Indiana Interagency Autism Coordinating Council

ANNUAL REPORT

2017-2018



ABOUT IIACC

The primary mission of the Indiana Interagency Autism Coordinating Council (IIACC) is to facilitate the efficient and effective exchange of information on autism-related activities among the member agencies, and to leverage resources and experiences to address common issues and outcomes, and to fill identified gaps. The Council serves as a forum to assist in implementation through informing the direction and assisting in increases of public understanding and awareness of the state's collective priorities, activities, programs, policies, and research, and in bringing important matters of interest forward to enable and facilitate shared knowledge, discussion, and general access to the state resources and activities. In the current work, the IIACC serves as one essential forum and mechanism for information sharing as well as data driven decision making through review, discussion, and problem solving informed by the data collected through a comprehensive, systematic, and facilitated process.

Learn more about IIACC at https://youtu.be/RUFjU2uYiso



HANDS in Autism® Interdisciplinary Training & Resource Center facilitates the work of the IIACC to support bridging systems, growing local capacity, and collaborating across sectors of the community.



The Family and Social Services Administration provides oversight and support to HANDS in Autism® in facilitating this effort.

Citation:

HANDS in Autism. (2018). *Indiana Interagency Autism Coordinating Council (IIACC): Annual report, 2017-2018.* Retrieved from the Family and Social Services Administration, Division of Disability and Rehabilitative Services website: https://www.in.gov/fssa/files/IIACC_Report_2018.pdf



GET INVOLVED

www.IndianaNetwork.org

- INformation Network
- Professional Learning Communities
- Needs Assessment Survey
- Sexual Health Class Survey

www.HANDSinAutism.IUPUI.edu or

hands@iupui.edu

- HANDS in Autism® Interdisciplinary
 Training & Resource Center
- Local Community Cadres

EXECUTIVE SUMMARY

Collectively, the IIACC membership and HANDS in Autism® facilitators used data from state-wide gap analyses, general community input, and other state and national data to inform and develop a number of tangible resources and products. These include the INformation Network website towards more effective triage to the many resources for autism spectrum disorder (ASD) in Indiana as well as one-page documents for legislators and other stakeholders in alignment with justice (Goal 7; see back of the report for goal descriptions) and cultural (Goal 8) goals within the Indiana Comprehensive State Plan. Further, to enable more informed, effective and ongoing discussions, as well as further action towards greater shared understanding and dissemination, two professional learning communities have been initiated to further the focused attention and efforts related to Justice and Public Safety and Cultural Responsivity.

IIACC meetings continue to occur 3-4 times annually and are open to the public participation live or online with registration. Involvement in topical Professional Learning Communities (PLCs) is also open by contacting the HANDS facilitators to join meetings or provide other input. Other involvements are available by joining regional Local Community Cadres (LCCs) and providing input to the INformation Network website (www.IndianaNetwork.org). Contact HANDS to learn more!

Looking forward, the added framework and dimension of the PLCs will be expanded in terms of improving upon the framework, coordinating and collaborating to further the efforts of the IIACC and larger community, and continuing to develop PLC communities for added focused effort and coordination pertaining to other priority areas identified through state assessment (e.g., Transition to Adulthood - Goal 5).

Full Indiana Comprehensive State Plan for Autism is available on the FSSA website: https://bit.ly/2Gi5kx5



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IIACC MEMBERSHIP

About Special Kids (ASK) Adult and Child Health Advocacy Links, LLC Agape Riding **ALEC Program** Answers for Autism Anthem Arc of Indiana/Erskine Green Training Institute Autism Society of Indiana (ASI) Autism Speaks Ball State, Center for ASD Ball State, Special Education Ball State/YOC **BDDS** Behavior Works ABA Benchmark Human Services Bona Vista, Community Preparedness **BOIS** Bureau of Child Development Services (First Steps) **BVIS CARS** Catholic Charities Indianapolis Centerstone Central Dispatch, City of Evansville CHIIS (Center for Health Innovation and Implementation Science Child Care Answers Children's Bureau, Hamilton County Church, Church, Hittle & Antrim (special education law) CIP Commission on Improving the Status of Children Commission on Public Health. Behavioral Health, & Human Services CYACC DDB DDRS/BDDS Department of Correction, Juvenile Services, Central

