

Indiana Service System Analysis

September 30, 2014

Executive Summary

The University of New Hampshire Institute on Disability (IOD) was invited to conduct an analysis of the current service system in Indiana for individuals with intellectual developmental disorders (IDD) and mental health needs. In April 2014, the Division of Disability & Rehabilitative Services of the Indiana Family & Social Services Administration (DDARS) convened a multi-stakeholder group of participants and asked them to form a task force, the Indiana IDD/MH Task Force. The Task Force was asked to gather and report information from across the state on the service needs of individuals with IDD requiring mental or behavioral health services.

The questions to be addressed were:

- How effective is the current community system of care in the state of Indiana in addressing the needs of individuals with intellectual/developmental disabilities and mental illness/challenging behavior?
- How can Indiana enhance the existing service delivery system to improve services and supports to those in need?
- What are the current mental health service experiences from the perspective of family caregivers?

A multi-pronged approach was utilized to ensure that as many constituents as possible had an opportunity to contribute to the process and share their experiences. Available claims data was reviewed to assess targeted Medicaid expenditures. An evidence-informed web-based survey was made available across the state, 9 focus groups were held across constituency groups, and individual interviews were conducted with 40 family caregivers using a telephonic research-based survey. Participants represented a broad range of stakeholders and included self-advocates, families, service providers, and first responders. All participants volunteered to be part of the process with approximately 1400 Indiana citizens contributing across the state.

Several common themes emerged from analysis of information gathered. These themes were consistent across all constituent groups regardless of location in the state as well as across all the collection methods, including those that reported direct and recent experiences.

An analysis of both Medicaid IDD Waiver expenditures and Medicaid mental health expenses for calendar years 2012 and 2013 revealed a possible over-reliance on enhanced staffing to manage challenging behavior and mental health needs. These staffing patterns are both expensive and restrictive and compensate for what was reported to be a dearth of effective mental health and IDD services. The review also showed a significant number of service users accessed mental health wrap around. While some individuals used inpatient services, some experienced frequent re-admissions and some appeared to get stuck in the hospital for months at a time. Improvements in services and networking may help to reduce costs while improving experiences and outcomes of all involved.

Overall participants identified several important gaps in the current service system. While it is important to note that there is a great commitment on the part of stakeholders and some areas where people report good outcomes, the lack of training and expertise was the most prevalent issue. The chief concerns reported are the need for greater crisis supports (80%); inpatient and outpatient mental health services (70%); and IDD services, especially vocational training (55%).

Recommendations related to the concerns clustered into three prevalent themes:

1. Increase training and expertise across the state (this was the number one recommendation);
2. Prevent and respond to crises (not just to “handle” them, but to know what to do so things do not get to the point of calling crisis supports and police); and
3. Improve access to specific services particularly in rural areas, including better communication about how to access existing services across systems of care.

As reported by participants, prior experiences with crisis supports that are no longer available due to funding cuts, while helpful and needed, did not result in improved abilities within the system as a whole. Families, care providers, mental health inpatient providers, mental health outpatient providers, vocational service providers, etc., did not develop the needed skills to reduce dependence on crisis services. Perhaps as a result, when the crisis response resources were eliminated, the gap in knowledge of how to help individuals in crisis may have widened due to dependency on a program that was no longer available.

Given the diversity of the people needing services, the changing landscape with regard to research and training, and the commitment across providers and systems, it is suggested that any remedy going forward expand capacity across the system of care in addition to reducing the need for increased staffing and acute crisis response over time. **An analysis of Indiana Medicaid claims data indicated that considerable cost savings could occur if the current dependence on staffing as the remedy to challenging behavior/mental illness could be replaced by improved capacity in treatment and services. With a 10% reduction in the use of enhanced staffing, a savings of 22 million dollars would be possible.** While this cannot occur without improvements in services as described in this report, it makes

a compelling argument for the need to put considerable effort into improving capacity within the system. Mental Health claims data indicate that while wrap around services are widely used; the use of inpatient services indicates long lengths of stay and repeat admissions for several service users; together this suggests possible ineffective treatment and networking (i.e., people getting stuck in hospitals).

In response to the information reported in this analysis following is a list of next steps. A specific plan to implement these steps is listed at the end of this report

Recommended Next Steps:

1. Implementation of established ongoing cost effective curriculum and teaching forums for MDs, PhDs, case managers, advocates, educators, family members, IDD and mental health providers.
2. The establishment of a crisis intervention continuum that begins with what to do at home, how to call for help early on, and a safety net in times of crisis. Standards to improve practices and reduce dependence on enhanced staffing should occur.
3. Improved service provider networking using existing model in Indiana.
4. Publication and information about existing services and how to access them can be provided through the state website and other communication mechanisms. All service providers need to know what is available and accessible as well as how to assist families and service users in getting needed supports as soon as they become concerned that things are not going well and before needing to call 911.

It is suggested that the State convene a planning group (perhaps the current one) to review models and approaches with proven track records that address the needs identified in this summary and to develop a plan to pilot a selected model. Rather than bringing in a single provider, the State may want to consider the development of networks using the current system of providers, with resources to fill in gaps when needed. This would foster increased knowledge in the system overall. Goals would include a decrease in the need for enhanced staffing and an increase in access to vocational and other meaningful opportunities for service users. A review of current Medicaid codes in both IDD and MH systems should occur to help determine what services may be billable in the existing system.

A more detailed outline of the plan is listed at the end of this report and was reviewed by Nicole Novell the Director of Disability and Rehab services for the state of Indiana.

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Analysis of Indiana Community System of Care for Persons with Intellectual/Developmental Disabilities and Mental Health Needs.

Introduction

Across the United States approximately 1.5% to 2.5% of the population has an intellectual developmental disorder (IDD) (1). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM5) defines IDD as a disability that involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks. In Indiana, there are approximately 18,000 individuals receiving services through the Division of Disability and Rehabilitative Services (DDRS). Epidemiological studies have established that the incidence and prevalence of mental illness for people with intellectual disability is typically 2 to 3 times that of the general population (2). It is also well-established in the literature that mental health symptoms often contribute to challenging behavior in individuals with IDD (3) and that aggression and self-injurious behavior is one of the most common reasons for referrals for mental health services (4). In order to improve services and outcomes, the Indiana State Senate requested a comprehensive assessment of the current system of care in Indiana be conducted by the University of New Hampshire Institute on Disability Center for START Services. The analysis was conducted using evidence-based methods in collaboration with a stakeholder committee assembled by DDRS. The goals of this analysis were to learn about what is working in Indiana, to facilitate dialogue and discussion amongst stakeholders, and to determine next steps to improve services and outcomes.

Information for this analysis was gathered through several methods. The largest number of participants responded to an online survey designed to learn about service effectiveness of both IDD and Mental Health (MH) services based on three factors: access, appropriateness, and helpfulness (accountability) (5) of the service systems. In addition, small focus groups of specified constituencies, including family members, self-advocates, MH providers, IDD providers, law enforcement personnel, and behavior specialists, were conducted in several locations across the state to get direct feedback from individuals within the system on their experiences. To ensure that families were afforded an opportunity to provide direct feedback, research-based telephonic surveys (6) were conducted with family members of individuals with IDD who had used mental health services in the past year. A final component of the gap analysis was a review of Medicaid claims data and other cost data related to current service use for this group.

The multistep analysis includes overall impressions of the system, a review of current spending trends, and direct experiences of recent service users. While differences in perspective did emerge between groups, several prevailing themes arose that offer the opportunity to plan next steps. The outstanding support from the citizens of Indiana in this process overall suggests a strong commitment to improving the system on the part of many.

Methods of Analysis

There were three overarching questions in the process. Citizens were asked to assess:

1. How effective is the current community system of care in the state of Indiana in addressing the needs of individuals with intellectual/developmental disabilities and mental illness/challenging behavior?
2. How can Indiana enhance the existing service delivery system to improve services and supports to those in need?
3. What are the experiences of family caregivers whose loved ones with IDD use the mental health system?

Four methods were employed to gather information about the existing service system and to create opportunities for constituents to provide feedback about how to address issues. The methods were: claims data analysis, focus groups, an online survey, and telephonic family caregiver interviews. All methods were reviewed with the stakeholder group and the online survey was modified as needed with their input (see tools used in Appendix A). The Indiana IDD/MH Task Force (see Appendix B) played a key role in distributing the survey across the state as well as collecting information to access volunteers for this analysis.

Claims Data Review

Medicaid claims data were reviewed for individuals identified within the system as receiving both IDD and mental health services. The periods reviewed were calendar years 2012 and 2013. Claims were analyzed to determine the most frequently used services by this population as well as the current cost for individuals identified as having the highest level of need within the IDD system.

Focus Groups

The University of New Hampshire IOD conducted nine focus groups across the state with a variety of constituents. Each focus group represented specific types of constituents, so that they could provide insight from the perspective of the people they represented. The groups represented: self-advocates (people who use services); family members; mental health service providers; IDD providers; law enforcement personnel; behavior specialists; and staff from the Department of Children's Services (see Appendix C for a complete list of groups).

Each focus group participated in small group discussions that focused on two primary questions: "Was there any particular service that you need that is not currently available?" and "What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?" Each group was facilitated in-person by an IOD staff member and a second staff person was present via telephone to take notes on the discussion. All discussion notes were coded using qualitative

data analysis software (7) so that prevailing trends could be identified. This review led to the identification of themes that could be compared with the data from both the online survey and the family interviews.

Online Survey

The Indiana IDD/MH task force reviewed, helped to edit, and helped to distribute the electronic survey link to constituents across the state including, but not limited to: IDD providers, mental health providers, family members, policy makers, medical and court staff, self-advocates, and special education personnel. In addition to emailing the link to individuals, a link to the survey was put on several state agency websites and social media. The goal of this effort was to receive feedback from as many people across the state as possible with experiences to share regarding the IDD/MH system. In examining overall mental health service experiences for individuals with IDD in Indiana, the analysis focused on three primary areas: Access (timeliness, location, ability to use), appropriateness (do they match needs/wants, expertise is available), and accountability (are individuals satisfied with the services, do they help?) (5). People who completed the survey were asked to consider a variety of mental health services for each of these three criteria.

