

## PARENT'S VIEW OF RESPITE

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The theme of Respite is always a topical issue for families, as a break from our children is something that we all want and need at one time or another. An observation though is that we don't use words like respite when we are talking about our child who is not disabled.

All our children need to spend time with other children or extended family members. Sleepovers are one way that children begin to learn how to be away from mum and dad and the familiar surrounds of home. Many parents talk about how their disabled child has so few friends, if any, that sleepovers don't get a chance to happen. Parents tell me how they have never been away from their child overnight, because they can't find anyone to look after their child. They talk about people's willingness to have their non-disabled sibling but not their child who is seen as "different." This is the hard stuff to take in when you are a parent of a disabled child who you love dearly and would walk on hot coals for.

I absolutely appreciate why many families make the decision to seek and receive formal respite services. All too often it is the respite that keeps the family functioning on a daily basis and keeps many marriages and relationships together. We need to remember that respite comes in many forms and families need to decide for themselves what that looks like for them. For some that could be a few hours with a baby sitter a week or participating in a community activity on a regular basis.

I can recall that when my son was about 15 months old (he is now 20 years), a disability service provider was offering Shared Care as part of their menu of services. At the time I was heavily pregnant with our third child and a break sounded like heaven. As I believed at the time that "they knew best" I decided to go along with the idea and met a family that had put their name forward to do the Shared Care. They sounded and looked like good people and we left our wee boy with them for an afternoon to try it out. When I returned to collect him I remember vividly thinking that there was no way in the world I would have done this if he was not disabled. I decided then and there that it would never happen again. This decision then forced me to find other ways of getting a break. Over time I developed good friendships with other local woman with young children and we found ways to share the care of our children.

As families I believe that we need to explore lots of different ways to meet our needs. There will never be enough government resources to meet all of our family's needs or that of our sons or daughters. Respite is only a part of the list of funded and unfunded services available to families. Knowing what else is possible and support to find it is something that PFRC can help families with.

In March of this year a colleague and I had the opportunity to travel to Canada to attend a conference in Vancouver Changing the World One Person at a Time. While there we were invited to a Families Conference in Edmonton. Both of the conferences really showed to me that there is a strong desire of families around the globe to start to take greater control and governance over how they live their lives and how they would like to services to take a back seat and to have a less dominant presence. One of the lessons we brought home was that we need to keep discussing and exploring ways that this can happen.

Bridget Snedden