

NEW MEXICO
**Developmental Disabilities
Planning Council**

New Mexico Adults with Autism State Plan

Needs Assessment and Best Practices Review

November 2010

ACKNOWLEDGEMENTS

The project staff wishes to express sincere gratitude to the adults with autism and their family members who participated in the focus groups and online survey, as well as the policy personnel and administrators who actively contributed to the production of this plan. Special thanks are extended to Valery Milovic for the artwork she contributed to this document.

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This project was funded by the New Mexico Developmental Disabilities Planning Council. The opinions expressed in this report do not necessarily reflect the views of the New Mexico Developmental Disabilities Planning Council or Davis Innovations, Inc.

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Executive Summary

The New Mexico Developmental Disabilities Planning Council (DDPC) recognizes the significance of improving the lives of adults with autism in New Mexico. To this end, DDPC staff contracted with Davis Innovations, Inc. (DI), a Santa Fe based organizational development firm, to identify the needs of adults with autism and to develop a New Mexico Adults with Autism State Plan. An Advisory Committee of administrators, service providers, adults with autism, and parents of individuals with autism was established to provide project input and oversight.

The Advisory Committee spent six months identifying, deliberating and considering the needs of adults with autism in New Mexico. The Committee members identified the following priority areas for the New Mexico Adults with Autism State Plan to address: Employment, Education, Health and Wellness, Housing, Transportation, Recreation, Self-Advocacy, Community Supports, and Social Groups. Training and safety needs were also identified as sub-topic areas to be explored.

Advisory Committee members helped to determine the research methodology and based on a series of discussions, it was decided that the New Mexico Adults with Autism State Plan would be informed by:

- a review of best practices;
- in-depth interviews conducted with 26 policy makers and administrators from around New Mexico;
- four focus groups facilitated with adults with autism and parents of adults with autism; and
- an online survey conducted with 86 adults with autism and their family members.

This report, entitled “The New Mexico Adults with Autism State Plan” puts forward a series of recommendations informed by best practices and the results of the research methodology. The recommendations are organized into the following categories:

- recommendations for individual providers;
- programmatic operational recommendations;
- recommendations for provider groups (i.e., educators, employers, health professionals, service providers, and public safety personnel); and
- recommendations for statewide integrated programs.

The results of the research activities that informed these recommendations are presented in the body of this report. The findings are organized into the following sections:

- Employment
- Education
- Health and Wellness
- Housing
- Transportation

- Recreation
- Self-Advocacy
- Social Groups
- Community Supports
- Safety

Recommendations for New Mexico

Qualitative data collected through the focus groups and in-depth interviews were transcribed and emergent themes were identified. A summary of the qualitative data, as well as quotations reflecting emergent themes are included in the results section of this plan. The adaptation of best practices, as well as the quantitative and qualitative data was used to identify the following recommendations:

A. Recommendations for Individual Providers

- i. Individualize supports for the person with autism that strongly consider his or her desires and needs as well as the family's values and needs.
- ii. Support and teach individuals with autism to access transportation.
- iii. Teach individuals with autism about safety (social networking, sex, dating, cell phones etc.).
- iv. Provide opportunities for individuals with autism to barter services, participate in peer mentoring, share experiences, engage in advocacy, and network.
- v. Identify a process for offering advocacy for adults who have minimal or no family supports.

B. Programmatic Operational Recommendations

- i. Adopt a common philosophy that is embraced by all providers who serve adults with autism. The common philosophy shall recognize the recommendations included in this Plan.
- ii. Programs need to implement small administrative structures to support adults with autism in ways that are individualized, flexible, and responsive to individual preferences and family concerns.
- iii. Encourage collaboration and communication among organizations and between different departments within an organization.
- iv. Providers must implement practices that are evidence-based.
- v. Establish funding that is diversified and sustainable, using both public and private resources.

C. Recommendations for Provider Groups (i.e., educators, employers, health professionals, service providers, public safety personnel etc.)

- i. Providers should participate in autism specific trainings.

- ii. Providers shall recognize the individual needs of adults with autism and tailor services to the individual.
- iii. Providers should be creative when identifying post-secondary opportunities for adults with autism.
- iv. Providers shall identify goals based on the individual, needs, preferences, and skills.

D. Recommendations for Integrated Statewide Programs

- i. Organizations should work collaboratively to create and integrate a coordinated system of services. They shall collaborate and integrate services seamlessly across the areas of housing, transportation, education, employment, recreation, health care, community supports, social supports, etc.
- ii. Create a clearing house, where consumers and professionals can obtain information about autism, and autism related services.
- iii. Establish an authoritative committee or task an existing committee to bring the various organizations currently working in silos together. The committee shall work with the legislature to procure funds to better serve adults with autism.
- iv. Focus on local priorities using local teams of professionals and organizations.
- v. Conduct a study to determine the number, location and demographics of adults within autism in New Mexico.
- vi. Increase awareness about autism by providing free or low cost training to educators, employers, health professionals, service providers, public safety personnel etc. which enables them to acquire CEU's.
- vii. Be people-focused and engage adults with autism in decision making processes that impact them.
- viii. Design a plan to address the needs of adults with autism that do not qualify for the DD waiver.
- ix. Develop a plan to address the housing needs of adults with autism who do not qualify for the DD waiver, are currently institutionalized out of state, and will not have a place to live after their parents pass away.
- x. Determine a way to provide adequate diagnosis services to adults with autism in New Mexico.

Background on Autism Spectrum Disorder (ASD)

Definition

Autism Spectrum Disorder (ASD) is a neurobiological disorder that interferes with the development of communication and social interaction skills and may result in impaired development of life skills.¹ ASD includes the specific diagnosis of Autistic Disorder; Asperger Syndrome; and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS).²

ASD typically appears during the first three years of life. Individuals with ASD demonstrate deficits in social interaction, verbal and nonverbal communication, and repetitive behaviors or interests. In addition, they will often have unusual responses to sensory experiences, such as certain sounds or the way objects look.³ Because ASD is a “spectrum disorder”, individuals are affected differently and to varying degrees. Some characteristics and indicators of ASD include, but are not limited to:¹

- difficulty initiating or maintaining conversation;
- lack or delay in spoken language;
- repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects);
- little or no eye contact;
- lack of interest in peer relationships;
- lack of spontaneous or pretend play;
- persistent fixation on parts of objects;
- marked impairment in understanding non-verbal language; and
- under or over-sensitivity to sounds, light, touch, smell, taste, pain, movement or other sensory input.

What distinguishes Asperger's Syndrome from autism is the severity of the symptoms and the absence of language delays.¹

Causes and Diagnosis

There is no known single cause of ASD and no medical test for diagnosing ASD.¹ Diagnosis remains subjective and is determined by a psychologist, psychiatrist or M.D. Researchers are investigating a number of theories including the connection between heredity and genetics, as

¹ Autism Society. 2009. “What are Autism Spectrum Disorders?” Retrieved September 20, 2010. (http://www.autism-society.org/site/PageServer?pagename=about_what).

² Centers for Disease Control and Prevention. 2010. “Facts About ASDs” Retrieved September 20, 2010. (<http://www.cdc.gov/ncbddd/autism/facts.html>).

³National Institute of Mental Health. 2009. “What are the Autism Spectrum Disorders?” Retrieved September 20, 2010. (<http://www.nimh.nih.gov/health/publications/autism/what-are-the-autism-spectrum-disorders.shtml>).

well as the link between abnormalities in brain structure and ASD.⁴ Although ASD has no known cure, appropriate early intervention based on the unique needs and abilities of the individual, along with persistent and consistent educational and therapeutic exposure, can enhance the ability of people with Autism to be contributing members of their families and communities, hold full-time jobs and pay taxes.

Prevalence of Autism Spectrum Disorder

The average ASD prevalence was 8 per 1,000 8-year-olds in 2004 and 9 per 1,000 8-year-olds in 2006 in several areas of the United States. That’s about 1 in 110 children.⁵ Although ASD occurs across racial, ethnic and socioeconomic groups, ASD is four to five times more likely to occur in boys than girls.⁵ Currently, ASD is estimated to affect as many as 1 in 94 males.⁴ Although, a specific study has not been completed to determine the number of people in New Mexico who have ASD, data from the Department of Education, Office of Special Education Programs, highlights the number of students ages 3-21 who have autism and receive special education services in New Mexico.⁶

- In 2000, 231 children (0.44%) ages 3-21, who received special education services in New Mexico, were diagnosed as having Autism.
- In 2007-2008, 902 or 1.94% of children with disabilities ages 3-21, who received special education services in New Mexico, were diagnosed as having Autism.

Table 1: Children with Autism in New Mexico for 1999-2000 and 2007-2008⁶

Age (yrs)	1999-2000	2007-2008	Increase (%)
3-5	6	139	2220
6-11	120	397	231
12-17	86	293	241
18-21	19	73	284
Totals: Age 3-21	231	902	290%

⁴ New Mexico Autism Society. 2009. “What is Autism Spectrum Disorder?” Retrieved September 21, 2010. (http://www.nmautismsociety.org/about_autism.php?post_ID=6).

⁵ Centers for Disease Control and Prevention. 2010. “Genomics and Health.” Retrieved September 21, 2010. (<http://www.cdc.gov/genomics/resources/diseases/autism.htm>).

⁶ State of New Mexico in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs

Project Background

Purpose

The New Mexico Developmental Disabilities Planning Council (DDPC) recognizes the significance of improving the lives of adults with autism in New Mexico. The DDPC's mission is to engage in advocacy, capacity building, and systemic change activities that contribute to a culturally competent and coordinated individual and family-centered and -directed, comprehensive system of community services, individualized supports and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, to be independent, to be productive and to be integrated into, and to be included in all facets of community life.⁷ To identify the needs of adults with autism in order to develop a New Mexico Adults with Autism State Plan, DDPC staff contracted with Davis Innovations, Inc. (DI), a Santa Fe based organizational development firm. As a part of this project, DI staff and DDPC personnel established an Advisory Committee of administrators, service providers, adults with autism, and parents of individuals with autism to provide project oversight. The Advisory Committee Membership Roster is included in Appendix A. The Advisory Committee held five meetings at the Center for Self-Advocacy in Albuquerque, New Mexico. The group convened on the following dates:

- Friday March 26, 2010
- Friday May 14, 2010
- Friday June 18, 2010
- Friday July 30, 2010
- Friday, October 29, 2010

During these meetings, the Advisory Committee members identified the following priority areas for the New Mexico Adults with Autism State Plan:

- Employment,
- Education,
- Health and Wellness,
- Housing,
- Transportation,
- Recreation,
- Self-Advocacy,
- Community Supports, and
- Social Groups.

⁷ New Mexico Developmental Disability. 2010. Planning Council. "Our Mission." Retrieved October 21, 2010. <http://www.nmddpc.com/page/office-of-guardianship>.

In addition, training and safety were identified as sub-topic areas. The Advisory Committee assisted in determining the research methodology utilized to identify the needs of adults with autism in New Mexico. Based on a series of discussions, it was determined that the New Mexico Adults with Autism State Plan would be informed by:

- A review of best practices;
- In-depth interviews conducted with policy makers and administrators from around New Mexico;
- Focus groups facilitated with adults with autism and parents of adults with autism; and
- An online survey conducted with adults with autism and their family members.

Policymakers, adults with autism, and parents of adults with autism were invited to serve on the Advisory Committee and were actively engaged throughout the research process. A detailed description of the research methodology is provided in the subsequent section.

Methodology

Best Practices

DI staff began the research study with a review of other state plans, as well as a formal literature review of best practices in effectively serving adults with autism. DI staff found very little information that was specific to providing an effective continuum of services and supports for adults with autism. The exception was a study conducted by Dr. Peterson (from here on out referred to as the “Delaware Study”) which was funded by the Delaware Division of Developmental Disabilities Services. The Delaware Study was based on 24 telephone interviews with key staff and eight site visits in seven states at program sites that reported comprehensive approaches to supporting adults with autism. Each of the programs displayed a number of exemplary practices. In the Delaware Study, a list of best practices was recognized as specific to supporting adults with autism in Delaware. Best Practices were identified as “those services that are appropriate, flexible, highly individualized, and have a good cost-benefit ratio”.⁸

In-depth Interviews with New Mexico Policy Makers and Administrators

The New Mexico Adults with Autism State Plan Advisory Committee formulated a list of 41 policy makers and administrators who they recognized as experts in one or more of the identified topic areas: Employment, Education, Health and Wellness, Housing, Transportation, Recreation, Self-Advocacy, Community Supports, and Social Groups. DI staff conducted in-depth telephone interviews with 26 of these policy makers and administrators. Of the individuals who completed an interview, 13 were from Bernalillo County, 7 from Santa Fe County, 2 from San Juan County, 2 from San Miguel County, 1 from Eddy County, and 1 from Dona Ana County. Eleven policy makers and administrators completed interviews which focused on more than one priority area. The total number of interviews completed in each priority area is presented in the table 2 below:

⁸ Autism Society of Delaware. (2005). *Best Practices for Serving Adults with Autism: Results of the study on services and support for adults on the autism spectrum across the United States*. Wilmington, DE: Autism Society of Delaware.

Table 2: In-depth Interviews with Policy Makers and Administrators

Priority Areas	Total # of Interviews Completed
Employment	6
Education	9
Health	4
Housing	2
Transportation	2
Recreation	4
Self-Advocacy	1
Community Supports	9
Social Groups	2
Total	39

DI interviewing staff followed a semi-structured format which allowed for flexibility and adaptation. Each interviewer was provided with a list of general topic areas they were required to address. The general topics included: available opportunities, needs, barriers, infrastructure, collaborations, best practices, training, and safety. Interviewers were also provided with interview guidelines consisting of sample questions. The interview guidelines for each priority area are included in Appendix D. While it was recommended that the interviews use the sample questions to elicit information, the wording and ordering for each question was not rigid. Interviewers were allowed to modify questions as necessary, ask for clarifications, and/or ask additional questions to probe for more detailed or supplementary information. This enabled the interviewers to collect information on sub-topics areas that were not specifically identified by the Advisory Committee but that are relevant to the development of the plan.

