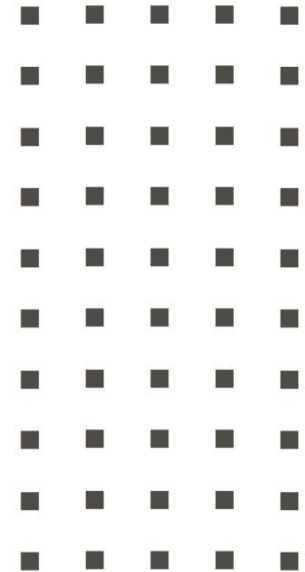




The Arc's Webinar Series Presents...

# 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?
- Goals for advocacy?
- Pain Points

Photo	Name - Primary Persona	
	What's next Willy	
	Tagline/#Hashtagline	
	#Whatsnext #idontknow #checklistplease	
	Background/Deomgraphics	Motivation
	Age/Gender	47
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	
Personality Traits/Characteristics		
<p>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</p>		
Goals	Narrative	
<ul style="list-style-type: none"> <li>• To do what the grief counselor told him to do, which is get guardianship</li> <li>• What are my next steps?</li> <li>• Tell me what to do!</li> </ul>	<p>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.</p>	
Frustrations/Pain Points		
<ul style="list-style-type: none"> <li>• Grief</li> <li>• Overwhelmed</li> <li>• Loss of partner</li> <li>• New responsibilities</li> </ul>		

# Steps Along the Journey

---

I learned about The Arc/I knew about The Arc

---

I reached out 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

---

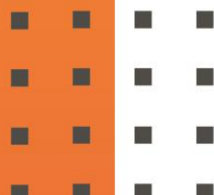
I reconnected with my advocate

---

My presenting issue was resolved/not resolved

---

Positive or negative unintended consequences



# Persona Experience

---

Actions Taken

---

What I'm thinking about

---

What I'm feeling

---

What I didn't tell my advocate

---

What went well or happy moments

---

What didn't go well or pain points

---

What opportunities do we see?





# Sample Journey

Persona Name:	What's Next Willy?								
Presenting Issue:	Guardianship								
				These steps will loop					
	I learned about The Arc/I knew about The Arc	I reached out 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 reconnected with my advocate	My presenting issue was resolved or not resolved	Positive or negative unintended consequences
Actions Taken	Heard about The Arc through the grief counselor	Reviewed wife's files and looked for The Arc/guardianship info - didn't find any; Filled out the online form	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.	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;	I read the information before the call; I came up with questions; I asked my questions and listened carefully	We reviewed the Advocacy Agreement; We determined next steps	My advocate gave me deeper information about the services available to my son in the school system and out of the school system as an adult; she told me to get a copy of the IEP; got info on guardianship and other options	Resolved - I asked for information and I got it Unresolved - I still need to make a decision in the future	Possible re-traumatization when we discuss successor guardianship
What I'm thinking about	I don't know what this all means, but they must know what they're talking about	I'm doing what I was told and now they'll do things for me.	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!	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	This is a lot to digest	This is a formal kind of process; what if I need more help? This seems a lot more serious than I thought; I thought this would be a one-time ask for help, and now I realize it will be a lifetime of next steps	I learned that the IEP will have more information for me; I didn't realize that I would have to have a successor guardian and my daughter is still grieving this recent loss of her mother;	I hope I understand everything I got; I am thinking about what my next step will be and when	
What I'm feeling	Curiosity	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	Overwhelmed; frustrated; grief; alone; hopeful that someone will help; relief that there's no rush;	Holy &! There's even more stuff I don't know! Really relieved and confident that the advocate has skills and knows this stuff!	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	grieving the diagnosis all over again as my son becomes an adult; fear of the unknown;	defensive about not thinking to include my son; I'm not ready to do this; I can't bring this up to my daughter now	hopeful; organized; competent; tired; grateful; supported	
What I didn't tell my advocate		I didn't share how inadequate I feel; not saying that his mother-in-law is leaving and he will need help			I haven't asked my son what he thinks about how much help he needs and in what areas				
What went well/happy moments	grief counselor knew where to send him	So happy he filled something out online and didn't have to call; appreciated the form was clear and easy;	They responded more quickly than I expected, given the note on the website; I was told I'm on the right track; I feel validated; 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	We had a great Q&A - I got my questions answered and now I know more about guardianship	I finally feel like I'm getting somewhere	continuing to learn more about the process and what I can expect; glad there are people to help with this;	I have time to breathe and think and no one is pushing me to do anything immediately;	When I'm ready, The Arc will be there and I know how to reach my advocate when I have questions or need more help	
What didn't go well/pain points		I am missing some paperwork; Form had terms on it that I didn't understand;	Disappointment that the dates/times are during my work day and I've been off for a while and it's hard for me to take time off now		I have more work to do and I'm already doing so much!	This process is just not what I expected; I'm not ready to have a conversation with my son yet			
Opportunities		Could we provide clarity for terms that aren't common language?	Could we provide after hours advocacy hours on a limited basis in a more formalized manner? Could we offer a training online?	Could/should we do more in the process? How can we strengthen the advocacy skills in all who come to us for support?	Is the information presented in the best possible way as to not overwhelm Willie further?	Could we involve the son more? Is there an opportunity to build self-advocacy skills in him? How could we help parents understand how important these skills will be for his future	Recognize that there are competing priorities in people's lives and we have to meet them where they are;		consistency across teams and across advocates is important - it informs what they'll expect next time