Office Agency

Security

Department of Homeland

Department of Insurance

Developmental Pediatrics

DHHS Division of Family Resources (DFR) **DMHA** System of Care & Children's Advisory Board DOC Down Syndrome Indiana (DSI) Early Learning Indiana Easter Seals Crossroads Families United for Support and Encouragement (FUSE) Family and Social Services Administration Family Voices **FSSA** Gibault Children's Services Grupo de Apoyo para Latinos con Autismo (GALA) H2 Foundation (Hope & Healing) **HABA** Hamilton Center HeadStart HeadStart **IACCR** IAPSS (superintendents) IASP (principals) IASP (psychologists) **ICASE** IDOE IN Law Enforcement Academy (ILEA) IN School Resource Officer (SRO) Association **INABC** INAFP (family practice) Indiana ABA Parents, Journey to Adulthood (Indiana Parents of Children with Autism) Indiana AHEC Network Indiana Association for the Education of Young Children (IAEYC) Indiana Association of Rehabilitation Facilities, Inc. (INARF)

Indiana Association of

Indiana Department of

(IARCA)

Services (DCS)

Resources and Child Advocacy

Indiana Department of Child

Workforce Development Indiana Disability Rights (previously known as IPAS) Indiana Legal Services, Inc. Indiana Prosecuting Attorneys Council Indiana Public Defender Council Indiana Sheriff's Association Indiana Small & Rural Schools Association Indiana Statewide Independent Living Council (INSILC) Indiana Supreme Court Indiana University Center for Aging Research/Regenstrief Institute Indy Adults on the Spectrum Infant & Toddler Institute **INPEA InPEAT INSOURCE IPSEC IRCA** IRN **ISCA** ISDH (Maternal and Child Health (MCH) and Children's Special Health Care Services (CSHCS) Divisions at the Indiana State Department of Health) **ISHA** ISTA/NEA **IU Heath Emergency** Response Training Institute IU, Emergency Management and Continuity IUPUI, Education IUPUI, Psychology IUPUI, School of Social Work Law Enforcement Legal Representatives Logan Center/Sonya Ansari **Autism Center** Marion County Public Health Department, Emergency **Preparedness** Mental Health America of Indiana (MHAI) Meridian Health Services MESH Coalition

Metlife Midtown Community MHC NAMI NDBS (IU School of Med. CHIP in for Qual) Nemours/CDC Taking Steps to Healthy Success Noble Office of Early Childhood & School Learning Office of Medicaid & Policy Planning Opportunities for Positive Growth, Inc. Optional Rhythms, Inc./ ACCESS Academy Partnerships for Early Learners Project Launch, DMHA & ISDH Psychiatry, CSATC Purdue University Rauch Inc. Riley Child Development/ LEND & CDC Rose-Hulman Institute of Technology Safety Store @ Riley School Safety Academy Self-Advocates of IN (ASD rep) Shelbyville VC Aktion Club SITE Program Special Olympics St. Vincent's Hospital State Board of Education Systems of Care (SOC) That's My Baby, Inc. The Arc of IN The Equity Project Tristate Trauma Network University of Indiana Valle Vista Voyage Support Services **VR** Representatives VR, #Work4Life, Project search WOTC Youth Law TEAM of Indiana, Zeilbeck Group

IMPACT AT A GLANCE

205% INCREASE IN IIACC MEMBERS

INCREASED DIVERSITY OF IIACC MEMBERS

64 PAGES

RELEASED INFORMATION NETWORK WEBSITE, INFORMED BY THE IIACC MEMBERS

2

PROFESSIONAL LEARNING
COMMUNITIES (PLCs) STARTED AS A
FRAMEWORK OF DELIVERY

EARNED HONORABLE MENTION FOR PRESENTATION AS A PREMIER MODEL OF STATE FACILITATION AND IMPLEMENTATION 2018 START NATIONAL CONFERENCE, BOSTON, MA, MAY 7-9.

