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Navigating Autism: Parent Experiences with Coping and Service Connection

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NAVIGATING AUTISM

Parent Experiences with Coping and Service Connection

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OCALICON 2012
Friday November 16, 2012
Columbus, OH
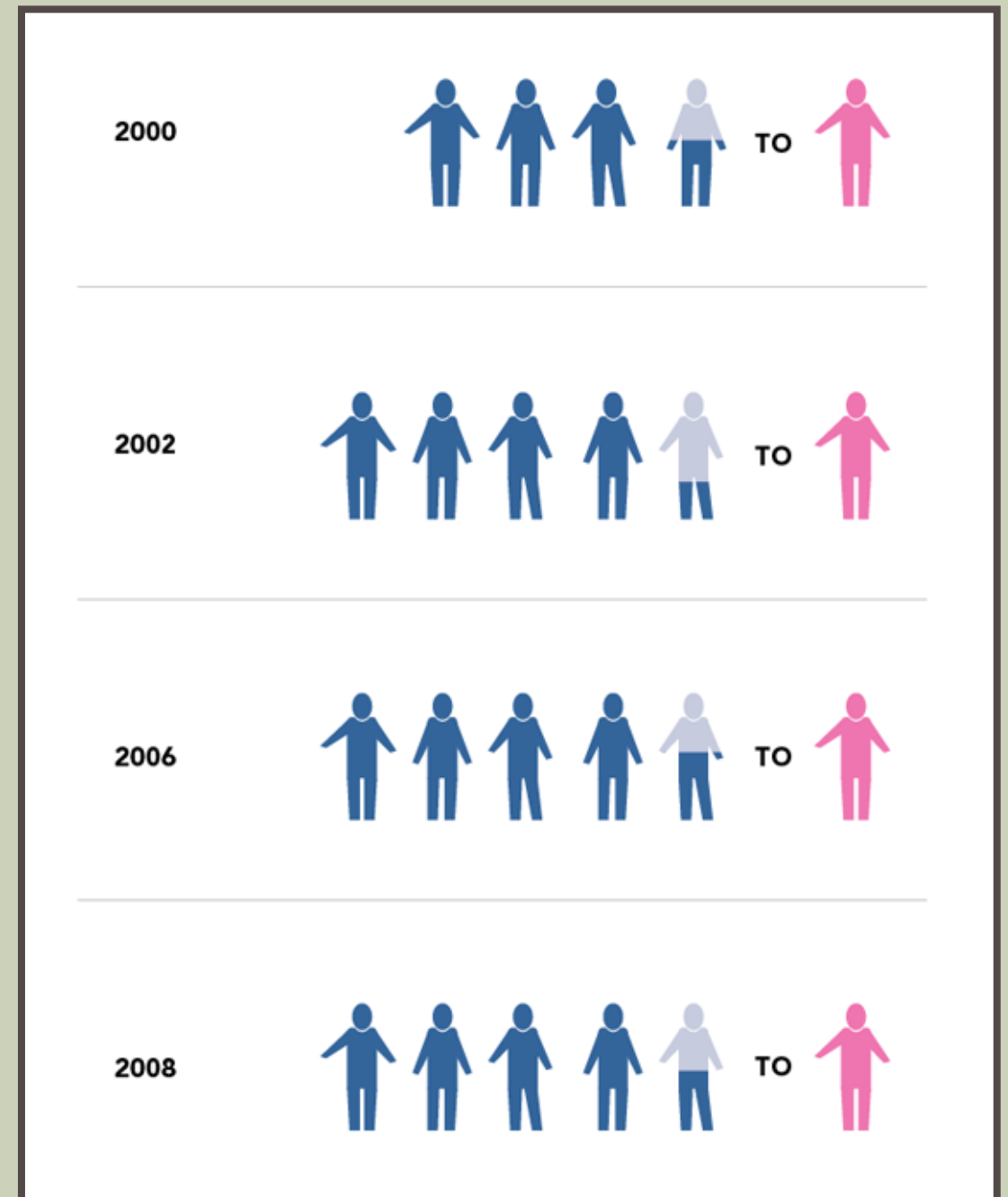
OVERVIEW

