I/DD Task Force Approves Recommendations for System Change

The Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities, created by House Enrolled Act 1102 in the 2017 session of the Indiana General Assembly, is nearing completion of its work. The task force was charged with preparing a comprehensive plan for implementation of community-based services provided to people with intellectual and developmental disabilities no later than November 1, 2018.

Meetings have been held around the state for the past several months to focus on different areas of programs and services and to gather information and input from families, people with disabilities, advocates and providers.

The Arc of Indiana submitted recommendations to the task force on August 22, 2018. All recommendations included in the report, “Reshaping Indiana’s Supports and Services for People with Intellectual and Developmental Disabilities,” were approved by the task force.

The Arc believes that the following recommendations will start laying the foundation for a service and supports system that is based on our core principles of valuing people and providing them opportunities that lead to a good life.

Create a system that supports and promotes self-advocacy and independence which leads to a good life.

We must start talking with families early and share consistent information on natural and community supports. The LifeCourse and Communities of Practice should guide us in how those conversations are structured. The goal for families can provide background that leads to fewer guardianships and more conversations about alternatives to guardianship that provides for great independence.

Create a system that invests in people with disabilities as early as possible, knowing that early intervention services leads to less demand for services later through special education and Medicaid services.

In the first three years of a child’s life, critical brain development takes place that will impact their life. Indiana’s First Steps program provides critical early intervention services that serves as the foundation for developmental growth.

Create an array of employment options for people with intellectual and developmental disabilities to ensure informed choice that leads to a good life with independence and respect. The array of options should provide opportunities for people with all abilities to work in an environment that provides for growth, respect, preferences and interests.

Employment is a cornerstone of our life. Through work we feel value and respect. We are able to earn income that allows us to enjoy our hobbies and interests, and working positively impacts our health and state of mind.

Create an array of living settings that support people with disabilities living in a setting of their choice that allows them to enjoy their interests, hobbies and preferred lifestyle.

Where people live is important, and for people with disabilities it is no different. People should be able to choose not only where they live, but also who they live with. We realize that some people may need a more structured living arrangement that allows for more oversight of medical or behavioral needs, but that can still happen with respect and choice.

The report also includes a vision statement. Following is a portion of that statement.

“For years Indiana has set the bar for innovative approaches and supports to provide people with disabilities an opportunity for a life full of options and independence. What has always set Indiana apart from the rest is our commitment to our fundamental principles that should continue to guide..."
Self-Advocates of Indiana had a busy summer, including traveling all around the state and even nationally.

We kicked off the summer with a trip to Birmingham, Alabama for the 2018 National Self-Advocates Becoming Empowered (SABE) Conference. Seven SAI board members were able to go and learn about important issues and meet self-advocates from around the country.

Self-Advocates, a self-advocacy organization in Vermont. It is also created to be taught by a person with a disability and a support person. Teams will be trained on the curriculum and how to teach this subject. Facilitators will be paid for their training on the curriculum and for each class they teach.

In addition to many events and trainings, our advocates have been busy speaking up about issues that are important to them. Several members took the opportunity to share comments at the 1102 Taskforce meetings, sharing their concerns and hopes for their supports and services in Indiana. We have also been active on several committees to make sure self-advocates are heard. Some of these groups include a Statewide Abuse Prevention Taskforce, Incident Reporting Taskforce, Supported Decision Making Workgroup and many more.

As we move into fall, we look forward to our conference, annual meeting, and board elections – taking place October 24th. We hope to see you there!
Executive Director’s Column

Kim Dodson

I joined The Arc of Indiana in August of 1998 and just celebrated my 20th Anniversary... WOW, that’s a long time.

I have been asked a lot lately to reflect and think about the best and worst moments over those 20 years. Worst moments are easy, as there really haven’t been many, and I can sum it up within a specific time frame – the 2011 legislative budget session. Those were hard times.

For best moments, these are only hard because there have been so many. Specific legislation comes to mind where wonderful memories were made. The health insurance mandate was fun, as there is nothing better than beating the powerful insurance and business lobby and seeing legislators vote for what is right rather than who is going to fund their next campaigns. I smile when I think of the conversation with David Goatee that led to a state contract for The Arc of Indiana that allowed us to have self-advocates like Betty Williams join The Arc team. There are a few victories and occasions like these over the years that I hold dear.

