

FRIDAY, DECEMBER 8, 2017

THE ARC OF DEARBORN COUNTY MEETING AGENDA

Notes from previous meeting

Treasurer's Report

OLD BUSINESS

Regional resources for medical, dental, etc. homework

2018 Disabilities Awareness Month packets/contents

Swim Instructions?

2018 GUEST CONVERSATIONS — TENTATIVE

Jill Ginn, The Arc of Indiana on The Arc Trusts and INvestABLE—how they work, how they can all be used together

Rachel Deaton, Eastern IN Autism Ally, The Indiana Autism Society

NEW BUSINESS

Kindergarten presentations

Spring Dance date (incorporate Dis. Awareness theme?)

Update the website (use Square Space?)

Immediately take down Resource page as most information is inactive or obsolete

FOR CONVERSATION

Takeaways: State Conference, The Arc of Indiana

"We are not self made, we are community made." ~ Zach Anner (speaker at the Impact Awards Luncheon)

Sharing our Story was one of the workshops at the Nov. 15 conference. We were reminded of the value of telling our stories and introduced to creative ways to do so by a crew from the Stone Belt Arc. Stories are captured on video and shared across online platforms to capture attention, build awareness and make political change. Stone Belt was greatly involved in raising DSP wage issues to the forefront. Just during the workshop, I thought of transportation and what a barrier the lack of transportation and the spotty alternatives for our region. What would the picture be if we could videotape individuals attempting to secure transportation? What if we told about missed opportunities for work or medical appointment snafus?

ADEC was another presenter and their staff told of learning how to use video editing to share "these are the people we serve" and "this is what we do."

Beth DeHoff of BD Health Communications shared on how to impact legislation. **She noted:**

Just ten contacts from constituents on one issue gets the attention of our representatives.

Pick one thing that affects you personally, learn all you can and tell your story.

Check websites for where reps will be during recesses and attend—tell your story.

Use [Resistbot](#) to easily send a message to representatives—text 50409

Invite State reps to lunch; email, march or protest to make an impact

Melissa Keyes, Legal Director of Indiana Disability Rights spoke on **the use of supported decision making as an alternative to guardianship**. This is becoming a more prevalent way for individuals to maintain their independence in decision making without losing their rights to personhood as a result of guardianship. Guardianship is still important for those unable to express their decisions—but

supported decision making respects the autonomy of people who have I/DD and gives them support over areas of their life where they are able to express their wishes and have control of their lives with the assistance of others.

The Arc Master Trust and [INvestABLE](#) are ways to help Hoosiers with I/DD save while preserving their Medicaid and SSI benefits. Jill Ginn shared on how each works and how they can work together. Important to learn more and share.

The LifeCourse Framework is being introduced throughout the state as a way to look beyond traditional services to “learn how individuals can experience a full life by connecting to their community and natural supports.” The LifeCourse Framework is a tool you can use to plan your vision for a full, good life (being introduced from a services aspect) If implemented well through help of case managers and service provider representatives and staff, this Framework should provide a balance and improvement to help people realize a life of fulfillment. It offers tools to help people peel back and identify what they want and do not want for themselves and their days.

As a very intentional, personal and purposeful human approach, we have introduced our friends from Good Life Networks (GLN) in Cincinnati with MAPS and PLAN to help in building natural supports. GLN’s vision statement describes their group as: A purposeful, family driven organization focusing on creating genuine friendships and intentional relationships that replace loneliness and isolation, ensuring peace of mind and a sense of belonging in our community.

In our group (the local Arc chapter), we recognize that there is a whole life to live outside of service hours and this is greatly where natural supports exist. Each of us hopes to have a purpose in life. For many of us parents, it seems, we begin when our children are very young to hear the (appreciated) voice of professionals, of physicians and specialists that help direct our children’s lives and we fall into place with a “system of support.” Many people who have I/DD receive good services but lack in natural supports that allow for flexibility, for forming relationships and friendships that will be in place even while people who provide service may cycle in and out of lives.

The use of both the tools of LifeCourse Framework and the very humanly engaged GLN approach, when used in tandem, may be useful and helpful when stating and addressing changes to work toward a more gratifying life.

