



Utah health status update

Key findings

- Fewer than half (40.8%) of 4-year-olds diagnosed with autism had a standard autism screening test in their records.
- One-third (32.9%) of children who screened "at-risk" for autism were not referred for an autism assessment **or** early intervention.
- Children who were screened for autism were diagnosed **3 months** sooner than those who were not screened.
- Children who were screened "at-risk" for autism and referred for an assessment were diagnosed with autism **8 months** sooner than those who were not referred.
- When children screen "at-risk" for autism, they should be referred for an autism assessment **and** early intervention without delay.

Screening and diagnostic delays for autism spectrum disorder in Utah

Autism spectrum disorder (autism) is a developmental disability that can cause social, communication, and behavioral challenges. Screening and early identification may help to determine the best interventions for that child.

The American Academy of Pediatrics recommends that all children be screened for autism at 18 and 24 months of age, with their development monitored regularly. If a child is identified as "at-risk" for autism, they should be referred for an assessment and early intervention. An assessment can help families access early interventions that can help their child develop skills as they grow.

Screening for autism can be performed during well-child visits to identify signs of autism. The autism screening tools most used in Utah are the Modified Checklist for Autism in Toddlers, Revised/Follow-Up (M-CHAT-R/F), and the Parent's Observations of Social Interactions (POSI). The M-CHAT-R/F and POSI ask the parents a series of questions designed to assess the risk for autism in toddlers. Not all children who score "at-risk" will be diagnosed with autism.

Call to action

In Utah, we are below the national average for identifying children with autism. The national average for early identification of 4-year-olds is 2.9%. However, in Utah, only 1.8% of 4-year-olds are identified with autism.¹ While Utah has made some progress in early diagnosis, families and children still miss critical periods for early intervention services.

The Utah Registry of Autism and Developmental Disabilities (URADD) estimates the number of individuals with autism in Utah. Two of URADD's goals are to increase access to autism screening and to improve early identification of autism.





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As a result, in 2024, URADD looked at whether screening tools lead to earlier identification of children with autism and gathered information on children born between 2012 and 2018 from 3 northern Utah counties.

The data was reviewed to answer these questions:

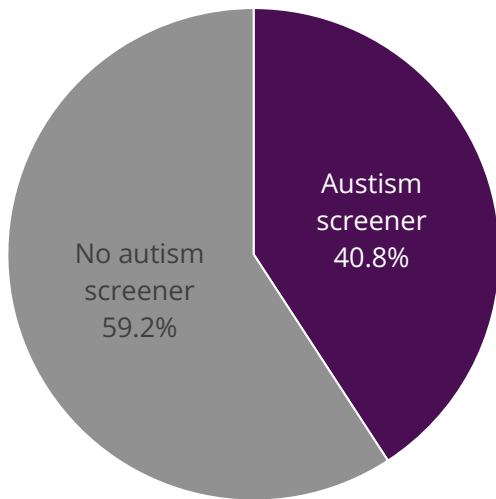
1. Are children with autism screened correctly?
2. Does autism screening lower the age at which children are diagnosed?
3. Are children who score "at-risk" for autism referred for an assessment?

Screening for autism and referrals

Among the 4-year-old children with autism, fewer than half (40.8%) had an M-CHAT R/F or POSI in their records (Figure 1). Alarming, nearly half (41.4%) of children "at-risk" for autism were **not** referred for an assessment by their healthcare provider. Of those, one-third (32.9%) did not receive a referral (Figure 2).

Figure 1. Children with autism who had an autism screening in their records

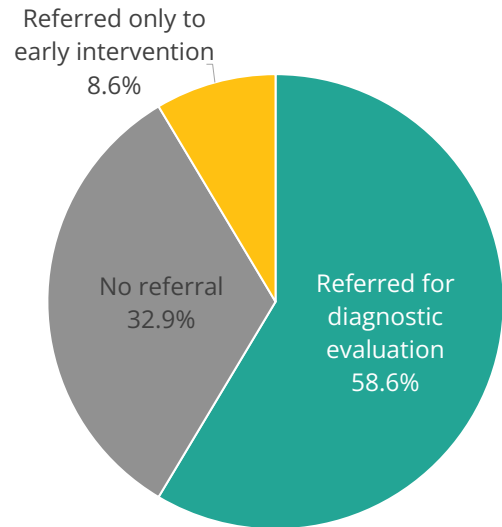
Among the 4-year-old children later diagnosed with autism, fewer than half (40.8%) had an autism screening in their records.



