

Indiana Autism Support Services Gap Analysis

Executive Summary: June 30, 2016

Dear Colleagues,

By request of the State, HANDS in Autism® has continued with the gap analysis process that commenced in 2014 and is continuing at the current time to further determine the state of the state in autism services in Indiana. The gap analysis process continues in progress to ensure that adequate representation of all willing and interested stakeholders are given opportunity to participate in this evaluation. This will lead to assurance that there is a sufficient baseline upon which to base the success of future efforts statewide. The purpose of the current report is to report as of June 30, 2016, the status of the analyses and the directions forward in the coming months and year. This report will briefly reiterate the basic significance, process and approach taken to achieve these results. Further information related to these may be accessed from in the previous 2014-2015 report located at <http://www.in.gov/fssa/ddrs/3355.htm> . In addition, we have updated overarching themes as well as noted strengths and gaps that have been collectively noted across the period of 2014-2016. Given the scope of the analyses, this time period and into the fall of 2016 will serve as the baseline status upon which future comparisons of perspectives, actions and progress will be drawn. Further analyses and conclusions will consider both state and national trends in ASD as well.

In the current reporting year, concentrated efforts have been taken to increase the accessibility of the needs assessment survey as well as other means for involvement and input. In this document, we have updated the results of the gap analyses to this time point, with analyses continuing in coming months as further activities targeted to increase consumer input is sought. Given the scope of effort and desired outcome of effecting systems change, it is essential that adequate attempts to engage and incorporate all interested stakeholders take place. Both recruitment efforts and analyses must be thorough and comprehensive to ensure that the recommendations for services, training, and resources are based upon a true state representation of stakeholders. In this way, the collaborative efforts of the Indiana Interagency Autism Coordinating Council (IIACC), its workgroups, the Local Community Cadres (LCCs) and others to isolate priorities and take action steps related to the Comprehensive State Plan (CSP) will be relevant, functional and meaningful to each and every consumer across the state.

Data driven decision making is being utilized at each step to progressively and systematically move forward with identified state priorities based upon the gap analyses results, teaming within the IIACC and related work and study groups, as well as using the Comprehensive State Plan as a base framework for all activities. Also required in this process has been the development of foundational systems and processes to encourage meaningful and progressive communication and collaboration.

In addition to furthering the reach of the gap analysis, the current year has been a time of developing and trialing a number of systems and processes with feedback encouraged and utilized from users to establish multiple usable formats to engage and involve stakeholders in ways that they find engaging

and feasible so as to keep the ongoing work on identified priorities in motion. These systems and processes with a focus on engagement, transparency and action-orientation will be further discussed in this 2015-2016 report.

Indiana has experienced a surge of attention across State and community efforts to bridge and effectively coordinate and collaborate on various initiatives. There has been very purposeful attention to integrating systems statewide which reflects growing awareness of the real potential for failed outcomes and increasing needs resulting from tolerance and persistence on silos of practice. Such siloed efforts are not be conducive to systems change and implementation. The IIACC has been intentionally inclusive of membership from policy makers, practitioners, and the larger communities. Many of these individuals are similarly integrated with other integrated workgroups and efforts and are able to foster information sharing both to and from the IIACC regarding efforts pertinent in addressing the needs, goals, objectives, and missions aligned with autism and related services.

The gap analysis process, work with the IIACC, workgroups and LCCs has continued with commitment from a number of busy leaders and consumers across the state. A growing number and scope of organizations, workgroups and systems groups are represented and invested in the systematic and deliberate process towards systems implementation progress and positive outcomes that has been demonstrated by group efforts thus far. At this juncture, the process is shifting towards a more action-oriented path in initially addressing some of the long-standing “low hanging fruits” that involve similar talking points and concerns across multiple goals within the Comprehensive Plan. Such action steps are feasible areas to begin while the baseline gap analyses are ultimately completed in the coming year. The HANDS team, as the Chairs of the IIACC and facilitators of the gap analysis and efforts in addressing the Comprehensive Plan, are committed to inclusiveness, transparency and systematic and productive efforts towards improving autism services and access. Progress can only occur with collectiveness of effort represented by the IIACC and other partnerships; HANDS will continue to foster increasing avenues for sharing input and becoming involved in any desired aspect of the process.

Thank you for the opportunity to continue to team with the State as well as the many incredibly passionate and committed partners in this ongoing project. We look forward to the continued and ongoing evaluation and progress related to Indiana autism services this coming year.

Respectfully,

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GAP ANALYSIS: INDIANA AUTISM SUPPORT SERVICES

INTRODUCTION

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 like tantrums, aggression, and/or self-injurious behavior (American Psychiatric Association [APA], 2000, 2013). ASD is currently the fastest growing developmental disability in the United States with a prevalence of 1 in 68. This represents a greater than 600% increase in ASD diagnosis over the past 20 years, with a 72% increase over the past 5 years alone (Centers for Disease Control and Prevention [CDC], 2015).

Despite the significant prevalence of the disorder, there is still much that is not well understood within the communities and systems that support these individuals and their families. Adequate supports across the lifespan are necessary for individuals to reach their potential and to access quality of life. Active involvement and communication with diverse factions and the community-at-large provides added awareness, engagement and advocacy of effective practices across a greater number of settings and individuals playing a role in servicing, supporting and providing opportunities for ASD. Given the ever dynamic and changing landscape of ASD and related services and the potential for community impact on funding, information and resources pertaining to the state of autism, it is essential for there to be a process to stay connected, current and progressive in this field. The National IIACC, established in 2000, serves as a model for states to develop such a forum and network of community stakeholders with special interest in Autism services to ensure ongoing dialogue, discussion and progress forward.

As outlined in the 2014-2015 Report, Indiana has had a distinctly positive trajectory in pursuit of supporting individuals and families with ASD. Community networks and collaboration has been a staple in the community for the past couple of decades with recognized need for following national trends as well as with collaboration and joint effort at varied levels of coordination and leadership. Currently, the Family and Social Services Administration (FSSA) is the oversight body for the Indiana IACC which has served as the primary body assisting in the ongoing analyses of the larger sets of data collected from across systems and statewide and helping to inform the priorities and trajectories of effort per the Comprehensive State Plan and based upon the ongoing analyses of the state of the state. Since 2014, HANDS in Autism® has served as the Chair of the IIACC and helps to facilitate the work of the IIACC, the workgroups and the Local Community Cadres, collecting data, developing forums for input and generally maintaining the efforts towards a firm foundation for systematic analysis, review and implementation pertaining to the Comprehensive State Plan and the state of the state in autism.

This process began with a high level gap analysis and overview of state autism services in 2014 with further analyses targeting those with lesser representation to present day. In particular, at the time of the 2014-2015 report, it was identified that, despite a response rate of over 800 informants across the state, that a number of groups and interest groups were not adequately represented. As such, a primary goal in the current year has been to specifically work to engage these underrepresented factions: individuals with ASD, justice personnel/first responders, behavioral and community mental health providers, early childhood, insurance representatives, and state agency representation. Further underrepresented groups included those in rural areas as well as of varying cultural descent. Through more directed dissemination of the needs assessment, generation of novel contact lists aimed towards the specific target groups, as well as development of innovative and practical means for input, groups have been increasingly engaged whether attending IIACC meetings,

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providing other regular input, or completing the survey. In general, and as reflected in the 2015-2016 data in comparison to the 2014-2016 gap analysis data, more awareness and participation of these groups *has* resulted in increased participation in the needs assessment survey.

General accessibility and input from a larger breadth and depth of the communities across the state has been a premier effort in the following ways: (1) making the needs assessment survey more accessible (e.g., translating to Spanish, refining questions for more meaningful input), (2) providing further communication outlets for ease of participation and sharing (e.g., providing shared input where and when available—meetings, conferences--rather than needing to be present for phone or live meetings), (3) sponsoring workgroup feedback through online mechanisms (e.g., google docs, survey gizmo questions). As such, though the previous and more traditional focus groups and interviews described in detail previously (see 2014-2015 report) have continued, there are now more options for communication and partnership that provide stakeholders with more flexible options regarding the level, timeframe and format of participation for added convenience and opportunity.

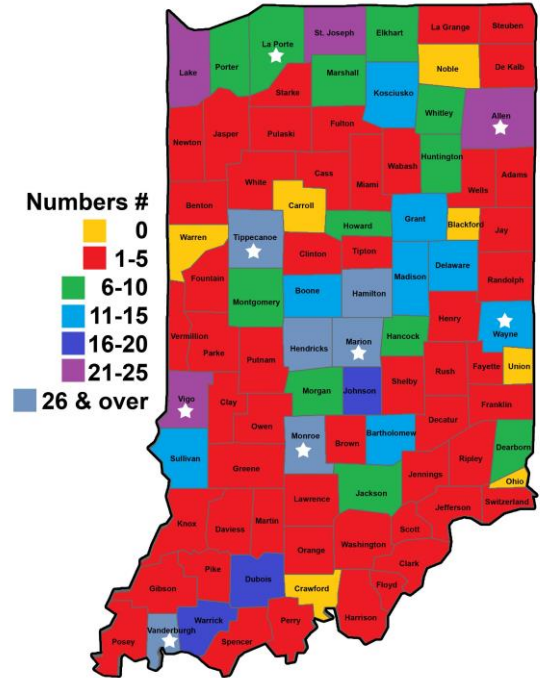
The ultimate outcomes of all of this work continue to surround the creation of a foundation for a more enhanced ability to fully assess and inform future state policies and work towards improving the comprehensive care and quality of life to individuals with ASD within their local communities by actively engaging the communities in systems change and implementation efforts. After the multilevel and multimodal analysis last year and continuing at a greater depth and breadth ongoing into the upcoming year, a number of overall conclusions have provided the basis for initial targeted work that will become further refined ongoing as data and insights continue to be collected across the state. Newly created documents have been developed for learning and reference (State of the State summaries from across the nation and a table to align state and national goals and activities) as well as to ensure that stakeholder ideas are being considered in relation to both state and national activities and priorities. Collectively and through iterative processes, we have established a viable and comprehensive process and platform for engaging stakeholders across systems and the state in multiple formats to best conducting gap analyses and utilize the resulting information to inform the state of state in autism services now and in the future.

RESULTS OF GAP ANALYSES:

WHO WERE THE INFORMANTS?

Updated in 2014-2015, 826 total responses were collected to reflect levels of state participation across all formats of the gap analysis: focus groups, study groups, individual interviews and the needs assessment survey. Relative participation is reflected in the graphic below. Though 300+ further responses were collected, this particular graphic was last updated in 2015 with further updates to follow. Though most counties were represented, the highest concentration of responses were in the donut areas surrounding the LCCs.

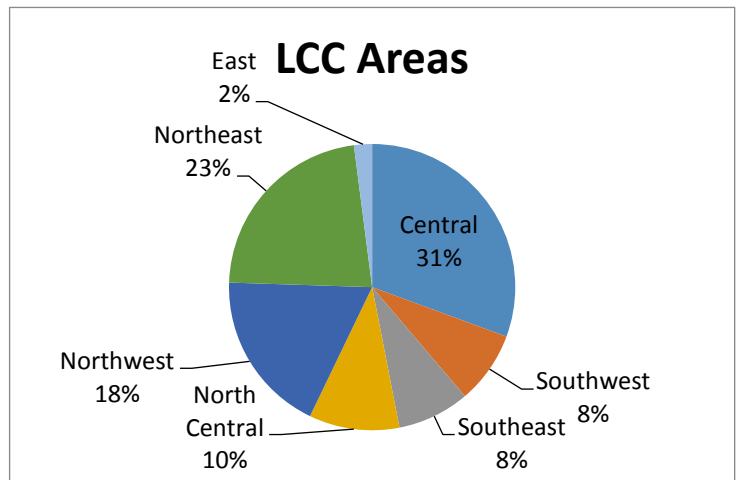
Regional Responses



NEEDS ASSESSMENT 2014-2016 (N=1136)

As previously noted, the current year's focus was less on raw numbers and more on an increased push for representation of groups previously underrepresented.

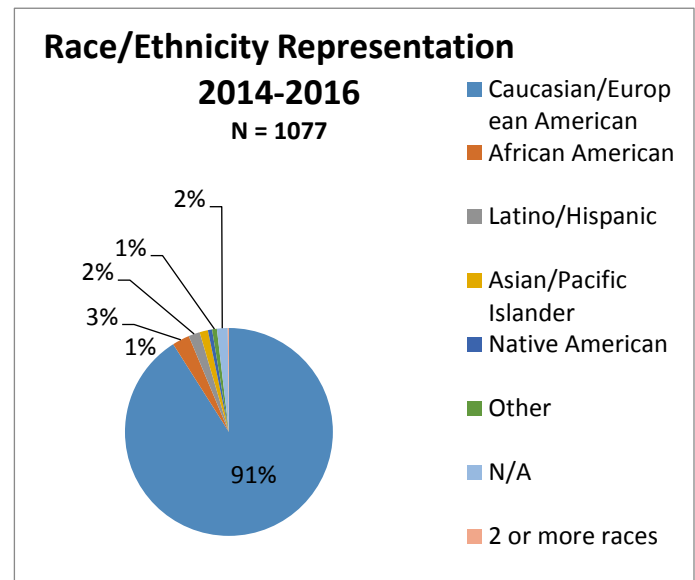
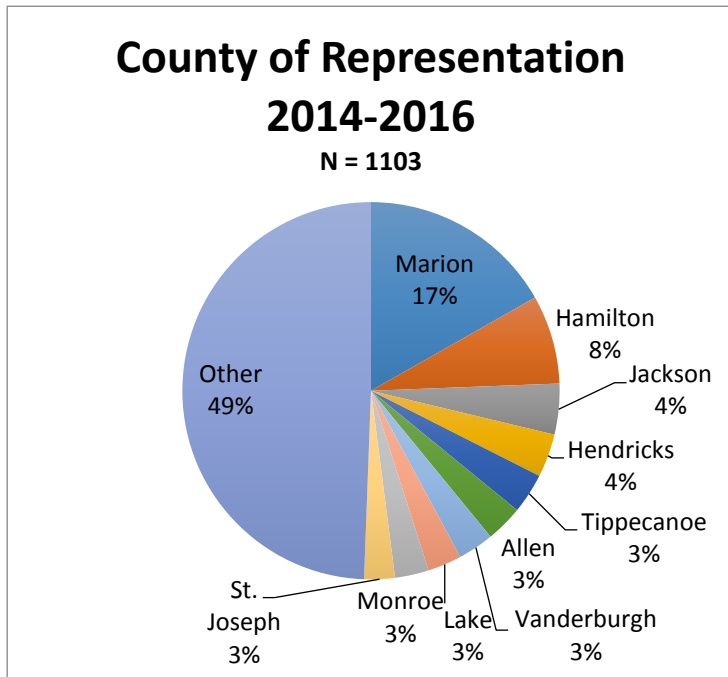
From the data to the right, though most informants are located in Central Indiana, there was decent representation and pockets of more intense response from all of the LCC areas, similar to the map above. Even the most recently formed LCCs centralized in Richmond (East) and LaPorte (Northwest) were notable in response rate.



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However, as also represented in the county representation below, it is notable that the highest concentration of responses on the 2015-2016 Needs Assessment came from just a few counties, with many of them being in the northern or central regions.



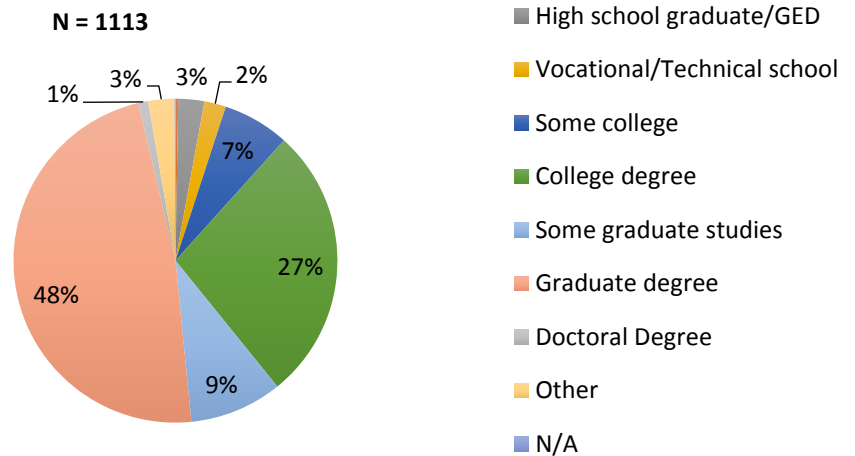
Of further note, out of 1136 respondents and 1077 responding to this question, 91% of those surveyed classify themselves as Caucasian or European American, an increase from the respondents last year. However, results from this adding data this year to the total do demonstrate some increased range of cultural diversity despite the actual increase of the singular Caucasian/European American finding. Increasing attention to the need for cultural diversity in the people recruited for the survey has been targeted currently with specific resources going towards building a database of groups involving or serving individuals of different cultures. These groups are in the process of being contacted to increase awareness and exposure to the survey, the IIACC and the Comprehensive State Plan. In addition, efforts will be allocated to learn the best avenues for improving access and dissemination to these populations. Similarly, a Spanish version of the needs assessment has been developed during the current report year to increase access for this population. Dissemination efforts have begun with a few responses to date and more to come for reporting at the next cycle.

