



Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Strategic Plan Outreach Approach

Introduction

There are a number of key stakeholders that should be engaged to confirm the key needs of individuals living with autism, and to explore what areas within the existing system need to be expanded, changed, discontinued or legislated to better meet current and future needs of these individuals. There are three distinct ways in which outreach will occur to solicit stakeholder feedback. They include key informant interviews, Commission Subcommittee discussions, and consumer surveys. Each is described more fully below.

Key informant interviews

Using an initial contact list, SEI will schedule and conduct key informant interviews with stakeholders by telephone to gather insight on the strengths and challenges related to the existing system(s) for individuals with ASD. Key informant interview will be conducted by SEI and compiled into a summary report which the Strategic Planning Committee will use to identify critical issues within the service system and potential goals/actions for plan inclusion. There is an allowance for up to 15 interviews at the state and local level. Key informants will be identified and approved by the Commission with input provided by each of the Commission Subcommittees. When conducting the key informant interviews, the following protocol and questions will be used.

Introduction:

- Provide information regarding the purpose of the interview: Key Informant Interviews are being conducted to assist SEI in understanding the most pressing needs of individuals living with ASD in Nevada, how the system serves those people, and opportunities to improve that system.
- Provide purpose of Key Informant contribution: Describe why the key informant has been chosen to participate in the interview process (how they were identified, content knowledge expertise).
- Confirm Understanding: Inform the key informant that the call should last approximately 30 minutes, and ask if they have any questions regarding the process before you begin.

Draft Key Informant Interview Questions—August 2014

1. What communities and/or constituent groups related to individuals with ASD do you feel you can represent the best?
2. In those communities and constituent groups, what are the most significant needs or challenges facing people who need/use services?
3. To what extent are those needs currently being met?
4. What are the biggest gaps in services? Are there any gaps that are particularly pronounced based on region?

5. What works and what doesn't when seeking services? What are the major barriers to accessing services for people with ASD?
6. What opportunities or concerns do you think the Affordable Care Act will have on ASD services/systems in Nevada?
7. How well are programs and services coordinated across systems?
8. How well do individuals with ASD and those that care for them know about services that are available?
9. What are areas of ongoing strengths within the various systems that serve individuals with ASD in Nevada that should be maintained, expanded or leveraged in other areas?
10. What are the most critical issues that Nevada needs to address to meet the needs of people living with ASD now and in the future?
11. What policy level changes are needed to improve services for people with ASD at the local, regional, and/or state level?
12. What practical changes are needed to improve services for people with ASD at the local, regional, and/or state level?
13. Are there any other insights you would like to share at this time?

Subcommittee Discussions

Discussions will be held with each of the Commission Subcommittees; Early Childhood, Youth and Transition, Adult and Aging, and Rural Populations. The purpose of these discussions is to further gather perspectives and recommendations regarding priorities and strategies relevant to each service and geographic area. SEI will facilitate a discussion with each of the subcommittees based on a date of their choosing (discussions may be held as a component of their regularly scheduled meetings or as a separate event). There is an allowance for one discussion with each of the subcommittees in the following locations:

Early Childhood – INSERT LOCATION

Youth & Transition - INSERT LOCATION

Adults & Aging – INSERT LOCATION

Rural Populations - INSERT LOCATION

The discussions for each subcommittee will be based on the following framework. Progress made since the publication of the 2008 Autism Task Force Report will be identified as will recommendations for future action.

Early Childhood	Youth & Transition	Adults & Aging	Rural Communities
<i>Explore issues pertaining to Early Intervention, school system supports and training of teachers/aids, and parental voice in process</i>	<i>Explore issues pertaining to HS graduation rates, transition assistance, and skill development in the following areas: personal management, employment readiness and higher education access/assistance.</i>	<i>Explore issues pertaining to later-life identification, HCBS Issues (housing, employment, community engagement) and self-determination.</i>	<i>Explore barriers to care specifically due to geographical limitations.</i>

Consumer Surveys

A statewide survey will be issued to consumers, family members, care providers, and advocates to solicit input regarding the strengths and weaknesses of the current system as well as their suggested solutions for any identified deficiencies. It will be available in English and Spanish for the public and distributed through service providers identified by the Commission Steering Committee. It will be available electronically and in hard copy in both languages.

The purpose of the survey is to collect anonymous feedback from individuals living with ASD across the state. Participation is voluntary.