Focus Groups with Adults with Autism and Parents of Adults with Autism

DI staff facilitated four focus groups with adults with autism and parents of adults with autism. Two focus groups were held with adults with autism and two were held with parents of individuals with autism. Three focus groups were conducted at the Center for Self-Advocacy in Albuquerque and one parent focus group was conducted via conference call in an effort to engage participants in other geographic locations. Overall, 14 parents and 9 adults with autism participated in the focus groups. The focus groups provided participants with an opportunity to express their opinions regarding needs, barriers, and preferences in each priority area. DI staff developed moderator guides that were specific to each target population. The moderator guides are included in Appendix E. The table below (table 3) identifies the date and location of the focus groups, as well as the number of participants, their gender, and the geographical area they live.

Table 3: Focus Groups with Adults with Autism and Family Members*

Date	Focus Group Type	Location	Number of Respondents			Geographical Area
			Males	Females	Total	
9.10.10	Parents	Center for Self-Advocacy	0	7	7	Participants were from Albuquerque.
9.10.10	Adults with Autism / Self-Advocates	Center for Self-Advocacy	3	3	6	Participants were from Albuquerque.
9.13.10	Adults with Autism / Self-Advocates	Center for Self-Advocacy	2	1	3	Participants were from Albuquerque.
9.20.10	Parents	Conference Call	3	4	7	Participants were from Albuquerque, Las Cruces, Carlsbad, and Alamogordo.

Online Survey with Adults with Autism and their Families and Friends

DI staff designed a survey instrument based on the nine priority areas identified by the Advisory Committee. The survey consisted of demographic and general questions, as well as a series of questions which specifically addressed the priority areas. A few of the general questions included in the survey instrument were adapted from a questionnaire designed by the New Jersey Adults with Autism Task Force.⁹ The survey is included in Appendix F. The survey included two types of questions for each priority area. The first question inquired about the importance of each issue and the second question inquired about the respondent’s satisfaction with each issue. The first question was rated on a 5-point Likert scale where “1” indicated *very important* and “5” indicated *not important*. The second question was rated on a 5-point Likert scale where “1” indicated *very satisfied* and “5” indicated *not satisfied*.

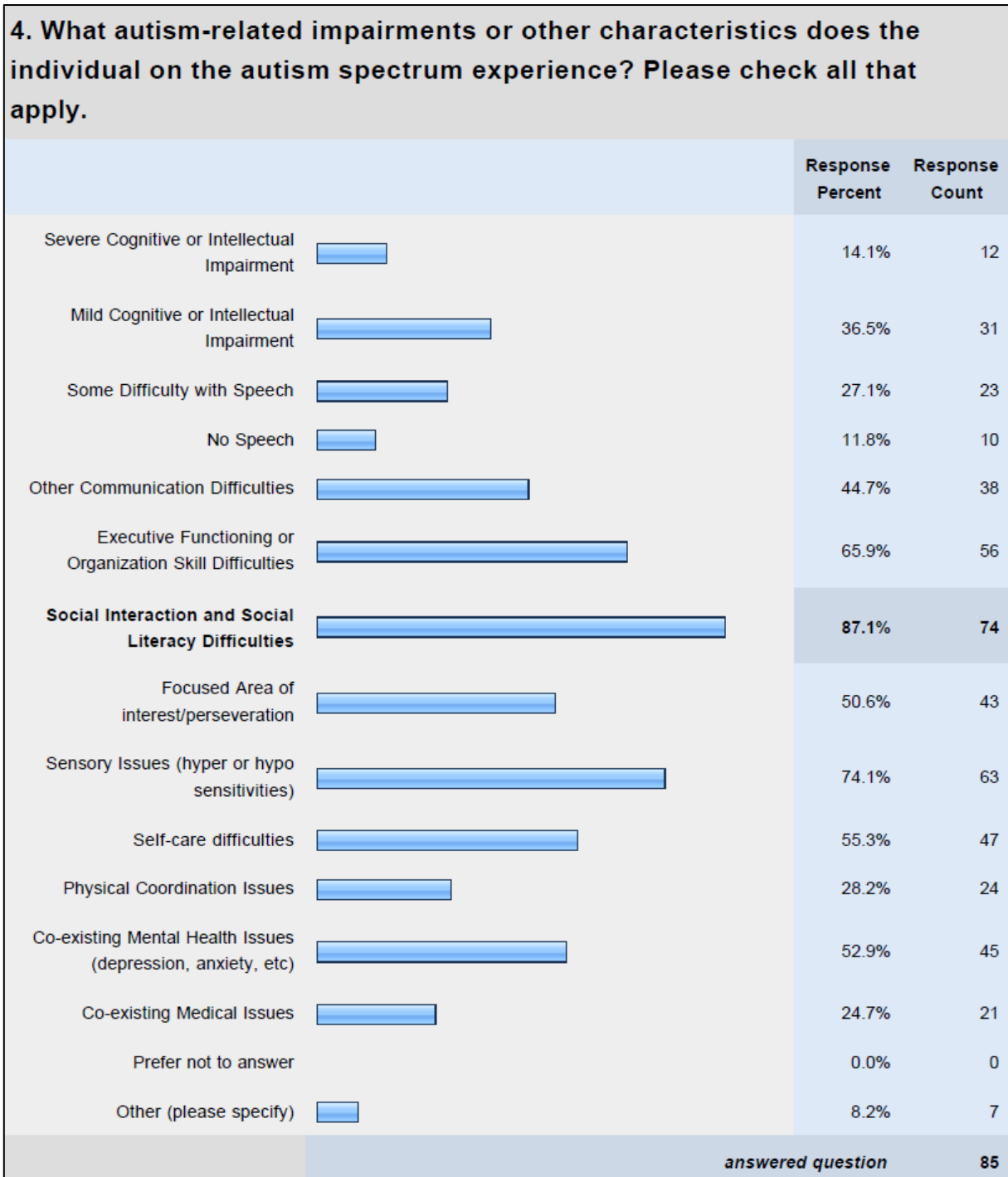
Advisory Committee members sent emails to their respective listservs requesting that adults with autism and family members of individuals with autism complete the online survey. Emails with links to the online survey were sent to the following listservs: The New Mexico Autism Society, New Mexico Ticket Partners, WISE Notice, New Mexico Consortium of Career Educators and Employers, Community Work Incentive Coordinators, and the New Mexico Department of Vocational Rehabilitation.

* While participants represented people across the spectrum, most of the lower functioning adults with autism were represented by their parents. Consequently, the needs, barriers, and challenges identified were not the opinions of these individuals but rather the perspectives of their parents. Moreover, the adults with autism who participated in the focus groups were not representative of New Mexico’s socioeconomic, cultural and ethnic diversity.

⁹ Adults with Autism Task Force. 2009. *Addressing the Needs of Adults with Autism Spectrum Disorder: Recommendations for a Plan of Action for the State of New Jersey*.

In total, 86 individuals responded to the survey. Approximately, 9.3% of the respondents were adults with autism, whereas 46.5% were parents, 14.0% were friends, 4.7% were siblings, and 4.7% were grandparents. Nearly one in five (19.8%) respondents reported that they were related in an “other” way and 1.2% chose not to disclose their relationship. Since 90.7% of the respondents were not the person with autism, participants were asked to think about the individual with autism when answering the survey questions. They were also asked to provide background information regarding the person with autism. Consistent with the literature, the individuals with autism varied by age and autism related impairments. Their ages ranged from younger than five to older than 65. The median age group was 18-21. The autism-related impairment most commonly experienced by the group was social interaction and social literacy difficulties. Approximately 87.1% of the individuals with autism experienced this impairment. The prevalent social difficulty was followed by sensory issues (74.1%) and executive functioning or organizational skill difficulties (65.9%). Chart 1 presents a summary of impairments experienced by the individuals with autism.

Chart 1: Online Survey – Autism-related Impairments



Data Analysis

DI staff analyzed data from the surveys using IBM SPSS. Descriptive statistics were used to describe participants' responses to the quantitative survey questions. DI staff created an itemized list of needs based on the analyses compiled from the two questions asked in each priority area. The items, which were rated high in importance but low in satisfaction, are ranked as the highest needs. The itemized list is included in the results section of this report. Qualitative data collected through the focus groups and in-depth interviews were transcribed and emergent themes were identified. A summary of the qualitative data, as well as quotations reflecting emergent themes are included in the results section of this plan. The adaptation of best practices, as well as the quantitative and qualitative data was used to develop the recommendations identified in this Plan.

Best Practices

The Delaware Study, which consisted of interviews with key staff and site visits with exemplary programs, revealed that "Best Practice" in serving and supporting adults with autism requires the following practices:¹⁰

- Integrating activities seamlessly throughout the day and week, across the areas of domestic life, employment, recreation and social relationships. That is, the person's life should not be divided into compartments such as "residential services" and "employment services" for which different groups of staff have different responsibilities.
- Adopting a common philosophy in New Mexico. There must be a clear, shared philosophy that is embraced by all of the stakeholders of the support program. Staff at all levels must not only articulate the philosophy, but "live" it. This enhances the consistency in the quality of services delivered.
- Establishing funding that is diversified and sustainable, using ALL resources within the community (e.g. small business loans, food stamps) thus promoting flexibility and program survival. It must be integrated and coordinated without the constraints of an elaborative administrative "system".
- Building a New Mexico local focus. The program and providers should be "homegrown," focused on local priorities, specific to individuals' needs, and directed by a simple organizational structure with minimal administrative hierarchy. Programs must be responsive to local needs and not distant administrations.
- Adopting a family-driven, family-directed approach that is culturally appropriate. The individual, with his or her own perspective and preferences, is part of a family and must be recognized as such.
- Adopting procedures for effective and efficient use of all resources including fiscal and human resources across persons served.
- Incorporating systematic evaluation and accountability. This takes place from the individual all the way to the systems level. It should reflect the local ecology.

¹⁰ These practices have been modified slightly to reflect the cultural diversity and needs of New Mexicans.

New Mexico Study: What are the Needs of Adults with Autism?

People with autism display a wide range of ability levels and behavioral characteristics. They have individual differences, preferences, and experiences. The research findings illustrate the diverse needs of adults with autism in New Mexico, as well as the challenges and barriers they encounter.

Overall Perceived Service Needs for Adults with Autism

The results of the online survey administered to adults with autism and those closely related to them demonstrates their dissatisfaction with the current provision of services. As mentioned in the methodology section, the survey included two types of questions for each priority area (i.e. education, employment, housing, etc.). The first question asked about the importance of the issue and the second question asked about the respondents’ satisfaction with the issue. The first question was rated on a 5-point Likert scale where “1” indicated *very important* and “5” indicated *not important*. The second question was rated on a 5-point Likert scale where “1” indicated *very satisfied* and “5” indicated *not satisfied*. The outcome of the data analysis is a prioritized list of service needs which were used to inform the recommendations identified in the Plan. Service needs are considered survey items that the majority of the participants (51% or more) rated high in importance (“1” or “2”) and low in satisfaction (“4” or “5”). The majority of participants rated ten items high in importance and low in satisfaction. These items are presented in table 4.

Table 4: Online Survey: Needs and Priorities for Adults with Autism

Issues	% of respondents rating item high in importance and low in satisfaction
Availability of continuing education opportunities for adults with autism	75.4%
Availability of employment opportunities for adults with autism	65.7%
Availability of other community supports for adults with autism	60.9%
A coordinated system of services	60.5%
Ability of educators, employers, and service providers to meet the individual needs of adults with autism	60.0%
Availability of post-secondary vocational opportunities for adults with autism	56.9%
Availability of housing opportunities for adults with autism	56.1%
Ability of health care providers to treat individuals with autism	54.3%
Availability of post-secondary educational opportunities for adults with autism	51.6%
Availability of autism specific trainings for educators, employers, and services providers	51.4%

The most commonly identified service needs are continuing education, employment opportunities, community supports, a coordinated system of services, and the ability of educators, employers, and service providers to meet the individual needs of adults with autism. Several participants also rated additional issues high in importance and low in satisfaction. Additional needs and priorities are presented in table 4. The survey results exemplify the multifarious needs of adults with autism in New Mexico.

Table 5: Online Survey: Additional Needs and Priorities for Adults with Autism

Issues	% of respondents rating item high in importance and low in satisfaction
Availability of social support groups for adults with autism	50.0%
Availability of recreational activities for adults with autism	49.3%
Ability of health care providers to correctly diagnose individuals with autism	48.5%
Availability of public transportation for adults with autism	48.4%
Availability of self-advocacy trainings for adults with autism	43.8%
Availability of volunteer opportunities for adults with autism	38.3%
Availability of peer mentoring opportunities for adults with autism	35.0%
Ability of the media to educate the public about the varying strengths, challenges and abilities of the adult autism community	29.0%

Coordinated System of Services

There is a great need in New Mexico to implement a coordinated system of services that recognizes and meets the individual needs of adults with autism. Approximately three-fifths of adults with autism and those closely related to them who participated in the online survey rated a coordinated system of services and the ability of educators, employers, and service providers to meet the individual needs of adults with autism high in importance and low in satisfaction. Their concerns were echoed in both the in-depth interviews with policy makers and administrators and focus groups with parents and adults with autism. Several policy makers, as well as adults with autism and parents of individuals with autism expressed their frustration with:

- The lack of collaboration between organizations,
- Inconsistencies between agencies, and
- The inability of providers to offer information beyond their immediate organization or department.

