



Children with Disabilities and Serious Illness: A Sibling's Perspective

There are enormous amounts of research on the positive and negative experiences a parent goes through when living with a child with disabilities. However, have researchers considered the experience of a sibling?

Whether they are older or younger, a sister or brother, from Australia or Iran, siblings of children with disabilities are everywhere. People that interact regularly may never know that they are the proud sibling of a child with additional needs. Proud, because they are just like any other child in the world, and have needs like everyone else in the world. Although this article is around a sibling's perspective of having a sibling with disabilities, it will also be about what parents, families and friends can do to support these siblings through those few days where it can be a difficult journey. Whilst researching this topic, it became evident that "less is known about the effect on other children in these families" (Nixon & Cummings, 1999). However there has been a shift in focus from the parent's lifestyle changes to siblings. There are many hypotheses from around the world around what impact having a child with additional needs can do to a sibling. For example, there are studies claiming that siblings often have responsibilities beyond what it is expected of that age (Cleveland & Miller cited in Nixon & Cummings 1999), having an increased risk of future mental health problems (Hastings, 2003) and feeling left out (Hames & McCaffrey, 2005). Notice the one common thread that links these studies together; it's about the negative experiences and negative impact on the sibling. It's important to not only hear about the adverse impacts children with disabilities can have on a sibling, but to also hear

about what research has found around what a child with disabilities can positively effect families. The predominant positive impression left on a sibling of a child with disabilities is long term behaviours and characteristics. Traits like a high tolerance and openness for all walks of life, compassion, empathy, nurturing and "appreciation of their own health and abilities" (Dyke, Mulroy & Leonard, 2008) are just a few examples.

No matter whether we're talking positive or negative, it is important for siblings to have a committed support network to call on when times get difficult. Families will be able to assist the most as a result of being able to relate and living under the same roof together. It is essential for siblings to understand from an early age that it is okay to feel emotional about their sibling; whether it be frustration (because they are not able to play with them like their other friends), sadness (a grieving process about losing the sibling that he or she had hoped for), or anger (due to the lack of attention that the sibling receives over their brother or sister with special needs). In general, children cope with emotions and stress in two ways; either act out and release their emotions and thoughts on others around them, or isolate themselves from others to suppress their feelings. Neither of these are wrong, but they are not going to assist the child's psychological future. Families and friends need to ensure they are able to actively listen to the child's thoughts, concerns and emotions and reassure them that there is no judgement and that telling people how you're feeling is okay (Hames & McCaffrey, 2005). If this is not possible due to being time poor or maybe the sibling isn't keen on expressing their feelings, there are plenty of resources out there for them.

This could be in the form of books (a great book that is highly recommended is by Hames & McCaffrey, 2005. See back page for a full reference), websites (another highly recommended resources is Sibling Support Project, see resources on page 2), or support groups where they can meet children who are in a similar situation as them. The most important thing for a sibling of a child with disabilities is that they feel valued, they feel comfortable with their sibling and they have plenty of support if needed. Siblings learn so much and experience such an enormous range of environments because of their brother or sister and it is a privilege to grow up beside them.

If you have a child that you think may be struggling with their brother or sister's disability or illness, you have a number of options. Go online and see what is being said around the world. There are many international sites dedicated to parents where there are discussions boards filled with ideas, advice and stories to share. If you want a more national or local support, going to your community center and asking for resources will be very helpful. If that isn't for you, maybe sitting down with your local GP or a counsellor to give some ideas as to what direction you and your family should take. Medical centers have numerous services and access to information that suits your situation. If none of those services suit the family situation you are seeking assistance for, please come into Daffodil kindergarten during business hours and we are happy to sit down with you and your family to help in any way we can. Don't ever feel like you or your children will be left alone. All over the world there are families in exactly the same situation as you and there is help when you need it.