DATA HIGHLIGHTS

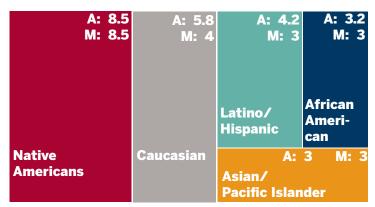
We use data to guide the IIACC actions and address the goals outlined in the Indiana Comprehensive State Plan for Autism. Since 2012, over 4,000 Indiana residents (English and Spanish-speaking) across all 92 counties have responded regarding their needs:

- Individuals with ASD
- Families
- Educators
- Healthcare personnel

- First responders
- Justice and law enforcement
- Other service providers

Based on the analysis results, topics related to Justice and Public Safety and Cultural Responsivity were often brought up as an issue and need to address by Indiana respondents.

MEAN (A) AND MEDIAN (M) AGE OF DIAGNOSIS BY RACE



• 12.2 % reported police being called

- 2.5% reported police warning being issued
- 1.1% served time in juvenile detention facility

RESPONSES BY REGION TYPES*

| | 49.8% | 25.8% | 24.4% |
|-----------------------|-------|----------------------|----------------------------|
| Urban (> 100 thou) | | Rural (< 40 thou) | Mixed (40 -100 thou) |

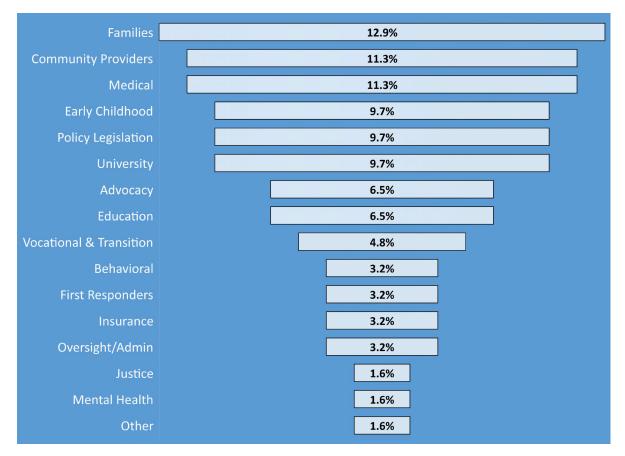
^{*} Largely representative of the types of regions compared to census data in Indiana and nationwide

Breakdown by Race

| | Survey Respondents | Indiana Census | US Census |
|------------------------|-----------------------|-------------------|--------------|
| African American | 5.2% | 9.7% | 13.3% |
| Asian/Pacific Islander | 0.9% | 2.3% | 5.9% |
| Caucasian | 89.0% | 85.6% | 61.3% |
| Latino/Hispanic | 4.5% | 6.8% | 17.8% |
| Native American | 0.5% | 0.4% | 1.3% |

Additionally, funding, time, and practical information were frequently reported as barriers to implementation of best practices in working with individuals with ASD within the scope of the two goals.

GROWING MEMBERSHIP DIVERSITY







* Includes social media for IIACC and Local Community Cadres, facilitated by HANDS in Autism®, which allows for broader dissemination of IIACC message and community engagement.

The increase in membership can be explained by:

- Jointly set goals, objectives, values, vision, and projects
- Ongoing engagement during and between meetings
- Opportunities to learn and share expertise
- Focus on action, implementation, and systems change
- Facilitated development of connectedness and trust
- Community-wide and state-wide projects
- Encouragement of open and autonomous communication
- Focus on evidence-based practices

YEAR OF GROWTH & NNOVATION

IIACC members help build statewide capacity by addressing the goals included in the Indiana Comprehensive State Plan for Individuals with Autism Spectrum Disorder (ASD).

- Aligning activities with community, state, and federal priorities
- Presentation of the IIACC as a model of facilitation and state implementation efforts at both community, state and national forums
- New goal added: Cultural Responsivity (Goal 8)
- Goals addressed: Justice System and Public Safety (Goal 7); Cultural Responsivity (Goal 8)

IIACC is the voice for the Indiana professionals, families, and individuals with ASD by exploring and addressing state-wide needs explored through gap analyses involving interviews, focus groups, and the Indiana Needs Assessment.

- Systematic process for identifying the needs of the state and clarity on priorities based on stakeholder input
- Providing for involvement of all levels of stakeholders through varied levels and means of participation
- Providing for activities informed by and consistent with known experts and literature in the areas of focus

IIACC members collaborate to inform the development and dissemination of resources and high-quality training to support providers, families, and individuals with ASD.