Important system changes have also taken place over the past twenty years – the closing of state-run institutions, the move to more community based settings, making Indiana an employment first state, and the creation of the ABLE Program, just to name a few. This progress demonstrates that Indiana is making decisions for all the right reasons and working to improve the lives of people with intellectual and developmental disabilities.

So as people ask me to reflect on the 20 years I’ve been with The Arc, they also ask me what’s left to do. I giggle, as I want to say, “Are you serious?” So much is left to do! This is why we promoted the passage of legislation to create the 1102 Task Force and why we are working hard to make sure their final report is used as the roadmap to drive state policies and programs for the next 5-10 years. I don’t know what the next 20 years will bring, but I am excited to find out.

I take a lot of pride in seeing how our state has improved over the last 20 years and credit a lot to my predecessor John Dickerson and others in key positions. I am truly blessed to work for this great organization and to work alongside so many passionate people.

So, for everyone asking what the next 20 years may bring (and I don’t plan to be here for another 20 years, I promise), I think that although I have been with The Arc for 20 years, I have only been the Executive Director for three. So for me, I think the best is yet to come!

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us as we look to re-shape our system in the next few years.

A shift in our culture is needed to achieve the change we envision based on our principles, and it begins with families and people with intellectual and developmental disabilities. The shift must take place over time to allow families to understand and embrace a new way of thinking, for providers to adjust, and for the system to evolve. There must be a long-term vision coupled with ongoing short term strategies that move toward the guiding principles, but do not cause instability to a system already rocked by uncertainty.

Change will be viewed in different ways depending upon the life status of families and people with disabilities. Families with young children have very different goals than families in their 60’s and beyond. Cultural change must address different phases of families’ lives— those with young children, children leaving high school, children in their 20’s and 30’s and families of adult children. In addition, respect and consideration must be given to the effects of poverty, unemployment and individual capabilities. Flexible approaches are necessary for families’ socio-economic differences.

To achieve this transformational change it will be essential to optimize the benefit from every dollar spent. All funds saved must be reinvested into the system to allow for continued change.

If families, individuals with disabilities, and providers embrace transformational change, there must be a clear intention to use money wisely, maximize the benefits as far as possible, retain savings within the system, and support tremendous demands in new ways.”

Find The Arc of Indiana’s full report and continued task force updates, including their final recommendations, in the “Latest News” section of our website: arcind.org/news

We are The Arc

With over 27,000 members and 43 chapters in Indiana, and 140,000 members in over 700 chapters nationwide, The Arc is on the front lines to:

- Empower families with information and resources to assist them in their journey of raising a child with a disability to lead a full and meaningful life.
- Empower people with intellectual and 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 combined strength of local Arcs, state Arcs and The Arc of the United States makes The Arc the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

Find a chapter of The Arc in your area at: arcind.org/about-the-arc/local-chapters

Find information about membership at: arcind.org/get-involved/membership

The Arc Advocacy Network

The Arc Advocacy Network provides information, referral and advocacy to assist and guide individuals with intellectual and developmental disabilities and their families with a wide range of issues, including:

• Understanding and applying for government programs, including Medicaid, Medicaid Waivers, SSI, and Vocational Rehabilitation; and sharing information on state and federal policies and procedures including rights and appeals.

• Developing relationships within the community and using resources and supports that may already exist.

• Using the LifeCourse Framework to help families and people with disabilities identify their vision of a good life and identify strengths, resources and supports to achieve that vision.

• Assisting families in navigating their healthcare coverage, increasing knowledge of basic healthcare coverage issues, and finding resources to cover additional healthcare costs.

• Providing information and resources available for individuals interested in transitioning from nursing facilities and group homes to a home in the community.

• Learning about and accessing community employment, career pathways and vocational rehabilitation.

• Becoming a Self-Advocate and connecting to Self-Advocates of Indiana.

The Arc Advocacy Network team is available to assist families and individuals in applying for Medicaid Waiver services, to present on Indiana’s Medicaid Waiver program and other topics, and to exhibit at local events.