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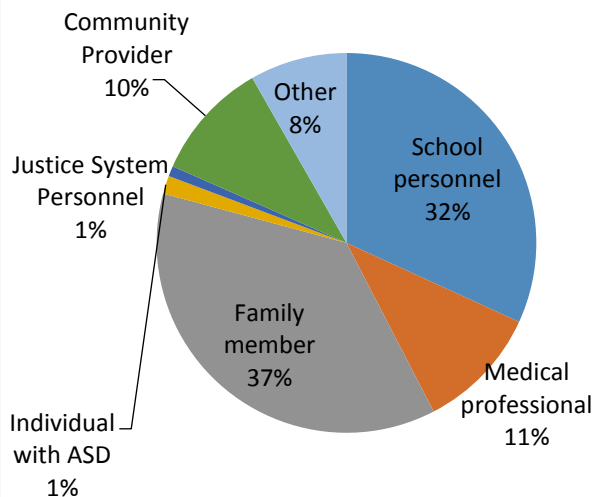
Of 1113 respondents completing the survey across the time period of 2014-2016, most had at least a college degree (approximately 87%) with 60% of those individuals having some level of graduate study and close to that number with a culminating graduate degree. As such, a more diverse set of respondents is necessary for a clarity on any impact on the responses and/or comments as a result of the needs assessment survey.

Highest Level of Education 2014-2016



Participant Role 2014-2015

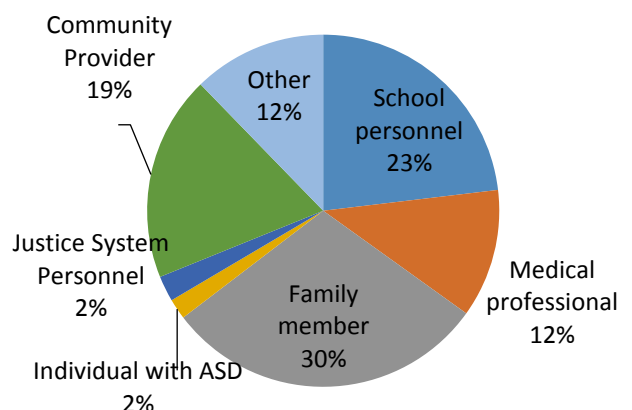
N = 908



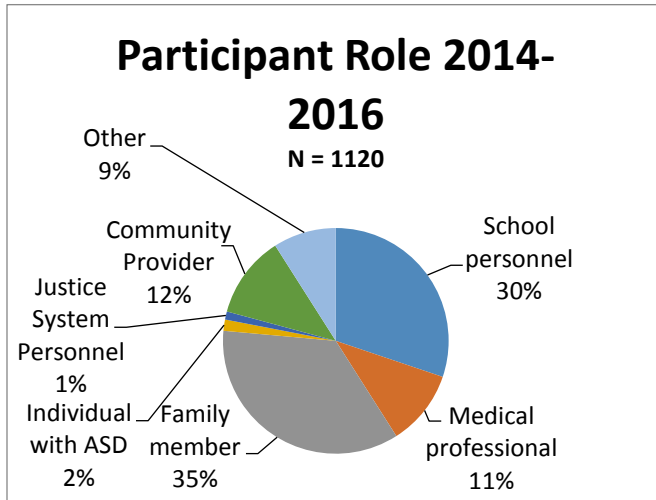
Participant Role 2015-2016

2016

N = 212

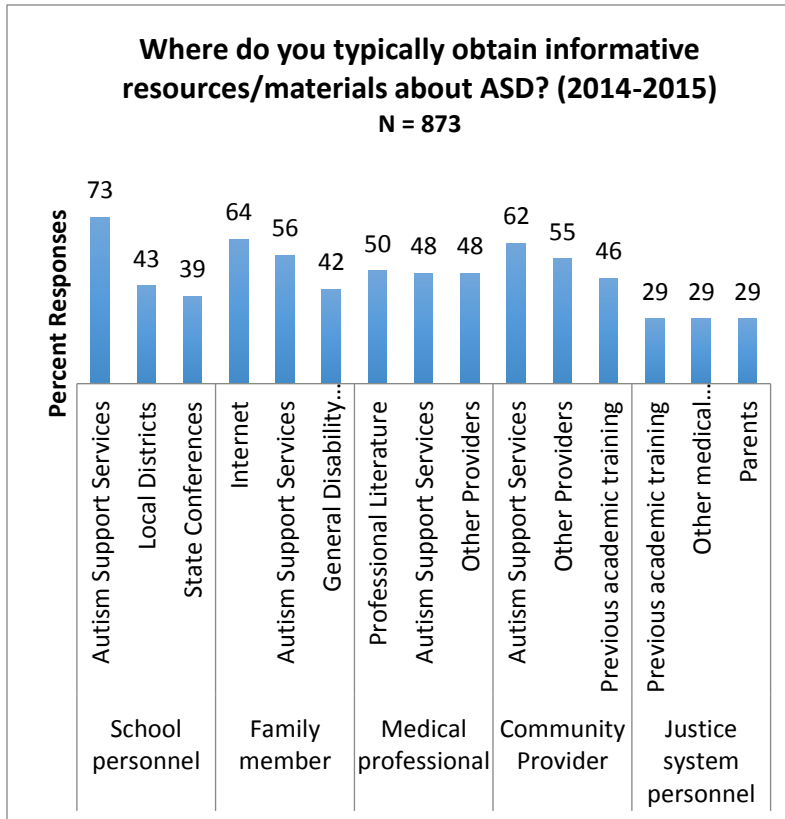


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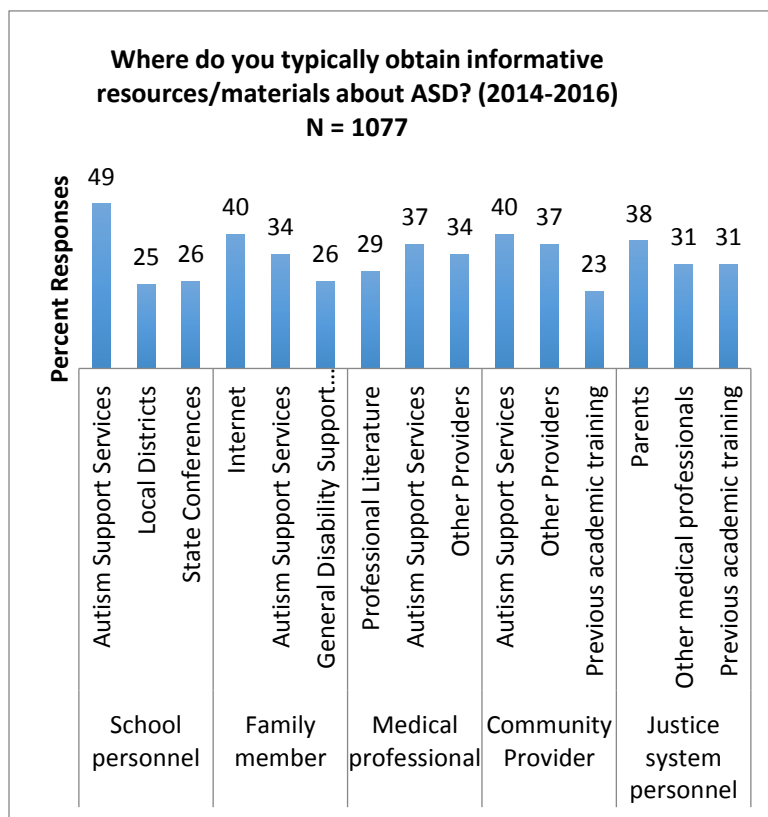
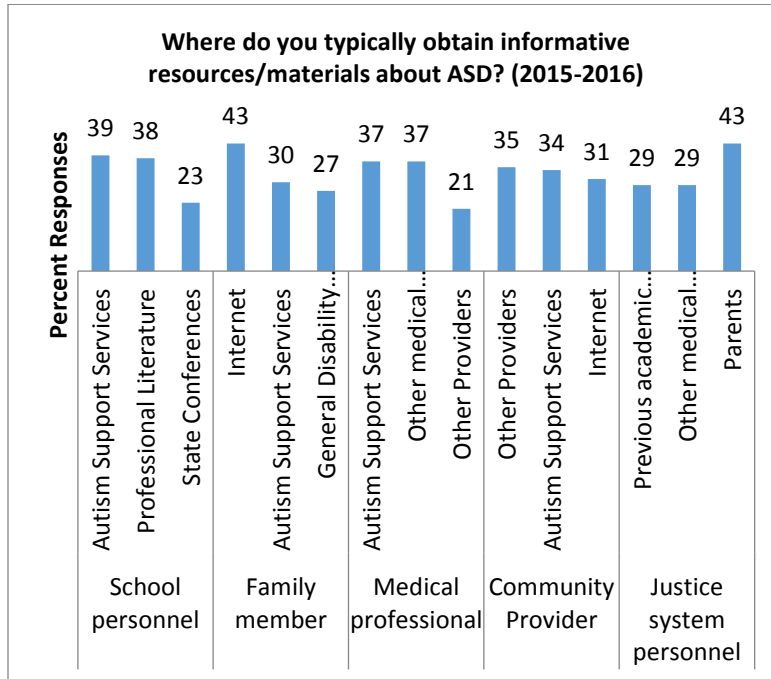


In reviewing responses across the last couple of years and in total across both years, the largest set of respondents were consistently school personnel and families while justice system personnel and individuals with ASD represented the smallest informant group. Given the focus and concentration in this year for determining the best strategies for increasing the respondents from particular stakeholder groups, the data reflect these increased efforts with some increase in responses from

justice personnel and individuals with ASD as well as more substantial increases with the community providers which would include some of the needed response groups. This trend will be expected to increase as the large number of contacts gathered and utilized to pursue these stakeholders are utilized to recruit more in these groups, again in pursuit of a more diverse population of respondents.



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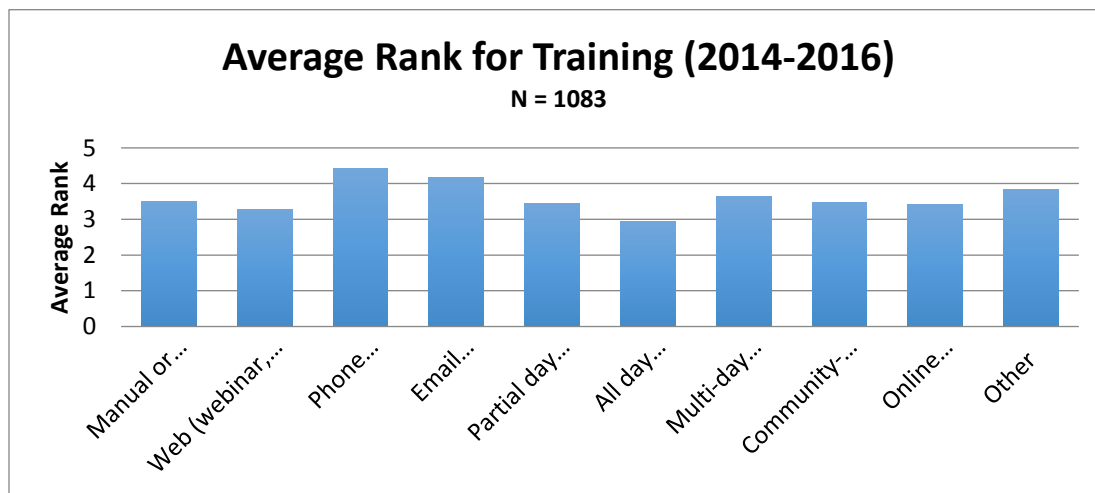


Another area in which some trends appear to be changing in the recent year (if not yet overall), is when asked to convey where most likely to get information about ASD. Across the last couple of years and overall, the trends across all groups, except justice system personnel, remain consistent with access to autism support services (e.g., HANDS in Autism®, ASI, IRCA) as one of their top 3 choices. It remains the top clear choice for school personnel, more readily reaching out to their community resources. Potentially, this involvement with the community autism resources could reflect increased knowledge, access

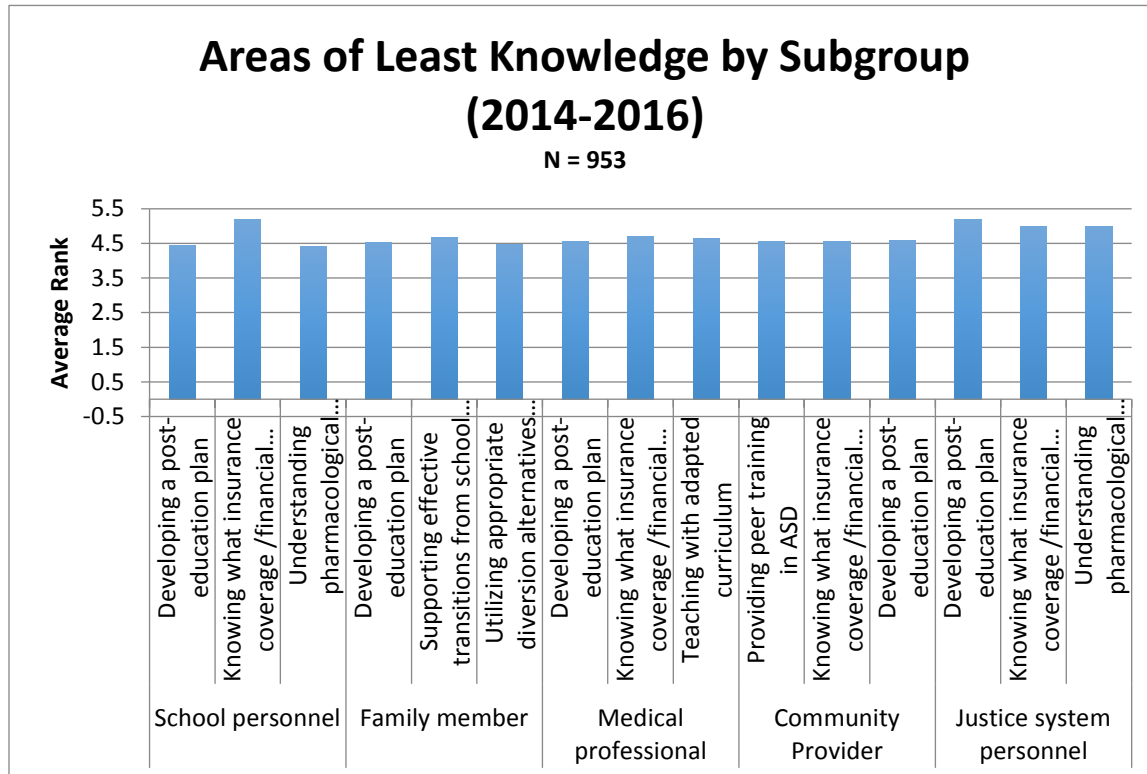
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or satisfaction with such services in recent years. Family members of individuals with ASD are still most likely to go to the internet for information and training about ASD and community providers, with large caseloads are tending in this direction as well. Highlights of potentially beginning changes include school personnel’s shift towards more literature, perhaps given more training and messaging about the need for evidence-based strategies and data-driven decision making. Medical professionals, however, are noted, at least in this past year, to be less interested in gaining information through the literature and more from other medical professionals or providers. Further, justice personnel are reporting seeking out information from parents much more so than other resources. Overall, the trends from the past year (2015-2016) reflect some progression away from getting resources and information internally or relying upon past knowledge or training and more to professional resources, families and the internet.



Despite the fact that trainings are often provided as online options, manualized treatments or single day workshops, stakeholders across Indiana have a stated and continued preference for more personalized (e.g., email and phone communications relevant to their own scenarios) and in depth trainings (e.g., multiday workshops) than more traditionally provided. Anecdotally, this information goes along with the routine requests for information more practical and relevant to the stakeholder’s setting and situation.