In all, a total of 1,337 Indiana citizens responded to the survey between May and July 2014. A copy of the survey can be found in Appendix A of this report. The majority (63%) (N=788) of people who participated in the online survey were IDD and Mental Health Service Providers. IDD providers made up approximately 60% (N=473) of this group, while mental providers made up the remaining 40% (N=315). The providers reported significant experience in the field with an average of just over 20 years of service. 16% (N=205) of the people who completed the online survey were family members, and 83% (N=170) of the family members were parents of service users. The 12% (N=151) of persons responding to the survey listed as other had very diverse roles within the service system including sign language interpreters, insurance fraud investigators, medical personnel and individuals working in child protective services. Figure 1 below shows the breakdown of persons responding to the survey.

Figure 1: Online Survey Respondents

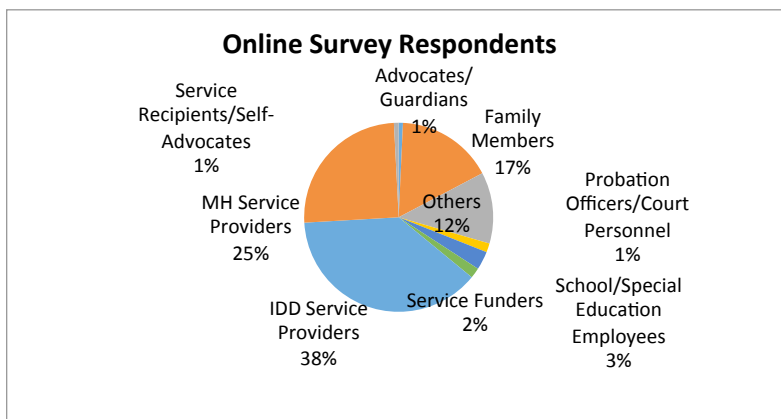
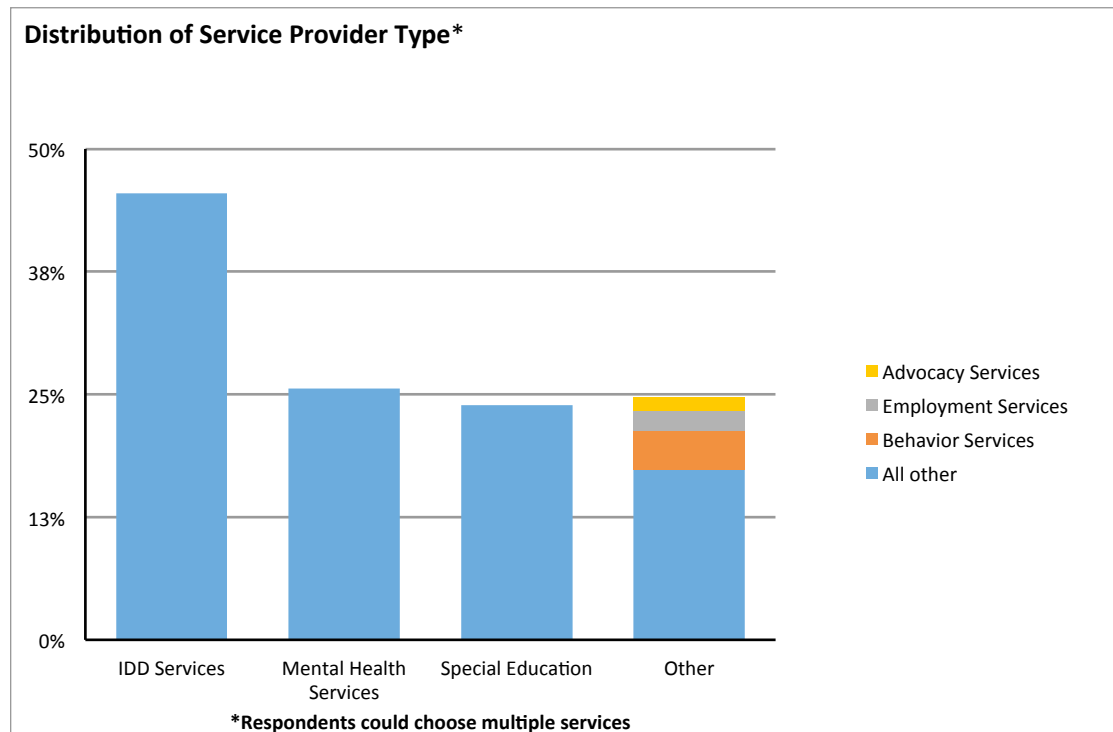


Figure 2 below shows the types of services provided by people who responded to the online survey. For individuals who chose “other,” a breakdown of the most common responses is included. The remainder of services included in that category includes such things as medical services, legal services, foster care and adoption services, and recreational services. Service providers responding to the survey reported serving individuals across all age ranges in a fairly even distribution.

Figure 2: Type of Services Provided



Family Caregiver Experience Interviews

To elicit opinions of family members, a research validated telephone survey instrument was developed based on one module of the Family Experiences Interview Schedule (FEIS) developed by Tessler and Gamache (1995) (6). It was used to measure significant aspects of mental health service effectiveness from a family member perspective. The survey results presented in this report address the recent experiences of family members. More details of this analysis will be presented later in the report.

Analysis of Findings

System Strengths

While the analysis of the Indiana service system revealed multiple areas for development, the analysis also reported important strengths within the current system.

1. Commitment: There is a strong level of commitment on the part of stakeholders across the system to improve. The fact that a significant number of mental health providers participated in this process is a promising finding. A strong desire on the part of both the IDD and the MH systems to increase collaboration and remove some of the barriers (distinct funding streams, lack of cross-training) that undermine mental health service access for individuals with co-occurring IDD and mental health challenges was reported. There were numerous references to previous efforts within the state to improve access to crisis services, and many expressed a willingness to participate in future collaborative efforts.

2. Some Existing Expertise: While training and lack of expertise did emerge as a central theme, all groups referenced several providers across the state that had significant success in serving the target population. Several community mental health agencies were mentioned as having services specifically designed for individuals with IDD, and on the IDD side, there are several providers who have come up with local solutions within their own communities. Some of these solutions include: 1) having a trained behavior support specialist to accompany an individual to all mental health intake appointments in order to provide information important to services; 2) the cultivation of relationships with private providers in order to better access services; and 3) offering training by experts from IDD staff to local law enforcement and other first responders.

3. Ready to Meet the Challenge: Across the state there was strong acknowledgement by all groups that the current system has significant gaps. Both mental health and IDD providers were forthright in describing historical issues that have contributed to the separation of the MH and IDD systems. The conversations across the state were solution focused. Both systems acknowledged weaknesses in their own services as well as a strong desire to work towards solutions.

Review of Data

IDD Waiver Claims Data Review

The review of Medicaid claims data provided to the IOD by Indiana revealed several findings that may be helpful in assessing where some future cost savings might be obtained.

In the first analysis, staff supports for individuals living in multi-person residential settings were examined. 3150 individuals with the highest level of “behavioral needs” as determined by the Indiana Algo Scale (level 4 or 5) had an average of 10 staff hours each per day for an annual cost of over \$224 million dollars. If the behavioral needs of individuals in this group could be reduced by even 1 hour/day with improved staff training and better crisis planning, that would result in about a 10% savings in staff costs alone (over \$22 million dollars annually). In addition to the potential savings, even a slight modification in staff coverage decreases the restrictiveness of residential settings and allows individuals more freedom of movement and autonomy in day-to-day activities. Another potential cost savings can be found in day programming costs. In an analysis of individuals (N=224) with high behavioral needs

whose day service costs currently exceed the suggested waiver maximum of \$18,500/year, a reduction in service needs that allows for services to be provided at the recommended waiver maximum would result in a savings of about \$2 million dollars annually.

Mental Health Medicaid Claims Data

With regard to analysis of psychiatric inpatient data, we reviewed claims for a total of 104 individuals with inpatient stays in 2012-2013. For these individuals there were a total of 190 hospital episodes. There were 28 individuals with multiple visits ranging from 2-19 separate hospitalizations. 5 individuals had total hospital days in this period that exceeded 80 days and one individual was hospitalized for 718 days in the two-year period. The billed costs for these five individuals alone were over \$900,000. This indicates that while a small number of individuals had hospitalizations, services were ineffective and or the system failed to work together. The rate of repeat admissions and the long lengths of stay, if decreased, could improve service outcomes and result in considerable cost savings over time.

The biggest mental health expenditure analyzed was MH wrap-around support. The state spent over \$9 million dollars on this service in 2 years and served 1125 individuals. That was over 80% of all the outpatient mental health services provided. That comes out to approximately \$8000 per person for two years of this service. This may be the most effective service that has been provided to date and may help to explain the reports from family members that there are some services that help them to get the support they need.

Focus Group and Survey Results

A review of the system through the use of the focus group discussions, as well as the online survey data, revealed several common themes across all constituent groups. A detailed description of each of those themes is presented below.

Theme 1: Increase access to expertise and training to develop expertise across the state

The most prevalent theme to emerge was the need for ongoing training and access to expertise within the state on co-occurring IDD and mental health challenges. Within the focus groups, the need for improved training was the most frequently cited issue. Of the focus group comments, approximately 33% of constituent representatives related to the lack of providers trained to effectively support individuals with co-occurring IDD and MH needs. **Family members, self-advocates, IDD providers, and police all listed expertise as the number one need within the system, and for both families and self-advocates this need was cited more than all other needs combined.**

“As a parent, there is no place for parents to get a good referral for who is really specialized, has a passion/desire and an expertise in the community.” -Family Focus Group Participant

The online survey listed three questions specific to training and expertise:

- 1) Are MH staff trained and qualified to support individuals with IDD?
- 2) Is technical support in IDD available to MH providers?
- 3) Is consultation provided by specialists in the field?

As with all the survey questions, people responding to the survey were asked to rate each question for Access (does the service exist and is it available), appropriateness (does it match the needs), and accountability (is it satisfactory, helpful).

Results showed that more than half (57%) of stakeholders reported not enough available IDD-trained mental health professionals and 61% did not believe the options available matched their needs. See Table 1 below. **Of the groups responding, families were least likely to see training as available and appropriate, and this was consistent across all locations in the state.** There were almost no differences in the responses of MH and IDD providers with regard to training.

