The Arc’s Webinar Series Presents...

Shifting Our View

A Person-Centered Journey
Housekeeping Items

• All participants have their microphone off during the presentation
• There will be time at the end for Q&A, but you may ask questions using the chatbox function at any time
• If you are having any technical issues, please send us a chat and we will do our best to assist you
• Please fill out survey at the end of webinar to let us know of future topics you’d like to learn more about
Why?
What did we do?

1. Created personas
2. Mapped journeys through advocacy
3. Learned from those journeys – saw opportunities
4. Big Picture Questions
5. Ah HA!
6. Strategic Change
Sample Persona

**Who is Willy?**

- Dad of 17 y/o son
- White
- Jeff co, Lakewood
- SPED, private

**Goals for advocacy?**

- Worried about Guardianship
- Don’t know what services are available after H.S.

**Pain Points**

- Grief
- Overwhelmed
- Loss of partner
- New responsibilities

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<table>
<thead>
<tr>
<th>Goals</th>
<th>Narrative</th>
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<tbody>
<tr>
<td>• To do what the grief counselor told him to do, which is get guardianship</td>
<td>Dad of transition aged 17 year old male with a medical diagnosis of down syndrome. 1st semester of Senior year (12th grade) in significant support needs center based program, special education eligibility is multiple (Intellectual and Speech), not eligible for any Children’s Medicaid Waivers. Was referred to The Arc by grief counselor who stated Dad needed to get Guardianship. The son has been evaluated by the school for SPED eligibility which did not include an I.Q. test. Mom is recently deceased. She was the stay at home mom that took care of all of the children’s needs. She was kept Dad in the loop with high level overview. Family moved from Texas about 6 years ago and pleased with the educational services in Colorado and the SIE Center at Children’s hospital. He has a 13 y/o daughter who is in the GT program and involved in competitive sports. Mother in law moved in 3 months ago to help provide help but is returning to Florida in the next month.</td>
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<tr>
<td>• What are my next steps?</td>
<td>• Tell me what to do!</td>
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<table>
<thead>
<tr>
<th>Background/Deomgraphics</th>
<th>Motivation</th>
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<tbody>
<tr>
<td>Age/Gender</td>
<td>47</td>
</tr>
<tr>
<td>Relationship to person with I/DD</td>
<td>Father of 17 y/o son</td>
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<tr>
<td>Race/Ethnicity</td>
<td>White</td>
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<tr>
<td>Primary Language</td>
<td>English</td>
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<tr>
<td>County of Residence</td>
<td>Jeff co, Lakewood</td>
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<tr>
<td>Benefits/Services</td>
<td>SPED, private</td>
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**Personality Traits/Characteristics**

- Greiving loss of his wife. Feeling overwhelmed and unorganized. Doesn’t understand what all the paperwork means in his wife’s office. Hopeful that an advocate will pick up from where wife left off. Dad understands basics (that son is in special education and on IEP and that b/c of Down syndrome his son will need support throughout his life). Agreeable and compliant. Trying to support his children through loss of their mom. Dad is realistic and understands his limitations.

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**Backgound/Deomgraphics**

- Age/Gender: 47, Father of 17 y/o son, White
- Relationship to person with I/DD: Father of 17 y/o son
- Race/Ethnicity: White
- Primary Language: English
- County of Residence: Jeff co, Lakewood
- Benefits/Services: SPED, private

**Tagline/#Hashtagline**

#Whatsnext #dontknow #checklistplease

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**Motivation**

- Worried about Guardianship
- Don’t know what services are available after H.S.
- Was told by grief counselor to call The Arc for guardianship
- He is anxious about what he doesn’t know

**English**

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**Goals**

- To do what the grief counselor told him to do, which is get guardianship
- What are my next steps?
- Tell me what to do!
<table>
<thead>
<tr>
<th>Steps Along the Journey</th>
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<tbody>
<tr>
<td>I learned about The Arc/I knew about The Arc</td>
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<tr>
<td>I reached out to The Arc or someone did on my behalf</td>
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<tr>
<td>I had an experience Connecting with an advocate</td>
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<tr>
<td>My advocate did some stuff</td>
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<tr>
<td>I did some stuff</td>
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<tr>
<td>My advocate and I did some stuff together</td>
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<tr>
<td>I reconnected with my advocate</td>
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<tr>
<td>My presenting issue was resolved/not resolved</td>
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<tr>
<td>Positive or negative unintended consequences</td>
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## Persona Experience