Contact Us
We’re Here to Help
317-977-2375  800-382-9100  thearc@arcind.org

Medicaid Waiver Case Management Amendments Approved

The Division of Disability and Rehabilitative Services received approval from the Centers for Medicare and Medicaid Services for amendments to the Community Integration and Habilitation (CIH) and Family Support (FSW) Medicaid Waivers, effective August 1, 2018. These amendments were specifically designed to more closely align case management services with person-centered planning expectations and practices.

Changes include:
• A 5 percent rate increase for FSW case management activities.
• An increase in the monthly individual FSW case management rate to $131.25. The FSW cap remains at $17,300.
• Ability for case managers to be paid for targeted case management for individuals transitioning out of a specified institutional setting onto the CIH waiver.
• Ability for case managers to add an annual $150 per member line to the Cost Comparison Budget (CCB) following finalization of a person-centered individual support plan.
• Specific services will be limited for Medicaid Waiver authorization for individuals age 21 and over, due to the existing availability of these services on the Medicaid State Plan. This includes:
  — Level 1 and 2 Intensive Behavioral Intervention
  — Occupational Therapy
  — Physical Therapy
  — Group and individual Psychological Therapy
  — Speech Therapy
• Ability for a registered or licensed practical nurse to work under the supervision of a registered nurse in the provision of structured family caregiving.
• Lifts the restriction limiting individuals from accessing extended services and prevocational services.
• Lifts the 10 hour community habilitation limit for instances where the individual’s residential provider is also the community habilitation provider.
• Modifies language in the extended services definition to address allowable travel as part of the service for the extended services provider.
• Individual choice in accessing residential habilitation hourly or daily for individuals who are designated Algos 3, 4, 5, and share staffing, is now specified in the service definitions.
DDRS Adopts LifeCourse Framework and Principles as Part of Systems Change

Over two years ago, Indiana’s Division of Disability and Rehabilitative Services (DDRS) began a discussion on the need to transform how Indiana provides services and supports to people with intellectual and developmental disabilities. They consulted with self-advocates, families, case managers, providers and others to better understand the collective vision for services and supports for Hoosiers with disabilities and what could be done to move forward new approaches to supporting individuals and families in their community. These discussions continue as possible changes evolve.

During this time, DDRS has focused on person centered practices by embracing the LifeCourse Framework Principles as well as reviewing case management services. These areas were targeted due to the central role both play in supporting individuals and families in designing meaningful plans, tied to effective supports and services, to get individuals closer to their definition of a good life. This has led to an amendment to the waivers that made several changes, including an updated service definition of case management to more closely align with person-centered planning expectations and practices.

In addition, BDDS has introduced the Person Centered Individualized Support Plan (PCISP) within the Family Supports Waiver (FSW) and the Community Integration and Habilitation (CIH) Waiver. The PCISP works to integrate the principles of the LifeCourse Framework to assist individuals in achieving their vision for a good life.

The LifeCourse Framework and Principles is a program developed by families for families by the staff and stakeholders of Missouri Family to Family to help individuals and families of all abilities and at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead and start thinking about life experiences now that will help move them toward an inclusive, productive life in the future. The framework is designed to help any citizen think about their life, not just individuals known by the service system.

Even though the framework was originally developed for people with disabilities, it is designed universally, and can be used by any family making a life plan, whether they have a member with a disability or not.

DDRS Director Kylee Hope has noted that it is her goal to keep individuals and their families at the forefront of these changes. “It is this recognition that has motivated our endorsement and use of the LifeCourse Framework and Principles in shaping these changes and conversations. As an entire system and community, it is my aspiration that collectively we can use these efforts to fulfill long-time self-advocate Betty Williams’s vision that Hoosiers with disabilities are ‘supported in having friends, contributing to the community, giving back, and being viewed as more than [their] disability,’” Hope stated.

Charting the LifeCourse™

Guiding Principles

Core Belief: All people have the right to live, love, work, play and pursue their life aspirations just as others do in their community.

Focusing on ALL

100%
4.9 million citizens with developmental disabilities

75%
25%
25% national percentage receiving state DD services

Life Stages and Life Domains

Meaningful Day & Employment: What you do as part of everyday life—school, employment, volunteering, communication, routines, life skills.

Community Living: Where and how you live—housing and living options, community access, transportation, home modifications.

