



Informing, Empowering and Changing Lives Training Conference 2014

Supporting parents of children with Down's syndrome

Compiled by Claire Fisher, with contributions by the parents of WDDSSG

"I think there's something to be said about how hard it can be, being a parent to a child with Down's syndrome. My daughter herself brings challenges, but those aren't really the hardest thing for me - I love her to the moon and back, and will do what I can to parent her well, just as much as I will my other children. But what also comes along is a stream of challenges in the world outside the family - we have to inspire, educate, even fight for basic understanding and appropriate language. Many of us have to deal with a number of serious health concerns, medications, glasses that won't stay on, even clothes that won't fit, behaviour issues and sleep issues to different extents. We all have to deal with the challenges of multiple appointments, forms and so on. Many of us get involved with supporting others in one way or another (whether in person or via social media, etc.) and there is emotional strain involved in that. There are extra layers and issues to consider all the time in even the most routine of daily activities. In general, parents have an amazing way of coping with all of this and much more I haven't got time or space to list - but I find it is rarely appreciated by professionals, often hearing stories of people not being treated well, not being listened to, or treated as if they don't know best, in schools, hospitals and so on."

The importance of person-centred language

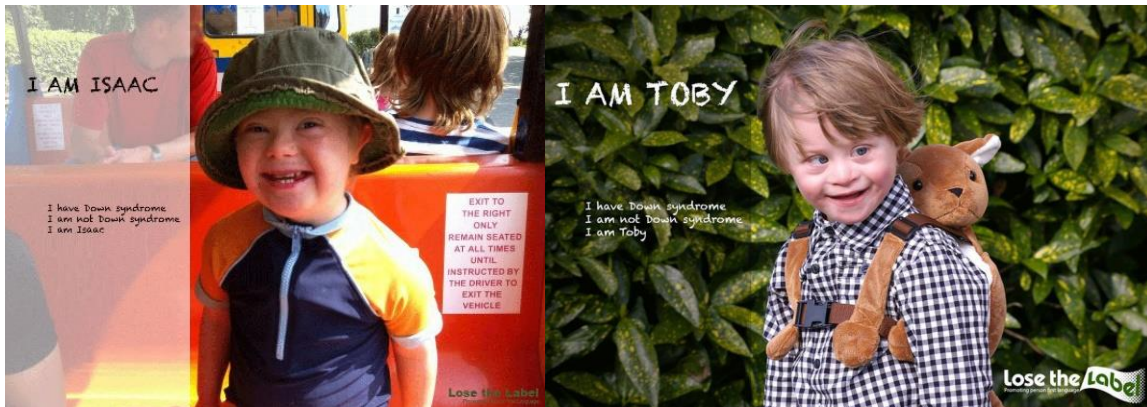
For parents it is important that their child is defined by who they are and not the extra chromosome they have. It is best to say "people with Down's syndrome" or a "child with Down's syndrome". Please do not use the words "Down's syndrome children" for example. Some parents in WDDSSG have even had their child referred to as "a Down's syndrome" or simply "a Down's". Although most of the time this is not intended to cause offence, it gives the impression that is the Down's syndrome that is first, and the child second.

There are various words which are occasionally used to describe children with Down's syndrome which may upset parents and are generally best avoided. The following words are often used in a derogatory manner by misinformed people: retard, Mongol, spastic, and window lickers among others. There are also some phrases that our parents don't find encouraging to hear: "I could never handle what you handle," "it's the special parents who get the special kids", "everything happens for a reason." There are days when we can't handle what we are faced with and we have to find some sort of coping mechanism. All children are special. Children with Down's syndrome



are just as special, no more, no less, than any other child. It may or may not be true that everything happens for a reason but that doesn't help us cope with what we are faced with.

The Lose The Label campaign has recently featured two of our members in their advertising to try and promote person centred language. More information on the lose the label campaign can be found at www.facebook.com/losethelabel



The importance of building a relationship with parents

Parents of children with Down's syndrome will for the most part know their child intimately. Many will have read books on various aspects of Down's syndrome, and others will have accessed formal training to learn more about Down's syndrome and how it may affect their child. When a child starts school many parents like to be involved in their child's education. Parents will have for the most part been very involved in their child's education through the various therapies and also through portage. It is a difficult transition process going from providing the education for your child yourself to the school or nursery providing it. It is helpful for parents to know what their child is learning in class, what the new vocabulary is for the week, what the class topic is so they can support this learning at home. Most children with Down's syndrome will not be able to communicate what they have done at school during the day. Parents naturally want to know what they have been up to and a system should be put in place to make sure they can find out, such as a home-school diary. This can then be used to give parents the reassurance they need that the school are working towards the various goals.



In schools it can be helpful to focus on how well a child with Down's syndrome is doing, but it is also important to be honest. To say "he was fine" every day is not always helpful. Instead try to tell the parents about something the child has achieved during the day, for instance good sitting on the carpet, or trying really hard with their work, or some other achievement. It means so much more to hear something positive about our children. Parents for the most part want to help with their child's development. If there is a behaviour problem with a child, why not consult with the parents on how they handle it? The chances are the child exhibits this behaviour at home and the parents might have strategies in place to deal with it that can be transferred into school. If the parents are struggling with the behaviour it will be important to have consistency between home and school. It may be that parents know information about their child that will help schools or nursery to educate their child better. Parents often have a wealth of knowledge about their child and it will be beneficial to the child if the relationship between school and home are communicative and positive.



It is also beneficial to a child with Down's syndrome if the professionals involved in giving advice either to school or home have a good relationship with the parents. Understanding the needs of the family and the child are key to giving the right and appropriate advice. Parents may struggle with the demands of all the different therapies and the different appointments. If the therapists understand these difficulties they will be able to support the family better.

The importance of enjoying the unique child

Parents of children with Down's syndrome typically want to be able to enjoy their child for who they are and what they have achieved. It is important to remember that every child with Down's syndrome is unique and will have their own strengths, weaknesses and personalities. Parents don't find it especially helpful when people refer to stereotypes, especially as few of our children fit the stereotypes.

Some parents may find it harder to enjoy their child than others. It is important for parents to be able to have some time to themselves, away from the demands of caring for the child and away from the demands of the house. It is amazing how much a break from everything can help a parent to cope with the challenges they deal with on a daily basis. Parents may also need to be encouraged to take some time out from the demands of appointments and therapies to spend some time enjoying their child. This is not always easy due to the demands placed on a parent, but many parents find it refreshing to enjoy the child for who they are.

Schools should celebrate the achievements of the child and not be tempted to be too rigid in comparing to peers. Many of our parents are often upset when it comes to the end of year school report. Many schools grade children as achieving 'not expected, expected or exceeding'. All our children will inevitably get 'not expected' every year, in every report. Whilst this is true when compared to their peers, it does not show the progress they have made during the year, nor does it tell the parents the level the child is working at. When our children get older and read their school reports we want them to be proud of how hard they have worked and not be reminded of how they achieved compared to their peers.



No matter what level of academic achievement a child attains, the child should be celebrated for who they are and not just their level of ability and understanding. Parents of children with Down's syndrome, like all other parents, find it really encouraging when someone praises their child or makes a positive comment about them. It is important to remember to see the individual and not the condition of Down's syndrome.