



A priority for the state is a need to bridge and refine systems among ever-changing policies, practices, and processes that affect individuals with Autism Spectrum Disorder (ASD) across the lifespan. Much attention at federal and state levels has been directed towards making interventions and/or supports available; however, similar efforts have not been provided to effectively put such interventions into practice and to communicate and combine efforts across systems, providers, families, and individuals. To support such movement and at the request of the State, the HANDS in Autism® Center conducted an analysis of the status of ASD services or a gap analysis of autism support services in Indiana as of June 30, 2015.

In this brief report, the basic importance, process and approach taken to determine the current status of ASD services in Indiana is outlined. Similarly, overall recommendations for services, training, and resources that were made based upon the gap analysis findings are highlighted. The findings and recommendations of the gap analysis that are shared here were shared with workgroups as part of the Indiana Interagency Autism Coordinating Council (IIACC). Through these analyses and combined input, updates were made to the Indiana Comprehensive State Plan for Individuals with Autism Spectrum Disorder (ASD). Additional information and recommendations relating to the IIACC and other foundational processes that will support ongoing evaluation and movement towards accomplishing the outcomes noted in the Comprehensive Plan are also outlined within this brief report.

INTRODUCTION

According to the American Psychiatric Association (APA), Autism Spectrum Disorder (ASD) is a lifetime condition characterized by atypical development of social skills, communication, and repetitive or stereotyped behaviors that may also be accompanied by mild to severe outbursts or behaviors such as tantrums, aggression, and/or self-injurious behavior. The Centers for Disease Control and Prevention (CDC) highlighted that ASD is currently the fastest growing developmental disability in the United States affecting 1-2% of the population. This represents a greater than 600% increase in ASD diagnoses over the past 20 years, with a 72% increase over the past 5 years alone.

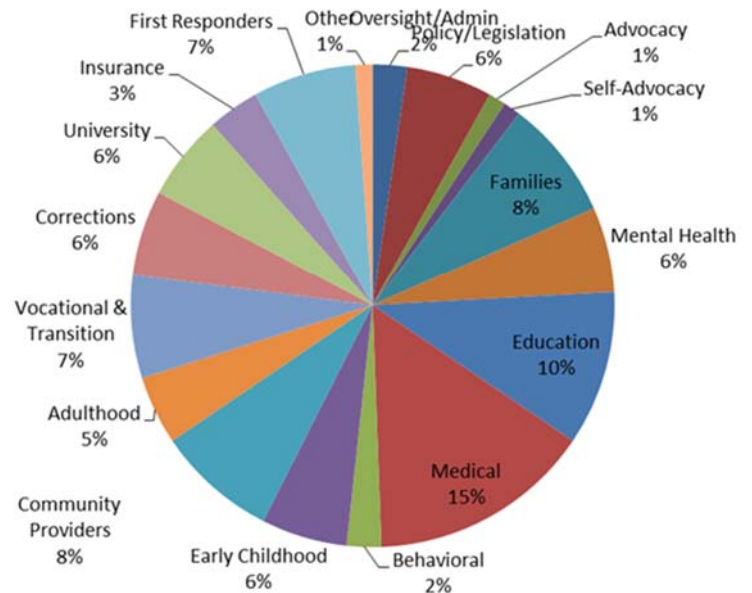
The current project was designed to address three primary needs of the State: (1) reviewing, revising and maintaining the current Indiana Comprehensive State Plan for Individuals with ASD, (2) leading and coordinating the Indiana Interagency Autism Coordinating Council (IIACC), and (3) conducting a high level needs assessment regarding the gaps in ASD services in Indiana. This brief report provides an



overview of the approach that was taken and findings from the gap analysis that was completed to determine the current status of ASD services in Indiana.

The gap analysis was completed by the HANDS in Autism® team in three basic phases: (1) information gathering, (2) data collection, and (3) data representation and analyses. Information gathering and data collection were completed by gaining input and data from a wide range of professionals and stakeholders as part of the IIACC (see IIACC Current Membership by Category), focus groups, regional study groups, individual interviewees, and other key informants. Representation and analyses of this data resulted in a number of overall impressions and conclusions with such data serving as a baseline for the State and others to understand the current status, needs, and priorities for services and supports and also a comparison from which further work will be able to be successfully and effectively evaluated in measuring outcomes and progress towards priorities and key short-term activities reflected in the Comprehensive Plan.