- Engaging in education and dissemination activities to facilitate sharing (i.e., collaboration, outreach, direct service) of identified needs for services and resources
- Releasing of INformation Network website
- Releasing information pertaining to legislation and cultural responsivity

IIACC members participate informing the necessary resources and products to promote shared dialogue, responsibility and dissemination across communities and the state.

- Gaining information at and relevant to all stakeholders to evaluate need for services and resources
- Initiating Professional Learning Communities (PLCs)
- Holding regular quarterly meetings
- Collaborating with Local Community Cadres (LCCs) to inform efforts and disseminate information

PROFESSIONAL LEARNING COMMUNITIES

The IIACC Professional Learning Communities (PLCs) are facilitated groups of professionals, families, and other community members with shared interest in actively engaging in the deliberation and development of information and products collectively informed by the IIACC and Indiana

communities. The PLCs strive to foster greater awareness, improve

WHAT IS A PROFESSIONAL LEARNING

COMMUNITY?

navigation of resources and services, and increase dissemination efforts which will benefit individuals with ASD and their families in accessing successful outcomes statewide.

Problem solving

Networking and resource sharing

Networking and personal growth

Multi-system collaboration

PROFESSIONAL LEARNING COMMUNITY

INDIANA INTERAGENCY AUTISM COORDINATING COUNCIL

Creative

Diversity and

inclusion

Learn more about PLCs at https://youtu.be/P5oGYTeW5-E

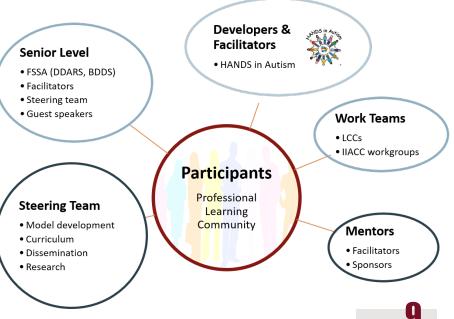
PLC STRUCTURE AND STAKEHOLDERS

The PLC members and their supporting network have clearly defined roles. Participants (in the center) are the members of the PLCs. Senior levels are PLC governance body, steering team, facilitators, and speakers.

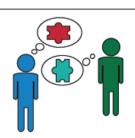
HANDS in Autism® serves as developers and facilitators of the PLC process and groups.

Members of the steering team include leaders in respective fields.

Work teams are Local Community Cadres and IIACC workgroups that help by informing and supporting dissemination and implementation efforts. Finally, mentors provide day-to-day support to review action plans, suggest resources and contacts, help remove barriers, give advice, and discuss lessons learned.



INNOVATION EFFORTS



Preconditions

- Consideration of adequacy of resources
- Selection of an "influential champion" to engage cross-sector decision makers and stakeholders
- A "sense of urgency" for change
- Common understanding that current approaches are inadequate



Phase 1: Initiating Action

- Understanding of the landscape of key players and existing resources
- Baseline data on the needs and social problem to develop the case for change
- Initial governance structure with strong champions



Phase 2: Organizing for Action

- Establishing processes for the group(s)
- Creation of an infrastructure for organizing and facilitating partners
- Establishing a common agenda with outlined goals and strategies
- Developing shared metrics and an overall system of measurement
- Creating workgroups and tasks
- Engaging the community and public



Phase 3: Sustaining Action & Impact

- Implementation of tasks and strategies
- Collection, tracking and reporting of progress data
- Engagement and advocacy among community
- Continuous communication to refine and further the work
- Create a method to reflect and identify improvements
- Focus on innovation and creating approaches rather than adopting existing approaches

