMS)
• **Task Analysis & Chaining:** A process in which an activity or behavior is divided into small, manageable steps in order to assess and teach the skill. Other practices, such as reinforcement, video modeling, or time delay, are often used to facilitate acquisition of the smaller steps. (NPDC) Included in Behavioral Strategies category; Behavioral Package (NSP2 & CMS)
Cognitive Behavioral Interventions: Interventions designed to change negative or unrealistic thought patterns and behaviors with the aim of positively influencing emotions and life functioning. (CMS) Also described as instruction on the management or control of cognitive processes that lead to changes in overt behavior. (NPDC) Referred to as Cognitive Behavioral Intervention Package by NSP2 & CMS; AHRQ identified the specific use of CBT with anxiety as showing Established Evidence. NPDC identified "Schema-based Strategy Instruction" as showing emerging evidence (i.e., insufficient evidence to be included in the Established Evidence category).

INTERVENTION DESCRIPTIONS
Computer-aided Treatment /(Technology-aided) Instruction: These interventions require the presentation of instructional materials using the medium of computers or related technologies. (CMS) NPDC used a category called Technology-aided Instruction and Intervention. CMS & NSP2 used a category called "Technology-based Treatment. NPDC included the definition of technology as "any electronic item/equipment/application/or virtual network that is used intentionally to increase/maintain, and/or improve daily living, work/productivity, and recreation/leisure capabilities of adolescents with autism spectrum disorder (Odom, Thompson, et al., 2013). (NPDC).
Developmental Relationship–based Treatment: Interventions involving a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. (CMS). This category overlaps with Parent Training (AHRQ) since they included DIR/Floortime Research in their Parent Training category.
Exercise: Interventions involving an increase in physical exertion as a means of reducing problem behaviors or increasing appropriate behavior. (CMS) NPDC – found established evidence for use of exercise to decrease problem behaviors and increase positive behaviors. NSP2 found an emerging level of evidence.
Joint Attention (JA) Intervention (Intervention and Outcome): Interventions involving teaching a child to respond to the nonverbal social bids of others or to initiate joint attention interactions. (CMS) CMS treated JA as an intervention. JA has been linked to increases in communication and symbolic play. NSP2 included JA in the Behavioral Package. NPDC & AHRQ treated JA as an outcome. Interventions in this category overlap with multiple NPDC categories including JA-Symbolic Play Instruction; AHRQ - Play-based intervention for JA as outcome.
Language Training: Interventions that have as their primary goal to increase speech production. (CMS) CMS identified Language Production as having an emerging level of evidence. NSP2 identified more studies that showed established evidence for Language Training (production). NSP2 included Language Training for Understanding (comprehension) as an emerging evidence category.
Modeling: Interventions relying on an adult or peer providing a demonstration of the target behavior that should result in an imitation of the target behavior by the individual with ASD. (CMS) NPDC noted that modeling is often combined with prompting and reinforcement. NPDC included both Modeling and Video Modeling (use of video recording) as separate established evidence categories. CMS included modeling in the emerging evidence category. NSP2 also included a new category called Imitation-based Intervention – and showed emerging evidence for this intervention.

INTERVENTION DESCRIPTIONS
Multi-component Package: These interventions involve a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations. These treatments do not better fit one of the other treatment "packages" listed above nor are they associated with specific treatment programs. Examples are: The Family Support Program, Multicomponent Teaching Package.
Music Therapy: Interventions that teach individuals skills through music *(NPDC, CMS, NSP2)*
Naturalistic Interventions: Interventions involving using primarily child-directed interactions to teach functional skills in the natural environment. They often focus on providing a stimulating environment, modeling how to play, encouraging conversation, providing choices and direct/natural reinforcers, and rewarding reasonable attempts. (CMS); Intervention strategies usually occur during typical setting/activities/routines; establish the learner's interest through arrangement of the setting/activity/routine, provide necessary support for the learner to engage in the targeted behavior when it occurs, and arrange natural consequences for the targeted behavior. (NPDC) *NSP2 & CMS use the term Naturalistic Teaching Strategies*
Parent Implemented Interventions: Interventions involving parents delivering the intervention to their child to improve/increase a wide variety of skills and/or to reduce interfering behaviors. Parents learn to deliver interventions in their home and/or community through a structured parent training program. Parent Training Approaches/ overlap with Symbolic Play and Play-based Interventions. (AHRQ) AHRQ included DIR/Floortime studies in this group. Examples include: Social Communication Intervention, ESDM, DIR/Floortime; Joint Attention Intervention, Joint Attention Symbolic Play Engagement and Regulation (JASPER). NPDC & NSP2 grouped studies that were identified as showing established evidence. AHRQ identified the category at the emerging level.
Peer Mediated Interventions: Typically developing peers interact with and/or help children and youth with ASD to acquire new behavior, communication, and social skills by increasing social and learning opportunities within natural environments. Teachers/service providers systematically teach peers strategies for engaging children and youth with ASD in positive and extended social interactions in both teacher-directed and learner-initiated activities. (NPDC). NSP2 and CMS use Peer Training Package; NPDC also uses Structured Play Group (a group including both typically developing peers and children with ASD); NSP2 included Initiation Training (in the emerging evidence category).

INTERVENTION DESCRIPTIONS
Picture Exchange Communication System (PECS): This intervention involves the application of a specific augmentative and alternative communication system based on behavioral principles that are designed to teach functional communication to children with limited verbal and/or communication skills. (CMS) Learners are initially taught to give a picture of a desired item to a communicative partner in exchange for a desired item. (NPDC). *NPDC, NSP2 & CMS consistently use this term.*
Pivotal Response Training (PRT): This treatment is also referred to as PRT, Pivotal Response Teaching, and Pivotal Response Treatment. PRT focuses on targeting "pivotal" behavior areas, such as motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues, with development of these areas having the goal of very widespread and fluently integrated collateral improvements. (CMS) Term used by NPDC; Pivotal Response Treatment (NSP2 & CMS); Included in Parent Training Approaches (AHRQ)
Schedules: Interventions involving the presentation of a task that communicates a series of activities or steps required to complete a specific activity. Schedules are often supplemented by other interventions such as reinforcement. (CMS) NSP2 & CMS included schedules. This overlaps with Structured Work Systems and Visual Supports (NPDC)
Sensory/Massage – Sensory Regulation: This category utilizes sensory input: tactile, vestibular, auditory, and proprioceptive - to improve behavior. • **Massage** (CMS included Touch w/ Massage): Interventions involving the provision of deep tissue stimulation (CMS) • **Music Intensity:** Different levels of music volume (auditory input) used to affect vocal stereotypy (NPDC) • **Sensory Diet:** Sensory based activities integrated into child routines to meet sensory needs. (NPDC) • **Sensory Integration & Fine Motor Intervention:** Therapeutic activities characterized by enhanced sensation, especially tactile, vestibular, and proprioceptive; with active participation and adaptive interaction paired with individual fine motor instruction from OT. (NPDC) • **Touch-Point Instruction:** Tactile and number line materials used to introduce math and numeracy concepts. (NPDC)
Self-Management: These interventions involve independence by teaching individuals with ASD to regulate their behavior by recording the occurrence/non-occurrence of the target behavior, and securing reinforcement for doing so. Initial skills development may involve other strategies and may include the task of setting one's own goals. (CMS) This term is used consistently by NPDC, NSP2 & CMS; Self-Regulatory Strategy Development Writing (NSP2)

INTERVENTION DESCRIPTIONS
Social Communication Intervention: These interventions psychosocial interventions involve targeting some combination of impairments such as pragmatic communication skills, and the ability to successfully read social situations. (CMS) Interventions included in this category by NSP2 & CMS are included in the AHRQ Parent Training Approaches Category
Social Narratives: These treatments involve a written description of the situations under which specific behaviors are expected to occur. Stories may be supplemented with additional components (e.g., prompting, reinforcement, discussion, etc.). (CMS) These narratives describe in some detail the relevant cues of social situations and offer examples of appropriate responding. (NPDC) This intervention overlaps with Story-based Intervention Package (NSP2 & CMS) overlaps with Scripting (NSP2 & CMS)
Social Skills Intervention: These interventions seek to build social interaction skills in children with ASD by targeting basic responses (e.g., eye contact, name response) to complex social skills (e.g., how to initiate or maintain a conversation). (CMS) Social Skills Training Group (NPDC) is similar to Social Skills Package (NSP2 & CMS) and Social Skills Training (AHRQ); Initiation Training (CMS)
Speech Generating Strategies: Interventions involving the use of high or low devices to facilitate communication. Examples include but are not restricted to: pictures (PECS), photographs, symbols, communication books, computers, or other electronic devices. (NPDC) also referred to as VOCA overlaps with Augmentative and Alternative Communication Devices (NSP2 & CMS); NPDC Aided Language Modeling; Sign Instruction (NSP2)
Theory of Mind: These interventions are designed to teach individuals with ASD to recognize and identify mental states (i.e., a person's thoughts, beliefs, intentions, desires, and emotions) in oneself or in others and to be able to take the perspective of another person in order to predict their actions. (CMS) CMS, NPDC & NSP2 identified category at the emerging level.
Toilet Training: Modifications of toilet training program developed by Arin & Fox (1971). (NPDC) An isolated skill.

1. (**NPDC**) National Professional Development Center/Autism Evidence-Based Practice Review Group at UNC Chapel Hill: Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., Schultz, T. R. (2014). *Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder.* Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.
2. (**CMS**) The Centers for Medicaid & Medicare Services commissioned a review of existing services for ASD: U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. (2010). *Autism Spectrum Disorders Services (ASDs): Final report on environmental scan.* Baltimore, MD: Young, J., Corea, C., Kimani, J., & Mandell, D.
3. (**NSP2**) National Standards Project – Phase 2: National Autism Center, A Center of May Institute: National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Randolph, MA.
4. (**DHHS/AHRQ**) The Department of Health and Human Services and the Agency for Healthcare Research and Quality commissioned Vanderbilt University to complete a systematic review of the ASD research: Weitlauf A.S., McPheeters M.L., Peters B., Sathe N., Travis R., Aiello R., Williamson E., Veenstra-VanderWeele J., Krishnaswami S., Jerome R., Warren Z. *Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137.* (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2012-00009-I.) AHRQ Publication No. 14-EHC036-EF. Rockville, MD: Agency for Healthcare Research and Quality; August 2014. www.effectivehealthcare.ahrq.gov/reports/final.cfm.

SYSTEMATIC REVIEWS OF ASD RESEARCH WITH TARGET/OUTCOMES

(T. Matteo, Ph.D./ C. Hoard, EdD.) November 2015

For each of the four reviews in the table below, symbols represent the following categories:

- Level 1: Established Evidence (solid bullet)
- * Level 2: Emerging Evidence (asterisk)

The absence of a symbol indicates that the intervention was not addressed in the study.

