

Iowa's System of Care for Children and Youth with Autism Spectrum Disorder

Summary of Findings from the 2013 Statewide Needs Assessment

Conducted by the

Regional Autism Assistance Program

Child Health Specialty Clinics, Division of Child and Community Health

The University of Iowa

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Bureau/Division of Student and Family Support Services

The findings presented in this report were obtained from the statewide needs assessment conducted in two separate phases between April and September 2013. The following report compiles results from both phases and complements other needs assessments conducted by the Iowa Department of Education, the Iowa Autism Council, and others interested in improving the statewide system of care for children and youth with an Autism Spectrum Disorder (ASD) and their families. Building on the capital strengths, collaborative efforts, and existing relationships will assist in advancing Iowa's ASD system of care.

This report is dedicated to Sue Baker (1951 – 2014).

Sue Baker was an Autism Consultant with the Regional Autism Services Program for the state of Iowa for over 20 years. Sue was a long-time advocate and educator who worked tirelessly on advancing Iowa's system of care for children and youth with Autism Spectrum Disorder (ASD). Many of the strengths noted in the current ASD system of care, as well as ideas generated for future efforts, can be attributed to Sue's passionate vision for providing optimum services for children with ASD and their families.

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INTRODUCTION

The prevalence of Autism Spectrum Disorder (ASD) is on the rise. According to a report released from the Center for Disease Control and Prevention on March 27, 2014, 1 in 68 children have an ASD.¹ This new estimate is significant and supports the urgent need for Iowans to have access to effective interventions and additional programs to support children with ASD and their families.

In May 2013, the Regional Autism Assistance Program (RAP) with Child Health Specialty Clinics (CHSC), Division of Child and Community Health at The University of Iowa, began conducting a statewide needs assessment to obtain a comprehensive view of the current system of care for Iowa's children and youth with an Autism Spectrum Disorder (ASD) and their families.² This assessment was in response to a contractual agreement funded by the State of Iowa Department of Education, Bureau/Division of Student and Family Support Services. *Iowa's System of Care for Children and Youth with Autism Spectrum Disorder: Summary of Findings from the 2013 Statewide Needs Assessment* is an executive summary of the findings of this project.

This needs assessment was conducted using two phases of interviews. Phase I occurred between April – June 2013 and included interviews with four overall categories of stakeholder³ groups representing 20 different organizations. Phase II occurred between July – September 2013 and included interviews with 11 groups representing 32 different organizations. In total, 15 groups were interviewed, representing 52 organizations. The groups selected to be interviewed were from intersecting service systems and included representation from the health, education, and human services systems from both public and private funding sources. These groups were targeted to achieve a comprehensive view of the current system of care for Iowa's children and youth with an ASD and their families.

It is important to note that the increasing incidence and visibility of Autism Spectrum Disorder (ASD) has led to a number of statewide efforts to improve services for children and youth with ASD, and that Iowa's current infrastructure and system of care for children with ASD and their families has several strong areas upon which to build. The results from this needs assessment is not meant to criticize previous efforts within the ASD system of care; rather, it is to highlight the strengths of the current system while considering ways to advance Iowa's current system of care for children and youth with ASD and their families.

¹ Center for Disease Control and Prevention (CDC). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010, March 28, 2014 / 63(SS02);1-21.

² Throughout this document, we use the term “families” rather than “parents” to reflect the unique structure of many families today.

³ The term “stakeholder” in the context of this document refers to a person, group or organization that has an interest or concern in Autism Spectrum Disorder (ASD).

METHODOLOGY

The method used to determine the current needs, strengths, and opportunities across Iowa's ASD system of care was qualitative interviews conducted via teleconferencing calls (see Attachment 1 for a more detailed methodology).

The Regional Autism Assistance Program (RAP) staff identified major groups of stakeholders who influence all aspects of the ASD system of care. These stakeholder groups were selected from intersecting service systems, both publicly and privately funded, and included the health, education, and human services systems. Emphasis was placed on collecting input from families at all levels of these service systems. After groups were created, key informants from each broad category were identified and invited to participate.

