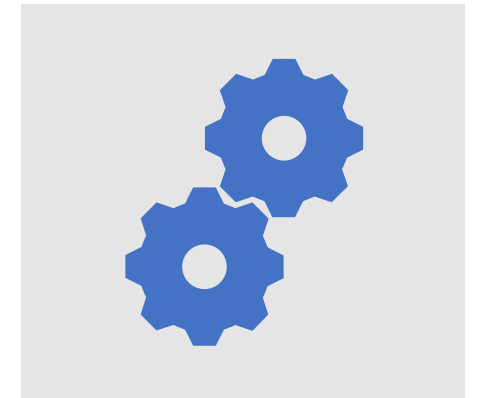


Input to Implementation



Leveraging parent perspectives to make meaningful clinical change



Presentation Description

- ❖ This presentation will describe research centered on parents of children with ASD and discuss how to translate study findings into meaningful clinic change to support families of students with ASD.

Author



- Assistant Professor at California State University Long Beach
- Bilingual (English/Spanish) Speech-Language Pathologist
- Specialty area in ASD especially parent mediated intervention and counseling across the lifespan

Learning Objectives

- At the conclusion of this program, participants will be able to:
 1. List common challenges facing parents of children with ASD across the lifespan.
 2. Describe at least three different clinical approaches to support parents of students with autism.

Poll – What
is your
role?