INTERVENTION	NPDC 2014	CMS - IMPAQ 2010	NSP2 2014	DHHS - AHRQ 2014	SOCIAL	COMMUNICATION	BEHAVIOR	ACADEMIC/ COGNITIVE	ADAPTIVE
	SYSTEMATIC REVIEWS				TARGET/OUTCOMES				
COMPREHENSIVE INTERVENTIONS									
Comprehensive Behavioral Intervention Programs for Young Children *(NSP2 & CMS) also referred to as Early Intensive Behavioral and Developmental Interventions (AHRQ); Early Intensive Behavior Interventions (EIB) or behavioral inclusive programs (NSP2). All utilize ABA principles. Ex. LEAP, ESDM, UCLA Young Autism Project.*	•	•	•	• *	√ √	√	√ √	√	√ √
Structured Teaching *(NSP2 & CMS) describes programs such as TEACCH; (AHRQ) and overlaps with Structured Work Systems which are one component of Structured Teaching in TEACCH and LEAP.*		•	*	• *	√ √	√	√ √	√	√ √
FOCUSED INTERVENTIONS									
Academic *(CMS)*		*			√	√		√	√
• **Direct Instruction** *(NPDC)*	*						√		
• **Collaborative Coaching** *(NPDC)*	*							√	
• **Collaborative Learning** *(NPDC)*	*				√			√	
• **Handwriting Without Tears** (NPDC)	*							√	
• **Sentence Combining Technique** *(NPDC)*	*							√	
• **Test Taking Strategy Instruction** *(NPDC)*	*							√	

SYSTEMATIC REVIEWS OF ASD RESEARCH WITH TARGET/OUTCOMES

(T. Matteo, Ph.D./ C. Hoard, EdD.) November 2015

INTERVENTION	NPDC 2014	CMS - IMPAQ 2010	NSP2 2014	DHHS - AHRQ 2014	SOCIAL	COMMUNICATION	BEHAVIOR	ACADEMIC/ COGNITIVE	ADAPTIVE
	SYSTEMATIC REVIEWS				TARGET/OUTCOMES				
Antecedent Intervention/Package *(NSP2 & CMS) groups a variety of antecedent-based Interventions; NPDC uses 3 categories: Prompting, Time Delay and Stimulus Control/Environmental Modification (also referred to as Antecedent-based Interventions)*	•	•			√	√	√		√
• **Prompting** *Term used by NPDC and included in Behavioral Strategies category; Antecedent Package (NSP2 & CMS)*	•		•		√	√	√	√	√
• **Stimulus Control/ Environmental Modification** *Term used by NPDC interchangeably with Antecedent-based Interventions and included in overall category of Positive Behavioral Support Strategies: Antecedent Package (NSP2 & CMS)*	•								
Auditory Integration Training *(NPDC)*	*								
FOCUSED INTERVENTIONS (cont.)									
Behavioral Package *(NSP2 & CMS) groups a variety of behaviorally based interventions: NPDC lists nine separate interventions that fit within this category as well as Behavior Momentum Intervention. NSP2 & CMS use Reductive Package within this category*	•	•	•		√	√	√	√	√
• **Differential Reinforcement** *Term used by NPDC and in overall category of Positive Behavior Support Strategies; Behavioral Package (NSP2 & CMS)*	•				√	√	√	√	√
• **Exposure** *Term used by (NSP2)*	*		*						
• **Extinction** *Term used by NPDC and in overall category of Positive Behavior Support Strategies; Behavioral Package (NSP2 & CMS)*	•					√	√		√

SYSTEMATIC REVIEWS OF ASD RESEARCH WITH TARGET/OUTCOMES

(T. Matteo, Ph.D./ C. Hoard, EdD.) November 2015

INTERVENTION	NPDC 2014	CMS - IMPAQ 2010	NSP2 2014	DHHS - AHRQ 2014	SOCIAL	COMMUNICATION	BEHAVIOR	ACADEMIC/ COGNITIVE	ADAPTIVE
	SYSTEMATIC REVIEWS				TARGET/OUTCOMES				
• **Functional Behavior Assessment *Term*** *used by NPDC and in overall category of Positive Behavior Support Strategies; Behavioral Package (NSP2 & CMS)*	•		*			√	√		√
• **Functional Communication Training** *Term used by NPDC and in overall category of Positive Behavior Support Strategies; Behavioral Package (NSP2 & CMS)*	•				√	√	√		√
• **Reinforcement** *Term used by NPDC and included in Behavioral strategies category; Behavioral Package (NSP2 & CMS)*	•				√	√	√	√	√
• **Removal of Restraints** *NPDC included in Behavioral strategies category*	*								
• **Response Interruption/Redirecting** *Term used by NPDC and in overall category of Positive Behavior Support Strategies; Behavioral Package (NSP2 & CMS)*	•				√	√	√	√	√

FOCUSED INTERVENTIONS (cont.)									
• **Task Analysis & Chaining** *Terms used by NPDC and included in Behavioral strategies category; Behavioral Package (NSP2 & CMS)*	•					√			
Cognitive Behavioral Interventions *Cognitive Behavioral Intervention Package (NSP2 & CMS); Cognitive Behavioral Therapy – specific for anxiety (AHRQ)* *Schema-Based Strategy Instruction (NPDC)*	• *	•	•	•	√ √	√	√	√	√
Computer-aided Treatment/Technology-aided Instruction *Use of Technology-based Treatment (CMS, NSP2); Technology-aided instruction (NPDC)*	•	•	*		√	√	√	√	√
Developmental Relationship–based *(CMS); Developmental-Relationship-based Treatment (NSP2): Overlaps with Parent Training (AHRQ)*		*	*		√	√	√		√
Exercise (*NSP2 &NPDC)*	•		*						
Joint Attention Intervention (Intervention and Outcome) *(CMS) treated JA as intervention; NSP2 included JA in Behavioral Package: NPDC & AHRQ treated joint attention as an outcome, interventions in this category overlap with multiple NPDC categories including JA-Symbolic Play Instruction; AHRQ - play-based intervention for JA as outcome.*	*	•	•	•	√	√	√	√	
Language Training (*NSP2) also referred to as Language Production (CMS); NSP2 (also included Language Training for Understanding (emerging category)*		*	• *		√	√			
Modeling *(NSP2 & CMS) overlaps with Video Modeling (NPDC); Imitation-based Intervention (NSP2)*	•	*	•		√	√		√	√

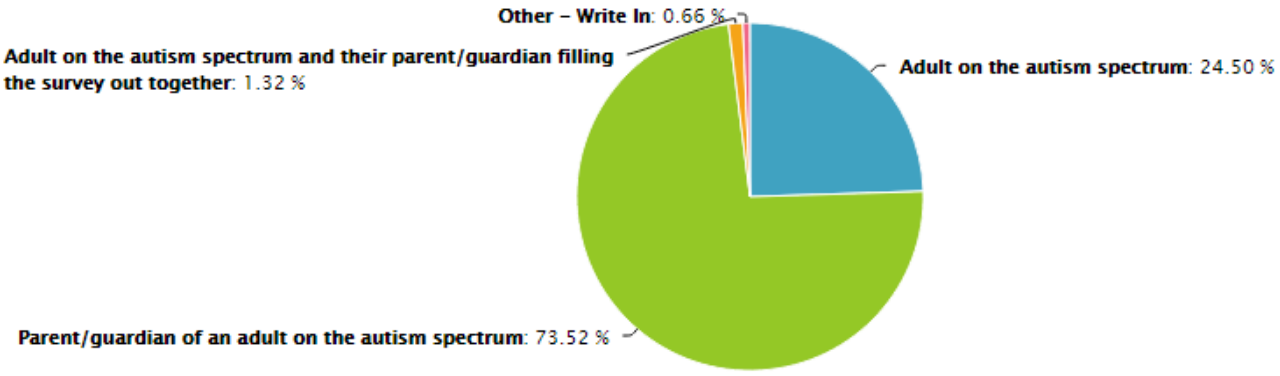
FOCUSED INTERVENTIONS (cont.)									
Multi-component Package *This term is used only by NSP2 and CMS to describe interventions that do not clearly fit in another category*		•	*		√	√	√	√	√
Music Therapy *(NPDC, CMS, NSP2)*	*	*	*		√	√	√	√	√
Naturalistic Interventions • *Term used by NPDC; NSP2 & CMS uses the term Naturalistic Teaching Strategies*	•	•	•		√	√	√		
Parent Implemented Interventions *Parent Training Approaches/ overlap with Symbolic Play and Play-based Interventions (AHRQ)* *(New to NSP2) AHRQ included DIR/Floortime studies in this group.*	•		•	*	√	√	√		√
Peer Mediated Interventions *Term used by NPDC; NSP2and CMS use Peer Training Package; NPDC also uses Structured Play Group; NSP2 uses Initiation Training as well*	•	•	•		√	√		√	
Picture Exchange Communication System (PECS) *NPDC, NSP2 and CMS consistently use this term.*	•	•	*		√	√	√		
Pivotal Response Training (PRT) *Term used by NPDC; Pivotal Response Treatment (NSP2 & CMS); included in Parent Training Approaches (AHRQ)*	•	*	•	*	√	√	√		
Schedules *(NSP2& CMS) overlaps with Structured Work Systems and Visual Supports (NPDC)*		•	•		√	√	√	√	√

FOCUSED INTERVENTIONS (cont.)									
Sensory/Massage – Sensory Regulation • **Massage** *(CMS included Touch w/ Massage)* • **Music Intensity** *(has to do with sensory input)* • **Sensory Diet** • **Sensory Integration & Fine Motor Intervention** • **Touch Point Instruction/Touch Therapy**	* * * *	*	*						
Self-Management *This term is used consistently by NPDC, NSP2 & CMS; Self-Regulatory Strategy Development Writing (NSP2)*	•	*	•		√	√	√	√	
Social Communication Intervention *Interventions included in this category by NSP2 & CMS are included in the AHRQ Parent Training Approaches Category*		•	*		√	√			
Social Narratives *(NPDC) overlaps with Story-based Intervention Package (NSP2 & CMS) overlaps with Scripting (NSP2 & CMS)*	•	•	•		√	√	√	√	√
Social Skills Intervention *Social Skills Training Group (NPDC) is similar to Social Skills Package (NSP2 & CMS) and Social Skills Training (AHRQ); Initiation Training (CMS)*	•	•	•		√	√	√		
Speech Generating Strategies *(NPDC) also referred to as VOCA overlaps with Augmentative and Alternative Communication Devices (NSP2 & CMS); NPDC Aided Language Modeling; Sign Instruction (NSP2)*	*	*	*		√	√			
Theory of Mind	*	*	*		√	√		√	
Toilet Training *(NPDC, isolated skill)*	*								√

Appendix I: Job Survey Report

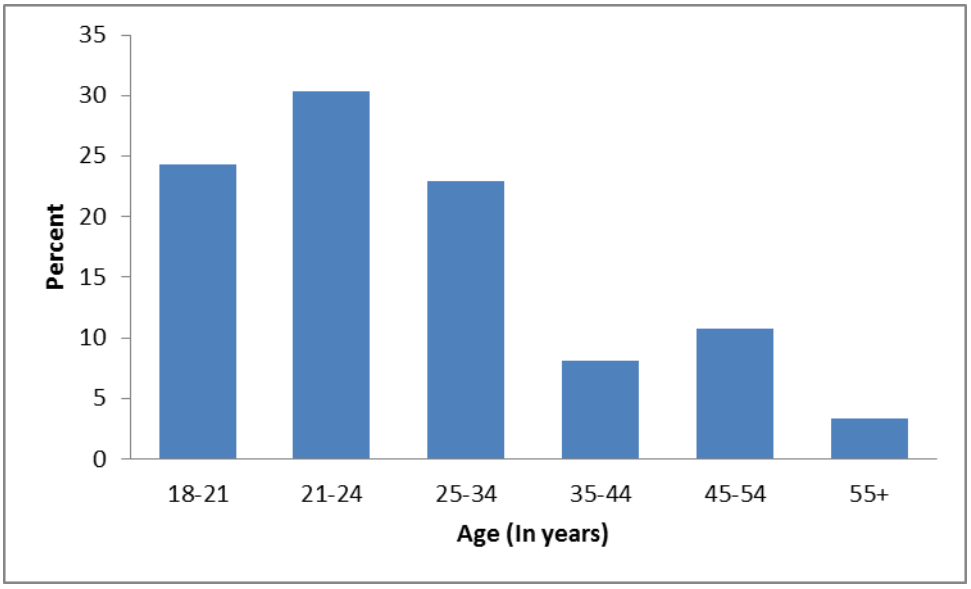
Responses as of October 28, 2015

1. Who is filling out this survey?

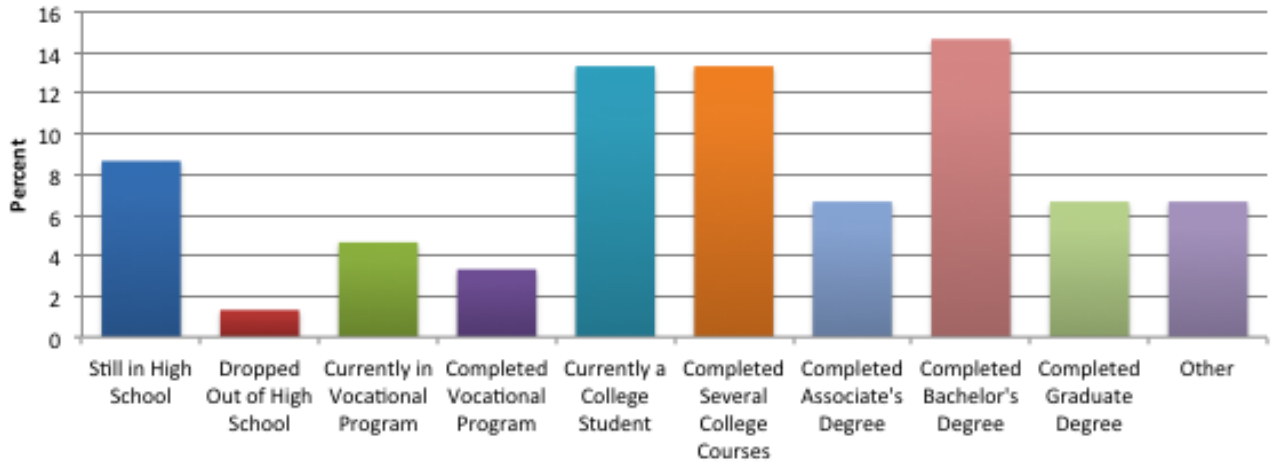


Note: The one "Other – Write In" response was a sister of an adult on the autism spectrum.