Seeking Assistance and Assessment - The Steps

At Daffodil Kindergarten, we have received a number of calls this year from concerned parents unsure about their child's development and whether they need to be assessed. It is completely understandable that it is a frightening experience to consider the lengthy process of evaluating your child, with a risk you may come out the other side with no answers. Daffodil Kindergarten staff have collaborated to create this article so we can assist as many parents as possible. Researchers have found (As noted in Stone et al. (1990)) children can often have symptoms and common behaviours from as early as 18 months, however it is much more likely to get an accurate diagnosis at approximately 4 years of age. Parents often seek advice after they had noticed that their child is "different" or developing at a different pace. This is okay, children do develop at various paces for no medical reason. One of the most important elements before contacting services is to do your own research. Referring to resources like books and websites, there are pages and pages of information, services, advice, discussions and enormous lists of behaviours which are common characteristics of children with Autism. As discussed in Volkmar & Wiesner (2009) this does not mean that these "symptoms" connect to an official diagnosis. However, these information pages can be an assistant towards creating an understanding of the disorder and whether a family should consider seeking out assessment. Use the research to inform your family, Ensure that the sources found are valid and from credible authors. Another important step towards understanding and seeking assistance for assessment and diagnosis is discussing with

the child's educator. Using the partnership created between the child's teacher and family, discuss any concerns or feelings around their development. It may be that the educator agrees and has been noticing similar behaviours. On the other hand, this information could be opening up the educator's eyes to a child they had not observed carefully. Each teacher will have varying levels of experience and resources to share and can assist in observations and research. It may also mean that seeking services to assess and support families is significantly easier due to the center's connections. By including the centre in this process, the services, support and information will be efficiently collected. Taking the next step can be challenging, but with the right support and a well informed and researched family; advice will be given quickly by professionals. By visiting the Department of Education and Early Childhood Development website, families will discover the contact details of government-funded intervention services that can help. The assessments the professionals use to evaluate each child are made of four areas: "A developmental history, cognitive testing, speech and language testing [and] behavioural observations" (Autism Victoria, 2010). None of these involve any physical or medical testing, however pediatricians with experience in developmental delays will be involved. If families have researched and are unsure of what procedures will take place to assess the child, do not hesitate to ask questions to the professionals involved and to any staff in the child's classroom. Daffodil Kindergarten is here to support families and each child to reach their full potential. Please contact us if families are concerned, confused or need some guidance with this challenging but very rewarding journey.

The readers are the family

What have our Daffodils been doing this month?

The Gumnuts built their first scarecrow

Thanks to a few generous Gumnut Dads, the Gumnuts were able to put up their new "Farmer Ted" scarecrow in the vegetable garden. Photos will be up on the photo-board soon.

The Desert Peas are learning about the letter "H"



Rebecca and her Desert Peas are learning about the alphabet. Here is a picture of Bella drawing a house which starts with the letter "H".

A Teddy Bear Picnic!

Each of the Daffodil classes spent a sunny afternoon outside with their picnic food. Each Daffodil bought their favourite Teddy Bear to join in the picnic celebrations.

Wattles save their water

Last month, Timothy had told his teacher that the taps were dripping in the bathrooms and we needed to save water. Thanks to the Wattles, all the bathrooms and taps in the centre have a bucket to catch the water. All the recycled water is now used to water the vegetable garden. Thanks Wattles!

Daffodils learn about the library

This month we have been discussing libraries. We have built our own libraries in our rooms and have learnt how to borrow books. Next month, we will be organising an excursion to visit a library and see what goes on. We can't wait!

SLIP, SLOP, SLAP

A reminder for parents that the spring is around the corner and we're spending afternoons outside.

We ask parents to ensure that children have sunscreen, hat and protective clothing in their bag. We will collect the hats and put them in a tub near the door. Please ensure that your child's hat is labelled.



REFERENCE LIST - This is where you can learn more about where Daffodil Kindergarten get their information from.

The references are split into articles so you can find information easily. Happy researching!