Table 1: Staff Training

| | Staff Training (% all or some) | | |
|-------------------|--------------------------------|---------------|--------|
| Group Responding | Available | Matched Needs | Helped |
| Family Members | 37.86% | 34.31% | 32.04% |
| Service Providers | 45.02% | 39.78% | 43.26% |
| Variance | 7.16% | 5.47% | 11.22% |

With regard to consultation, even fewer people responding to the survey felt that all or most of the expertise they needed was available and helpful to them. See Tables 2 and 3 below. Respondents overall reported that helpful consultation was not available. Family feedback with regard to the usefulness of existing consultation services was more negative than providers', but all respondents clearly reported a lack of this important resource overall. It is noteworthy that consultation to help service providers (day, residential, education, etc.) was reported to be less useful and available than

clinical consultation (individual treatment needs), although the majority of all consultation provided is reported to need improvement.

Table 2: Service Consultation

| | Service Consultation (% all or some) | | |
|-------------------|--------------------------------------|---------------|--------|
| Group Responding | Available | Matched Needs | Helped |
| Family Members | 20.20% | 22.22% | 19.00% |
| Service Providers | 28.82% | 34.59% | 33.92% |
| Variance | 8.62% | 12.37% | 14.92% |

Table 3: Clinical Consultation

| | Clinical Consultation (% all or some) | | |
|-------------------|---------------------------------------|---------------|--------|
| Group Responding | Available | Matched Needs | Helped |
| Family Members | 37.25% | 36.89% | 34.31% |
| Service Providers | 48.54% | 46.33% | 47.75% |
| Variance | 11.29% | 9.44% | 13.44% |

Table 4 provides a summary of the overall Responses for training and consultation services. While training and clinical consultation had low rates of persons who answered 'don't know', there was a 31% 'don't know' response for service consultation. **The majority of "don't know" responses came from families and individuals in the school system or the court system, which suggests that there is a need to improve communication about available resources between the IDD and mental systems and other systems involved with this population.**

Table 4: Summary of Responses (Training and Consultation)

| Service Type | Available | | | Matched Needs | | | Helpful | | |
|-----------------------|-----------|--------|------------|---------------|--------|------------|---------|--------|------------|
| | Yes | No | Don't Know | Yes | No | Don't Know | Yes | No | Don't Know |
| Staff Training | 42.79% | 48.74% | 8.47% | 38.66% | 52.54% | 8.81% | 40.39% | 52.01% | 7.60% |
| Service Consultation | 30.47% | 38.44% | 31.09% | 31.50% | 37.16% | 31.35% | 30.47% | 39.05% | 30.47% |
| Clinical Consultation | 44.10% | 41.50% | 14.40% | 41.95% | 43.77% | 14.29% | 42.42% | 43.34% | 14.24% |

All respondents who rated a service area as 'None' or 'Very Little' were asked to provide an explanation for that response. A review of the concerns related to training revealed that 72% of individuals reported that training was simply not available. This concern was consistent across respondents from both rural counties and more urban centers, with less than 6% of respondents specifically citing location as the primary barrier. The chart below shows the primary reasons cited for dissatisfaction with staff training.

Figure 3: Training Concerns



Availability (72%): The following are a sample of survey comments related to availability.

- “There are few opportunities for MH staff training.”
- “Difficult to access & staff not well-trained on the IDD needs.”
- “Do not know how to work with challenges or don't want to.”

Lack of Knowledge (11%): The following are a sample of survey comments related to knowledge gaps.

- “Psychiatric issues are dismissed as strictly behavioral in nature.”
- “Need more training for people with IDD, need more available services and service providers-people tend to shy away from people with IDD.”
- “No specialized training for behavioral staff or staff who work with individuals who are dually diagnosed (MH-IDD).”

Lack of Funding (7%): The following are a sample of survey comments related to funding gaps.

- “This seems to be an area that is overlooked and possibly money may be an issue.”
- “There is no money in state budget for the training you are talking about.”

It is important to note that the lack training in co-occurring IDD and MH emerged as the primary concern for families and individuals using the system. **It also was cited by all groups answering the survey as one of the primary reasons that other mental health services such as crisis services and outpatient treatment were not effective and available to individuals with co-occurring diagnoses.**

“Sometimes when you are having a problem, people just think you are having a fit. Really, you are angry at the situation at the time. Nobody was really listening to me and I had to take a break. I went to the mental hospital. A friend took me there. Staff didn’t recognize that I was on the edge.” -Self-Advocate Focus Group Participant

Theme 2: Increase Capacity to Effectively Intervene in Crisis Situations

The next theme to emerge was the need to increase capacity within Indiana to effectively meet the needs of individuals experiencing a crisis. The central reported issues in examining crisis services

include: lack of qualified mental health service providers, lack of resources to pay for services, and lack of appropriate mental health services for people with IDD. In addition, there was an overall concern expressed that people did not know how to get the help they needed in times of crisis.

The lack of crisis services available to individuals with IDD was the second most prevalent issue discussed within the focus groups. Of interest is that there were significant differences in the responses of the providers within the mental health and IDD communities. Mental health providers listed crisis services as the biggest gap in the system. They overwhelmingly expressed a willingness to include individuals with IDD in their services, including inpatient hospitalization, but cited concerns about the lack of expertise and the risk of not getting paid as the primary barriers.

“Community mental health centers want to serve these kids, but state that “we don’t have the expertise,” but really it’s a reimbursement issue. For them, it is a financial risk and don’t want to take the risk.” -Mental Health Provider Focus Group Participant

IDD providers reported a lack of willingness to accept individuals with IDD into services (even when funding was not an issue) because the individuals were viewed as difficult to work with, disruptive to the milieu, or unable to meaningfully participate in services.

“They don’t think that someone with IDD would function well with the population of patients that they have. Don’t have a unit for people with IDD. Can’t participate in groups—often the reason given for not admitting. There is no milieu! When they do get them in, they keep them in an isolated room, have no expectations, don’t change medication or provide evaluation, and then state, ‘haven’t had any behavior issues’ and discharged.” -IDD Provider Focus Group Participant

The online survey listed five questions specific to crisis capacity.

These are:

- 1) Mobile Crisis Services: Are available first responders trained in mental health for people with IDD?
- 2) Are there Crisis stabilization/Hospital Diversion Beds?
- 3) Are there Community-Based Psychiatric Inpatient Beds?
- 4) Are there out-of-home Crisis Respite Services?
- 5) Crisis Intervention Services: Are there people to call (other than police) to assist in a crisis?

Crisis intervention services were rated available by 26% of respondents. However, families rated those services as appropriate and helpful only about 20% of the time. **This suggests that close to 80% of families were not satisfied with outcomes associated with the few crisis services they were able to access or knew were available.** There were also a significant percentage of people completing the

survey (about 30%) who reported not having enough information about available crisis services to respond. See Table 5. **This suggests that a significant number of Indiana citizens do not have information on who to call or where to go in times of crisis.**

Families were the least likely to have information about crisis services. 41% of families responded don't know compared with 28% of providers and 33% of other respondents. There was virtually no difference between the percent of IDD providers and mental health providers who answered don't know.

Table 5: Summary of Responses (Crisis Services)

| Service Type | Available | | | Matched Needs | | | Helpful | | |
|---|-----------|--------|------------|---------------|--------|------------|---------|--------|------------|
| | Yes | No | Don't Know | Yes | No | Don't Know | Yes | No | Don't Know |
| Mobile Crisis Services | 21.59% | 47.17% | 31.24% | 21.04% | 48.48% | 30.49% | 21.32% | 48.31% | 30.37% |
| Crisis Stabilization/ Hospital Diversion | 18.73% | 49.23% | 32.04% | 17.44% | 51.54% | 31.02% | 17.62% | 50.85% | 31.53% |
| Out-of-Home Crisis Respite Services | 17.67% | 46.70% | 35.64% | 18.47% | 46.87% | 34.66% | 18.10% | 46.93% | 34.97% |
| Community-Based Psychiatric Inpatient Beds | 23.96% | 50.70% | 25.35% | 23.35% | 52.07% | 24.58% | 23.49% | 51.31% | 25.19% |
| Crisis Intervention Services | 25.54% | 56.31% | 18.15% | 24.92% | 57.69% | 17.38% | 25.38% | 56.77% | 17.85% |

There was very little reported difference between families and providers with regard to their perceptions of crisis capacity within the system. The biggest difference between the two groups was in the area of inpatient psychiatric beds, in which families were about 9% less likely to report that service

capacity existed than providers. Families were also about 9% less likely than providers to report that inpatient services were appropriate to their needs and helpful.

When asked to comment on inpatient mental health services, family members and law enforcement personnel both expressed a concern that the lack of inpatient care would lead to tragedy when individuals who were aggressive or self-injurious were sent home. This concern was greatest among families who live in rural areas of the state, with close to 40% of them reporting a lack of services in their area or having to drive long distances to get assistance.

“Many families do not have the option of going to Indianapolis for services; thus their children do not get the inpatient services needed until injury occurs.”

Few participants overall reported that out-of-home emergency respite and crisis intervention services were available. Families were the least likely to report these as available. In addition, less than 25% of crisis services were reported as meeting the needs of the person in crisis. See Tables 6, 7, and 8 below.

Table 6: Availability of Service by Respondent

| Availability of Service (% all or some of what is needed) | | | | |
|---|-----------|-----------|----------|----------|
| Service | Available | Providers | Families | Variance |
| Mobile Crisis Services | 21.59% | 20.84% | 20.79% | 0.05% |
| Crisis Stabilization/Hospital Diversion | 18.73% | 18.16% | 17.35% | 0.81% |
| Out-of-Home Crisis Respite Services | 17.67% | 18.85% | 12.37% | 6.48% |
| Community-Based Psychiatric Inpatient Beds | 23.96% | 25.95% | 16.84% | 9.11% |
| Crisis Intervention Services | 25.54% | 25.61% | 19.59% | 6.02% |

Table 7: Appropriateness of Service by Respondent

| Matched Needs (% all or some of what is needed) | | | | |
|---|-----------|-----------|----------|----------|
| Service | Available | Providers | Families | Variance |
| Mobile Crisis Services | 21.04% | 19.73% | 22.55% | -2.82% |
| Crisis Stabilization/Hospital Diversion | 17.44% | 16.78% | 17.35% | -0.57% |
| Out-of-Home Crisis Respite Services | 18.47% | 19.07% | 19.59% | -0.52% |
| Community-Based Psychiatric Inpatient Beds | 23.35% | 25.11% | 16.67% | 8.44% |
| Crisis Intervention Services | 24.92% | 24.72% | 22.68% | 2.04% |

Table 8: Helpfulness of Service by Respondent

| Helpful (% all or some of what is needed) | | | | |
|--|-----------|-----------|----------|----------|
| Service | Available | Providers | Families | Variance |
| Mobile Crisis Services | 21.32% | 20.09% | 20.79% | -0.70% |
| Crisis Stabilization/Hospital Diversion | 17.62% | 17.23% | 15.31% | 1.92% |
| Out-of-Home Crisis Respite Services | 18.10% | 18.81% | 15.46% | 3.35% |
| Community-Based Psychiatric Inpatient Beds | 23.49% | 25.28% | 16.84% | 8.44% |
| Crisis Intervention Services | 25.38% | 25.33% | 20.83% | 4.5% |

Mobile Crisis

Mobile crisis services are services that come to the person in their home, work, or other community setting in time of need. **When asked to comment about mobile crisis services, the vast majority of respondents reported that the police were often the only available first responders in the event of an emergency.**

In addition, 60% of respondents who reported little or no mobile crisis capacity reported that the local police lacked training to effectively deal with situations involving individuals with IDD.