- Project purpose
- Background
- Methods
- Results
- Discussion
- Conclusion

PROJECT PURPOSE

- Explore the experiences of parents and caregivers of children with autism spectrum disorders (ASD)
- Explore the experiences of service providers working with individuals with ASD

BACKGROUND
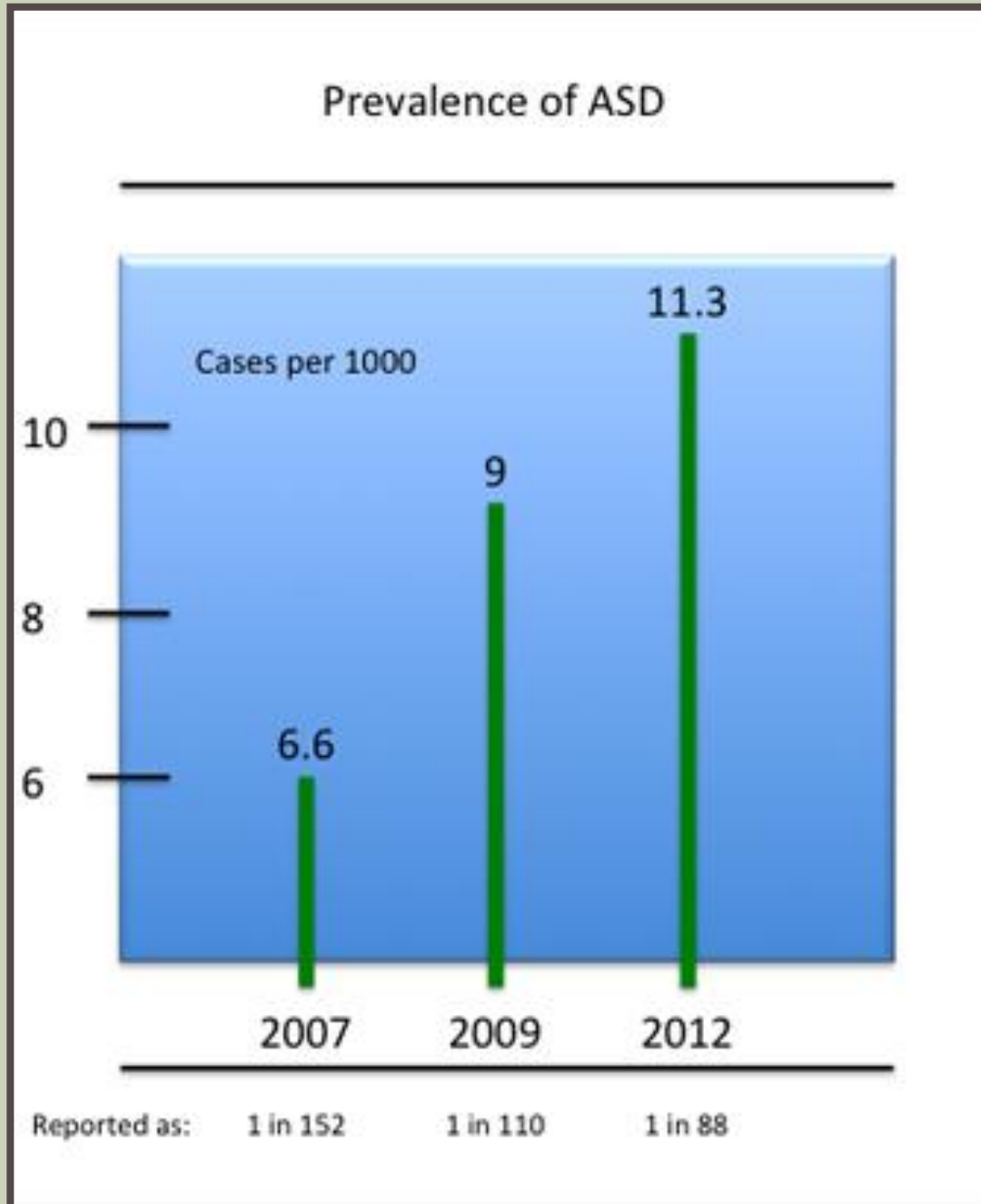
BACKGROUND

- Needed services and challenges:
  - Education on signs of autism
  - Access to expert diagnosticians
  - Early screening and intervention
  - Services across the lifespan
  - Transition supports