Participants identified New Mexico organization’s reluctance to implement a coordinated system of services as problematic. Rather than compartmentalizing services, it was recommended that

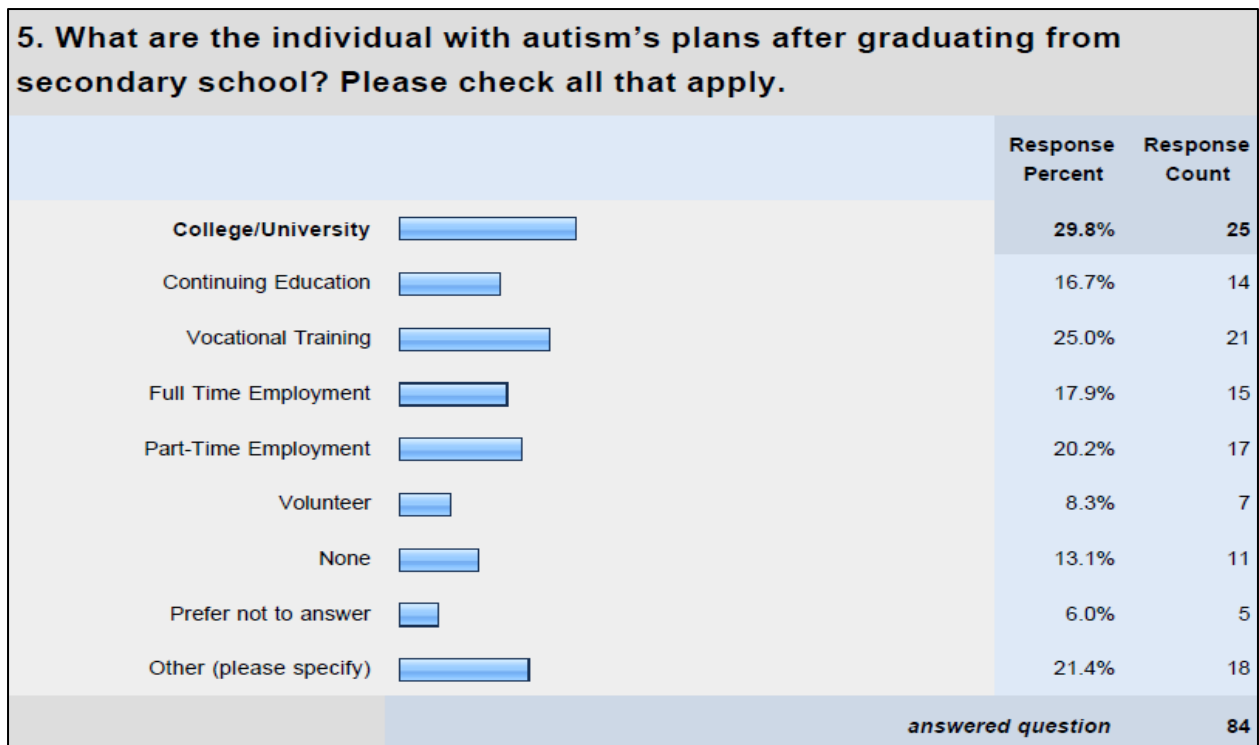
the state should follow best practices which involve **adopting a common philosophy** and **integrating activities seamlessly** across the areas of domestic life, employment, recreation and social relationships for adults with autism. Moreover, focus group participants pointed to the importance of **creating a central location** where consumers and providers alike can obtain information, resources, and referrals regarding autism services in New Mexico.

Employment

Current Situation

The results of the online survey illustrate broad post-secondary interests for adults with autism. When survey respondents were asked about the individual's with autism plans after graduating from secondary school, 29.8% reported college or university, **25.0% vocational training**, **20.2% part-time employment**, **17.9% full-time employment**, 16.7% continuing education, **8.3% volunteer work**, and 21.4% reported "other". Results do not sum to a 100.0% because respondents were asked to check all that apply.

Chart 2: Online Survey – Post-Secondary School Interests



Employment has been shown to promote personal dignity, enhance quality of life, and improve cognitive performance in adults with autism.¹¹ Yet, the results of the online survey, focus groups, and in-depth interviews illustrate a bleak employment situation for adults with autism in New Mexico. A majority of survey participants rated four issues related to employment high in importance and low in satisfaction. The percentages are presented in table 6.

Table 6: Online Survey: Employment Needs and Priorities for Adults with Autism

Employment Issues	% of respondents rating item high in importance and low in satisfaction
Availability of employment opportunities for adults with autism	65.7%
Ability of educators, employers, and service providers to meet the individual needs of adults with autism	60.0%
Availability of post-secondary vocational opportunities for adults with autism	56.9%
Availability of autism specific trainings for educators, employers, and services providers	51.4%
Availability of volunteer opportunities for adults with autism	38.3%
Availability of peer mentoring opportunities for adults with autism	35.0%

Nearly two-thirds (65.7%) of the focus group participants rated the availability of employment opportunities for adults with autism as high in importance and low in satisfaction. This quantitative data is substantiated by qualitative accounts derived from in-depth interviews and focus groups. Policy personnel and administrators reported that few jobs are available to adults with autism. Some policy personnel and administrators indicated that opportunities for job creation are non-existent while others stated that they are limited. Policy personnel and administrators agreed that when an opportunity does arise, most adults with autism have to navigate the employment sector on their own unless they have a job developer/coach who can find a good job match, work with the employer, and remain at the job site with the employee until he/she is fully acclimated.

The views and concerns of policy personnel and administrators were echoed by adults with autism and parents of individuals with autism. Focus group participants explained that many adults with autism do not fit into the labor market. They indicated that it is not uncommon for adults with autism to work temporary jobs or to be unemployed. Some of the participants described scenarios in which they frequently moved from job to job or struggled with under and unemployment. Moreover, some of the participants felt that they were pushed into jobs that were isolating, stereotypical and exploitative.

¹¹ Hendricks, Dawn. 2010. "Employment and Adults with Autism and Spectrum Disorders: Challenges and Strategies for Success." *Journal of Vocational Rehabilitation*, 32:125-134.

Focus group participants stressed the negative implications unemployment and underemployment has on other aspects of an individual's life. Without wages earned from employment, adults with autism cannot support themselves nor can they pursue their interests. Unemployment and underemployment hinders their ability to share in the entitlements enjoyed by employed populations within society.⁸

A few of the focus group participants stated that they and others they knew were self-employed. Several participants with autism who were not currently self-employed expressed a desire to learn how to start their own business. While most of the participants were optimistic regarding the opportunities surrounding self-employment, they expressed some anxiety regarding the potential for a lack of health benefits and limited access to healthcare. In some instances, employment was not a primary concern for the focus group participants, as the family was focused on ensuring the basic needs of the person with autism.

According to interview participants, the current employment infrastructure consists of the New Mexico Developmental Disability Supports Division (NMDDSD), DD waiver programs, New Mexico Developmental Disabilities Planning Council (NMDDPC), and the New Mexico Division of Vocational Rehabilitation (NMDVR). Some of the parents of individuals with autism and adults with autism who participated in the focus groups expressed frustrations with NMDVR. A few were unsure of NMDVR's function, whereas others claimed that staff members were not helpful and failed to follow up with clients. Some of the adults with autism reported that NMDVR's services failed to work.

The in-depth interviews with policy makers and administrators revealed that employment best practices are not currently being implemented in New Mexico. In spite of this, they acknowledged the promising practices of the New Mexico Department of Health (NMDOH). Similarly, most of the interview participants agreed that there are few autism specific trainings for employers. A few of the interview participants indicated that job coaches were typically responsible for training and educating employers. Participants who were aware of formal trainings reported that the following entities had conducted them:

- The University of Arkansas via webinar;
- University of New Mexico Center for Development and Disability (UNM CDD);
- New Mexico Autism Society; and
- The Behavioral Health Collaborative.

Interview participants voiced concerns about the lack of awareness regarding the trainings, as well as the apathy amongst employers to devote time to trainings.

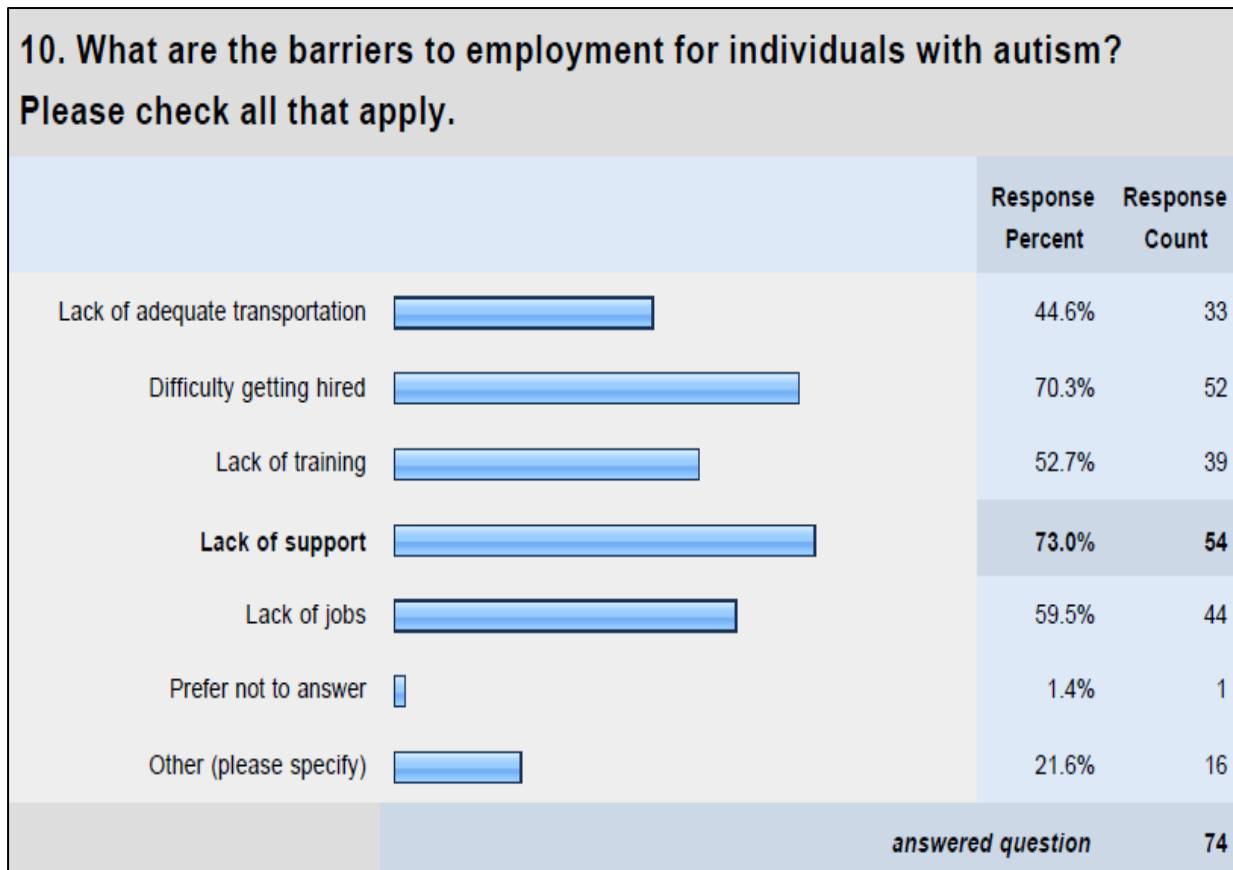
To determine the incentives currently available to employers, DI staff asked policy makers and administrators to identify the methods used to motivate employers to hire adults with autism. Policy makers and administrators reported that although they were not aware of specific incentives for employers to hire adults with autism, more general incentives for hiring people with disabilities do exist. They include:

- The general push to hire people with disabilities;

- Work Opportunity Tax Credits (WOTC);
- On the job training (OJT);
- Support to employers through DVR or waiver programs (job coaches, training, etc.);
- Social Security incentives for employees that directly affect work, such as the PASS (Plan for self sufficiency); and
- DVR and EN's (Employment Networks) who have already done individual screening and job-matching.

Barriers to Employment

Chart 3: Online Survey – Barriers to Employment



Survey participants were asked about barriers to employment for individuals with autism. The top three barriers reported by respondents include: **lack of support, difficulty getting hired, and lack of jobs**. Nearly three-quarters (73.0%) of respondents identified lack of support as a barrier, 70.3% reported difficulty getting hired, and 50.5% pointed to a lack of jobs. Additionally, 52.7% of respondents identified lack of training as a barrier and 44.6% reported a lack of adequate transportation. The percentages sum to more than 100.0% because participants were instructed to check all that apply.

Similar challenges were identified during the in-depth interviews with policy makers and administrators and were discussed by parents of individuals with autism and adults with autism in the focus groups. Additionally, adults with autism, parents, and policy makers and administrators identified the following barriers to employment:

- Lack of transportation;
- Unmanaged behavioral issues;
- Anxiety induced from office settings;
- Employers' fear of behavioral issues;
- Stereotypes of people with autism;
- Environmental sensitivities within the workplace;
- Employers inability to understand the blanket term "autism spectrum disorder" because it defines individuals with wide ranging disabilities and complexities;
- Employers refusing to hire adults with autism due to their apprehension of dealing with the liability of a job coach; and
- Insufficient funding for job supports, including the higher functioning adults with autism who need them but aren't eligible to receive them through the Developmental Disabilities (DD) Waiver.

Employment Needs

To determine the employment needs of adults with autism, survey participants were asked to identify the additional assistance needed for adults with autism to procure and sustain employment. The top three needs identified by respondents include: **more support from employers / co-workers, on the job supports / job coach, and job accommodations**. Slightly more than three-quarters (78.4%) of respondents reported needing more support from employers / co-workers, 77.0% indicated needing on the job supports / job coach, and 63.5% pointed to a need for job accommodations. Additionally, 52.1% of respondents stated that they needed an increased amount of job coaching. The percentages sum to more than 100.0% because participants were instructed to check all that apply.

Chart 4: Online Survey – Employment Needs



These needs were thoroughly discussed in both the in-depth interviews and focus groups. The qualitative research results provide rich stories behind the employment needs of adults with autism and their preferences. Policy personnel and administrators, parents, and adults with autism emphasized the need to **increase awareness about autism, alert industries about how adults with autism can contribute to the workforce**, and to **educate people about autism** in the employment sector. They advocated for employer and staff trainings, which are specific to working with adults with autism, as well as trainings designed to teach providers how to work with employers. Several of the focus group participants mentioned that they had personally facilitated trainings and felt that it is highly effective when adults with autism lead the trainings. This not only provides employment personnel with pertinent information, but it allows them to see firsthand the unique characteristics and diverse abilities of people with autism. Additional needs identified by policy personnel and administrators include: **funding for long-term supported employment, job coaching tailored to the individual**, and creating **opportunities for supported self-employment**. Policy makers and administrators viewed job coaches and behavioral therapy supports, as having the potential to create jobs for adults with autism with successful outcomes.