2. What is the age of the person with ASD (in years)?



3. What is the educational background of the person with ASD?



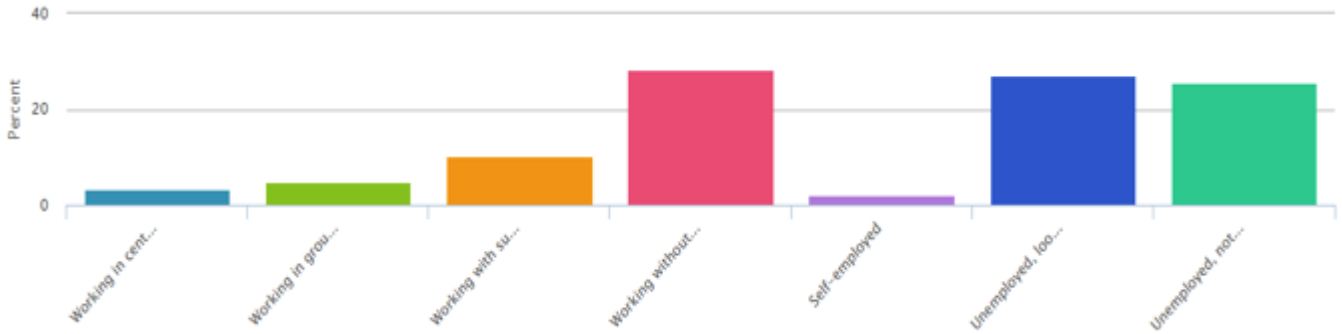
Note: Atleast 89% completed high school

Options (in order shown above):

- Still in high school
- Dropped out of high school
- Completed high school or GED
- Currently in Vocational program (please name the program) Please enter an 'other' value for this selection.
- Completed Vocational program (please name the program) Please enter an 'other' value for this selection.
- Currently a college student
- Completed several college courses
- Completed Associate's degree
- Completed Graduate degree
- Other – Write in

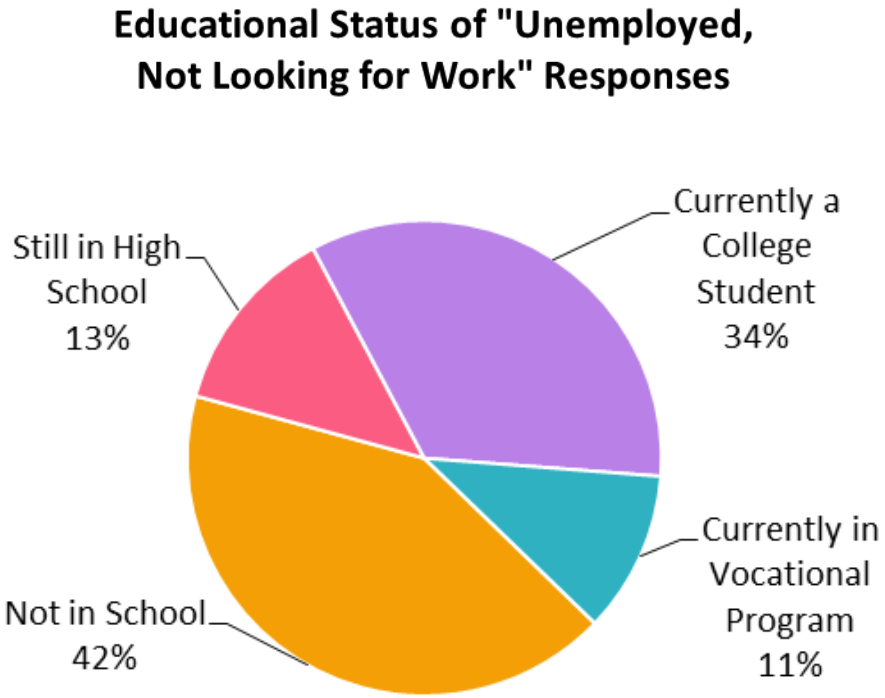
"Other" Write-In Responses
Aged out of high school at 21
Attended school, functioning level is still unknown
Completed 2 year ford asset program at comm college certificates not assoc degree
Currently enrolled in a day training program
Currently in transitional program (First Place, Phoenix, AZ)
Post high school programs
Training with RMG Imaging Artists In Mesa, AZ
He could not function in a college environment or at trade school. He dropped out of both - this was before he had a diagnosis of PDD-NOS so no special IEP was in place at either institutiion of higher learning.

4. What is their current job situation? You can select more than one option.



Options (in order shown above):

- Working in center-based employment (sheltered workshop)
- Working in group-based employment
- Working with supports in regular employment
- Working without supports in regular employment
- Self-employed
- Unemployed, looking for work
- Unemployed, not looking for work



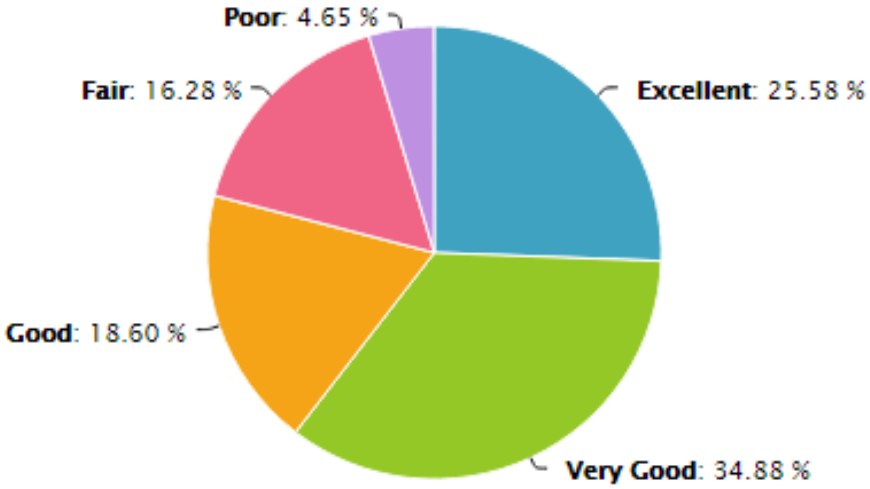
5. Please tell us where they work currently and what they do.

This question was only shown if one of the following answers were selected for question #4: *working in center-based employment* or *working in group-based employment* or *working with supports in regular employment* or *working without supports in regular employment* or *self-employed.*

Responses
Professional Level Job
Head to Toe Therapy, Speech Language Pathology Assistant
Clinical Director of an Addiction Treatment Center Partner in an outpatient counseling clinic.
Adult rehabilitation, geriatrics, and pediatrics in a hospital, home-based, and long-term care as an occupational therapist.
Recently accepted a new job in technology in the Silicon Valley of California. Previously employed in Phoenix as a business intelligence developer for a software development company.
I work for ADEQ (Arizona Department of Environmental Quality) as a GIS Analyst and the author of the help systems for the software developed by ADEQ.
I am a speech language pathologist in a long-term facility.
O'Reilly autoparts. Data analyst
I had a career as a software engineer, which was reasonably successful. I would still be doing that, but my autism is not a good fit for corporate politics. Currently, I am starting a new career as a professional writer.
heard elementary. teacher of science, technology, engineering, art and math 6th grade thru 8th
Speech language therapy assistant
School psychologist
Entry Level Jobs
Hacienda Healthcare - internship position
After school recreation program
Night custodian at elementary school on Litchfield school district
I work at Sprouts Farmers Market at 16th st and Glendale in Phoenix , Arizona and I am a Courtesy Clerk Bag Groceries , Mop up spills , Empty all the trashes in the store , Gather Up The Shopping Carts , What ever the Head Cashier asks me to do and manager ask me to do , Clean Bathrooms and so much more
Peoria Unified School District They are a government organization who hire people that need a job and want to work for their district.
Kids zone employee at a health club. Helps watch and entertain children while parents are working out at the gym.
Home Caregiver and Contractor at PHX Sky Harbor Airport
Works at a local car dealership as a runner delivering cars, washing cars, picking up and dropping off customers.
Floor and Decor Assist and Department Manager
Courtesy clerk at a grocery store.
OTR with geriatrics, adults, and peds
MARC CTR. 2 HALF DAYS A WEEK. PACKAGING, ETC, WORK
Beacon group Balboa ave, tucson az Assembles fasteners (places washer on rivet) using fixture prior to press fit by supervisor
Harkins Theater
Frys grocery. Cleaning, shopping cart help, bagging.
My son is training in a private business called RMG Imaging Artists. He's been in training for 2 years. Within the first year he was also hired by the company to be a training assistant for the new class. This year he has been hired to actually train. He is currently training 1 student. His own training continues for one more year.
My son worked over the summer in a senior center and for a food bank. We are currently waiting for an afternoon opening at a thrift shop.
Snack Shop at Partners-in-Recovery Clinic Marc Center Supported training; cash register, customer service, stocking, cleaning counters, making change with close supervision.
Gryphen Specialty Products. Bake and sell all natural dog treats.

#5 Responses Cont.
Gryphen Specialty Products. Bake and sell all natural dog treats.
Albertson's Grocery Store as a courtesy clerk. He will attend a three-day training session for cashier in November.
In peoples homes. I work for my Dad who's a contractor, and I work for my Mom as a Respite provider taking care of my Autistic sister for Community Care solutions.
Hospitality position at a Chick fil A restaurant
Courtesy clerk for Fry's Grocery Store with assistance from a ABA 1:1 job coach always present
My brother works at Dixon Golf in Tempe and is an event researcher (looks for specific types of golf events on the computer and updates the corporate database).
Working part time at a community college in the library/computer tech area helping students with things like resetting pass words at the help desk.
Fry's, part time, bagging groceries
ACCEL Adult Services. Works on the maintenance crew.
Subway, on the week_end only.
Harkins Theaters
Fractured Prune Donughts, Phoenix, AZ. Customer service (taking orders, making change, running cash register, etc)., and making donughts.
Goodwill - Processor (Book/Media) Area
Truck driver,i am over the road
Working at home. Underemployed after layoff in November 2010.
new way academy janitorial duties
Fractured Prune Making donuts, cleaning, cash register
K-Mart as a cashier and shoe department
Confidential
Civitan
Sharing economy, Amazon Turk, Uber, Lyft. You need a category for working AND under-employed AND looking. Changing somebody from unemployed to employed because they work with low hours or low pay is RIDICULOUS.
Kneaders bakery and cafe Jamba Juice-Smoothie maker
They are going to school three days a week and working with a landscaping team with the school district. They have a 1-1 aide, work 1/2 day and the return to school. Two other days of the week they are working in landscaping for another provider 1/2 day with 1-1 aide. In those afternoons they return to school.
In a major Grocery Store Deli Dept.
I currently do not have athe job, but I am in job training in an intern program for hospitality.
CVS. Performs a variety of functions such as receiving, stocking, cashiering and customer service.
Sprouts- Courtesy Clerk
She is working at Village Laundry folding clothing items and etc. Part-time.
Circle K as a Cashier/Customer Service Associate
Custodial worker 2 at The Pioneer Home Prescott AZ employer is State
Fry's Food Store. Cashier and Customer Service counter.
Trader Joes. Crew member. Bags. Cart runs, stocking shelves and facing.
Sprouts as a bigger and Whitehouse Design Events Planners trimming flowers and general odd jobs.
Manpower - Data Entry
AMC Theatre as an usher and in the concession area
One Step Beyond, Inc. Culinary Program One day (6 hours) per week GSE paid by DDD
Peoria Ave Preschool-- works as teachers aide. Also graduated from the culinary program at One Step Beyond & works in the culinary dept & catering team.
Desert survivors. Nursery work

6. Please rate their satisfaction with their current job.



This question was only shown if one of the following answers were selected for question #4: *working without supports in regular employment* or *self-employed*.

