Talking Matters

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Talking with your child about diagnosis

When a child is diagnosed with disability such as autism or Asperger's syndrome one of the first questions many parents ask is "Who should I tell?" Many ask whether they should tell, teachers, friends or family members and many wonder what to say to siblings. Often a big question is "what and when do I tell my child about their diagnosis?"



When to share a diagnosis something parents need to decide for themselves. Every child is different and no-one knows that child better than their parents. Some parents choose to tell their child when they are young, while others may choose to wait until their child is older. Some tell their child at the time of the diagnosis and others wait until the child begins to ask questions. Parents are the best judge of their child's social and emotional maturity and when their child is ready to find out about their diagnosis.

Some points to consider:

- most children with special needs are aware that they are different. Finding out there is a name for their "difference" and that there are other children like them can come as a relief
- hearing about their diagnosis in a caring way is better than overhearing things from others or finding out by accident, possibly in a less supportive way
- having a planned conversation means that you can make sure your child has the right kind of information and a chance to clarify any questions or concerns that they may have

When planning to talk with your child think about:

- choosing a person your child feels comfortable talking with. This may be a parent or another relative or even someone else such as a therapist or psychologist that your child trusts.
- trying to have the conversation at a time and place when both you and your child are comfortable, relaxed and not likely to be interrupted. Your child may need time to process the information and ask questions.
- talking to siblings separately. They will need a chance to ask honest questions but this may not be helpful for the child with the diagnosis to hear.

Make sure your child knows:

- their diagnosis is not an illness, they will not die from it and others will not
 "catch it" from them
- not all people with the same diagnosis are the same. They may know another child with the same diagnosis and may be concerned about this.
- that they can come to you to talk some more whenever they have concerns or questions



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A good way to start the conversation is to talk about individual differences:

- begin by looking at the strengths and weaknesses of different family members, trying to keep this balanced, with every family member having both good characteristics and challenges.
- next tell your child that there are others who share their particular pattern of strengths and weaknesses and that there is a name for this pattern.
- you could then talk in more detail about your child's diagnosis
- remember to keep information to a level suitable for your child's understanding, their personal situation and characteristics
- keep positive, remember that your child has plenty of strengths and talents
- present negatives from your child's perspective "you know how it is hard for you to...."
- make sure your child knows that you will do your best to help them with their challenges
- make sure your child knows that everyone has challenges and times when they need support
- you may like to share some books with your child about their diagnosis. There are a number of good ones available for a range of ages.
- your child may like to know about famous people with the same diagnosis who have done great things. There is information about this in books and on websites
- your child may like to meet other children with the same diagnosis and this could be arranged through a support group
- if you are concerned about how your child has reacted to their diagnosis do seek support through a therapist or support organisation

Who else do I tell? Parents often wonder whether they should tell family, friends, teachers and other people in their child's life.

- It is not necessary to tell everyone about your child's diagnosis. It is useful to tell people when there is a benefit to your child such as extra support or understanding.
- It is usually very helpful to tell people involved in your child's education.
- Your child's opinion should be considered and relation to telling peers and classmates
- Others such as coaches, scout leaders, dance teachers and so on can be told if they can be trusted to keep the information confidential and is it to your child's benefit for them to know.
- With friends and family consider the way each person will understand and use the information. You may choose to tell trusted, supportive friends if this will help you, as a parent, feel more supported and have an outlet to express your thoughts, emotions and concerns.
- You may choose to join a support group of parents who understand your situation

Having a diagnosis can lead to better understanding and more appropriate support and so can be of a major benefit to children and families. To find out more about sharing a diagnosis with your child check out these links:

http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis/diagnosis-telling-a-child-about-their-diagnosis.aspx

http://www.iancommunity.org/cs/articles/telling a child about his asd

http://www.ahany.org/ShouldYouExplainTheDiagnosis.htm

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