

STATE-WIDE RESOURCES FOR ASD

Naomi Swiezy, Ph.D., HSPP

Director, HANDS in Autism® Interdisciplinary Training and Resource Center

Department of Psychiatry

IU School of Medicine



AGENDA

- Objective:
 - general awareness and understanding of the state-wide resources and options available to address the service needs of individuals with ASD, families and service providers
- Providing only a sample of the resources with access across the state that provide broad supports and will assist in navigation to others needed—but not exhaustive



RANGE OF RESOURCES NEEDED

- Information—about disorder, effective interventions, supports available
- Services—for individual behavior and skills training, family coping
- Training—for individual, caregivers, providers
- Advocacy/self-advocacy—for individual, caregivers, providers
- Navigating range of options available
- Funding options—for services, training, devices*
- Other considerations:
 - Autism and/or disability specific
 - Lifespan
 - Range of functioning

- Large range of needs and of options to suit those needs
- Some overlap in function so not presented by category
- Present primarily those with statewide access and presence



^{*}covered last session

THE ARC OF INDIANA

- Committed to individuals with developmental disabilities "...realizing their goals of learning, living, working, and playing in the community."
- Established in 1956 by parents of children with intellectual and developmental disabilities (I/DD) who joined to build a better and more accepting world for their children.
- Over 27,000 members and 43 chapters in Indiana
- Seeks to:
 - Empower families with information and resources to assist in helping their child with a disability to lead a full and meaningful life.
 - Empower people with intellectual and other developmental disabilities to be self-sufficient and independent to the greatest extent possible.
 - Inspire positive change in public policy and public attitudes.
 - **Prevent disabilities** through education about the dangers of drugs and alcohol while pregnant and advocating for all women to have quality prenatal care.
 - Serve as a **spokesperson and advocate** for families and their loved ones.
- "The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families."

@HANDSinAutism

www.arcind.org



ASI – AUTISM SOCIETY OF INDIANA

- "The Autism Society of Indiana (ASI) exist to ensure that every individual and every family
 affected by autism in the State of Indiana receives the high-quality services they deserve."
- Serves to:
 - Train families, educators, medical professionals, and others about autism
 - Provide support in person, over the phone, and through email
 - **Build relationships** within the community to allow for collaboration in the support and interventions of individuals with ASD
 - Offer local references or referrals by city or county
 - Work with state agencies such as BDDS to ensure up-to -date information
 - Sponsor and Co-sponsor events within the state
- Area Support Coordinators are personally affected by autism (or are individuals with ASD themselves) and **live in the communities they serve**, with a goal of knowing the services provided in their area. They take calls from families needing support, conduct training for families, providers, and the public, and build partnerships with local providers by:
 - one-on-one, peer-to-peer support to individuals and families
 - Provide care coordination to families
 - Identify service gaps in each region and build direct relationships
 - Participate in district committees and task forces
 - Deliver training to health care providers, therapists, and other service providers
 - Connect with local support groups or initiate new support groups
 - Update the Autism Resource Network of Indiana (ARNI) on an ongoing basis.

autismsocietyofindiana.org



ASK — ABOUT SPECIAL KIDS

- "Parent to Parent" organization in Indiana that answers questions, provides peer support, information, and resources as well as partnerships with professionals and communities
- Staff are extensively and continually trained as well as parents of children with special needs
- They help other families and professionals understand the various systems that families encounter related to special needs through support, education and training
- Parent liaison in each region of the state with central office location in Indianapolis.

www.aboutspecialkids.org



FAMILY VOICES OF INDIANA

- Is the state affiliate organization for Family Voices and serve as Indiana's Familyto-Family Health Information Center.
- Provides **information**, **training**, **and one-on-one support** to families of children and youth **with special health care needs** (i.e., complex care needs or disabilities), and the professionals who serve them.
- They aim to provide families with tools to make informed decisions, advocate for improved systems and policies, and **build partnerships** between professionals and families.
- Ultimate goal is a world where all children and youth experiencing complex care needs or disabilities thrive.
- Family Voices is staffed by trained family leaders who have children with special health care needs, and expertise in these programs such as:
 - First Steps
 - Special Education
 - Medicaid
 - Medicaid Waivers
 - Respite
 - Health Care Funding
 - Health Care Services
- www.fvindiana.org