The Title V of the Social Security Act Index (Index) provided the organizational structure for the needs assessment questions. The Index was developed by the National Initiative for Children's Healthcare Quality (NICHQ) and is a tool widely used by state Title V programs to assess systems of care for children and youth with special healthcare needs (see Attachment 2 for the NICHQ tool). The NICHQ Title V Index has six strategic areas:

- 1) Strategic Leadership
- 2) Partnerships across Public and Private Sectors
- 3) Quality Improvement
- 4) Use of Available Resources
- 5) Coordination of Service Delivery
- 6) Data Infrastructure

Two additional strategic areas were added based on information contained in a 2011 brief from the Association of Maternal and Child Health Programs:⁴

- 7) Family Participation
- 8) Outreach and Awareness

The interview tool was finalized and invitations, along with a copy of the interview questions, were emailed to the groups asking them to participate in an interview. The questions used for the interviews were organized within the above eight strategic areas (see Attachment 3 for the sample question set). Responses from stakeholder groups were not scored or graded by the assessment team. Responses were recorded as given to use for the data collection portion of this study and to obtain an overview from stakeholders' perspectives. Fifty-two (52) organizations were interviewed during this statewide needs assessment survey (see Attachment 4 for complete listing of groups interviewed).

⁴ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *Roles for State Title V Programs: Building Systems of Care for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities*. October 2011.

The interview process consisted of teleconferenced meetings between two members from the CHSC RAP study team and each interview group. One member of the RAP study team asked the interview questions while the other captured the notes. The interviewees were encouraged to assemble other staff members to join the meeting in order to obtain a variety of perspectives and expertise. The interviews were recorded to verify that the responses were accurately captured. Each interview was completed between the timeframe of 45 minutes to 1 hour and 45 minutes.

One limitation of this study was the varying sample sizes of the different interview groups. Although the RAP study team sampled many different geographic regions and interview groups in order to identify similar themes between responses, the sample sizes from respective stakeholder groups varied depending on availability of key respondents. Another limitation of this study included the varying skillsets of the interviewers. For example, the interviewees were not always probed for additional information or clarification of responses due to these variations in skillsets.

SUMMARY OF FINDINGS

STRATEGIC LEADERSHIP

Strategic Leadership refers to an organizational body designated to providing a strategic plan that addresses all aspects of services for individuals with an Autism Spectrum Disorder (ASD). The majority of organizations interviewed expressed the need for such leadership and expressed desire for a strategic plan covering all aspects of ASD including: medical, dental, education, treatments/ interventions, vocational rehabilitation programs, institutions of higher learning, family organizations and other organizations that impact individuals with ASD and their families. This organizational body should involve all entities serving those with ASD. The organization must have authority to set standards, and provide oversight and compliance with regulations. Interviewees recognized this is not only necessary, but essential for the realization of best practice services.

The agencies most frequently identified as contributing to Iowa’s strategic planning for ASD were: The University of Iowa’s Autism Center, Child Health Specialty Clinics (CHSC), The University of Iowa’s Center for Disabilities and Development (CDD), Iowa Department of Education, Medicaid, Iowa Department of Human Services, Iowa Legislature, Vocational Rehabilitation, Disability Rights Iowa, Iowa Autism Council, and Area Education Agencies (AEAs).

All interviewees had various suggestions for what elements should be included in a strategic plan for Iowa. The most common need identified was better communication between families, providers, and service agencies. Another frequent need identified by interviewees to be included in a strategic plan was the development of a resource guide. It was recommended by some interviewees that this resource guide be managed and maintained by one organizational body.

Several interviewees emphasized the important role of families throughout the system of care and gaining family “buy in” early in the process, including obtaining family input on perceived outcomes of treatments. Many interviewees suggested having families serve in leadership roles for the strategic planning process.

