

or anxiety, they need support to work through and understand the legacy and develop strength and self acceptance. Many siblings have taken mainly positive experiences from their childhood, and certainly many siblings remain lovingly involved with their brother or sister with a disability. However, they can still benefit from greater understanding of the different reactions they have brought from childhood, and the opportunity to share their stories. Even if siblings are happy to be in the lives of their brother or sister they can still struggle with their role and how to incorporate it into other aspects of their lives. Adult siblings from around the world have expressed the same issues, via internet forums and books, and talked about the value of having contact with other siblings. As one Italian brother (31) of a man (33) with Down syndrome said: "I joined our group (a support group based in Rome) and since then I've learnt that the best way to feel better as a sibling is to share one's experience with people who live the same situation." Some siblings have sought counselling and for some it has been a very useful exercise. For others it has been frustrating to find the lack of understanding of sibling issues amongst the counselling profession.

Adult siblings might also need practical support in their role as a carer (primary or secondary) for the person with a disability. Some feel comfortable taking over more responsibility as their parents age. Others are given the responsibility, with little choice, when parents die, often without any resources to cope with the decisions and actions that need to occur. Siblings might need support to deal with a mix of issues including accommodation, financial planning, and medical care for their brother or sister. If siblings are not in daily contact with the family, they may not be aware of their brother or sister's support needs, or understand community services. Of course it is much better if planning for the future can start much earlier, with all members of the family involved in the discussions, but it is a difficult subject and one that many parents and siblings avoid.

<sup>1</sup> *The Wellbeing of Australians: Carer Health and Wellbeing* <http://www.carers-sa.asn.au/healthandwellbeing.html>

<sup>2</sup> Lamorey, Suzanne. (1999). *Parentification of Siblings of Children with Disability or Chronic Disease*. In Nancy D. Chase (Ed.), *Burdened Children: Theory, Research and Treatment of Parentification*. Thousand Oaks, California: Sage Publications

<sup>3</sup> Strohm, K. E., (2002) *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press: Adelaide



## To promote friendship at a school level

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- Think about your school culture – does it merely tolerate or does it welcome the presence of the student with Down syndrome?
- Support constant physical presence – classes/ recreation/leisure.
- Reduce barriers that lessen the chance for contact:
  - segregated programs
  - aides
  - even formal buddies can isolate students.
- Support relationships in 'real life' rather than in special programs.
- Provide opportunities for members of the school community to discuss disability. Remove the unknown. Allow time and space to work through discomforts.
- Provide opportunities for members of the school community to learn about the students support needs, including how the student communicates.
- Develop the capacity of the school community to include a student with Down syndrome. This requires leadership and facilitation.
- Think about who will initiate/facilitate/support relationships.
- Support meaningful social participation – not just receiver of tutoring/help – opportunities for authentic contributions.
- Recognise that lunch breaks with their lack of structure can be difficult times for a student with Down syndrome but...
- Also that support does not always mean organised activities. Also provide space and opportunities for students to find their own connections.
- Recognise and use common interests of all students.
- Think about the 'image' of students. Do others see them as fellow learners? Do they have an authentic involvement in school programs?
- 'Unlearn' some of your socialisation around friendship – how you define it, what expectations you have of it. Re-think the nature of how students can 'be' together.