IN*SOURCE

- Provide parents, families, and service providers in Indiana the information and training necessary to assure effective educational programs and appropriate services for children and young adults with disabilities.
- Believes in the value of the parent-to-parent model and the need for parents to acquire knowledge and develop skills to be effective participants on decision-making teams. Training and information from those who can identify with and relate to their needs and living within their own communities
- Since the 1980's, they provide parent-to-parent training and information, disseminate information and materials and conduct training workshops throughout Indiana, instructing parents about their rights and responsibilities in the early intervention and special education processes under state and federal laws.
- Help parents, educators and local communities work together to address a variety of challenges as well as **facilitate communication** amongst families and various groups to promote sharing of ideas and resources and to foster the development of regional and state networks.
- Receives funding and works in collaboration with the Indiana Department of Education, Division of Special Education
- Staff located in nine different communities in the state and over 300 Regional Parent Resources statewide.

@HANDSinAutism

Insource@insource.org



IRCA - Indiana Resource Center for Autism

- Develop and distribute
 - written and video materials (some free, some for purchase)
 - free newsletter 3 times a year
- Maintain
 - listserv
 - lending library
 - Up-to-date website for families and professionals
- Conduct
 - diverse regional and statewide trainings
 - training events that involve nationally recognized speakers
 - Intense training and ongoing support for teams of local special educators
 - **Individual consultations** by observing the individual and collaborating with families to suggest appropriate services and supports
- In association with Indiana University, they also teach certain courses as well as individual lectures
- Conduct research on strategies and policies that will enhance the quality of life for individuals with ASD
- IRCA staff members active on various national/state/ local boards as well as in a volunteer capacity.
- Do not:
 - attend case conferences, conduct formal assessments, evaluations, or testing, or provide diagnostic services.
 - promote one intervention method or a single approach

www.iidc.indiana.edu/irca



FIRST STEPS

- Local system that provides early intervention services to babies and children (birth 3yrs) who are experiencing developmental delays. It is available in every county in Indiana!
- Families are eligible to participate in First Steps if they have a child between the ages
 of birth to three years old who are experiencing developmental delays, and/or have
 a diagnosed condition that has a high probability of resulting in a developmental
 delay
- Families will either be **referred** to the First Steps program by their doctor, **or they may be "self-referrals"** and contact First Steps on their own if they are concerned about their child's development.
- Once there, families will schedule an initial assessment and evaluation that is paid for by First Steps. The multidisciplinary team, including parents/caregivers, will get together and then identify any developmental delay or disability, as well as recommend services that may benefit the child.
- Parents will then discuss with their service coordinator what services they need, what resources are available in the community, and what their goals will be. This information will be recorded into an **Individualized Family Service Plan (IFSP)** which will plan and guide services. This will include major goals for the child, how progress will be measured, and what services will be provided, along with the location and duration of those services. It will also include methods of payment and the transition plan upon the child's third birthday.

www.firststeps.IN.gov



VOCATIONAL REHABILITATION SERVICES (VRS)

- State funded program that provides individualized services to support people with disabilities to prepare for, retain, and maintain employment.
- To be eligible, an adult must have a **disability that substantially interferes with their ability to do work**, which would then make services necessary to become employable. The services available are job placement assistance and supported employment, job training, and vocational counseling and guidance.
- To Apply:
 - Schedule an appointment to complete the application
 - · Client is found eligible within 60 days
 - Meet with a VR counselor to determine what services will be needed
 - Student chooses a Provider Agency to receive services from
- Under the Workforce Innovation Opportunity Act (WIOA; GovTrack.us, 2020), an amendment to
 the Rehabilitation Act of 1973, Vocational Rehabilitation was required to utilize a portion of
 federal funds for the provision of Pre-Employment Transition Services (Pre-ETS) for individuals
 with disabilities, 14-22 years of age who are enrolled in an educational program and are eligible
 or potentially eligible for VR services. Services are often delivered in either an individual or groupbased format with five core service categories as follows:
 - · Job exploration counseling
 - Work-based learning experiences
 - Counseling on postsecondary opportunities
 - Workplace readiness training
 - Instruction in self-advocacy
- Upon referral for Pre-ETS services, an intake would help extend the conversation and determine the service needs and applicable categories for the individual with ASD.

