

INFORMATION FOR
PARENTS OF INFANTS
AND TODDLERS ON
THE EARLY SIGNS OF
AUTISM SPECTRUM
DISORDERS



Results from the High Risk Baby Siblings Research Consortium

November 2013

Younger siblings of children with an autism spectrum disorder (ASD) are at increased risk for developing ASD and other developmental challenges.



#### In this statement, we address three questions asked most often by parents:

- If I have a child with ASD, how likely is it that my next child will have ASD or related developmental challenges?
- 2. What are the earliest signs of ASD and when do they appear?
- 3. What can parents do if they are concerned about their child's development?

More information on specific early symptoms of ASD can be found at autismspeaks.org/signs

Over the past decade, researchers have been studying these 'baby siblings', to learn more about their early development, and identify the first signs and symptoms of ASD. This is deepening our understanding of the developmental course and causes of ASD.

The goal of the **Baby Sibling Research Consortium** is to improve the lives of individuals affected with ASD by making discoveries that will help researchers develop new ways to treat or even prevent some debilitating symptoms by intervening at an early age. The pace of this research has grown exponentially over the past decade, supported by the formation of the consortium, which has enabled researchers from around the world to meet and share their ideas, methods, and data. Consortium members carry out their own studies focusing primarily on younger siblings of children with ASD or other high risk infants. Each member is supported by public, private or foundation funding. The group collaborates on studies and publications, pooling collective data and knowledge to enhance our ability to contribute to this important area of research and provide help to families.

## How likely is it that my next child will have ASD or related developmental challenges?

Studies show that if you have a child diagnosed with an autism spectrum disorder, the risk of the next child also being diagnosed with an ASD is between 10 and 20 percent.

The risk for ASD is higher for boys than girls, and higher for baby siblings who have more than one older sibling with ASD.

By three years of age, about one in five baby siblings who does not meet criteria for ASD will show milder delays in social development, language, and/or cognitive skills.

## What are the earliest signs of ASD and when do these signs appear?

Early signs for ASD include:

Inadequate social responsiveness and social initiations. This includes limited and inconsistent eye contact, lack of shared emotion, imitation, social smiling, and no response to calling their to name.

Difficulties in the use of communication and communicative gestures. This includes difficulty with joint attention behaviors, such as problems shifting eye gaze between a social partner and an object or event of interest. It can also be a lack of pointing to object of interest, not following another person's pointing gesture or not holding up objects to show to others.

Unusual ways of looking at or playing with objects, intense and unusual interest in certain objects or parts of objects, or unusual sensory interests.

Loss of speech, babbling or social skills at any age.

Distinct signs of ASD may begin to appear in the first year of life. These signs become more pronounced by 18 to 24 months.



Most affected children can be diagnosed reliably with ASD between their 2nd and 3rd birthdays. While parents may notice signs and symptoms before age 2, in most cases, a formal diagnosis cannot be made before then. However, intervention can take place before that formal diagnosis.

As babies, younger siblings who will go on to be diagnosed with ASD often show several of these risk signs. No single behavior is consistently the first to emerge, and no single behavior on its own is highly predictive or diagnostic of ASD. These behaviors may be seen in infants who do not go on to meet criteria for ASD.

Children with ASD often display delays in language, motor, and cognitive skills. However, these delays can also be observed in children with other developmental difficulties and therefore are not specific to ASD.

ASD is related to early changes in brain development and consortium researchers are investigating when and how these changes can be observed and documented, using a variety of brain imaging techniques and experimental methods including eye-tracking and behavioral studies.

# What can parents do if they are concerned about their child's development?

Information for concerned parents can be found at *autismspeaks.org/ early-access-care*. Specific tools and resources for those with a diagnosis can be found on the Autism Speaks Family Services page: *autismspeaks.org/family-services*.

Do not wait. When parents have concerns about their child's development, no matter what the baby's age, they should communicate their concerns to their health care provider and local public school system.

Access to specialized diagnostic services may take time, but in the interim parents can learn about the early signs of ASD (*autismspeaks.org/signs*), and may ask their community physician or other health care provider for referral to their local birth-to-three (or infant development) programs. More information can be found at *autismspeaks.org/early-access-care* and *cdc.gov/ncbddd/actearly*.

Infants showing any of the risk signs described above should be closely monitored by a professional, such as the pediatrician, educator or other developmental expert, over the first few years of life. Such monitoring should continue whether or not intervention services or other supports are being received.

All children with early signs of a developmental delay, no matter how intense or subtle, should have the opportunity to receive the benefits of intervention, resources and services as early as possible. Early intervention for ASD symptoms has been shown to produce significant and long lasting improvements in behavior and improve the quality of life for most children.

All parents, regardless of their child's diagnosis, can support their infant's early social, communication, play and language development at home.

Daily activities such as play, mealtimes and bath time provide great opportunities for engaging in face-to-face interactions. These interactions will encourage the child's communication, speech and social engagement.

When playing with toys, follow the interest of the child, and help extend the child's play routines in a variety of ways with the goal of encouraging imitation, turn-taking, pretend play, social interaction and language.

Information on services for families, provided in Spanish and English, can be found on the Autism Speaks website: autismspeaks.org/early-access-care

None of these advances in research would be possible without the dedication of the families enrolled in these studies.





#### Summary

Infants with an older sibling with ASD are at higher risk for developing ASD than are infants in the general population. However, most infant siblings of children with autism (over 80%) will not develop ASD.

Making a diagnosis of ASD in toddlers is challenging and requires expert assessment of the child's social, communication, play, cognitive, and adaptive skills.

There are no consistent ASD diagnostic markers that appear in the first year of life. Instead, the research suggests that we should look for 'risk signs,' such as less typical social, communication, and play behaviors, or the presence of developmental delays. It may also include loss of language. These should be monitored over time.

Parents know their children best, and if they observe something that concerns them, they should seek professional help.

Infants showing significant risk signs should receive appropriate specialist evaluations as soon as possible to determine the need for intervention. Parents need not wait for a confirmed diagnosis to begin accessing support.

Parents can play an important role in supporting and encouraging their children's social, communicative, language, and play development though a variety of activities during play and daily routines.

#### Additional resources

For references to these findings, and for readers interested in learning more about the work of the **Baby Sibling Research Consortium** and its members please see:

autismspeaks.org/science/research-initiatives/high-risk-baby-sibs.