IIACC Current Membership by Category



METHODS

As noted above, the gap analysis was conducted in three phases: (1) information gathering, (2) data collection, and (3) data representation and analyses. Information gathering occurred via review of materials and data as well as through input from various professionals and stakeholders that form the IIACC. Data collection was completed across multiple forms including a comprehensive statewide survey, focus groups (i.e., phone conferences with specific participant groups), study groups (i.e., live meetings with participants of Local Community Cadre (LCC) regions), and informant interviews (i.e., phone and live interviews with caregivers and individuals with ASD). Advertisement for the survey, focus groups, and interviews occurred through flyers, listserv communications, websites, newsletters, social media (i.e., Facebook, Twitter, LinkedIn), and events such as conferences, meetings and other group



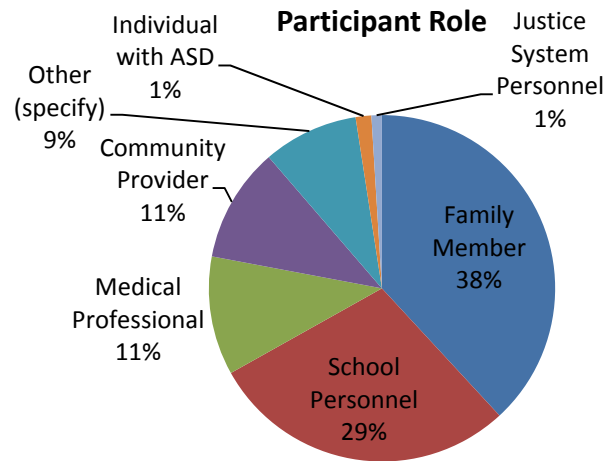
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opportunities. Additional recruitment was possible through efforts of the IIACC and HANDS in Autism® Local Community Cadre (LCC) members. Accessibility for the survey was increased with the survey being available in both online and hard copy forms as well as availability of HANDS staff and volunteers to assist those who requested help by phone or other means (e.g., enlargement of print, questions or clarification of items, etc.). Focus groups, study groups, and informant interviews were conducted both in person and via phone with volunteers who responded to the noted advertisements expressing a willingness to host, participate and/or recruit individuals for participation.

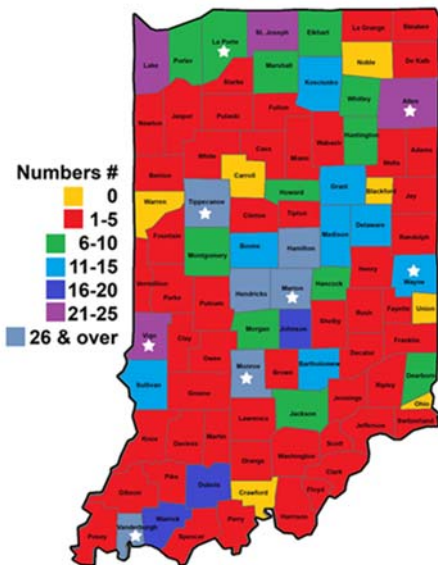
RESULTS

Participants. In total, 826 individuals completed the needs assessment survey while 17 groups (i.e., 9 focus groups and 8 regional study groups) and 21 informant interviews were conducted. As seen in the Participant Role diagram, most participants noted their primary role as family members (38%) or school personnel (29%) with the remaining participants (33%) representing medical, justice and other community providers as well as individuals with ASD (1%).



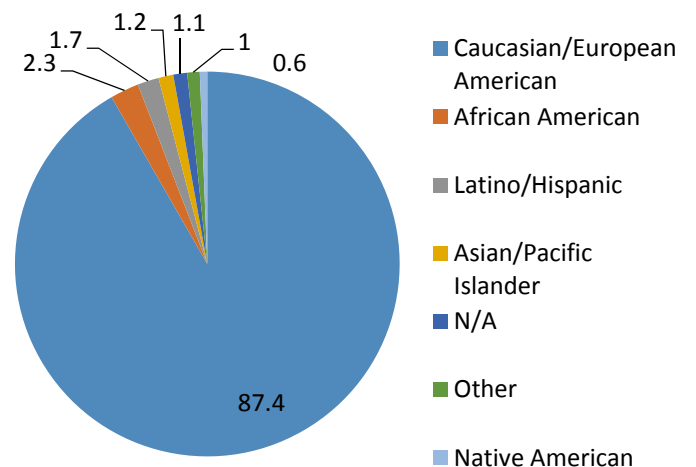
Participants represented 85 counties in Indiana with a larger proportion of participants being from

County Representation



the central and northern regions of the state (see County Representation diagram). With respect to race and ethnicity, 87.4% of those surveyed classify themselves as Caucasian or European American (see Race/Ethnicity Representation diagram).