7. What is their typical hourly wage (dollars per hour)?

Percent under $4/hour	12%
Percent between $5 and $8/hour	4%
Average Hourly Wage	$13/ hour
Median Hourly Wage	$9/ hour

Average Hourly Wage Based on Type of Employment	
Working in center-based employment (sheltered workshop)	$3/hr
Working in group-based employment	$3/hr
Working with supports in regular employment	$9/hr
Working without supports in regular employment	$16/hr
Self-employed	$9/hr

This question was only shown if one of the following answers were selected for question #4: *working in center-based employment* or *working in group-based employment* or *working with supports in regular employment* or *working without supports in regular employment* or *self-employed*.

8. How many hours/week do they typically work?
9. How many hours/week would they like to work?

Average Hours/Week Typically Worked	27 hours/week
Average Hours/Week Would Like to Work	33 hours/week

These questions were only shown if one of the following answers were selected for question #4: *working in center-based employment* or *working in group-based employment* or *working with supports in regular employment* or *working without supports in regular employment* or *self-employed.*

10. How much, if any, support do they receive from social security, food stamps, or other government sources (dollars per month)?

Average Support ($/month)	$358
How Many Didn't Answer	33
Percent Who Didn't Answer	22%

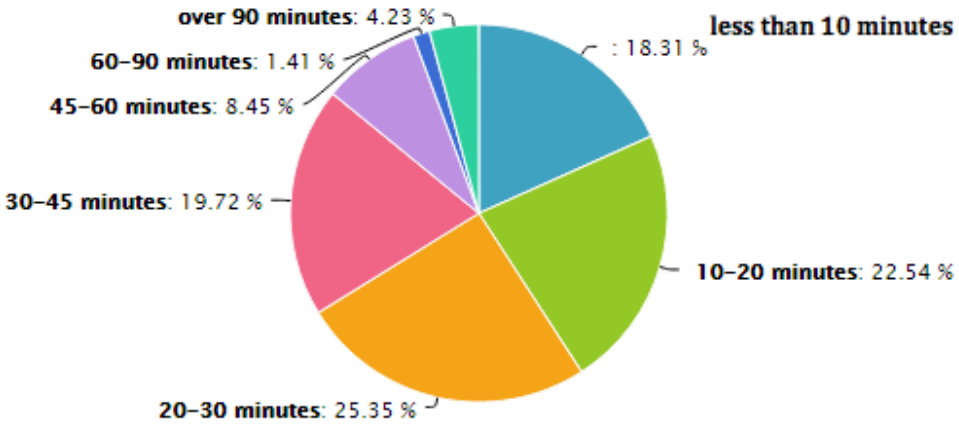
This might be an over-estimation due to the 22% of the people who didn't answer.

11. How much, if any, support do they receive from family, friends, trusts, or similar sources (dollars per month)? If housing is provided for free, count as $500.

Average Support ($/month)	$712
How Many Didn't Answer	40
Percent Who Didn't Answer	26%

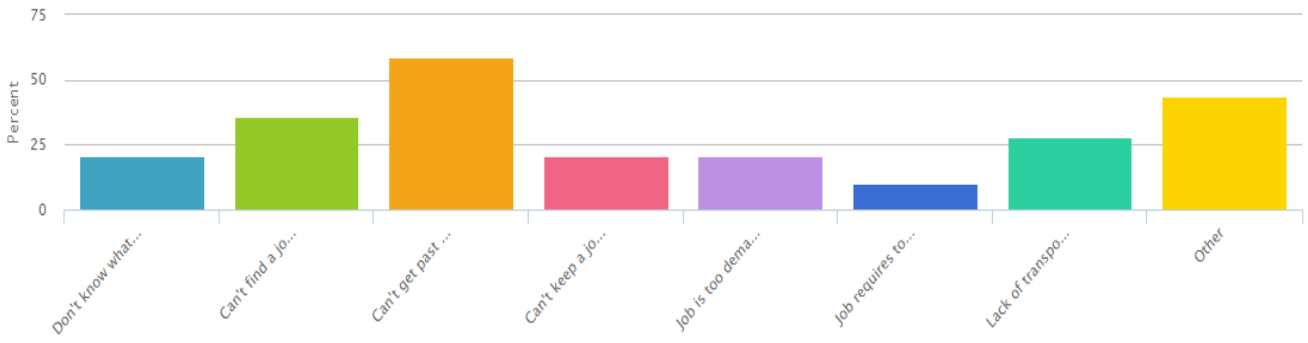
This might be an over-estimation due to the 26% of the people who didn't answer.

12. How much time do they spend commuting to work (one way)?



This question was only shown if one of the following answers were selected for question #4: *working in center-based employment* or *working in group-based employment* or *working with supports in regular employment* or *working without supports in regular employment* or *self-employed.*

13. What barriers are there to finding employment?



This question was only shown if one of the following answers were selected for question #4: *unemployed, looking for work.*

Options (in order shown above):

- Don't know what kind of work they want to do
- Can't find a job to apply for
- Can't get past interviews
- Can't keep a job
- Job is too demanding
- Job requires too many hours of work
- Lack of transportation
- Other

"Other" Write-In Responses
Awaiting RIS program offered by SARRC
Can't even get an interview
Can't find a job to match his skill level.
Can't get interview
Caretaker for other family
currently in day program, making transition from moving
emotionally unstable
Fear of bad influences at low paying jobs b/c he is easily manipulated
For the jobs I'm interested in - I need more experience and more education
irregular hours=no rythm in daily life
minimal accommodation
need help in acquiring jobs suited for him
need support at job and no way to fund
Needs help
Needs job coaching
Needs job training

14. Please explain more about the challenges they have finding or keeping a job.

This question was only shown if one of the following answers were selected for question #4: *unemployed, looking for work.*

Responses
Problems Getting or Getting Past an Interview
Completing applications but not getting any calls to interview.
does not get called for interviews when she does apply for jobs.
He applies for jobs and he never gets an interview.
He has applied for many jobs but rarely even receives acknowledgement if his application
He is not able to get past an initial interview. He is seen as angry and not able to communicate
Most job application are on line so that is a barrier.
Never offered a job, after filling out numerous applications and completing numerous interviews. I am not sure if my child can keep a job until she is given an opportunity.
Lack of Support from Current Services
DDD does not provide any services unless the individual qualifies for ALTCS, that makes them very low functioning. The higher functioning individuals don't seem to get any help. VR stated he is not "employable" and dropped him as they don't have programs that provide the support needed. Was told no DDD services available.
Getting the help from DOR and Workability to get coordinated in an effort to have job developers and coaches engaged helping college students since they don't give them what they need from Workability if they have The Spectrum. Young adults come out of college and they dont make the most of their skills and after a year or worse have no career jobs. I had to insist after 6 months of time wastedon minimal supports.
My son is a hard worker her went through the program provided by the state and worked for like .35 cents an hour and was assured of a job at successful completion. He was never offered work.
Requires 1 on 1 and the state is saying there are not enough providers in the Mesa area to get employment or into a day program!
Unable to qualify for ALTECS. Very frustrating that the state of Arizona has such a low view of helping those with disabilities.
Need Job Training/Support or Work Experience
Just graduated high school and only have limited job experience.
Graduated from the AZ Vocational Rehab program in 2008 - right when there were no jobs available for anyone. He is considerate, punctual and a hard worker ... but still can't get hired with no experience, even in fast food.
I think that lack of actual work experience is a big hurdle. My son has volunteered, had an internship, even done Americorps, but he's never had a paid job. He finally worked hard to get his associates degree, hoping it would help, but still hasn't had any luck in over a year since.
Minimal work experience
Mix of skill levels often means can do some of the job but not all of the job.
MUST have a job coach as difficult to stay on task.
My biggest concern is that he's had so many accommodations in school so that he can progress, but we aren't able to find a job situation where he's able to perform at a level that's payable. I wish there were apprenticeships out there, because my son needs training that I'm not capable of giving him.
My son can do more than just repetitious work, but having difficulty finding who will employ them. A mentor program or internship program would be valuable.
She has done volunteer work but has no paid experience

Autism Symptoms Inhibiting Job Acquisition
Although he interviews well as far as answering questions goes, he always needs to wear a hood (sensory protection) and doesn't shake hands. So I imagine most interviewers are put off by that.
Extreme anxiety over the interview process.
He is terrified of work and is a slow learner. He gives the appearance of being lazy when, in fact, he gets confused and shuts down.
He prefers not to work directly with public, prefers to work in a warehouse. Cannot work outside due to dermatology issues. Very limited social skills, prefers not to verbally communicate much.
He presents neurotypical on good days, and on bad days he's unable to shower or brush his teeth, let alone work
It is apparent he has a developmental disability and it hinders his ability to apply for jobs. And when he does get an interview, he never moves beyond that. He graduates from ASU in December and has no prospects.
My son has a physical disability Asa well as 2 learning disabilities .
My son has problems focusing and following more than 4 steps in a process
Physical appearance (hare lip), Asperger's.
Sometimes the communication part confuses me because I don't always understand why or what people need from me. Mis - understandings occur
Stigma and discrimination
Too much anxiety about working; not motivated to work ("pros" do not outweigh the "cons", as he sees it)
Need Someone with Understanding of ASD to Work with Possible Employers
Most service positions, ie, grocery/retail/etc, have irregular hours that change every day/every week. The individual w/autism cannot find any rhythm in daily life; it keeps the individual AND family in constant tension in getting to work on time.
Person has had many jobs in past and had 2 tries with VR but they know little about people on the spectrum and never could find a good fit, utilizing his talents and skills. He does require support person/job coach and no agency will fund this. Family offered to volunteer, but employers won't allow this. Finally gave up looking
Will often say he has a disability and that ends the chances right there. Entry level jobs often have more than one manager or managers change a lot.

Recommendations:

1) Need to bypass interviews with job finder
2) Eliminate gap between VR and DDD – if doesn't qualify for DDD, then needs VR
3) Need for more work experience
4) Need accommodations for ASD symptoms (sensory, fixed schedule)

15. What help do they most need to find and keep a job?

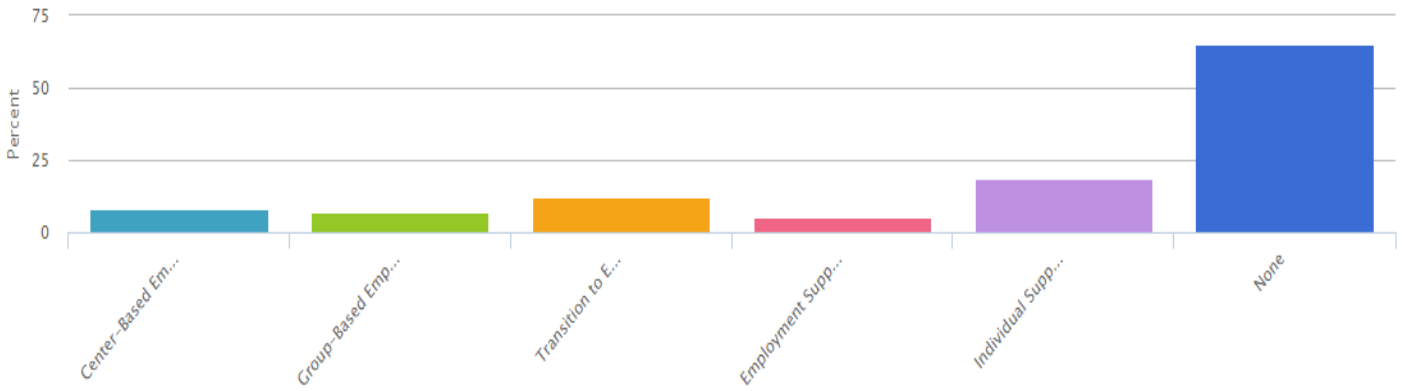
This question was only shown if one of the following answers were selected for question #4: *unemployed, looking for work.*