METHODS

- **Recruitment**
  - **Ohio Center for Autism and Low Incidence (OCALI) identified potential parent/caregiver participants who were contacted by email or phone**
  - **Service providers were identified through the OCALI website service provider database and emailed recruitment letters**

METHODS

- Data collection
  - Parents and caregivers interviewed by phone
  - Providers were interviewed in a focus group or phone interview
- Measures
  - Parents and caregivers were interviewed using a semi-structured interview with 19 questions
  - Providers were interviewed using a semi-structured interview with 5 questions

PARENT INTERVIEW GUIDE

- Parent & Caregiver Interview Guide
  - First signs
  - Diagnosis
  - Services (e.g., locating, accessing, funds for)
  - Interactions with various service delivery systems (e.g., medical, early education, school system, vocational)
  - Significant life events
  - Interactions with other parents
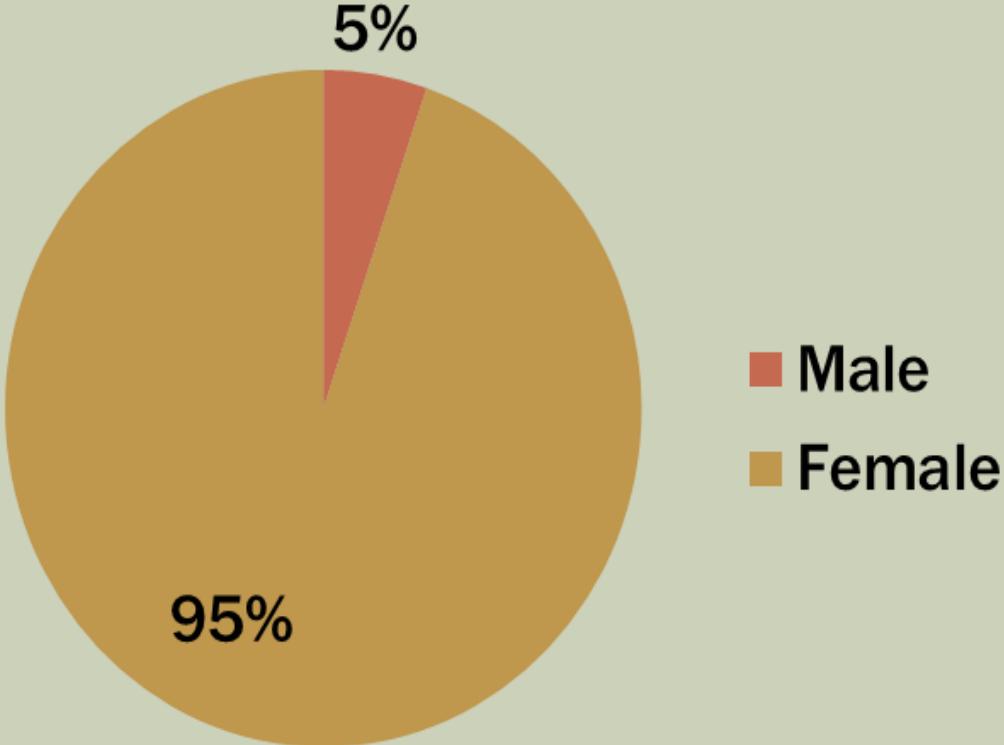
PROVIDER INTERVIEW GUIDE

- What is your role? In what ways do you support service delivery for individuals with autism or other disability?
- What, if any, gaps have you found in the service delivery system? What happens when families aren't able to access the type of service they need? Where do they go?
- What do you suggest would help improve the quality of the service you provide?
- What are the primary funding streams that support the services you provide to individuals with ASD? How does your agency receive this funding?
- What, if any, are the current gaps in funding or funding needs for supports and services to individuals with an ASD?