Parent

Interventionist

Researcher

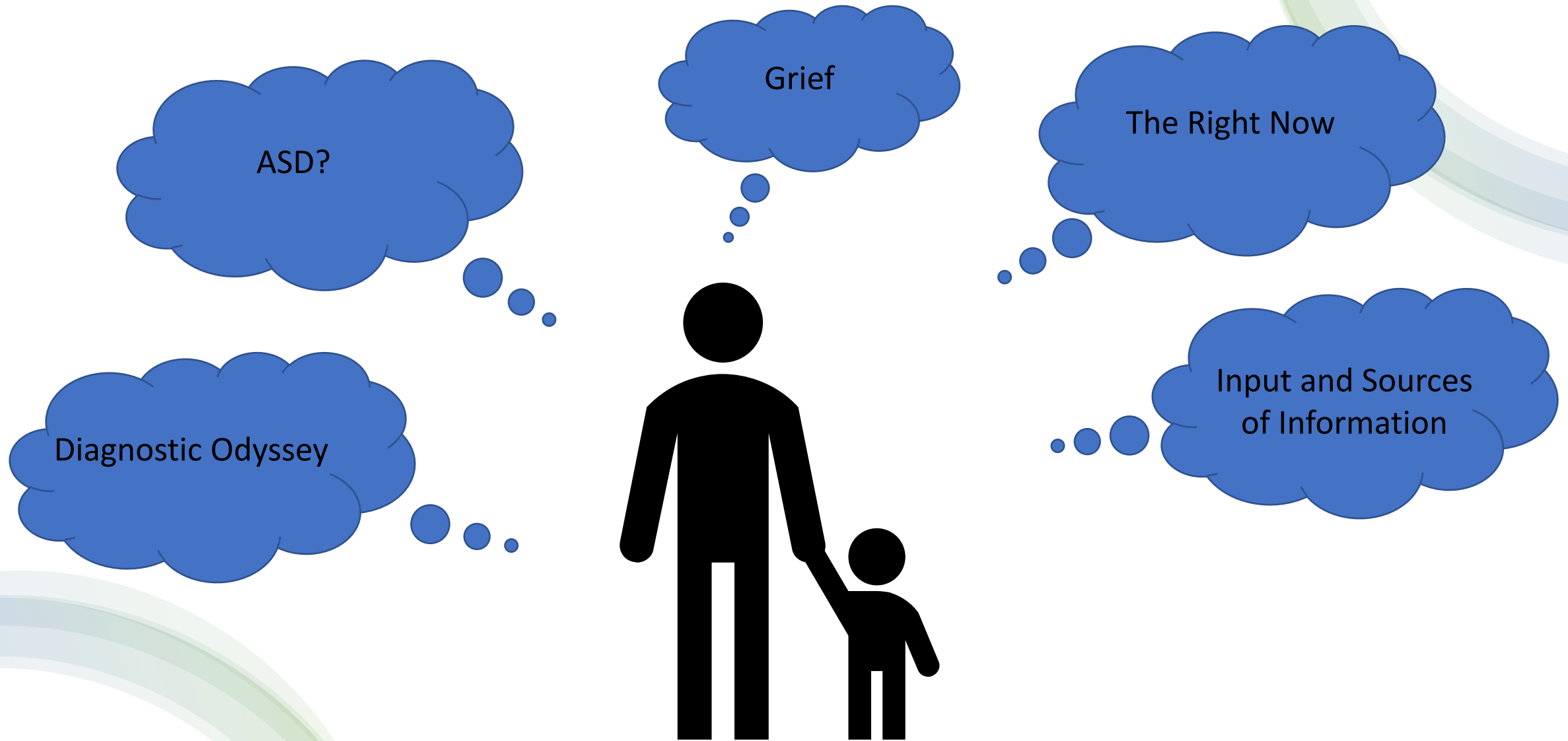
Autistic individual

Other

Common Challenges of Parents of Children with ASD Across the Lifespan

Two Key Demographics

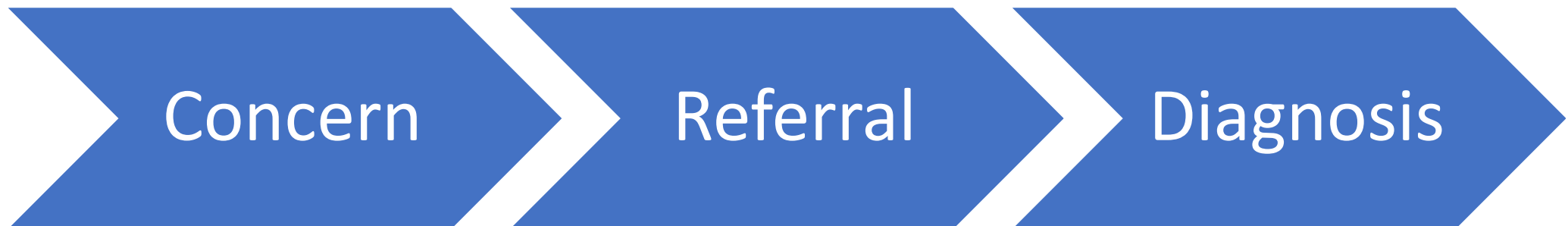




Parents of School Age Children with ASD

Common Challenges of Parents of School Age Children with ASD: **Diagnostic Odyssey**

- Looking for answers
- Suspect delays or seeking to refute others
- What is “normal”?
- Understanding typical development
- Diagnostic process



Common Challenges of Parents of School Age Children with ASD: Understanding the Diagnosis

What is autism?

Cultural influence of the perception of disability

Common Challenges of Parents of School Age Children with ASD: **Grief**

- *Is this my fault?*

- ❖ Losses felt by families of persons with communication disorders

Kubler-Ross's Stages of Grief



- *What caused this?*

Blame Game
<ul style="list-style-type: none">• Wanting to know how and why?• “Who’s fault is it?”

Overwhelmed
<ul style="list-style-type: none">• Not know what to do• Internet/information inundated

Quick Fix
<ul style="list-style-type: none">• How long will he/she need therapy?• Cures