Responses
Job Coaching/ Job Training
Training on how to handle the stresses that might arise, and practice on what's appropriate work behavior, in their particular occupatuon.
Assistance on the job
good job coaches that will work with our son and his non verbal ways of communication.
Job coach to assist when employed to help understanding directions.
job carving customized and coaching supports periodically. great employers offering to make an effort to work things out at the beginning instead of after 3 days -sorry not working out withn out haqving the supports there.
Job coach/support person
job coaching and training
Job experience or volunteer work
Job preparation, job video-modeling opportunities, etc. to help reduce anxiety.
job training opportunities and job coach
Maybe practice scenarios - I could problem solve and practice what I would do in different situations
Job Coach with weekly reports;
Training on tasks and finding job fit
To keep a job - how to function once job coach leaves and how to push for basic accommodations when they won't.
short term job coaching when she finds independent employment.
Teaching interview Skills/ Application Skills
Filling out applications
Getting accepted after the interview, to stand out
He's worked with job developers on interview skills, and how to search and apply for jobs, so is mostly doing that on his own. He's even begun to ask for accommodations for the interview (he lets them know that he doesn't shake hands and he wears a hood, and he needs a hard chair without a cushion.) Can't say what he would need in order to keep a job since he's never had one. He is ready, willing and able to work, and he is very discouraged that he can't find a job.
I think it would be helpful if there was some way of training them for job interviews and helping them land at least one job with some support to get them started in the work force. I am not sure where/how to get this help.
Interview skills
Interviewing skills
No one will give him a chance past the interview.
Work adjustment training, placement help
Unless it is a job for people with disability, how to get a job without talking about his disability or being obvious during interview.
Need Someone with Understanding of ASD to Work with Possible Employers
A set schedule with no late night hours
A referral. Because he seems odd and has poor social skills, no one wants to hire him.
In terms of keeping a job, I would like to find an employer who is willing to work WITH my AS traits instead of looking to fire me because of them.
An employer willing to give him a chance
Willingness to work with someone "different". Acceptance of difference.
Help finding employers open to hiring folks with communication difficulties, training, on the job support and flexible hours.
On-site support from a supervisor, co-worker, or someone who can help explain and demonstrate tasks.
Personal attention, to help stay on task.
negotiates between employee and management to improve in needed skills/interactions
Someone to give him a chance to show that he is an actual good employee.
Transportation
Transportation (he doesn't drive)
He will need a ride to and from work until he can get his drivers license.
A way to get there
Other
Cognitive support. Receiving SLP and OT from the State.
For SARRC to fallow through with the RIS program offered, continued education, and continued job coaching.

Recommendations:

1) Job Coach: Job shadowing; practice skills if needed; work on-site with coach; continued assistance as needed
2) For job interviews, need job finder to explain person's disability and strengths, and then have them meet applicant; portfolio/referrals
3) Job Buddy — Someone always available and ready to help if problem arises, as part of their job; possibly paid extra by VR or DDD
4) Help with transportation — Possible car pool?

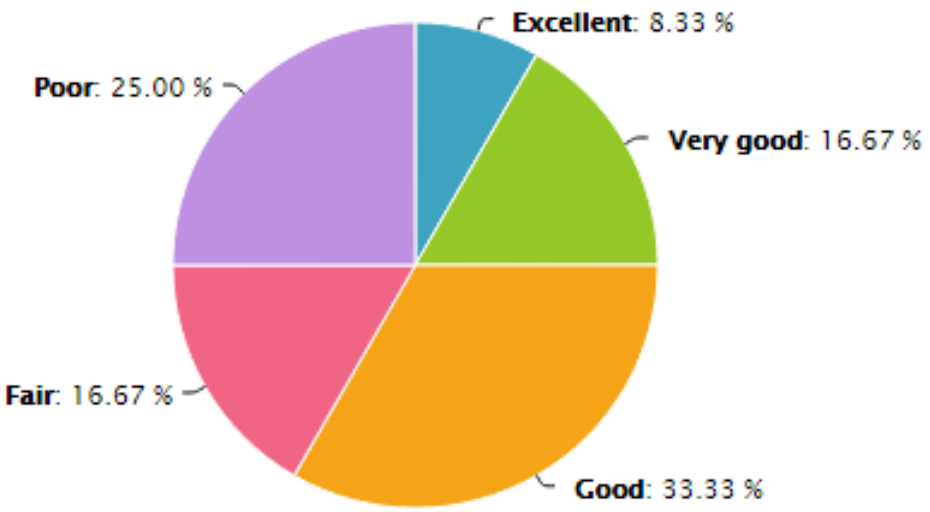
16. Please check any of the following DDD services which were used, either currently or in the past:



Options (in order shown above):

- Center-Based Employment (sheltered workshop)
- Group-Based Employment
- Transition to Employment (instruction, training, job shadowing)
- Employment Support Aide (1:1 aide who is always present in the workplace)
- Individual Supported Employment (job coach who helps with finding and keeping a job)
- None

17. What is/was your overall satisfaction with Center-Based Employment?



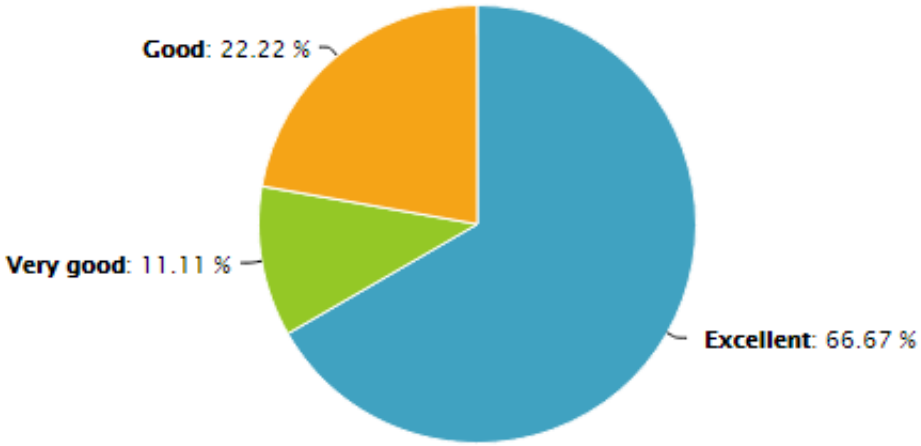
18. What suggestions do you have to improve Center-Based Employment?

Responses
Better Work/ Actual Work
About 60% of the time they ran out of real work, and just did pretend work (sorting blocks). They needed to be doing real work
All he did was sort beans and rice... He is pretty high functioning...
Consistent Work
Transition to more normal employment
Work consistently with parent and employee to develop short and long term employment goals. Consistent communication.
I feel once they have gone thru initial training at a center based program then maybe they should have a transition program to place the young adults in a permanent position within the community.
More opportunities to explore talents.
Teach More Skills
They are getting their initial training at the center. Basic skills- arriving to work on time, punching in/out for lunch and at the end of the day. Listening to instruction and so forth.
More coaching in the beginning. Better support ratio, especially in the beginning.
Teach skills, correct behaviors, coach care givers
Other
CONTINUE CENTER BASED. DON'T CUT SERVICE, OTHERWISE ADULT SITS AT HOME IN ROOM ALONE. IT IS MORE THAN JUST WORK FOR THE ADULT. ALL OF US GO TO WORK IN PART TO BE WITH OTHERS.
Known expectations.
My member only earned sub minimum wage. His paycheck wasn't enough to buy a combo meal at a fast food restaurant
My brother hated it. He was extremely uncomfortable with the work environment. It brought his disability to the forefront. He became very agitated and depressed. More opportunities need to be offered to people of different skill levels.

Recommendations:

1) For center-based employment, DDD needs to allocate a staff person to find work for the clients to do. Alternatively, use a portion of each client's paycheck to pay for the work finder.
2) For center-based employment, create long-term plan for client to learn more skills to become more employable and independent

19. What is/was your overall satisfaction with Group-Based Employment?



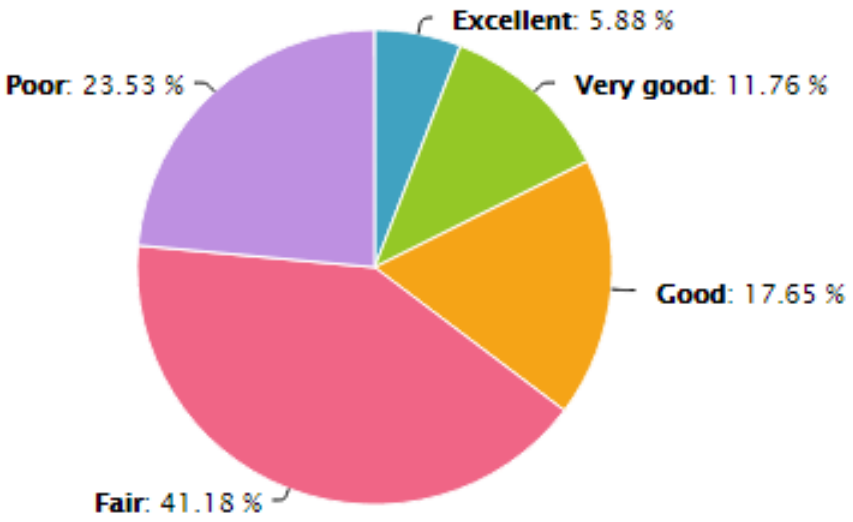
20. What suggestions do you have to improve Group-Based Employment?

Responses
More varied work experiences
Need many more career paths my son only had access to grocery , landscape or custodial that is
People who are trained and have a knowledge of those on the spectrum should be the job coaches. My experience most don't have general knowledge of their typical behaviors and how it effects their job performance. Also, when the client becomes efficient at the job, the coaches should pull back and let them discover how to navigate the work place. When my son left group based employment, he couldn't function on his own because he was told what to do for so long, he had no independent thinking skills- there should be some way to strike a
The services through DDD have been good thus far. Counselor was able to get our son into a work environment quickly, within two weeks of our request. Our son began working within the two months of our request. He likes it very much. It does not pay much, but he is able to see the difference between his "trade" job vs other job. The trade will pay more as his skills
To have additional resources like Voc Rehab involved

Recommendations:

1) Optional rotation among group-based employment opportunities to build skills
2) Train DDD support staff about ASD and how to fade supports to increase independence and ability

21. What is/was your overall satisfaction with Transition to Employment?



22. What suggestions do you have to improve Transition to Employment?

Responses
Train the managers to work with disabled.
The job coach should meet with the new employer and educate him or her on the skill level of the client and set up goals to meet. Also would be nice to get a sense of what is expected from the employer- co -workers should be educated on the disability as well.
Broader Training Opportunities
Find more realistic jobs rather than those the school or facility gets as sponsors. Can't all work in grocery stores or Goodwill.
Skill training. A ladder to educational opportunities
Better natural skill development.
Very little opportunity for training. Everything was geared towards sheltered workshop employment. Nothing was offered to help my brother find a "real" job. Need broader training for real-world skills.
Better Staff Knowledge of ASD
Treat these people fairly, follow-up, do what you are saying and documenting that you are doing.
VR FOUND MY SON INELIGIBLE IN H.S. THIS WAS A SYSTEM FAILURE. THE YOUNG MAN IS VERY CAPABLE WITH HELP. LIMITED LANGUAGE IS PART OF AUTISM. THERE NEVER WAS AN INTELLECTUAL OR BEHAVIORAL REASON NOT TO HELP FURTHER.
I don't even know where to begin other than use a different agency Stars does not hire staff that are equipped or educated appropriately to work with autistic or other disabled individuals
The job coaches were marginal. The programs offered up as coaching did not take into consideration weaknesses in their clients which made the training even more frustrating and destined for failure.
Other
More employment choices
Let parents know about their options early on. Job fairs don't work because parents don't know the questions to ask.
M's experience was over 20 years ago, but as a parent new to this state I found it very difficult to figure out the system, find the right agencies (who don't coordinate well)
More assistance with finding a job.