PARTNERSHIPS ACROSS PUBLIC AND PRIVATE SECTORS

Establishing effective and collaborative partnerships across public and private sectors, including state and local agencies and community-based programs, is essential for maximizing efforts, increasing efficiency, and expanding services to support a comprehensive system of care. There are several opportunities for extensive collaboration between and among organizations. Many partnerships described by interviewees were developed because one organization recognized the importance of this collaboration and worked to make it happen. Many interviewees described how partnerships were formed to share the cost of a speaker or training

program. A few interviewees mentioned that it is a challenge not having a statewide strategic plan outlining or defining partnerships, or that provides guidance to agencies on how to build and maintain those partnerships.

There was a consensus among the Directors of Special Education in recognizing the established partnerships between local school districts and the Area Education Agencies (AEAs). Many school districts interviewed for this needs assessment reported a number of quality trainings related to ASD that are, or have been, provided by their respective AEA. All school districts interviewed recognized the value in training para-educators since these individuals often spend the most one-on-one time with students.

Although the interviewees appreciate the ASD trainings offered by AEAs, all respondents emphasized the need for more ASD training opportunities for teachers, para-educators, families, and service providers.

QUALITY IMPROVEMENT

Quality improvement (QI) refers to the systematic and continuous actions that lead to measurable improvement in services and outcomes for individuals with ASD. Developing guidelines and standards, as well as continually improving services, requires collaborative efforts among state programs, families, communities, clinicians and others at the state and local level; therefore, dedicated and consistent QI efforts across all service sectors are essential elements of a quality system of care for children and youth with ASD and their families.

This study illuminated a variety of QI efforts being done statewide, but most groups lacked ongoing and dedicated improvement programming. While some interviewees described relatively high-level QI programs, a common theme identified within these same groups were that follow-up and collaborative procedures with schools, families, or other service agencies are not consistent.

While many interviewees mentioned QI activities from their individual agencies, coordinated statewide QI approaches were not identified. Some of the successful QI elements mentioned included team-based consultations and communication, and sharing evidence-based practices. Other themes described by most of the interviewees included QI methods using simpler tools, such as feedback and satisfaction surveys from patients and families.

While a dedicated QI team can better measure outcomes for families, every agency that was interviewed responded that they are unable to support one. Interviewees suggested that coordination and sharing efforts between agencies could promote and sustain QI, but coordination with other agencies is difficult without standard practices and protocols. Common obstacles mentioned several times by interviewees on why their agency was unable to maintain a dedicated QI team were the lack of: 1) financial resources, 2) well-trained QI staff, and 3) knowledge on how to collect data.

USE OF AVAILABLE RESOURCES

Linking and leveraging resources in a fragmented system is a challenging but necessary task to ensure access to needed services. Resources may include funding, services, or access to information. Some of the utilized resources that were identified by respondents across the state include: Autism Resource Teams and Challenging Behavior Teams available in most AEAs, the Early ACCESS service providers, private service providers, and expert faculty and staff from the UIHC – CDD. However, a common theme identified throughout the needs assessment is the lack of accessible ASD resources across the state. All interviewees expressed concern with the gap in resources available for rural families when compared to resources available for urban families.

Another concern mentioned by multiple interviewees was the long wait times to see a diagnostic provider. Because of the limited number of diagnosticians in Iowa, families often have to wait many months from the time of referral to receiving a diagnostic evaluation.

Many of the family groups interviewed expressed the need for more information on strategies for teaching based on evidence-based research, and for more information on Applied Behavior Analysis. Increased accessibility for intervention services, such as the number of Applied Behavior Analysis (ABA) providers in Iowa, was also mentioned as a need by most interviewees.

There is concern among many of the families and professionals interviewed with regard to the lack of funding for ASD services. Many interviewees expressed concern with the varying insurance coverage policies related to ASD services. Some interviewees stated the need for an ASD-specific waiver. Themes repeated several times by families of older children were on the overall lack of resources for adults, including transitional services and vocational resources.