Unlike training, access to mobile crisis services varied between rural and urban communities, with location being cited as a barrier by approximately 40% of respondents answering little or no capacity.

- “First responders have often become part of the problem during crises.”
- “If police need to be called, it is very likely you will hear them tell the individual to 'be good' and 'don't do this ever again'.”

Some respondents reported that there had been an increase in some training within police departments, but felt that the training was inconsistent. Law enforcement personnel voiced a similar concern about the lack of mandated training. Many departments participate in voluntary training provided by local provider agencies, but felt that they still often did not have enough information going into crisis situations.

“We are often asked to respond as mental health workers, but we respond as police.” -Police Focus Group Participant

Law enforcement personnel also expressed frustration at not having any options for individuals in crisis other than the emergency room or jail.

“We take someone to the emergency room and sometimes they leave before we get the paperwork done. They go back home and sometimes we get another call later that same night, because the problem didn't go away.” -Police Focus Group Participant

Facility-Based Crisis Capacity

When asked to comment on the reasons for little or no mental health crisis stabilization capacity, almost 54% of respondents cited the lack of local availability as the primary barrier. An unwillingness to serve individuals with IDD was cited as a barrier by 42% of individuals responding to this question.

- “Some hospitals refuse to take the DD/ID consumers in crisis - mental health facilities do as well - say it's not due to MH, etc.”
- “Often no beds available. Providers reluctant to admit patients with IDD.”
- “Clients have routinely been turned away due to not having a high enough IQ (per the hospital) to participate in the therapies; they admittedly are not always well trained to manage the behavioral needs of these clients so it's a major concern.”

Crisis Response Services

Comments in this section focused almost exclusively on the lack of availability of crisis response services. Most respondents again referred to police as being the only option. The reports did not differ widely by location, which indicates a systemic issue rather than one of geographic location.

- “They have crisis numbers, but they usually tell you to call the Crisis Intervention Team which are the police.”
- “Most services are not trained to deal with IDD challenges and prefer to have providers handle problems themselves.”
- “I do not know of any crisis intervention services other than police. Our school district has trained many employees in Crisis Prevention & Intervention through CPI, but this is a short term solution.”

Theme 3: There is a need to increase access to mental health services, especially psychiatry, in all areas of the state

The next theme to emerge was the need to increase the availability, appropriateness and helpfulness of outpatient mental health services. Within the focus groups, three primary barriers were identified: 1) a lack of collaboration between systems; 2) a lack of services in rural areas; and 3) confusion about funding. Both mental health and IDD providers expressed confusion about the ability to use Medicaid to pay for mental health services for individuals on an ID Medicaid Waiver, as well as concern that individuals with IDD might not meet standards for medical necessity for mental health services.

One of the most critical findings to emerge is the existence of a significant gap between provider and family perceptions about service availability. Table 9 below shows the variance in the percentage of providers who felt that all or some of the services were available and the percentage of families who responded that all or some were available. The variance is most striking for those services that were rated as most available overall. It is also important to note that the biggest variance was reported in primary care services, such as therapy, assessment and prevention. **This suggests that family caregivers may not have the knowledge to access available needed services and this may lead to greater use of emergency services such as police.**

Table 9: Availability of Service Variance by Respondent Type

| Availability of Service (% all or some of what is needed) | | | | |
|---|----------------------|-----------|----------|----------|
| Service | Overall Availability | Providers | Families | Variance |
| Outpatient mental health Therapy | 48.87% | 51.32% | 38.83% | 12.48% |
| Clinical Consultation | 44.10% | 48.54% | 37.25% | 11.29% |
| Staff Training | 42.79% | 45.02% | 37.86% | 7.16% |
| Outpatient Psychiatry | 41.64% | 44.27% | 35.35% | 8.92% |
| Diagnostic Assessment | 40.00% | 42.41% | 29.90% | 12.51% |
| Crisis Prevention Services | 37.31% | 40.18% | 27.18% | 12.99% |
| Substance Abuse Treatment | 33.79% | 32.59% | 23.47% | 9.12% |
| Service Consultation | 30.47% | 28.82% | 20.20% | 8.62% |
| Crisis Intervention Services | 25.54% | 25.61% | 19.59% | 6.02% |
| Community-Based Psychiatric Inpatient Beds | 23.96% | 25.95% | 16.84% | 9.11% |
| Mobile Crisis Services | 21.59% | 20.84% | 20.79% | 0.05% |
| Crisis Stabilization/Hospital Diversion | 18.73% | 18.16% | 17.35% | 0.81% |
| Out-of-Home Crisis Respite Services | 17.67% | 18.85% | 12.37% | 6.48% |

While outpatient therapy was rated as the most widely available mental health service, still less than half of respondents (49%) reported that the service was always or mostly available when they needed it and family members were 12% less likely than providers to think the service was available to them. When asked to comment on ‘no’ or ‘very little’ responses, the comments clustered in three main areas with lack of training for outpatient mental health providers cited as the most common reason for dissatisfaction with service availability and appropriateness (49%).

- “There are few providers of mental health therapy/counseling with an expertise in IDD.”
- “Very few experienced professionals working in this field understanding the dual diagnosis.”
- “It is more difficult to locate MEANINGFUL outpatient therapy; many therapists lack specific experience relating to the IDD population.”

In addition to lack of training, the lack of availability of providers in rural areas was the next most frequently cited reason for a negative response (33%) followed by concerns about funding, especially the ability to bill Medicaid for mental health services to individuals with IDD (18%).

- “We must travel over 50 miles to receive services.”
- “Current funding structures are a barrier to the provision of integrated MH/DD service.”
- “Most places will not accept Medicaid insurance (private pay or private ins. only) or work with people with Autism.”

As found with the crisis services, families were once again the group least likely to report knowledge of outpatient mental health services. In fact, based on the distribution, families were more than twice as likely as expected to answer “don’t know” when asked to rate these outpatient services. There were also a higher percentage of IDD providers, particularly direct care and residential staff that did not have information about outpatient mental health services. This suggests that more outreach to families and IDD providers about the mental health services available should be provided.

When looking at the comments submitted by respondents who answered ‘no’ or ‘very little’ for service accessibility, the comments for substance abuse treatment and assessment services clustered in a similar distribution to those for outpatient therapy, with the lack of training being the most prevalent response. For psychiatry services, however, over 75% of the comments focused on the lack of trained psychiatrists in rural areas of the state. The low reimbursement rate for psychiatrists was reported as the major reason for this, specifically that many psychiatrists refuse to accept Medicaid at all or that the rate was not sufficient to cover the additional time needed to treat individuals with IDD.

- “It is near impossible to get into a Psychiatrist in our area. If they are on Medicaid they need to go to Indy which is 3 hours away.”
- “In southern Indiana there are few options for mental health, as well as significant deficit of Psychiatrists willing to work with IDD clients. Most of my clients have to travel more than 1.5 hours (one way) for medication management for psychotropic medications.”
- “We do not have many psychiatrists in the field trained specifically on IDD and those that are do not always accept Medicaid.”

Other Findings

Overall, IDD services were rated as more available than mental health services by people completing the survey. Only an average of 28% felt that little or no services existed (need to be developed) compared with an average of 41% for mental health services in general. See Table 10. Approximately 50% of respondents felt that services could be improved with greatest concern expressed in two areas:

vocational training and mental health crisis services. In addition, a significant number of respondents had no knowledge of whether or not needed services were available. In addition, more rural communities experienced the greatest problem with access to services.

When asked about the IDD services in their communities, respondents were fairly consistent in their responses. Less than one fifth of the population, or 18% of respondents overall, were completely satisfied with services (work well), while the majority (55%) felt that they needed improvement (could be strengthened) and slightly more than ¼ of the respondents (28%) reporting that they lacked needed services in their communities.

The table below shows the responses for each particular service. The services cited as least effective were employment services (8%) and crisis/emergency services (10%). Crisis services also had the highest percentage of respondents indicate that they needed to be developed in their communities (49%).

The services with the highest percent of individuals indicating that they worked well were special education (25%) and IDD case management (22%). However, these numbers were considerably lower than would have been expected. It is important to note that this analysis is for the IDD population with mental health needs and challenging behavior. The findings may indicate that the system as a whole is underperforming with this population in the view of respondents.

As with mental health services, families were the most likely to feel that the services need to be developed and transportation, employment, and crisis services were most often cited by family members of needing to be developed.

Table 10: IDD Services

| IDD/DD Community Services | Works well | Works, but could be strengthened | Needs to be developed |
|---------------------------------------|-------------------|---|------------------------------|
| Facility-Based Services (5+people) | 18% | 54% | 28% |
| Day Services/Programs | 20% | 55% | 25% |
| Employment Opportunities | 8% | 51% | 40% |
| Transportation Services | 15% | 50% | 34% |
| Medical Services | 20% | 63% | 17% |
| Crisis/Emergency Services | 10% | 41% | 49% |
| IDD Behavioral Supports | 20% | 55% | 25% |
| IDD Case Management | 22% | 59% | 19% |
| Residential Supports (1-4 persons) | 19% | 58% | 22% |
| Residential Supports (In family home) | 18% | 58% | 24% |
| Vocational/Pre-vocational training | 16% | 57% | 27% |
| Planned Family Respite | 17% | 51% | 32% |
| Special Education | 25% | 61% | 14% |
| Other Therapies (music, recreational) | 18% | 50% | 32% |
| Average | 18% | 55% | 28% |

These outcomes may reflect what was reported earlier, the need to improve capacity of the system overall through better training, consultation, and technical support to providers of services to people with IDD and Mental Health needs.