Recommendations:

1) Volunteer Internships in Group Setting (if no paid work available)
2) VR staff and VR agencies need autism-specific training
3) Employer and other employees need ASD training tailored to the individual they are going to work with

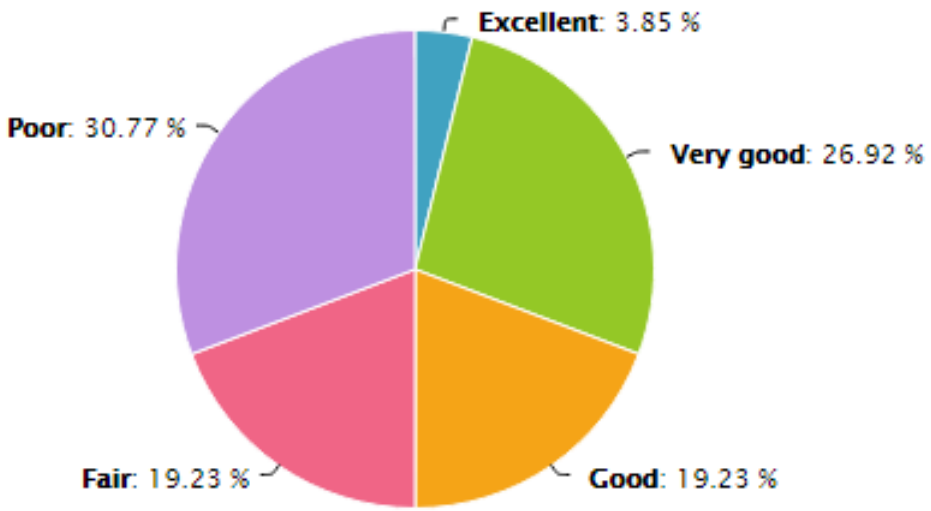
23. What is/was your overall satisfaction with Employment Support Aide?

24. What suggestions do you have to improve Employment Support Aide?

Responses
1. Detailed on-the-job instruction 2. Summaries of improvement in skills, transitions, and memorization of schedule
I think we are moving too fast in removing the support. My son has become VERY attached to his aide which I know is not a good thing but just removing him after two weeks at 4 hours a day and then leaving him there for the full day without that aide is scarey. That is supposed to start next week.
Need people who are more reliable (show up to help everyday) and more knowledgeable about the person's disability that they are shadowing. Very few understood the intricate nature of autism.
Need to push a little more?
training about people on the spectrum

Recommendation: Have job buddy— train them about ASD and client

25. What is/was your overall satisfaction with Individual Supported Employment?



26. What suggestions do you have to improve Individual Supported Employment?

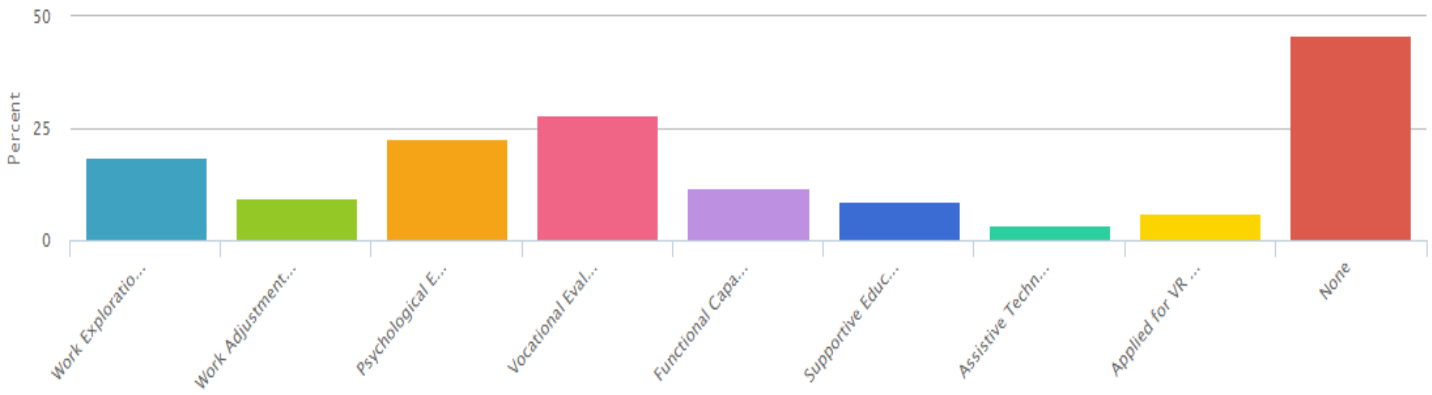
Responses
Better Training of Staff
Hire people who are competent
Incompetent DDD employees and case workers.
The job coach was very inconsistent as to when my son needed to be at work. It was a different time everyday.
The job coaches didn't have the expertise for the type of job they were coaching. Most of the job coaches are just typical people who may not even have any job experience themselves. Job coaches need to have some qualifications. Also the case loads are too high so most of the time you are lucky if you even see your job coach often but they are still being paid. Also the low expectations that job coaches have for the individuals just wanting to rush and place rather than find a fit that will meet the needs, interests, and qualifications of individuals on the spectrum to last longer term.
Again, everything was geared towards placing my brother in a sheltered workshop. I found him his job. I took him to interviews. I applied for the jobs. I helped coach him for how to handle himself on interviews. I kept records of the jobs that were pursued and what the outcomes were. My brother's DDD representative offered ME a job since no one else had any success helping him find work!
Education of the world these individuals live in. They Need people to understand that they take communication literally. if it's not literal they don't understand and get confused and scared. They live in a world that they don't understand. They live in fear, anxiety and environment overload, so they withdrawal to feel safe. We need to educate parents teacher emloyers to welcome them into ours so they too can be able . to thrive. Study them as if they were aliens from a different planet. If situations were reversed and we were plunged into their world how would we feel? How would we cope? How would we integrate ourselves in and adapt?

More Support
There should be more of an effort to check in with employer to make sure things are going well.
I would suggest that the job coaches keep in longer contact with the ASD clients who they have placed. My son felt like he was abandoned right after he obtained his job.
More support. Allowing aide or family to help with communication disabilities. Better training for voc rehab counselors and Job coaches on varied disabilities
Not enough time spent with current job coach to offer any coherent, reasonable suggestions.
Do not bring other casework with them when working with one person. Give more feedback and talk with all employees not just manager and all managers if they change. Ask everyone, including client, was is/is not working; train more.
More job opportunities
More employment opportunities in west valley
More job opportunities provided through SARRC.
Other
Make it more convenient for the work supervisors and be respectful of their time constraints
more consistency at the work place and dialogue with employer on a continual basis.
The job coaches that I had previously were able to provide suggestions and tips but could have improved by spending more time with me in job interviewing and finding appropriate job placement areas, such as speaking with recruiters and employers involved in IT firms.
None they do a great job Beacon Group Phoenix , Arizona
Having him work for change on the hour and not coming through with what was agreed upon was so disappointing and seems like it should be a violation of his rights or the work ethic of the Voc Rehab.
exactly the opposite of what they do now. cultivate prgs to actually accomplish something

Recommendations

1) Higher expectations of person with ASD
2) Longer term job coach, and transition to job buddy
3) Need job buddy to communicate with family/guardian or with client

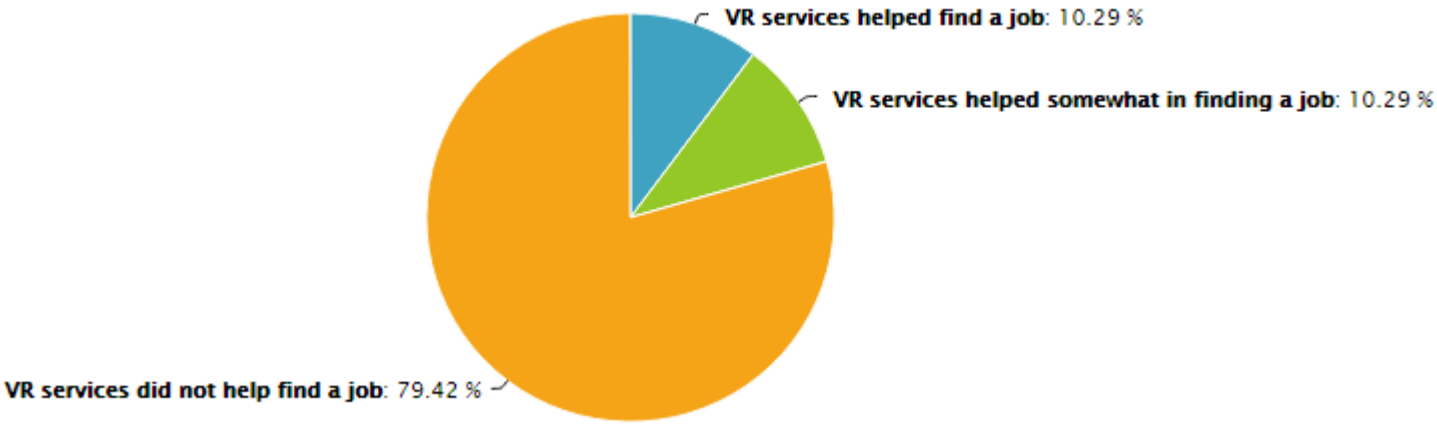
27. Please select any services received from Vocational Rehabilitation (VR) either currently or in the past.



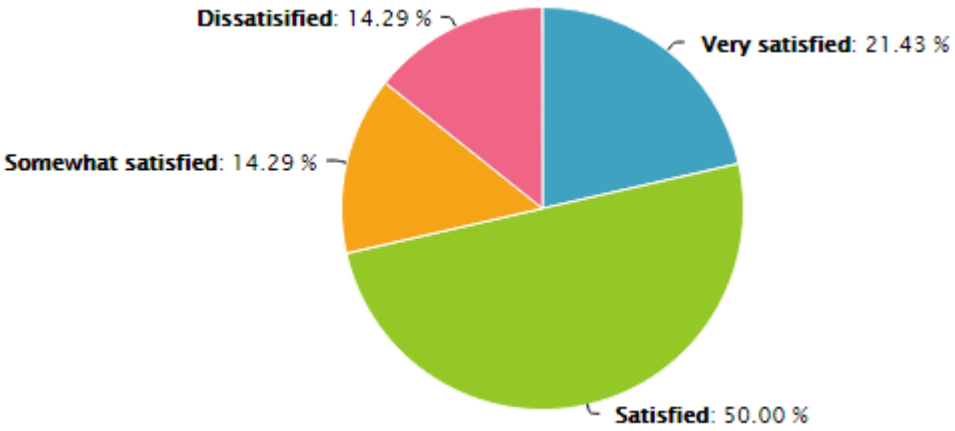
Options (in order shown above):

- Work Exploration (individuals explore different occupations with the help of a specialist hired by VR)
- Work Adjustment Training (WAT) (individuals work at a specific site in order to develop positive work habits.)
- Psychological Evaluations
- Vocational Evaluations
- Functional Capacity Evaluation
- Supportive Education (school tuition)
- Assistive Technology
- Applied for VR services but was denied
- None

28. Were VR services helpful in finding a job?



29. What was their overall satisfaction with the job they found with VR's help?



This question was only shown if one of the following answers were selected for question #28: *VR services helped find a job* or *VR services helped somewhat in finding a job.*

30. What is/was your overall satisfaction with Work Exploration?

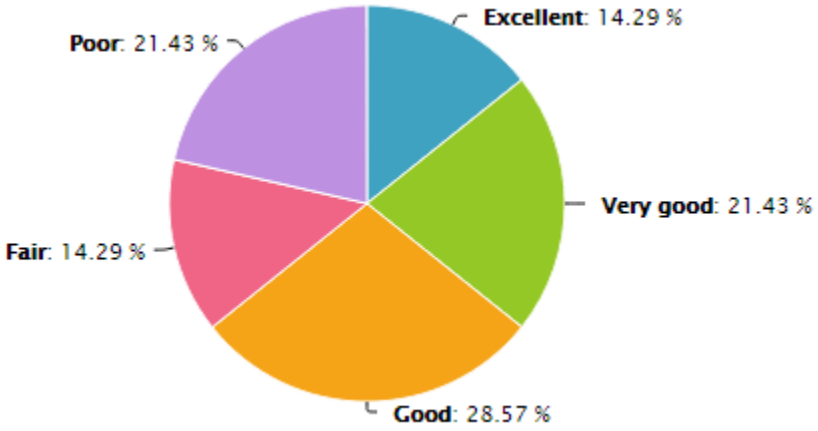
31. What suggestions do you have to improve Work Exploration?