<table>
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<tr>
<th>Actions Taken</th>
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<tbody>
<tr>
<td>What I’m thinking about</td>
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<tr>
<td>What I’m feeling</td>
</tr>
<tr>
<td>What I didn’t tell my advocate</td>
</tr>
<tr>
<td>What went well or happy moments</td>
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<tr>
<td>What didn’t go well or pain points</td>
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<tr>
<td>What opportunities do we see?</td>
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</tbody>
</table>
Persona Name: What's Next Willy?  
Presenting Issue: Guardianship
I learned about The Arc/I knew about The Arc
I talked to The Arc (or someone did on my behalf)  
I had an experience connecting with an advocate
My advocate did some stuff  
I did some stuff  
My advocate and I did some stuff together  
I reviewed the Advocacy Agreement; We determined next steps
Possible re-traumatization when we discuss success: Guardianship

Actions Taken

 Heard about the Arc through the phone counselor; reviewed the Arc's website and booked an initial meeting with the advocate

What I'm thinking about

I don't know what the all means, but they must know what they're talking about  
I'm doing what I was told and how they'd like me to do things
When we're going to have time to read this stuff? Why can't they come over here on Saturday and just get this done? There's a lot of information here! I don't even know what I don't know!

What I'm feeling

Curious  
Anticipating answers; no brick production; proud he's handling this, right that someone can help, unsure that someone will come here in the future to help, unsure that there's no end  
Help or? There's even more stuff? I don't know! Really, believed and confident that the advocate has skills and knows this stuff

What didn't tell my advocate

I didn't tell my advocate about the  
I didn't tell my advocate about the  
I didn't tell my advocate about the  
I didn't tell my advocate about the

What went well/what I appreciate

So happy he filled something out online and didn't have to call anyone  
The advocate is going work with me and I have options for dates/times to choose from - I can make this work with my schedule  

What didn't go well/what I need more help with

I'm missing some paperwork; I didn't find any; I filled out the online form  
I'm missing some paperwork; I didn't find any; I filled out the online form  
I'm missing some paperwork; I didn't find any; I filled out the online form

Opportunities

Could we provide clarity for items that aren't common language?  
Could we provide after hours advocacy/leave a limited basis is a more formalized manner? Could we offer a training session?

Unresolved - I still need to make a decision in the future

Resolved - I asked for information and I got it; I still need to make a decision in the future

Possible re-traumatization when we discuss success: Guardianship

These steps will loop

Positive or negative unintended consequences

Positive or negative unintended consequences

Next steps

These steps will loop
# A closer look at the experience

<table>
<thead>
<tr>
<th>Actions Taken</th>
<th>I learned about The Arc/I knew about The Arc</th>
<th>I reached out to The Arc (or someone did on my behalf)</th>
<th>I had an experience connecting with an Advocate</th>
<th>My advocate did some stuff</th>
<th>I did some stuff</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Heard about The Arc through the grief counselor</td>
<td>Reviewed wife's files and looked for The Arc/guardianship info - didn’t find any; Filled out the online form</td>
<td>I got an email response and they said they want to help me. They provided some guardianship information and asked me to schedule a time for a phone meeting with the advocate.</td>
<td>My advocate called me for our appointment; she asked me what questions I had about the info she sent; I asked my questions and she answered them; then she asked me some questions; she taught me about the supports and services available to my son as an adult;</td>
<td>I read the information before the call; I came up with questions; I asked my questions and listened carefully</td>
</tr>
<tr>
<td>What I’m thinking about</td>
<td>I don’t know what this all means, but they must know what they’re talking about</td>
<td>I’m doing what I was told and now they’ll do things for me.</td>
<td>When am I going to have time to read this stuff? Why can’t they come over here on Saturday and just get this done? There’s a lot of information here! I don’t even know what I don’t know!</td>
<td>She sure knows what she’s talking about! She listened to me and asked about my family; I’m glad to have someone to help me understand this stuff</td>
<td>This is a lot to digest</td>
</tr>
<tr>
<td>What I’m feeling</td>
<td>Curiosity</td>
<td>Anticipating answers; on track; productive; proud he’s handling this; relief that now someone can help; anxiety that someone will tell me I’ve done something wrong or that they’re going to add to my to-do list</td>
<td>Overwhelmed; frustrated; grief; alone; hopeful that someone will help; relief that there’s no rush;</td>
<td>Holy &amp;!^! There’s even more stuff I don’t know! Really relieved and confident that the advocate has skills and knows this stuff!</td>
<td>Missing my wife and appreciating all she did; still overwhelmed; at least I know what questions I have now - I didn’t even know there were questions to ask</td>
</tr>
<tr>
<td>What I didn’t tell my advocate</td>
<td>I didn’t share how inadequate I feel; not saying that his mother-in-law is leaving and he will need help</td>
<td></td>
<td></td>
<td></td>
<td>I haven’t asked my son what he thinks about how much help he needs and in what areas</td>
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Summary of Opportunities

