Alabama Interagency Autism Interagency Coordinating Council

Family Questionnaire Regarding Autism Spectrum Disorder (ASD)

If you have multiple family members with ASD, please complete a separate survey/form for each individual.

The Alabama Interagency Autism Coordinating Council (AIACC) guides a collaborative effort to facilitate a lifelong system of care and support for persons with Autism Spectrum Disorder or associated conditions and their families, so that they may enjoy a meaningful and successful life.

You are invited by the AIACC to complete a survey to discuss programs and services for family members with ASD. The information you provide will be used to summarize program strengths and recommendations for improvement to supports and services and to monitor progress in achieving AIACC's mission. The survey will take about 10 minutes. There is no obligation to complete any or all of the information in this survey; if there are any specific questions you do not wish to answer, please skip them and move to the next question. You may not personally benefit from your participation in this survey; however, your participation will be helpful to indicate areas of program strength and needed improvements for people with ASD. Your personal identity information will not be collected. Contact State Autism Coordinator Anna McConnell with any questions (anna.mcconnell@mh.alabama.gov, 205-478-3402).

We want and need to hear from you. Thank you for participating.

1. **What is your zip code?** ____

2. **What is your ethnicity?** *Check all that apply.*
   - ❒ American Indian or Alaskan Native
   - ❒ Asian or Pacific Islander
   - ❒ Black or African American
   - ❒ Hispanic or Latino
   - ❒ White/Caucasian

3. **What is your marital status?**
   - ❒ Single
   - ❒ Married
   - ❒ Separated
   - ❒ Divorced
   - ❒ Widowed
   - ❒ Other

4. **In what range is your family income?**
   - ❒ $20,000 or less
   - ❒ $20,001 - $40,000
   - ❒ $40,001 - $60,000
   - ❒ $60,001 - $80,000
   - ❒ More than $80,000

5. **How many members of your family (your siblings, children, parents) have been diagnosed with Autism Spectrum Disorder (ASD)?** ____

6. **How many family members with ASD live with you?** ____

7. **Are there formal support networks for ASD in your community?**
   - ❒ Yes
   - ❒ No
   - ❒ Don't Know

8. **Do you participate in any of these support groups?**
   - ❒ Yes
   - ❒ No
   - ❒ Not Applicable

Please tell us about your family member diagnosed with ASD.

9. **Please select the gender of your family member diagnosed with ASD.**
   - ❒ Male
   - ❒ Female

10. Please enter the age, in years, of your family member diagnosed with ASD. ___________________________

11. Where does your family member with ASD live?

- ❐ At home
- ❐ In foster care
- ❐ In residential placement
- ❐ At college
- ❐ In his/her own apartment or home
- ❐ With another family member
- ❐ Other

12. What is the language ability of your family member with ASD?

- ❐ Nonverbal
- ❐ Makes simple sounds
- ❐ Uses single words
- ❐ Speaks short sentences
- ❐ Speaks complex sentences

13. Does your family member with ASD engage others in conversation?

- ❐ Usually
- ❐ Sometimes
- ❐ Rarely
- ❐ Never

14. Does your family member with ASD use any of the following to help him/her communicate? *Select all that apply. If no assistance is needed, select "None."*

- ❐ Picture Exchange / Picture Symbols
- ❐ Talking Device
- ❐ Sign Language
- ❐ None
- ❐ Other: ____

15. For each of the following activities, please indicate how well your family member with ASD is able to perform the activity. *Mark only one per row.*

	Independently	With Help or Support	Does Not Have This Skill Yet
Feeding	❐	❐	❐
Dressing	❐	❐	❐
Bathing	❐	❐	❐
Toileting	❐	❐	❐
Cooking	❐	❐	❐
Managing Money	❐	❐	❐
Transporting Him/Herself (driving, riding a bus)	❐	❐	❐

Diagnosis

16. **How many different service providers evaluated your family member with ASD before you were given a diagnosis? ____**

17. **What is the length of time (number of months) between your first concern and receiving a diagnosis for your family member with ASD? ____**

18. **At what age, in years, did your family member with ASD receive a diagnosis? ______________**

19. **Do you believe you received an accurate diagnosis for your family member with ASD?**
    - ❒ Yes
    - ❒ No
    - ❒ Don't Know

20. **Was your family member with ASD diagnosed in Alabama?**
    - ❒ Yes
    - ❒ No
    - ❒ Don't Know