Most family groups interviewed mentioned the confusion families have with regard to the Waivers and Individualized Education Plans (IEPs). The interviewees expressed need for additional training opportunities for families and service providers in both of these areas.

A few interviewees identified the need for dedicated resources for training healthcare providers on evidence-based ASD screening and assessment tools.

COORDINATION OF SERVICE DELIVERY

Care coordination, access to a medical home, and family-centered and culturally competent services are considered key elements of coordinated services for children and youth with ASD. However, fragmentation of these services presents one of the biggest service delivery challenges for a range of human service delivery systems, including the ASD community. As different functions of services become fragmented or siloed into distinct service categories, clients fall through the cracks of the system because the connections between services are either absent or problematic. As a result, human service agencies are encouraged to ‘coordinate’ their services with one another under the assumption that collaborative activity can facilitate access to services, reduce unnecessary duplication of effort, and produce a more effective and efficient social service system. This section, therefore, served to assess how well agencies across the state

engage in a process of exchanging needed resources, and adjust in response to one another to accomplish shared tasks or goals.

Many respondents stated that although coordination of care is considered the gold standard, there are not consistent resources in place for providing this service to families. Many groups interviewed indicated that information that is shared is not always consistent or timely.

Many interviewees also indicated the need for standardized guidelines for transitional planning. Most indicated that a state-level entity should lead in the development for transitional guidelines with input from all agencies and partners. The need for transition planning was emphasized throughout the needs assessment. In addition to transition planning, many interviewees expressed the need for more supports for adults with ASD in their communities.

Several family advocacy organizations interviewed expressed concern with many physicians' discomfort in making an ASD diagnosis. This concern was also expressed by physicians. However, physicians also expressed concern with unnecessarily labeling a child with an ASD diagnosis. The interviewees from family advocacy organizations fear that a delay in the diagnostic process may contribute to children not receiving the most appropriate intervention services as early as possible.

The medical and diagnostic providers interviewed for this needs assessment felt their staff were up-to-date on ASD research and the recommended best practices. Some groups agreed that it would be valuable for families to receive the same training that the medical and educational professionals receive to assure consistency between interventions and best practice approaches.

DATA INFRASTRUCTURE

One of the most challenging aspects to achieving a statewide system of care is establishing some type of shared measurement—the use of a common set of measures to monitor performance, track progress toward goals, and learn what is or is not working. In order to develop and move a coordinated system forward, all sectors need to be in agreement with identified goals and how those goals are to be measured, establishing some type of shared data.

Incomplete data on the numbers, functional level and location of children and youth with ASD in Iowa continue to frustrate efforts to accurately conduct comprehensive needs assessments and develop appropriate systems of care for this population. Interviewees identified the strong need for accurate data to complete such quantitative information about individuals with ASD in Iowa and that having accessible data would benefit future program planning. However, many mentioned that there is a lack of coordinated or shared databases which interferes with effectively accessing such data across the state.

Another concern expressed by most interviewees was that in the education field, Iowa is considered a non-categorical state. Students are evaluated to determine if they are eligible for special education services, but a specific label of disability is not required. Many interviewees stated that this contributes to the difficulty of obtaining objective data regarding prevalence rates of ASD, as well as other information regarding what services individuals with ASD are or are

not receiving. This lack of objective data also impacts the ability to examine the effectiveness and impact of evidence-based interventions.

FAMILY PARTICIPATION

Research shows that greater family engagement improves children's outcomes. Parents of children and young people with ASD care passionately about the services they receive, whether agencies are working together and most of all whether the needs of their child are truly being met. By engaging families and encouraging family participation, we can draw on parents' expertise and knowledge about their children, achieve family-centered services, create more responsive/effective services, and develop good working relationships across settings. There needs to be a continuous partnership between family, school and community to ensure that children with ASD continue to learn and grow.