Source: 2024 Utah Registry of Autism and Developmental Disabilities (URADD) study

Figure 2. Missed referrals for children who screened "at-risk" for autism

One-third (32.9%) of children who screened "at-risk" for autism were not referred for any services. An additional 8.6% were referred only to early intervention.



Source: 2024 Utah Registry of Autism and Developmental Disabilities (URADD) study

Does screening for autism make a difference?

The average age at diagnosis for those who were not screened for autism was 39.9 months. In contrast, children who were screened for autism, regardless of the outcome or referral status, were diagnosed with autism **3 months earlier** (36.6 months).

Children identified as "at-risk" for autism but **not** referred for assessment had the poorest outcomes, with an average diagnosis age of 40 months.

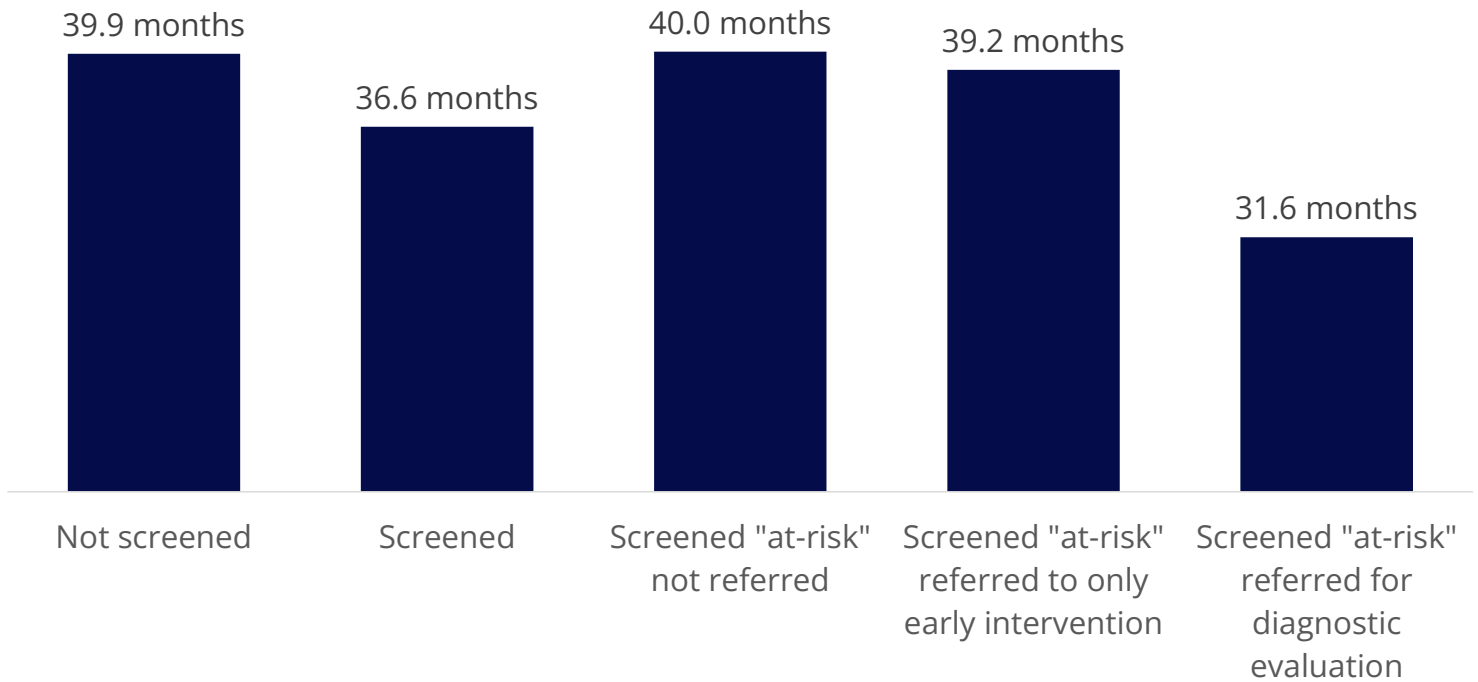
Children who scored "at-risk" for autism and **were** referred for an assessment had the best outcomes and were diagnosed with autism **8 months earlier** (31.6 months, Figure 3).