Safety & Security: Staying safe and secure—emergencies, well-being, guardianship options, legal rights and issues.

Healthy Living: Managing and accessing health care and staying well—medical, mental health, behavior, developmental, wellness and nutrition.

Social & Spirituality: Building friendships and relationships, leisure activities, personal networks, faith community.

Citizenship & Advocacy: Building valued roles, making choices, setting goals, assuming responsibility and driving how one’s own life is lived.

Prenatal/Infancy: Early years, wondering if meeting developmental milestones

Early Childhood: Preschool age, getting a diagnosis

School Age: Everyday life during school years

Transition: Transitions from school to adult life—Realizing school is almost over!

Adulthood: Living life as an adult

Aging: Getting older and preparing for end of life (parent/family/individual)

Based on 1.49% prevalence; US Census 2013. Braddock et al, State of the State 2013

© UMKC IHD, UCEDD. More materials at lifecoursetools.com November 2017
EGTI Changing Lives

Erskine Green Training Institute (EGTI), founded by The Arc of Indiana Foundation, is the first of its kind postsecondary vocational training program in the country. Opened in 2016, EGTI provides training in hospitality, food service, healthcare, and inventory distribution.

Housed within the Courtyard by Marriott in Muncie, Indiana, the program provides a uniquely personalized training experience for each student. During the 10 to 13 week training sessions, students attend class, master key job skills and gain valuable work experience through an internship.

In addition to hands-on job training, the curriculum addresses critical soft skills like appropriate workplace etiquette, teamwork, taking direction and effective communication skills. Every aspect of the program is designed to promote not only employment skills but also increased self-esteem and confidence.

Prospective students and their families are encouraged to visit EGTI by registering for one of the monthly general tours. Individual tours can be scheduled by contacting info@egti.org.

Career Sampling Sessions are offered several times throughout the year and provide a two-day opportunity for potential students to observe and try the various jobs. EGTI staff work one on one with participants to assess their employment strengths and challenges. Participants also complete a self-assessment to reflect their thoughts about each job. These assessments assist participants in determining which program best fits their interest and skillset.

For more information, contact info@egti.org. Visit egti.org. Follow EGTI on Facebook @ erskinegreen-institute and on Twitter and Instagram @erskinegreen.

Student Data
Erskine Green Training Institute
A Program of The Arc of Indiana Foundation

Erskine Green Training Institute (EGTI) provides a postsecondary training opportunity for people with disabilities. The following graphics identify the profiles of EGTI students.

EDTI’s programming is designed for individuals whose academic, social, communication, and adaptive skills are affected due to a disability. Most applicants would have received special education services in K-12 settings and exited their secondary school with a diploma, GED or certificate of completion.

Upon completion of the program, students leave with a certificate, resume, practiced interview skills and a list of open positions in the community they are returning to after graduation. More importantly, they leave connected to the EGTI team and other resources including an alumni group for ongoing support and information.

601 S. High Street | Muncie, IN 47305 | www.egti.org | 765.381.8071

Revised: August, 2018
The Arc of Indiana

The Arc Master Trust
Celebrating 30 Years of Service

Melissa Justice, Trust Director

On October 24, 1988, The Arc of Indiana board of directors voted to form The Arc of Indiana Master Trust. It was the first pooled special needs trust in the state and one of the first in the country. Although creating special needs trusts had been possible since 1983, in 1988 they were still very much unknown to most people.

The original trust director, Alan Kemp, was the force behind The Arc Master Trust, and many of his visions and foundations are still in use today. He worked closely with well-known attorneys, Thomas Evbank, Robert Hulett and Gordon Wishard to develop the legal documents to administer the trust. Those legal documents helped form many pooled special needs trusts around the country—that, again, are still in use today.

Trust I, our original trust, offers a way for parents or grandparents to provide for a loved one after they have passed away. This trust has grown to have a balance of $21,698,043 and serves 839 beneficiaries as of June 30, 2018.

It was the first pooled special needs trust in the state and one of the first in the country.

Trust II, established in 1995, allows individuals with disabilities to establish and save their own funds in a trust. Trust II beneficiaries can easily access their funds by simply contacting their trust account manager by phone, email, fax or our online form. This trust has a balance of $51,000,252 and serves 2,641 beneficiaries as of June 30, 2018.