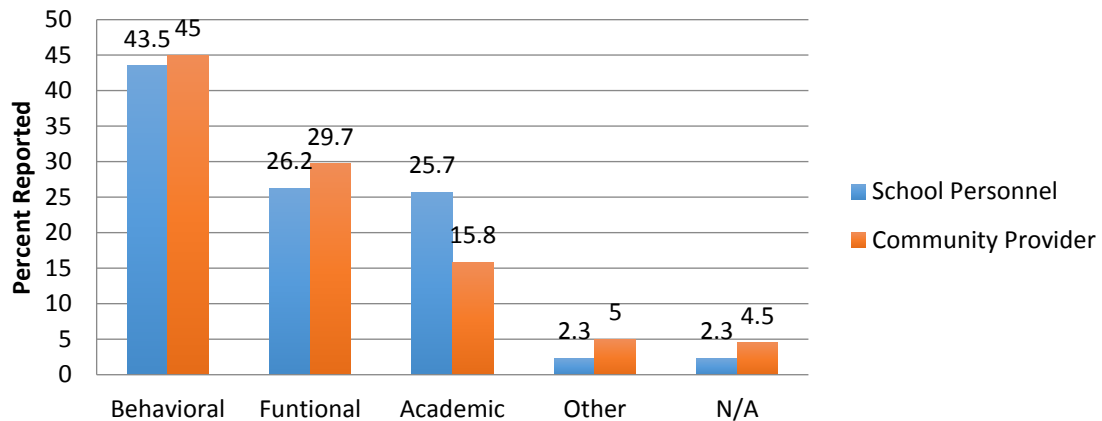
Though behavior, skills training, and data practices emerged as common themes in the earlier version of the needs assessment survey, in the current year’s project, overriding issues and areas of noted need for information include transition/post education planning and insurance coverage. These areas align with areas of national prominence and are key goal areas targeted for action in the Indiana Comprehensive State Plan. For more information, the Comprehensive Plan can be retrieved at the State website:

<http://www.in.gov/fssa/ddrs/3355.htm>.



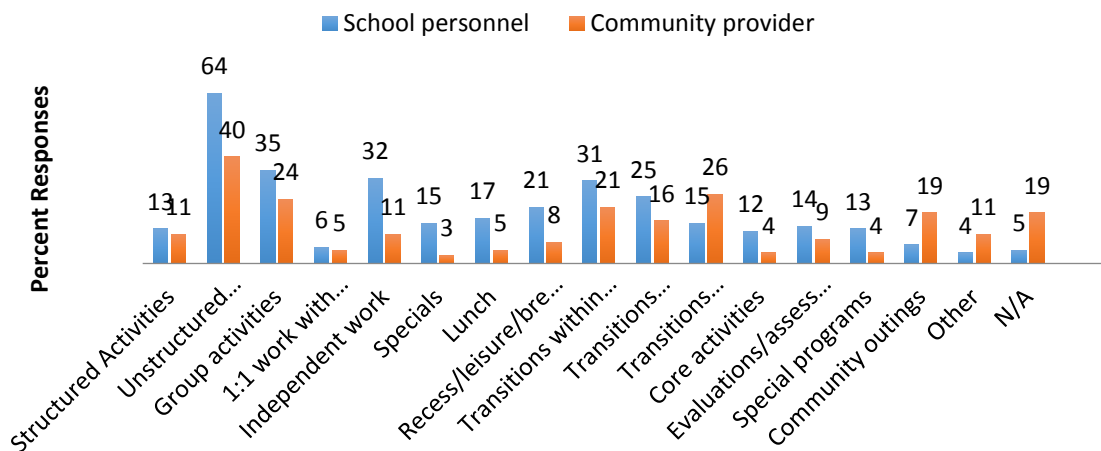
Challenges Faced with ASD Individuals 2014-2016

School personnel N = 642; Community provider N = 404



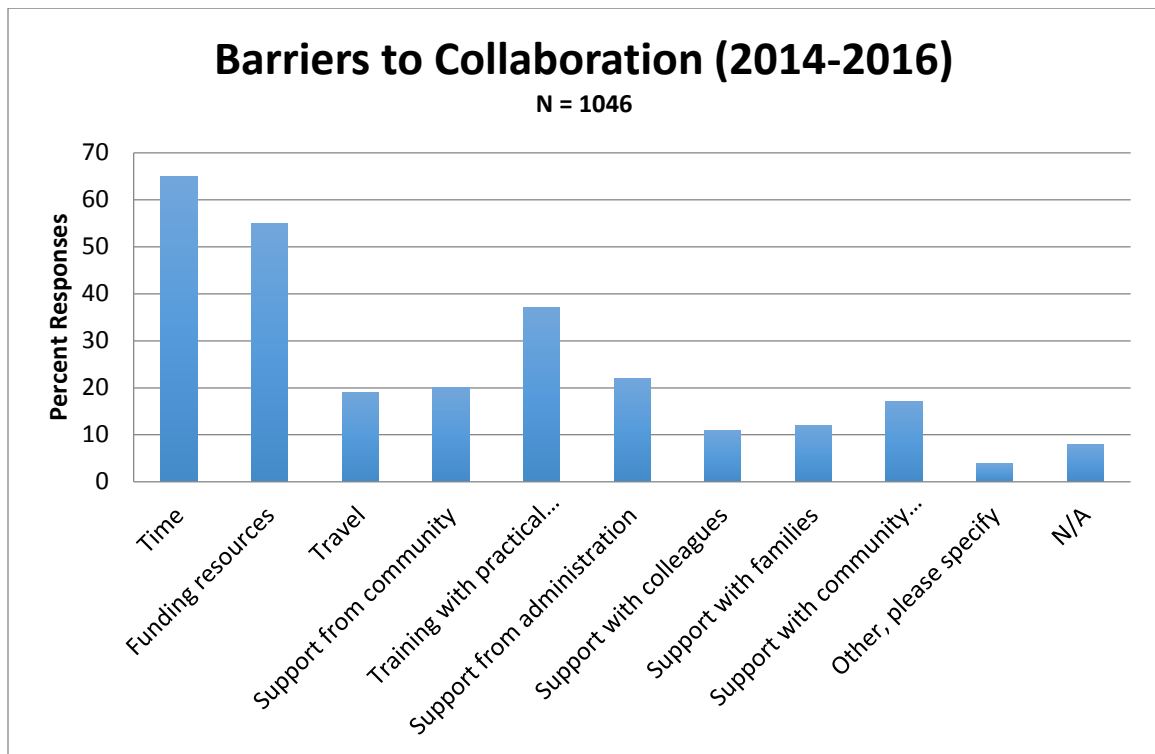
Setting with Most Challenges 2014-2016

School personnel N = 334; Community provider N = 228



When school personnel and community providers were asked about the challenges they face when working with individuals with ASD they were most likely to face behavioral challenges, but a significant number of those surveyed in both groups also listed functional challenges (e.g., self-help, socialization, communication, leisure/play skills). Additionally, both stakeholder groups listed unstructured activities (e.g., play/leisure time, recess) most frequently as the setting in which they face the most challenges.

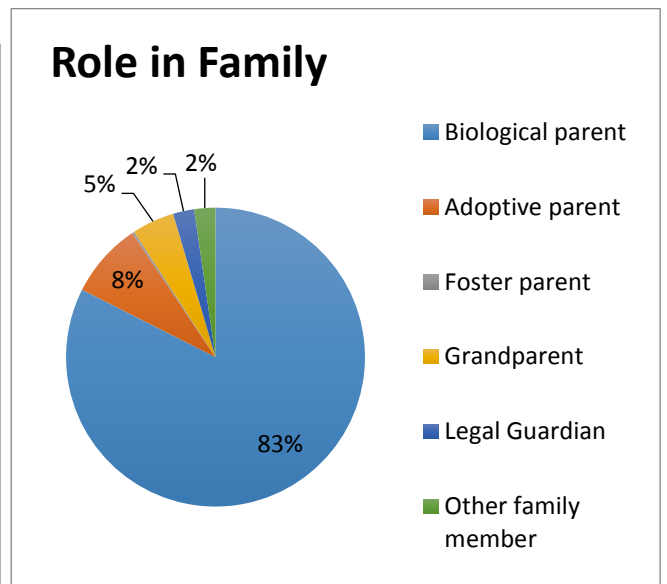
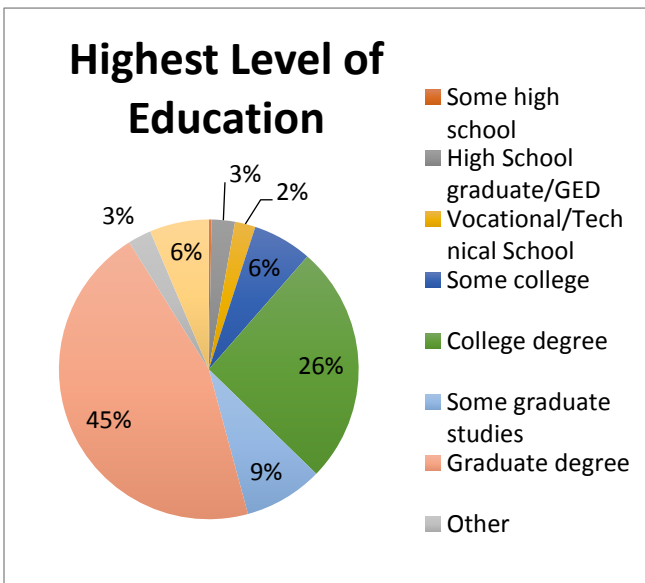
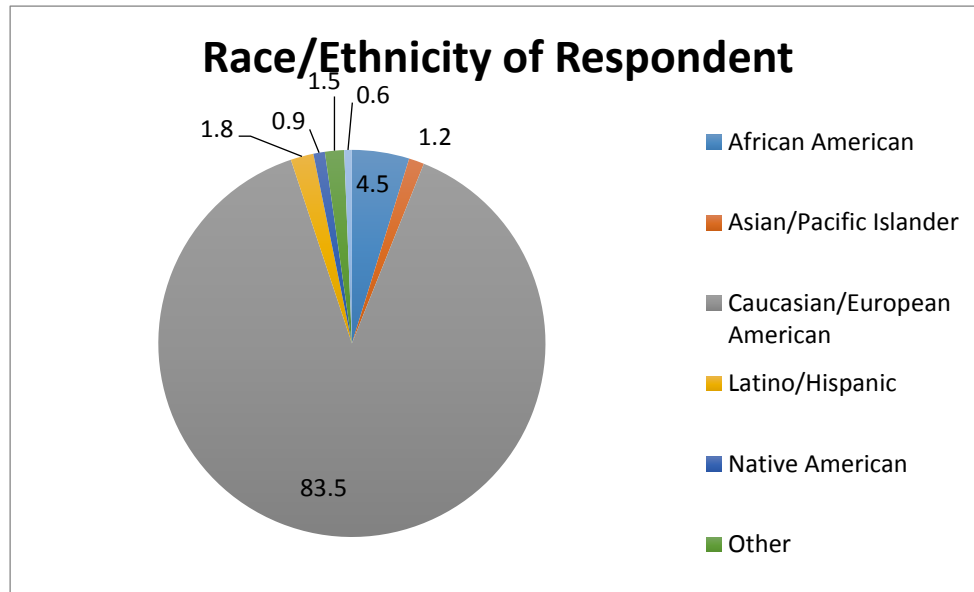
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Various stakeholder groups were in agreement with regards to the primary barriers to collaboration. The top three noted included time, funding resources, and training that entails learning practical information.

SUBGROUP RESULTS:
FAMILY MEMBERS: N = 399

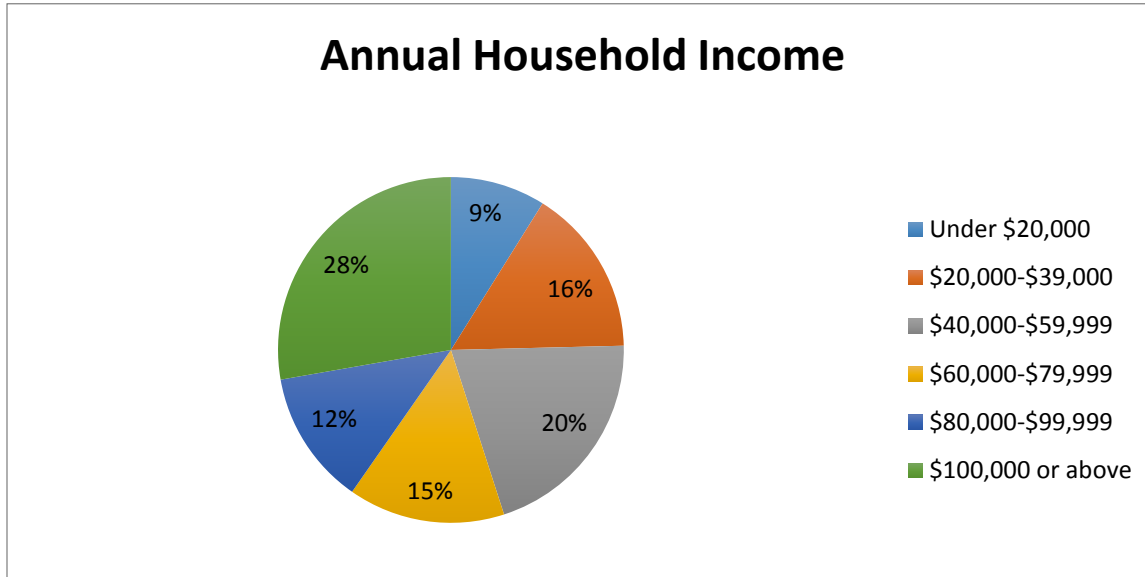
Out of 399 families responding state-wide, 83.5% of respondents identify as Caucasian/European American and 80% of them have a college or graduate degree. 83% described their role in the family as a biological parent, 8% as adoptive parent and others included foster parents, legal guardians, grandparents as well as sibling, stepparent, and aunt as their role.



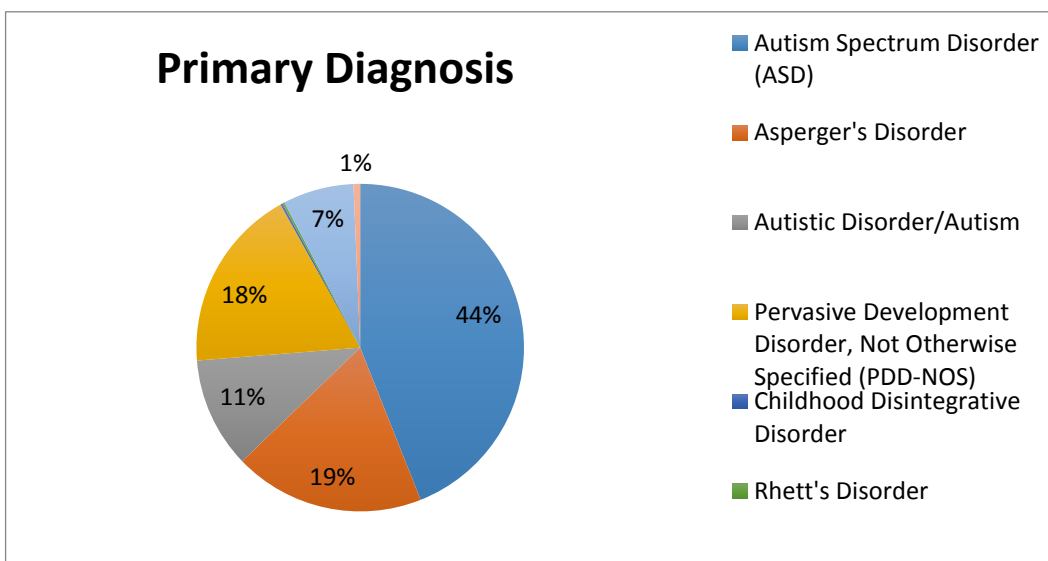
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The annual household income was spread relatively evenly across potential responses as follows:



Just under half (44%) of the respondents listed the child as having been diagnosed with the newer DSM-5 classification, Autism Spectrum Disorder (ASD) with approximately 48% of respondents with some combination of the previous categories of ASD (i.e., Autistic Disorder, Asperger’s Disorder, PDD-NOS) and 7% responding with an Other category.