The draft survey is found on the following pages.



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We are collecting information to help the state understand what kind of services are needed to support Nevada residents with Autism Spectrum Disorder (ASD). We are also trying to identify what prevents people who need assistance from getting the help they require.

All responses will remain anonymous. If you would like to take this survey online, please go to: [insert link](#)

RESPONDENT PROFILE QUESTIONS

1. What is your gender?

- Male Female

2. What is your age?

- 0-12 25-44
 13-17 45-64
 18-20 65-74
 21-24 75+

3. What is your race/ethnicity?

- White
 Hispanic
 Black/African American
 American Indian/Alaskan
 Pacific Islander
 Asian
 Mixed Race
 Other

4. What county do you live in?

- Carson City Lincoln
 Churchill Lyon
 Clark Mineral
 Douglas Nye
 Elko Pershing
 Esmeralda Storey
 Eureka Washoe
 Humboldt White Pine
 Lander

5. Do you currently or have you ever received services because of an autism diagnosis?

- Yes No

If you answered yes, please indicate below which agencies you have received ASD services through (check all that apply).

- NV Early intervention Services
 NV Division of Public and Behavioral Health
 NV Division of Health Care Financing & Policy
 School System Supports (IEP, Behavioral Interventionist, etc.)
 Autism Treatment Assistance Program
 Regional Center
 Vocational Rehabilitation

6. Which of the following best describes you?

- Current consumer of ASD services
 Former consumer of ASD services
 Friend/family member of someone with ASD
 Parent of a child with ASD, currently receiving services
 Parent of a child with ASD, no longer receiving services
 Someone in need of ASD services but not currently receiving them
 Not sure

SURVEY QUESTIONS

1. There are a variety of services that are provided to individuals with ASD. Please indicate which of the following type of services you or someone you know have used and the extent to which it served your/their needs.

Type of Services Used	Have you used this service?		If you answered yes, please indicate to what extent you believe the level of care received was sufficient to meet the need?			
	No	Yes	Always met my needs	Usually met my needs	Sometimes met my needs	Never met my needs
INSERT						
INSERT						
INSERT						
INSERT						
INSERT						
INSERT						
INSERT						
INSERT						
INSERT						

2. There are a number of reasons that people may not receive the assistance they need. We want to understand why people who need services may not be able to access care. Please indicate which of the following you believe prevents you or other people from accessing services and the severity of the issue.

Barriers to Services	Is this an issue?		If you answered yes, please indicate to what extent you believe this issue prevents you/others from accessing care.			
	No	Yes	Big Problem	Medium Problem	Little Problem	Isolated Issue
No local services available						
Lack of transportation						
Lack of medical insurance						
Insurance doesn't cover treatment						
Cost prohibitive						
Long wait lists						
Not enough services available						
Not enough service providers						
Don't know where to get help						
Service providers are rude						

SURVEY QUESTIONS

3. How significant of an issue is services to individuals with ASD in your community?

- This is a big issue – there are a lot of needs that remain unaddressed
- This is a moderate issue – there are ongoing needs, but services are available
- This is a minor issue – there are system improvements needed, but they are minor and do not affect the critical health or quality of life for individuals with ASD.
- This is not an issue – services being provided are sufficient to meet the needs of people.

4. On a scale of 1-10, how well do you think the current system responds to your needs or the needs of someone you know with ASD?

- | | |
|--|---|
| <input type="checkbox"/> 1 – Responds in the best way possible | <input type="checkbox"/> 6 |
| <input type="checkbox"/> 2 | <input type="checkbox"/> 7 |
| <input type="checkbox"/> 3 | <input type="checkbox"/> 8 |
| <input type="checkbox"/> 4 | <input type="checkbox"/> 9 |
| <input type="checkbox"/> 5 | <input type="checkbox"/> 10- Responds in the worst way possible |

5. What do you think the state should focus on to address the needs of people with ASD? Please list them in order of importance.

Most important issue to address for people with ASD:

Second most important issue to address for people with ASD:

Third most important issue to address for people with ASD:

6. It is important for us to understand unique family experiences of individuals who live with ASD. Please provide us with an experience that you have had as someone with ASD, or as someone who cares for someone with ASD that will help us describe living with ASD in Nevada.

Thank you for taking the time to complete this survey. Your input is valuable and appreciated!