vrs.in.gov



iPSEC – Indiana Postsecondary Education Coalition

- Statewide organization comprised of many advocacy organizations, educators, parents, and self-advocates that are fostering college options for students with developmental or intellectual disabilities.
- The goal is to use person centered planning as individuals transition from high school to **involve a college experience** including academics, social, and vocational (e.g., work experience through internships, etc.) components as a means of supporting future employment opportunities.
- With grant funding, Indiana University's Indiana Institute on Disability and Community created a demonstration program for successful transition into higher education. Indiana University-Purdue University Indianapolis currently has a program called S.I.T.E. for Indianapolis Public School students and a couple neighboring township schools. Because of S.I.T.E.'s success, similar programming has expanded across Indiana:
 - Franklin College- INSPIRE
 - Indiana Wesleyan University- GWA (Giant Wildcat Academy)
 - Purdue University Fort Wayne- Bridges to Education and Careers
 - Vincennes University Jasper- AIM (Advocacy, Independence, Mastery)
 - Huntington University- ABLE (Achieving Balance in Life through Education)

www.thinkcollegeindiana.org



SELF-ADVOCATES OF IN

- "AS SELF-ADVOCATES, We are citizens who speak out, advocate, and educate for equal rights, respect, and inclusion for all in the community."
- Established as a part of the ARC of Indiana with chapters across the state
- Providing a forum for engagement of those with disabilities through trainings, website, resources, speaker's bureau and a variety of activities and events.

https://www.saind.org/



Indiana Statewide Independent Living Council (INSILC)

- Established by the Rehabilitation Act of 1973, as amended
- Is a 501c3 non-profit, governor-appointed council, independent and autonomous from the state, federally-required to be led by a majority of individuals with disabilities (> 51%) from all regions of Indiana with different backgrounds and experiences
- INSILC is tasked with **promoting the philosophy of Independent Living** and believes that people with disabilities should have the same civil rights, choices, options, and control over their lives as do people without disabilities.
- Recent focus on educating and supporting the process of shared decision making



Indiana Disability Rights

- Service arm of the Indiana Protection and Advocacy Services (IPAS) Commission.
- Mission is "to protect and promote the rights of individuals with disabilities through empowerment and advocacy."
- Vision is "to live in a society where persons with disabilities are free from abuse and neglect, are free to be effective self-advocates, and are free of discrimination; allowing for full inclusion in society."
- Current year goals:
 - GOAL 1: Preventing, finding, and stopping abuse, neglect, and exploitation of persons with disabilities in facilities.
 - GOAL 2: Breaking down barriers and ensuring supports are available for persons with disabilities to ensure equity and inclusion in society.
 - GOAL 3: **Empowering persons with disabilities** by serving as a partner in rights issues, providing resources for self-advocacy and by bringing awareness through outreach to society to eliminate discrimination.

@HANDSinAutism

Pro bono consultations and support



HANDS IN AUTISM®

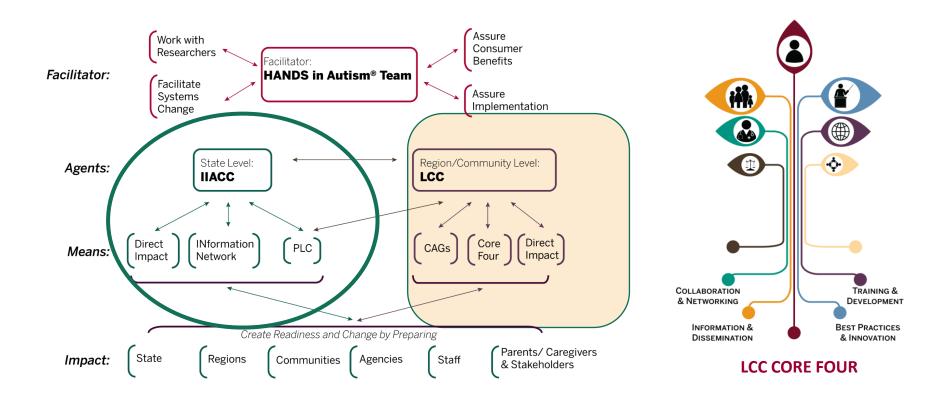
- Provide unique learning opportunities designed to improve understanding of the process and increase skills in working with individuals with ASD and a range of other disabilities through hands-on and coaching experiences
- Build bridges of information, resources and collaboration across family, educational, medical and community systems
- Ultimate goal to build local capacity through continuous learning and demonstrations of effective implementation of evidence-based practices and regional community networks
- Philosophy rooted in ABA
- Trainers are active practitioners in the field
- Services range from informational tools, videos and handouts to consultation and workshops to multi-year development of demonstration sites trained in the HANDS in Autism® Curriculum, Framework and Process