On November 20, 2017 Karen, Anne and Pauline traveled to Bosma Enterprises for the first listening session for the 1102 Task Force to assess services. This might be the one most important thing going on in the state for people who have I/DD at present! We were happy to see that many of the task force members have children or a family member who has I/DD and two self-advocates were a part of the board. As a side note and for context, 20 years ago the last such effort, [317 task force](#), was completed and resulted in closure of two large state institutions and moving 200+ individuals into community settings in one-year’s time.

If you haven’t yet, we have included [a link](#) to information and a survey for 1102 Task Force so you might participate. **At these sessions, the task force would like family members of people with I/DD, and people with I/DD, to share their comments on current and needed services and supports to provide a broad range of opportunities for people with I/DD to live a healthy and meaningful life in the community.**

The task force was created by the passage of HB 1102 in the 2017 session of the Indiana General Assembly.

If you are unable to attend but wish to share, email Kristina.blankenship@fssa.in.gov

We aim to attend the December 19 listening session in Bloomington. Craft your story and consider attending to speak to the panel in person. Two minutes are allotted and you also have a chance to speak to task force members in person or you may email your story to Kristina Blankenship (see above).

The 2017 state conference of the Indiana Governor’s Council for People with Disabilities just ended on Tuesday, December 5. Pauline and Kyle, Karen and Anne attended the event and it was a fantastic learning experience. This conference had some 30+ sessions. Many-to-most attendees had disabilities that did not include intellectual and developmental disabilities; however, the information was supportive and similar. We left learning of the difficult every-day existence of people who have disabilities and the tenacity they live their lives with. Retired [Senator Tom Harkin](#), an author of the 1990 Americans with Disabilities Act (ADA) was keynote speaker and set the tone for the event.

Takeaway: All new technology, and all planning and design should be built initially with disabilities in mind. “Clearing a path for people with special needs clears the path for everyone.”

The theme for the 2018 IN Disabilities Awareness Month is “Be Cool. We Are.”

Emily Munson, Esq. with Indiana Disability Rights spoke on Choice Through Consumer-Directed Care at one session. Presently, there are about 400 Hoosiers with disabilities who have moved from the model of agency care to self-directed care. There are currently no individuals in our state who have I/DD that have moved to this choice and it is more associated with aging care. Something for us to learn more about as people who have I/DD begin to exercise their rights more and more.

In **June of 2016 Indiana was selected to be one of 16 states to participate** in a Community of Practice on Supporting Families through the LifeCourse Framework. (See notes from the state Arc conference). Additionally, our group may consider how we might begin to talk to the public at large to invite them in to get to naturally and personally take interest in knowing people who have I/DD.

Jonathan Martinis with the National Resource Center for Supported Decision-Making (and last year's keynote speaker) spoke on Supported Decision-Making and recent developments in Supported Decision-Making across the U.S. Essentially, supported decision-making empowers people to self-determination and to have control over their own lives. (See notes from state Arc conference).

Creating a Care Notebook we were introduced to several tools and ideas to accomplish this. *This may be something we want to spend a meeting on.

The Tragedy of the Commons: A Primer for Designing Communities for All Ages and Abilities

The session was led by architect, Zachary Benedict, MKM Architects and was a look at the physical building of communities to bring people together and touched on how some design has historically separated people from the community. When combined with some of the community and relationship building workshops we've participated in, this is a good fit and we can share briefly at our meeting.

A boiler plate for discussion...

For consideration... how do we use our funds? What are our goals to help make our region inclusive? Thoughts to consider are growing existing funds to offer for projects such as accessible community playground or pool project supplements; a resource library; continue to offer timely information events; work toward helping people access person-centered care planning. Where do our strengths in meeting inclusion goals exist?

With recommendation to formally establish a Board of Directors over the year 2018, comprised of the President, Vice President, Secretary, Treasurer, immediate Past President, 10+ Directors and a minimum of one from each county we represent (with a preference of self-advocates, family members, community members with professional backgrounds who may contribute to driving goals and that may include from the fields of IT, medicine, education, the arts, research or data analysis, business/communications/marketing, banking, law, or other public service)