

Supporting Families with a Child with ASD Adjustment to a New Sibling

A Guide for Professionals



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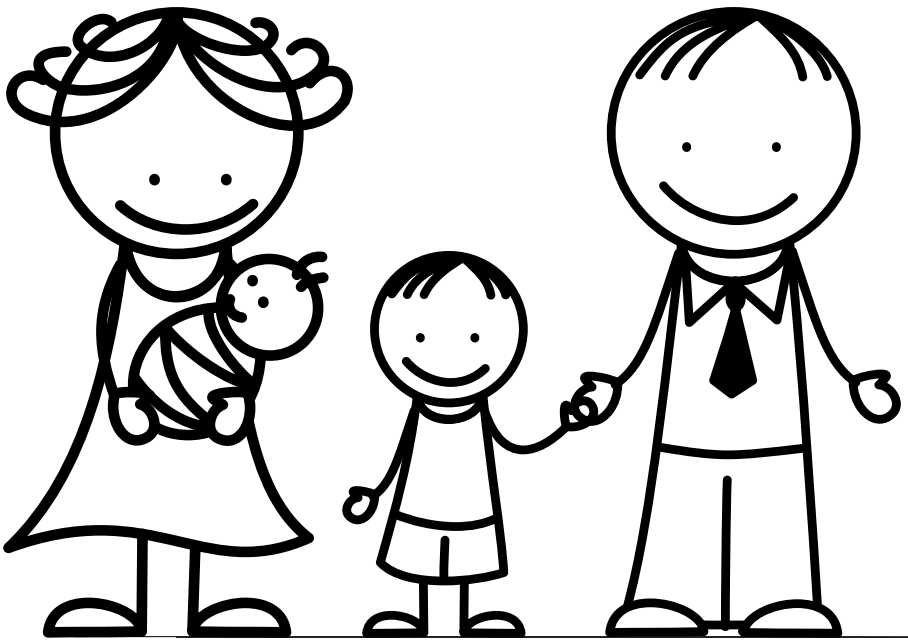
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Supporting Families with a Child with ASD Adjustment to a New Sibling

Preparing for, and managing to welcome a new baby into a home with older siblings can be an exciting and happy experience, but it can also be a difficult time of adjustment for any family. When older siblings have autism spectrum disorder (ASD), they may need additional consideration, support and attention to assist them to cope with this dramatic change in their life.

Why might it be difficult for the child with ASD?

Many siblings struggle with mixed feelings when they hear their mother is going to have another baby – excited about having someone new at home, scared that parents will have less time for them, and uncertain about how life at home will change. When a child has ASD, these mixed feelings may be more intense depending on his/her level of functioning and unique traits associated with ASD.

Communication:



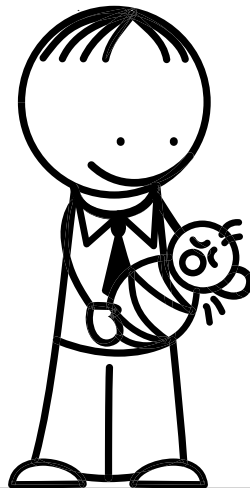
Many children with ASD struggle with being able to communicate verbally with others, so it may be difficult for them to ask questions they may be wondering about, or talk about emotions they may be feeling. Many have challenges understanding what is said to them so they may not understand information told to them about their mother's pregnancy, the birth process, what having a new baby will be like and safety rules that need to be in place once the baby is home.

Perspective Taking:

Children with ASD also have challenges with Theory of Mind (ToM) or the ability to anticipate the thoughts and feelings of others. They may not understand that others have thoughts and feelings different from their own, and in those with ASD with an intellectual disability, they may interact with others as if they were objects instead of people with feelings. When interacting with infants, there could be concern that they may treat them as 'dolls' or 'play things' with lack of insight into the impact of their behaviour on the infant.

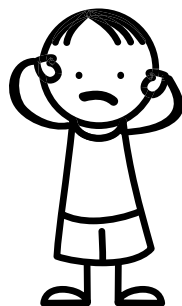
Managing Change:

Children with ASD often have difficulty with managing changes – big and small. Having a new baby in the house leads to many changes – availability of mom and dad/other family members, changes in rules (need to be quiet when baby is sleeping), changes in sleeping routines (child may need to move to his/her own bed, a different bedroom), and changes in caregivers while mom is in hospital and then when home when busy with the baby. Reactions to these changes may include more extreme behaviours, including increased tantrums, aggression, rigidity, withdrawal and/or sleeping/eating problems.