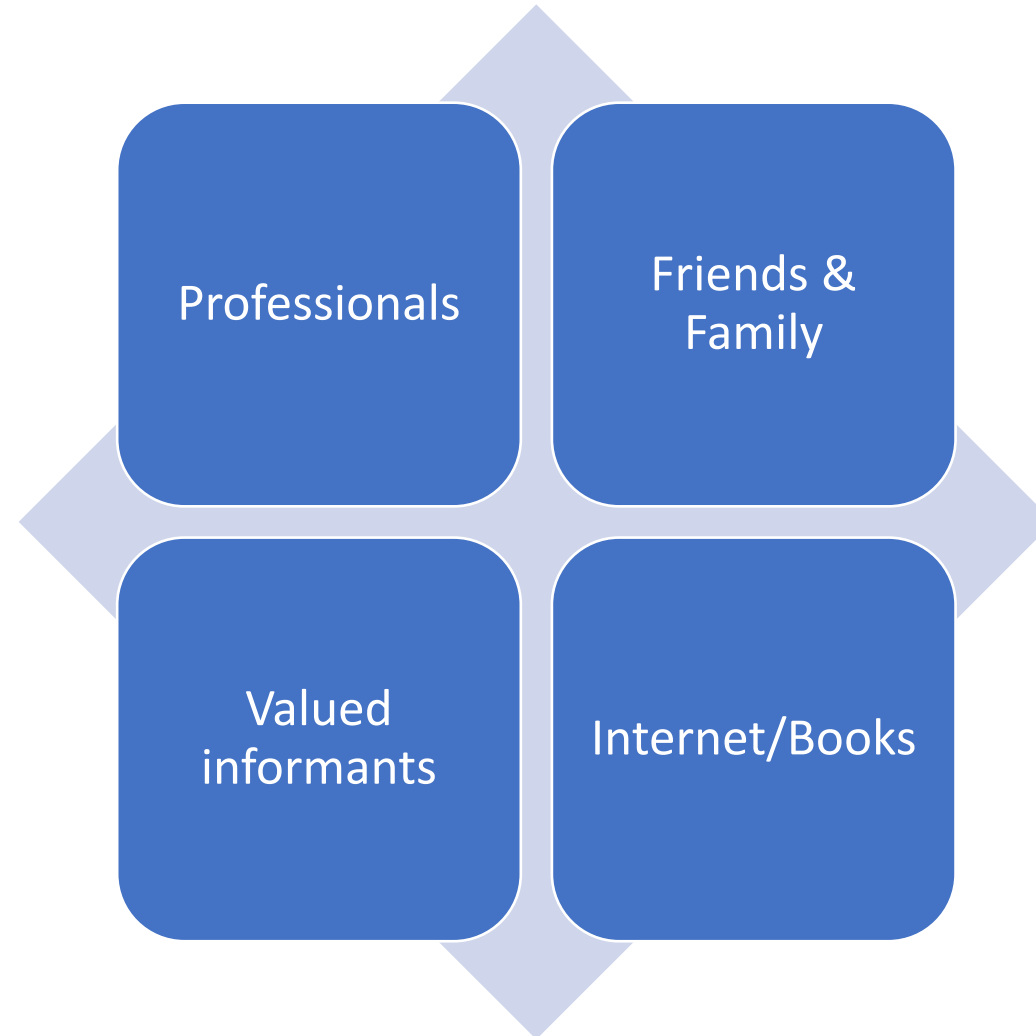
Common Challenges of Parents of School Age Children with ASD: **The Right Now**

Now what?

What's next?

What does this mean for us?

Common Challenges of Parents of School Age Children with ASD: **Input & Sources of Information**



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Input from Research

propinquity
exposure
networks
siblings

barriers

Parent Perceptions of Barriers to Friendship Development for Children with
Autism Spectrum Disorders (Daugherty, 2019)

Background and Methods

Background

- Children with ASD often have difficulty establishing and maintaining friendships.
- Social difficulties may be exacerbated for children with ASD who also do not attend their neighborhood school.
- Propinquity has been explored as a barrier for friendship development for typical children, but not for children with ASD.

Methods

- Participants were 10 parents of school-age children with ASD in mainstream classrooms
 - 5 attended neighborhood schools
 - 5 attended non-neighborhood schools
- Qualitative data was collected via a semi-structured interview.

Findings Pointed to 5 Themes

1. Propinquity

2. Attempts at social exposure

3. Common social problems within ASD

4. Siblings as a protective factor

5. Parent networks

Common themes emerged from parents who did and did not attend a neighborhood school.