21. **What type of professional provided the diagnosis for your family member with ASD?**
    - ❒ Physician (pediatrician, neurologist, psychiatrist)
    - ❒ Psychologist
    - ❒ School Professional
    - ❒ Other: ____

Early Intervention Services

22. **Does/did your family member with ASD receive early intervention services (between 0-2)?** *If you answer "Never", skip to Question # 27.*
    - ❒ Currently receives early intervention services
    - ❒ Previously received early intervention services
    - ❒ Never received early intervention services
    - ❒ Don't Know

23. **How many months after diagnosis did it take before you could begin therapy for your family member with ASD? ____**

24. **Do/did you receive any of the following early intervention services for your family member with ASD?** *Check all that apply*.
    - ❒ Behavior Therapy/ABA
    - ❒ Mental Health Counseling
    - ❒ Nutritional Counseling
    - ❒ Occupational Therapy

- ❒ Parenting Skills
- ❒ Physical Therapy
- ❒ Social Skills Training
- ❒ Speech Therapy
- ❒ None
- ❒ Other: ____

25. How many hours PER MONTH of specialized services (including special education pre-school and individual therapies) does/did your family member with ASD receive from a professional before 3 years of age? *Do not include hours in general daycare.* ____

26. Do/did you receive training from a professional on how to provide therapy at home for your family member with ASD?
- ❒ Yes
- ❒ No
- ❒ Don't Know

Pre-School Services

27. Do/did your family member with ASD receive pre-school services (between ages 3-5)? *If you answer "Never", skip to Question # 31.*
- ❒ Currently receives pre-school services
- ❒ Previously received pre-school services
- ❒ Never received pre-school services
- ❒ Don't Know

28. Do/did you receive any of the following pre-school services for your family member with ASD? *Check all that apply*.
- ❒ Behavior Therapy/ABA
- ❒ Mental Health Counseling
- ❒ Nutritional Counseling
- ❒ Occupational Therapy
- ❒ Parenting Skills
- ❒ Physical Therapy
- ❒ Pre-School Classroom Attendance
- ❒ Social Skills Training
- ❒ Speech Therapy
- ❒ None
- ❒ Other: ____

29. How many hours PER MONTH of specialized services (including special education pre-school and individual therapies) does/did your family member with ASD receive from a professional between ages 3 and 5 years? *Do not include hours in general daycare.* ____

30. **Do/did you receive training from a professional on how to provide therapy at home for your family member with ASD who was 3, 4, or 5 years of age?**
   - ❒ Yes
   - ❒ No
   - ❒ Don't Know

Services Through Public Schools

31. **Do/did your family member with ASD receive services through public schools?** *If you answer "Never", skip to Question #36.*
   - ❒ Currently receives services through public schools
   - ❒ Previously received services through public schools
   - ❒ Never received services through public schools
   - ❒ Don't Know

32. **Does/did your school system provide the resources necessary to support your family member with ASD?**
   - ❒ Yes
   - ❒ No
   - ❒ Don't Know

33. **Do/did you receive any of the following school-based services for your family member with ASD?** *Check all that apply*.
   - ❒ Behavior Therapy/ABA
   - ❒ Job Training/Coaching
   - ❒ Mental Health Counseling
   - ❒ Nutritional Counseling
   - ❒ Occupational Therapy
   - ❒ Parenting Skills
   - ❒ Physical Therapy
   - ❒ Recreation/Exercise Therapy
   - ❒ Social Skills Training
   - ❒ Speech Therapy
   - ❒ None
   - ❒ Other: ______________________________

34. **How effective is/was your school at meeting the following needs of your family member with ASD?**

	Very Effective	Somewhat Effective	Somewhat Ineffective	Very Ineffective	Don't Know
Academic Needs	❒	❒	❒	❒	❒
Behavioral Needs	❒	❒	❒	❒	❒
Communication Needs	❒	❒	❒	❒	❒
Social Needs	❒	❒	❒	❒	❒

35. During IEP Meetings, does/did anyone discuss services after high school for your family member with ASD?

- ❒ Yes
- ❒ No
- ❒ Don't Know

Services For Adults

36. How much supervision does your family member with ASD need as an adult? *If your family member with ASD is not yet an adult, how much supervision do you think he or she will need as an adult?*

- ❒ No Supervision
- ❒ Occasional Supervision
- ❒ Frequent Supervision
- ❒ Continuous Supervision
- ❒ Don't Know/Unsure