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Figure 3. Average age of autism diagnosis (months)

Children who scored “at-risk” for autism and were referred for an assessment were diagnosed 8 months earlier than those who scored “at-risk” but were not referred for an assessment.



Source: 2024 Utah Registry of Autism and Developmental Disabilities (URADD) study

Missed referrals

While most children who screened "at-risk" for autism were referred for an assessment by their provider, a small percentage (8.6%) were only referred to early intervention services without any assessment referral. This missed referral led to a diagnostic delay of more than 7 months.

Local resources and support

Utah has made progress in the early identification of autism, however, there is still more to do. Families can talk to their pediatrician about autism screening. If families do not have a pediatrician, Help Me Grow Utah offers free autism screenings and referrals. Additionally, families concerned about autism can find a list of autism assessment providers on the [Children with Special Health Care Needs website](#).

Screening

Help Me Grow Utah
Phone: (801) 691-5322
Website: helpmegrowutah.org

Assessment

A list of autism assessment providers can be found at <https://familyhealth.utah.gov/cshcn/asd/>.



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Early intervention

Baby Watch Early Intervention

Phone: (801) 273-2800

Website: familyhealth.utah.gov/oec

More help

Utah Parent Center

Phone: 1-800-468-1160

Website: utahparentcenter.org

Integrated Services Program

Phone: (801) 273-2800

Website: familyhealth.utah.gov/cshcn

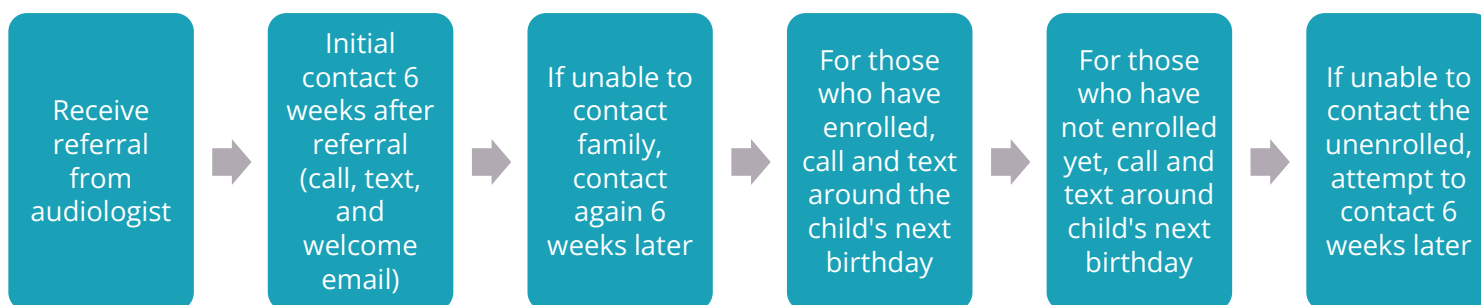
1. Shaw KA, Williams S, Patrick ME, et al. Prevalence and Early Identification of Autism Spectrum Disorder Among Children Aged 4 and 8 Years — Autism and Developmental Disabilities Monitoring Network, 16 Sites, United States, 2022. *MMWR Surveill Summ* 2025;74(No. SS-2):1–22.

Parent-to-parent support for children who are deaf or hard of hearing

Hearing loss is one of the most common birth conditions and affects approximately 2 per 1,000 births.¹ Parents are faced with many decisions and feel overwhelmed when they receive their baby's diagnosis.

The Utah Department of Health and Human Services Early Hearing Detection and Intervention (EHDI) program has contracted with 2 parent consultants (PC) through the Utah Parent Center to help support parents throughout their child's diagnosis. After a baby is diagnosed with permanent hearing loss, the audiologist can refer the family to PC services. Between July 1, 2023 and June 30, 2024, 116 babies were diagnosed with permanent hearing loss. Of these babies, 89 (76.7%) were referred to the PCs. The PCs attempted to contact 87 (97.8%) of the referred families. The PCs primarily used phone calls when they made a first contact effort, but they sometimes used text. The PCs made 83 initial phone calls: 44 families responded (53%), and 39 (47%) did not respond. Of those who did not respond, 30 received voicemails. The PCs also sent a welcome email to every referral who had an email address. Of the 87 families the PCs reached out to, 82 were contacted by email.²

Parent consultant process for contacting referrals for parent-to-parent support program