Proximity

- Challenges of distance with maintaining connections with families who lived further away.
 - *“He hasn’t had really any playdates even though he talks about some friends all the time. It looks like everyone is from different areas.”*
- Difficulty maintaining relationships with other parents when they moved out of the neighborhood or when children changed schools

Attempts at Social Exposure

- All parents reported attempting to facilitate peer interaction via social activities.
 - ✓ social skills groups
 - ✓ after school programs
 - ✓ park play dates
 - ✓ karate class
 - ✓ Boy Scouts
 - ✓ Jujitsu class
 - ✓ swim class
 - ✓ Volunteer to walk kids to school
 - *“That’s what I want him to do. . . learn how to play with other kids more and try to get along with them.”*

Common ASD Social Skills Barriers

Difficulty with:

- conversation and play
- taking on others' perspectives
- turn taking
- following social norms
- selecting age-appropriate activities and play partners

demonstrating a preference for social isolation

- *“he’s a little awkward . . . generally he likes to play by himself.”*
- *“He doesn’t have any friends.”*

Siblings as a Protective Factor

- Older siblings served as an extended parent.
 - *“My oldest daughter. . . she’ll take charge. She’s playing my role like a parent because my job changed so she would take care of him.”*
- Play partners.
 - *“They share a room and they play together all the time. They play video games against one another, and they also go to the same school.”*
- Comparative success.
- Friendship was less of a concern in comparison to a severely impacted sibling.

Parent Networks

Conscious efforts to build a network

“Like I really wanted him to have long lasting friends, so I figured if I became friends with particular moms and we were compatible and it worked out, then I figured that our kids would still be friends.”

“We had a little support group that we started with me and four or five other moms and their kids. . . We would hook up and go to the park or pizza parlor. Most of them [kids] had special needs except for one. . . It just kinda gave them a friendship circle.”

Discussion

This study sought explore difficulties parents face facilitating friendships for children with autism.

Results suggest *propinquity matters* to maintaining friendships between children with ASD and peers.

Further investigation is needed to explore possible solutions to help parents better support friendship development.