37. Does your family have long-term care plans for your family member with ASD?

- ❒ Yes
- ❒ No
- ❒ Don't Know

38. Are you on a waiting list for residential services for your family member with ASD?

- ❒ Yes
- ❒ No
- ❒ Don't Know

39. Is your family member with ASD an adult (21 years or older)? *If you answer "No", skip to Question #42.*

- ❒ Yes
- ❒ No

40. Do you receive any of the following services for your family member with ASD who is an adult? *Check all that apply.*

- ❒ Family Respite
- ❒ Job Training/Coaching
- ❒ Mental Health Counseling
- ❒ Nutritional Counseling
- ❒ Occupational Therapy
- ❒ Physical Therapy
- ❒ Recreation/Exercise Therapy
- ❒ Social Skills Training
- ❒ Speech Therapy
- ❒ None
- ❒ Other: ____

41. **How many hours per week is your family member with ASD engaged in each of the following activities?**

	0 hr	1 hr	2 hrs	3 hrs	4 hrs	5 hrs	10 hrs	15 hrs	20 hrs	25 hrs	30 hrs	35 hrs	40 hrs
College/Post-Secondary School	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒
Adult Day Habilitation	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒
Employed	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒
Social Activities with Friends	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒
Vocational Training	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒
Volunteer Activities	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒	❒

Health Care/Medical Services

42. **What medications have been prescribed to treat your family member with ASD?** *Select all that apply. If none, select "None."*

- ❒ Abilify
- ❒ Adderall
- ❒ Clonidine
- ❒ Concerta
- ❒ Focalin
- ❒ Prozac
- ❒ Risperdal
- ❒ Ritalin/Metadate
- ❒ Seroquel
- ❒ Zoloft
- ❒ None
- ❒ Other:____

43. **What alternative medical treatments have you used for your family member with ASD** *Select all that apply. If none, select "None."*

- ❒ Auditory Integration
- ❒ Biomedical Intervention
- ❒ Chelation
- ❒ Defeat Autism Now (DAN)
- ❒ Dietary Changes
- ❒ Dietary Supplements
- ❒ Enzymes
- ❒ Gluten Free/Casein Free Diet
- ❒ Homeopathic
- ❒ Hyperbaric
- ❒ Medication
- ❒ Secretion
- ❒ Sensory Integration

- ❒ Vitamin Supplements
- ❒ Yeast
- ❒ None
- ❒ Other:____

44. What other conditions have been diagnosed for your family member with ASD? *If none, select "None."*

- ❒ ADD/ADHD
- ❒ Allergies
- ❒ Anxiety/Phobias/Panic Attacks
- ❒ Apraxia/Dyspraxia/Language Delay/Speech Delay
- ❒ Asthma
- ❒ Bipolar Disorder/Personality Disorder
- ❒ Blind/Visual Impairments
- ❒ Central Auditory Processing Disorder
- ❒ Depression
- ❒ Developmental Delays
- ❒ Diabetes
- ❒ Down Syndrome
- ❒ Eczema
- ❒ Gastrointestinal Disorders
- ❒ Hearing Loss/Deafness
- ❒ Hypertension
- ❒ Intellectual Disability
- ❒ Obsessive-Compulsive Disorder
- ❒ Oppositional Defiant Disorder
- ❒ Psychosis
- ❒ Seizures
- ❒ Sensory Processing Disorder
- ❒ Tourette's Tics
- ❒ None
- ❒ Other:____

45. Has your family member with ASD received care from the following?

- ❒ Psychologist
- ❒ Psychiatrist
- ❒ Don't Know

46. What type of health insurance do you have for your family member with ASD? *Select all that apply. If you do not have health insurance for your family member with ASD, select "none."*

- ❒ ALL Kids
- ❒ Employer-Provided Insurance Plan
- ❒ Medicaid
- ❒ None
- ❒ Other:____

47. Does your health insurance cover services needed for your family member with ASD?

- ❐ No Services are Covered
- ❐ Some Services are Covered
- ❐ All Services are Covered
- ❐ Don't Know/Unsure
- ❐ Not Applicable

48. Would you like to provide additional comments about services you have received for your family member diagnosed with ASD?

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<u>Return this questionnaire to:</u>

Anna.McConnell@mh.alabama.gov

OR

Alabama Interagency Autism Coordinating Council (AIACC)
Attn: Anna McConnell
11 West Oxmoor Tower
Suite 325
Birmingham, AL 35209

THANK YOU!