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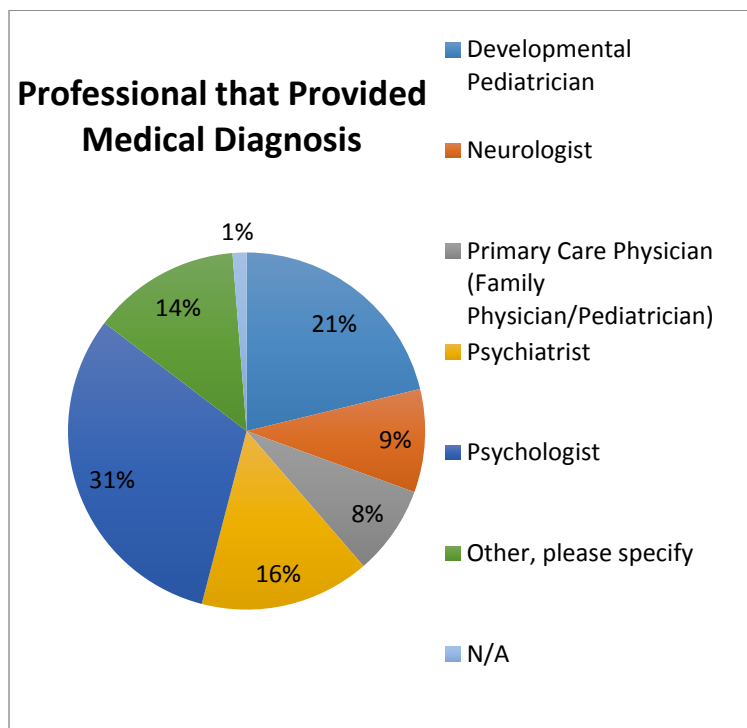


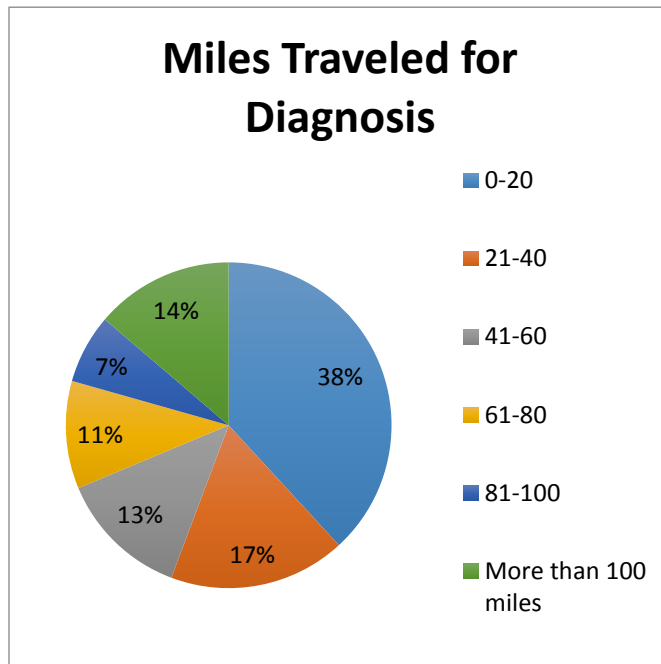
When asked if the individual had any other diagnoses, the top three responses were Attention Deficit/Hyperactive Disorder (ADHD), anxiety disorder, and communication disorder.

| Top 3 Other Diagnoses | | |
|--|-----------|---------|
| Diagnosis | Frequency | Percent |
| Attention Deficit/Hyperactivity Disorder | 134 | 35% |
| Anxiety Disorder | 164 | 42% |
| Communication Disorder | 112 | 29% |

74.1% of respondents said the individual had an educational classification of ASD in addition to a medical diagnosis, and 16.9% of those individuals received the educational classification prior to the medical diagnosis. In addition, for 17.6% of the individuals with ASD, the educational classification was different than the medical diagnosis at one point.

The diagnosing medical professional was most often a psychologist (31%), 16% by a psychiatrist and at least 38% by another category of medical doctor.





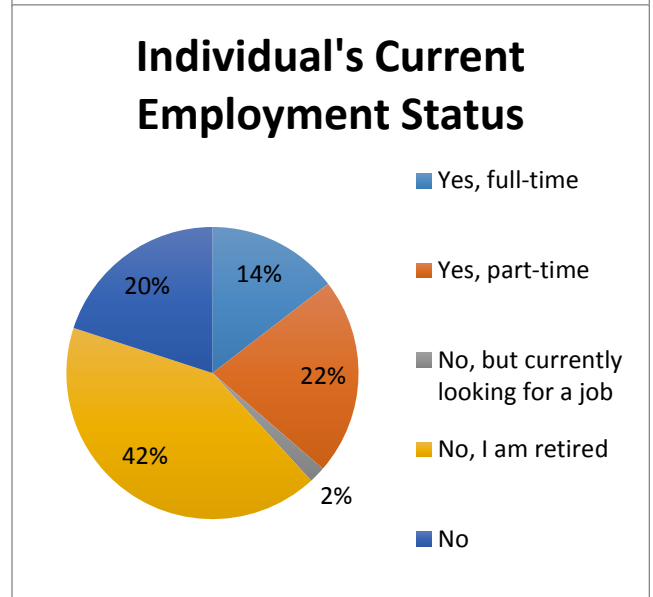
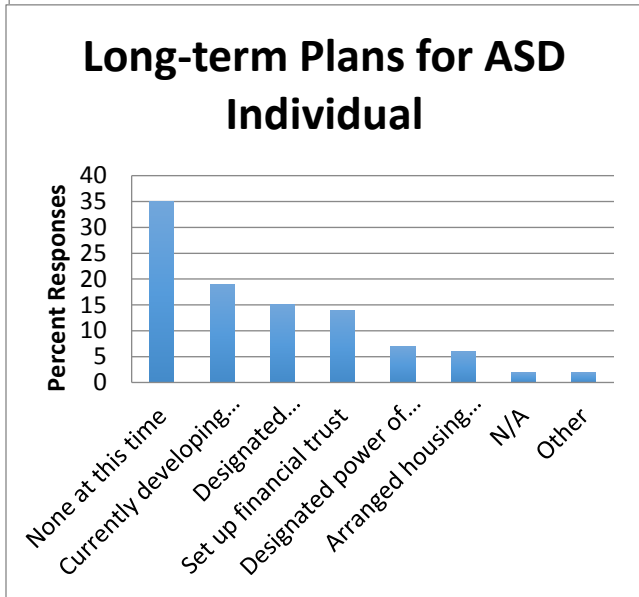
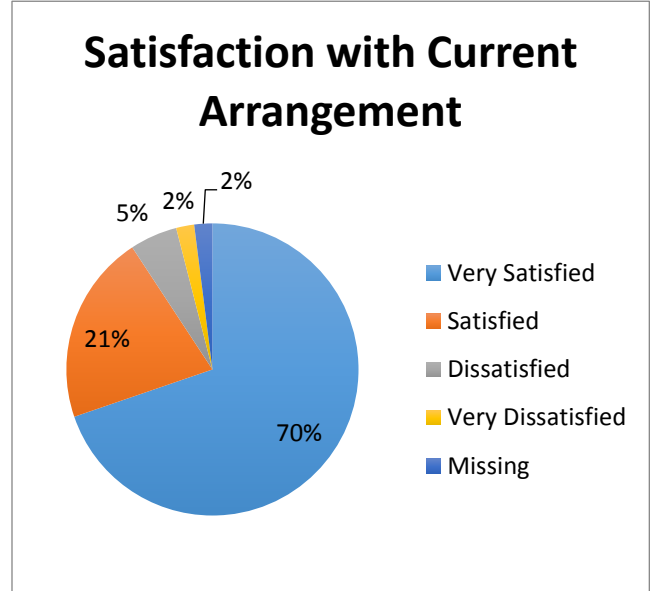
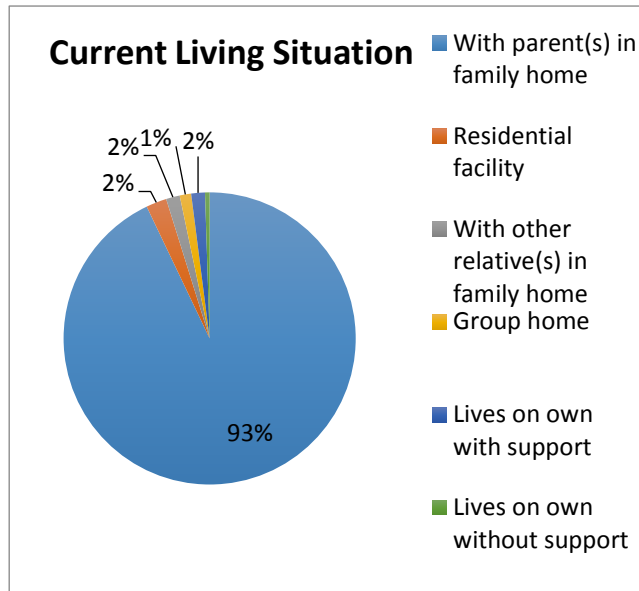
Most individuals (55%) were able to drive less than 40 miles for a diagnosis, but 14% of respondents had to drive more than 100 miles to get a diagnosis.

Almost all of the respondents said they were given other resources at the time of diagnosis, but 13.7% were given no follow up resources. The most common follow-up resource was a second appointment with the diagnosing professional. To pay for these services, 61.3% of respondents claimed their private insurance was covering payment, though 41.8% of individuals claimed they had to pay out-of-pocket for services.

Almost all of the individuals with ASD were living with parents in a family home (93%) and less than 10% of ASD individuals were living in another facility. Fortunately, 70% of respondents were very satisfied with the living arrangement of the individual with ASD.

Twenty-two percent (22%) of respondents claimed that the individual with ASD was unemployed. 36% of respondents said that the individual with ASD had either full or part-time employment.

When asked about long term plans for the individual with ASD, 35% claimed there was no long term plan, and 18% were in the process of developing a plan. It would be important to be assessing the age of the individuals with ASD that were the basis of this data to further understand the context of these responses (e.g., too young for employment, still in school).



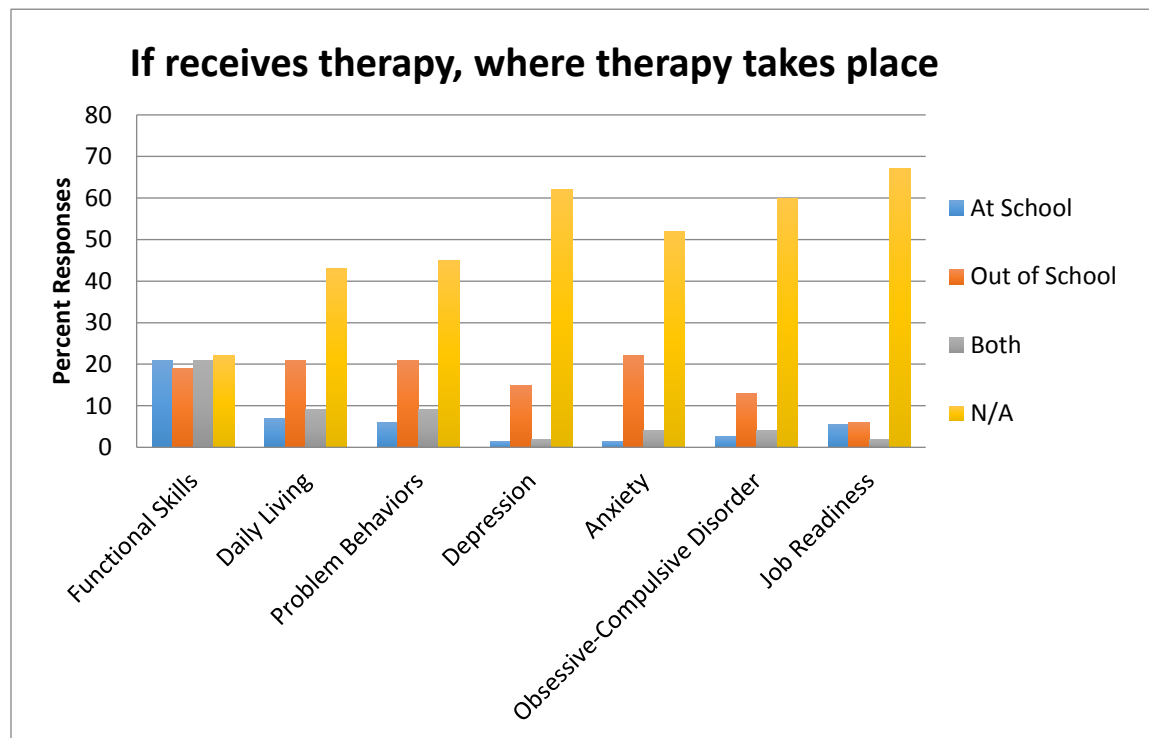
When asked about the therapies the child was receiving, it appeared that if the child needed therapy, there was a greater percentage of individuals who were able to receive it than not; however, approximately 20% of responses for each category of therapy were noted as not being received but in need of such therapies and/or services. This was particularly the case for job readiness/transition planning with over half of the respondents (52.2%) indicating the need for the service but only 16% of all respondents indicating that it was in place.

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| Is Individual with ASD receiving interventions for the following? | | | | |
|---|-------------------|--------------------------|------------------|-------------------------|
| Therapy | Yes, and needs it | Yes, but doesn't need it | No, and needs it | No, but doesn't need it |
| Functional Skills | 69.1% | 0.2% | 24.6% | 6.5% |
| Daily Living | 39.1% | 2.1% | 22.7% | 36.8% |
| Problem Behaviors | 39.9% | 1.0% | 22.1% | 38.3% |
| Depression | 18.1% | 0.7% | 11.9% | 69.4% |
| Anxiety | 35.1% | 0.5% | 25.9% | 38.9% |
| Obsessive-Compulsive Disorder | 20.4% | 2.3% | 21.6% | 56.0% |
| Job Readiness | 16.1% | 0.2% | 36.1% | 48.2% |

With regards to therapy locations, most therapies occur out of school or are not occurring (perhaps dependent on the age of the child). The one exception is with functional skills that are most regularly (approximately 21%) taking place about equally in, out or in both school and out of school forums.



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| Top 3 Perceived Limitations to Accessing Care | |
|--|-----------------|
| Limitation | Average Percent |
| None | 38.5 |
| Cost of services/insurance does not cover available services | 23.5 |
| Shortage of service providers in the area | 23.4 |

38.5% of families responding do not feel that there are limits to accessing care. However, for those who do, the limitations most often cited were cost/lack of insurance coverage, or a shortage of service providers in the area.

Similarly and as noted below, the limitations most notable for accessing family supports and specialty care include the cost/lack of insurance coverage and shortage of service providers in the area. However, an added limit to access were scheduling issues.

| Top 3 Limits to Accessing Family Support Services | | |
|---|-----------|---------|
| Limitation | Frequency | Percent |
| Cost of services/insurance does not cover available services | 130 | 34.1 |
| Scheduling issues | 95 | 27.1 |
| Shortage of service providers in the area | 26 | 44.8 |
| Top 3 Limits to accessing specialty health and education services | | |
| Limitation | Frequency | Percent |
| Shortage of service providers in the area | 161 | 45.1 |
| Cost of services/insurance does not cover available services | 165 | 43.7 |
| Scheduling issues | 90 | 24.7 |

Family members most commonly consulted the internet for both information resources and materials as well as for training; they also listed autism support services as the second most common source for information and training. Not surprisingly, their top three preferences for training were community-based coaching and mentoring, the internet, and partial day conferences or workshops.

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| Top 3 Sources for Information | | |
|-------------------------------------|-----------|---------|
| Source | Frequency | Percent |
| Internet | 246 | 64.8 |
| Autism support services | 211 | 51.6 |
| General disability support networks | 160 | 41.7 |

| Top 3 Sources for Training | | |
|----------------------------|-----------|---------|
| Source | Frequency | Percent |
| Internet | 113 | 27.1 |
| Other providers | 100 | 26.5 |
| Autism support services | 99 | 23.6 |

| Top 3 Training Preferences | |
|--|--------------|
| Type | Average rank |
| Web | 3.15 |
| Community-based coaching and mentoring | 3.15 |
| Partial day conference/workshop | 3.21 |

When asked who they most often collaborate with, families were most likely to collaborate with other families or medical professionals, and least likely to collaborate with justice system personnel. The top 3 barriers they listed for collaboration are time, funding resources, and training that provides practical information.

| Top 3 Barriers to Collaboration | | |
|---------------------------------|-----------|---------|
| Barrier | Frequency | Percent |
| Time | 180 | 49.3 |
| Funding Resources | 167 | 46.6 |
| Training w/ practical info | 21 | 43.1 |

Indiana Autism Support Services Gap Analysis

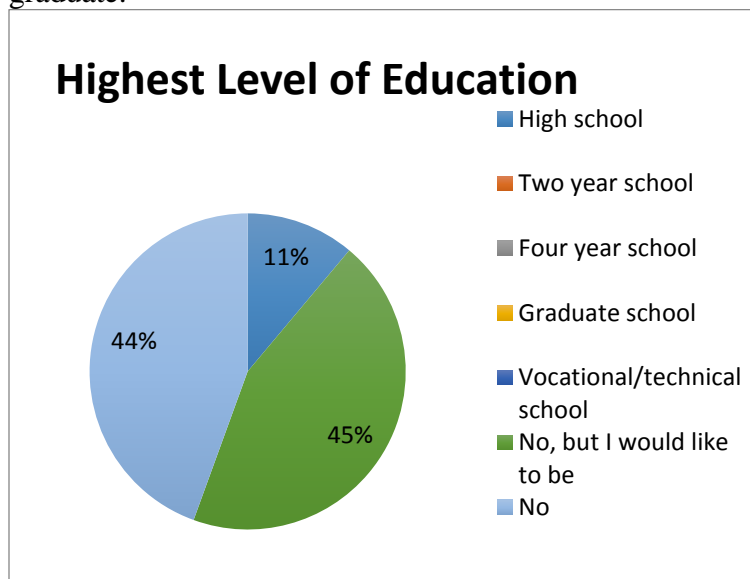


Family members felt they had the most knowledge in understanding characteristics and learning styles of individuals with ASD, explaining the disorder to family and friends, and understanding early signs of the disorder. They felt they were least knowledgeable on utilizing appropriate diversion alternatives, supporting effective transitions from school to vocation, and developing a post-education plan. When asked which areas they would like more information, the top three responses were understanding laws and policy related to ASD, knowing what insurance/financial support options are available and what services they cover, as well as effectively advocating for the individual with ASD.

| Top 3 Areas for More Info | | |
|---|-----------|---------|
| Area | Frequency | Percent |
| Understanding laws and policy related to ASD | 197 | 55.5 |
| Knowing what insurance/financial support options are available and what services they cover | 171 | 49.3 |
| Effectively advocating for individual with ASD | 169 | 46.9 |

INDIVIDUALS WITH ASD: N = 18

Of the individuals with ASD who participated in the survey (n=18), 11% had graduated high school, 44% had not graduated, and 45% had not graduated but would like to be a graduate.