PICTURE REFERENCES:

Front page: <http://www.flickr.com/photos/livinjoy/823446215/sizes/m/in/photostream/>

Girl Drawing: http://www.toddlercraft.net/wp-content/uploads/2009/07/Fotolia_3126464_XS.jpg

Children on the floor: http://www.onlineuniversities-weblog.com/50226711/istock_5943646.jpg

All images retrieved on 16th August, 2011

SIBLING SUPPORT:

Dyke, P., Mulroy, S. & Leonard, H. (2008) Siblings of children with disabilities: challenges and opportunities. The Author(s)/Journal Compilation - Foundation Acta. p 23-24. Retrieved from dc35.4shared.com/download/102779546/de8a482/8Siblings_of_children_with_disabilities.pdf

> Hames, A. & McCaffrey, M. (2005). Special Brothers and Sisters: Stories and Tips for Siblings of Children with a Disability or Serious Illness. London: Jessica Kingsley Publishers

> Hastings, R. (2003). Report: Behavioural Adjustments of Siblings of Children with Autism. *Journal of Autism and Developmental Disorders*, 33 (1). Retrieved from EBSCOhost.

> Kindering Center. (2010) The Sibling Support Project. Retrieved from www.siblingsupportproject.org

> Nixon, C. & Cummings, M. (1999). Sibling Disability and Children's Reactivity to Conflicts involving family members. *Journal of Family Psychology*, 13 (2), p 274-285. Retrieved from EBSCOhost.

ASSESSMENT FOR AUTISM:

> Autism Victoria. (2010) Autism Victoria - Services - Getting Assessed. Retrieved from www.autismvictoria.org.au/services/getting_assessed.php

> AutismWeb. (2011). Symptoms of autism and pervasive developmental disorder. Retrieved from <http://www.autismweb.com/signs.htm>

> Department of Education and Early Childhood Development. (2011). Early Childhood Intervention Services. Retrieved from <http://www.education.vic.gov.au/ecsmangement/intervention/default.htm>

> Raising Children Network. (2010). Worried you child has autism spectrum disorder: what to do. Retrieved from http://raisingchildren.net.au/articles/autism_spectrum_disorder_worries.html

> Stone et. al. (1990) Play and imitation skills in the diagnosis of autism in young children. *Pediatrics*, 86 (2), p267. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=pbh&AN=4744859&site=ehost-live>

> Volkmar, F. & Wiesner, L. (2009) A practical guide to autism: what every parent, family member, and teacher needs to know. New Jersey: John Wiley & Sons. Online access from <http://site.ebrary.com.ezproxy1.acu.edu.au/lib/australiancathu/docDetail.action?docID=10333002>

Resources

These resources are here for you and your family relating to what has been discussed in this month's newsletter. If you want to take your research a step further, all information referenced in these articles are listed on the back page.

Sibling Support Project:

Sibling Support Project is a national initiative to assist siblings of children with additional needs. The organization gives children the opportunity to share their feelings and stories, seek support from professionals other children in the same situation, join in workshops and community programs. There are addresses and local details on the page for you to contact to get involved. www.siblingsupportproject.org

Early Intervention & Assessment Services:

This is a fantastic resource for parents who are unsure of what steps they need to consider in order to assist their child. This page also includes details on what assessments and evaluations are out there, what each of them entail and also addresses for services around Victoria. www.autismvictoria.org.au/services/getting_assessed.php

IMPORTANT DATES FOR AUGUST



GENERAL DATES:

13th: WORKING BEE (SEE NOTICE BOARD OR ASK STAFF FOR MORE INFORMATION)

22nd-26th: MULTICULTURAL WEEK (SEE NOTICE BOARD FOR MORE INFORMATION)

GUMNUTS (3 YEARS)

> 12th: SUPERHERO DAY

> 19th: FAMILY BBQ NIGHT

WATTLES (4 YEARS)

> 10th: AFTERNOON EXCURSION

> 12th: FAMILY BBQ NIGHT

DESERT PEAS (4 YEARS)

> 25th: 'DIDGERIDOO MAN' INCURSION

> 5th: FAMILY BBQ NIGHT