Implementation to Practice

Leveraging Parent Perspectives to Make *Meaningful* Clinical Change

Suggestions to Support Parents

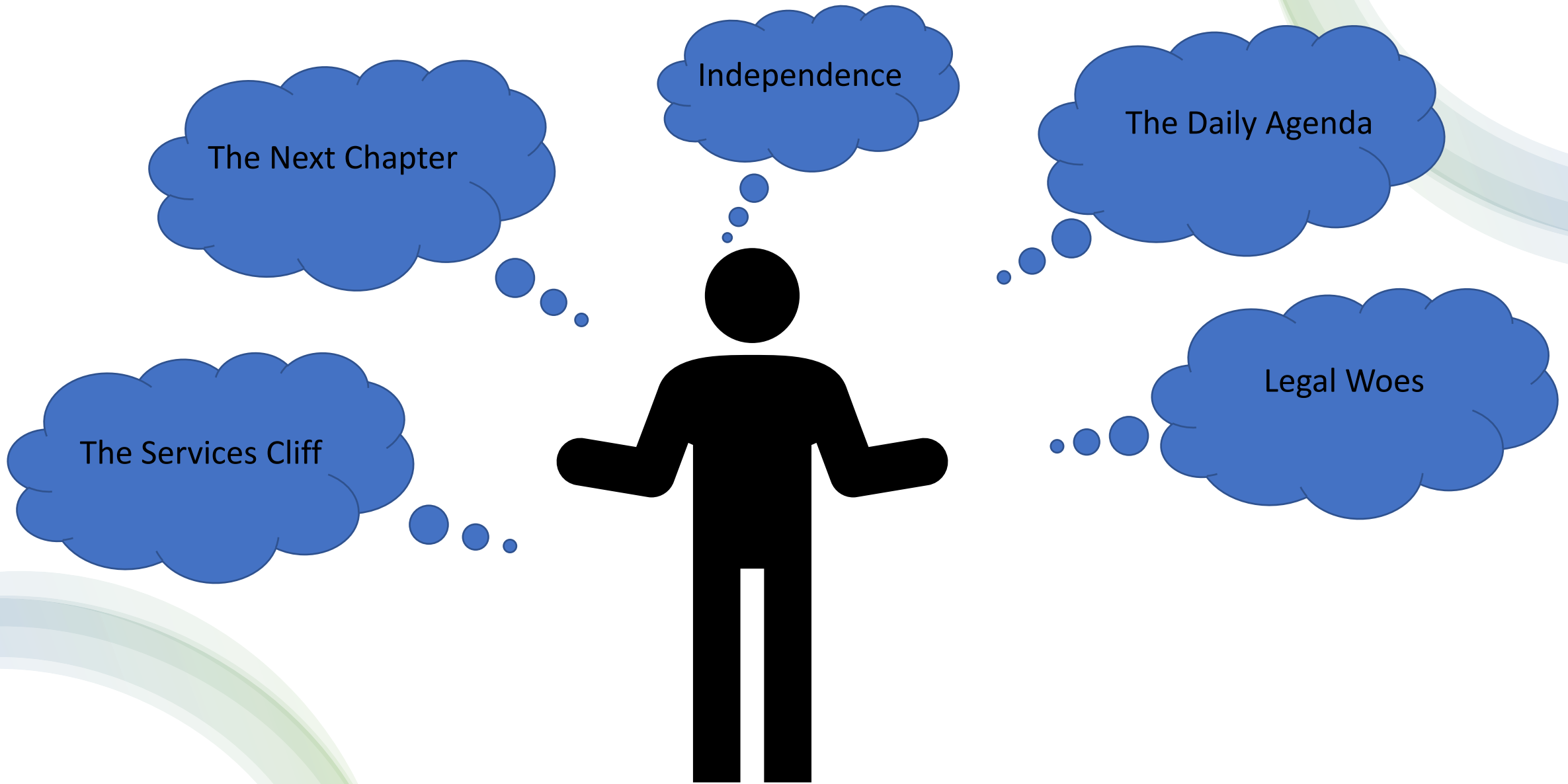
Create social opportunities

Alert parents of child connections

Facilitate travel solutions

Two Key Demographics





Parents of High School/Young Adult Children with ASD



Common Challenges of Parents of High School Age Children with ASD: **The Services Cliff**

- Transition from 12+ years in the special education system
- *Now what?*



Common Challenges of Parents of High School Age
Children with ASD: **The Next Chapter**

Decisions on the path forward

Common Challenges of Parents of High School Age Children with ASD: Independence

Facilitating vs.
Infantalizing

Calculated
risk



Common Challenges of Parents of High School Age Children with ASD: **The Daily Agenda**

What will every day look like?

Common Challenges of Parents of High School Age Children with ASD: **Legal Woes**

- Who is responsible?
- Blurred lines
- Advocacy



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Input from Research



relationships
support
independence
employment

Parent Reported Challenges for Teens with ASD Transitioning to Young Adulthood

(Daughrity, Ellis, & Wiley Johnson, 2021)

Background and Methods

Background

- Young adults with autism can experience challenges with transitioning out of high school and into young adulthood.
- Exploring parent perceptions of challenges during this time is critical to best support the needs of an increasing diverse population of children receiving intervention services.

Methods

- Participants were 13 parents of 11 culturally and/or linguistically diverse teens with an existing diagnosis of ASD.
- Parents participated in a 90-minute focus group to explore their perceptions about perceived challenges with their child's transition to young adulthood.

Results – 4 Primary Themes

Employment

Independence

Transition support

Meaningful reciprocal relationships

Employment

- *meaningful* employment appropriately matched to interests and ability levels.
 - *“more options if they can’t just you know clean up or be bus boys.”*
- Financial security
- *“They can pay the bills.”*
- Finding employment that is both fulfilling and provides financial stability.



Independence

“We just want him to be able to make it without us.”

“Hopefully he can be independent and doesn’t need us all the time.”