Sensory Considerations:

Children with ASD may also experience sensory input differently than others. They may be overly (hyper) sensitive to sounds, smells and touch, or they may seek out that kind of sensory input because of being under (hypo) sensitive. The addition of a new baby often leads to increased noise in the house (crying) and potentially increased odours from dirty diapers. Babies may also reach out and grab hair or feel very heavy when placed in a sibling with ASD's arms or lap, which may lead to an intense, perhaps aggressive, response. Children with ASD that are under sensitive to sensory input may not realize when they are being rough when they are trying to touch, hold or rock the baby.



Why might adding a new baby to the family be more difficult for parents with a child with ASD?

Parents who have been coping with a child with ASD, are already likely under a great deal of stress. Depending on the age of their child and the timing of the diagnosis, they may still be dealing with the shock of the diagnosis and be struggling to understand what impact it will have on their child and their family. They may also still be in the phase of trying to sort out the myriad of services, financial forms and multiple appointments that are common following a diagnosis. When families are experiencing that level of stress, adding a

pregnancy and the worry of an upcoming birth, can lead parents into even greater turmoil. The mother may feel unwell during her pregnancy and then be faced with the physical demands of a young child with ASD who may not sleep well at night, demonstrate extreme behaviours and tantrums and/or require hours of additional care during the day and night.

Parents may also be very worried about the recurrence of ASD in the new baby, given that studies show ASD is a genetic neurological condition. Parents may be aware that siblings of a child with ASD are at a higher risk of having ASD and be pre-occupied with concern regarding their infant's development.

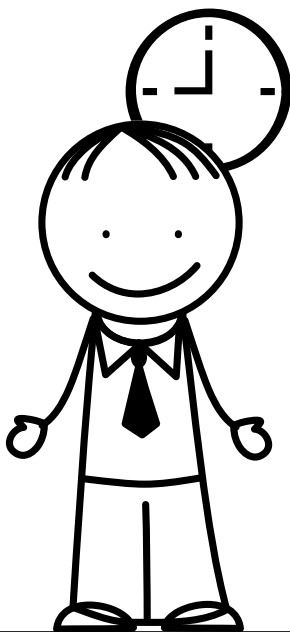
Many families, once they receive the diagnosis for their child, are not informed about the characteristics of ASD or what specific areas of their child's development may be affected. Parents may think that their child understands everything that is said to him/her and that he/she understands

concepts that are much too abstract for that child. They may also believe that some of the ways the characteristics of ASD are demonstrated, such as difficulty coping with change and difficulties self-regulating, are willful challenging behaviours that are within the child's control to stop. They may not have a repertoire of strategies that they can effectively use with their child to manage behavioural concerns.


Lastly, families with children with ASD may be lacking in extended family support. Many families cope with feelings of shame, helplessness and anger after their child receives an ASD diagnosis. For some, this change leads to reduced support and contact with close friends and family – the very people that most new parents rely on for help after the birth of each child. In addition, if family members are available to assist after the baby's birth, they may not have adequate or correct information regarding the nature of ASD and the possible issues that may emerge once a new baby is added into the family.

Start providing support early in the mother's pregnancy.

The family will need to start planning and putting in place some strategies well before the baby is born. Getting involved early allows you to assist the parents with figuring out time lines for introducing their child with ASD to the idea of a new sibling. Refer the family to the resources in this package “Helping your Child with ASD Adjust to New Siblings: Before the Baby's Birth” and other examples of visuals and social narratives.



Support the family to choose relevant books /videos /pictures that they will use.




Depending on the child with ASD's age and developmental profile, certain materials (see our resource list) would be more easily understood than others. Some children with ASD attend to, and learn more easily from videos, especially if the characters (e.g., Arthur, Dora the Explorer) are familiar to them. Parents may need assistance to obtain or borrow the materials. Walk them through how to create their “picture book” and model how it can be used to promote conversations about families, new babies, relationships, etc.

Assist the family to make arrangements for child care, if appropriate.

Having their child with ASD enrolled in day care (if they are not in full time school) may be beneficial to provide parents with relief as well as a stimulating environment for the child. There may be wait lists and arrangements to organize additional support and resources into these settings, so starting early is very important. The child with ASD should be attending the day care program at least 1 – 2 months prior to baby's birth to minimize difficulties with multiple changes all at once.