Several examples of family participation and engagement were identified in this assessment. Several family groups interviewed recalled how others had supported them when they first became part of the ASD network. Nearly all of the family groups interviewed have advisory boards with family member representation. Most family advocacy groups interviewed report being active in training families on the political process and how to write and talk with their legislative leaders. The interviewees also stated that many families are extremely vested in advocacy. Interviewees noted countless examples of parents spending time, effort and money to help their children and others.

The Department of Education and Area Education Agency (AEA) representatives interviewed for this needs assessment noted that a large part of their efforts are dedicated to empowering families in the education of their children.

All groups interviewed agreed there needs to be more outreach to Iowa's culturally diverse families. Of the respondents interviewed, a small number of interviewees were familiar with specific cultural competency programs or other activities offered that assure families from diverse backgrounds are appropriately served. Although few interviewees were familiar with these types of programs, all of the groups acknowledged the need to provide culturally competent services.

Another result from this needs assessment identified gaps in services for Iowa's military families. Most of the interviewees who participated in this needs assessment could not identify one program that reaches out to military families of children with ASD. Although Iowa does not have a military base, there are military families who are serving and living in Iowa. All interviewees recognized that military families have their own set of unique needs.

OUTREACH AND AWARENESS

Outreach and awareness efforts are activities used to educate and raise awareness of ASD as well as increase knowledge of existing, accessible resources and services within communities. Some examples of outreach and awareness activities for ASD provided by some of the interviewees included: participating in local community events, such as an ASD walk; promoting early screening of ASD by posting resources on websites; offering workshops to educators; and participating in technical assistance activities with respective training directors.

Most interviewees agreed that more outreach and awareness efforts are needed. Although most interviewees reported having small budgets for marketing and outreach efforts, all interviewees recognized the benefit to families and communities by having staff attend outreach activities. Many interviewees described relying on other organizations to raise awareness of ASD and promote early screening/detection.

Attachment 1: Detailed Methodology

A qualitative method was used in both Phase 1 and Phase 2 of the needs assessment to determine the current strengths, needs, and opportunities across Iowa's ASD system of care. Regional Autism Assistance Program (RAP) staff first identified the major categories of stakeholders who influence all aspects of the ASD system of care. Stakeholder groups were selected from intersecting service systems, both publicly and privately funded, and included the health, education, and human services systems. Emphasis was placed on collecting input from families at all levels of the service system. After the major categories were created, key informants from each broad category were identified and invited to participate. The RAP study team sampled from as many different geographic regions as possible in order to identify themes in similarities and differences between responses within like groups.

The questions used for the interviews were organized within the topic areas. An interviewing tool was finalized. Copies of the interview questions were e-mailed to the stakeholders inviting them to participate in an interview. Responses from stakeholder groups were not scored or graded by the assessment team. Responses were recorded, as given, to use for the data collection portion of this study and to obtain an overview from stakeholders' perspectives.

The interview process consisted of teleconferenced meetings with two members from the CHSC team meeting with each stakeholder group. One member of the CHSC team asked the interview questions, the other took notes. Interviewees were encouraged to assemble other staff members to join the meeting in order to obtain the maximum perspectives and expertise. The interviews were recorded to verify responses were accurately noted. Each interview was completed between the timeframe of 45 minutes to 1 hour and 45 minutes.

After all interviews were conducted, team members compiled the responses for the overall categories (e.g. Iowa Family Advocacy Groups, Area Education Agencies, Medical and Diagnostic Providers, and Iowa Department of Education). RAP team members analyzed the responses to identify themes within each of the eight strategic system of care areas and across the organizations within each category. Data from the first four groups were then analyzed and themes were identified.