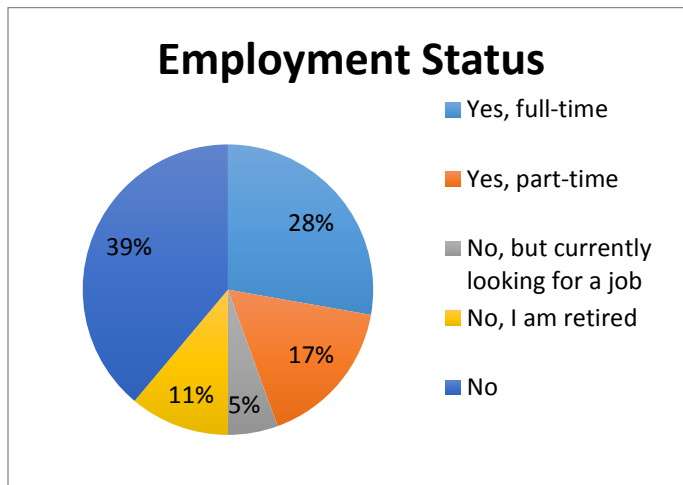


Of those responding, 61% had never been married, 22% were married and 17% were divorced. Almost half (45%) had children or were interested in doing so.

| What is your current marital status? | | | |
|--------------------------------------|-----------|---------|--|
| Status | Frequency | Percent | |
| Married | 4 | 22 | |
| Separated/Divorced | 3 | 17 | |
| Never been married | 11 | 61 | |

| Do you have any children? | | | |
|---------------------------------|-----------|---------|--|
| Children | Frequency | Percent | |
| Yes | 5 | 28 | |
| No, but planning on having them | 3 | 17 | |
| No, undecided | 4 | 22 | |
| No, and I don't want children | 6 | 33 | |

When asked about employment, 55% of respondents were currently unemployed (44% unemployed or looking, 11% retired). Only 28% were employed full time.



In searching for employment, most common resources included the internet, word of mouth, and newspaper.

| Top 3 Ways to Look for Work | | | |
|-----------------------------|-----------|---------|--|
| Area | Frequency | Percent | |
| Internet | 14 | 78 | |
| Word of Mouth | 8 | 44 | |
| Newspaper | 6 | 33 | |

Indiana Autism Support Services Gap Analysis



Individuals felt discriminated against in a variety of ways (i.e., skills underutilized, without appropriate compensation/promotions/raises or support, and only 1 respondent claimed to feel no discrimination. Only 22% of those responding indicated that all at their place of employment know of their disability. All others had only shared with a subset or do not feel comfortable sharing.

| Do you feel discriminated against in the workplace? | | |
|---|-----------|---------|
| Discrimination | Frequency | Percent |
| My skills are underused | 4 | 28.6 |
| I don't receive appropriate compensation | 2 | 14.3 |
| I don't receive promotions/raises | 1 | 7.1 |
| I don't receive appropriate accommodations or support | 3 | 21.4 |
| None | 1 | 7.1 |
| Other | 3 | 21.4 |
| Coworkers aware of autism? | | |
| Awareness | Frequency | Percent |
| Yes, everyone knows | 2 | 22.2 |
| Yes, but only my supervisors know | 2 | 22.2 |
| Yes, but only my peers/coworkers know | 2 | 22.2 |
| No, I don't feel comfortable sharing | 3 | 33.3 |

Individuals with ASD responding to this survey between 2014-2016 engage in a number of activities but the top three include household chores/duties, hobbies or special interests and volunteering. Only 50% transport independently (i.e., drive or public transport) to work/school while approximately 33% depend on others.

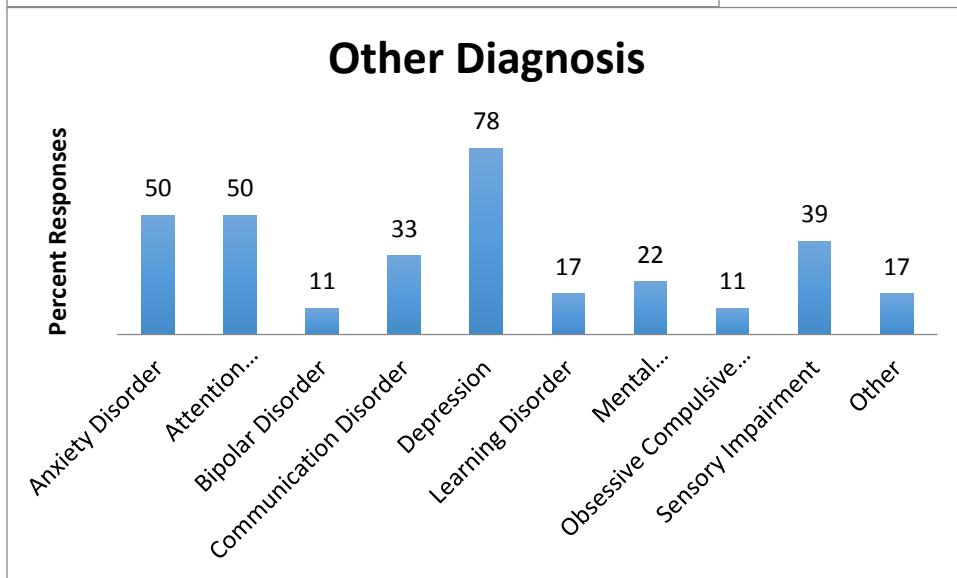
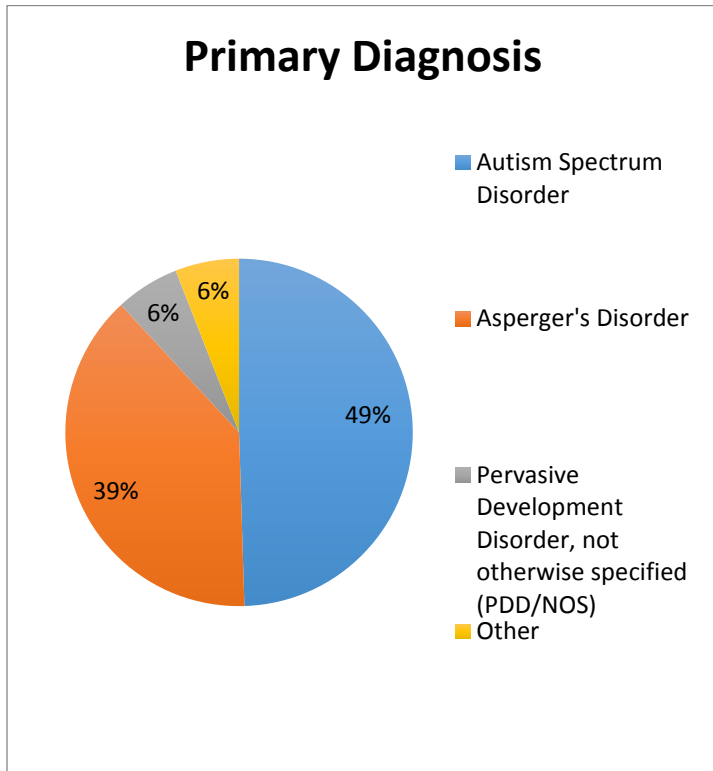
| Top 3 Activities | | |
|-----------------------------|-----------|---------|
| Activities | Frequency | Percent |
| Household chores/duties | 17 | 94.4 |
| Hobbies or special interest | 15 | 83.3 |
| Volunteer | 11 | 61.1 |

| Travel to work, school, etc. | | |
|---|-----------|---------|
| Method | Frequency | Percent |
| Drive myself or use public transportation on my own | 9 | 50 |
| Depend on family member or friend for support | 5 | 27.7 |
| Use transportation provided by school or work | 1 | 5.5 |

Indiana Autism Support Services Gap Analysis



Autism Spectrum Disorder was listed as the most common primary diagnosis, and 75% of respondents said they were also diagnosed with depression.



Indiana Autism Support Services Gap Analysis



The top three limits to accessing services were noted to be shortage of service providers and the cost of those services though scheduling was also noted. Services were most commonly paid for out-of-pocket and through state-funded processes.

| Limitations to Accessing Services | | |
|---|-----------|---------|
| Limitation | Frequency | Percent |
| Cost of services/My insurance does not cover available services | 7 | 39 |
| Shortage of service providers | 7 | 39 |
| Other | 5 | 28 |
| No service providers in the area | 4 | 22 |
| How are services paid for | | |
| Payment method | Frequency | Percent |
| Out-of-pocket | 5 | 28 |
| State-funded processes | 5 | 28 |
| Private health insurance | 3 | 17 |
| Medicaid | 3 | 17 |
| I don't know | 2 | 11 |
| Other | 1 | 6 |
| N/A | 1 | 6 |

Individuals were receiving a variety of treatments as reflected in the chart below:

| Specialty health and education needs | | | | | |
|--------------------------------------|----------------|-------------------------------|---------------------------------|------------------------------|--------------------|
| Category | I am receiving | I am receiving, but need more | I am receiving, but do not need | I am not receiving, but need | I am not receiving |
| Mental health counseling | 29.2 | 0 | 0 | 20.9 | 50 |
| Speech/language therapy | 12.5 | 0 | 4.2 | 8.4 | 75 |
| Occupational therapy | 4.2 | 0 | 0 | 29.2 | 66.7 |
| Physical therapy | 0 | 4.2 | 0 | 41.7 | 50 |
| Social skills training | 16.7 | 4.2 | 0 | 37.5 | 41.7 |
| One-to-one support | 16.7 | 0 | 0 | 29.2 | 54.2 |
| Behavior intervention | 16.7 | 0 | 0 | 8.4 | 75 |
| Case management | 29.2 | 0 | 0 | 16.7 | 54.2 |
| Medication management | 29.2 | 12.5 | 0 | 4.2 | 54.2 |

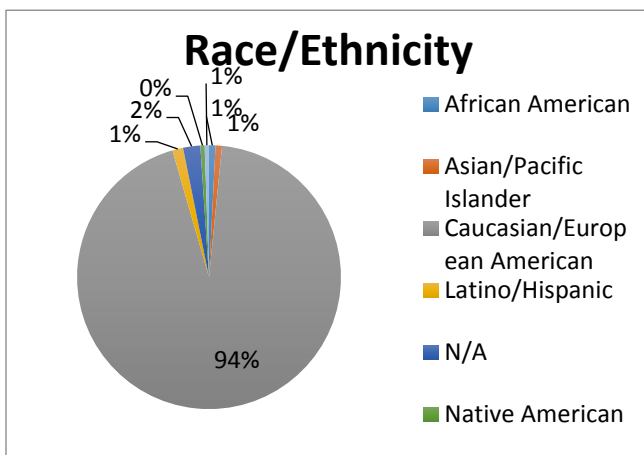
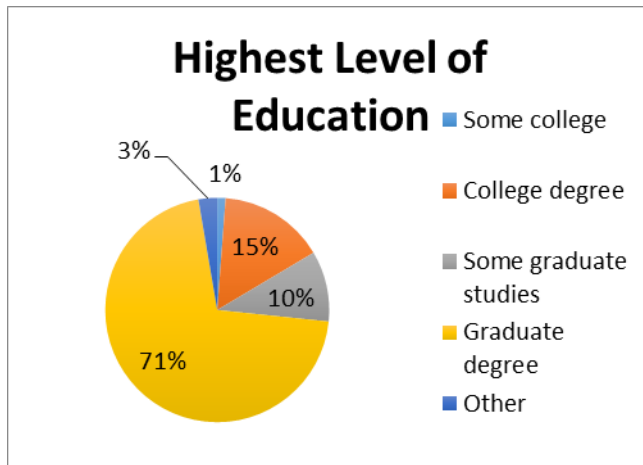
Indiana Autism Support Services Gap Analysis



| | | | | | |
|-----------------------------|------|-----|------|------|------|
| Summer camp | 0 | 4.2 | 0 | 8.4 | 87.5 |
| Summer school | 12.5 | 0 | 0 | 0 | 70.9 |
| Relationship counseling | 0 | 0 | 0 | 29.2 | 70.9 |
| Drug and alcohol counseling | 0 | 0 | 0 | 4.2 | 95.9 |
| Case management | 12.5 | 0 | 12.5 | 16.7 | 58.4 |
| Vocational training | 0 | 0 | 12.5 | 25 | 75 |
| Transition planning | 0 | 0 | 12.5 | 12.5 | 75 |
| Supported employment | 0 | 0 | 0 | 16.7 | 83.4 |
| Career counseling | 4.2 | 0 | 0 | 33.3 | 62.5 |

SCHOOL PERSONNEL: N = 379

Of the 379 school personnel surveyed, most respondents (94%) described themselves as Caucasian or European American. 71% of respondents listed a graduate degree as their highest level of education.

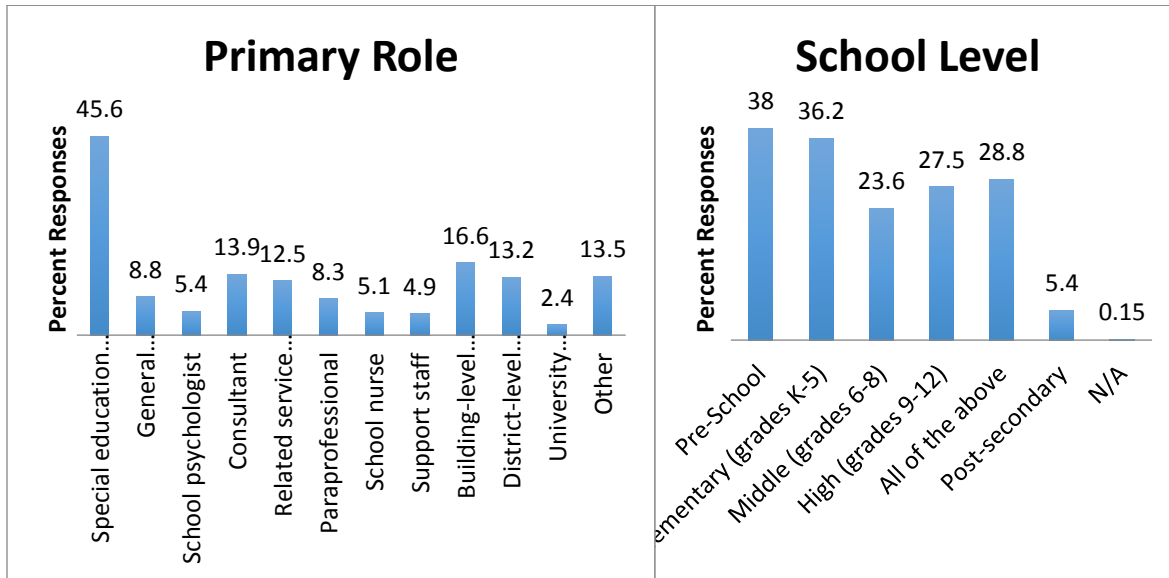


The largest portion of respondents work in central/eastern Indiana (38%), 33% in the southern region and 28% in the northern region, demonstrating adequate diversity and representation of these informants.