Source: Utah Department of Health and Human Services, Early Hearing Detection and Intervention (EHDI) Program

The PCs do more than provide one-on-one support to families. They also provide chances for families to connect with other families who have children who are deaf or hard of hearing (D/HH) and the professionals who work with them. Every other month the PCs hold 'WebinEARS' where guest speakers share their expertise on topics related to hearing loss. Parents also get a newsletter every other month with helpful tips, resources, and a spotlight on a Utah family who has a child that is D/HH. The PCs lead a Parent Volunteer Network that is composed of parents and D/HH professionals. Their network has statewide representation that plans and hosts activities for D/HH families. The PCs have been able to provide quality assistance for families of D/HH children by hosting events and providing resources, information, and individualized support. For more information on the Utah EHDI parent-to-parent support program at the Utah Parent Center, visit <https://utahparentcenter.org/projects/early-hearing-detection-and-intervention/> or earlyhearing.utah.gov.

1. Utah Department of Health Early Hearing Detection and Intervention. Accessed 03/04/2025. <https://familyhealth.utah.gov/cshcn/ehdi/#parents>

2. The Utah Department of Health Early Hearing Detection & Intervention HiTrack Data Management System (Utah Births July 1, 2023 - June 30, 2024)

Child abuse is preventable

Child abuse is a serious public health issue with long-term impacts on the health and well-being of children, families, and communities. It is also costly, with an estimated \$592 billion lifetime economic burden in the United States in 2018.¹

Prevention efforts can reduce these impacts for children, families, and their communities. Prevention starts when you know the factors that increase the risk of child abuse, such as parents facing a high level of stress or isolated families that lack social support.

Effective child abuse prevention programs and services work with families before abuse ever happens. These programs and services work with individuals and families to build protective factors. Strong protective factors give them the skills to face problems, which reduces the risk of child abuse and neglect. These protective factors include:

1. Social connections: Support from friends, family, and the community. Families are stronger when they have people they trust to provide emotional support.
2. Concrete needs: Stress is reduced and parents have more time to focus on their children's well-being when they have access to goods and services that meet the families basic needs. When parents understand where they can find resources, families are stronger.
3. Knowledge of parenting and child development: Kids don't come with instructions. Parents need to know what is normal for their child's age and development. When parents learn positive parenting skills it helps kids feel safe and grow up confident.
4. Resilience: Families need the knowledge and skills to recover and handle tough situations.
5. Social and emotional competence of children: Teach children social and emotional skills. When a family can help their child manage their emotions and respond appropriately in social situations, the child can form positive relationships and excel in life.

When these protective factors are strengthened, parents can focus on positive relationships with their children and make sure they are safe and emotionally healthy.

We can all play a role in preventing child abuse. Here are some ideas of what you can do to help keep children safe and prevent child abuse.

1. Learn about the prevention services and resources available in your community. Some resources can be found at strongfamilies.utah.gov.
2. Raise awareness about child abuse prevention strategies.
3. Offer support to a family when they are in need. Examples include: Offer to watch their kids or bring them dinner to give them a break. Let them know you are there if they want to talk or need help finding resources.
4. Become a person other people trust and will ask for help. People need to feel safe to seek support and not feel judged.
5. Get involved with your community and advocate for families to have access to support, services, and resources they need.
6. Encourage others who are struggling to seek assistance.

The prevention team with the Utah Department of Health and Human Services Division of Child and Family Services (DCFS) provides support, through contracts, to programs and services that work to strengthen families to reduce the risks of child abuse. Find programs that help strengthen families and prevent child abuse at strongfamilies.utah.gov.

When a community works together, we can prevent child abuse.

In 2024, the child abuse prevention programs supported by the DCFS prevention team have served the following number of families.

Federal fiscal year 2024 Number served through DCFS contracted child abuse prevention program	
Number of children served	49,280
Number of children served with a known disability	1,856
Number of adults served	48,333
Number of adults served with a known disability	1,042
Number of families served	40,179
Number of public awareness and outreach activities completed	1,169
Estimated number of people reached through public awareness and outreach activities	582,842

1. Klika JB, Rosenzweig J, Merrick M. Economic burden of known cases of child maltreatment from 2018 in each state. *Child and adolescent social work journal*. 2020 Jun;37(3):227-34. Retrieved March 10, 2025. <https://www.cdc.gov/child-abuse-neglect/about/index.html>