# A closer look at the experience

	I learned about The Arc/I knew about The Arc	I reached out 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
<b>Actions Taken</b>	Heard about The Arc through the grief counselor	Reviewed wife's files and looked for The Arc/guardianship info - didn't find any; Filled out the online form	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.	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;	I read the information before the call; I came up with questions; I asked my questions and listened carefully
<b>What I'm thinking about</b>	I don't know what this all means, but they must know what they're talking about	I'm doing what I was told and now they'll do things for me.	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!	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	This is a lot to digest
<b>What I'm feeling</b>	Curiosity	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	Overwhelmed; frustrated; grief; alone; hopeful that someone will help; relief that there's no rush;	Holy &!^! There's even more stuff I don't know! Really relieved and confident that the advocate has skills and knows this stuff!	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
<b>What I didn't tell my advocate</b>		I didn't share how inadequate I feel; not saying that his mother-in-law is leaving and he will need help			I haven't asked my son what he thinks about how much help he needs and in what areas

# 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.

# Summary of Opportunities (cont.)

- **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.



Identify  
Opportunities  
Take Action  
Create Change

# 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

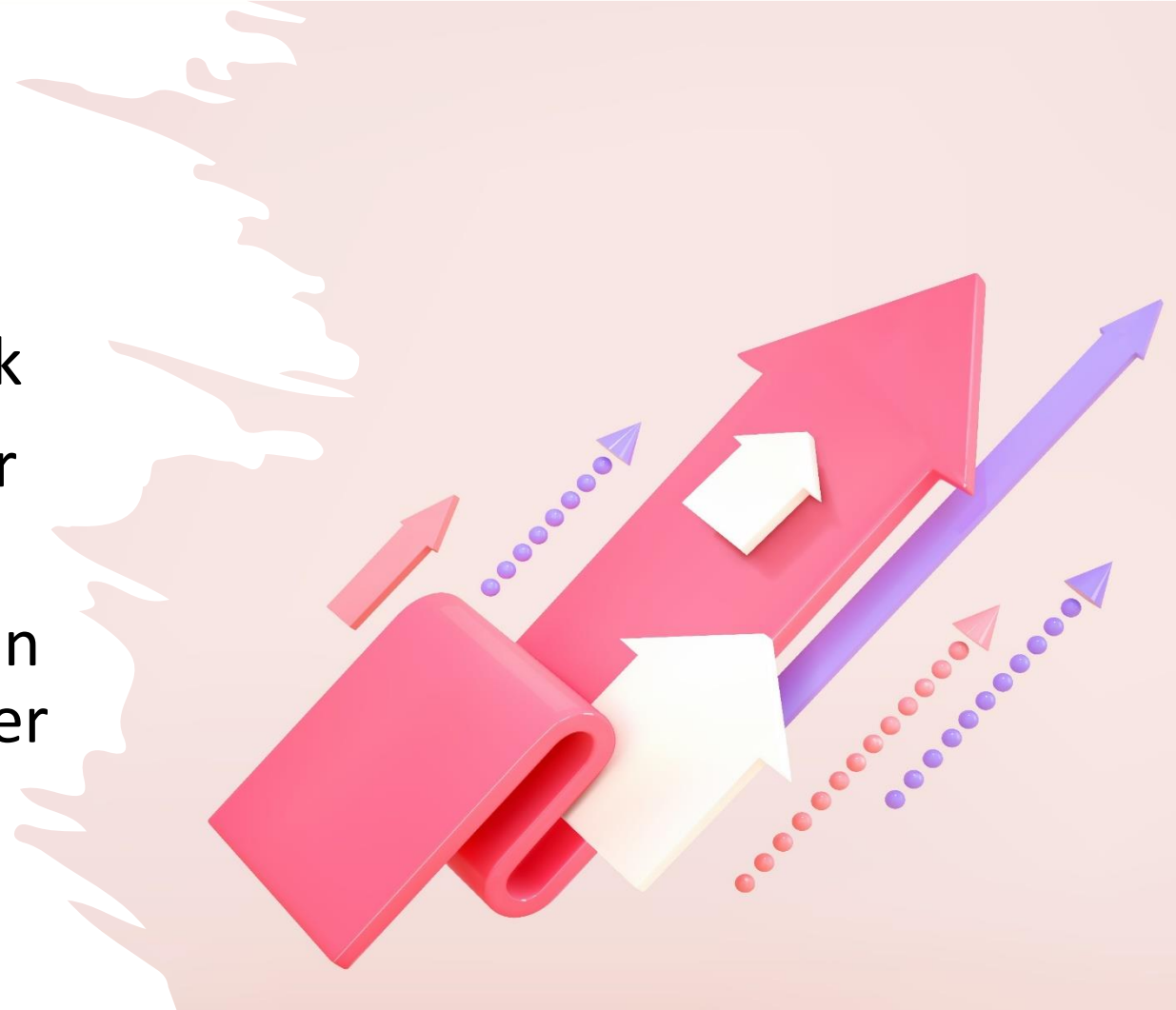


# Impact: Shifting Our View enabled us to

- 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





# The Arc's Strategic Plan FY23-25



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](mailto:lori@arcjc.org)