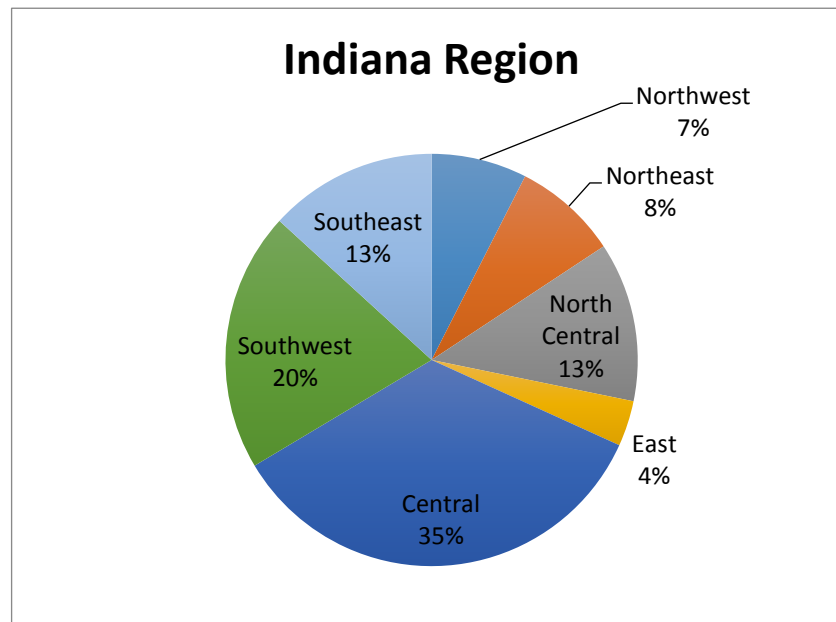
Indiana Autism Support Services Gap Analysis



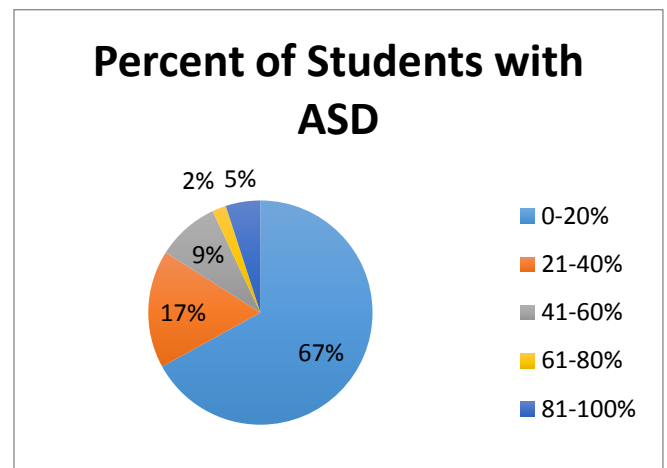
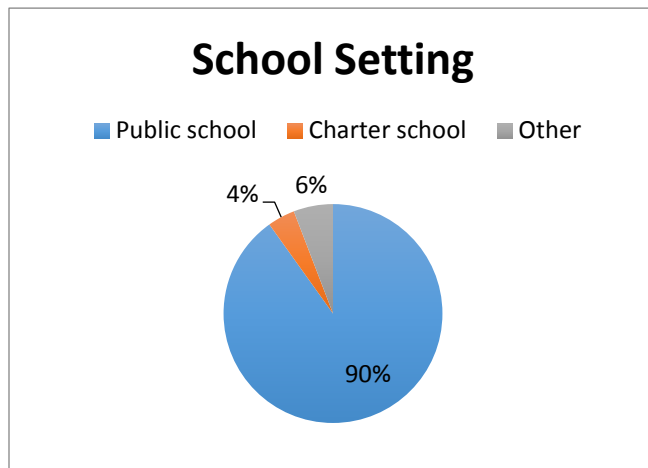
45.6% of respondents describe their role as a special education teacher primarily in elementary school, but 28.8% of respondents work across all school-age education levels with all levels with reasonably similar representation. Fewer respondents were noted to work in other school personnel positions or in post-secondary work.



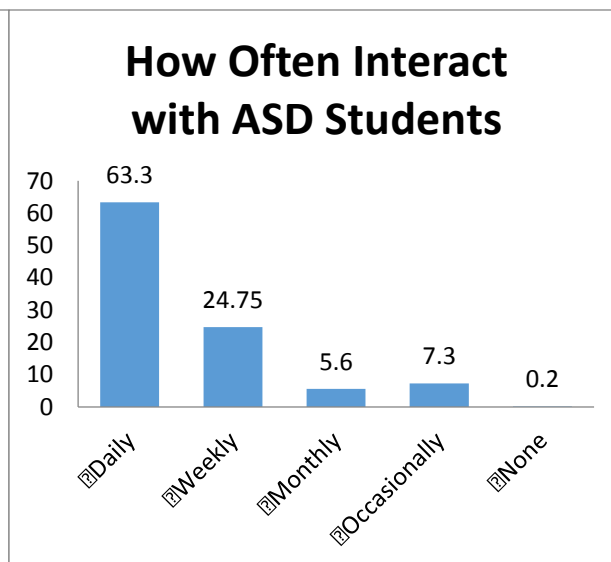
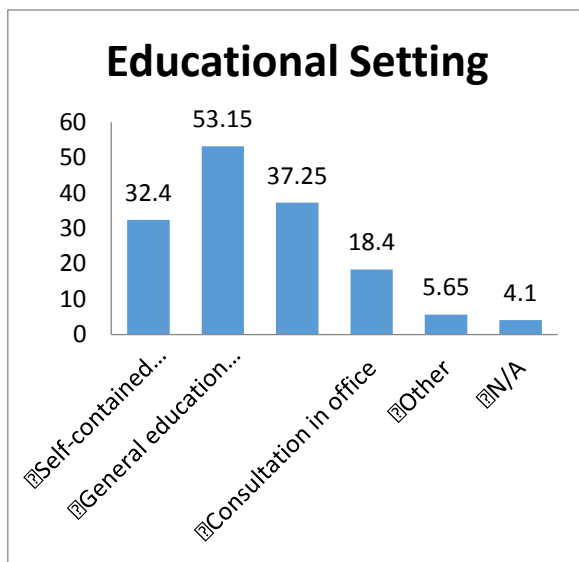
90% of those responding work in public schools indicating the need for insight from those in charter, private schools and/or other teaching settings (e.g., ABA centers). Most (69%) of informants having over 60% of their caseload as students with ASD.



Indiana Autism Support Services Gap Analysis



The top educational setting served by respondents is the general education classrooms. 67.4% of respondents answered that they work with ASD students daily. They experienced a variety of challenges in a number of settings, but primarily in unstructured activities, group activities, and independent work. A large number of respondents claimed that they face behavioral challenges, functional and academic challenges.



Indiana Autism Support Services Gap Analysis



While school personnel utilized a variety of different sources for information and materials on ASD, the top three responses were autism support services, professional literature, and local districts’ autism teams and/or consultants. As such school personnel are working as collaborative partners with collaborations inside and out of the school.

| Top 3 Sources for Info | | |
|---------------------------------|-----------|---------|
| Source | Frequency | Percent |
| Autism Support Services | 196 | 40% |
| Professional Literature | 154 | 31% |
| Local District(s)' Autism Teams | 139 | 28% |

Training sources were most commonly noted as state conferences, support services and local districts’ autism teams and/or consultants. Preferences for training format were indicated to be partial day workshops, followed by full day workshops and onsite coaching and mentoring. Barriers to training were listed as funding resources, time, and class coverage as their top three barriers.

| Top 3 Sources for Training | | |
|---------------------------------|-----------|---------|
| Source | Frequency | Percent |
| State Conferences | 143 | 0.40 |
| Autism Support Services | 116 | 0.33 |
| Local District(s)' Autism Teams | 107 | 0.27 |

| Top 3 Training Preferences | |
|-------------------------------|------|
| Source | Rank |
| Partial day workshop | 2.46 |
| All day workshop | 2.86 |
| Onsite coaching and mentoring | 2.99 |

| Top 3 Barriers to Training | | |
|----------------------------|-----------|---------|
| Barrier | Frequency | Percent |
| Funding Resources | 245 | 0.43 |
| Time | 204 | 0.36 |
| Staff class coverage | 123 | 0.22 |

When queried about the various required services in their district, many of the school personnel said their district was required to provide full services. However, when asked about various services available, respondents were most confident that their district had the capacity to deliver related services, special transportation and paraprofessional supports. However, they were less confident that capacity existed to provide opportunities for outside consultation/training, low student to teacher ratios or ongoing internal training and support.

Indiana Autism Support Services Gap Analysis



| What capacity does your district have to provide if needed? | | | | | |
|---|--------|---------|--------|--------|---------|
| Service | Full | Partial | Some | None | Missing |
| Related Services | 0.667 | 0.165 | 0.1355 | 0.013 | 0.029 |
| Special Transportation | 0.7855 | 0.072 | 0.0555 | 0.0615 | 0.0255 |
| Outside Consultation/Training | 0.204 | 0.29 | 0.311 | 0.166 | 0.0395 |
| Paraprofessionals | 0.491 | 0.318 | 0.1505 | 0.0235 | 0.027 |
| Low Student/Teacher Ratio | 0.1915 | 0.396 | 0.1875 | 0.0965 | 0.0635 |
| On-Going Training/Support (from internal staff) | 0.2445 | 0.3465 | 0.3045 | 0.073 | 0.042 |

When asked about discipline policies, positive/proactive policies, school wide positive behavior supports, and response to instruction processes, most of the respondents believed these to be somewhat effective, if not better.

| Discipline Policy Effectiveness | | |
|--|-----------|---------|
| Effectiveness | Frequency | Percent |
| Very effective | 39 | 0.15 |
| Somewhat effective | 183 | 0.71 |
| Makes no difference | 12 | 0.05 |
| Somewhat ineffective | 18 | 0.07 |
| Very ineffective | 7 | 0.03 |
| Effectiveness of positive/proactive strategies | | |
| Effectiveness | Frequency | Percent |
| Very effective | 39 | 18.4% |
| Somewhat effective | 164 | 77.4% |
| Makes no difference | 6 | 2.8% |
| Somewhat ineffective | 1 | 0.5% |
| Very ineffective | 2 | 0.9% |
| Effectiveness of SWPBS | | |
| Effectiveness | Frequency | Percent |
| Very effective | 30 | 0.20 |
| Somewhat effective | 106 | 0.72 |
| Makes no difference | 7 | 0.05 |
| Somewhat ineffective | 3 | 0.02 |
| Very ineffective | 2 | 0.01 |

Indiana Autism Support Services Gap Analysis



| Effectiveness of RtI | | |
|----------------------|-----------|---------|
| Effectiveness | Frequency | Percent |
| Very effective | 46 | 22.7% |
| Somewhat effective | 134 | 66.0% |
| Makes no difference | 13 | 6.4% |
| Somewhat ineffective | 7 | 3.4% |
| Very ineffective | 3 | 1.5% |

Of the school personnel surveyed, they most often collaborated with colleagues and families to implement best practices methods, and they were least likely to collaborate with justice system personnel. The top three barriers they listed to collaboration are time, funding resources, and training with practical information.

| Top 3 Barriers to Collaboration | | |
|-------------------------------------|-----------|---------|
| Barrier | Frequency | Percent |
| Time | 226 | 0.46 |
| Funding | 165 | 0.34 |
| Training with Practical Information | 101 | 0.21 |

School personnel were also asked to rank how much knowledge they felt they had in certain areas. They felt that they had the most knowledge in understanding the characteristics and learning styles of individuals with ASD as well as the more proactive strategies of providing visual structure and support, and using positive behavioral support methods. On average, they felt they had the least amount of knowledge in insurance coverage or financial support options available and what services are covered as well as understanding of pharmacological interventions and generally developing post education plans. The three most acknowledged areas for needing more information were understanding ASD laws and policy, accessing appropriate mental health services, and providing support and training to others about ASD.

| Top 3 Areas of Knowledge | |
|---|--------------|
| Area | Average Rank |
| Understanding general characteristics and learning styles of individuals with ASD | 2.25 |
| Using positive behavioral supports | 2.35 |
| Providing visual structure and supports | 2.5 |

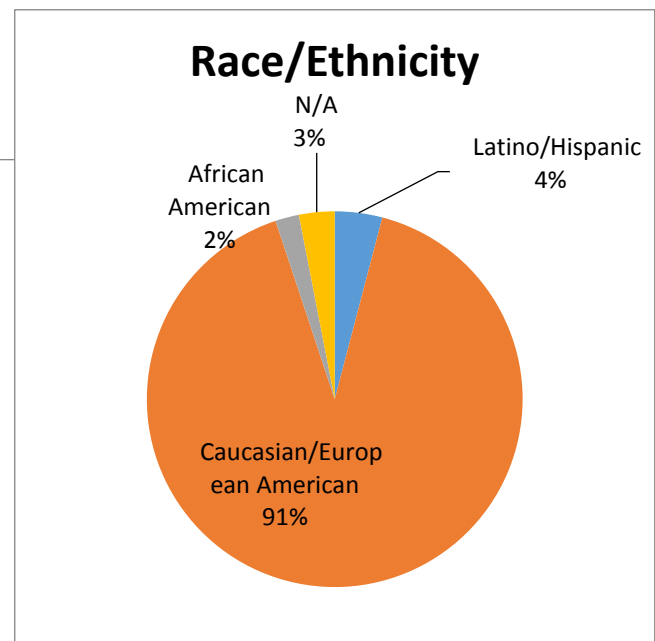
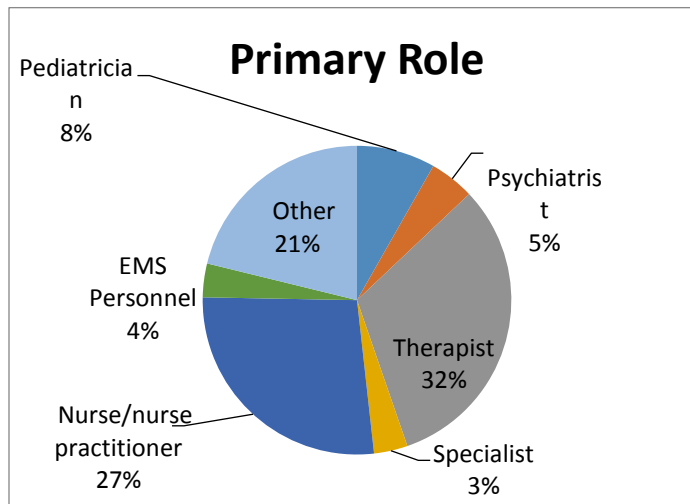
Indiana Autism Support Services Gap Analysis



| Bottom 3 Areas of Knowledge | | |
|--|--------------|---------|
| Area | Average Rank | |
| Knowing what insurance coverage/financial support options are available and what services they cover | 4.74 | |
| Understanding pharmacological interventions | 4.42 | |
| Developing a post-education plan | 4.81 | |
| Top 3 Areas for More Info | | |
| Area | Frequency | Percent |
| Understanding laws and policy related to ASD | 115 | 34.8% |
| Accessing appropriate mental health services | 108 | 32.7% |
| Providing support and training to others about ASD | 107 | 32.4% |

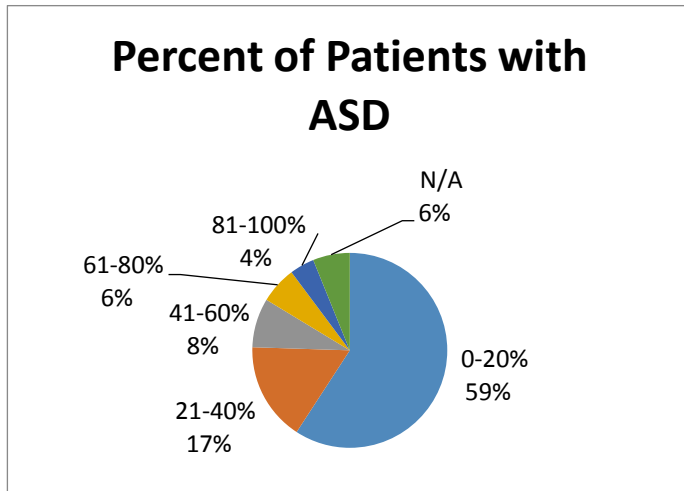
MEDICAL PERSONNEL: N = 121

There were 121 medical professionals surveyed, and 91% described themselves as

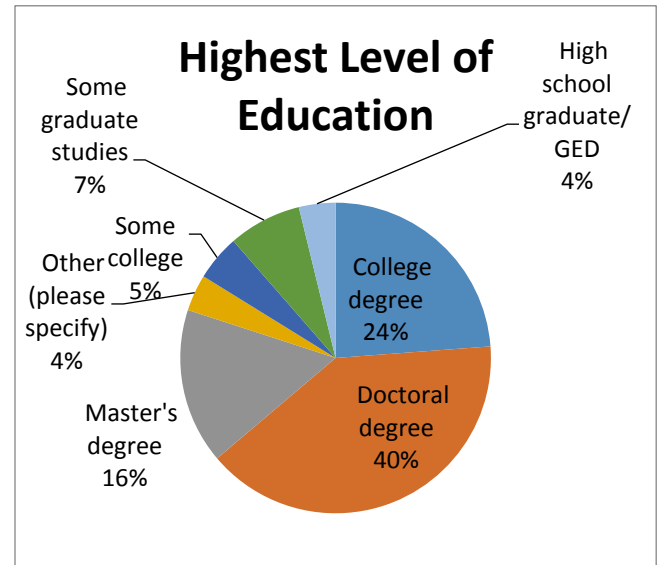


Caucasian/European American. The highest level of education for 56% percent of respondents was a graduate degree. Their roles within the medical profession were varied, but most 59% were therapists or nursing staff.