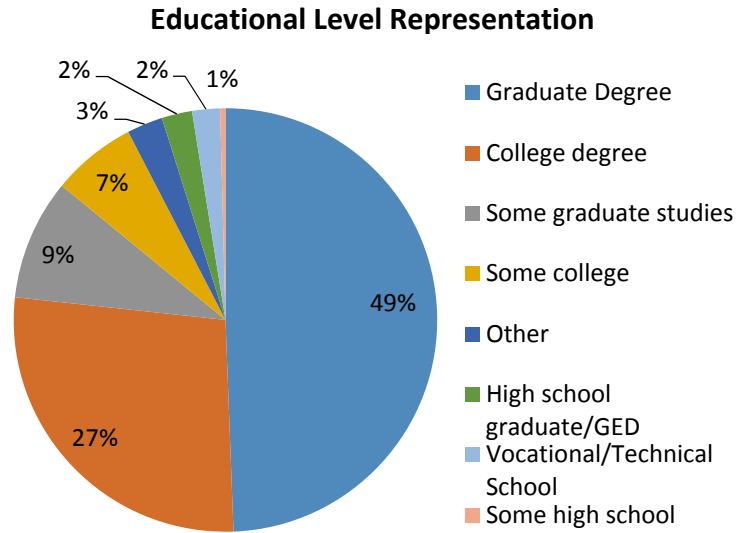
Race/Ethnicity Representation





Out of the 826 people surveyed, just under half or 49% of the people surveyed had a graduate degree (see Educational Level Representation diagram).

Among the subgroups (i.e., families, individuals with ASD, school personnel, medical professionals, justice system personnel, community providers) who participated in the survey, the primary roles or settings within the subgroups were reflected as follows:



- **Families/Caregivers:** 82% described their role in the family as a biological parent while 16% of participants reported their role as another family member.
- **School Personnel:** The top two educational settings served by respondents were general education and self-contained classrooms with 67% of school personnel participants indicating they work with students with ASD daily.
- **Medical Professionals:** The roles noted within the medical profession were varied overall; however, 33% noted roles as therapists while 26% indicated their primary role as a medical resident.
- **Justice System Personnel:** Within the justice system, 7 participants reported their primary role as a justice system personnel with 6 identified as police officers and 1 as a parole/probation officer.
- **Community Providers:** Most claimed that the role they play as a community provider is classified as “other”. Many of the providers also noted an administrative role as part of their position.

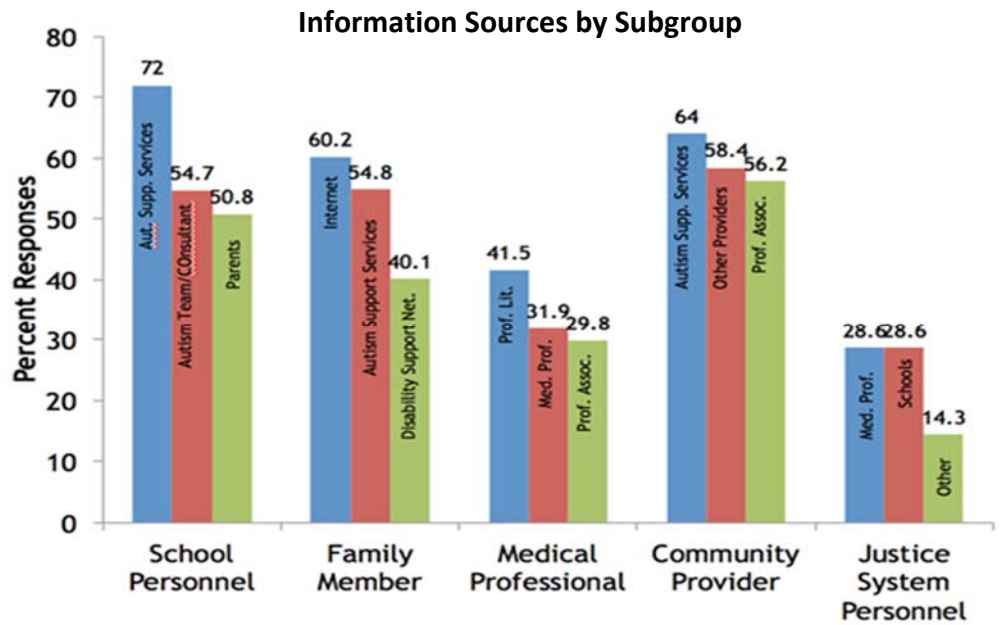


NEEDS ASSESSMENT SURVEY

Findings are highlighted from the comprehensive survey as follows:

ASD Information and Challenges. With regards to where information about ASD is obtained (see Information Sources by Subgroup diagram), school personnel and community providers indicated they consult mostly with autism support services (e.g., Autism Society of Indiana, HANDS in Autism®, Indiana Resource Center for Autism). In contrast, medical providers report most often seeking information and

training from professional journals with autism support services serving as a secondary source for gathering information. Justice system personnel noted they were most likely to consult medical professionals or schools for information about ASD and to attend conferences for training.



