



[www.learninglinks.org.au](http://www.learninglinks.org.au)

Information Sheet 49

# Family perspectives on issues related to children with disabilities and challenging behaviours

By Sandra Samuel, Director Family Services, Learning Links

**This article describes family experiences observed in the course of providing support to families with children with disabilities. Challenging behaviours have enormous impact on everyone involved with the care of the child but most significantly on the family of the child. Emotions raised are difficult for all concerned. This article addresses the context within which challenging behaviours are addressed in the family and it highlights the importance of delivering services from a family centred framework.**

A child with a significant disability invariably leads to great emotional and financial stress in the home. While some children have needs primarily in the areas of medical intervention, therapy and personal care others have long-term behavioural patterns that include regular violence to themselves or others, chewing or breaking furniture and house fittings, screeching or being noisy at all hours, eating inappropriate items, smearing faeces, or running away.

Particular syndromes such as Autism, Williams, Prader Willi and Smith Magennis to name a few are often associated with more challenging behaviours and impact more intensively on the family.

Despite pharmacological and behavioural interventions there may be very slow development, or regression at various stages of the desired behaviours. Families often report that the care required is stressful, demanding, labour-intensive, constant and relentless, costly, tiring and mostly unacknowledged.

Other reported impacts on the family include:

- very little social life;
- reduced time and energy for other family members;
- conflicts regarding treatment pathways and interventions;
- dual role of parent to be a therapist;
- expectations on other children to share physical and emotional caring;
- restrictions on types of family activities eg, camping;
- very little time off and few holidays;
- reduced career opportunities;
- working part rather than full-time or not being able to work at all;
- coping alone when carers are sick or on leave;
- extra demands of school holidays;
- physical and emotional tiredness; and
- feelings of low self-esteem and worth.

Having a child with a disability and challenging behaviours can severely restrict the family's choices on a range of levels – physical, social and emotional.

**Learning Links is a non-profit charity assisting children who have difficulty learning and their families.**

We raise funds to help children from birth to 18 years by offering a range of services including the following.

**Early Childhood Services** for children from birth to six years.

Early childhood intervention and support for very young children.

- An inclusive preschool for children with and without special needs.
- An assessment and consultancy service for families who are concerned about their young child's development.
- Specialist early childhood teaching and therapy.

**School Age Services** for children from Kindergarten to Year 12 who have low support needs.

- Comprehensive assessments.
- Small group tuition and therapy.
- Occupational and speech therapy programs combining specialist education services and therapy.
- Outreach programs.
- The Ronald McDonald Learning Program for seriously ill children; Reading for Life for children falling behind in reading and Counting for Life for children falling behind in numeracy.

**Family Services** helping and supporting families and health professionals.

- Centre and home-based family counselling.
- Parenting Programs and groups for families.
- Case Management Services.

**Professional Development** for teachers and health professionals.

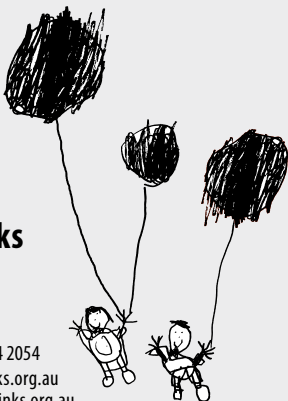
Presentations, workshops and advice on identifying and helping children with learning difficulties, learning disabilities and developmental delays.

**Learning Links has branches in six Sydney locations at Peakhurst, Penshurst, Fairfield, Miller, Brookvale and Randwick. We also offer some services to children in country NSW, the ACT, Western Australia, Victoria and New Zealand. A complete list of branch locations and contact numbers is on the back cover.**

## Learning Links

### Head Office

12-14 Pindari Road  
Peakhurst NSW 2210  
Tel: 9534 1710 Fax: 9584 2054  
Email: [mail@learninglinks.org.au](mailto:mail@learninglinks.org.au)  
Website: [www.learninglinks.org.au](http://www.learninglinks.org.au)



Enquiries regarding this Information Sheet should be directed to Robyn Collins  
Tel: (02) 9534 1710 Fax: (02) 9584 2054 Email: [rcollins@learninglinks.org.au](mailto:rcollins@learninglinks.org.au)

© Learning Links 2006. The material in this publication cannot be reproduced without the written permission of Learning Links.

While many parents of children with disabilities are very close emotionally to the child being cared for, some parents find that the caring demands place a greater strain on the relationship with the child and in some cases this results in a destructive and perhaps abusive relationship for both parties.

Single parents are often the loneliest and lack the day-to-day support of a partner to back them up. Some parents find it difficult to make friends due to the demands on their time and the difficulty often in reciprocating support and friendship.