Transition Support

- Dwindling support services as children age - dichotomy between the abundance of services for younger children compared to limited programs for teens and young adults.
 - *“As they become older, the support becomes less.”*
 - *“That’s one of the biggest things we’ve seen. Like when he was in elementary, the support was everywhere. Then from junior high the support went down. . . and then high school the support even went lower so that’s our fear is once he becomes an adult in the real world.”*

Meaningful Reciprocal Relationships

- Fears about future loneliness
 - *“I pray to God maybe God will send him someone in any way. . . Wife, friend, or somebody to continue his life with.”*
- Discerning true friendships and relationships
 - *“The lack of self-awareness. I worry about trusting everybody. Like he trusts everybody.”*
- A parental figure
 - *“I want him to be safe. If I die or something happen to me, my son in a good hand. Not only for money, money you can leave in a trust for them or a bank account, but I really would love to feel safe if I’m gone or, you know, he’s alone there is someone looking after him.”*



Discussion

Parents have significant reservations with limited knowledge of supports during this transition.



Implementation to Practice

Leveraging Parent Perspectives to Make *Meaningful* Clinical Change

Suggestions to Support Parents



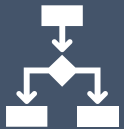
Engage

Engage in intervention focused on prevocational goals early and often



Promote

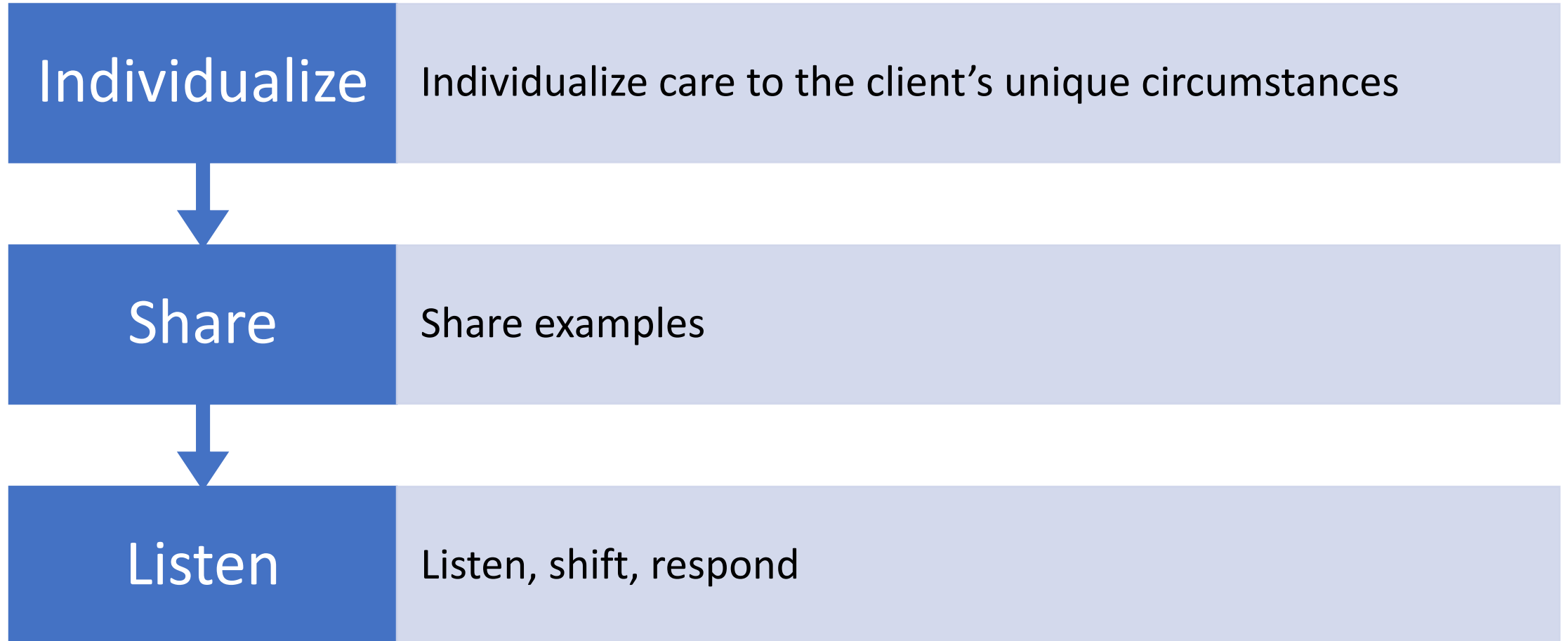
Promote pipelines to employment within the community



Share

Intentionally share “positive” outcomes with parents.