Though family members reported they use autism support services as a source for information and training, they more frequently consulted the internet for both information and training.

Areas of Least Knowledge or Reported Need for Increased Knowledge. When asked about areas of least knowledge (see Areas of Least Knowledge by Subgroup diagram on page 6), family members reported the desire for more knowledge regarding transition and post-secondary planning as well as diversion options. Family members also noted they would like to have increased understanding of laws and policy, effective advocacy, as well as insurance and financial support options.

School personnel noted having the least knowledge in the areas of insurance coverage, pharmacological or medical interventions, and planning for postsecondary options. They noted wanting more information to assist with decreasing interfering behaviors, understanding pharmacological or medical intervention and teaching replacement skills.



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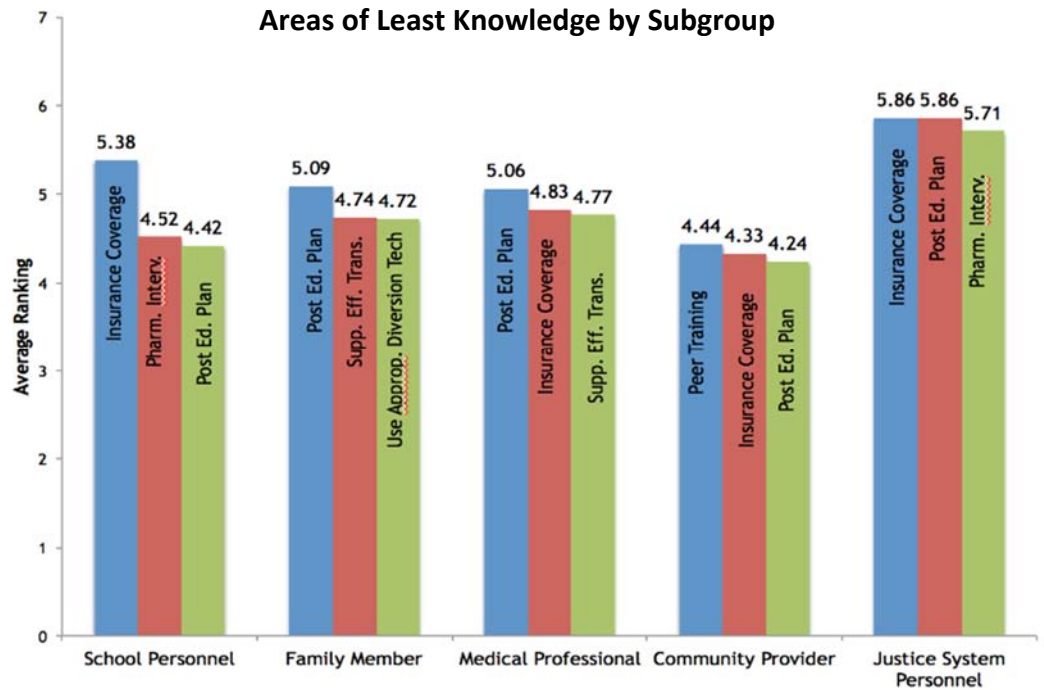
Medical personnel felt least knowledgeable about developing a post-education plan and knowing about insurance coverage, and/or financial support options. Medical personnel also indicated a need for more information regarding law and policy related to ASD and decreasing interfering behaviors.

Community providers felt least knowledgeable about developing a post-secondary education plan, knowing what insurance coverage and financial support

options were available, and providing peer training. They indicated a desire for increased information related to law and policy as well as information to support caregiver needs and siblings.

In contrast to the other groups, justice system personnel did not feel extremely knowledgeable relating to any of the categories surveyed, but the top area of concern or need for increased knowledge was related to an understanding of laws and policy related to ASD as well as understanding of general characteristics and learning styles of individuals with ASD.