Focus group participants stated that they were extremely interested in **self-employment**. Several focus group participants recommended creating a support structure where adults with autism could learn to start their own business experiences. Individuals were interested in **bartering services, peer mentorships, sharing experiences**, and **networking** in order to sustain self-employment and/or to obtain employment in the workforce.

The focus group participants emphasized the need for employers and job coaches to **recognize the individuality and unique capabilities of persons with autism**. They also stressed the importance of being placed in jobs with **genuine, patient employers** who are willing to work

with people with disabilities. Many participants also highlighted the need for service providers, families, and job coaches to **be creative when identifying employment**.

Focus group participants also recommended connecting adults with autism to **higher paying, quality jobs**. To accomplish this, focus group participants pointed to the need for **collaborative efforts** between educators, employers, behavioral health services, etc. They also stressed the importance of actively engaging the person with autism in the process and identifying employment goals that are based on the individuals, needs, preferences, and skills. Similarly, policy personnel and administrators recommended that more emphasis be placed on identifying employment opportunities in K-12.

Education

Current Situation

The results of the online survey revealed that some adults with autism in New Mexico are interested in pursuing post-secondary education. When survey respondents were asked about the individual’s with autism plans after graduating from secondary school, **29.8% reported college or university, 25.0% vocational training, 20.2% part-time employment, 17.9% full-time employment, 16.7% continuing education, 8.3% volunteer work, and 21.4% reported “other”**. Percentages do not sum to 100.0% because participants were instructed to check all that applied.

In spite of this, adults with autism have limited educational opportunities. The majority of survey participants rated four educational items high in importance and low in satisfaction. The percentages are presented in table 7.

Table 7: Online Survey: Educational Needs and Priorities for Adults with Autism

Educational Issues	% of respondents rating item high in importance and low in satisfaction
Availability of continuing education opportunities for adults with autism	75.4%
Ability of educators, employers, and service providers to meet the individual needs of adults with autism	60.0%
Availability of post-secondary educational opportunities for adults with autism	51.6%
Availability of autism specific trainings for educators, employers, and services providers	51.4%

In line with the results of the survey data, policy personnel and administrators reported that post-secondary educational opportunities for adults with autism in New Mexico are limited. They indicated that the current educational infrastructure is comprised of NMDVR, DD waiver, Developmental Disabilities Support Division/ NMDOH, Eastern New Mexico, ARCA, Co-Tech, Realizing Confidence and Independence, The Center for Self-Advocacy, University of New Mexico (UNM)/ Center for Development and Disability (CDD), Very Special Arts, and the Albuquerque Public Schools (APS). Interview participants agreed that collaboration between the

organizations is minimal with too many entities operating in silos that are not singularly strong enough to have desired effects.

Eastern New Mexico University – Roswell was identified as the only 2 or 4 year institution in New Mexico that operates a unique occupational special services program for students with disabilities. In spite of this, policy personnel and administrators reported that institutions of higher learning in New Mexico are becoming more aware of the need to implement programs that can help adults with autism and other disabilities pursue a degree. For instance, one interview participant indicated that UNM is currently testing a peer mentor program on campus to accomplish this goal. Moreover, some of the policy personnel and administrators reported that there is a movement in New Mexico to implement a “Think College” model. One interview participant reported that a study group recently applied for a three year grant to develop a program for individuals with intellectual disabilities. Policy personnel and administrators identified the following educational opportunities for adults with autism:

- Co-Tech System (18-22 year olds);
- Continuing education courses;
- Community college classes;
- ARCA ;
- Realizing Confidence and Independence - courses in adult literacy;
- The Center for Self-Advocacy - financial literacy courses;
- UNM/ CDD trainings;
- Very Special Arts - educational opportunities; and
- APS programs.

Interview participants stressed that the programs identified above are not necessarily degree oriented nor are they sufficiently funded.

The in-depth interviews with policy makers and administrators revealed that educational best practices are not currently being implemented in New Mexico. Nevertheless, interview participants acknowledged the promising practices of CDD/UNM, Optum Health, and the New Mexico Center for Self-Advocacy. Most of the interview participants agreed that there is few autism specific training offered to educators. However, the following training opportunities were identified:

- UNM College of Education – Offers a Transcribed Graduate Certificate;
- UNM/CDD provides some training;
- New Mexico State University (NMSU) – Offers classes with an emphasis in autism and is seeking approval to offer a minor in autism for students studying special education and communication disorders;
- NMSU offers full day trainings and workshops to school districts, administrators and social workers in Southern New Mexico; and

- New Mexico Highlands University (NMHU) offers a rehabilitation counseling program (not autism specific).

Parents and adults with autism who participated in the focus groups expressed their frustration with the lack of opportunities available to adults with autism, as well as the shortage of trained professionals.

Educational Barriers

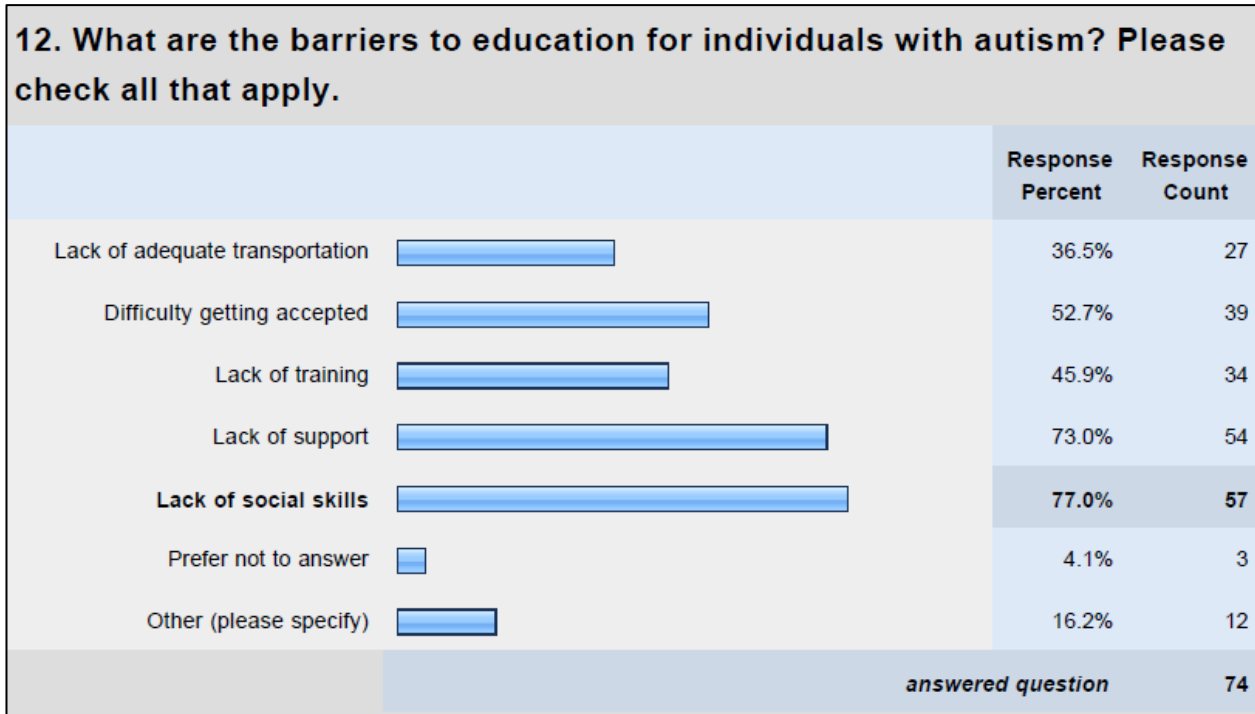
Survey participants were asked about barriers to education for individuals with autism. The top three barriers reported by respondents include: **lack of social skills, lack of support, and difficulty getting accepted**. Slightly more than three-quarters (77.0%) of respondents identified lack of social skills as a barrier, 73.0% reported lack of support, and 52.7% indicated that they had difficulty getting accepted. Additionally, 45.9% of respondents identified lack of training as a barrier and 35.6% reported a lack of adequate transportation. The percentages sum to more than 100.0% because participants were instructed to check all that apply.

These same challenges were identified during the in-depth interviews with policy makers and administrators and were discussed by parents of individuals with autism and adults with autism in the focus groups.

Additionally, adults with autism, parents, and policy makers and administrators identified the following barriers to education:

- Disclosing the diagnosis of autism;
- Stereotypical beliefs and attitudes about people with autism;
- Lack of preparation / Inadequate skill sets due to segregation in grades K-12;
- Insufficient funding to provide programs and supports for students with disabilities;
- Inability of professors to understand the wide ranging implications of autism; and
- Over-sensitivity to sounds, light, touch, smell, taste, pain, movement or other sensory input.

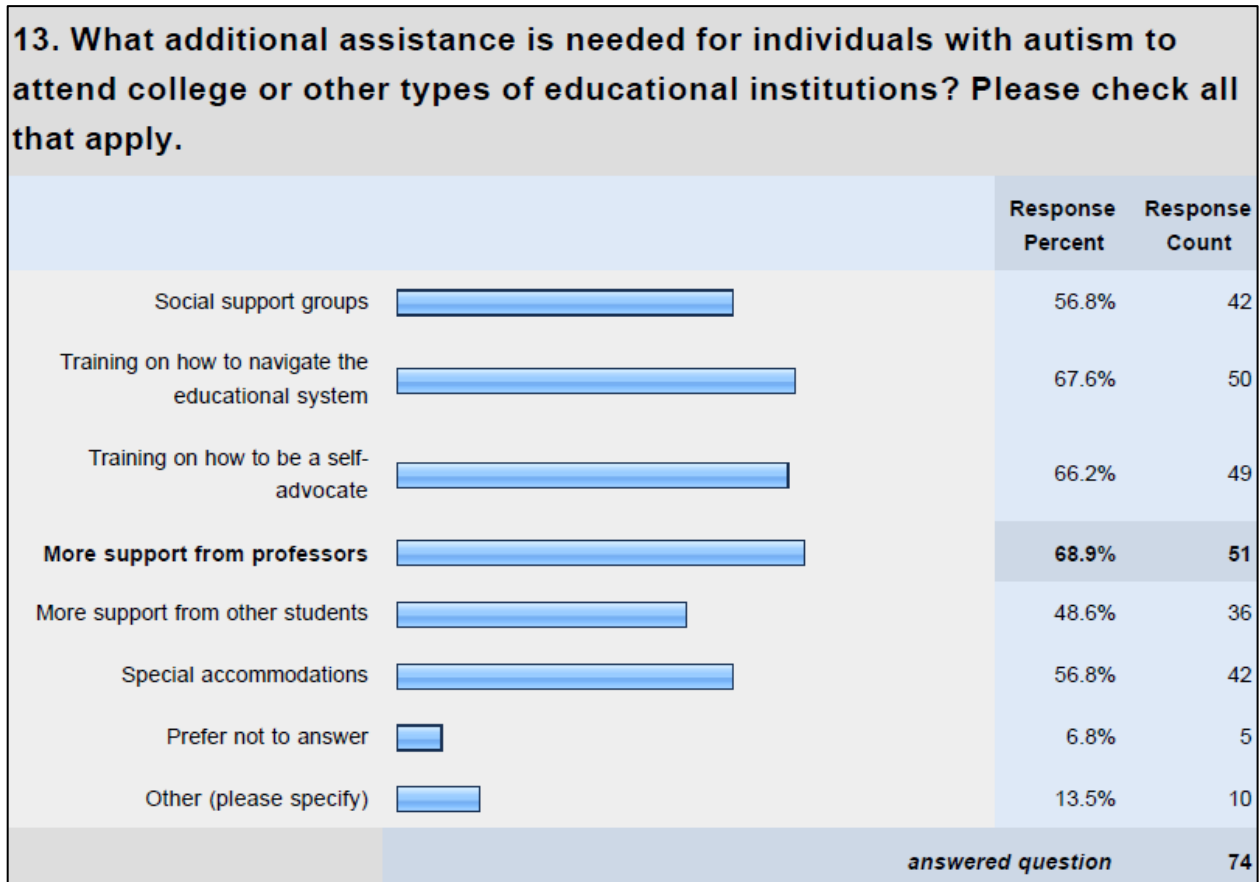
Chart 5: Online Survey – Educational Barriers



Educational Needs

To determine the educational needs of adults with autism, survey participants were asked to identify the additional assistance needed for adults with autism to attend college or other types of educational institutions. The top three needs identified by respondents include: **more support from professors, training on how to navigate the educational system, and training on how to be a self-advocate.** Sixty-eight percent (68.9%) of respondents reported needing more support from professors, 67.6% indicated that they needed training on how to navigate the educational system, and 66.2% stated that they needed training on how to self-advocate. Additionally, 56.8% of respondents stated that they needed social support groups, 56.8% indicated that they needed special accommodations, and 48.6% suggested that they needed more support from other students. The percentages sum to more than 100.0% because participants were instructed to check all that apply.

Chart 6: Online Survey: Educational Needs



These needs were thoroughly discussed in both the in-depth interviews and focus groups. In line with the online survey results, policy personnel and administrators, parents of individuals with autism, and adults with autism emphasized the need to build self-advocacy skills, including basic organizational and time management skills in K-12. They also urged professors to recognize the individual needs of students with autism and work with them to achieve their goals. Additional educational needs identified in the interviews and focus groups include:

- Assistive technology to support successful educational outcomes;
- Freshman Orientation for students with autism to help them assimilate into the campus culture;
- Peer mentoring;
- An organized place on campuses for students with autism to share resources and receive support;
- Engaging people with autism on educational boards, Office of Disability, etc.;
- Creating cultural change within higher education to accept anyone who wants to pursue post-secondary outcomes;

- Autism-specific training provided by the Offices of Disability on college campuses;
- An interim program to fill the gaps and enable students with autism to build the skills necessary to apply to a 2 or 4 year institution or employment;
- Outreach to diffuse myths about people with autism being uneducable ; and
- Outreach to adults with autism about educational opportunities in New Mexico.