Responses
Almost set up as a staffing service. Have a pool of qualified applicants and work with companies to produce tested and qualified applicants for their open position. Maybe have a 30 day trial period where actual on-site job training could take place.
An individual who has experience with adults with Autism to help translate interpersonal communication.
Better job support and training.
Education, training, understanding .
First VR coach needed to consider seizures as a factor in appropriate employment opportunities.
If locate an opportunity and some time in a job, explain better to client that not permanent job. Don't give out one good job trial first followed by several bad ones (e.g., filing job followed by cleaning out horse stall or sweeping floors). Understand that VR contracts most if not all of their work to subcontractors that they often cannot or do not entirely control or have limited or outdated skills. Subcontractors will push jobs they have in their files - often only one type of job (e.g. telemarking only).
More exploration of businesses in community besides contracted vendors and better organization at VR for facilitating and coordinating WAT.
More flexibility with clients already working part time
My grandson was uncertain about job choices and finally decided upon stocking in a grocery store. That was not the position he trained for nor the position he received. With encouragement, I believe he is more suited for a technological position as he is fairly well versed in the world of computers. He doubted his ability so did not suggest that as a preferred option. I feel he would have had more opportunities for advancement.
Need someone to find an appropriate job placement that takes advantage of my daughers skills
Our son was approved by DDD but denied by ALTC for any services. VocRehab was NOT prepared to work with someone with autism; the personal was rude to our face and the caseworkers kept taking him to job sites that did not fit his capabilities :(One VR employee literally suggested our son consider a job picking up dog poop!!!
Process is slow, need more employer partners to assist in placing people with disabilities.
Voc Rehab should have started with my son's college major. Instead , they tested him for two months and came to the conclusion that he should look for a job working with animals. That's what we have been working towards all along.

Recommendations:

1) Consider parents or Special Ed teachers/aides (especially in summer) as possible job coaches for other families since they understand ASD
2) Job shadow before trying job or internship
3) Minimize underemployment (not working at capacity)

32. What is/was your overall satisfaction with Work Adjustment Training?



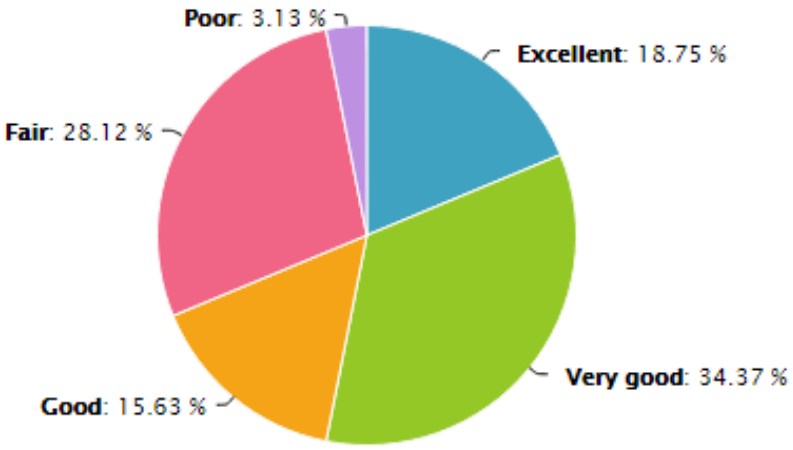
33. What suggestions do you have to improve Work Adjustment Training?

Responses
Having a trainer who has more experience and would more consistently go to the work place would be helpful
He loved the WAT job, and was even extended for an extra month. I think it's a great program.
His counselor was often absent or sat in the deli far from his work area. Observations were not made on a regular basis.
It wasn't able to help my son's needs.
More consistency in the job training.
My son loved the SARRC program and so did we. They treated him like a human being. He learned a lot there but Voc Rehab was horrible to him.
None, it was done through the school district at the Goodwill, not through VR, We did have to take the district to court to have them comply with transitional services after he graduated, as they did nothing prior. Voc Rehab did attend meetings at his first job with the supervisor of Goodwill.

Recommendations:

1) VR needs to respect clients with ASD
2) Need a work buddy who has some minimal training

34. What is/was your overall satisfaction with the Psychological Evaluations?



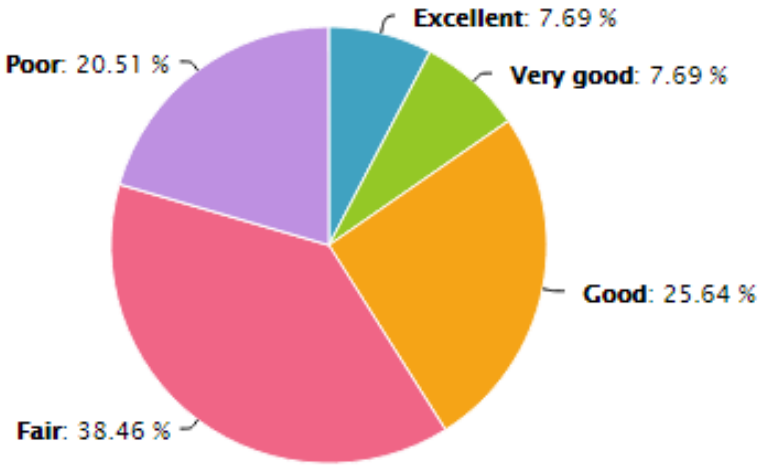
35. What suggestions do you have to improve the Psychological Evaluations?

Responses
follow up, where do we go from there
I have found that psychologists employed by the school district are less-thorough and less-objective, and tend to err on the side of denying disability when the subject may be considered mildly handicapped on some scales, even though significant handicap is identified by others.
Longer time based evaluation
none, it seemed accurate
Provide options, everyone is employable to some degree, to say "not employable" and drop him is a cop out
Really do not know why one is necessary when their should already be one in place from high school and an IEP. Waste of time.
The psych told me to fill out as much of the survey until it got to the questions that my son doing things totally on his own. I did. In his report, it said that I did not finish the survey, so he could not complete a portion of the psych evaluation that was based on my input. That was disappointing.
The psychologist was great in providing me the evaluation as needed.
This is one area where Vocational Rehab did all right they hired a pretty knowledgeable Neuro Psychologist to do the evaluation who was very optimistic and encouraging also had some great ideas. It is just that the job developers did not follow through on those ideas.
This needs to be offered on the initial interview process.
Use an accredited Psychiatrists instead of the limited experience of the psychologist. They do not have the physiological education to understand the difference in anatomy or operation of the autistic brain. Dr. H. could not make the cognitive leap to incorporate the physiological differences. and there fore left IQ test results being at least 2 "T" score off. the only decisions was if you could return to work or not, that's it, and leaves the Autistic individual's service flat and unrevealing.
Was fairly accurate but no real connection between person doing evaluation and the people who do employment placement, esp. if they are the subcontractors.

Recommendations:

1) Only do psychological evaluations if necessary
2) Make sure psychological evaluation report is communicated to and relevant to job finder and client

36. What is/was your overall satisfaction with the Vocational Evaluations?



37. What suggestions do you have to improve the Vocational Evaluations?

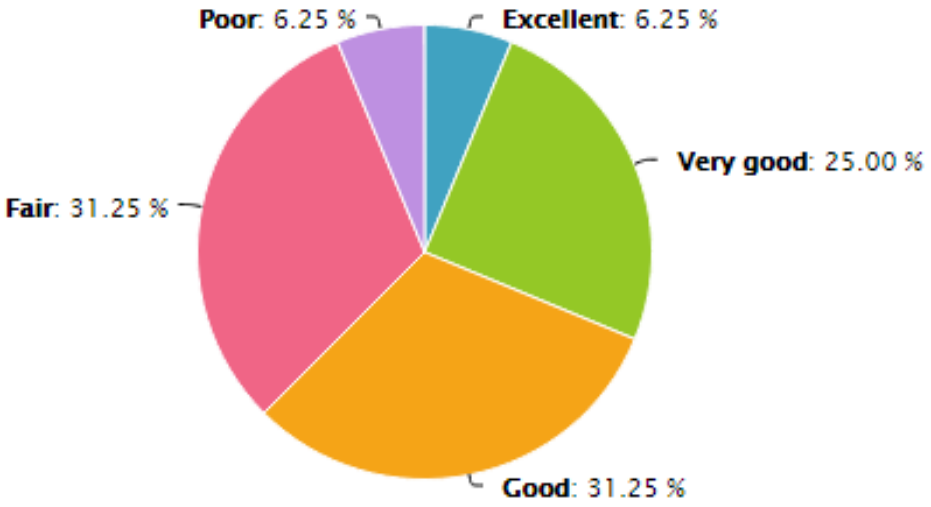
Responses
Bad placement
Despite having a BA, VR only considered menial jobs for me, such as librarian aide or gardener.
I don't know, he has High Functioning Autism and was put off by the stigma that he was not visibly disabled, the program seems to be more for physical disabilities even though Autism is a physical disability inside the brain. Anyway the program did not appeal to him, so some how you need to find a way to engage him so that the program is more attractive.
Your rating does not go low enough to express our lack of satisfaction with voc-rehab. If the government needs to save tax dollars, this is where to cut. We have been in voc rehab for four years with nothing to show for it. The first counselor wanted to put my son in a workshop, which was not appropriate. This was after two years. Even his DDD case manager was shocked at the suggestion. DDD case manager and voc rehab counselor met with to discuss appropriate programs such as job exploration. To date, we are still fighting to get his current training paid for by voc rehab. Two other clients already have their training paid by voc rehab. Frustrating. We found [blank] through AZ Assist, and this business has delivered what they projected.
Follow Up
Follow up on results
Why give someone a great evaluations and not follow through with the agreements made?
Generally of No Assistance/ Help
That they actually work with the client and listen to what the client needs/wants. Since my son opted to take a fifth year, they will not talk with him at all. We'd like to do some career exploration while he's in his fifth year. We are doing our own research at this point.
he was excited to attend art college, and VR was supposed to pay for it....but VR asked for forms the school couldn't relate to. After being accepted, he was dropped because VR wouldn't work with the school to get him enrolled.
Vocational Rehab was of almost no use at all. Rehab Specialist was incompetent.
Need more dedicated case workers. The voc rehab involvement was minimal and did not tell us anything that we did not already know.
In our case the evaluator was making an assessment and decision without meeting the client!
Faster Process
Process takes too long once evaluations are done.
Provide enough funding to complete process expeditiously
My son is WANTING to work or train for a job, and if left to voc rehab's schedule, he'll be waiting for a long time after he graduates.

Better Staff Knowledge of ASD and related issues
The vr counselor should have a wealth of knowledge about every diagnosed disability. And what the barriers to emolument are for each disability
Personnel need to be better trained in dealing with people with autism Needs to be a list of work-site jobs where a person with autism could be successful
Little knowledge or understanding of ASD and employment issues for people on the spectrum
It would be helpful if DDD caseworker was more informed on opportunties
Other
The employees at the [blank] sat around bad mouthing each other behind their backs including the elevator [blank]. at one point having the manager having given me multiple contradictory instruction for the same process, even [blank] stepped up took items out of my hands and told me an additional contradictory version of how to do it right. After the shop had closed [blank] forced me to do dished while trapping myself between herself and [blank] the closer while they continues to bad mouth the manager. Finally the manager handed me a list before leaving and said " since we have this free labor I want you to do this list of cleaning we do not normally get to." she wanted me to clean behind the icebox, and espresso press, etc.... If that were not bad enough this was allowed to be blamed on my autism in the evaluation in the form of negating point in the review for having complained. Moreover in this report which [blank] handed directly to me in the closing interview, the negative performance was laid at my feet though errors in the time of day and how busy the environment due to the change to mornings shift. having three witness to state that it was the same shift she finally made revisions. however the reports still lays the responsibility for these individuals behavior on my Autism. More over [blank] and [blank] both recommended a program RIS and now nobody will return my phone call regarding a referral for these services.
During the in-depth vocational evaluation by SARRC individuals acted in unprofessionally and after I complained the complaint was forwarded to the person doing the first days observational assessment, which was then written into the evaluation as negative behavior on my parts negatively affecting the assessment with the individuals bias over my complaint.
Overhaul the program and make it performance based. Understand your client's strengths and weaknesses before engaging in a solution.