Overall, the greatest areas of reported need related to transition, post-secondary education planning, and insurance coverage or financial options to access services. Such challenges or needs align with areas of national importance. Despite the fact that trainings to address the noted topics are often provided through online options and single-day workshops, participants across Indiana stated a preference for more personalized trainings and support (e.g., email and phone communications related to their own scenarios) and more in-depth trainings (e.g., multi-day workshops) than those typically provided.



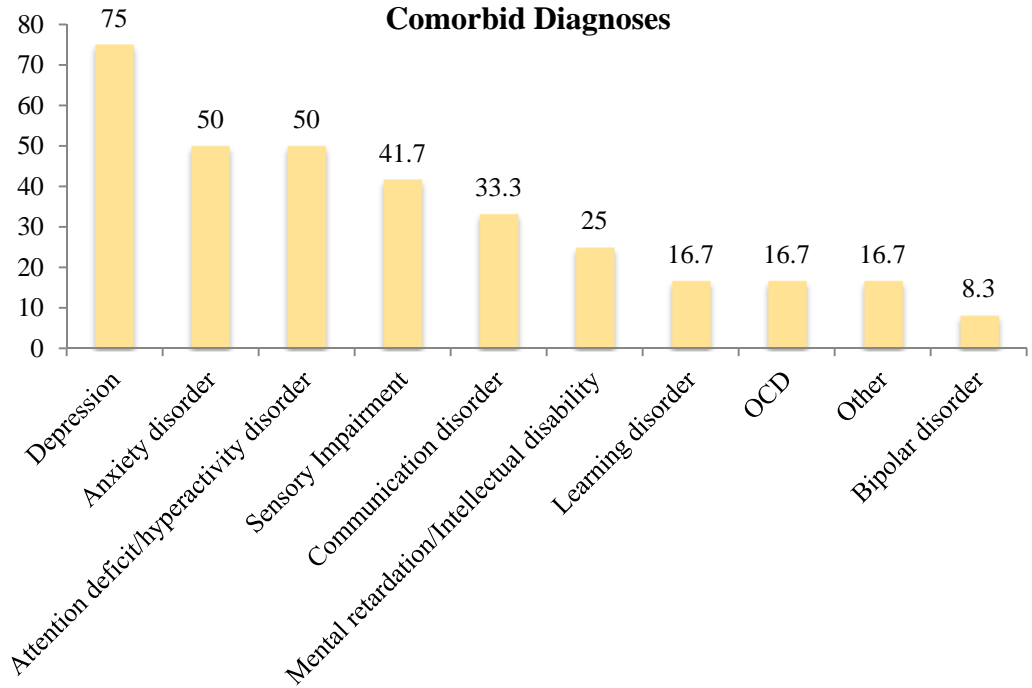


Diagnosis and Insurance. With regards to diagnosis, the diagnosing medical professional was most often a psychologist; however, medical doctors were noted to have made 36% of diagnoses for families and individuals with ASD.

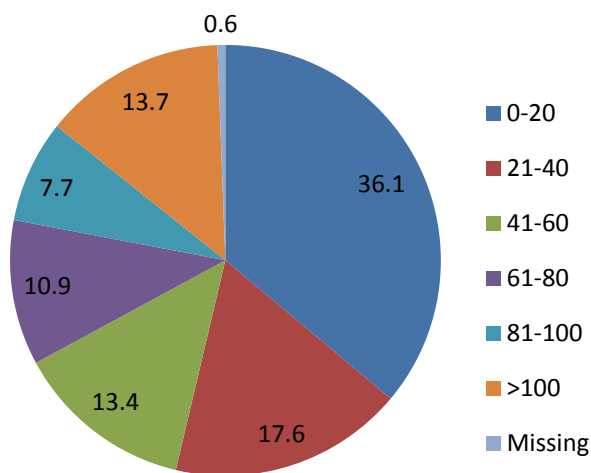
All individual participants stated ASD was the primary diagnosis with 75% of respondents indicating they had also received a diagnosis of depression.

Family respondents noted Attention-Deficit/Hyperactivity Disorder (ADHD), Anxiety Disorder, and Communication Disorder were the most popular

secondary conditions. Only 3% indicated that there were no other secondary conditions. Thus, among participants, it was very common to have ASD in combination with other disorders (see Comorbid Diagnoses diagram).



Miles Traveled for Diagnosis



According to family participants, most were able to drive less than 40 miles for a diagnosis for their child (see Miles Traveled for Diagnosis diagram), but 14% of respondents had to drive more than 100 miles from their hometown to get a diagnosis. Among participants, 61% of families indicated that private insurance was covering payment while 42% noted they had to pay out-of-pocket for services.