Finally, policy personnel and administrators pointed to the need to enhance the current infrastructure to provide a **continuum of services**. They stressed the need for K-12, post-secondary, higher education, employers, NMDVR, and disability offices on college campuses to **communicate and collaborate** to create a more **integrated setting** for students with autism. Policy personnel and administrators also stressed the importance of creating a birth to death comprehensive, **seamless statewide system** to include: education, training, job placement, life and social skills for students with autism. They emphasized the need for K-12 educational entities to map out a future for youth with autism that is followed through by NMDVR, post-secondary institutions, and other service providers, including behavioral health professionals. According to Kay (2008), best practices for K- 12 vocational transitional plans include: 1) Ensuring the plan is based on the individual needs, preferences, and skills of the person with autism; 2) Orientating the plan to life after high school; 3) Designing a master plan which includes long range goals and a coordinated set of activities for each; and 4) Providing services that promote positive movement towards a life after school.¹²

Health and Wellness

Current Situation

The results of the online survey, in-depth interviews, and focus groups illustrate several health and wellness needs for adults with autism in New Mexico. A majority of participants rated three health and wellness issues high in importance and low in satisfaction. The fourth item's ratings approached 50.0%. The percentages are presented in table 8.

In line with the results of the survey data, policy personnel and administrators reported concerns with the healthcare system in New Mexico. They indicated that the situation in the rural regions of the state is even direr than in urban areas, such as Albuquerque which has access to programs at UNM. Policy personnel and administrators reported that the current health care infrastructure consists of behavioral health, NMDVR, private insurance companies, Medicaid insurance providers, and Independent Living Centers. Interview participants reported that there was limited to no collaboration between these entities and no pool of existing healthcare providers that specialize in autism. Moreover, none of the interviewees were aware of best practices being implemented for adults with autism in New Mexico. Most policy personnel and administrators reported that autism specific trainings for health care professionals are limited, whereas others stated that they are available if health professionals actively search for them. Recent trainings have been provided by:

¹² Kay, Margaret J. "Best Practices in Vocational Transition Assessment for Adults with Autistic Spectrum Disorders." Presented at Penn Autism Network's 3 rd Annual Conference "Facing the Future with Optimism." March 28, 2008.

- New Mexico Autism Society;
- Behavioral Health;
- NMDOH;
- CDD;
- Navajo Nation Parent Conference ;
- UNM – Dr. Allison Reed; and
- Optum Health webcasts.

Table 8: Online Survey: Health and Wellness Needs and Priorities for Adults with Autism

Health and Wellness Issues	% of respondents rating item high in importance and low in satisfaction
5. Ability of educators, employers, and service providers to meet the individual needs of adults with autism	60.0%
8. Ability of health care providers to treat individuals with autism	54.3%
10. Availability of autism specific trainings for educators, employers, and services providers	51.4%
13. Ability of health care providers to correctly diagnose individuals with autism	48.5%

Health and Wellness Barriers

The in-depth interviews and focus groups revealed a plethora of barriers to adults with autism receiving adequate health care services. Adults with autism viewed the **vague definition of autism**, as well as **confusion surrounding its origin** as being problematic.

Policy personnel and administrators, as well as parents and adults with autism also pointed to a **lack of adequate health insurance** and **limited access to healthcare** in general as major barriers. They reported that Medicaid is only available through the waiver program to more severely affected adults with autism. Along these same lines, arguments between physical health providers and behavioral health providers regarding what should be paid and to whom it should be paid were identified as a barrier.

Focus group participants and interview participants indicated that the **shortage of health professionals who understand autism** and the **lack of training** as barriers. Policy personnel and administrators reported that the lack of doctors, including behaviorists, dentists, primary care doctors, psychiatrists, women’s health providers, and emergency room staff who understand autism makes it difficult for adults with autism to access healthcare. Interview participants pointed to the increased likelihood for compromised healthcare delivery in emergency situations due to emergency room staff’s insufficient knowledge about autism. Policy personnel and administrators expressed concerns with insufficient funding to train and recruit healthcare professionals, as well as the transferring of patients with autism between physical and behavioral modalities of treatment. Adults with autism and parents of individuals with autism echoed these

concerns. They also viewed the **close mindedness of health professionals, lack of communication between health professions, high turnover of staff and bureaucratic processes** as significant barriers.

Focus group participants also identified **HIPPA** as a barrier to adequate health care, as well as **problems with the provision of medication, high medication costs, and the promotion of drug treatments.**

Diagnosis

The online survey results indicate that 48.5% of participants rated the ability of health care providers to correctly diagnose individuals with autism as high in importance and low in satisfaction. Parents of individuals with autism and adults with autism identified several barriers to diagnosis. They include:

- There is no place to refer adults for diagnosis;
- The state's lacks the ability to provide diagnostic services to all the adults who need it;
- Long wait times to get diagnosed; and
- Bureaucratic processes which hinder many adults with autism from being able to follow through with the diagnostic process.

Health and Wellness Needs

Adults with autism, parents of individuals with autism, and policy personnel and administrators identified several health and wellness needs. They include:

- Educating health professionals (dentist, primary care physicians, women's health providers etc.) about autism;
- Creating a resource directory or referral source for health professionals and consumers;
- Providing holistic care;
- Examining the gaps in the current waiver program which don't provide for higher functioning adults;
- Providing adequate diagnosis services to adults with autism; and
- Implementing the Medical Home Model in New Mexico.

Housing

Current Situation

The results of the online survey, in-depth interviews, and focus groups illustrate a bleak housing situation for adults with autism in New Mexico. A majority of participants rated each housing issues high in importance and low in satisfaction. The rankings and percentages are presented in table 9. Policy personnel and administrators indicated that housing opportunities to live independently are only available to adults with autism who can pay for housing or who are eligible for the DD waiver. Policy personnel and administrators reported that, for this subset of the population, there is some peer mentoring in Independent Living Centers around the state that teach social skills and self-advocacy to prepare people with disabilities to live in their own housing, but it is not autism-specific. Interview participants were not aware of any best practices

being implemented in New Mexico nor were they aware of any autism-specific training currently being offered to housing personnel or supportive service providers.

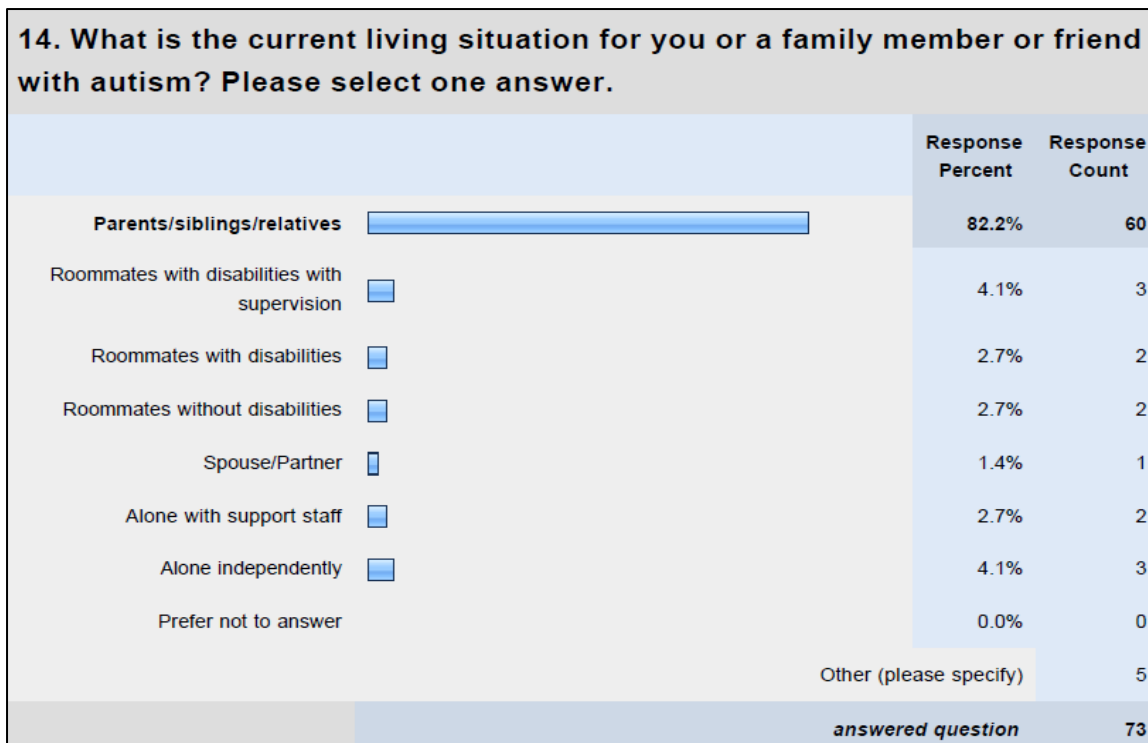
Table 9: Online Survey: Housing Needs and Priorities for Adults with Autism

Issues	% of respondents rating item high in importance and low in satisfaction
5. Ability of educators, employers, and service providers to meet the individual needs of adults with autism	60.0%
7. Availability of housing opportunities for adults with autism	56.1%
10. Availability of autism specific trainings for educators, employers, and services providers	51.4%

Current Living Situation

Survey participants were asked about the individual’s with autism current living situation and their preferred living situation. Nearly four out of five (82.2%) participants reported that the person with autism currently lives with their parents, relatives, or siblings. During the focus groups, parents of individuals with autism pointed to the problem of people with autism being **institutionalized out of state**. Parents expressed concerns about their not being a place available for their adult child with autism to live independently in New Mexico.

Chart 7: Online Survey: Current Living Situation



Preferred Living Situation

When survey participants were asked about the preferred living situation, 35.6% of participants indicated that the individual with autism preferred to live with their parents, sibling or relatives. Fifteen percent (15.1%) of participants reported that the preferred living situation is with a roommate with disabilities with supervision, 12.3% indicated that they preferred to live alone independently, and 11.0% indicated that they wished to live with a spouse or partner. In addition, 8.2% reported that they wanted to live alone with support staff, and 5.5% indicated that they wanted to live with roommates without disabilities.

Chart 8: Online Survey: Preferred Living Situation



Housing Barriers

The in-depth interviews and focus groups revealed several barriers to adults with autism accessing housing that enables them to live independently. To begin with, policy personnel identified the following barriers to housing:

- Lack of available housing;
- Long wait time for waiver services and supported housing (at least 3-5 years);
- No housing available to adults with autism who don't qualify for the waiver;
- Lack of funding to provide adequate housing; and
- Insufficient regulations to monitor slum lords.

Additionally, focus group participants identified **insufficient financial resources, lack of services in rural areas, bureaucratic processes, poorly trained service providers, and high staff turnover** as barriers to housing. Although some parents who participated in the focus group indicated they were able to purchase a house for their adult child with autism, most did not have the money to do so. Parents who live in rural areas of New Mexico stated that they felt particularly isolated from housing opportunities and supportive services. Rather than offering services in the remote areas of the state, the solution has typically been for families to migrate to more urban areas of the state. One parent was asked if she “*could move to Albuquerque*”. The lack of training and high turnover amongst staff was noted as a significant barrier to housing.

Parents over protectiveness, insufficient life skills and limited social skills were also identified as barriers to adequate housing. Focus group participants also noted **vulnerability** and **public safety** as barriers to adequate housing.

Housing Needs

Adults with autism, parents of individuals with autism, and policy personnel and administrators identified several housing needs. They include:

- Creating a plan to address the housing needs of adults with autism who:
 - don’t qualify for the DD waiver
 - are currently institutionalized out of state
 - will not have a place to live after their parents pass away
- Diversifying funding streams;
- Decreasing wait times for housing;
- Ensuring that housing opportunities are supplied with adequate supports;
- Collaborating with organizations from different priority areas to provide a seamless continuum of supports; and
- Engaging people with autism in decision making and encouraging self-advocacy.

Transportation

Current Situation

The results of the online survey, in-depth interviews, and focus groups illustrate that transportation is limited for adults with autism in New Mexico. Nearly half (48.4%) of survey respondents rated the availability of public transportation for adults with autism as high in importance and low in satisfaction. The percentage is presented in table 10. Slightly more than one-fifth (20.7%) of the survey respondents reported that the individuals with autism had participated in training on transportation.

Policy personnel and administrators reported that current collaborative efforts to enhance transportation in New Mexico are led by the NMDOH Transportation Sub-Committee. In the Albuquerque metro area, partnerships include: the Mayor’s office, Director of Transit and Bob Turner Ford. Policy personnel and administrators identified the following transportation options:

- Rail Runner;
- Albuquerque Ride;
- Sun Van;
- Gallup Express;
- Taos Chile Express;
- 50 cent taxi rides in Socorro;
- Door of Opportunity;
- Bus going through Anthony; and
- Safe Ride.

Table 10: Online Survey: Transportation Needs and Priorities for Adults with Autism

Transportation Issues	% of respondents rating item high in importance and low in satisfaction
14. Availability of public transportation for adults with autism	48.4%

It is important to note that policy personnel and administrators knowledge of transportation options beyond their geographical location was limited.

Policy personnel and administrators expressed mixed views regarding the implementation of best practices in New Mexico. One participant claimed that no best practices were currently being implemented, whereas another participant cited the Americans with Disabilities Act Standards as best practices. Policy personnel and administrators agreed that disability training is currently provided to drivers transporting people with disabilities and to the Director of Transit in Albuquerque. Yet, they indicated that the training is not autism-specific.

Transportation Barriers

The in-depth interviews and focus groups revealed several barriers to adults with autism having access to transportation. They include:

- Lack of availability;
- Unreliable transportation;
- Safety;
- Insufficient supports; and
- Individuals’ with autism sensitivity to smells.

Barriers to transportation, such as the **lack of availability**, as well as **unreliability** create challenges in other aspects of adults with autism life. Reliable transportation is needed to ensure

the person with autism can participate in work, school, recreation, self-advocacy, social groups, etc. **Safety** is also a big concern and a barrier to transportation. Parents suggested that the providing the driver with an aid, requiring background checks, and training providers and drivers might reduce risks.

Transportation Needs

Adults with autism, parents of individuals with autism, and policy personnel and administrators identified several transportation needs. They include:

- Improving statewide transportation infrastructure with particular emphasis in rural areas;
- Focusing on ensuring reliability;
- Expanding weekend coverage/bus routes;
- Improving signage, announcements, digital readouts, bus routing communications, etc.;
- Enhancing collaborative efforts between state, county and city to diversify funding and improve access to transportation in all communities throughout New Mexico;
- Engaging people with autism in decision making regarding transportation;
- Making public transportation more mainstream;
- Training adults with autism to use transportation; and
- Offering autism-specific trainings to drivers.