Assist the family to make arrangements for informal child care or respite.



Talk with parents about the plan for child care when mom goes to the hospital and when she returns home and needs some relief. If a family member or friend is planning on helping out, make sure the child has multiple opportunities to meet this person and feel comfortable with him/her. If the child will be sleeping away from home, ensure there are several over night visits prior to the baby's birth. Respite services can be arranged by contacting www.respiteservices.com

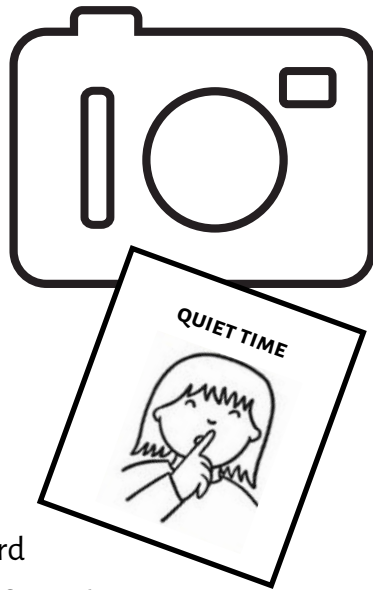
Support the parents in making changes to their routine before the baby is born.

Most people tend to leave things to the last minute and your gently prodding might help parents to begin changing sleeping arrangements, teaching toilet training/other self help skill and making other routine changes well in advance of the baby's birth. These new routines should be in place several months before the new baby arrives to reduce the number of changes that will occur once the baby is born.



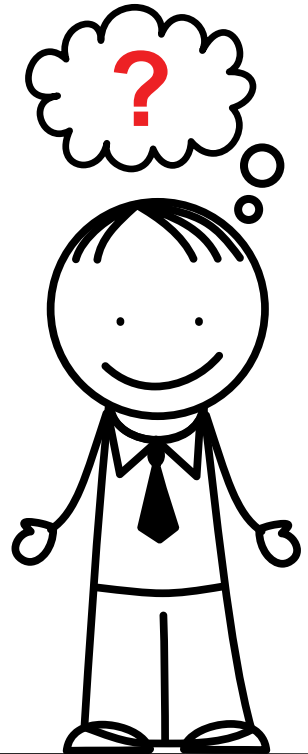
Assist the parents to make any visuals that might be useful.

The child with ASD may benefit from visual schedules and visual rules (see examples in the kit) in order to increase understanding of routines, when desired activities are coming up and new expectations. These visuals can be made with photos, clip art, google images, board maker or any other source of visuals available on the internet.




Have parents tell you their plan for ‘safety’.

Ask parents directly how they are going to manage contact between the child with ASD and the baby, where they will put the baby to sleep, what mom will do when she needs a day time nap, and how they will manage jealousy if it comes up. Be clear that even if a child with ASD has never shown any aggression, it does not mean that they will be gentle with a baby or understand what type of contact is safe. There is potential for a baby to be hurt without any ‘ill- intention’ from a child with ASD.



Be available for questions after the baby is born.



Many parents can not anticipate what difficulties they will encounter as this 'new baby' experience is new for everyone. Families may need referrals to other community services such as Public Health (for new baby visits), breast feeding clinics, recreation programs for the child with ASD, Early Years Centres, parent child drop in centres and many more. If good communication is established between you and the parents, they are more likely to feel comfortable expressing concerns or questions that can be vital in preventing problems and ensuring healthy family relationships amongst everyone.

Use an interpreter to translate the information in this kit to parents if necessary.

If one or more members of a family do not speak English, enlist the assistance of an interpreter to translate the information on the parent information sheets. It is important to ensure that all family members that are caring for the child with ASD and the baby understand the material and have the opportunity to discuss it in their native language, with someone knowledgeable.

Provide the family with information about the Autism Treatment Network's Sibling Study.

The Autism Treatment Network (ATN) is a joint research project between Bloorview Kids Rehab, Surrey Place Centre, and The Hospital for Sick Children (SickKids). The Sibling Study recruits families that have one child with ASD, and then provides assessments of new siblings for signs of ASD. These regular assessments may help families who are anxious that new siblings may be diagnosed with ASD in the future. Please note that research studies can change over time. For more information on the sibling study, please contact the Autism Research Unit at the Hospital for Sick Children 416-813-8748.