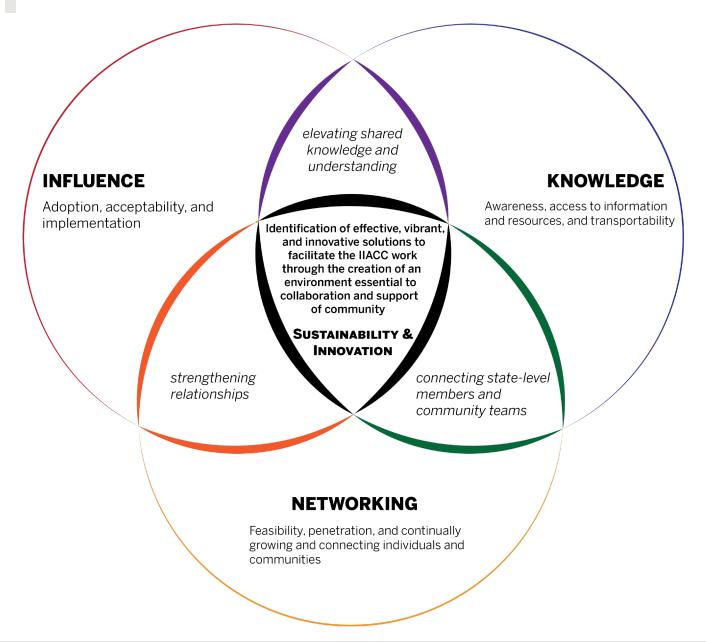
Years 1-2: Exploration

Year 3:
Installation &
Initial Implementation

Years 4+:
Full
Implementation

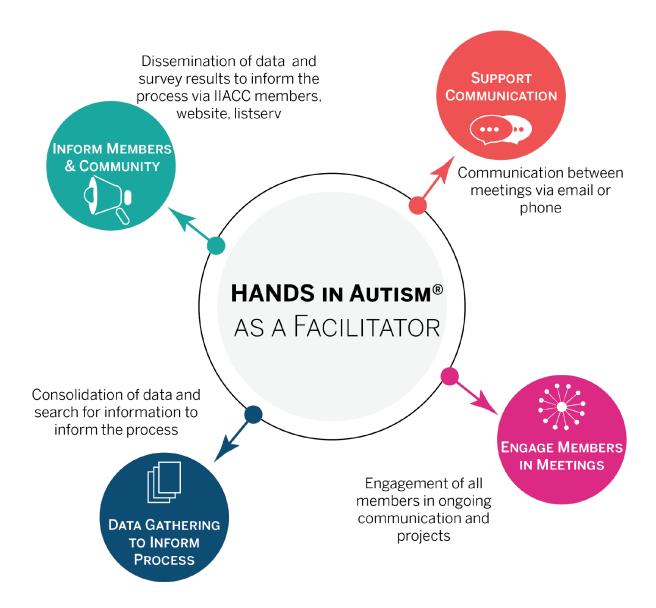
The intent of the IIACC at this phase of development was to move from Phase 2 (Organizing for Action) to Phase 3 (Sustaining Action and Impact). This also has aligned with the timeline for development and action initially proposed by HANDS in Autism® as facilitators of the IIACC and associated efforts towards systems change and implementation pertaining to autism services. Collectively, the IIACC membership and community input facilitated by HANDS in Autism® identified Goals 7 (Justice and Public Safety) and 8 (Cultural Responsivity) as the primary areas of needed concentration, effort, and resource development. As a next step, we created Professional Learning Communities that focus on these goals to further sustain the impact.

CORE FACILITATION ELEMENTS



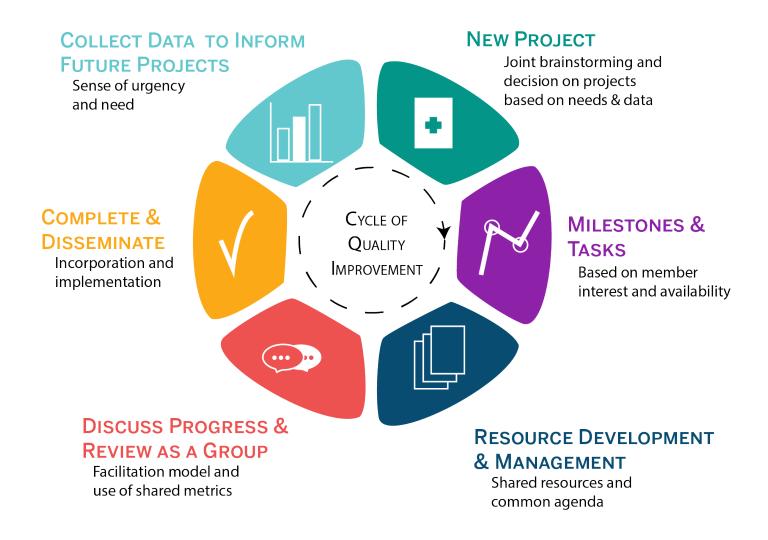
The focus of the HANDS in Autism® facilitation is innovation, collaboration, and integration of shared input and effort towards long-term sustainability. This is made possible by involvement of three key areas of emphasis: influence, knowledge, and networking. These areas of emphases result in connecting state-level members and community teams, strengthening relationships, and elevating shared knowledge and understanding.