Parents also report difficulties accessing adequate vacation and respite care and difficulties finding carers for respite with sufficient skills to cope with the challenging behaviours. Some comment on the impact of overwhelming grief, residual sometimes even from the time of diagnosis and other times prompted by a current situation which can leave them not knowing which way to turn.

The same parent can feel at other times so proud of the child's achievements but the day to day demands of living with what seems like a long dark tunnel stretches the limits of tolerance, understanding, patience and time.

Families with children with disabilities are **no** more likely to experience domestic violence, substance abuse and family breakdown than other families in the community but when they do the impacts of these problems exacerbate their difficulties and can heighten their sense of powerlessness. In some situations parents may feel compelled to remain in destructive relationships because of the difficulties of continuing to provide care for their child without another person being around should they separate.

Mental health issues such as depression and anxiety are intensified by the unending stress that many parents endure each day. Parents can be driven to abandon their child at a service, as they feel so unable to continue without sufficient support and relief from their continual caring role or may experience complete physical or mental breakdown.

The wellbeing and needs of siblings present additional anxieties for parents.

Siblings often may feel a sense of responsibility for their brother or sister beyond that felt by their peers and may take on caring roles that their peers would not generally have to. Some siblings may develop their own challenging behaviours because of the modelling experienced with an older challenging child and as a solution, though unconscious, to getting enough attention.

The day-to-day give and take relationship with opportunities for play and developing communication will be very different for the sibling of a child with a disability and may progress eventually to one of guardianship rather than the usual adult sibling relationship.

Feelings of fear, shame, anger and guilt particularly are increased when the child has challenging behaviours. At times siblings may want to protect their brother or sister from bullying by others and at other times they want to escape and not be seen with their sibling.

Siblings can feel confused and isolated by the range of their reactions and experience grief at the loss of a perceived normal family life and in some cases grief at their sibling's loss of a normal life. Some feel increased expectations and pressures to achieve their parents' dreams and may even opt out of the school system early rather than risk failure.

Parents are often helpless to protect their other children from the impact of the challenging behaviours making everyday life intolerable for some siblings with readily discernible impacts on their emotional and mental health.

Grandparents and other members of the extended family may be helpless to alleviate the stress the parents experience, as they may not feel capable of dealing with the challenging behaviours particularly as the child gets older and stronger. They also experience a range of difficult emotions often with little avenue for support.

Negotiating the medical and disability services field is a minefield for many parents.

Information about services is often limited and may be couched in difficult jargon. Parents at a recent Carers program commented on the attributes of good and bad services and highlighted the differences they found between services.

Parents highlighted experiences where they felt that they weren't listened to; they were judged; the process seemed to have no entry point – they had to go through quite complicated steps to gain access; and they felt that the depth of the problems they faced were not understood by the service providers. On the other hand they found that good services only had to provide what one would generally just expect from a reasonable service for parents to be satisfied – i.e. to be good listeners, knowledgeable, sensitive, provide referrals when they cannot help, return calls, emails, and generally provide timely feedback.

Parents of children with disabilities and challenging behaviours are often extremely anxious about the future especially about the post school times.

Issues such as their child's opportunities for work or for Community Participation Programs are extremely anxiety-provoking as they face the reality of the limited services available particularly for high needs children.

They fear having to reduce any outside work they may have been able to access because their caring role may increase, as the reality is that many children will only access programs for three short days. Issues also about who will care for their child when they are no longer around and the availability of supported accommodation options are in their minds often from the child's early years and they find little comfort in other parents' experiences as their children grow older.

Families with children with disabilities who come from culturally and linguistically diverse (CALD) communities face additional difficulties in accessing services and support.

Many parents have reported that they feel ashamed of their child's disability and often isolated from their extended families and communities. Various cultures have different interpretations of the meaning of parental responsibility for a child's disability. For some it is viewed as a punishment for sins in this or a former life.

When their child also has challenging behaviours these feelings are exacerbated and may prevent them from seeking external services. If a family is lucky enough to access help from workers who are from their own culture they may abandon services because they fear discussing their personal issues with people who they

fear may not respect their right to confidentiality or may judge them.

Cultural differences in expectations of families to look after members of their own families themselves without support can be a further issue.

The notion of the child with a disability becoming as independent as possible is not always accepted in some cultures. Transport difficulties may also be greater because of the lower rates of women's access to cars in some CALD families, increasing isolation and decreasing access to services.

Families from CALD backgrounds do not as easily access information about help and support available, as do families who are fluent in English.

For some, literacy issues impact on the family's ability to even access printed information in their own language. The ability to understand a diagnosis may be impacted by lack of interpreting opportunities. Where services are hard to access it is the families from CALD communities who will be more likely to miss out.