METHODS

- Data Analysis
  - Content analysis conducted by 3 researchers
    - Periodic credibility checks
  - Conceptual themes identified
  - Validity check using provider interviews

PARENT INTERVIEW DEMOGRAPHICS

Parent Gender

5%

95%

- Male
- Female

Child Gender

12%

88%

- Male
- Female

Average child age: 13.5
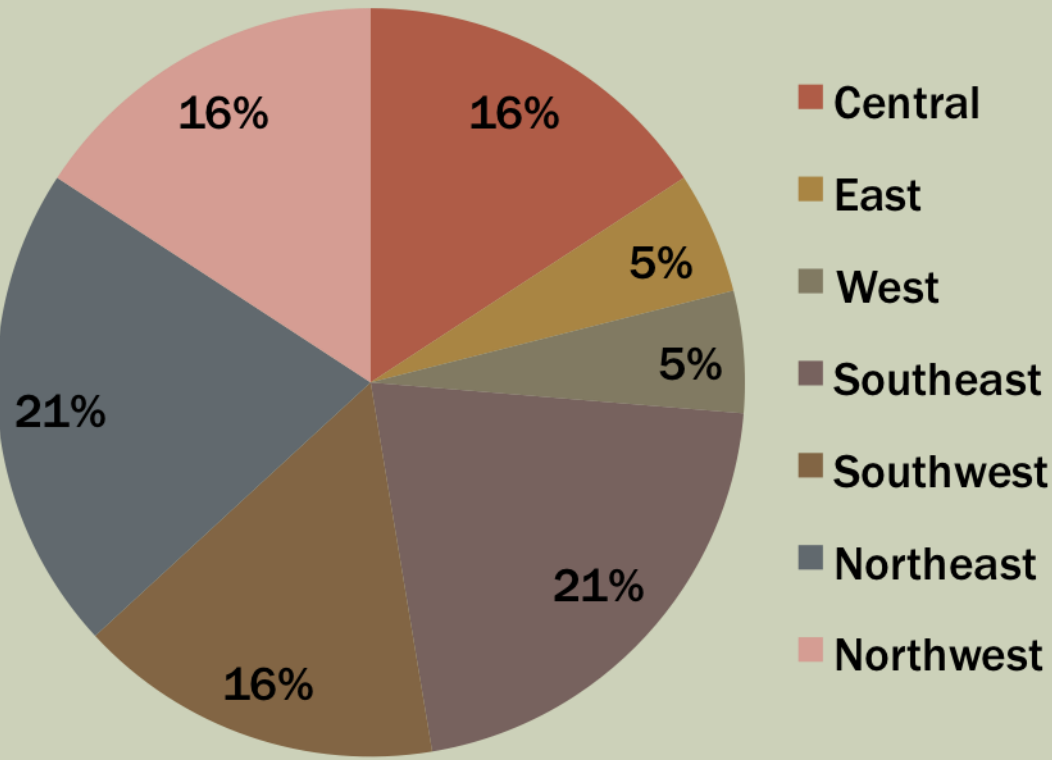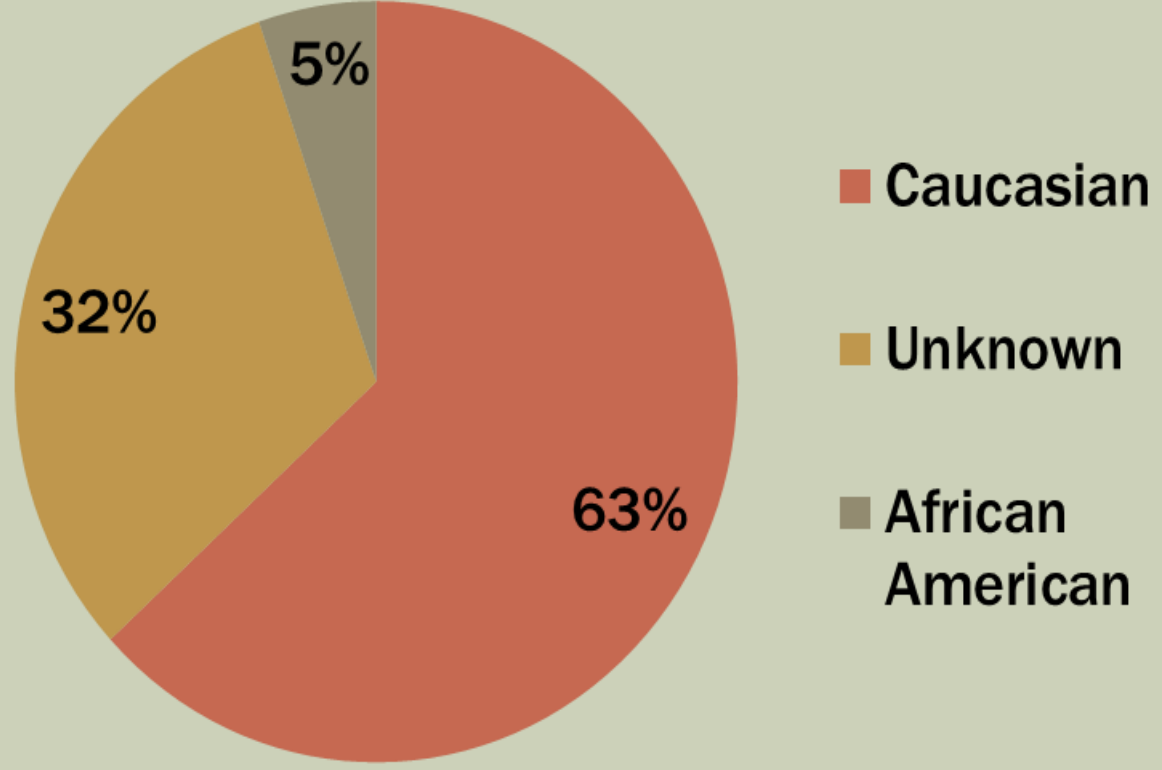
PROVIDER DEMOGRAPHICS