ONGOING SUPPORT OF IIACC



To reach the level of innovation and streamline IIACC activity planning and implementation, HANDS in Autism® is actively involved at diverse levels of support and facilitation, including fostering of communication and engagement of members during and between meetings, data gathering, and informing community, state and national stakeholders about efforts in Indiana.

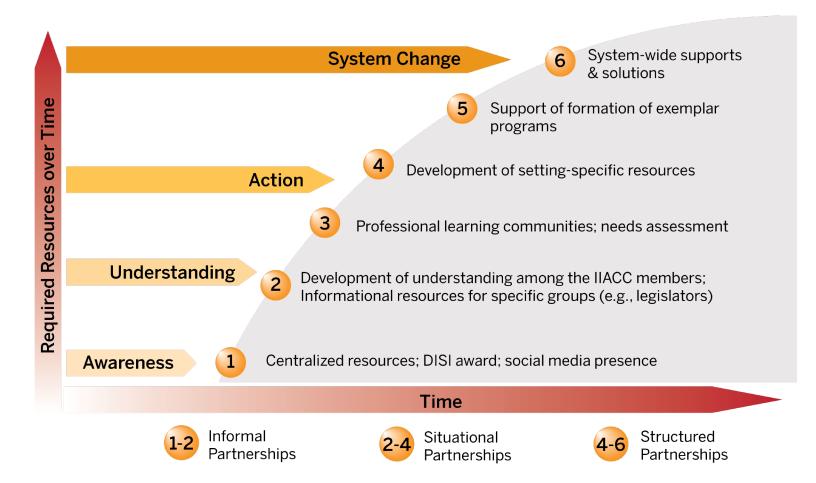
QUALITY IMPROVEMENT



Additionally, we engage in an ongoing quality improvement and an iterative approach to projects, in which IIACC members participate.

The focus on inclusiveness of all interested stakeholders as well as on quality improvement allows for ensuring implementation and shared goals, actions and messaging sustainability of projects.

IMPLEMENTATION EFFORTS



For continuous impact and sustainability of IIACC, efforts must be facilitated, apparent, and continuous across all levels of input, starting from basic awareness and progressing to the ultimate goal of shared information, dialogue, and systems change.

SAMPLE RESOURCES

The focus of dissemination during the report year was on collaborative design, information, and implementation of a website that would serve as a one-stop-shop for families and providers when seeking information and resources relevant to stakeholders in Indiana. Through conduits for information sharing, networking and collaborating, other products such as one-page "slicks" have been created to inform legislators, professionals, families and individuals on key topics relevant to access to and utilization of Indiana's autism services. We have also developed leaflets for legislators to inform about prevalence and needs of individuals with autism, their families, and professionals.

INDIANA AUTISM NEEDS ASSESSMENT: FOCUS ON STATEWIDE PRIORITIES

JUSTICE & AUTISM (ASD)

Reaching for the Gold Standard: Data, Exploration, & Application for Solutions

Data to Assist:

- Staying abreast of the current state of the state
- Promoting awareness & intervention
- Distribution of services and funds
- Service coordination & access
- Training options
- Policy & legislation planning
- Support resource sharing
- Early identification
- Disparity considerations
- Research prioritization
- Informing cost differences & funds differences & funds

INDIANA AUTISM NEEDS ASSESSMENT

Since 2012, over 4,000 Indiana residents (English and Spanish-speaking) across all 92 counties have responded regarding their needs:

BACKGROUND INFORMATION:

- Individuals with ASD are 7 times more likely to intersect with the criminal justice system, either as victims or offenders (Berryessa, 2014).
- 19.5% of youth with ASD have been stopped and questioned by police by the time they reached their early 20s. Of them, nearly 5% were subsequently arrested (Rava, Shattuck, Rast, & Roux, 2017).
- Yet, the prevalence of actual unlawful behavior of individuals with ASD is relatively low (Woodbury-Smith & Dein, 2014).
- Socio-emotional challenges present in ASD do not allow individuals to have an intent to purposefully harm another person (Berryessa 2014: Freckelton, 2013: Woodbury-Smith & Dein, 2014).
- Presence of co-morbid psychiatric disorders can be a strong underlying reason for offensive behaviors.
- 20% of children with autism have been physically or sexually abused. However, justice personnel is not sufficiently ready to interact and advocate for these victims (Mandell et al., 2005)

DEPARTMENT OF JUSTICE HIGHLIGHTS (2015):

- 19.5% of state and federal prisoners have cognitive disabilities CD; e.g., autism, Down syndrome)
- 30.9% of jail inmates have CD

a cognitive disability reported past 30-day serious psychological distress, compared to 11% of prisoners and 24% of jail inmates with a disability other than

A Brief History of the IIACC

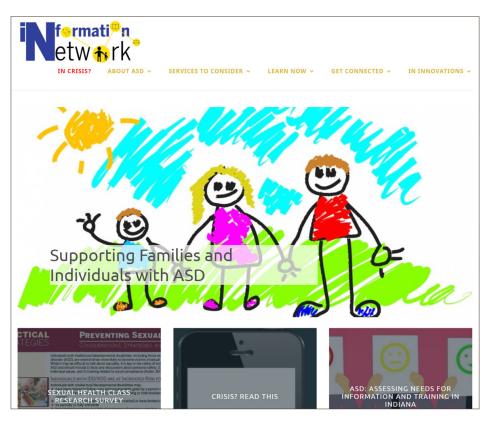




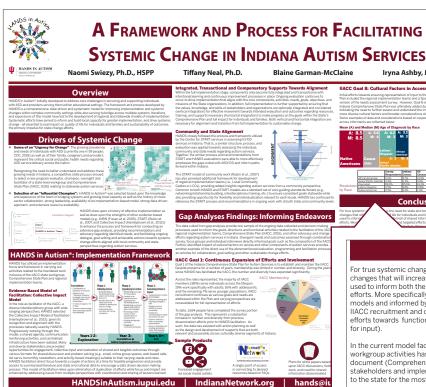
Indiana
Interagency
Autism
Coordinating
Council

TOP: Sample informational handout for legislators

LEFT: Promotional video about the IIACC. *View at https://youtu.be/RUFjU2uYiso*



LEFT: INformation Network website. View at www.IndianaNetwork.org



BOTTOM: Poster presented to highlight Indiana as a model of state-level impact and progress at the 2018 START national conference

Conclusions

For true systemic change, there is the need for state and local capacity to lead to systemic and sustainable changes that will increase quality of life for individuals and families. Th process of change has begun with data used to inform both the content and format of shared information as well as level of dissemination and training efforts. More specifically, concentrated and targeted efforts have been inspired by noted evidence-based models and informed by systematic data collected. These efforts are improving understanding in areas (e.g., IIACC recruitment and cultural responsivity) outlined within the Indiana Comprehensive State Plan and focusing efforts towards functional and meaningful outcomes across systems (e.g., shared resources, diverse formats

In the current model facilitated by HANDS, the process and framework of the IIACC with ongoing discussion. workgroup activities has resulted in outcomes including a more operationally defined and shared working document (Comprehensive State Plan), collaborations and shared perspective taking across diverse state stakeholders and implementation teams, and collectively informed guidelines and recommendations reported to the state for the most effective advocacy, policy and outcomes pertaining to this special population.

The foundation has been set for ongoing and productive collaboration across levels, sectors and settings providing the backbone, impetus, feedback and vehicle for long-term success and implementation of state change efforts related to ASD as well as more global ID/DD services.. The ultimate goal is for improved integration of supports, **shared resources** and **navigation** for better access, utilization and satisfaction with autism services statewide and these plans are beginning to be realized as a result of evidence-based and systematic evaluation and facilitation processes.

Irvna Ashby, MSEd

Shared resources improve management of care and improve communication and coordination among providers, specialists, and community resources. Shared resources can range from community networks to community health teams and regional centers among other coordination and care systems and support implementation of actions across goals and stages.