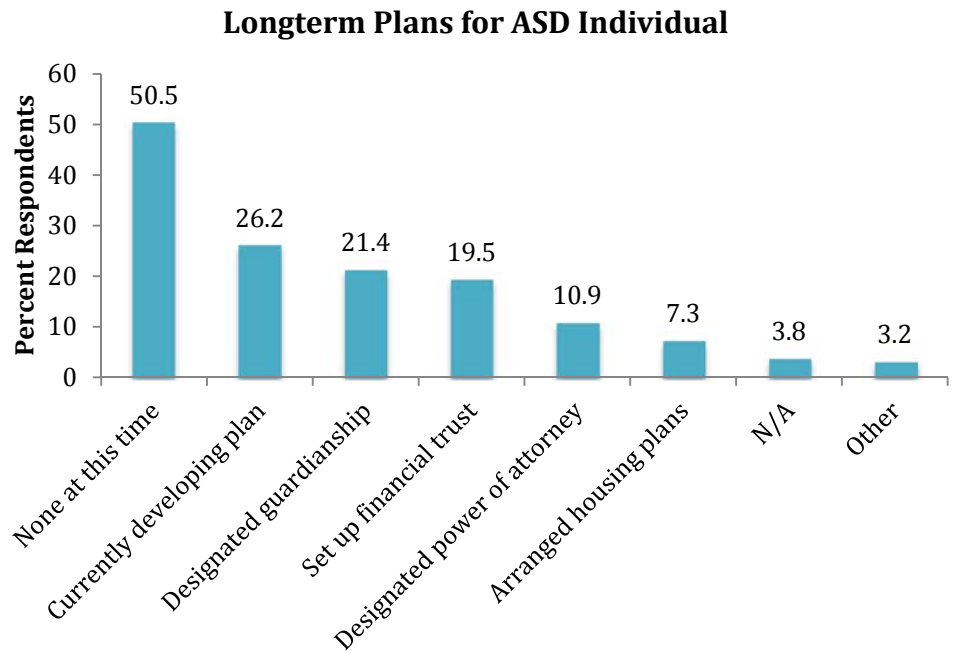


Additional Areas of Challenge and Subgroup-Specific Information. Across participant groups, when asked about barriers to collaboration between these groups, the top three responses were consistently the same: time, funding resources and training with useful information.

- Families/Caregivers.** Almost all family participants (i.e., 93%) with transition-aged children indicated that the individual with ASD was living with parents in their family home with less than 10% living in another facility or with other relatives. Among the individuals with ASD who were responded to the survey and were transition-aged, 58% were living with parents or other

relatives. Among the family and individual participants, 73% of family respondents and 17% of individuals with ASD were very satisfied with the current living arrangement. A significant number of the family participants (i.e., 80%) indicated that

the individual with ASD had not looked for employment, 51% claimed there was no long-term plan, and 26% were in the process of developing a plan. According to responses from individuals with ASD, 58% take part in various activities and hobbies but need to drive themselves or travel using public transportation. When asked about limitations to accessing care for the individual with ASD, the most common limitations reported were related to the cost of services, a shortage of providers in their area, and scheduling; however, 37% of family participants claimed there were no limitations.





- **Individuals with ASD.** Among transition-aged individuals with ASD, approximately 42% reported similar challenges in accessing care in relationship to coverage of costs, a shortage of providers, and scheduling. In regards to areas of challenge or need as it relates to accessing specialty healthcare and education, 42% of individuals with ASD reported that the greatest need was in the area of specialty healthcare as it pertains to the availability of mental health services and/or counseling.
- **School Personnel and Community Providers.** In areas noted as presenting the most challenge in working with individuals with ASD, school personnel and community providers both reported support for behavioral issues and teaching functional skills. Within the school setting, school personnel felt that policies and procedures in place within their setting were generally effective (i.e., rated as somewhat to very effective) as they pertain to school discipline and policy (78%), Response to Instruction (RtI or data driven decision making; 64%) and School Wide Positive Behavior Support (SWPBIS; 49%). Furthermore, community providers were generally knowledgeable about routine guidelines at their Centers (i.e., over 75%) with most of these providers reporting that the policies and procedures for crisis management, positive/proactive strategies and positive behavioral supports were at least somewhat effective.