Recreation

Current Situation

Approximately half (49.3%) of survey participants rated the availability of recreational activities for adults with autism high in importance and low in satisfaction. The percentage is presented in table 11.

Table 11: Online Survey: Recreational Needs and Priorities for Adults with Autism

Recreational Issues	% of respondents rating item high in importance and low in satisfaction
12. Availability of recreational activities for adults with autism	49.3%

Modell and Valdez (2002) recognize the importance of recreational activities in enhancing quality of life for people with disabilities.¹³ They state:

¹³ Modell, Scott J. and Lindy A. Valdez. 2002. "Beyond Bowling Transition Planning for Students with Disabilities." *Teaching Exceptional Children*, 34(6):46-53.

From a social perspective, participation in a variety of physical and recreational activities can serve to increase enjoyment and quality of life. The social skills and relationships that are formed can have lifelong implications. People who have a variety of life experiences and can share those with others usually become more interesting companions and friends. Being able to communicate or share activities that one has been involved in can stimulate interactions and relationships off the court or field, thus adding to the quality of a person’s life.

The adults with autism who participated in the focus groups reported participating in a plethora of activities during their leisure or free time. Activities ranged from volunteer work to the arts to sports. The artwork of one focus group participant is displayed at the close of this document. A list of activities adults with autism reported participating in and/or expressed interest in are given below:

Photography	Basketball	Music
Art	Writing	Cycling
Hiking	Swimming	Exercise
Read	GRASP	Theater Group
Alone Time	Soccer	Hockey
Gardening	Construction	Community Programs
Volunteer at Residential Treatment Center	Volunteer at Planned Parenthood	Volunteer at Habitat for Humanity
Center for Self-Advocacy	Attend Sporting Events	Thrift Shopping
Surf Internet	Woodwork	Public Speaking
Work Out at the Gym	Israeli Dancing	Celeb Hound
Painting	Game Days	BBQ’s
Picnics	Movies	Camp
Volunteer with Transportation Associations	Volunteer with the Democratic Party	Volunteer at Meals on Wheel
Social Networking	Volunteer at Sierra Club	Irish Dancing

In spite of the focus group participants’ interests in an array of recreational activities, adults with autism, parents of individuals with autism, and policy personnel and administrators reported that

there are few **organized** recreational opportunities available to adults with autism. Currently, the following organizations provide some organized recreational opportunities:

- Camp Rising Sun;
- Abrazos – swimming, camping, miniature golf;
- The Center for Self-Advocacy;
- GRASP (The Global and Regional Asperger Syndrome Partnership) – “Bring your own game” day, picnics, walks, etc.; and
- Very Special Arts.

Policy personnel and administrators reported that they were not aware of best practices for serving adults. They noted that while there is best practice information available for serving children with autism, it does not extend to the adult population. Moreover, interview participants were not aware of autism specific training to recreational providers. However, they did mention that the UNM/CDD and the NMDOH offer general autism specific trainings.

Barriers to Recreational Activities

The in-depth interviews and focus groups revealed several barriers to adults with autism having access to recreation. They include:

- Lack of social and communication skills;
- Sports performance anxiety;
- Heavy supervision in group homes that limit access to recreational activities;
- Cost of activities;
- Insufficient Transportation;
- Lack of Awareness about Activities; and
- Disparate groups of people with varying capabilities.

Recreational Needs

Adults with autism, parents of individuals with autism, and policy personnel and administrators identified the following recreational needs:

- Collaborations between NMDDSD, UNM/CDD, The Center for Self-Advocacy, GRASP, Best Buddies, Very Special Arts, and the behavioral health collaborative to integrate recreational services statewide and leverage funding;
- Social skills training to help adults with autism integrate in recreational settings;
- Individualized services;
- A network of volunteers to plan informal gatherings and facilitate activities; and
- Train providers in community and recreational centers how to accommodate adults with autism.

While the focus groups participants indicated that they are interested in agencies offering organized recreational activities, they showed particular interests in **informal gatherings and activities**. Many of the participants expressed interests in participating in activities that would allow them to give back to their caregivers and other people with disabilities.

Self-Advocacy

Current Situation

The results of the online survey, in-depth interviews, and focus groups illustrate the importance of self-advocacy in ensuring access to employment, education, healthcare, housing, transportation, and recreation for adults with autism in New Mexico. Approximately two-fifths (43.8%) of the online survey respondents rated the availability of self-advocacy trainings for adults with autism high in importance and low in satisfaction.

Table 12: Online Survey: Self-Advocacy Needs and Priorities for Adults with Autism

Issues	% of respondents rating item high in importance and low in satisfaction
15. Availability of self-advocacy trainings for adults with autism	43.8%

Policy personnel, adults with autism, and parents of individuals with autism identified The Center for Self-Advocacy and GRASP as advocacy groups in New Mexico. In addition, they identified a program at the UNM Accessibility Resource Center, where 24 students with autism are learning to socialize and build self-advocacy skills.

Self-Advocacy, Advocacy, Community Building

The adults with autism who participated in the focus groups had different opinions regarding the term self-advocate. One individual noted that she viewed the term as “disabling”. Several participants stated that were more interested in advocacy and community building in general, whereas others identified themselves as self-advocates. The adults with autism who identified as self-advocates explained what self-advocacy meant to them. They recognized the importance of **banning labels** and **standing up for themselves**. The focus group participants who were interested in advocacy in general engaged in a lively discussion about what it means to “**advocate for the truth**”. They identified problems of greed and propaganda regarding media, corporations, and the medical industry. They expressed their desire to help people get in touch with people who are “educated with the truth”. Focus group participants pointed to the importance of **educating and training employers, educators, and service providers, as well people within the autism community**. They reported that since the autism spectrum is so wide ranging, many people do not understand the unique challenges people with autism (of varying functioning levels) experience.

Barriers and Needs

Interview participants reported that at the policy level, the **lack of collaboration** between NMDVR, educational institutions of higher learning, counseling offices, public school systems, etc. create barriers for adults with autism to build self-advocacy skills. Policy personnel and administrators recognize that skills cannot be generalized for people with autism; therefore, there

needs to be strong collaboration between entities which provide consistent life-long support to adults with autism.

Adults with autism identified the **lack of networking and communication** between people with autism and other disabilities, as well as **low awareness about community activities and social action** as barriers to advocacy and community building. One participant with autism mentioned that there are many resources, including media and marketing resources available to advocates. However, she reported that *“it is difficult to find the ‘people’ to participate”*. The focus group participants mentioned that there is a need to **recruit facilitators** from either inside the autism community or outside to help organize these types of activities. In addition, focus group participants with autism reported that there is a need to **create a website for mentorship** where individuals could provide and exchange individual expertise.

Social Supports

Current Situation

The results of the online survey, in-depth interviews, and focus groups illustrate the importance of social supports for adults with autism in regards to employment, education, healthcare, housing, transportation, and recreation. Half (50.0%) of the online survey respondents rated the availability of social support groups for adults with autism high in importance and low in satisfaction.

Table 13: Online Survey: Social Support Needs and Priorities for Adults with Autism

Social Support Issues	% of respondents rating item high in importance and low in satisfaction
11. Availability of social support groups for adults with autism	50.0%

Policy personnel and administrators reported that social supports are lacking for adults with autism. They indicated that in most organizations structures are formed when a need arises. However, there is typically no proactive, formal team in place ahead of time to offer social supports. In spite of this, policy personnel and administrators identified the New Mexico Autism Society, New Mexico Center for Self-Advocacy, GRASP, and the program at UNM as providing some social supports. The UNM Autism Coach reported that her program does heavy socialization at the UNM Accessibility Resource Center in order to help adults with autism develop friendships and access programs on campus within which they can become involved. Policy personnel and administrators reported that autism specific training for staff is limited. Some examples of current trainings include:

- A yearly training at UNM open to counselors, educators and parents; and
- UNM Accessibility Resource Center has provided a couple short trainings for dorm residence advisors and for the Counseling Office, but the budget would not allow for expanded training.

Several of the focus group participants who have autism reported that they find social supports through social networking.

Barriers

Policy personnel and administrators agreed that the lack of social skills amongst adults with autism creates **stereotypes**. The focus group participants with autism expressed their frustration with having to “*prove everyone wrong*” because of the stereotypes.

These stereotypes and the stress associated with it create barriers for people with autism. Policy personnel and administrators also mentioned that since skills are not generalized in people with autism, the **skills taught in K-12 do not translate into adulthood** creating barriers to integration for adults with autism. Participants also mentioned the **lack of disclosure** as a barrier to accessing supports in all settings.

Social Support Needs

In-depth interviews with policy personnel and administrators reported several needs at the systems, program and individual level. They include:

- Building and strengthening collaborations among entities, such as educational institutions of higher learning, NMDVR, public schools, business and industry, government agencies, etc. to address social supports during the transition phase and beyond;
- Building and strengthening collaborations within entities, such as between counseling offices, Special education, etc. to provide social supports;
- Engaging teaching assistants and doctoral students in the facilitation of social support groups in university settings;
- Creating a Center for Autism Spectrum Disorder as a cradle-grave, to provide infrastructure necessary to help adults with autism with each new challenge along the way;
- Developing mentoring programs for adults with autism to illuminate their true skills;
- Providing sexual education to teach adults with autism appropriate behaviors in the dating world, as well as in all social settings where males and females interact;
- Providing training to employers, educators, service providers, etc. to teach them how to recognize cues to better understand people with autism; and
- Engaging adults with autism on committees that make decision that directly impact people with disabilities.

In addition, focus group participants with autism identified the need to provide parents of individuals with autism with social support groups.

Community Supports

Current Situation

The results of the online survey, in-depth interviews, and focus groups illustrate the importance of community supports for adults with autism in regards to employment, education, healthcare, housing, transportation, and recreation. Slightly more than three-fifths (60.9%) of the online survey respondents rated the availability of community support groups for adults with autism high in importance and low in satisfaction.

Table 14: Online Survey: Community Support Needs and Priorities for Adults with Autism

Community Support Issues	% of respondents rating item high in importance and low in satisfaction
3. Availability of other community supports for adults with autism	60.9%

Policy personnel and administrators reported that the following organizations comprise the community support infrastructure in New Mexico:

- UNM/CDD;
- NMDVR;
- DD Waiver;
- NMDDPC;
- SWAN (Southwest Autism Network);
- New Mexico Center for Self-Advocacy;
- Navajo Nation Disability Council;
- Independent Living Centers;
- NM Autism Society; and
- Mandy’s Farm for Adult Women with Autism.

Policy personnel and administrators suggest that there is a disconnection between the organizations. While a few interview respondents indicated there is some collaboration between NMDDPC, NM Autism Society, UNM/CDD, and NMDVR, most participants stated there was a lack of collaboration. Moreover, policy personnel and administrators reported that most community support services are limited to the Albuquerque metro area. They also indicated that community supports, with the exception of some technical assistance and vocational services, are only available to adults with autism who qualify for the DD waiver. Policy personnel and administrators reported that to their knowledge, best practices are currently not being implemented in New Mexico. They also suggested that although there is a lot of training for educators and providers of children with autism, training for providers who serve adults is limited. Recent trainings have been provided by: UNM/CDD, SWAN, City of Albuquerque and UNM/CDD, NM Autism Society, and Optum Health.

Barriers

The in-depth interviews and focus groups revealed several barriers to adults with autism receiving adequate community supports. These barriers include:

- Lack of community services in rural areas of the state;
- Lack of accessible and reliable transportation;
- Lack of public awareness about autism;
- Cultural attitudes and perceptions;
- Language barriers;
- Segregation and isolation;
- Turnover of programs and services;
- Inability for higher functioning adults who are not on the waiver to be eligible for services; and
- Bureaucracy of the system.

The barrier that was most commonly noted in both the focus groups and in-depth interviews was the **bureaucracy of the system** and the challenges adults with autism, parents of individuals with autism, and other family members experienced when attempting to navigate the system.

Community Needs

Adults with autism, parents of individuals with autism, and policy personnel and administrators identified the following community needs:

- Build and strengthen collaboration between higher education, secondary public education, business and industry, behavioral health, etc. to provide a seamless continuum of services;
- Form a Task Force to create an authoritative Office of Autism which connects funding and all groups in a cohesive infrastructure;
- Create a central clearing house or at least a 1-800 number for consumers and professionals to access resources and to obtain reliable information about resources for adults with autism;
- Develop a common philosophy and guidelines regarding autism in New Mexico;
- Diversify funding streams;
- Increase public awareness about autism;
- Provide autism specific training to services providers, educators, employers, health professionals, law enforcement officers, public safety personnel, etc.; and
- Engage adults with autism in decisions that affect them.

Safety

Safety was initially identified as a subtopic by the Advisory Committee. However, because of the importance of the topic during this research study, it is presented in its own section. Online survey respondents reported that 43.9% of the individuals with autism had participated in training on safety. To increase safety and reduce risk, policy personnel and administrators recommended the following:

- Recognizing that adults with autism are individuals first and therefore have different needs;
- Strengthening self-advocacy skills;
- Providing adults with autism with social supports;
- Ensuring employers have zero tolerance for abuse/exploitation of employees;
- Providing autism-specific trainings to employers, educators, service providers, health care providers law enforcements, drivers, etc.; and
- Providing trainings to adults with autism about sexuality, safety, emergency situations, social networking, cell phones, using public transportation etc.

Conclusions

The New Mexico Developmental Disabilities Planning Council (DDPC) recognizes the significance of improving the lives of adults with autism in New Mexico. The DDPC's mission is to engage in advocacy, capacity building, and systemic change activities that contribute to a culturally competent and coordinated individual and family-centered and -directed, comprehensive system of community services, individualized supports and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, to be independent, to be productive and to be integrated into, and to be included in all facets of community life. In an effort to develop a New Mexico Adults with Autism State Plan, the DDPC staff contracted with Davis Innovations, Inc., a Santa Fe based organizational development firm, to identify the needs of adults with autism in New Mexico. As a part of this project, DI staff and DDPC personnel established an Advisory Committee of administrators, service providers, adults with autism, and parents of individuals with autism to provide project oversight

The Advisory Committee spent six months identifying, deliberating and considering the needs of adults with autism in New Mexico. The Committee members identified the following priority areas for the New Mexico Adults with Autism State Plan to address: Employment, Education, Health and Wellness, Housing, Transportation, Recreation, Self-Advocacy, Community Supports, and Social Groups. Training and safety needs were also identified as sub-topic areas to be explored.