Indiana Autism Support Services Gap Analysis



More than half of the respondents indicated that 0-20% of their patients have ASD with only 10% seeing mostly those with ASD. Medical providers surveyed here note that they are most likely to interact with them in a community or hospital based office or clinic.



In obtaining information relevant to ASD, medical personnel were most likely to consult professional literature, autism support services, and other providers. Their top sources for training about ASD were professional literature, professional associations and other medical professionals. With regards to the types of training preferred, most notable were partial day events, web-based learning and manuals or other written materials.

| Top 3 Sources for Training | | |
|----------------------------------|--------------|---------|
| Source | Frequency | Percent |
| Professional Literature | 46 | 39% |
| Professional associations | 37 | 32% |
| Other medical professionals | 34 | 29% |
| Top 3 Preferences for Training | | |
| Preference | Average Rank | |
| Partial day conference/workshop | 2.67 | |
| Web | 2.83 | |
| Manual or other written material | 2.92 | |

Indiana Autism Support Services Gap Analysis



According to reports, medical providers were most likely to interact with colleagues, families, and other medical professionals to implement best practice strategies, and they were least likely to interact with justice system personnel. The top barriers to collaboration listed were funding resources, training with practical information, and time.

| Top 3 Barriers to Collaboration | | |
|-------------------------------------|-----------|---------|
| Barrier | Frequency | Percent |
| Funding resources | 71 | 0.44 |
| Training with practical information | 53 | 0.33 |
| Time | 37 | 0.23 |

Areas that medical providers felt most knowledgeable about include understanding how to access appropriate mental health services, an area of concern for school personnel. On the other hand, they felt least knowledgeable about developing a post education plan and knowing what insurance coverage and financial support options are available and what they cover. They indicated the desire to have more information in understanding law and policy related to ASD, developing successful relationships/collaborations with caregivers of individuals with ASD and developing appropriate IEPs.

| Top 3 Areas for More Info | | |
|--|-----------|---------|
| Area | Frequency | Percent |
| Understanding laws and policy related to ASD | 42 | 0.45 |
| Developing successful relationships and collaborations with caregivers | 29 | 0.42 |
| Developing appropriate IEPs | 25 | 0.37 |

JUSTICE PERSONNEL: N = 13

Of the 13 justice system personnel surveyed, police officers as well as parole/probation officers were represented. All respondents had completed high school or a higher degree.

| Highest Level of Completed Education | | |
|--------------------------------------|-----------|---------|
| Level | Frequency | Percent |
| College degree | 9 | 75 |
| High School Graduate | 1 | 8.33 |
| Some College | 1 | 8.33 |
| Some Graduate Studies | 1 | 8.33 |
| Primary Role | | |
| Role | Frequency | Percent |
| Parole/Probation Officer | 5 | 0.45 |
| Police Officer | 6 | 0.55 |

Indiana Autism Support Services Gap Analysis



Relevant to responses, the justice personnel were likely to obtain informative resources from parents as well as medical and other providers and training at state conferences and from their professional associations. Justice personnel were most likely to interact with other justice system personnel overall. The top barriers to collaboration were noted as training with practical information, time and funding. Preferred modes of training include phone consultations and web-based learning and consultation.

| Where do you typically obtain training about ASD? | | |
|---|-----------|---------|
| Source | Frequency | Percent |
| State Conferences | 5 | 0.31 |
| Professional associations | 3 | 0.19 |
| Previous academic training | 1 | 0.06 |
| Lay literature | 1 | 0.06 |
| Professional associations | 2 | 0.13 |
| Service providers | 2 | 0.13 |
| N/A | 2 | 0.13 |

| Top 3 Barriers to Collaboration | | |
|-------------------------------------|-----------|---------|
| Barrier | Frequency | Percent |
| Training with practical information | 6 | 0.40 |
| Time | 5 | 0.33 |
| Funding resources | 4 | 0.27 |

| Top 3 Preferences in Training | |
|---|--------------|
| Source | Average Rank |
| Phone Consultation | 4.6 |
| Web (webinar, self-paced modules/ webcasts) | 5.4 |
| Online Consultation | 5.6 |

On average, the justice system personnel did not feel they were extremely knowledgeable on any of the categories surveyed. They wanted more information about understanding policy and law related to ASD as well as developing successful relationships and collaborations with caregivers of individuals with ASD, both essential to their key roles.

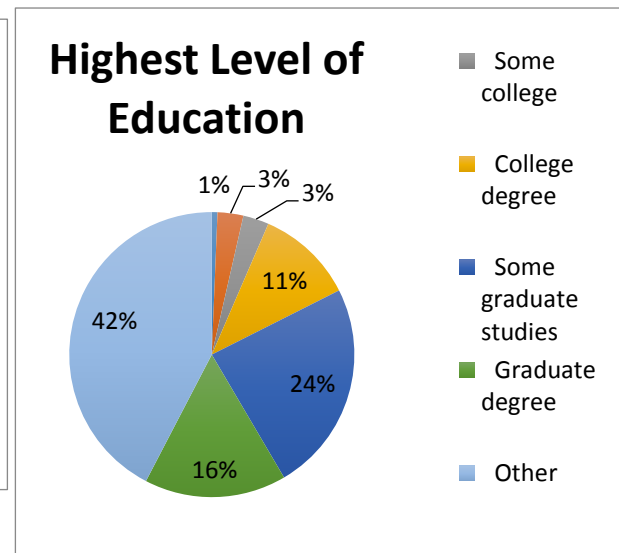
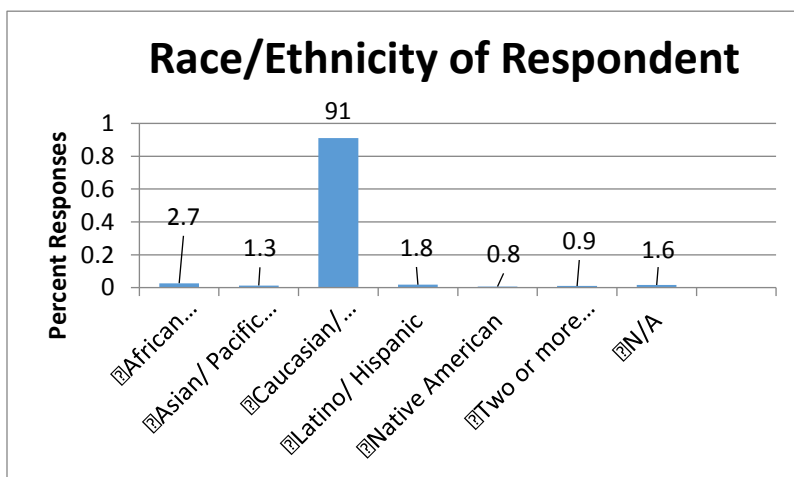
Indiana Autism Support Services Gap Analysis



| Top Areas for More Info | | |
|---|-----------|---------|
| Area | Frequency | Percent |
| Understanding laws and policy related to ASD | 7 | 0.27 |
| Developing successful relationships and collaborations with caregivers | 6 | 0.21 |
| Developing appropriate IEPs | 4 | 0.14 |
| Understanding general characteristics and learning styles of individuals with ASD | 4 | 0.14 |
| Identifying effective and research-based behavioral interventions | 4 | 0.14 |
| Effectively advocating for the individual with ASD | 4 | 0.14 |

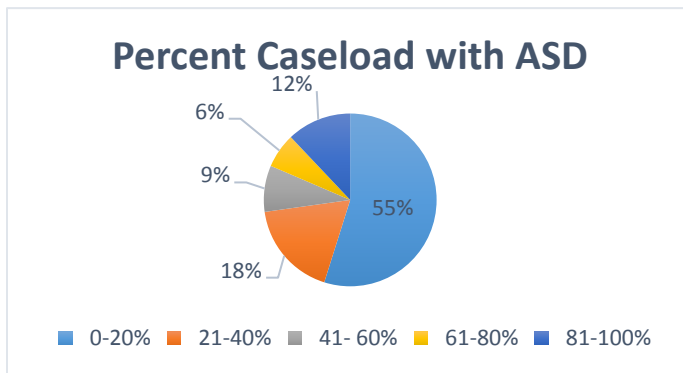
COMMUNITY PROVIDERS: N = 132

Almost all of the 132 community providers classified themselves as Caucasian/European American and 40% responded with indication that they have had at least some graduate training. The providers were a relatively even mixture of ABA/Behavior consultants, case workers, residential/day program personnel, respite provider, social worker or therapist. Many of the providers also noted an administrative role as part of their position.



Almost half of the community providers claimed that only 0-20% of their caseload involved individuals with ASD but a significant percent (18%) work almost exclusively with ASD individuals.

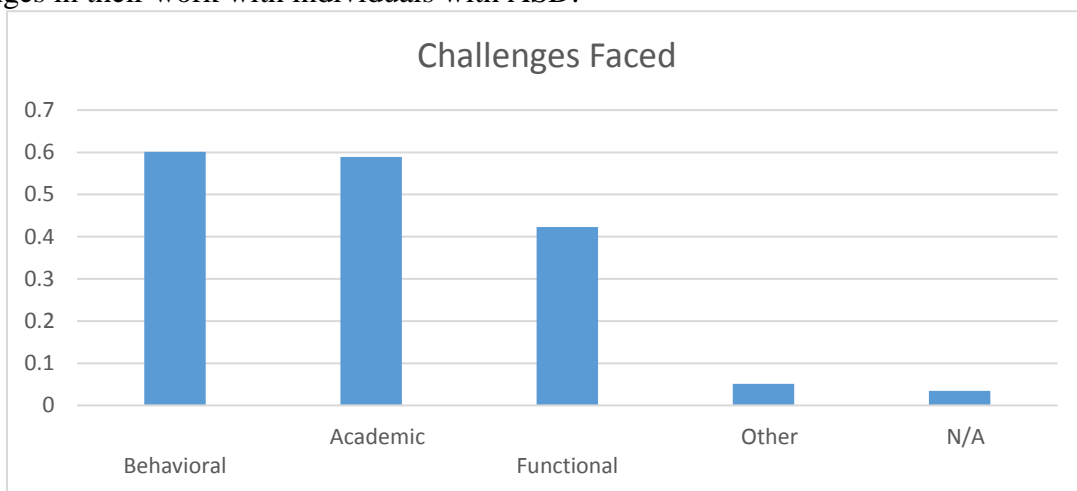
Indiana Autism Support Services Gap Analysis



When asked where they had the most challenges, the top three responses were unstructured activities, independent work and transitions between home and school, and group activities.

| Top 3 Challenging Setting | | |
|---|-----------|---------|
| Setting | Frequency | Percent |
| Unstructured activities | 92 | 47.42% |
| Independent work | 56 | 28.87% |
| Transitions within the classroom (to/from activities) | 46 | 23.71% |

Almost all respondents claimed that they had some behavioral, academic and/or functional challenges in their work with individuals with ASD.



When looking for information and resources or materials about ASD, community providers most often went to the internet, general disability and autism support services. When looking for training opportunities, they most often looked to other providers, disability support networks and the internet.

Indiana Autism Support Services Gap Analysis



| Top 3 Resources | | |
|-------------------------------------|-----------|---------|
| Source | Frequency | Percent |
| Autism Support Services | 81 | 31.76% |
| General Disability Support Networks | 83 | 32.55% |
| Internet | 91 | 35.69% |
| Top 3 Training Sources | | |
| Source | Frequency | Percent |
| Other providers | 78 | 46.15% |
| General Disability Support Networks | 49 | 28.99% |
| Internet | 42 | 24.85% |

Their preferences for training were very broad, but when the rankings were averaged the top three were partial/full day conferences and online downloadable resources.

| Top 3 Training Preferences | |
|---------------------------------|-----------------|
| Source | Average Ranking |
| Partial Day Conference/Workshop | 2.59 |
| All Day Conference Workshops | 2.91 |
| Online Downloadable Resources | 2.93 |

When asked about various procedures that their institutions have in place, most community providers responded to knowing about those procedures. Generally, the community providers that knew about the procedures believed that the policies were at least somewhat effective, if not better.

| How Effective are Crisis Management Procedures | | |
|---|-----------|---------|
| Answer | Frequency | Percent |
| Somewhat Effective | 58 | 53.21% |
| Very Effective | 49 | 44.95% |
| Makes No Difference | 2 | 1.83% |
| How effective are positive/proactive strategies | | |
| Answer | Frequency | Percent |
| Makes no difference | 29 | 24.37% |
| Somewhat effective | 69 | 57.98% |
| Very effective | 19 | 15.97% |
| Very ineffective | 2 | 1.68% |

Indiana Autism Support Services Gap Analysis



| How effective are positive behavior supports | | |
|--|-----------|---------|
| Answer | Frequency | Percent |
| Makes No Difference | 29 | 27.10% |
| Somewhat Effective | 63 | 58.88% |
| Very Effective | 15 | 14.02% |

Community providers were most likely to collaborate with colleagues and other families, and they were least likely to collaborate with justice system personnel. When asked about what they believed the top 3 barriers to this collaboration were they responded time, funding resources, and needed training with practical information. However, frequently travel and support from the community and community providers were also noted barriers.

| Top 3 Barriers to Collaboration | | |
|-------------------------------------|-----------|---------|
| Barrier | Frequency | Percent |
| Time | 176 | 37.53% |
| Funding resources | 159 | 33.90% |
| Training with practical information | 134 | 28.57% |

The community providers felt they were most knowledgeable about understanding the characteristics and learning styles of individuals with ASD, using positive behavioral supports, and setting up the environment for success. They felt they were least knowledgeable about developing a post education plan, knowing what insurance coverage/financial support options are available and what services they cover, and providing peer training in ASD. However, when asked in which areas they wanted more information, their top three responses were gaining information to support the needs of the caregiver, understanding law and policy related to ASD, and decreasing interfering behaviors.

| Top 3 Areas of More Information | | |
|--|-----------|---------|
| Area | Frequency | Percent |
| Gaining information to support the needs of caregivers | 61 | 37.42% |
| Understanding laws and policy related to ASD | 54 | 33.13% |
| Decreasing of interfering behaviors | 48 | 29.45% |

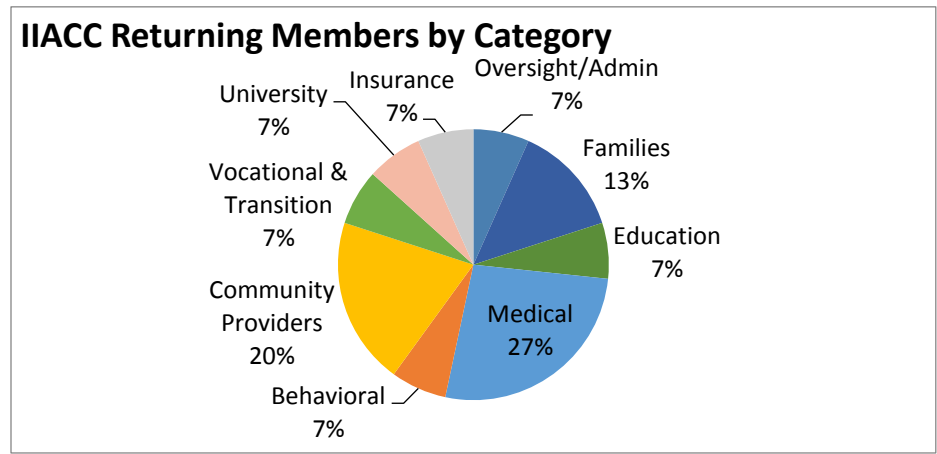
ONGOING PROCESSES:

Indiana Interagency Autism Coordinating Council (IIACC):

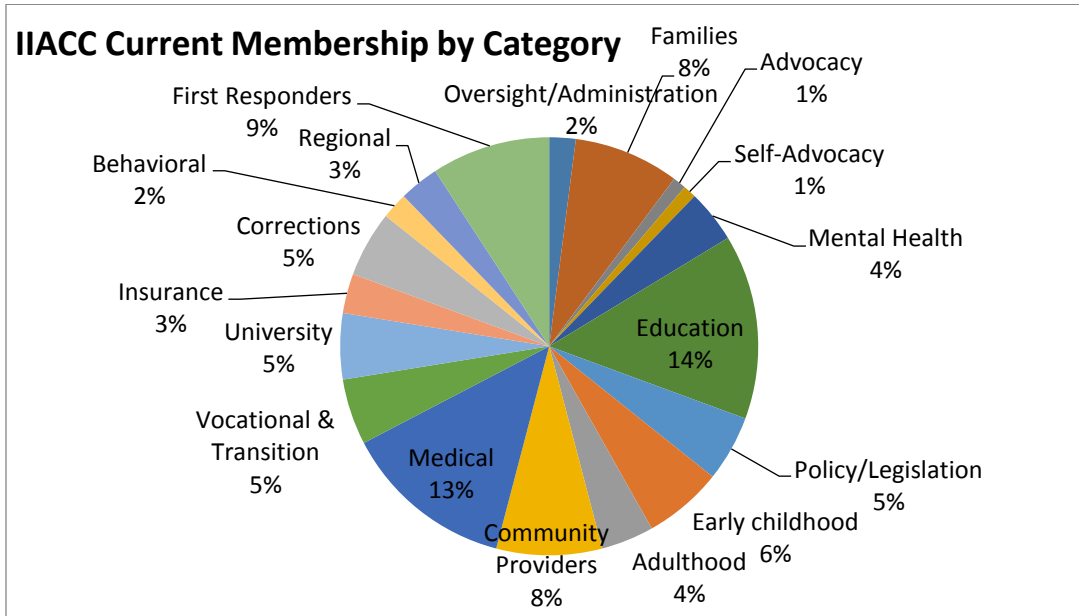
One of the initial roles prescribed by FSSA for HANDS in Autism® was to oversee, continually assess, and make needed alterations and expansions to ensure an inclusive positive, transparent, action-based trajectory with the IIACC.