FOCUS GROUPS

Focus Group Summaries. As noted previously, nine focus groups were completed and represented the following focus areas with one to two groups per focus area: first responders, community physicians, university/post-secondary personnel, educators, early intervention and advocacy personnel. The groups were asked to respond to prompts designed to foster discussion of their stories, scenarios and situations. Responses and discussions were transcribed following each group for additional analyses with primary themes emerging as (1) a gap in resources, (2) gaps in trainings, (3) gaps in collaboration, and (4) a large amount of information being accessed and pulled from the internet and shared among families rather than accessing and seeking information and resources from professional and reputable sources.



STUDY GROUPS

Regional Study Group Summaries. Eight regional study groups were conducted through live meetings that were recorded and transcribed for later analyses across eight communities (i.e., Indianapolis, Terre Haute, Lafayette, Evansville, Bloomington, Richmond, Fort Wayne, La Porte areas). Prompts used within the focus groups were used to gather information pertaining to the resources, trainings, strengths, weaknesses, and gaps in ASD services specific to each of the community areas. Common themes emerged across regional areas reflecting ongoing and persistent challenges including but not limited to the need for increased access to resources and services. Concerns regarding insurance coverage and greater support across phases of early childhood and post-secondary transition and planning were noted within communities. With respect to resources and trainings, it was reported that trainings occur but with inadequate customization to the targeted groups or not being practical in nature such that targeted groups are not able to immediately apply or use the information or strategies trained.

Areas reported as emerging or current strengths for various regions could serve as motivation and examples for further statewide changes and efforts. For example, various community partnerships were noted as of value and desirable across systems to most effectively support individuals and families and represent an area for further exploration moving forward.

INFORMANT INTERVIEWS

Individual Interview Summaries. Twenty-one informant interviews were conducted with caregivers and/or individuals with ASD with overall themes analyzed and reflected in this brief report. While caregivers of individuals with ASD reported feeling a moderate to heavy burden in caring for their children with ASD, they openly shared about the good that comes from being the caregiver of a child with ASD. Many caregivers indicated they find their children to be bright, funny, and believe that their children will flourish with the right supports. Caregivers noted taking great joy in seeing their children improve and make progress; however, the same caregivers expressed the reality that they are often unsure about future plans for their children. The desire for their children to move into independent living and be successful was frequently expressed but caregivers were not always positive that this would be a possibility.



Most caregivers indicated they do not have extra help in the form of paid staff, caregivers, or respite care and often expressed feeling they were the only advocates for their children. They find they have to go to great lengths to research and identify appropriate services despite the ability to readily identify what it is that their child needs. Challenges in accessing services were noted in regards to knowing the appropriate steps and process to access services, locating and accessing specialists within the community, knowing who will and who should include them in the planning process, and knowing what providers are accessible financially since many services are rarely covered in full by insurance. Families generally reported large differences in the level of education and knowledge of those serving in support roles (e.g., paraprofessional, support staff, etc.) with indication that they wish for greater education across all community groups to increase awareness and readiness in supporting the family.

Overall Themes. Across the above forums, a number of themes regarding challenges faced in accessing and receiving services emerged with challenges noted in relationship to the ability to (1) access Medicaid and waiver providers, as well as providers who understand dual diagnosis and those that can address more intensive needs; (2) access to comprehensive lists for referrals, support groups, therapists, school resources, and respite care; (3) access to resources such as visit templates, practical supports, and research-based materials to more effectively advocate for, streamline, support and collaborate with and among personnel and providers, (4) access to training and services that are more accessible in regards to the times of training, scheduling, cost, and travel, with such trainings needing to provide more practical information that supports immediate application through strategies that can be applied to their situations and settings, and (5) access to support for individuals with intensive behavior and mental health challenges.

DISCUSSION

The HANDS in Autism® team has led the formation of a systematic and sustainable process for conducting a detailed gap analysis that provides a comprehensive view of the status of ASD services in Indiana. The process is objective in nature given the focus on collaborative, data-driven decisions that lead to greater sustainability than other approaches which may focus upon isolated evaluation and intervention strategies that are informed with a top-down approach whereby administration and leadership groups determine priorities and allocate resources rather than



seeking information from consumers to inform priorities and resources. The vision beyond the current project cycle and when fully carried out, is for regional areas to have both greater local capacity for accessing ASD-related information and services and increased engagement at a state level to ensure the continued two-way flow of information from community to state and state to community informs and shapes progress collaboratively across systems and at each level for years to come.

Given that the needs, goals, objectives, and missions of the State exist within an ever-changing combination of community, state, and federal priorities, and social, economic, cultural, and political climates and policies, a structure and process that purposely and systematically engages various regional groups (e.g., HANDS in Autism® Local Community Cadres or LCCs) must be present to assist communities in putting such changes into practice at a local level. These same communities and groups also have to be flexible and responsive to change directions as state and national trends shift. The LCCs and their representation on the IIACC as part of the Community Advisory Group (CAG) will continue to have the capacity to communicate local concerns or needs and highlight progress or steps forward for consideration by the State to inform programs and initiatives in the field.