A limitation of this study included the varying sample sizes of the different interview groups. Although the RAP study team sampled from many different geographic regions and interview groups in order to identify similar themes between responses, the sample sizes from respective stakeholder groups varied depending on availability of key respondents. Another limitation of this study included the varying skillsets of the interviewers. For example, the interviewees were not always probed for additional information or clarification of responses due to these variations in skillsets.

Attachment 2: NICHQ Title V Index

| Preparation | Preliminary action steps | Implementation | Mastery | Sustainability |
|---|--|--|--|---|
| 1. Strategic leadership <p>A strategic plan for the Title V program has been established.</p> | <p>The strategic plan has been shared and communicated across the Title V program.</p> | <p>The will and trust for realizing the strategic plan has been established within the Title V program and key stakeholders and partners.</p> | <p>The strategic plan is embedded within the Title V program. A number of goals associated with the strategic plan have been achieved and long term plans for sustaining these achievements are being developed.</p> | <p>Goals associated with the strategic plan are met consistently. Lessons learned are shared and acted on across the Title V program in an environment of mutual trust. Plans for the long term sustainability of the goals are being executed.</p> |
| 2. Partnerships across public and private sectors: <p>The Title V program strategic plan includes areas that are specific to partnerships across public and private sectors/constituency.</p> | <p>Key public and private sector constituencies have been identified and initial relationships have been established.</p> | <p>A number of programs have begun to partner effectively with key public and private sector constituencies.</p> | <p>A number of targets in the Title V strategic plan have been met in partnership with key public and private sector constituencies.</p> | <p>Partnerships with key public and private sector constituencies have been sustained and have led to the realization of relevant targets in the Title V program strategic plan.</p> |
| 3. Quality Improvement: <p>The Title V program strategic plan includes areas that are specific to quality improvement.</p> | <p>The quality improvement strategic plan has been shared and communicated across key stakeholders and partners</p> | <p>A number of quality improvement projects, in partnership with key stakeholders, partners and families are underway.</p> | <p>A number of quality improvement projects, in partnership with key stakeholders, partners and families have achieved positive results.</p> | <p>Quality improvement is embedded in all programs and process. Sustained results have been achieved. Lessons learned are consistently shared across key stakeholders, partners and families.</p> |
| 4. Use of available resources: <p>The Title V program understands the need to maximize the use of available resources.</p> | <p>The Title V program is cognizant of available resources, including financial, personnel skill sets and knowledge systems.</p> | <p>Are actively engaged in maximizing productivity in some system of care areas by directly or indirectly influencing available resources.</p> | <p>Has achieved some success in achieving targets by directly or indirectly influencing available resources effectively.</p> | <p>Available resources are consistently levered so as to maximize the likelihood that the targets associated with the overall strategic plan are achieved.</p> |
| 5. Coordination of service delivery: <p>The Title V program strategic plan includes areas that are specific to service coordination.</p> | <p>Have identified where there are gaps in the provision and coordination of services.</p> | <p>Plans are in place to reduce gaps in the provision and coordination of services.</p> | <p>Some success has been achieved in reducing gaps in the provision and coordination of services.</p> | <p>Rapid improvements in service and coordination are consistently realized in partnership with key stakeholders and families to remove these.</p> |
| 6. Data Infrastructure: <p>The Title V program strategic plan includes areas that are specific to data infrastructure.</p> | <p>The need to establish effective data systems has been communicated across key stakeholders and partners.</p> | <p>A number of data systems have been established.</p> | <p>A number of data systems exist and are routinely used to share system of care performance information across key partners and stakeholders.</p> | <p>Information of the whole system of care is shared routinely across key partners and stakeholders in a manner that informs the knowledge and actions required to meet the targets of the overall strategic plan of the Title V program.</p> |

This Index was developed by NICHQ as part of the Learning Collaborative, "Improving the System of Care for Children and Youth with Special Healthcare Needs"