Representation on the IIACC

HANDS regularly fosters an assessment of the membership, actions and goals to ensure that all is progressing and in tandem with state priorities (i.e., as specified within the Comprehensive State Plan on the previously noted FSSA webpage. Outreach and recruitment efforts have been conducted ongoing, continually reassessing to ensure that organizations who were mentioned or could inform the components of the Comprehensive Plan were represented. Further recruitment increased representation of systems, roles (e.g., those “on the ground”) and geographic regions. A comparison of the previous and current constellation of membership is presented below with a notable increase in categories and representation of stakeholder groups and interests in membership. Categories of IIACC member organizations represented at minimum include the following: oversight and administration, policy and legislation, advocacy/self-advocacy, families, mental health, education, medical, behavioral, early childhood, community providers, adulthood, vocational and transition, justice system and corrections, university/post-secondary, insurance, and first responders.



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IIACC Meeting Process

As the facilitator of the IIACC, HANDS is continually analyzing the infrastructure of the IIACC to identify if it is addressing the needs, goals, and objectives of the IIACC, the Comprehensive State Plan and FSSA. As part of the management of the IIACC, the membership, contributions, satisfaction, and progress are continually assessed both formally (e.g., post meeting satisfaction and input surveys) and informally (e.g., anecdotal input via emails, conversations, observations during meetings) to determine any additional needs with respect to organizations or entities actively working alongside individuals on the spectrum or impacting the work of those who do that should be recruited and/or involved as a member or an invited participant. With a core structure, connections, and activities, the continuation of an energized, cohesive and productive workgroup environment has been effectively and efficiently facilitated.

Meetings have been at the Government Center, held in a town hall style, and available through both live and via teleconference options. HANDS has facilitated meetings ensuring a combination of full group and small group activities to encourage participation. Unique stakeholders have been invited to meetings as appropriate to inform and progress particular tasks at hand as well as to ensure adequate input and representation towards specific subgroups as individuals shift positions. In addition, membership is based on organizational representation rather than a unique individual. As such, the lead contact is always encouraged to send a delegate in their stead should they be unable to attend.

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Three to four two-hour live IIACC meetings are conducted each year. Within these meetings, a brief PowerPoint and overview of progress since last meeting is presented with the goals to ensure well-defined and targeted activities for a productive and, therefore, rewarding experience with a sense of accomplishment and direction taken given the relatively brief timeframe allotted for meeting each quarter. Workgroups are commonly divided based on the goals of the Comprehensive Plan and the goals and action items discussed, data reviewed, and info gathering, review or discussion task assigned are all relevant to that particular goal. Each workgroup is provided with a work packet and any supporting materials, HANDS members facilitate and monitor discussions, a recorder is assigned for the group and a work packet is turned in at the culmination of the meeting for HANDS to incorporate within the data set and to inform progression forward.

In addition, ongoing communications with workgroups and LCCs continue throughout the year to maintain communications, address specific task related activities and conversations relevant to the goals outlined in the Comprehensive State Plan and to the identified priorities and action steps identified as a result of each IIACC meeting and work session. This process maintains HANDS as the facilitators pulling together all needed informants, data and focus, the IIACC as providing directed input to inform the targeted priorities and next actions, the workgroups and LCCs as a further layer of depth and involvement needed to gauge and inform for practical and feasible outcomes and usability, and other involvements of HANDS, IIACC and community members further inform ongoing through the bidirectional sharing of information in relevant workgroups and community activities. This multilevel, coordinated and interdisciplinary process has upheld the pace and sufficiently maintained engagement of stakeholders.

FOCUS GROUPS, LCC STUDY GROUPS, & INFORMANT INTERVIEWS

In addition to the general management and oversight of the IIACC, HANDS in Autism® fosters the involvement of many Indiana agencies and organizations bridging between the nonprofit and profit sectors. Partnership and collaboration across levels, sectors, and settings helps to provide the backbone, impetus, feedback and vehicle for the current project's ultimate success and implementation.

As described in the 2014-2015 report, a structured process of gathering information beyond the broadly focused needs assessment survey and the primarily state-level representation in the IIACC, entailed conducting focus groups, study groups and individual interviews. Given that many potential interest groups were not adequately represented, a primary goal in the current year was to specifically target engagement of these underrepresented factions:

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individuals with ASD, justice personnel/first responders, behavioral and community mental health providers, early childhood, insurance representatives, and state agency representation. In addition, other underrepresented groups identified included *those in rural areas as well as of varying cultural descent.* Though the option to continue with the focus group, study group and individual interviews structure remains and interested parties are continually encouraged and recruited to contact HANDS throughout the year, it became evident that, for some groups, a different type of pursuit and involvement might be necessary to encourage input.

Through more directed dissemination of the needs assessment, generation of novel and comprehensive contact lists aimed towards the specific target groups, as well as development of innovative and practical means for input, groups have been increasingly engaged whether attending IACC meetings, providing other regular input, or completing the survey. Specifically, general accessibility and input from a larger breadth and depth of the communities across the state has been a premier effort. This has been fostered in the following ways: (1) increasing accessibility of the needs assessment survey (e.g., translating to Spanish, refining questions for more meaningful input), (2) increasing communication outlets for ease of participation and sharing (e.g., availability at conferences and state/community meetings to meet where they are), (3) sponsoring feedback and communication through online mechanisms (e.g., google docs, survey gizmo questions) and newsletters. These and other options have expanded opportunities for shared dialogue and input, enhancing stakeholder involvement as represented by distinct increases specifically with:

- Specific increases in representation on the needs assessment survey were noted for the following interest groups:
 - Justice personnel
 - Individuals with ASD
 - Community providers
 - Culturally diverse individuals—a number of individuals have responded to the Spanish version of the needs assessment survey
- Coordination efforts with stakeholders within the above groups has increased upcoming and ongoing opportunities for coordination and information gathering to individualized groups
 - Justice personnel—collaborations have resulted in opportunities for surveying at upcoming conferences/activities
 - Individuals with ASD—
 - continued contacts from individuals with interest in completing an interview
 - contacts have been made and plans for dissemination during upcoming conferences/activities
 - Culturally diverse individuals—a number of organizations and individuals have been targeted for contact to assist with wider dissemination such that a more representative number can be reported for 2016-2017

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Ultimately, through development, piloting, and a number of iterations, there now exist multiple and varied formats to encourage input such that future state policies and work towards improving the comprehensive care and quality of life to individuals with ASD and their families will have adequate and representative data from not only state-level stakeholders, but also communities and individuals for whom the efforts are to effectively impact. Multilevel and multisystem analyses provide the basis for initial targeted work. In addition, multiple reference documents have been adapted from comprehensive documents outlining national and state by state information such that any priorities and actions can be appropriately informed and aligned with not only communities and individuals but the national trends.

The viable and comprehensive process and platform for engaging stakeholders across systems and the state in multiple formats will enable the most efficient and effective gap analysis. The data can be utilized to inform the state of the state in autism services, indicate essential priorities and processes, as well as suggest initiatives and partnerships to develop, continue, and/or enhance to collectively inform and address the status of autism services in Indiana.

COMPREHENSIVE PLAN

As noted in the 2014-2015 report, the first comprehensive plan was not mandated and was bulky and not sufficiently measurable. Similarly, the state plan in place prior to the currently updated version was noted to be in draft form, categories without goals and action items without adequate operationalization to be observable and measurable. As such, for an effective working document, the previous iteration initially modified to increase the measurability of various components. Subsequently, a number of iterations have taken place based upon IIACC, LCC and workgroup feedback as well as in using the 2014-2015 needs assessment data to inform revisions and priority score the actions. The current version of the Comprehensive State Plan resides at <http://www.in.gov/fssa/ddrs/3355.htm>.

In current form the Comprehensive State Plan includes the following sections with associated goals and action items: IIACC; Families and Professional Partnerships; Early and Continuous Developmental and Medical Screening; Access to Needed Health, Mental, Education and Social Services; Successful Youth Transition to Adult Services, Work, and Independence; Adequate Public/Private Insurance; and Justice System and Safety. Continued iterations of the action items will occur as priority action items are continually analyzed for progress. Action items completed and/or no longer necessitated will be removed and new action items based upon current trends will be added as needed and

appropriate such that the Comprehensive State Plan is a dynamic, living document.

DISCUSSION AND RECOMMENDATIONS

To date, a thorough gap analysis for a comprehensive baseline view of the state of the state in autism services in Indiana has been accomplished. In addition, a similar process has been applied in the analysis, management, support and monitoring of the IIACC and Comprehensive State Plan. The process is defensible in that it is data-driven and leads to greater sustainability than other approaches which may focus upon isolated evaluation and intervention strategies as well as a top-down approaches to communities and constituents. The integrated approach towards identifying achievable and meaningful outcomes is based upon input from key stakeholders.

Utilizing the infrastructure of the IIACC, LCC regional networks, and the Comprehensive State Plan as well as the information derived from the comprehensive needs assessment along with other assessments has facilitated the analyses of the state of the state in ASD as well as the vision of next steps towards measurable progress in state efforts. Beyond state efforts, the vision is for regional areas to have both greater local capacity for accessing ASD-related information and services as well as active input and engagement at a state level to inform and shape progress at each level.

Given that the needs, goals, objectives, and missions of the State exist within a shifting ecology of community, state, and federal priorities, amidst changing social, economic, cultural, and political climates and policies, a structure that embraces and incorporates information exchange and support at a local level as well as the flexibility to revise directions as state and national trends do. Ongoing discussions in which stakeholders communicate concerns and progress for consideration by the State with respect to the impact such changes have on programs and initiatives in the field as well as the translation in local communities is essential.

According to national trends, there has been a recent focus on: increasing early identification of individuals with ASD; increasing information and options pertaining to job-related skills development; pushing towards access of reliable information regarding interventions; and needing to close the gap in cost effective services that are accessible across environments. These areas largely align with the state of the state of autism services in Indiana as reflected above. According to respondents on the current needs assessment, stakeholders make note of the need for increased training with an emphasis on trainings that

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are practical to the particular consumers served (i.e., in terms of content, scenarios and format) such that the information can be more feasibly and effectively utilized. Online training is considered a viable and preferable mode for some. In addition, access to services that are specifically accessible with respect to cost and proximity remains an issue in Indiana due to insurance coverage and lack of available and trained providers in all areas of the state.

NEXT STEPS AND OVERALL RECOMMENDATIONS:

- This will be the final phase of recruitment, dissemination and data collection for the baseline gap analysis. Though data collection and analyses will be ongoing to measure progress on prioritized goals and activities specified by stakeholders of the IIACC, workgroups, LCCs and other informants and in relation to the Comprehensive State Plan, it is essential to have the most representative sample of informants in this process such that any actions and results will be meaningful to the intended stakeholders.
- The IIACC, workgroups, LCCs and the larger community will be essential to this process in continuing to inform contacts and formats that will enhance recruitment as well as being actively involved in disseminating flyers, discussing the importance within external meetings and workgroups, and providing contacts and venues for getting the word out.
- Common needs were voiced with respect to need for information and training regarding areas of transition and insurance as well as forming effective partnerships between families and providers. Some of these needs underscore these same trends nationally. These common needs present potential opportunities, particularly for the more general awareness training, for shared learning options such as within conferences and/or online learning options.
- However as noted even in collecting input pertaining to perspectives across interest groups and in information shared through the above gap analysis, the specific needs for training, information and resources need also to be individualized to particular interest groups given their distinctly different roles, avenues for gaining information, and general interest in various format, length and source of information. Various stakeholder groups are open to more intensive training options (e.g. full day events) as long as the information is individualized so that it can be practical and relevant.
- Communities continue to look beyond their own training and field to derive information and support with the understanding that it takes a full community to support individuals with ASD. Providers appreciate the first-hand knowledge of family members and family members are appreciative of the training challenges and needs of providers in the community. In addition, there has been a clear shift in the level to which these sectors are reaching out to community autism support services (e.g., ASI, IRCA, and HANDS). This change could reflect a change in the value, benefit, and/or accessibility placed on

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the services that such organizations are offering. This outlook sets the stage for open coordination and collaboration opportunities.

- Barriers to collaboration continue to consistently note time, funding, and practical training across stakeholder groups. As such, it is essential to identify cost and time efficient means that are also practical in nature. Many groups naturally seek online training which has the benefit of providing awareness and a common message (as well as regular booster information) to a large number of individuals (even those in remote areas can access internet and training with school or library computing resources or on their mobile devices).
- However, there remains a need for a full continuum of training to ensure that the training formats (e.g., lecture, demonstration, coaching and feedback) fit the consumer role and interest in working with ASD.
- IIACC membership continues to grow and evolve. The structure and membership will continually be evaluated and adapted depending upon the goals and activities given priority at various junctures. Some activities will require invites to particular groups to more specifically inform the activity with content experts in the field and/or will require more small or full group collaboration and discussion depending.
- State personnel involvement in dissemination efforts, IIACC, workgroups, and LCCs will be essential to the process. These personnel will be essential in lending State perspective on any issue, clarifying any misunderstandings related to state policies and/or procedures, demonstrating clear and undisputable support of the IIACC/State Plan efforts, and disseminating information and resources pertaining to the Comprehensive State Plan.
- As the initial baseline phase draws to a close, IIACC and workgroup activities will become less information-gathering oriented and more action oriented, remaining centered upon the Comprehensive State Plan goals and priorities initially identified. However, given that the gap analysis and needs assessment provides beginning clarification and definition to the state of the state in autism services, the IIACC and workgroups will continue to discuss and drill down on the data that has been collected to further understand and query the feedback delivered (e.g., families indicate that a barrier to services is lack of services “within the area”—how should this be defined? What is a reasonable distance to drive?)
- Upcoming meetings will include opportunities to hear from representatives of initiatives that are closely aligned to Comprehensive Plan goals, represent a more broad-based (i.e., not ASD specific) but pertinent model for further work on the Comprehensive State Plan, can inform activities and/or collaborations (e.g., Systems of Care (SOC))

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initiative, implementation science models, Neurodevelopmental Behavioral System (NDBS) hubs), and/or have been identified by the IIACC as integral to our process going forward. This will be essential to stay effectively informed and to bridge with entities with a similar scope and purpose to facilitate collaboration, coordination and integration and to minimize any potentially duplicative or complicating efforts.

- To enable such further networking and information sharing, the history, development, and foundational concepts routinely shared at the IIACC meetings will be recorded and available for review prior to each meeting for those with interest or as first time participants or delegates to the IIACC and also for the general community awareness as to this statewide effort.
- Currently, the State has made available overall IIACC meeting dates, annual reports and Comprehensive State Plan on the State information portal. However, there is also a need for a neutral location to post materials utilized for reference and dialogue ongoing for both IIACC members and the wider community for transparency and to encourage ongoing involvement in active dialogue, accessibility of information, as well as ease for regular and ongoing community sharing of content, information, and resources in ASD statewide.
- Finally, many innovative and underutilized resources and services within the state of Indiana. Given involvement of IIACC members across many of these entities, a new mechanism has been developed to nominate an individual, organization, initiative, or other as a DISI or Driver of Innovative Services in Implementation. These nominations can be made by IIACC members or others, followed by contact of the nominee to obtain description, and future publication in newsletter format.

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