The aforementioned findings make a compelling argument that to address the needs of people with IDD and mental health issues, improvements in services and supports that promote independence and quality of life (e.g., vocational services) need to coincide with better crisis response. This suggestion is supported by research that indicates that the quality of an individual’s life contributes to their mental health.

Family Caregiver Experience with Mental Health System Interviews

While the focus groups and online survey portray perceptions of a large number of stakeholders about the service system, it is important to consider the opinions of families who had direct and recent experiences using mental health services for their family member with IDD. The Family Experiences Interview Schedule (FEIS) gathered information from 40 family members who had recent experiences (within the last year) with mental health services for their family member with IDD. The surveys sought family feedback in three primary areas:

- (1) Relationships between family caregivers and professionals;
- (2) Family caregivers' impressions of service effectiveness; and
- (3) Experiences of family members with the system.

In addition, family members were asked to assess whether there continued to be unmet service needs, and, in two open ended questions, they were asked to give advice to service planners.

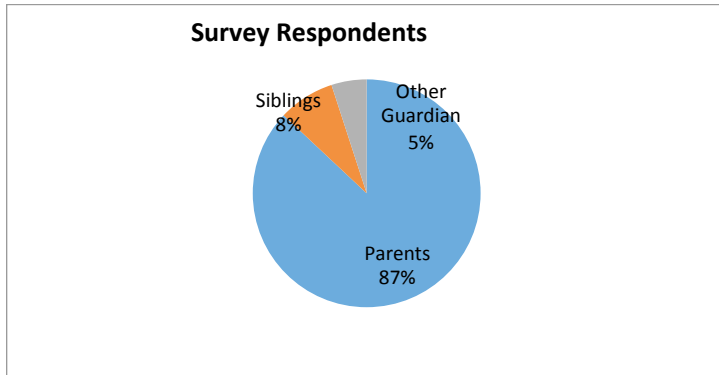
Their responses echo the overall needs of the findings from the broader community survey and focus groups.

Description of Family Member Respondents

As see in Figure 4 below, 87% (N=40) of the survey recipients were parents of an individual with IDD. 84% of respondents were female and their average age was 55. The majority of respondents (95%) reported having some college education and 70% were working either full or part-time. 73% reported a family income of at least \$50,000 annually. 86% reported that their own health was excellent or good.

Survey respondents were recruited across the state with the assistance of advocacy organizations, family support networks and provider organizations. Many of these organizations put notices on social media or their websites and approximately 60% of the interview participants contacted IOD staff directly in order to take part in the interview process. Interview participants represented all regions of the state.

Figure 4: Relationship of Survey Respondents



The family members they discussed were 63% male and had an average age of 26.

For those families participating in the telephone survey, 62% were caring for their family member at home. The remaining individuals were living mostly in group homes or supported living situations. Two individuals currently live in residential treatment facilities, one in a long-term psychiatric hospital and one individual is deceased. Of those individuals not currently living at home, 67% lived at home until recently (within the last two years).

Figure 5 shows a break-down of the services currently received. While 64% of the individuals are currently receiving mental health services, there was a wide variation in the locations where those services were being provided, as seen in Figure 6 below.

Figure 5: Types of Services Received

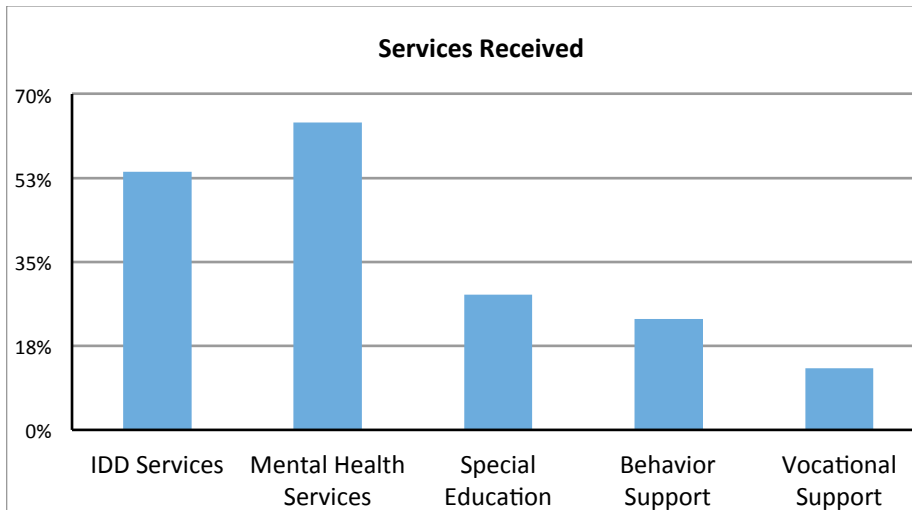
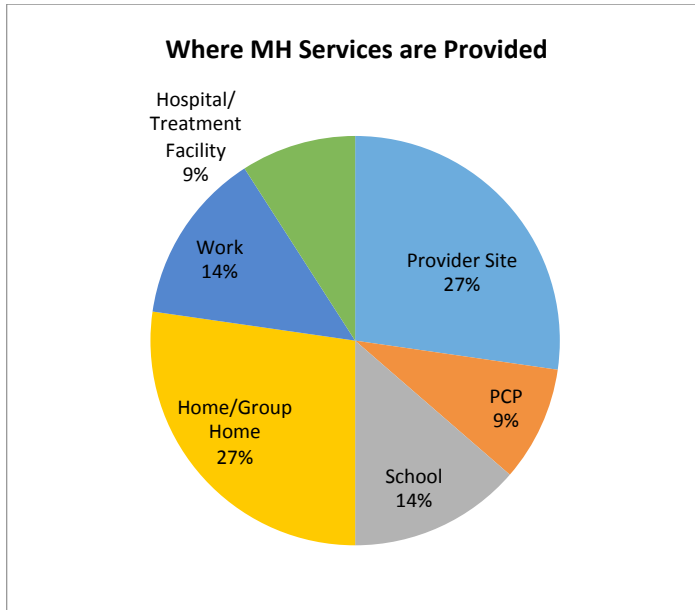


Figure 6: Where Services are Received



An analysis of the family interviews revealed the following findings:

Issue 1: Family member’s views regarding service Involvement.

Finding: Families are satisfied with their role in treatment, but do not feel they are given adequate information.

In the area of family relationship with mental health providers, families overwhelmingly felt that they had at least some of what they needed with regard to their involvement in the service recipient’s treatment. 87% rated the degree of contact favorable and 71% rated both their own involvement and the degree to which their opinions were taken into account favorably. (See Table 11).

Finding: Families were dissatisfied with the amount of information from providers.

While family members felt encouraged by providers to take an active role in their family member’s treatment (65%), almost half (47%) felt like they were given no or very little information about their family member’s illness, and a significant majority (68%) felt they were given no or very little information about what to do or who to call in a crisis. **A little more than half of the families (53%) also felt that care providers did not recognize the burdens that families were facing.**

Table 11: Service Involvement

| Question | None at all | Very little | Some, but not as much as was needed/wanted | All that was wanted/needed | Did not know/answer |
|--|-------------|-------------|--|----------------------------|---------------------|
| How much information did you receive about illness? | 18% | 26% | 24% | 29% | 3% |
| How much information did you receive about what to do in a crisis? | 39% | 29% | 18% | 13% | 0% |
| How much information did you get about who to call in a crisis? | 39% | 29% | 13% | 18% | 0% |
| Encouraged to take an active role? | 14% | 19% | 22% | 43% | 3% |
| How much did providers respond to your concerns? | 8% | 37% | 24% | 32% | 0% |
| How much did providers take into account your opinions? | 8% | 21% | 32% | 39% | 0% |
| How involved were you in treatment? | 3% | 21% | 18% | 53% | 5% |
| Did providers recognize burdens on families? | 32% | 21% | 21% | 26% | 0% |

Issue 2: Family Member Evaluations of Client (Service Recipient) Services

Finding: Only half of the families were at least somewhat satisfied overall with mental health services.

In general half of the family members felt somewhat satisfied with outpatient services overall (52%) and slightly more reported that the services offered were the ones that they needed (56%). A greater majority felt that services were flexible enough to meet their needs (63%) and convenient (63%). (See Table 12).

This finding indicates that there are effective mental health services provided some of the time, but there is room for growth.

Finding: Families are less satisfied with the availability of crisis services.

Families felt that they had no or very little choice in either services (55%) or service providers (53%) and the vast majority (76%) felt that there was little or no option for crisis services outside of the hospital.

Table 12: Service Evaluation

| Question | None at all | Very little | Some, but not as much as was needed/wanted | All that was wanted/needed | Did not know/answer |
|---|-------------|-------------|--|----------------------------|---------------------|
| Were the available services the ones needed? | 35% | 5% | 24% | 32% | 3% |
| Was there opportunity to express your opinion? | 11% | 5% | 32% | 51% | 0% |
| Was there opportunity to choose mental health services? | 37% | 18% | 16% | 26% | 3% |
| Was their opportunity to choose provider? | 37% | 16% | 13% | 32% | 3% |
| Were inpatient services helpful? | 33% | 13% | 7% | 7% | 40% |
| Are there crisis options outside the hospital? | 71% | 5% | 8% | 0% | 16% |
| How convenient were services? | 16% | 21% | 34% | 29% | 0% |
| Were services flexible enough to meet needs? | 34% | 3% | 37% | 26% | 0% |
| How satisfied were you with outpatient services? | 29% | 18% | 26% | 26% | 0% |

Issue 3: Family Member Evaluations of System Responsiveness

Finding: The vast majority of family members were at least somewhat satisfied with responsiveness of the service system.

Of special interest were the family member evaluations of the service system’s responsiveness to family needs. The vast majority of family members (86%) were satisfied with their role and a similarly large group (82%) felt that they had all or some say in the outpatient services their family member received. (See Table 13).

Finding: The majority of families reported crisis support after hours was not available.

Most families (64%) felt that there was very little or no crisis help available to them on nights or weekends.

