THE ARC OF INDIANA

- Started in 1956 by families
- OUR MISSION: The Arc of Indiana is committed to all people with intellectual and developmental disabilities realizing their goals of learning, living, working and fully participating in the community.
- A statewide advocacy organization for issues important to people with intellectual and other developmental disabilities.
  - 43 local chapters
  - Over 30,000 individual members
COVID RELATED CONVERSATIONS

- Since mid March The Arc of Indiana’s team has had 869 conversations with 371 different individuals.
- Since mid March, Self Advocates of Indiana has held 13 COVID specific phone calls with 154 self advocates around the state participating.
- Conversations ranged from concerns about how the COVID crisis was being handled, specifics about issues related to Stimulus packages, concerns from self advocates regarding provider re-opening procedures.
Covid related conversations

- In March and early April, family conversations centered on new service delivery model as day programs closed their doors and many services moved to remote, as well as overwhelming concern about what would happen if their loved one became ill with the virus and needed to enter a hospital.

- As federal Stimulus packages passed, families had questions on stimulus checks and impact of checks on asset limits, etc.
Covid related conversations

- In mid April, conversations turned to what does service delivery look like in future.

- Increased anxiety regarding health and safety protocols as providers planned for re-opening their doors.

- Concern about timing of re-opening of services and how that impacted rest of family returning to work.
Covid related conversations

- In late April, The Arc held a specific call with families regarding the re-opening plans of providers to make sure their concerns would be heard.

- A dozen families participated in the calls and a dozen more provided feedback via email.
The conversation with families centered on several themes:

- Health and safety of those being served;
- Communication must be strong between provider-family-person receiving services;
- Tiered approach to re-opening;
- Need for training for staff as well as people receiving services.
Families expressed needing to have confidence that their providers were following appropriate procedures regarding cleaning, use of masks, and social distances.

Concern was expressed about the health and safety of the entire family as many people receiving services still live at home with their families who may be older and have health concerns of their own.
COVID – STRONG COMMUNICATION IS NEEDED

- Families want providers to clearly communicate plans for re-opening, health and safety procedures and expectations providers are placing on families.

- Case Managers need to be communicating more during this re-opening timeframe.
Covid – Tiered Approach to Re-opening

- Families agreed that bringing everyone back into services at once was not a good option.

- Concern was expressed from families who work and have loved one at home regarding potential timing conflict.
COVID – Training Needed for Everyone

- Discussion focused on needing everyone to be trained regarding the “new normal”.
- Providers need to be well-trained on cleaning and safety protocols.
- Families need to be trained on what are expectations for them.
- People receiving services need to be trained on why there are new needs and what that means.
- Expressed desire for videos, webinars – anything to help with consistent messaging.
COVID – SELF ADVOCATE CONVERSATIONS

Self advocates discussed a series of concerns throughout the COVID experience and then also made suggestions for providers as they look at reopening.

Communication was a consistent concern. Described communication as poor during crisis and strong need to improve communication going forward from case managers and providers.
Concern about new health and safety procedures though they understand need.

Masks will be difficult for some people to wear due to allergies, anxiety, asthma, sensory issues, etc. Recommend having face shields as an option for some.

Social distancing will be difficult for some as they like to show affection and some need very “hands on” type of assistance.
COVID – SELF ADVOCATE CONCERNS

- We need to be aware of increased behaviors due to anxiety and isolation during the last two months.
- Also new behaviors should be expected in a change of routine as people learn and get used to new health and safety precautions.
- Many may experience decline in social skills that have been learned and again, may lead to new behavior issues.
- Self advocates suggest using video, webinars to help prior to transition back to services to help with anxiety and hope to decrease behaviors.
COVID – Self Advocate Concerns

- Self Advocates have a strong relationship with their Direct Support Professionals and are concerned when they see a change when someone is providing their care.
- They are concerned about DSPs who are providing care to people who are COVID positive.
- There is a big concern about the lack of PPE and will there be enough.
Many expressed that they are ready to return to work and services. They are bored, growing depressed and anxious due to isolation.

There is strong concern about availability to go back to community jobs that were lost and eager to learn from VR what they plan to do to help gain back jobs for those who lost them.
THANK YOU FOR THE OPPORTUNITY

QUESTIONS/CONCERNS

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