

Qualitative Analysis

PRELIMINARY -- KEY THEMES

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Structured Interviews

2 DBHDD field office administrators

1 provider organization CEO

1 family advocate

- referred by advisory committee members

- experiences in subject matter

Focus Groups with Family Members

3 at Emory Autism Center (Regions 1, 3, 6)

2 in Savannah (Region 5)

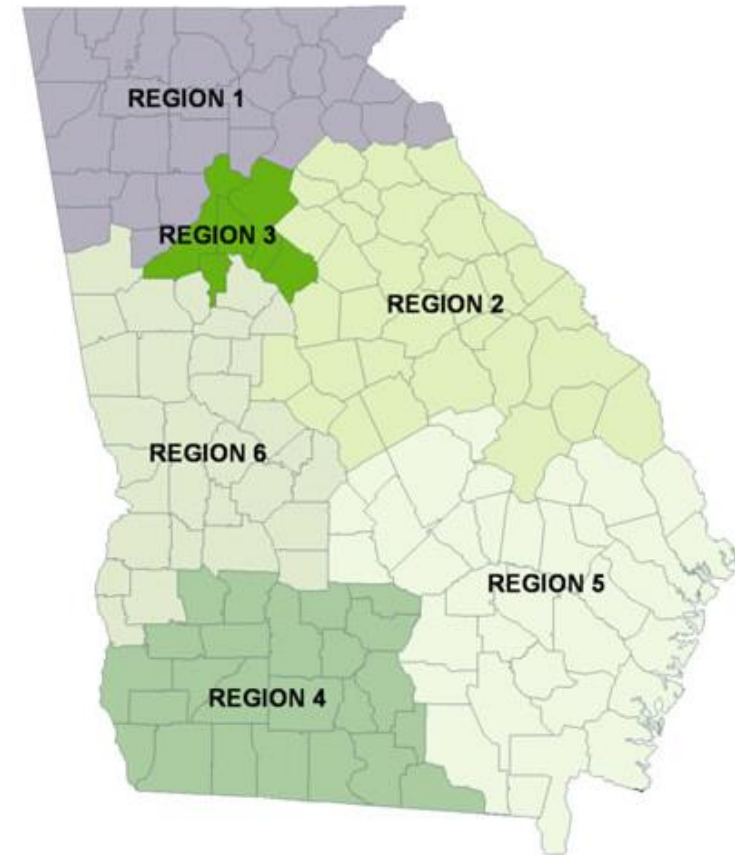
1 in Dalton (Region 1)

1 in Thomasville (Region 4)

38 different zip codes

- Recruited by regions' field offices (Regions 1 and 4), advisory committee members (Regions 1 and 5), and Emory Autism Center roster (Regions 1, 3, 6)

- Aim was to reach diverse segments of the population (e.g., income level, advocacy skills, race and ethnicity, age of individuals)





Aggregate Demographics Data

Voluntary, response rate about 90% (43/47)

Number family households: 47

Gender (family members and individuals): female = 91%; male = 9%

Age of family member with autism: Average = 28 y; Range = 18-46 y

Rural versus urban: Urban/suburban: 25%; Rural: 75%

Race and ethnicity: White: 54%; Black: 37%; Other/no answer: 9%; Hispanic: 5%

Insurance status: Public: 45%; Private: 14%; Mixed = 16%



Barriers to Access - Information

Information

- Difficulty finding information; fragmented
- Differing levels of knowledge about resources between families
- Biggest Concerns: long-term planning and transitioning to adulthood
- Most Helpful Resources: other families
- Most Important Key to Success: Advocacy and advocacy training is critical



Barriers to Access – Providers

Lack of access to appropriate, consistent, and timely identification of changing needs and treatments across all geographic areas

- Provider shortage
- Fragmentation with multiple diagnoses and multiple providers
- Lack of individualized/person-centered care
- Limited ASD-related training of providers
- Biggest concern for high functioning individuals: Finding and maintaining employment and independence
- Biggest concern for families with low functioning individuals: Safety and dignity
- Most Helpful Resources: other families and specific providers



Barriers to Access -Quality

Quality Direct/Daily Care

- Provider shortages
- No continuity of care because of high direct care staff turn-over
- Poor quality (day programs and group homes)
- Lack of transportation
- Lack of training for employers and co-workers
- Lack of emphasis on life skill development
- New regulations (making it harder to become an approved provider)
- Need routines, friendships, socialization opportunities among adults with autism and how to achieve this for adults/during transition

Most Helpful Resources: Providers that “get it” and know about the individualized needs for autism

Family Burden

Heavily burdened (financially, physically, and emotionally)

- Including grandparents, aunts, siblings, “The Village”
- Little financial assistance
- Many have to quit jobs or move to get better services
- Affects relationships and family dynamics
- No mental health support for families
- No support/incentives for innovative families creating solutions and filling gaps

Families not trained in promoting life skills

- Transition from high school to adult services is most difficult

Biggest Concerns: Flexible plans for long-term care and family “burn out”

Most Helpful Resources: Other families to get information about respite possibilities and other possible care arrangements; workshops for creating long-term care plans



Crisis System

Closing of hospitals and services

Lack of information about crisis hotline and support

- Many participants were unaware of GCAL

Long waits, inexperienced team members, ineffective strategies

Police officers

- Urban—more crisis intervention and de-escalation training but not trained with regard to autism
- Rural—more familiar with families, and therefore more accepting and understanding, but little crisis and de-escalation training

Biggest Concern: “crisis gap” for low-functioning individuals

Most Helpful Resources: Flexible behavioral intervention plans to prevent crisis; individual law-enforcement and providers with autism experience and training



Underserved Populations

African Americans worry about children's safety and being taken advantage of

Safety is especially a concern for males

Low levels of advocacy and information seeking skills

Importance of addressing cultural differences and individual family needs



Suggested Solutions—Training Needs

Families—autism training, behavioral supports, dealing with crises, available resources, accessing help with long-term planning, advocacy training, skill development, and transitioning

Direct Care Providers and Staff—autism training, behavioral supports, crisis interventions, individualized care plans, skill development

Law Enforcement—Autism- specific crisis intervention

Crisis System—fill crisis gap for low-functioning individuals, crisis management, teams trained in autism-specific interventions

Potential or Current Employers—autism and relevant accommodations

School System – training for transitioning, better outreach to DBHDD from schools



Suggested Solutions – Access to Information and Care

Create information portal with all resources, providers, and other families to provide roadmap

Create peer positions for parents paralleling the education parent peer model

Provide and encourage use of respite services to prevent burnout and crisis

Foster establishment of networks of families for support and information sharing

Need for interagency initiatives (e.g., Education)

- Recent MOU between DBHDD and GVRA could be a model with regard to DOE



Suggested Solutions – Provider and Staff Shortages

Train and compensate direct care staff to encourage retention

Allow training of two direct care staff at a time to encourages continuity

Provide seed money and/or technical assistance for families who want to start their own provider organization or services



Suggested Solutions--Policy

Revise current standards and policies with feedback from providers to assure easy access to high-quality care for adults with autism

Provide incentives for families to step up and provide care

Allow family and financial assistance to go towards legal fees for long-term planning



Suggested Solutions -- Transition

Start transition planning in schools much earlier –balance between life skills training and academic training

Need for interactive transition support

Provide individualized training for families

Potential role for family-to-family peer support (Parent System Navigator)



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Questions?