- 9 service providers and state leaders participated
- The service providers and leaders came from a variety of service areas such as education, rehabilitation, health, mental health, and advocacy

RESULTS

- **Parent Interview Themes**
  - **Coping Strategies**
    - 4 subthemes: Life changes, emotional responses, social support, determination, advocacy and empowerment
  - **Service Provider Experiences**
    - 2 subthemes: Positive and negative experiences
- **Service Provider Interview Themes**
  - Gaps in the service delivery system
  - Funding services
  - Importance of support for adults with ASD

COPING STRATEGIES: LIFE CHANGES

I had tried to continue working after diagnosis, but none of the daycare centers had skills or training on how to handle him, so I was in constant turmoil. I placed him in one off and on to give me a break and I told them he was on a strict diet, they didn't follow my instructions because they had a room full of typical kids. I just gave up and could not work, I quit my job, this all started from age 2-3.5.

Everything kept pulling us to Columbus. My mom was here in Columbus. We decided to move back to Columbus and started a home program. X was diagnosed in November, sold house, quit job, started home program in February 2002.

COPING STRATEGIES: EMOTIONAL RESPONSES

For our family it has really been a point where we have to sacrifice one child for the benefit of the other my daughter does not get to do the things she should nor do my husband or I get to. We haven't had anniversaries or birthdays for at least 6 years. We haven't participated in anything in life, all hands on deck. In fact when we moved into this house we still had not gotten a full extent of what was in store as far as the level of need and we haven't landscaped or put up curtains.

We finally know and the guilt of not knowing all of those years. {Child} would disappear and be in his room and I wouldn't notice... It's more noticeable now that we know and can see what is so different about him. It's sad that I didn't know when he was younger.

COPING STRATEGIES: SOCIAL SUPPORT

Early on I was much more active and involved and [they] were very much a support to me. I've gotten so far from it I've forgotten. I don't feel the need for the parent support thing… When {child} was diagnosed I knew no one who had a child with autism. Early on I needed that support because I didn't have any interactions or contacts. Just to talk to another parent who knew what I was struggling with was a big deal.