Attachment 3: Sample Interview Form and Question Set

Questions varied depending on group being interviewed

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| Family Participation | Describe how your organization empowers parents to be leaders. |
| | In what ways does your agency support and expand the network of families with ASD? |
| | If not already discussed, does your organization <u>fund</u> parent involvement and initiatives? If yes, please describe. |
| | What activities does your organization conduct to develop and maintain family involvement? |
| | In what ways to you try to reach military families? |
| | In what ways does your agency identify opportunities for parent to communicate with legislators or other policy makers to affect policy change? |
| | In what ways does your agency <u>develop</u> resource materials for families? |
| | In what ways do you <u>deliver</u> resource materials to families? |
| Building Partnerships Across Public and Private Sectors | Describe how your organization partners with other agencies to conduct trainings or staff development? |
| | Describe other ways your agency partners with other support groups and agencies both public and private. |
| Overall Leadership in the System of Care | What do you perceive to be the "strategic plan" for children/youth with ASD in Iowa? |
| | What entity is responsible for accomplishing the strategic plan? |
| | How does your organization interface with that strategic plan? |
| | How is progress on the strategic plan monitored? |
| | Do you have suggestions on how strategic planning might be improved for children and youth with ASD? |
| Quality Improvement | Do you feel Iowa has adequate guidelines or standards written for the care of children with ASD (e.g. for screening; for services to the child)? Why or why not? |
| | Do these guidelines have any compliance/enforcement mechanisms attached? |
| | Where are there still <u>gaps/needs</u> in the service system? |
| | What trainings are you aware of that are effective or need updating? |
| | What trainings are still needed? |

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| Use of Available Resources | Do parents in your organization have access to resources for care and waiver services to meet their needs? |
| | Do parents have access to diagnostic services? |
| | Do parents have access to therapies in crisis times? |
| | Do you feel that resources for families with children with ASD are well coordinated among providers and agencies? |
| | If not, what can be done to improve coordination among agencies? |
| | What do you feel can be done to reduce gaps in resources? |
| Coordination of Service Delivery | Do the families served by your organization typically have access to care coordination services? |
| | If yes, who provides the care coordination services? |
| | Do primary care practices provide any care coordination services to families served by your organization? |
| Data Infrastructure | Does your organization collect data on parent satisfaction with communicative events, trainings provided or other performance related data? Please describe. |
| | Does your organization/organization's strategic plan require any data gathering? |
| | Do any families in your organization belong to other state level ASD/CHSCN organization?(to help determine % of parents involved at state level organizations) |
| | Do you collect data regarding the number of families who attend chapter events across the state? |
| | Do you collect data regarding the number of families who attend conference events? |
| | Tell us about the breakdown of parents versus professional on your advisory board? |
| | Does your organization share data across other groups? If yes, in what ways? |
| Outreach and Awareness | Please describe any activities your organization conducts to raise awareness of Autism Spectrum Disorder? |

Attachment 4: Organizations Participating in the Needs Assessment – Phase 1

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|--|--|
| <p>Family Advocacy Groups Autism Society of Iowa (ASI) Board ASI - East Central Iowa Chapter, Cedar Rapids Parent Support Group- Siouxland Parent Support Group- Iowa City Family to Family Iowa/ASK Resource Center</p> | <p>Area Education Agencies (AEA) Autism Resource Teams Challenging Behavior Teams Directors of Special Education Parent Educator Connection Staff</p> |
| <p>Medical and Diagnostic Providers University of Iowa Children’s Hospital Autism Center University of Iowa Children’s Hospital, Center for Disabilities and Development University of Iowa Hospitals and Clinics, Division of Child and Adolescent Psychiatry Service Blank Children’s Developmental Center ChildServe Child Health Specialty Clinics’ Family Navigators Iowa’s Leadership Education in Neurodevelopmental and Related Disabilities</p> | <p>Iowa Department of Education Early ACCESS State Providers 3-5 Year Old Division Part B - Parent Education Coordinators Iowa Department of Education, Division of Mental Health</p> |