Overall Considerations

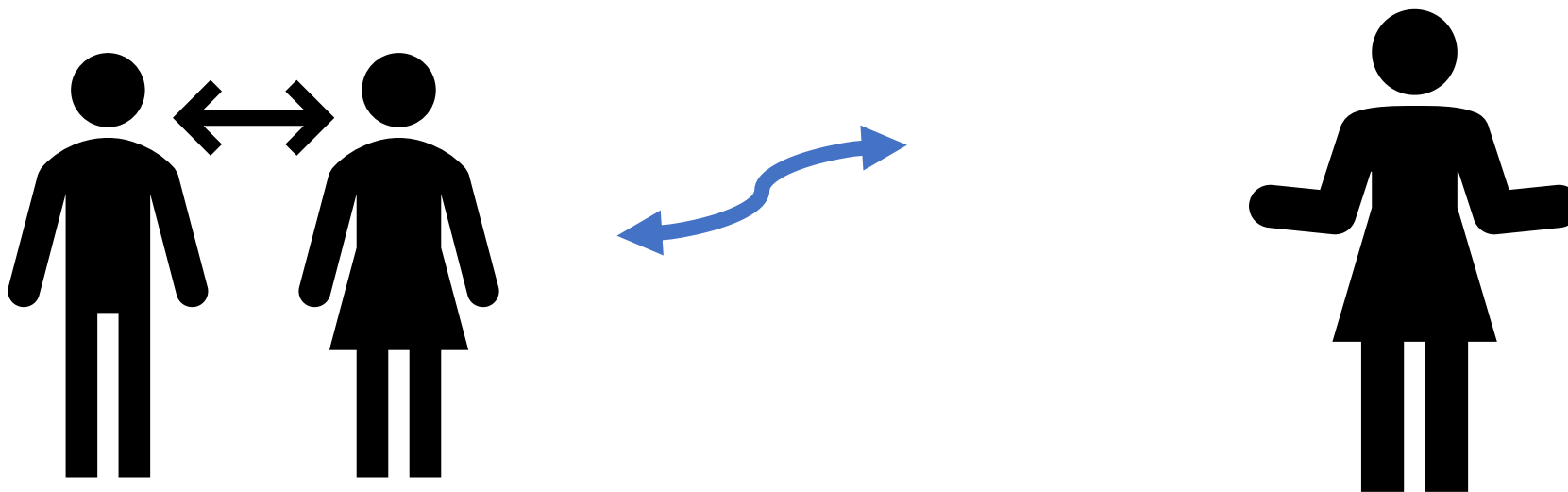
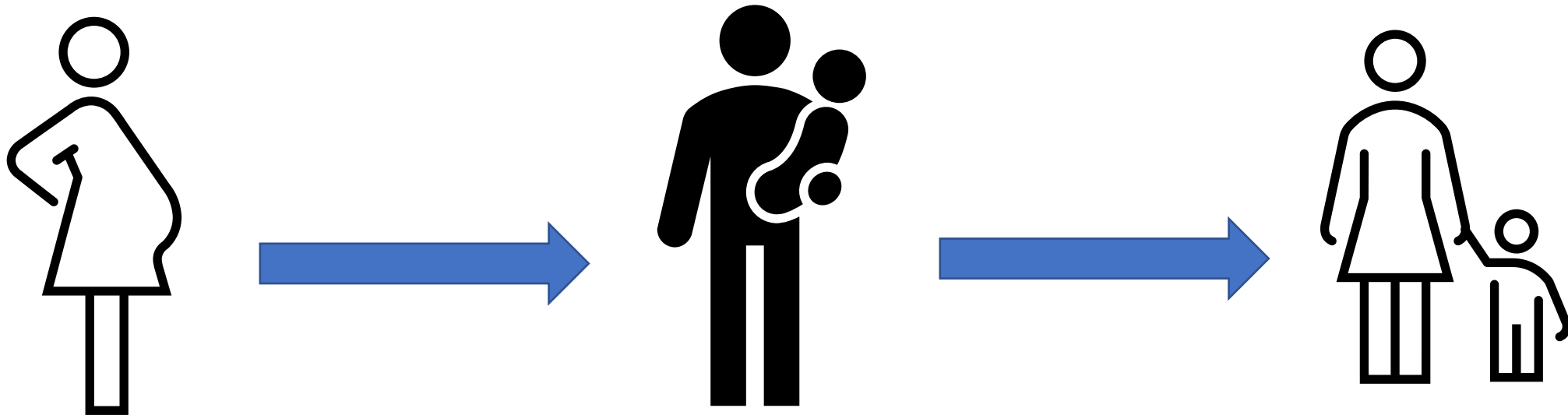