The trust staff has grown from a team of one to our current team of nine staff members. I am so proud to be only the 3rd Trust Director since 1988, and to have been with The Arc since 1995 to witness the growth and development of the trust. I have a dedicated and caring staff that work hard every day to better the lives of many Hoosiers across the state who have disabilities. I cannot imagine having a more rewarding position anywhere else.

Congratulations to The Arc of Indiana Board of Directors and all The Arc of Indiana staff on the 30th anniversary of The Arc of Indiana Master Trust. I am looking forward to many more!

For information about The Arc Master Trust, visit thearctrust.org, or contact us at: 317-977-2375 or 800-382-9100

2017 User Satisfaction Survey

The Arc of Indiana intends for its trust service to be easy to use. Each year we send a User Satisfaction Survey to people using our services. The survey asks about our responsiveness to requests—from the time people call and make a request to when they receive the check in the mail.

This survey provides valuable feedback for us. It identifies potential problem areas. It also helps families thinking about enrolling. “Is The Arc Trust easy to access?” “Is getting approval difficult?” As the survey shows, we are very accessible and rarely do not approve requests.

Following are responses from a few of the key questions asked on our User Satisfaction Survey.

When I call to use the trust, the person with whom I must speak is immediately available.

Usually or Always: 85%

Requesting disbursements is a positive experience for me. The person with whom I speak is receptive to how I want the trust used. He/she is encouraging and supportive of my efforts.

Usually or Always: 95%

When I make a request for using the trust, my request is approved.

Usually or Always: 96%

The person that I have spoken with at the Trust office is knowledgeable. If they don’t know the answer they find out promptly and return my call.

Usually or Always: 95%

When I call with a question on non-trust matters or need advice, the person with whom I speak is willing to help.

Usually or Always: 96%
Cruising for Dreams
January 26, 2019
Horizon Convention Center | Muncie, IN

Cruise away your winter blues and set sail for the Mediterranean Sea at Cruising for Dreams!

From the moment you cross the gangway, you’ll feel as though you’ve been swept away to the beautiful Greek Isles aboard a luxury cruise liner. Enjoy an evening of relaxation and fun with a Greek-inspired dinner, deck games, silent auction, art gallery, and more!

Cruising for Dreams supports Erskine Green Training Institute in providing postsecondary vocational training opportunities for people with disabilities. Since EGTI’s doors opened in 2016, nearly 100 students have completed the program and the employment rate for graduates is nearly 80%.

For more information, please contact Amie Brzozowski at amie@arcind.org

2018 Annual Conference and Impact Awards Luncheon
October 24, 2018
Wyndham Indianapolis West

Opening Plenary
Supported Decision Making
Featuring Jamie Beck and a Panel of Experts

Jamie Beck, a graduate of Erskine Green Training Institute, works full-time at IU Health Ball Memorial Hospital and lives in a Muncie apartment with a housemate. And, at age 28, she has regained the legal right to make her own decisions as the first Indiana resident to use a Supported Decision Making agreement and regain decision-making rights.

Jamie will share her journey to independence and a panel of experts will share information on supported decision making as an alternative to guardianship.

Impact Awards Luncheon Speaker
Katharine Muir

Katharine “Kat” Muir received her bachelor’s degree in Speech and Hearing Science at Miami University and her master’s degree in Bilingual Speech Pathology at Indiana University. She is fluent in many languages and it is her love of language that drew her to a career as a speech-language pathologist.

Diagnosed with autism at age 22, Kat uses her skills to her advantage – sensitive hearing is helpful for speech therapy sessions. During Kat’s six years at Easterseals Crossroads, she has served as an interpreter not only between languages, but between those on and off the autism spectrum.

Learn More & Register Online
arcind.org/event/conference

• Member of The Arc: $100
• Non-member: $150
• Self-Advocate: $25
• Personal Care Attendant: $25
• Family member of a person with a disability: $50
• Impact Awards Lunch Only: $50/person or $350 for table of 8

Breakout sessions will include information on recognizing signs of abuse, voting rights, education and employment, public policy updates from both the state and federal level, and more!

Visit our website for more information.

For information about sponsorship and exhibitor opportunities, contact Amie at amie@arcind.org