Table 13: Service Responsiveness

| Question | None at all | Very little | Some, but not as much as was needed/wanted | All that was wanted/needed | Did not know/answer |
|--|-------------|-------------|--|----------------------------|---------------------|
| Did services respond to wishes of family? | 32% | 21% | 29% | 18% | 0% |
| How much say did you have in outpatient services? | 5% | 13% | 37% | 45% | 0% |
| How satisfied were you with your role in treatment? | 3% | 11% | 47% | 39% | 0% |
| How much crisis help was available nights or weekends? | 53% | 11% | 11% | 18% | 8% |

The results of this section of the analysis indicated that for those who receive services, when compared to families who responded to the online survey who reported a lack of mental health service access, there continued to be concern about the availability and appropriateness of crisis services, despite their positive feelings about the system’s willingness to respond to their needs.

A final note from the family members interviewed is that they want to have a greater voice in the process because they know what their family members need. When asked what advice they would give to service planners, **79% of the families interviewed wanted service planners to listen to them when making decisions about services, because they understand what they need.**

“Look at the overall needs of the family and how the individual’s disability affects the whole family. Provide all the options available and let the family members decide what is best for the individual. Don't take offense if the family members don't agree with or feel that the professional’s recommendations will work for the individual.” -Parent of an individual with IDD

Recommendations

Following are recommendations based on the analysis of services in the state of Indiana:

It is important to develop a mission statement to outline a mutual understanding of remedies moving forward. After careful review of the analysis, joint recommendations between UNH and Indiana Office of Disability and Rehab services:

1. Pilot: Several steps outlined below but will include targeted reduction of reliance on enhanced staffing requests (to manage challenging behavior) and usage by 10%. Pilot will review



enhanced staffing, how it is used to reduce dependence on enhanced staffing, clients as part of the pilot, and work on methods to review and monitor future requests

2. Model pilot after the "first step" with contracts awarded to single points of entry for the system that include 24 hour crisis response; as well as network partnerships between DD providers, Community Mental Health Centers, hospitals, and psychiatric care. As part of this program, provide trained navigators to help train providers and coordinate services across systems for high risk individuals who work to enhance traditional case management until the individual is stable and they have a clear plan
3. Pilot will establish a standardized cross systems crisis intervention planning process that includes three levels of intervention beginning with what can occur at home, who to call for help and advise; and how to access emergency assistance right away. The process should focus on movement toward increasing successful home- based remedies.
4. Pilot will mentor and model for direct support residential and vocational support providers through ongoing outreach to program sites so that they are better able to effectively support individuals with IDD and challenging behavior to reduce the dependence on enhanced staffing. While the use of Behavior support plans can be part of this, the pilot will emphasis mentoring and coaching more directly until the plans in place can be effectively utilized.
5. During pilot period: train IDD providers on multidisciplinary approaches including wellness and positive psychology. Training must be easy to access and primarily web based and focus on evidence- based approaches.
6. During pilot period, new program will train and mentor MH teams on MH diagnosis and treatment of people with dial diagnosis include all forms of mental health care including psychotherapy . Training must be easy to access and primarily web based and focus on evidence-based approaches.
7. Pilot will collect and review data: establish a database and compare results with non piloted area; include satisfaction surveys of providers, family caregivers and service users
8. Pilot will work with an established Advisory Board that includes State leadership, MH and IDD providers, family members and self- advocates to review outcomes and develop next steps.

Additional recommendations system-wide recommendations:

1. Enhance rates for outpatient and inpatient care on traditional inpatient units who provide care to individuals with IDD.
2. Improve communication about existing resources



3. Work with stakeholders to look at an enhanced service under the waiver that allows for ongoing training as well as enhanced rate of pay for expertise through credentialing process to insure that providers have the expertise needed

4. Education for families, individuals, DD and mental health providers regarding the possibilities through Vocational Rehabilitation; provide training and support to vocational providers to increase access to these services for persons with a dual diagnosis of IDD and mental health needs.

This was an in depth and active process and included the input of many stakeholders. The collaboration, participation and cooperation is much appreciated.

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Appendix A: Data Collection Tools

See attached documents:

1. Community Support Survey
2. Family Experiences Interview Schedule (FEIS)
3. Family Focus Group Questionnaire
4. Law Enforcement Focus Group Questionnaire
5. Provider Focus Group Questionnaire
6. Service User Focus Group Questionnaire



Interviewer Name and ID#: _____

Section I: IDD Services

In this section, we would like you to consider the services and supports in your community that work well for individuals with IDD and co-occurring MH or behavioral challenges and their families.

Please consider these services:

| | | | |
|-------------------|----------------------------------|------------------------------|---------------------|
| Works Well | Works, | Needs to be developed | I Don't Know |
| | but could be strengthened | | |

Facility-Based Residential Services (5+people, large intensive care facility, group home)

Residential Supports (1-4 ppl, RHS in non-family home)

Residential Supports (In family home)

Day Services/Programs

Vocational/Pre-vocational Training

Employment Opportunities

Transportation Services

Medical Services

Crisis/Emergency Services

IDD Behavioral Supports

IDD Case Management

Planned Family Respite

Special Education

Other Therapies (music, recreational)

Section II: Mental Health Services

In this section, please consider the mental/behavioral health services that exist for individuals with IDD who are also diagnosed with co-occurring behavioral/mental health concerns. For each of the listed services, we wish to know if the service exists and is it available, accessible and satisfactory.

Below is a list of questions relating to services in your community. Please rate each question listed using the scale found below and put additional explanations on the line provided.

Scale: 1=None at all 2= Very little 3=Some, but not as much as wanted/needed 4=All that is wanted/needed 5=Do not know

Clicking on any field in the chart will produce a drop-down menu so you can make your selections
If you rate any service questions as a 1 or 2, please provide an explanation

| | 1=None at all 2= Very little 3=Some, but not as much as wanted/needed 4=All that is wanted/needed 5=Do not know | | | |
|---|---|---------------------------|-----------------------------------|------------------------------------|
| | Does it exist? | Are there enough Options? | Is it available when you need it? | Overall is it satisfactory to you? |
| 1. Staff Training and Development Are MH staff trained and qualified to support individuals with IDD? | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 2. Service Consultation Is technical support in IDD available to MH providers? | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 3. Clinical Consultation by specialists in the field | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 4. Crisis Prevention & Intervention Planning | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 5. Outpatient Therapy for individuals with IDD | | | | |
| a. Outpatient Mental Health Therapy/Counseling (Group and/or individual) | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| b. Substance Abuse Treatment (Alcohol/Drugs, Group Counseling, Individual Counseling) | Choose an item. | Choose an item. | Choose an item. | Choose an item. |

| | | | | |
|---|-----------------|-----------------|-----------------|-----------------|
| Comments: Type here to begin entering your explanations. | | | | |
| c. Outpatient Psychiatry Psychiatrists with training in IDD | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 6. MH Crisis Services for individuals with IDD | | | | |
| a. Mobile Crisis Services Available first responders trained in mental health for people with IDD | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| b. Crisis stabilization/Hospital Diversion Beds | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| c. Community-Based Psychiatric Inpatient Beds | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| d. Out of home Crisis Respite Services | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 7. Crisis Intervention Services People to call (other than police) to assist in a crisis | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 8. Diagnostic Assessments Individuals trained to diagnose co-occurring IDD and MH | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| 9. Other Clinical Services for individuals with IDD and mental/behavioral health needs | | | | |
| a. OT/Sensory Skills | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |



| | | | | |
|--|-----------------|-----------------|-----------------|-----------------|
| b. Speech/Communication Services | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| c. Deaf Services | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| d. Traumatic Brain Injury (TBI) Services | Choose an item. | Choose an item. | Choose an item. | Choose an item. |
| Comments: Type here to begin entering your explanations. | | | | |
| <p>10. In your community, who primarily prescribes mental health medications to individuals with IDD and MH needs? Check all that apply.</p> <p><input type="checkbox"/> Psychiatrist <input type="checkbox"/> General Practitioner <input type="checkbox"/> Neurologist <input type="checkbox"/> Physician’s Assistant <input type="checkbox"/> Nurse Practitioner</p> <p><input type="checkbox"/> Other, please describe:</p> | | | | |
| <p>11. Are there barriers to accessing prescribed mental health medications? Please check all that apply.</p> <p><input type="checkbox"/> Cost <input type="checkbox"/> Distance to pharmacy <input type="checkbox"/> Lack of availability of medication <input type="checkbox"/> Other, please describe:</p> | | | | |
| <p>12. Please describe any other services in your community that you would like us to know about: Type here to begin entering your comments.</p> | | | | |
| <p>13. Please tell us about any additional services that your community needs: Type here to begin entering your comments.</p> | | | | |
| <p>14. Additional Comments: Type here to begin entering your comments.</p> | | | | |



Family Experiences with Mental Health Services for Persons with Intellectual and Developmental Disabilities*

Respondent ID #: _____
Date of Interview: [Click here to enter a date.](#) Time Began: _____ Time Ended: _____

Name of Respondent: _____
(First) (Last)

Telephone Number: _____ Email: _____

Hello my name is _____. This survey, sponsored by the State of Indiana is being conducted by the Center for START Services at the University of New Hampshire Institute on Disability. Our goal is to promote effective community based services for people with disabilities and their families. The list of questions is intended to learn from you about mental health services in your community for people age 16 and older with Intellectual and developmental disabilities (IDD) including autism, who are diagnosed with co-occurring behavioral/mental health needs. The purpose of the survey is to learn more about the mental health experiences of family caregivers. Before I ask you about your service experiences, I would like to know a little bit about your situation at home.

(Interviewer Instructions: Insert the name of the individual with IDD if known. If not known, use "your family member")

County where you live: _____

Location where services are received: _____
(City) (State)

What is the name of your family member with IDD? _____

His/her gender: Male Female

His/her DOB: _____

What services does your family member currently receive? (Check all that apply): IDD Services
 MH Services Special Education

Other, please describe _____

Where do you receive services? Community Mental Health Center Private Clinic Provider Site
 PCP School Home/Group Home Other, please describe _____

Your relationship:
 Parent Step-parent Sibling Grandparent Other relative
 Non-parental legal guardian
 Other, please describe: _____

Interviewer Name and ID#: _____

Section A: Household Information

A1. Does (name of individual) continue to live with you? Yes No

If no, when did (name) move out of your home? [Click here to enter a date.](#)

Where does (name) live now: [Click here to enter text.](#)

A2. In general, how have things been for you and your family over the last year? [Click here to enter text.](#)

A3. What is the total number of people, including yourself, presently living in your household? Please indicate everyone who lives with you at least half of the time.

| Relationship | Number of People |
|-----------------------|------------------|
| Parents/Step-parents | |
| Siblings of (name) | |
| Children of (name) | |
| Other Relatives | |
| Other, please specify | |
| Total in Home | |

A4. Does (name) have other siblings not living with you? Yes No

If yes, please specify:

| Gender | Age | Gender | Age |
|-----------------|-----|-----------------|-----|
| Choose an item. | | Choose an item. | |
| Choose an item. | | Choose an item. | |
| Choose an item. | | Choose an item. | |

A5. Do any other members of your household help in caring for (name) on a regular basis?