Attempts to help families address challenging behaviours are often offered as a behaviour intervention strategy without sufficient consideration and intervention into the day to day stresses the family are experiencing and without sufficient support to implement changes or sufficient consideration of the areas the families consider problematic.

Many interventions may offer help to the mother without addressing the father's concerns and perspectives.

Families are the most essential resource that children with disabilities and challenging behaviours have and the most vulnerable. The supports available are often just not sufficient to support them in their endless tasks, stresses and challenges.

We know that the most effective way of supporting the family and addressing challenging behaviours is within the context of the presence of a trusting, reciprocal relationship between the family, professionals and all people working with the child. This often involves intensive family support – spending time to get to know and understand all the members of a family in their home and community context and dealing with the intense emotional areas of the family's life.

In this process the family need access to sufficient, consistent and affordable services. These services must address the range of their needs and priorities in a manner which is respectful to their culture and values as well as addressing behavioural difficulties which may be reported in the setting the child attends and in their home.

## Suggested Readings

Dunlap G., Robbins F.R., & Darrow M.A. (1994) Parents' Reports of their Childrens Challenging Behaviours; *Mental Retardation*, 32, 206-212

St George Resource Centre Inc. Report, Culturally and Linguistically Diverse Disability Research Project, October 2004

Strohm K., Siblings ; Brothers and Sisters of children with Special Needs, Wakefield Press, Adelaide, SA, 2002

Sutherland Shire Carer Support Project Who Cares – A Survey into the Needs of Families Living with a Disability in the Sutherland Shire, February 2000

Weise M., Stancliffe R. and Hemsley B., Review of Positive Behaviour Support Programs prepared for DADHC by CDDS, January 2005



[www.learninglinks.org.au](http://www.learninglinks.org.au)

**Early Childhood Services**  
– all enquiries to Head Office

**School Age Services**  
– contact your local branch

**Family Services**  
– contact your local branch

**All other enquiries**  
– Head Office

**Head Office**  
12-14 Pindari Road  
Peakhurst NSW 2210  
Telephone: (02) 9534 1710  
Preschool: (02) 9533 3283  
Facsimile: (02) 9584 2054  
Email: [mail@learninglinks.org.au](mailto:mail@learninglinks.org.au)

**Northern Suburbs Branch**  
2 Alfred Road  
PO Box 634  
Brookvale NSW 2100  
Telephone: (02) 9907 4222  
Facsimile: (02) 9907 4244  
Email: [nsb@learninglinks.org.au](mailto:nsb@learninglinks.org.au)

**Western Suburbs Branch**  
Unit 7/9 William Street  
PO Box 1026  
Fairfield NSW 1860 (2165)  
Telephone: (02) 9754 2377  
Facsimile: (02) 9755 9422  
Email: [wsb@learninglinks.org.au](mailto:wsb@learninglinks.org.au)

**Southern Suburbs Branch**  
10 Railway Parade  
Penshurst NSW 2222  
Telephone: (02) 9580 4888  
Facsimile: (02) 9580 4788  
Email: [ssb@learninglinks.org.au](mailto:ssb@learninglinks.org.au)

**South West Sydney Branch**  
88 Shropshire Street  
PO Box 42  
Miller NSW 2168  
Telephone: (02) 8783 7111  
Facsimile: (02) 8783 7222  
Email: [sws@learninglinks.org.au](mailto:sws@learninglinks.org.au)

**Eastern Suburbs Branch**  
1/20 Silver Street  
Randwick NSW 2032  
Telephone: (02) 9398 5188  
Facsimile: (02) 9326 5364  
Email: [esb@learninglinks.org.au](mailto:esb@learninglinks.org.au)

## Please help us help children

**Please PRINT**

- I would like to donate \$\_\_\_\_\_ to help kids who have difficulty learning.
- I would like to be a member of Learning Links. *Please tick appropriate box below.*
  - Individual or Family      \$45 (including GST)
  - Professional      \$45 (including GST)
  - Not for profit Organisation      \$55 (including GST)
  - Corporate      \$70 (including GST)

Individual, Family and professional membership includes one copy of *Learning Links News*

I enclose my:     Cheque     Money Order    **or**

Charge my:     BANKCARD     VISA     MASTERCARD     AMEX

Account No: \_\_\_\_\_ CCV\*: \_\_\_\_\_

*Visa and Mastercard last 3 digits on back of card.*

Account Name: \_\_\_\_\_ Expiry Date: \_\_\_\_ / \_\_\_\_

Signature: \_\_\_\_\_

Name (Dr, Mr, Mrs, Miss, Ms): \_\_\_\_\_

Organisation/Business: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Tel: (Home): \_\_\_\_\_ (Business): \_\_\_\_\_

**Please post to Learning Links:** 12-14 Pindari Road, Peakhurst NSW 2210. *Donations over \$2 are tax deductible and will be receipted.*