Advisory Committee members helped to determine the research methodology and based on a series of discussions, it was decided that the New Mexico Adults with Autism State Plan would be informed by:

- a review of best practices;
- in-depth interviews conducted with 26 policy makers and administrators from around New Mexico;
- four focus groups facilitated with adults with autism and parents of adults with autism; and
- an online survey conducted with 86 adults with autism and their family members.

This report, entitled “The New Mexico Adults with Autism State Plan” puts forward a series of recommendations informed by best practices and the results of the research methodology. The recommendations are organized into the following categories:

- recommendations for individual providers;
- programmatic operational recommendations;
- recommendations for provider groups (i.e., educators, employers, health professionals, service providers, and public safety personnel); and
- recommendations for statewide integrated programs.

The results of the research activities that informed these recommendations were presented in the body of this report. The findings were organized into the following sections:

- Employment
- Education

- Health and Wellness
- Housing
- Transportation
- Recreation
- Self-Advocacy
- Social Groups
- Community Supports
- Safety

Recommendations

Qualitative data collected through the focus groups and in-depth interviews were transcribed and emergent themes were identified. A summary of the qualitative data, as well as quotations reflecting emergent themes are included in the results section of this plan. The adaptation of best practices, as well as the quantitative and qualitative data was used to identify the following recommendations:

A. Recommendations for Individual Providers

- i. Individualize supports for the person with autism that strongly consider his or her desires and needs as well as the family’s values and needs.
- ii. Support and teach individuals with autism to access transportation.
- iii. Teach individuals with autism about safety (social networking, sex, dating, cell phones etc.).
- iv. Provide opportunities for individuals with autism to barter services, participate in peer mentoring, share experiences, engage in advocacy, and network.
- v. Identify a process for offering advocacy for adults who have minimal or no family supports.

B. Programmatic Operational Recommendations

- i. Adopt a common philosophy that is embraced by all providers who serve adults with autism. The common philosophy shall recognize the recommendations included in this Plan.
- ii. Programs need to implement small administrative structures to support adults with autism in ways that are individualized, flexible, and responsive to individual preferences and family concerns.
- iii. Encourage collaboration and communication among organizations and between different departments within an organization.
- iv. Providers must implement practices that are evidence-based.
- v. Establish funding that is diversified and sustainable, using both public and private resources.

C. Recommendations for Provider Groups (i.e., educators, employers, health professionals, service providers, public safety personnel etc.)

- i. Providers should participate in autism specific trainings.
- ii. Providers shall recognize the individual needs of adults with autism and tailor services to the individual.
- iii. Providers should be creative when identifying post-secondary opportunities for adults with autism.
- viii. Providers shall identify goals based on the individual, needs, preferences, and skills.

D. Recommendations for Integrated Statewide Programs

- i. Organizations should work collaboratively to create and integrate a coordinated system of services. They shall collaborate and integrate services seamlessly across the areas of housing, transportation, education, employment, recreation, health care, community supports, social supports, etc.
- ii. Create a clearing house, where consumers and professionals can obtain information about autism, and autism related services.
- iii. Establish an authoritative committee or task an existing committee to bring the various organizations currently working in silos together. The committee shall work with the legislature to procure funds to better serve adults with autism.
- iv. Focus on local priorities using local teams of professionals and organizations.
- v. Conduct a study to determine the number, location and demographics of adults within autism in New Mexico.
- vi. Increase awareness about autism by providing free or low cost training to educators, employers, health professionals, service providers, public safety personnel etc. which enables them to acquire CEU's.
- vii. Be people-focused and engage adults with autism in decision making processes that impact them.
- viii. Design a plan to address the needs of adults with autism that do not qualify for the DD waiver.
- ix. Develop a plan to address the housing needs of adults with autism who don't qualify for the DD waiver, are currently institutionalized out of state, and will not have a place to live after their parents pass away.
- x. Determine a way to provide adequate diagnosis services to adults with autism in New Mexico.

Limitations

This research study included adults with autism, parents of individuals with autism, and policy personnel and administrators from agencies and organizations throughout New Mexico that service adults with autism. While participants represented people across the autism spectrum,

most of the adults with autism who participated in this study are highly functioning. Adults with autism who are lower functioning were primarily represented by their parents. Consequently, the needs, barriers, and challenges identified were not necessarily the opinions of these individuals but rather the perspectives of their parents. Moreover, the adults with autism who participated in the focus groups were not a complete representation of New Mexico's socioeconomic, cultural and ethnic diversity.

Appendices

Appendix A: New Mexico Developmental Disabilities Planning Council's Adults with Autism State Plan Advisory Committee Membership Roster

Karen Courtney-Peterson, New Mexico Developmental Disabilities Planning Council

Liz Thompson, New Mexico Adult Autism Society

Travis Goldman, New Mexico Department of Health/DDSD

Wendy Corry, Optum Health

Daniel Ekman, New Mexico Center for Self-Advocacy

Cynthia Berkheimer, New Mexico Center for Self-Advocacy

MariEllen Berkheimer, New Mexico Developmental Disabilities Planning Council

Phyllis Shingle, Center for Development and Disability Information Network

Karen Wiley, New Mexico Department of Vocational Rehabilitation

Appendix B: References

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- State of New Mexico in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs

Appendix C: Resource List

Disclaimer: The resources included below are not an exhaustive list of autism related services. Moreover, the New Mexico Developmental Disabilities Planning Council does not endorse all the organizations provided in the resource list. The list was compiled based on information collected in the focus groups and in-depth interviews.

National Autism Resources

APSE: Advancing employment Connecting People, Supported Employment Group
Telephone: 301-279-0060; <http://www.apse.org>

Autism Society of America: www.autism-society.org
1-800-328-8476

Autism Speaks: Latest research on autism and links to other sources and video glossary for what autism looks like: contact; www.autismspeaks.org
Autism Response Team: 888-288-4762

Autism Resources: Links to many resources in U.S. and worldwide www.autism-resources.com

Daniel Jordan Fiddle Foundation: grant awarding association:
Focused on adults living with ASD providing grants for diverse population of adults with ASD to participate in and contribute to community life. Contact: info@djfiddlefoundation.org

Eden Institute: www.edenservices.org; Princeton, NJ; Lifespan services for children and adults with autism. Contact: Carol Markowitz, 609-989-0099

Independent Living Resource Centers: providing information/locations of ILRC's across America, including New Mexico; www.ILRU.gov

Medline plus.gov: Help for health questions: www.medlineplus.gov

Nat'l Professional Development Center: autism spectrum disorders- every two years they look at best practices and how to implement them. Waisman Center, University of Wisconsin; www.waisman.wisc.edu; Ellen Franzone: 608-890-1410; franzone@waisman.wisc.edu

OAR: Organization for autism research (Guide for transition to adulthood including for military families getting waivers for transients, etc. contact: www.operationautismonline.org; 866-366-9710

SW Disability Law Resource Center: Answers to questions about how ADA (Americans with Disabilities Act) federal law protects people with disabilities: 800-949-4232

TEACCH: To prepare people with autism for independent living and to conduct research on all aspects of autism.
teacch@unc.edu; telephone: 919-966-2174

The Gray Center: Located in Michigan for Social learning and understanding;
www.thegraycenter.org ; Telephone: 616-748-6030

Think College: <http://thinkcollege.net> (for people with intellectual disabilities for grants)
Current information on the doors to colleges opening to people with intellectual and other developmental disabilities. Contact: Cathryn.weir@umb.edu

The Ziggurat Model: private practice located in Plano, Texas; licensed psychologists Drs. Aspy and Grossman providing assessments services and dedicated to helping families. Contact: texasautism.com; telephone: 214-227-7741

Zac Browser: Totally free internet browser providing access to games and videos developed specially for young people living with variants of ASD and can also be helpful to adults.
<http://www.zacbrowser.com>

New Mexico Resources for Adults with Autism

ABRAZAS: In Bernalillo providing family support services and recreational respite services for adults. Contact: 505-867-3396; www.abrazosnm.org

ARCA: 1103 Lomas NE, Albuquerque, Customized services for persons with developmental disabilities to live, work and enjoy rich recreational program.
Contact: 505-332-6700; www.arc-a.org

Accessibility Resource Center/UNM: Social Supports for students at University of New Mexico; Social supports for self-identified students at UNM. Contact: 505-277-3506 or website: www.arc.unm.edu

Adelante Development Center: Albuquerque, Acting as employment Agency for for persons with disabilities with support services
Contact: 505-341-7124; website: www.goadelante.org

Alamogordo Autism Support Group: contact: 575-491-3188.

Assistive Technology: Division of Vocational Rehabilitation's NMTAP and ABLE Device Loan Programs: loaning assistive technology equipment (computers/software, other assistive devices) to persons with disabilities. Contact: Julie Martinez @ 505-954-8535; website: www.nmtap.com

Autism Support Circle: Autism support group in Silver City. Contact: 575/537-5159; website: <http://www.freewebs.com/autismsupportcircle/>

BEST BUDDIES New Mexico: Albuquerque, opportunity for one-to-one friendship, integrated employment and leadership development for people with intellectual and developmental disabilities. Contact: 505-559-4227; website: www.bestbuddiesnewmexico.org

Camp Rising Sun: New Mexico's Summer Camp for Individuals with Autism Spectrum Disorders. Contact: 505-272-3000; website <http://camprisingsunnm.org/index.html>

Casa de Corazon: Taos parent support group. Contact: 505-751-7037; website <http://casadecorazon.org/>

CDD/UNM (Center for Development and Disability at University of NM): Information/referral for all facets of living: Library Svcs: 800-827-6380; **all other info: 800-552-8195; Phyllis Shingle:** pshingle@salud.unm.edu – Information Center: Info/Resources-800-552-8195; office: 505-272-8549

Center for Self-Advocacy: Albuquerque, under the auspices of the DDPC. Providing self-advocacy skills, recreation, social skills, empowerment with the goal of maximum independence. Contact: Connie DeHerrera, Center Coordinator at 505-341-0036; email: connie.deherrera.state.nm.us

Developmental Disabilities Supports Division (DDSD): NM Department of Health providing Contact: Travis Goldman, Autism Services Program Manager @ 505-795-1126

Developmental Disabilities Waiver Program: To support people with developmental disabilities with an array of services to allow people to live in their communities among family and friends. Get more info on how to apply by calling UNM/CDD at 800-552-8195, or through Parents Reaching Out at 10800-524-5176 or website: www.health.state.nm.us/ddsd

Door of Opportunity Group: Artesia, NM; providing supports to people with disabilities including adults with autism; Contact: Byron Bartley @ bbartley@doorofopp.org

Employment Networks: helping those individuals with disabilities who are receiving SSI/SSDI with customized job placement and other employment supports: For a list of EN's in New Mexico, contact: -1866-968-7842 or go to website: www.workworld.org

Goodwill: providing supported employment opportunities for persons with barriers to employment. Contact: 1-866-376-0182; web: www.goodwillnm.org

GRASP (Global and Regional Asperberger Syndrome Partnership): Albuquerque Support groups and interactive for people with autism, not for parents, to improve lives of adults and teens on the autism spectrum. Contact: 888-474-7277; www.grasp.org or 505-345-2872 for schedules.

Independent Living Centers in New Mexico: For a list of ILC's nationwide, including New Mexico with contact information, go to www.ILRU.gov

Mandy's Farm: Albuquerque, A program for women with autism.
Contact: 505-873-1187

NM Aging and Disability Resource Center: Providing statewide information and referral for programs available to persons who are elderly and/or who have disabilities: 1-800-432-2080

NM Autism Society: www.nmautismsociety.org
505-332-0306

NM Developmental Disabilities Planning Council: myriad forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, productive and integrated into all facets of the community. Call 888-779-6183 for more information about the other Divisions under the auspices of DDPC.

NM Division of Vocational Rehabilitation (DVR): Offices Statewide serving all persons with disabilities who want to work: For locations and other info call 1-800-432-4682; website: www.dvrgetsjobs.com

New Mexico Family As Faculty: This program promotes family leadership skills and professional learning opportunities for future teachers and doctors that prepare them to work in partnerships with families to improve services, systems and outcomes. Contact: 505-247-0192; website <http://parentsreachingout.org/programs/faf/>

Optum Health: providing statewide behavioral health services and training for families and community: For locations and other info: 1-866-660-7185+, TTY 800-855-2881; www.optumhealthnewmexico.com

Parents Reaching Out (PRO): Statewide family services, one stop resources: contact: 1-800-524-5176; www.parentsreachingout.org

Presbyterian Behavioral Health Programs: providing behavioral health services: contact: Hotline: 1-866-661-5491; web: www.pms-inc.org

RCI, Inc. (Realizing Confidence and Independence): Serves adults with physical, developmental or behavioral challenges. Contact: Director of Community Services, Gwendolyn Kiwauka, gwenk@rci-nm.org; or go to website: www.rci-nm.org

San Juan Center for Independence: In Farmington with satellite office in Gallup, providing information/referral, peer mentoring and independent living skills and advocacy. Contact: 877-484-4500 for more information.

Special Services Program at Eastern New Mexico University: pioneers in autism; certificate programs pre AA degree; Special services, occupational training program-1-800-243-6687 or 575-624-7286

Sun Van: Transportation for people with disabilities in Albuquerque. Contact: (505) 243-7433

SWAN (SW Autism Network): Information on SWAN trainings through UNM/CDD Center for Development and Disability. Contact: 505-272-3000

The ARC of New Mexico: 3655 Carlisle NE, Albuquerque; Advocate for persons with developmental disabilities and their families. Contact: 800-358-6493 or 505-883-4630 in Alb. ; in Anthony, call 505-882-9208

Transportation Committee of NM: under the Advisory Council for Quality Assurance at the NM Department of Health to enhance and expand transportation opportunities throughout NM. Contact: Tony Chavez @ ucanreachme35@yahoo.com

Very Special Arts: Albuquerque, dedicated to full accessibility in the arts for people of all abilities, ages, cultures and economic levels. Contact: 505-345-2872 or info@vsartsnm.org; website: www.vsartsnm.org

Appendix D: Interview Guidelines and Form

Form 1

Code (Survey # + Initials) ____

	Topic Area
Available Opportunities	
Barriers for People with Autism	
Needs	
Infrastructure (current & needed)	
Collaborations (current & needed)	
Best Practices	
Training	
Engagement of People with Autism	
Safety	

What types of [insert topic area] opportunities are currently available to adults with autism in New Mexico?