Individualize care to the client's unique circumstances

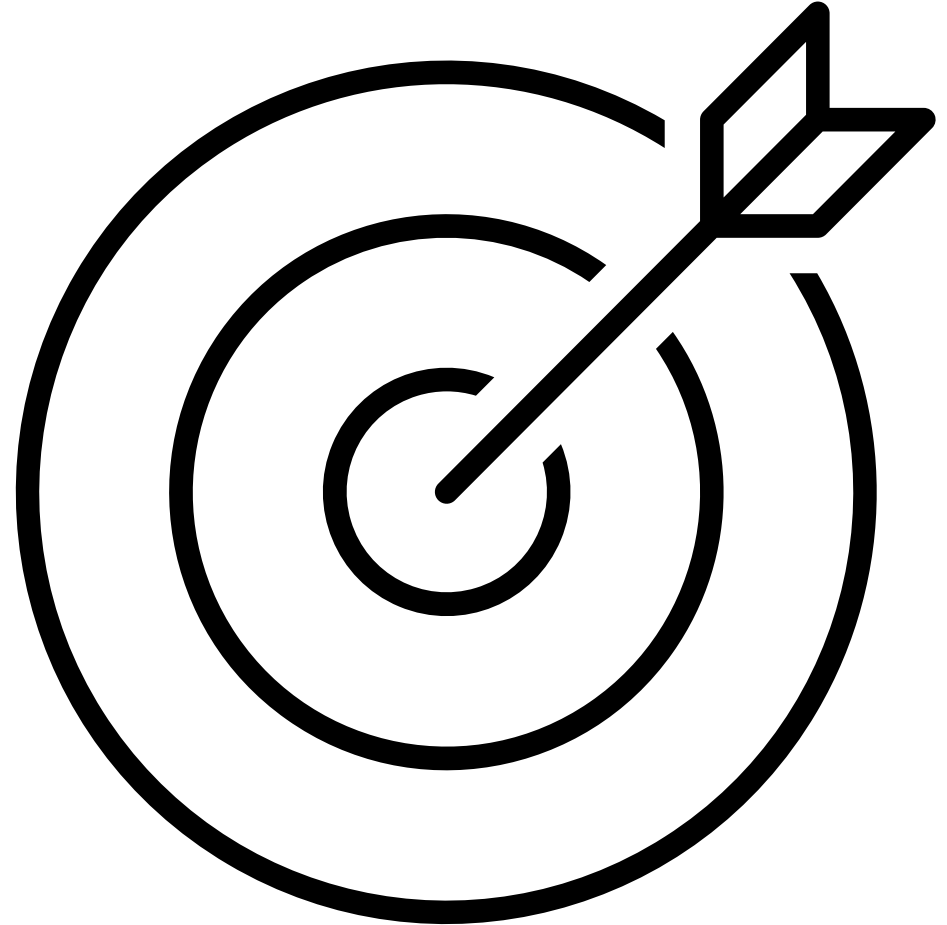
- Demonstrate *culturally responsive approaches*
- Prioritize **equity** over equality
- Listen to understand
- Be flexible
- Show empathy
- Think outside the box

Share Realistic Examples





Set Goals



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Questions

Belinda.Daughrity@csulb.edu