Yes No

If yes, describe who: _____

A6. Does your family member attend school, work or a day program during the day?

Yes No

If yes, where does he/she go? (check all that apply)

School Vocational Training

Work Day program

Other, please describe: _____

Section B: Family Evaluation of Mental Health Services

The next series of questions asks for your opinion about available services for your family member. I would like your general impressions of the mental health services you have used in the past year. For each of these questions please rate using the following scale:

1=Not at All 2= Very Little 3=Some, but not as much as I wanted/needed 4=All that was wanted/needed

(Interviewer Instructions: Do not read the option “Did not know/answer”, but simply mark it if the respondent does not know or cannot answer a question.)

B1. Over the past year, how much information did you receive from your family member’s mental health professionals (psychiatrist, therapist, case manager, etc.) regarding his/her illness? Choose an item.

B2. How much assistance did you get from mental health professionals regarding what to do if there were to be a crisis involving your family member? Choose an item.

B3. How much information did you get from mental health professionals regarding whom to call if there were to be a crisis involving your family member? Choose an item.

B4. How much were you encouraged by mental health professionals to take an active role in your family member’s outpatient treatment? Choose an item.

B5. During the past year, how much did mental health professionals respond to your concerns about your family member? Choose an item.

B6. How much did mental health professionals take into account your ideas and opinions about your family member’s treatment? Choose an item.

B7. When you had your family member’s permission, how much did mental health professionals involve you in his/her treatment? Choose an item.

B8. During the past year, how much did outpatient service providers recognize the burdens that family members like you face? Choose an item.

B9. For the most part, did you accompany your family member to his/her psychiatric or mental health appointments? Choose an item.

Yes No

If yes, how much contact did you have with any mental health professional on any matter pertaining to your family member’s care? Choose an item.

B10. Were the available mental health services for your family member the ones you thought were needed? Choose an item.

B11. How much opportunity was there for you to express your opinion to mental health providers about the treatment your family member received? Choose an item.

B12. How much opportunity did you or your family member have to choose between different mental health service options? Choose an item.

B13. During the past year, how much opportunity did you or your family member have to choose a particular case manager or therapist? Choose an item.

B14. During the past year, how convenient was it for your family member to use mental health services (i.e. were services easy to access)? Choose an item.

Could not access Difficult to access Somewhat difficult to access Somewhat easy to access Easy to access

If services were not easy to access, what were the primary barriers? (Check all that apply)

Services too far away Transportation Issues Inconvenient hours

Other, please describe: _____

B15. During the past year, have the services offered been flexible enough to meet the needs of you and your family member. Choose an item.

Not flexible at all Some flexibility, but not as much as needed/wanted As flexible as needed

B16. During the past year, in general how satisfied were you with the outpatient mental health services your family member received? Choose an item.

Not satisfied at all Somewhat dissatisfied Somewhat satisfied Very satisfied

B17. How much did you feel that the mental health system was responding to the wishes of family members like yourself? Choose an item.

B18. During the past year, how much say did you have in the outpatient mental health services that your family member received? Choose an item.

B19. How much satisfaction did you feel about your role in your family member's treatment? Choose an item.

B20. In the past year, did your family member use in-patient psychiatric services? Choose an item.

Yes No

If yes, were the inpatient services that your family member received helpful to him/her in your opinion? Choose an item.

B21. How much help was available to you at night or on weekends if your family member had a crisis? Choose an item.

B22. Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e. crisis/hospital diversion beds)? Choose an item.

B23. Who was the primary source of information about your family member's mental health services? Choose an item.

Your family member him/herself His/her service coordinator His/her therapist
 His/her psychiatrist No one Other

If other, please specify: _____

B24. During the past year, how much involvement did you want to have in your family member's treatment plan? Choose an item.

A lot Some Very little None at all

B25. Was there any particular service that your family member needed that was not available? Choose an item.

Yes No

If yes, please describe the service: _____

B26. What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?

Type here to begin entering your explanations.

Section C: Background Information

Thank you for taking the time to answer these questions. I will end the survey by asking you some general information questions about you.

- C1.** What is your date of birth? _____
- C2.** What is your gender? Male Female
- C3.** Are you currently? Married Living with a partner Widowed
 Separated Divorced Never married
- C4.** What is the highest grade of school or year of college you have completed?
 No schooling Elementary Schools High School
 Some College College Degree Graduate/Professional Degree
- C5.** Are you currently enrolled in school or college? Choose an item.
- C6.** Are you currently working?
 Full time Part time Retired Volunteer work Not working
- C7.** How would you describe your own health over the past year?
 Excellent Good Fair Poor
- C8.** Do any other family members in your home have a disability? Choose an item.
If yes, please specify their relationship to (name)? _____
- C9.** Please tell me which best reflects your total family income before taxes from all sources (including (name) if he/she lives with you)?
 Less than \$10,000 Between \$10,000 and \$29,000 Between \$30,000 and \$49,000
 Between \$50,000 and \$69,000 Between \$70,000 and \$89,000
 Between \$90,000 and \$99,000 Over \$100,000
- C10.** To the best of your knowledge, is your family member Medicaid eligible? Yes No
- C11.** Would you like to add anything before we end?

Type here to begin entering your explanations.

Thank you for participating in this survey. Would you like a copy of the results of this study when it is completed? Choose an item.

If yes, please provide your mailing address below and we will send them to you when the study is completed.

Name: _____

Street Name and Number: _____

City, State and Zip Code: _____

Section D: Interviewer Observation Questions

(Interviewer Instructions: Answer these questions immediately after the interview. Do not discuss them with the respondent.)

- D1.** During the interview, was the respondent generally: Choose an item.
- D2.** In general, how quickly did the respondent respond to questions? Choose an item.
- D3.** What is your perception of respondent's intelligence? Choose an item.
- D4.** How truthful did respondent seem? Choose an item.
- D5.** Was the interview conducted: Choose an item.
- D6.** Did respondent have difficulty understanding any questions? Choose an item.
If yes, please list the question number(s): _____
- D7.** What else, if anything, will help us interpret the data or give us a better understanding of the interview situation? [Click here to enter text.](#)



D8. I certify that I administered this interview with the designated respondent, that I followed all question specifications, and that I will keep all information obtained during the interview confidential. Choose an item.

Please list your interviewer ID#: _____

Section B: IDD Services

In this section, we would like you to consider the services and supports in your community that work well for individuals with IDD and their families.

Please consider these services:

| | Works Well | Works, but could be strengthened | Needs to be developed |
|-----------------------------------|-------------------|---|------------------------------|
| Residential Services | | | |
| Day Services/Programs | | | |
| Employment Opportunities | | | |
| Transportation Services | | | |
| Medical Services | | | |
| Emergency Services | | | |
| In-Home Supports | | | |
| Service Facilitation/Coordination | | | |

Section C: Mental Health Services

The next series of questions asks for your opinion about available services for your family member. I would like your general impressions of the mental health services you have used in the past year. For each of these questions please rate using the scale provided:

C1. How much assistance did you get regarding what to do if there were to be a crisis involving your family member?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C2. Were the available mental health services for your family member the ones you thought were needed?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C3. During the past year, how convenient was it for your family member to use outpatient mental health services (i.e. were services easy to access)?

- Could not access Difficult to access Somewhat difficult to access
 Somewhat easy to access Easy to access

If services were not easy to access, what were the primary barriers? (Check all that apply)

- Services too far away Transportation Issues Inconvenient hours
 Other, please describe: _____

C4. During the past year, have the services offered been flexible enough to meet the needs of you and your family member?

- Not flexible at all Very little flexibility Some flexibility, but not as much as wanted/needed
 As flexible as was wanted/needed

C5. During the past year, in general how satisfied were you with the outpatient mental health services your family member received?

- Not satisfied at all Somewhat dissatisfied Somewhat satisfied Very satisfied

C6. How much did you feel that the mental health system was responding to the wishes of family members like yourself?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C7. How much satisfaction did you feel about your role in your family member's treatment?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C8. In the past year, did your family member use in-patient psychiatric services? Yes No

If yes, were the inpatient services that your family member received helpful to him/her in your opinion?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C9. How much help was available to you at night or on weekends if your family member had a crisis?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C9A. Who do you call at night or on weekends if there is a crisis? _____

C9B. When there was a crisis did you get all you wanted and needed from the person you called?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C10. Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e. crisis/hospital diversion beds)?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

Section D: Discussion Questions

D1. Was there any particular service that your family member needed that was not available?

- Yes No

If yes, please describe the service: _____

D2. What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?

Section E: Demographic Information

Thank you for taking the time to answer these questions. Please answer a few general information questions about you.

E1. What is your date of birth? _____

E2. What is your gender? Male Female

E3. Are you currently? Married Living with a partner Widowed

Separated Divorced Never married

E4. What is the highest grade of school or year of college you have completed?

- No schooling Elementary Schools High School
 Some College College Degree Graduate/Professional Degree

E5. Are you currently enrolled in school or college? Yes No

E6. Are you currently working?

- Full time Part time Retired Volunteer work Not working

E7. How would you describe your own health over the past year?

Excellent Good Fair Poor

E8. Do any other family members in your home have a disability? Yes No

If yes, please specify their relationship to your family member? _____

E9. Please tell me which best reflects your total family income before taxes from all sources (including your family member if he/she lives with you)?

Less than \$10,000 Between \$10,000 and \$19,000 Between \$20,000 and \$29,000

Between \$30,000 and \$39,000 Between \$40,000 and \$49,000

Between \$50,000 and \$59,000 Over \$60,000

E10. Would you like to add anything before we end?