Family and individual navigation assists with guiding families through and around barriers in systems to assist in accessing and/or receiving care and resources. Family and individual navigation systems assist in addressing the family and individual challenges and barriers specifically highlighted within the comprehensive plan in areas such as early intervention, access to services, transition, and insurance or payment for services and supports.

2019: LOOKING FORWARD

Based on the progression of the IIACC efforts in compliance with state needs, as well as needs that emerged from the gap analysis, including interviews, focus groups, and Indiana Needs Assessment, the following project goals have been identified for the upcoming year:

Professional Learning Communities Movement Building

- Continued evolution of the framework, curriculum and process for development of the curriculum for Justice and Cultural Responsivity PLCs in collaboration with steering committee (leading professionals in respective fields)
- Implementation of the curriculum with PLC participants to foster learning and discussion to inform product innovations for dissemination
- Collaboration with PLCs to develop artifacts on curriculum topics and in formats for shared information sharing and dissemination across multiple stakeholder groups within communities and the state
- Vetting of artifacts to IIACC and PLC steering committee followed by IIACC facilitated dissemination statewide

GOAL 5: INITIATION OF DISCUSSIONS

 Initiation of data review, discussions, and planning pertaining to Goal 5 (Transition to Adulthood) of the Indiana Comprehensive State Plan during quarterly IIACC meetings

BUILDING CAPACITY FOR SOCIAL IMPACT

• Continued building of membership representing diverse ethnicities, professional groups, and geographic areas to further engage communities in building awareness and supportive environment for individuals with ASD

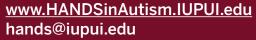
SCALING UP INNOVATIVE EFFORTS

- Collaboration with general IIACC and PLC members to investigate, develop, and disseminate innovative solutions to engage communities in building awareness and supportive environment for individuals with ASD
- Expanded collaboration with Local Community Cadres (LCCs), initiated by HANDS in Autism®, for regionally informed efforts and dissemination of products developed by PLCs





www.in.gov/fssa/ddrs/3355.htm







RTING FAMILIES AND INDIVIDUALS WITH ASD WWW.IndianaNetwork.org

IIACC GOALS

GOAL 1: IIACC HANDS in Autism® facilitates and coordinates the Indiana Interagency Autism Coordinating Council, as well as manages data collection and activities. HANDS reports on the status of services reflected in the Comprehensive State Plan.

GOAL 2: FAMILY AND PROFESSIONAL PARTNERSHIPS To create the opportunity for all individuals with ASD and families to be supported by healthcare professionals who will listen and provide input. Medical professionals will develop a plan to address concerns with attention to access and coordinating care during services.

GOAL 3: EARLY AND CONTINUOUS DEVELOPMENTAL AND MEDICAL SCREENING FOR ASD RESPONSES TO ensure service providers and families are knowledgeable of universal early screening, as well as the signs to identify ASD. Diagnosis would follow with a plan to refer individuals to coordinated service systems.

GOAL 4: ACCESS TO ALL NEEDED ASD HEALTH,
MENTAL, EDUCATION, AND SOCIAL SERVICES For individuals with ASD to have access to integrated health, mental health, education and social services provided by qualified providers throughout their lives.

GOAL 5: SUCCESSFUL YOUTH TRANSITION TO ADULT SERVICES, WORK, AND INDEPENDENCE To ensure families and providers understand what is needed for the planning of successful transitions.

GOAL 6: ADEQUATE PUBLIC / PRIVATE INSURANCE FOR ALL AFFECTED BY ASD To identify standards for accessible and affordable private and public insurance coverage for the entire life of an individual with ASD, as well as other mental health conditions.

GOAL 7: JUSTICE SYSTEM & PUBLIC SAFETY To ensure justice personnel, related agencies, and families are knowledgeable about signs of ASD, strategies for interaction and supports.

GOAL 8: CULTURALLY RESPONSIVE IMPLEMENTATION

To evaluate, develop, and implement a culturally responsive infrastructure within systems, supports, and services for ASD in Indiana to address the increasing diversity and support greater outcomes and equity.

Learn more at https://bit.ly/2Gi5kx5