- Effective **training** of - and information to - partner agencies and other organizations will create **appropriate referrals** and limit inappropriate ones.

- The agreement on and management of **clear and consistent expectations** is essential early in all relationships and should be reinforced throughout them.

- Advocacy must have a **clearly identifiable resolution** for both the advocate and the individual/family seeking advocacy.

- Our intake process and our communication choices should be **responsive, accessible, warm and effective**.

- An **advocacy Code of Ethics/Conduct** should guide all of our work and be provided to individuals/families who seek our support and partner agencies.

- The **clarification of terms**, whether with Individuals/Families, professionals, or just within The Arc, is **critical** to providing consistent information and support.
• **Empowerment is at the core** of what we do and should be actively encouraged for people of all ages.

• **Onboarding needs to reflect the culture** of advocacy at The Arc, not just the job responsibilities.

• **Systemic work** is time-intensive and indispensable to providing effective advocacy. **It is an investment** to proactively change the future.
Big Picture Questions

• What our chapter’s role in...?
  • Legal Advocacy
  • Medical Advocacy
  • Medical Proxy
  • Building Life Skills
  • Guardianship
  • Building Self-Advocacy Skills

• What environmental trends do we see?

• How do people want information?
  • What drains our time quickly?
  • How can we set up new advocates for success?

• Where do our current programs fit with our priorities? What are our programs?
What does The Arc do?

- Support Self-Advocacy
- Empower Families
- Expand Community Access
- Change Community Perceptions
Impact: Shifting Our View enabled us to

• More clearly define our work
• Learn to talk about what we do concisely (Board and Staff)
• Identify and create changes would ensure a great advocacy experience
• Create a new organizational structure to support our work
• Commit to further evaluation and change as a result of continued lived experience and feedback
• **Be better prepared to enter into the strategic planning process**
Better Prepared for Strategic Planning

• Shared with the Board of Directors
• Adopted new language to communicate about our work
• Helped create focal points for strategic thinking
• Common understanding when Board and Staff came together to plan
1. People with IDD and their families are at the center of everything we do. Intent: Engagement and guidance in decision making

2. The Arc is the destination for participation for our community. Intent: Participation

3. Understand and anticipate the needs of people with IDD and their families and prepare them to successfully navigate life transitions across the age spectrum. Intent: understanding for now and the future
Was it worth it? YES!

The Shifting Our View process provided our advocacy team the opportunity to strengthen our teamwork and to put people with I/DD at the center of everything we do. It felt good to engage in collaboration and creativity in pursuit of continuously improving our support of people with I/DD of all ages.

I appreciated the opportunity to think critically about the unique and individual needs of each person, and our dedication to growing a greater understanding of the people we serve through the practice of cognitive empathy.

--Jilda Falco, Director of Adult Advocacy
Questions?

For more information contact Lori Ropa at The Arc – Jefferson, Clear Creek & Gilpin Counties at lori@arcjc.org