

Interagency Work Group on Autism Family Survey Results

Ohio's Interagency Work Group on Autism (IWGA) was created in state law to improve the coordination of Ohio's efforts to address the needs of individuals with autism spectrum disorders and their families.

Pursuing Quality Lives (PQL) outlines the strategic priorities of the IWGA, and is based on the work of Quality Lives, Ohio's original autism recommendations.

In July 2019, OCALI's Office of Policy, on behalf of the IWGA, issued a survey to gain insight into family experiences around the time of diagnosis. **Over 280 families responded.** The results of this survey will further guide the IWGA's work in developing and disseminating resources for families.

Demographics

- Sex:
 - 80% of respondents had a male child
 - 20% female
- Age:
 - 0-5: 25%
 - 6-12: 35%
 - 13+: 40%
- Geography:
 - Urban: 20%
 - Suburban: 50%
 - Rural: 30%
- Ethnicity:
 - White: 90%
 - Black: 5%
 - Hispanic/Latino: 3%
 - Asian/Pacific Islander: 2%
- Family Income
 - \$80k+: 45%
 - \$40k-\$80K: 35%
 - Less than \$40k: 20%

Strengths

- Over 55% of respondents said their child was diagnosed by the age of three
- 80% of respondents were already connected with services/resources or got connected at the time of diagnosis
- 65% receive/received Early Intervention
- Over 90% receive/received services through school
- Almost 50% of families indicated services started within 3 months
- **Families reported the thing that helped them most...other families.**

Opportunities

- More needs to be learned about the experiences of racially and ethnically diverse families, single parents, and families living at or below the poverty line.
- Screening and evaluation should be early and often. Almost all families were initially told their child did not have autism or to "wait and see" – they were not referred for additional screening, evaluation, or services.
- Families should be given tools, information and resources if/when they have to wait on services or supports.

Resources for Families

[ASD Strategies in Action](#): Online video-based series that provides families with practical information, real-life examples, and skills to care for and support loved ones with autism spectrum disorder from early childhood through young adulthood.

[The Arc of Ohio](#): Statewide association made up of people with intellectual and developmental disabilities, their families, friends, interested citizens and professionals in the disability field.

[Autism Society of Ohio](#): Affiliate of the Autism Society of America. Their website provides links to local Autism Societies.

[OCALI Family Center](#): Equips and empowers families with knowledge, information, and resources to support the whole family.

[Ohio Coalition for the Education of Children with Disabilities](#): Statewide nonprofit organization that serves families of infants, toddlers, children and youth with disabilities in Ohio through the efforts of over 40 parent and professional disability organizations and over 70 individual members. Serves as the Parent Training and Information Center (PTI) for the state of Ohio

[Ohio Department of Developmental Disabilities Supporting Families](#): Tools and resources that support families.

Learn the Signs. Act Early.

Centers for Disease Control & Prevention (CDC)

[CDC's Milestone Tracker App](#)

Track your child's milestones with CDC's free *Milestone Tracker* app. Interactive checklists with photos and video examples of developmental milestones help you know what to look for in your child.

[Milestone Checklists](#)

Complete a milestone checklist for your child's age to track and celebrate the milestones that he or she is reaching.

[Milestones in Action](#)

See photo and video examples of important developmental milestones that children should reach from 2 months to 5 years of age.

Read the tips sheets [How to Help Your Child](#) and [How to Talk with the Doctor](#) for steps you can take to help you act on developmental concerns.

Get [more information and tips](#) on what to do if you have a concern about your child's development.