What barriers prevent adults with autism from being integrated into [insert topic area] settings?

What are the [insert topic area] needs of adults with autism in New Mexico?

What assistance/supports are needed to ensure adults with autism are effectively integrated into [insert topic area] settings?

What infrastructure is currently in place to address the [insert topic area] needs of adults with autism?

What infrastructure needs to be developed to better address the [insert topic area] needs of adults with autism?

What collaborations [private and public sector (city, county, state, and federal)] are currently in place to address the [insert topic area] needs of adults with autism?

What collaborations [private and public sector (city, county, state, and federal)] must be bridged to better address the [insert topic area] needs of adults with autism?

How are best practices regarding [insert topic area] adults with autism currently being implemented in New Mexico?

What types of autism-specific training is currently available to [insert topic area] providers and staff?

How do [insert topic area] providers and staff in New Mexico engage adults with autism in decision making processes that directly affect them?

What types of incentives are currently available to [insert topic area] providers and staff in New Mexico who hire adults with autism?

Appendix E: Focus Group Moderator Guides

FOCUS GROUP GUIDE WITH FAMILY MEMBERS

Introductions

Topic: Employment

- What types of employment opportunities are currently available to adults with autism in New Mexico?
- What barriers prevent adults with autism from being integrated into business and employment settings?
- What assistance/supports are needed to ensure adults with autism are effectively integrated into business and employment settings?

Topic: Education

- What educational and vocational opportunities are currently available to adults with autism?
- What barriers prevent adults with autism from being integrated into post-secondary educational/job training settings?
- What assistance/supports are needed to ensure adults with autism are effectively integrated into post-secondary educational/job training settings?

Topic: Health Benefits

- What are the health and wellness needs of adults with autism?
- What barriers prevent adults with autism from receiving adequate health care?
- What assistance/supports are needed to ensure adults with autism receive adequate health care?

Topic: Housing

- What types of housing are currently available to adults to autism in New Mexico? What barriers prevent adults with autism from accessing housing?
- What assistance/supports are needed to ensure adults with autism have access to housing and are able to live independently?

Topic: Transportation if there is time, we can discuss transportation and the others

- What types of travel options are currently available to adults with autism in New Mexico?
- What barriers prevent adults with autism from accessing transportation?
- What assistance/supports are needed to ensure adults with autism can access transportation?

Topic: Recreation

- What types of recreational activities are currently available to adults with autism?
- What barriers prevent adults with autism from being integrated into recreational settings?
- What assistance/supports are needed to ensure adults with autism are effectively integrated into recreational settings?

Topic: Self-Advocacy

- What self-advocacy training/support groups are currently available to adults with autism?
- What assistance does adults with autism need to help them become self-advocates?

Topic: Community Supports

- What community support services are available to adults with autism in New Mexico?
- What barriers prevent adults with autism from being integrated into community settings?
- What assistance/supports are needed to ensure adults with autism are effectively integrated into community settings?

Topic: Social Groups

- What social support groups are currently available to adults with autism in New Mexico?
- What barriers prevent adults with autism from being integrated into social settings?
- What assistance/supports are needed to ensure adults with autism are effectively integrated into social settings?

FOCUS GROUP GUIDE – SELF -ADVOCATES

Introductions (names)

1. Topic: Recreation

a. Current Status:

i. What types of recreational activities do you participate in?

1. Show visual representation of activities to stimulate discussion (i.e. bowling, gym, swimming, fishing, board games, musical instrument, art, video games, etc.)

b. Future Preferences:

i. What types of recreational activities would you like to participate in?

1. Show visual representation of activities to stimulate discussion (i.e. bowling, gym, swimming, fishing, board games, musical instrument, art, video games, etc.).

2. Topic: Employment

a. Current Status:

i. Do you have a job?

- ii. Do you work full-time, part-time or are you a volunteer? (Use white board to explain the various categories).

iii. What type of job do you have?

b. Future Preferences:

i. What type of job would you like to have?

1. Show visual representation of jobs to stimulate discussion (i.e. teacher, service job, business person, outdoor job).

ii. Would you prefer to work full-time, part-time, or be a volunteer?

3. Topic: Education

a. Current Status:

i. Have you attended university, community college, continuing education, vocational / trade school or GED training?

1. Show visual representation of various types of education to stimulate discussion (i.e. UNM, NMSU, CNM, Workforce Development, GED.)

b. Future Preferences:

i. What type(s) of education would you prefer to attend in the future?

1. Show visual representation of various types of education to stimulate discussion (i.e. UNM, NMSU, CNM, Workforce Development, GED).

ii. How would you prefer to access education?

1. Show visual representation of various ways to access education to stimulate discussion (i.e. lecturer hall, worksite, online)

4. Topic: Social Supports / Self Advocacy

a. Current Status:

i. Is anyone a self-advocate?

ii. What do you do as a self-advocate?

1. Show visual representation of various things self-advocates do (i.e. letter writing, blog, brochures, trainings).

iii. Does anyone participate in social support groups?

b. Future Preferences:

i. What are the names of the social support groups that you can join?

ii. Would you be interested in joining a social support group?

iii. Would you be interested in becoming a self-advocate?

5. Topic: Housing

a. Current Status:

i. What is your current living situation? Do you live in an apartment, house, and supportive living center?

1. Show visual representation of different types of living situations (i.e. apartment, house, supportive living center).
 - ii. Who do you live with?
 1. Show visual representation of different types of living situations (i.e. friends, family members, care giver individual living alone).
- b. Future Preferences:
 - i. What is your preferred living situation? Do you live in an apartment, house, and supportive living center?
 1. Show visual representation of different types of living situations (i.e. apartment, house, supportive living center).
 - ii. Who would you prefer to live with?
 1. Show visual representation of different types of living situations (i.e. friends, family members, care giver individual living alone).

6. Topic: Transportation

- a. Current Status:
 - i. What mode of transportation do you use?
 1. Show visual representation of different types of transportation (i.e. car, pedestrian, bike, bus, train, shuttle).
 - ii. Has anyone taught you how to use public transportation?
- b. Future Preferences:
 - i. What mode of transportation would prefer to use?
 1. Show visual representation of different types of transportation (i.e. car, pedestrian, bike, bus, train, shuttle).

7. Topic: Community Supports

- a. Current Status:
 - i. Does anyone have a mentor, coach or someone that helps you succeed at school, work or any other activity?
- b. Future Preferences:

- i. Would you want a mentor, coach or someone else to help you succeed at school, work or any other activity?
- ii. What would you like help with?

Appendix F: Online Survey Instrument

[INCLUDE IN EMAIL WITH LINK]

The New Mexico Developmental Disabilities Planning Council is in the process of developing an Adult Autism State Plan. We are seeking your input to help us identify the needs of adults with autism, as well as the gaps in New Mexico's current system. We'd greatly appreciate it if you could complete an eight minute survey. Please click on the link to begin. Thank you for your input. www.surveylink.com

[FIRST SCREEN]

Please answer the questions as honestly and completely as you can. As you begin, there are three important points to keep in mind:

- First, this is not a test. There are no 'right' or 'wrong' answers. Just try to give the answers that best show how you think or feel.
- Second, this survey is confidential. Your answers will be combined with other surveys and will never be looked at individually.
- Third, this survey is voluntary. We appreciate your participation. If there are any questions that you do not want to answer, you may check the box "*I prefer not to answer*".

[BEGIN QUESTIONS]

1. Are you personally, or is a family member or close friend of yours on the autism spectrum?

- a. Yes [Continue survey]
- b. No [Terminate survey]
- c. Prefer not to answer [Terminate survey]

2. What is your relationship with the person who has autism?

- a. I am the person who has autism
- b. Parent
- c. Grandparent
- d. Guardian
- e. Sibling
- f. Friend
- g. Other (please specify _____)
- h. Prefer not to answer

3. How old is the person who has autism?

- a. Younger than 5
- b. 5 – 10
- c. 11 – 13
- d. 14 – 17
- e. 18 – 21
- f. 22 – 45

- g. 46 – 65
- h. Over 65
- i. Prefer not to answer

4. What autism-related impairments or other characteristics does the individual on the autism spectrum experience? Please check all that apply.

- a. Severe Cognitive or Intellectual Impairment
- b. Mild Cognitive or Intellectual Impairment
- c. Some Difficulty with Speech
- d. No Speech
- e. Other Communication Difficulties
- f. Executive Functioning or Organization Skill Difficulties
- g. Social Interaction and Social Literacy Difficulties
- h. Focused Area of interest/perseveration
- i. Sensory Issues (hyper or hypo sensitivities)
- g. Self-care difficulties
- k. Physical Coordination Issues
- l. Co-existing Mental Health Issues (depression, anxiety, etc)
- m. Co-existing Medical Issues
- n. Other
- o. Prefer not to answer

5. What are the individual with autism's plans after graduating from secondary school? Please check all that apply.

- a. College/University
- b. Continuing Education
- c. Vocational Training
- e. Full Time Employment
- f. Part-Time Employment
- g. Volunteer
- h. None
- i. Other (please specify _____)
- j. Prefer not to answer

6. Has the person with autism received training on how to use public transportation?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

7. Has the person with autism received training regarding personal safety?

- a. Yes
- b. No

- c. Not sure
- d. Prefer not to answer

8. To what extent are the following issues _____ important to you? Rate each issue on a scale from “1” to “5” where “1” indicates *very important* and “5” indicates *not important*. Please put an X in the box that best describes how you feel.

	Very Important 1	2	3	4	Not Important 5	Prefer not to answer
Availability of employment opportunities for adults with autism						
Availability of post-secondary educational opportunities for adults with autism						
Availability of post-secondary vocational opportunities for adults with autism						
Availability of continuing education opportunities for adults with autism						
Availability of volunteer opportunities for adults with autism						
Ability of health care providers to correctly diagnose individuals with autism						
Ability of health care providers to treat individuals with autism						
Availability of housing opportunities for adults with autism						
Availability of public transportation for adults with autism						
Availability of recreational activities for adults with autism						
Availability of self-advocacy trainings for adults with autism						
Availability of peer mentoring opportunities for adults with autism						
Availability of social support groups for adults with autism						

	Very Important 1	2	3	4	Not Important 5	Prefer not to answer
Availability of other community supports for adults with autism						
Ability of educators, employers, and service providers to meet the individual needs of adults with autism						
Availability of autism specific trainings for educators, employers, and services providers						
Ability of the media to educate the public about the varying strengths, challenges and abilities of the adult autism community						
A coordinated system of services						

9. To what extent are you satisfied with New Mexico’s ability to address the following issues _____? Rate each issue on a scale from “1” to “5” where “1” indicates *very satisfied* and “5” indicates *not satisfied*. Please put an X in the box that best describes how you feel.

	Very Satisfied 1	2	3	4	Not Satisfied 5	Prefer not to answer
Availability of employment opportunities for adults with autism						
Availability of post-secondary educational opportunities for adults with autism						
Availability of post-secondary vocational opportunities for adults with autism						
Availability of continuing education opportunities for adults with autism						
Availability of volunteer opportunities for adults with autism						
Ability of health care providers to correctly diagnose individuals with autism						

	Very Satisfied 1	2	3	4	Not Satisfied 5	Prefer not to answer
Ability of health care providers to treat individuals with autism						
Availability of housing opportunities for adults with autism						
Availability of public transportation for adults with autism						
Availability of recreational activities for adults with autism						
Availability of self-advocacy trainings for adults with autism						
Availability of peer mentoring opportunities for adults with autism						
Availability of social support groups for adults with autism						
Availability of other community supports for adults with autism						
Ability of educators, employers, and service providers to meet the individual needs of adults with autism						
Availability of autism specific trainings for educators, employers, and services providers						
Ability of the media to educate the public about the varying strengths, challenges and abilities of the adult autism community						
A coordinated system of services						

10. What are the barriers to employment for individuals with autism? Please check all that apply.

- a. Lack of adequate transportation
- b. Difficulty getting hired
- c. Lack of training
- d. Lack of support
- e. Lack of Jobs

- f. Other (please specify: _____)
- f. Prefer not to answer

11. What additional assistance is needed for individuals with autism to obtain or maintain employment? Please check all that apply.

- a. On the job supports/job coach
- b. Increased amount of job coaching
- c. More support from employer and/or co-workers
- d. Job accommodations
- e. Other (please specify : _____)

12. What are the barriers to education for individuals with autism? Please check all that apply.

- a. Lack of adequate transportation
- b. Difficulty getting accepted
- c. Lack of training
- d. Lack of support
- e. Lack of social skills
- f. Other (please specify : _____)
- f. Prefer not to answer

13. What additional assistance is needed for individuals with autism to attend college or other types of educational institutions? Please check all that apply.

- a. Social support groups
- b. Training on how to navigate the system
- c. Training on how to be a self-advocate
- d. More support from professors/other students
- e. Special accommodations
- e. Other (please specify : _____)
- f. Prefer not to answer

14. What is the current living situation for you or a family member or friend with autism? What is the preferred living situation?

	Current Living Situation	Preferred Living Situation
Parents/Siblings/Relatives		
Roommates with Disabilities with Supervision		
Roommates with Disabilities		
Roommates without Disabilities		
Spouse/Partner		
Alone with support staff		
Alone independently		
Prefer not to answer		

15. Do you think a public awareness campaign highlighting the strengths, talents, and diversity of adults with autism would enhance opportunities for community support and participation?

- a. Yes
- b. No
- c. Not Sure
- d. Prefer not to answer

THANK YOU FOR COMPLETING THE SURVEY!



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Valery Milovic / www.brokentoyland.com.