Recommendations:

1) Get work experience while in high school or college, don't wait until you graduate
2) Need autism-specific VR staff
3) Job internships need to actually focus on training the skills that will be used in a real job; not useful to give volunteer work that will not lead to a real job

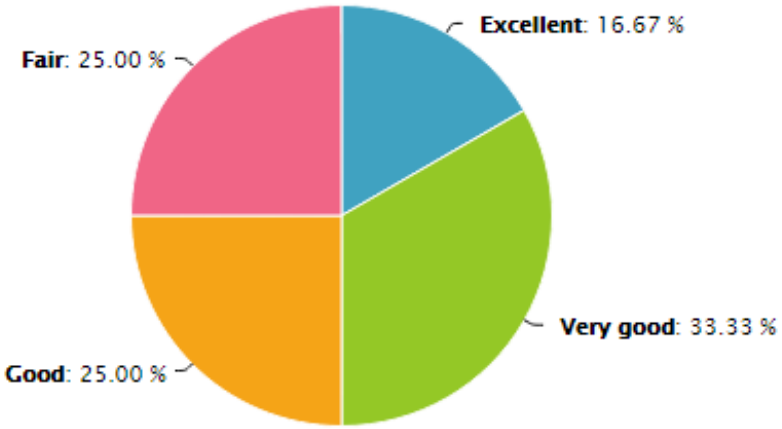
38. What is/was your overall satisfaction with the Functional Capacity Evaluation?



39. What suggestions do you have to improve the Functional Capacity Evaluation?

Responses
More options for the person
no follow through
not broad enough to capture the amazing niche skills of people on the spectrum
Overall survey opinion---The process for discovery of natural skills adn assessment to mitigate barriers to to employment need to happen during the onboarding process. Offer all tests and services as if the family and the individual with autism is in crisis. If a family reaches out they are already in crisis. and need all the support and programs that the SCARC has access to.

40. What is/was your overall satisfaction with the Supportive Education?



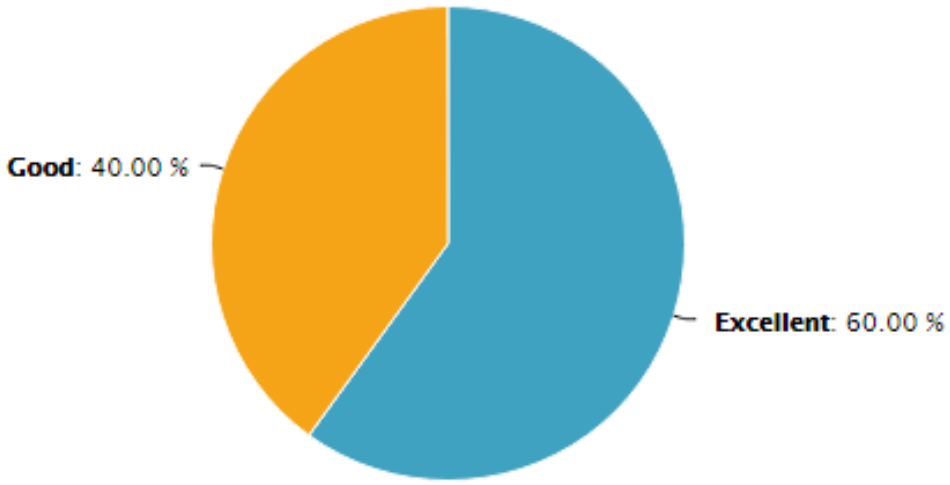
41. What suggestions do you have to improve the Supportive Education?

Responses
career vocational counseling and regular meetups to discuss how to coordinate the classroom with connecting to job agencies to help find supported employment. workability 4 at the college doesnt do job carving or coaching and barely helps to find work. Certainly doesn't coach on a job-should reconnect mid last yr of school with job agencies through DOR. Wasted 6 months job hunting alone and lost a first job due to no coach supported employment.
I intentionally did not enroll my son into VR, because until he had a good Community college record, because I didn't think they would take him serious. There is no supportive services to teach college study skills. I have had to do all the teaching myself. Many more people with autism could be great additions to the college educated work force, especially in the technology field, if more college prep. skills were taught and supported in HS, and community college, and tutoring. My son can get tutoring for Algebra, but not tutoring for keeping track of assignments, meeting college standard, notetaking, managing time, communicating with professors, group work etc.... He has taken a class on college skill, but this is not enough. He has needed college coaching to learn these necessary skill in college, and these will translate to the work place.
Always late, missed deadlines, slow to respond
More individual support and strategies in socialization.
Much, much more assistance is needed in placing workers in appropriate jobs. My daughter spent more than 2 years trying to get work and ended up seriously depressed. If there are placement services for folks with autism, we were not able to find them. My daughter was one of the lucky ones that located a job by sheer luck through a friend of mine.
None. In addition to helping with education, VR has been very supportive - the fact that VR services have not resulted in a job certainly is not from lack of trying. The current job developer my son is working with was set up and is paid for by VR.
They were great in providing me the university tuition needed to complete a Bachelor's degree, which my family was unable to fund at the time.

Recommendations:

1) Also provide links to academic success programs (study skills, career exploration, friendship, etc.)
2) Encourage internships during college

42. What is/was your overall satisfaction with the Assistive Technology?



43. What suggestions do you have to improve the Assistive Technology?

Responses
It need to be brought in over 2 years ago. The high schools should implement it much better. It was a battle to get the limited support we received. We have been doing the best we can as a family. Now that VR has sent an expert over, things are much easier at school and I can back off some. Some of the support he provided was to help with understanding which situation to use which technology. this student has severe dyslexia, and time management issues.
make sure employers provide it... i was taught in college how to use it to help with my dyslexia .. it has been tolerated at my own expense...some principals have found an under the table way to assist me with equipment ..rarely ... no one wants to believe that a highly trained professional has both autism and dyslexia/dysgraphia i am so able in tech no one believes i should have problems with writing, spelling, mispronounced words, hyper sensitivity to florescent lights and noise.... i still get the buck up look even after 30 years of teaching. .. the education profession needs to be reeducated about highly capable disabled people.. they think i am smarter than them .. i know i am smart different and dumb different....I wish everyone knew that general intelligence is a myth ... we all have our gifts and our shortcomings

Response Percentage for Each Question

#1	Who is filling out this survey?	100%
#2	What is the age of the person with ASD (in years)?	99%
#3	What is the educational background of the person with ASD?	100%
#4	What is their current job situation? You can select more than one option.	99%
#5	Please tell us where they work currently and what they do.	96%
#6	Please rate their satisfaction with their current job.	61%
#7	What is their typical hourly wage (dollars per hour)?	75%
#8	How many hours/week do they typically work?	89%
#9	How many hours/week would they like to work?	96%
#10	How much, if any, support do they receive from social security, food stamps, or other government sources (dollars per month)?	80%
#11	How much, if any, support do they receive from family, friends, trusts, or similar sources (dollars per month)? If housing is provided for free, count as $500.	76%
#12	How much time do they spend commuting to work (one way)?	99%
#13	What barriers are there to finding employment?	98%
#14	Please explain more about the challenges they have finding or keeping a job.	88%
#15	What help do they most need to find and keep a job?	85%
#16	Please check any of the following DDD services which were used, either currently or in the past:	98%
#17	What is/was your overall satisfaction with Center-Based Employment?	100%
#18	What suggestions do you have to improve Center-Based Employment?	91%
#19	What is/was your overall satisfaction with Group-Based Employment?	89%
#20	What suggestions do you have to improve Group-Based Employment?	78%
#21	What is/was your overall satisfaction with Transition to Employment?	94%
#22	What suggestions do you have to improve Transition to Employment?	82%
#23	What is/was your overall satisfaction with Employment Support Aide?	100%
#24	What suggestions do you have to improve Employment Support Aide?	75%
#25	What is/was your overall satisfaction with Individual Supported Employment?	93%
#26	What suggestions do you have to improve Individual Supported Employment?	71%
#27	Please select any services received from Vocational Rehabilitation (VR) either currently or in the past.	91%
#28	Were VR services helpful in finding a job?	96%
#29	What was their overall satisfaction with the job they found with VR's help?	100%
#30	What is/was your overall satisfaction with Work Exploration?	93%
#31	What suggestions do you have to improve Work Exploration?	56%
#32	What is/was your overall satisfaction with Work Adjustment Training?	100%
#33	What suggestions do you have to improve Work Adjustment Training?	50%
#34	What is/was your overall satisfaction with the Psychological Evaluations?	97%
#35	What suggestions do you have to improve the Psychological Evaluations?	58%
#36	What is/was your overall satisfaction with the Vocational Evaluations?	95%
#37	What suggestions do you have to improve the Vocational Evaluations?	63%
#38	What is/was your overall satisfaction with the Functional Capacity Evaluation?	94%
#39	What suggestions do you have to improve the Functional Capacity Evaluation?	53%
#40	What is/was your overall satisfaction with the Supportive Education?	92%
#41	What suggestions do you have to improve the Supportive Education?	62%
#42	What is/was your overall satisfaction with the Assistive Technology?	100%
#43	What suggestions do you have to improve the Assistive Technology?	50%

Summary of Recommendations

General

- Job shadow before trying job or internship
- Minimize underemployment (not working at capacity)
- Eliminate gap between VR and DDD – if doesn't qualify for DDD, then needs VR
- Higher expectations of person with ASD
- Give information for people to get work experience while in high school or college, don't wait until you graduate
- Job internships need to actually focus on training the skills that will be used in a real job; not useful to give volunteer work that will not lead to a real job
- Encourage internships during college

Service Specific Recommendations

- Optional rotation among group-based employment opportunities to build skills
- Only do psychological evaluations if necessary
- Make sure psychological evaluations report is communicated to and relevant to job finder and client
- Have supportive education also provide links to academic success programs (study skills, career exploration, friendship, etc.)
- For center-based employment, DDD needs to allocate a staff person to find work for the clients to do. Alternatively, use a portion of each client's paycheck to pay for the work finder.
- For center-based employment, create long-term plan for client to learn more skills to become more employable and independent
- Volunteer internships in group setting (if no paid work available)
- Have supportive education also provide links to academic success programs (study skills, career exploration, friendship, etc.)

ASD Knowledge

- Train DDD support staff about ASD and how to fade supports to increase independence and ability
- VR staff and VR agencies need autism-specific training
- Employer and other employees need ASD training tailored to the individual they are going to work with
- Need autism-specific VR staff
- VR needs to respect clients with ASD
- Help Getting/ Keeping a Job
- Need to bypass interviews with job finder
- Need for more work experience
- For job interviews, need job finder to explain person's disability and strengths, and then have them meet applicant; portfolio/referrals
- Need accommodations for ASD symptoms (sensory, fixed schedule)
- Help with Transportation – possible car pool?

Job Coaching/ Job Buddies

- Consider parents or special education teachers/aides (especially in summer) as possible job coaches for other families since they understand ASD
- Job coach: job shadowing; practice skills if needed; work on-site with coach; continued assistance as needed
- Longer term job coach, and transition to job buddy
- Need a job buddy who has some minimal training
- Have job buddy— train them about ASD and client
- Job Buddy – someone always available and ready to help if problem arises, as part of their job; possibly paid extra by VR or DDD
- Need job buddy to communicate with family/guardian or with client

Appendix J: Cross-Cutting Agency Issues/Recommendations

Entities assisting individuals with ASD in achieving a college education should focus on the following:

- Academic success: Advise students with ASD to take advantage of regular academic success programs, including tutoring, study sessions, writing centers and academic mentors.
- Peer mentors: Assign peer mentor to meet regularly (typically weekly) with students with ASD to provide guidance on academic and social areas, one of the most critical areas to improving the current low graduation rates of adults with ASD.
- Life skills and social communication classes: Support classes in life skills and social communication taught by experts and modeled after existing programs by Chapel Haven in Tucson and SARRC/First Place in Phoenix.
- Work experience: Encourage students to assume part-time or summer work, ensuring that they have work experience by the time they graduate, helping them overcome the major barrier to permanent employment—lack of experience. Engage the Arizona Department of Education to support expansion of Workbridge programs to high schools throughout Arizona. Workbridge programs dedicate part of the school day to internship rotations at different jobs in the community, providing job sampling, work experience and greater focus on career interests. Lack of work experience is one of the major impediments to permanent employment.