Focus Group: Law Enforcement Experiences with Mental Health Services for Persons with Intellectual and Developmental Disabilities

Section A: Background Information

- A1.** In what town/county do you work?
- A2.** Your primary role?
- A3.** Number of years in the field: _____
- A4.** Your Gender: Male Female

Section B: Community Crisis Services

The next series of questions asks for your opinion about available services for individuals experiencing a crisis. I would like your general impressions about the options available to you in these circumstances. For each of these questions please rate using the scale provided:

B1. How much information/training do you get regarding intellectual and developmental disabilities (IDD) in general?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

B2. When called to assist in a crisis, do you have the support and training you need to respond safely and effectively?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

B3. When responding to an incident involving an individual with IDD are there other resources in the community that can be called to assist?

- Yes No

If yes, please describe:

B4. When accessing other crisis resources did you get the assistance you needed?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

B5. Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e. crisis/hospital diversion beds)?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

Section C: Discussion Questions

C1. Are there any particular services needed in your community that are not available?

- Yes No

If yes, please describe the service: _____

C2. What advice would you give to service planners regarding crisis service needs of persons with IDD and their families?

Focus Group: Provider Experiences with Mental Health Services for Persons with Intellectual and Developmental Disabilities*

Section A: Background Information

- A1.** What services do you currently provide? (Check all that apply): IDD Services
 MH Services Other, please describe _____
- A2.** What is your primary role: Social worker Psychologist Mental health counselor
 Teacher Residential provider
 Day program provider PCP/Doctor Nurse Administrator Policy maker Case manager Service coordinator
 Other, please describe: _____
- A3.** Number of years in the field: _____
- A4.** Agency (if applicable): _____
- A5.** Age of service users you support (check all that apply):
 Child (Ages 6-11) Young Adult (Ages 26-40)
 Adolescent (Ages 12-18) Adults (Ages 41-55)
 Transitional youth (Ages 19-25) Older adults/aging (Ages 55 and over)
- A6.** Your Gender: Male Female

Section B: IDD Services

In this section, we would like you to consider the services and supports in your community that work well for individuals with IDD and their families.

Please consider these services:

| | Works Well | Works, but could be strengthened | Needs to be developed |
|-----------------------------------|-------------------|---|------------------------------|
| Residential Services | | | |
| Day Services/Programs | | | |
| Employment Opportunities | | | |
| Transportation Services | | | |
| Medical Services | | | |
| Emergency Services | | | |
| In-Home Supports | | | |
| Service Facilitation/Coordination | | | |

Section C: Mental Health Services

The next series of questions asks for your opinion about available services in your community. I would like your general impressions of the mental health services that are used by persons with IDD who also have behavioral/mental health challenges.

For each of these questions please rate using the scale provided:

- C1.** Are the available mental health services the ones you think are needed?
 Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C2. How accessible to you feel outpatient mental health services (i.e. were services easy to access) are for individuals and their families?

- Not accessible Difficult to access Somewhat difficult to access
 Somewhat easy to access Easy to access

If services are not easy to access, what do you feel are the primary barriers? (Check all that apply)

- Services too far away Transportation Issues Inconvenient hours
 Other, please describe: _____

C3. Are mental health services flexible to the needs of individuals and their families?

- Not flexible at all Very little flexibility Some flexibility, but not as much as wanted/needed
 As flexible as was wanted/needed

C4. How much collaboration is there between MH and IDD providers?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C5. Are the inpatient services available helpful to individuals with IDD?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C6. How much help was available to individuals who experience a crisis?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C6a. Who do individuals/families call at night or on weekends if there is a crisis?

C7. Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e. crisis/hospital diversion beds)?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

Section D: Discussion Questions

D1. Was there any particular services needed in your community that was not available?

- Yes No

If yes, please describe the service: _____

D2. What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?

D3. What are the barriers, if any, for individuals with IDD to receive mental health services?

Focus Group: Individual Experiences with Mental Health Services for Persons with Intellectual and Developmental Disabilities*

Section A: Background Information

A1. What services do you currently receive? (Check all that apply): IDD Services
 MH Services Other, please describe _____

A2. Do you currently live with your family? Yes No

If no, when did you move out of your family's home? _____
 (Enter date)

Where do you live now? _____

A3. Do you have other siblings not living with you? Yes No

If yes, please specify:

| Gender | Age |
|--------|-----|
| | |
| | |
| | |
| | |
| | |

A4. Do you attend school, work or a day program during the day?

Yes No

If yes, where do you go? (Check all that apply)

- School
- Work
- Vocational Training
- Day program
- Other, please describe: _____

Section B: IDD Services

In this section, we would like you to consider the services and supports in your community that work well for you and your family.

Please consider these services:

| | Works Well | Works, but could be strengthened | Needs to be developed |
|-----------------------------------|-------------------|---|------------------------------|
| Residential Services | | | |
| Day Services/Programs | | | |
| Employment Opportunities | | | |
| Transportation Services | | | |
| Medical Services | | | |
| Emergency Services | | | |
| In-Home Supports | | | |
| Service Facilitation/Coordination | | | |

Section C: Mental Health Services

The next series of questions asks for your opinion about available services in your community. I would like your general impressions of the mental health services you have used in the past year.

For each of these questions please rate using the scale provided:

C1. How much assistance did you get regarding what to do if there were experiencing a crisis?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C2. Were the available mental health services the ones you thought were needed?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C3. During the past year, how convenient was it for you to use outpatient mental health services (i.e. were services easy to access)?

- Could not access Difficult to access Somewhat difficult to access
 Somewhat easy to access Easy to access

If services were not easy to access, what were the primary barriers? (Check all that apply)

- Services too far away Transportation Issues Inconvenient hours
 Other, please describe: _____

C4. During the past year, have the services offered been flexible enough to meet your needs?

- Not flexible at all Very little flexibility Some flexibility, but not as much as wanted/needed
 As flexible as was wanted/needed

C5. During the past year, in general, how satisfied were you with the outpatient mental health services you received?

- Not satisfied at all Somewhat dissatisfied Somewhat satisfied Very satisfied

C6. How much did you feel that the mental health system was responding to the wishes of you and your family?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C7. How much satisfaction did you feel about your role in your treatment?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C8. In the past year, did you use in-patient psychiatric services? Yes No

If yes, were the inpatient services that you received helpful to you?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C9. How much help was available to you at night or on weekends if you experienced a crisis?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C9A. Who do you call at night or on weekends if there is a crisis? _____

C9B. When there was a crisis did you get all you wanted and needed from the person you called?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

C10. Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e. crisis/hospital diversion beds)?

- Not at All Very Little Some, but not as much as wanted/needed
 All that was wanted/needed

Section D: Discussion Questions

D1. Was there any particular service that you needed that was not available?

- Yes No

If yes, please describe the service: _____

D2. What advice would you give to service planners regarding the mental health service needs of persons with IDD and their families?

Section E: Demographic Information

Thank you for taking the time to answer these questions. Please answer a few general information questions about you.

E1. What is your date of birth? _____

E2. What is your gender? Male Female

E3. Are you currently? Married Living with a partner Widowed

Separated Divorced Never married

E4. What is the highest grade of school or year of college you have completed?

- No schooling Elementary Schools High School
 Some College College Degree Graduate/Professional Degree

E5. Are you currently enrolled in school or college? Yes No

E6. Are you currently working?

- Full time Part time Retired Volunteer work Not working

E7. How would you describe your own health over the past year?

- Excellent Good Fair Poor

E8. Do any other family members in your home have a disability? Yes No

If yes, please specify their relationship to your family member? _____

E9. Please tell me which best reflects your total family income before taxes from all sources)?

- Less than \$10,000 Between \$10,000 and \$19,000 Between \$20,000 and \$29,000
 Between \$30,000 and \$39,000 Between \$40,000 and \$49,000
 Between \$50,000 and \$59,000 Over \$60,000

E10. Would you like to add anything before we end?



Appendix B: Indiana IDD/MH Task Force Members

Leslie Jones, DDRS

Tiffany Neal, Hands in Autism

John Dickerson, The ARC of IN

Matt Brooks, ICCMHC

Mel Burks, Hamilton Center

Kelly Hartman, INABC

Madeline Sandberg, BCNWH Joint Services

Debbie Herrmann, DMHA

Tonya Wetzell, New Hope Services, Inc.

Betty Dunham, Rauch, Inc.

Kim Opsahl, INARF

Katie Connel, DCS

David Mank, IIDC/IU

Becky Reed, IDOE

Nicole Hicks, Autism Society of IN

Steve McCaffrey, Mental Health America

Julie Reynolds, BDDS

Nicole Norvell, DDRS

Dawn Downer, DDRS

Dana Renay, Autism Society of IN

Thomas Hayes, DDRS

Jill Ginn, The ARC of Indiana

Josh Sprunger, NAMI Indiana



Kevin Moore, FSSA

Laura Cummings, The ARC of IN

Melody Cooper, The ARC of IN

Naomi Swiezy, IUPUI

Regina Ashley, DCS

Matt Rodway, FSSA

Tracey Shriver, IDOE

Appendix C: Focus Group Protocols and Dates

Focus Group Protocols

Introduction: Introductions are made in order to gain better knowledge of the community and to foster positive relations between systems and the group facilitators. A short explanation of the purpose of the focus group will be provided.

Initial Assessment: The IOD has developed a questionnaire to collect information about IDD/MH services in the community. Participants in the focus groups will fill out the questionnaires when the focus group commences. Everyone will be given ample time and writing tools to complete the questionnaire, and there will be follow up conversation in regard to existing services and service needs.

Data Collection: After questionnaires collected the participants will be given the opportunity to expand on their thoughts in regard to questions about service delivery, service needs and training needs. This is also a time for IOD staff to learn more about families, providers, provider structure, existing systemic partnerships, and overall provider culture. While participants are sharing their thoughts and ideas, information will be recorded by an IOD staff member either in person or telephonically.

Final Question and Answer: In concluding the focus group all participants are given a chance to ask questions. Information will be given in regard to how results of the focus group will be used and how the final report will be distributed

List of Groups Conducted

| Date | Group | Number of Participants |
|---------------|-----------------------------------|------------------------|
| May 15, 2014 | Community Mental Health Providers | 7 |
| June 10, 2014 | Logansport Police | 6 |
| June 10, 2014 | Family Members | 11 |
| June 19, 2014 | Self-Advocates-Group 1 | 9 |
| June 19, 2014 | Self-Advocates-Group 2 | 10 |
| June 27, 2014 | IDD Providers | 5 |
| June 27, 2014 | IDD Providers | 6 |
| July 10, 2014 | Children's Services | 5 |
| July 18, 2014 | Behavior Consultants | 8 |