**Note: Although representatives were selected from each participating group, responses were not obtained from 100% of a group’s members.*

Attachment 4: Organizations Participating in the Needs Assessment – Phase 2

| | |
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| <p>Community Health Providers Mercy Hospital- Des Moines St. Luke’s Witwer Center Vera French- Davenport</p> | <p>Early Community Partners Childcare Provider- Iowa City Headstart- Department of Education Home Visiting Coordinators- Buchanan County 1st Five Coordinators Black Hawk and Taylor Counties Iowa Primary Care Association Title V, Iowa Department of Public Health WIC, Iowa Department of Public Health</p> |
| <p>Governor’s Office Iowa Autism Council <i>(A member of the Council was interviewed-but his responses were compiled with the agency he works for)</i></p> | <p>COMPASS - The University of Iowa</p> |
| <p>Insurance Industry Magellan Wellmark</p> | <p>School Districts – Directors of Special Education Ames Community School District Dubuque Community School District Iowa City Community School District Scattergood Friends School, Headmaster</p> |
| <p>Iowa Department of Human Services Autism Center – CDD, Family Navigator Project LAUNCH</p> | <p>Legal/Justice Advocates Attorney, Iowa City, specializing in Disability Rights</p> |
| <p>Screening or Community Providers Champions of Autism and ADHD Child Health Specialty Clinics: Council Bluffs Mason City Ottumwa Sioux City The Homestead Iowa City Children’s Center for Therapy Metro West</p> | <p>Institutes of Higher Education Briar Cliff University Division of Social and Behavioral Sciences Iowa State University College of Human Services Student Disability Services Kirkwood Community College Student Disability Coordinator University of Northern Iowa Special Education Department Student Disability Services The University of Iowa Department of Education REACH Program Student Disability Services</p> |
| <p>Medical and Diagnostic Providers <i>(Members from this group were interviewed in Phase 1. The agency below was added during Phase 2)</i> Tanager Place, Cedar Rapids</p> | <p>Vocational Rehabilitation</p> |

Attachment 5: Statements from Respondents

Strategic leadership

“There must be ‘a system-wide’ perspective.”

“We need someone to bring the public and private sectors together.”

“Schools cannot do it all; we need a lot of players at the table.”

“All professionals need to be on the same page through communication and collaboration.”

“We need easy access to best practice information that is scientific and reliable.”

Partnerships across public and private sectors

“Iowa needs to share behavioral interventionists. I wish there were more [behavioral interventionists] to go around.”

“There should be standardized screening tools for all pediatricians.”

Quality improvement

“Uniformity and commonality would assure a certain level of quality in screening that does not currently exist.”

Use of available resources

“We are getting by with what we have, but staffing and funding have not kept pace with the number of children diagnosed with ASD.”

“What is going to happen to my child in the future?”

“Iowa has a hole no one is filling.”

“We, as a state, are unprepared for the great challenge ahead of us as children with ASD become adults.”

“How will adults with ASD be financially supported and what about quality of life and life satisfaction?”

Coordination of service delivery

“Parents don’t have the luxury of waiting for the needed services for their child with ASD in Iowa.”

“We need enough people (professionals) with enough information about ASD for coordinated care.”

Data infrastructure

“The non-categorical status is a problem in Iowa because it makes it very difficult to track children with ASD, the treatments they have received, and what interventions have been successful.”

Family Participation

“Our goal is to make family members active in their own communities by offering many opportunities for family members to serve on state, regional, and federal boards.”

“If parents feel stronger and more powerful; they are better able to help their children.”

“The family’s abilities and involvement affect the success of the student.”

“After all these years parents still have to fight ‘tooth and nail’ for opportunities and for having their child’s needs met in schools and community settings.”

Outreach and Awareness

“Parents need to know where to go. There’s a tremendous need for outreach to let people know where the [ASD] services are.”

“Our agency is very involved in participating in community awareness activities, like ASD walks.”

