



Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Strategic Plan Outreach Approach

Revised 8-11-14

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.

- ❖ Need to approve final set of questions and establish how we will identify Key Stakeholders to interview.

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. Does your organization use Medicaid to fund services? If the answer is yes, can you give me a brief description of what and how you provide those services?
8. How well are programs and services coordinated across systems?
9. Where do you transition clients to after they have received ASD services from your agency and have aged out?
10. How well do individuals with ASD and those that care for them know about services that are available? What does your organization do to educate parents to services available?
11. 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?
12. 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?
13. What policy level changes are needed to improve services for people with ASD at the local, regional, and/or state level?
14. What practical changes are needed to improve services for people with ASD at the local, regional, and/or state level?
15. Are you aware of a project or approach that is occurring successfully in another state/location that should be considered for implementation in Nevada?
16. 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>

❖ Need to identify date for each Subcommittee Discussion.

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.

❖ Need to approve tool and determine when it will be distributed.



Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

We are collecting information from individuals across the state living with Autism Spectrum Disorder (consumers, family members, care providers, and advocates) 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

Please answer the following questions to help us understand who you are representing as you complete this survey.

1. Which of the following best describes you?

(check all that apply)

- 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
- Advocate for individuals living with ASD
- Someone in need of ASD services but not currently receiving them
- Not sure

2. At what age were you or the person that you care for identified as having an Autism Spectrum Disorder?

Please answer the following questions, as they relate to yourself.

3. What is your gender?

- Male
- Female

4. What is your age?

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

5. What is your race/ethnicity?

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

6. What County do you live in?

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

SURVEY QUESTIONS

<p>7. We are trying to understand the greatest needs of people who are living with ASD in Nevada. Can you please provide us with the 3 most pressing needs that you or the person you know with ASD has?</p>
<p>a.</p>
<p>b.</p>
<p>c.</p>
<p>8. Can you please share with us what your 3 most pressing concerns/worries are for yourself (as someone living with ASD) or for the person you know living with ASD? The may be current concerns or concerns in the future.</p>
<p>a.</p>
<p>b.</p>
<p>c.</p>
<p>9. Can you please tell us what is working well for you (as someone living with ASD), or for the person you know living with ASD?</p>
<p> </p>

<p>10. 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, treatments and/or supports and the severity of the issue.</p>						
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 needed services/treatment						
Cost prohibitive						
Long wait lists						
Not enough services available						
Not enough service providers						
Don't know where to get help						
Behavioral Issues						
Service providers are not well informed						
Service providers are rude						

SURVEY QUESTIONS

11. 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.

12. 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 |

13. 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:

14. 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!