- Direct service opportunities for individuals and families state-wide
- Facilitation of IIACC and LCCs



EVOLVING AUTISM ENGAGEMENT NETWORK: IIACC AND LCCs





@HANDSinAutism

Let your voice be heard: Needs Assessment, Focus Groups, Individual Interviews



INDIANA RESOURCE NETWORK



www.doe.in.gov/specialed/indiana-resource-network







































CHOOSING AMONGST RANGE OF PROVIDERS STATE, ABA, OTHER

- What is available, accessible and impactful will vary by the needs of the individual and family and by agency and region
- Asking the right questions (about intervention and providers) is critical:
 - Which behavior(s) does it target?
 - What positive effects should I expect to see? (short- term and long-term)
 - How will the provider assess the effectiveness of the treatment?
 - How long do I have to stay involved before I can expect to see any effects?
 - Are there any side effects?
 - What is the cost?
 - How much time does it take per week?
 - Is there scientific validation for this treatment?
 - Who has used this treatment before and what do they say about it (pros and cons)?
 - What training and qualifications are needed to provide this treatment?
 - Does the provider belong to a professional organization?
 - What role does the family play?
 - How are challenging behaviors handled?



CONDUCT EFFECTIVE DATA SEARCHES

Search for Credible Information

With an easy access to online resources, searching for information has become incredibly fast. Just open any search engine, like Google or Yahoo!, and the whole world is just one key stroke away. It might sound paradoxical, but such simple search can be exceedingly difficult, when we need to filter through pages and pages of resources to find the ones that are credible! So, what should we check on a website to make sure that the information we get is good?

1. Find out sources of Information

- Check where the information comes from and who an author is. Carefully read the URL address. Does the name make sense? Is it a government organization (.gov), an educational establishment (.edu), a non-profit organization (.org – though be careful, this extension does not apply only to non-profits any more), or a company/individual (.net, .com, or .biz).
- Also, check that the information presented by various supports or sponsors of the website is not biased.
- An author can be either a person who wrote an article or organization that posted it. If the organization is not familiar to you, make sure to read such sections of a website as "About Us," "Mission," "Background," or any other sections that would offer additional information about the author. In addition, make sure that the author is an expert on the topic. It would not make much sense to look for information on dental problems on a website owned by a podiatrisť.
- Check out the dates as well to make sure that the information is regularly updated.

2. Find out the main purpose of the content

Next, find out what the main purpose of the content is (general education, selling of a specific product or service, entertainment, etc.) and who should be reading the information (audience). The purpose may change the point of viewl

3. Check for the accuracy of Information

- Check how accurate the information is.
- This step might be harder if you are not familiar with the topic, but comparison of the information across several websites might be helpful. Another way to do that is to see related links on the page. Such cross-reference will help better understand both accuracy of the information and affiliation of the website.



NAVIGATING RESOURCES: STATE WEBSITES





SERVICES TO CONSIDER ~

LEARN NOW ~

GET CONNECTED

N INNOVATIONS V



Autism Engagement Network
Portal: For the Community, by the
Community



https://www.indianadisabilityresourcefinder.org/

ARNI through

https://www.autismsocietyofindiana.org/



HELP IN WHERE TO BEGIN THE PROCESS: LCCs and Next Steps™



Range of options for engagement





Choose Your ASD
Engagement &
Advocacy Pathway!





CONTACT US



For other resource assistance inclusive of information regarding national resources/websites for more information pertaining to ASD, education and research, advocacy and support, insurance and waiver info, family and provider support

Phone: 317/274-2675

Email: <u>HANDS@iupui.com</u>

Website: handsinautism.iupui.edu

Office hours: Tu and Th 3:30-5

