

Siblings Australia- A Principal/Parent Perspective

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Around Australia there is growing interest in the concerns of siblings of children with special needs. Much of this growing awareness is due to the activities of Siblings Australia, a national incorporated body that has grown out of the work of the Sibling Project based in the Department of Psychological Medicine at the Women's and Children's Hospital in Adelaide. It provides services for families where there is a child with special needs and training for service providers.

The Director of Siblings Australia and author of *Siblings: Brothers and Sisters of Children with Special Needs* (2002, Wakefield Press), Kate Strohm visited Perth in June of 2003 to present workshops for both parents and providers, and I was able to attend the one for parents. It certainly raised my awareness regarding this issue and the implications for school leaders and teachers. Kate's presentation prompted thought and interest and we are hopeful of Kate attending the 2004 Woodridge's WAPPA Conference.

Siblings often grow up in a stressful environment, and often without the cognitive and coping skills to deal with their experiences. However, it can be difficult for a child to highlight their concerns when watching parents who are already stressed and, besides, it is easy to believe that their own needs are insignificant when compared to a child with special needs.

Parents who are often emotionally and physically stretched themselves can miss the signs of problems with a sibling and service providers within a variety of sectors – disability, mental health and education – regularly overlook the needs of siblings. One of the difficulties in highlighting those needs is the variety of experiences. Some siblings do very well, others do quite poorly, but it is the first group that mainly gains attention in the media or community.

The sibling relationship is often the longest of any. Siblings can experience a range of feelings and reactions to having a brother or sister with special needs, and these can vary over a lifetime. Often there is confusion about those feelings. On the one hand, a child may feel loving and protective toward their brother or sister. At the same

time, they may feel isolation, resentment, embarrassment, guilt, sorrow and fear. Without the skills to understand, and without outlets for expressing those feelings, a child's self esteem can suffer. Anger and guilt can turn inward and lead to shame and a sense of worthlessness. The feelings might manifest in behaviours such as withdrawal, 'acting up', being a 'good child' or people pleaser, perfectionism, somatic complaints, school or social difficulties. Without support, longer term problems such as depression and anxiety can then follow.

However, if siblings are supported, not only can their self esteem and sense of competence be enhanced, they can also develop a range of positive qualities eg compassion, tolerance, and maturity. In addition, they are more likely to reach their own potential, and more likely to contribute to the quality of life of their brother or sister with special needs. Siblings need information/involvement, opportunities to express feelings - the good and not so good, they need to feel special and valued themselves, to learn competency/coping skills, and they need social support – from family/friends, other siblings, professionals – including doctors, allied health providers, teachers and school leaders. They also need help to deal with responsibility/lifetime issues.

Various researchers have identified a range of protective factors that can give children resilience in the face of difficulties and moderate the impact of stress on their social and emotional well-being. Many of these are addressed through various programs through schools. However, within the school setting, siblings of children with special needs (disability and chronic illness) are often overlooked when consideration is given to those children who might be 'at risk'.

There has been a trend in recent years to 'mainstream' children with special needs, not only in Western Australia, into regular schools. However, if a child with special needs does attend the same school, a sibling's responsibilities can be even more far-reaching. They may rarely have respite from the challenges as a sibling. It was interesting to get a perspective from Steve Adams, Principal of Mitcham Primary School, Adelaide during the APPA Conference in 2003. He has had some first

hand experience dealing with some of the issues under the guidance of Kate Strohm. Here are some of Steve's views:

“Mitcham Primary hosts a number of students with disabilities in its mainstream cohort. In addition, the school hosts an integration program for students with physical disabilities who are enrolled at Regency Park Centre but spend all of their school time in mainstream classes here. In our population of students with quite severe disabilities, three have twin siblings and two have siblings who are close in age and relationship. We are extremely proud of our levels of inclusivity at school, and the quality of our specialised support programs.

We had not though, until 2001, formally acknowledged the special needs of siblings of students with disabilities. Through the services of Kate Strohm, we established initial contact with families inviting comment about siblings' needs. We were astounded at the degrees of similarity that emerged from the initial contact. Kate spoke to a well attended meeting of parents hosted by our Council's Education Committee, and her contribution was well received. We then established opportunities for selected siblings to meet.

Our Special Education Teacher convened a lunch in a local cafe and invited siblings of a similar age along. Again, we were astounded at the degree of similarity between the expressed needs of the students, and at their appreciation of the opportunity to share time with each other. These students are not close friends, but given guided conversation, used the opportunity to talk freely with each other about attitudes, experiences and perceptions. The confidentiality of the meeting, and the need for ethical guidance were paramount in my mind at the time, but have proven to be of minimal concern twelve months or so “down the track”.

As a result of our increased empathy for these students, they were added to our data base of students potentially at risk, as siblings of students with severe disabilities. The consequence of this identification included higher priority in the class placement process for the following year. That process placed three siblings into one class. The class teacher was advised of the reasons for placement and monitors needs as they arise. The process has not placed any significant load onto the school or the staff, but it has resulted in increased understandings of and empathy towards the behaviour and attitudes of identified siblings. We will continue to include identified siblings as students who require special understanding.”

Siblings Australia, in addition to a range of other activities, is exploring ways of ensuring sibling needs are


considered in the school setting. There is a range of options, from the informal eg putting two siblings in the same class, to the more formal sibling support programs. There are also existing programs in schools where sibling issues can be addressed and are addressed extremely well. Siblings can also be put in touch with community resources including the discussion groups for siblings (child and teenagers) through the Siblings Australia website.


The main focus at this stage is to raise awareness within the education sector of the issues for siblings and how they can be supported. This does not mean pathologising the experience of these children, but just recognising their needs. When identifying the range of factors that may contribute to your Students At Educational Risk profiles this may be another that is added to the list.

If anyone would like to be involved in these developments Kate would welcome your input. It is highly likely that Kate will be attending our 2004 Wooldridges WAPPA Conference to present some concurrent sessions and run workshops for parents.


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