Limitations of the Analyses. Over the past year, the primary focus has been to establish the procedures, documentation, measures, and recruitment for the gap analysis. Similarly, efforts have taken place to facilitate adequate and representative participation for the IIACC to ensure a fluid and systematic process that would serve as a foundation for analyzing the status of ASD services statewide for years to come. In addition, this past year served as a means for establishing a baseline level with regards to identified gaps in ASD services. The response rate for the needs assessment survey was phenomenal for the first year of this project. However, despite significant overall participation, limited participation was noted for some subgroups to most appropriately inform needs and progress moving forward with such limitations expressed as follows:

- **Individuals with ASD:** Although the findings highlighted in this brief report provide some insights and align with that of other participants, more individuals with ASD are necessary to have a clearer picture of their particular perspectives and needs.



- **Racial/Ethnic Diversity:** Ideally, participants should be evenly distributed by race/ethnicity or, at minimum, the distribution reported should be similar to the demographic representation of the area to fully understand the needs and perspectives of those represented statewide. In the current analyses, most participants were noted as Caucasian which limits the ability to convey the findings across all races and ethnicities.

Therefore, the goal in the current year is to continue to expand and enrich participation across groups for a more representative database that allows for more comparisons year to year.

Areas for Improvement. In the current year, additional efforts will be taken in terms of recruitment to ensure a broader sampling of respondents with respect to gender, race and ethnicity. In addition, the needs assessment will be translated into Spanish and the HANDS in Autism® team along with collaborative partners will reach out to areas and populations with lower representation for a greater racial and ethnic diversity of respondents. Further, questions will be added to the current survey to assess such demographics as age and gender and information pertaining to not only the profile of the respondent but also of the client population served by providers. Additional participants will be sought from rural communities as well as the few communities or counties not represented in the prior year. Furthermore, greater representation will be sought to include more family members, medical practitioners and justice personnel.

As a follow-up to the prior data collection and analyses, a formal survey will be conducted to objectively assess the satisfaction and needed improvements to inform the coming year. Accountability and incentives will be increased to encourage even greater effort and participation on behalf of the IIACC and other members to ensure representation across multiple stakeholders and professionals across systems as well as those from the field of implementation science.

Next Steps. Though overriding themes reflective of national trends in the area of ASD were apparent (i.e., concerns regarding insurance and transition), distinct differences in stated needs were also voiced between participant groups that established the need for varied content, format, length and general presentation of information to various consumers and training participants. There continues to be a need and relevance for general awareness training across various groups (e.g., families and educators, school and early childhood, medical and school) in order for such groups to have greater ability to share information, have an understanding of each other's special



roles, and have increased awareness of successes and challenges. This shared effort and collaboration will not only be unifying but also educational and supportive at local and regional levels. The availability of events and resources at local and regional levels will provide networking opportunities among local community members thus enhancing partnerships while also allowing for events to focus on topics and formats that are immediately practical and relevant, which were noted as essential needs for training across groups.

Communities are eager and often reaching outside of their own networks and settings to access information and support with the understanding that it takes a full community to support individuals with ASD. There is a desire for statewide information to be readily shared and distributed within and across settings. Therefore, given the repeated and clearly stated interest in ASD Law and Policy across participant groups, the gap analysis process and the IIACC will benefit from adding additional state and legal groups to work on aligning and sharing information related to the legal components affecting resources, systems, agencies, services and supports for individuals with ASD.

In summary, the results shared within this brief report provide only a brief overview of the priorities for State as it applies to ASD services. The IIACC, LCCs and other community and participant groups will continue to be important participants in the ongoing process by informing priorities, identifying key participants and perspectives, and participating in the measurement and progression of activities incorporated within the Indiana Comprehensive State Plan for Individuals with ASD. Efforts will continue to be undertaken to ensure the membership of such groups are the most representative and to find improved options and methods for accessibility and engagement across groups.



ADDITIONAL RESOURCES

For further information about:

- IIACC and the Indiana State Plan of Individuals with ASD
- HANDS in Autism® Local Community Cadre regional groups
- Current Indiana ASD needs assessment survey
- Hard copies of the most current Indiana ASD needs assessment

Please contact HANDS in Autism® at hands@iupui.edu or handsinautism.iupui.edu

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