At the autism meetings, I went to a few but they got too depressing and I stopped going…I would leave crying every time

COPING STRATEGIES: DETERMINATION

It was difficult because the neurologist had a year long waiting list, so we got an appointment with someone else in that practice and he took a look at {child} and said let's wait and see. I said "no no no," because I wouldn't be able to access anything, so I went back to the pediatrician, got a new referral, started seeing a new neurologist who ordered a number of tests. We have to either fight for services or pay out of pocket.

We tried everything. In home schooling, going to Cincinnati, going to school, in home school again. We tried school again and that's now working.

COPING STRATEGIES: ADVOCACY AND EMPOWERMENT

It's a tough road but together we have power. We don't have to wait. Parents need to get together, share, and get busy helping. We don't have to wait for anyone's head nod. There's a lot we can do together, start organizations, tap into ones that have already been developed.

Now I can go into a meeting and take charge. There's no such thing as a stupid question. I don't even ask questions sometimes, I just go in and say what I want. I think about what's important to my kid. I don't worry about stepping on toes.

SERVICE ACCESS AND DELIVERY: POSITIVE EXPERIENCES

- Collaboration and communication
- Financial resources
- High quality services
- Insider knowledge
- Parent provided care
- Luck

SERVICE ACCESS AND DELIVERY: NEGATIVE EXPERIENCES

- Delays in diagnosis
- System disconnects
- Lack of information
- Inadequate service providers
- Financial and logistical challenges
- Devalued by experts
- Geographic inconsistencies

GAPS IN THE SERVICE DELIVERY SYSTEM

The levies have made the services county specific. So if I live in Franklin, the wealthiest, I have a better chance of accessing services than in Morrow County that hasn't passed a levy in 15 years. So if I live in Morrow County, I'm going to get education service but not much beyond. If I live in Franklin County I will get early intervention to aging services. You won't find that in other states in other states, where there isn't consistency it's because of distance and proximity. Where I live is who pays for the service. Even if I have the means to travel there is no means to pay unless I'm also poor but if I'm middle class my insurance isn't going to cover it and local tax dollars aren't.

The biggest problem is communication. Education doesn't talk to DD who doesn't talk to ODJFS who doesn't talk to ODH because we are funded so different each system keeps its own self going and there isn't a whole lot of time and energy to talk to anyone. If it was a team approach, we might be able to help people but systems aren't coordinated. That's a huge hole.

FUNDING SERVICES

Parents don't know who will pay for what; if we as a state looked at an integrative approached for funding it would help services are too fragmented and siloed.

If I provided behavioral therapy, I could finding the funding...there is very little funding to help parents find that behavioral therapist. It really takes one person telling another. It really takes me telling someone who tells someone and that's been a challenge.

IMPORTANCE OF SUPPORT FOR ADULTS WITH ASD

Integration and independence into your community: this is the most important thing; the long term things. We need housing to have this and transportation that does this long-term.

We don't have a shortage of jobs, we have a shortage of matches. How do I get at the skill set? How do I get to this and train/prepare? We are doing this in customized employment. We look past the person to what are the skills.

STUDY LIMITATIONS

- Sample size and representativeness
- Generalizability
- Participant recruitment
- Findings from one state

STUDY STRENGTHS

- Rich information gained will spark future research
- Reliability
- Validity

IMPLICATIONS

- Practice
  - Clear, concise, and coordinated communication
  - Collaboration among parents/caregivers, service providers, and other professionals
  - Professional development and pre-service training
    - Educators, medical professionals, and other relevant professionals

IMPLICATIONS

- **Research**
  - **Support groups and activities**
  - **ASD service providers**
- **Policy**
  - **Advocacy**
  - **Policy awareness**
  - **Policy translation**

CONCLUSION

- Picture of service delivery system and funding for ASD in Ohio
  - Optimism about the future
- Improvements to be made
- Next steps for practice, research, and policy

QUESTIONS

☐ Questions for us?

☐ Questions for you

- ☐ In your professional and personal experiences, what gaps and barriers in services for individuals with autism spectrum disorders have you noticed?

- ☐ In your professional and personal experience, what are the ways in which the service delivery system is working well?

- ☐ For practitioners, in what ways do you collaborate with parents in your practice and how could you change your practice to increase collaboration?

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