

## Talking to Families; Listening to Families

*A workshop with*

*Professor Barry Carpenter – a father  
Katie Carpenter – a daughter*

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**‘We have to learn  
together about  
our children.’**

A parent

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‘Parents hold key information and have critical  
role to play in their children’s education.  
They have unique strengths, knowledge and  
experience to contribute to the shared view  
of child’s needs and the best ways of  
supporting them.’

DfES, 2002

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‘Parents should be partners in the planning  
and delivery of services...parents are  
informed experts on their children.’

Wolfendale, 2000

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## Phases in parent–professional partnership

- ☐ Unsupported
- ☐ ‘Professional as expert’
- ☐ Transplant model
- ☐ Consumer model
- ☐ ...but do these models embrace families?

**‘Families are the heart of  
our Society and the basis  
of our future as a  
country.’**

UK Government

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## Family–School Partnerships

- ▶ “Families are the first and continuing educators of their children.”

Australian Government,(2005)

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## Three Principles

Children must come first.

Children need stability.

Families raise children.

Family and Parenting Institute, 2011

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Families are big, small, same-sex, extended, nuclear, multi-generational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage or from a desire for mutual support. A family is a culture unto itself, with different values and unique ways of realising its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighbourhoods, communities states and nations.

Carpenter, B. 2010  
'The Family context, community and society'  
Complex Needs Series Booklet 6  
<http://complexld.ssatrast.org.uk>

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## Vulnerable children – Fragile families

Carpenter, 2012

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‘It is difficult in a society that does not value disabled children to find help that is non-judgemental. Admitting that one’s child might be harder work than many does not come easily if you are trying to challenge outdated attitudes. Asking for support does mean that you do not love your child, or that you are wishing them away.’

Cornelia Wilson, May 2003  
'Pitiful situation'  
Guardian Society

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## Family Response Emotions

- ▶ Grief – bereavement
- ▶ Sorrow/prolonged mourning
- ▶ Chronic vulnerability

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## Assessment



**Plymouth City Council**  
**WHEELED BIN INFORMATION FORM**  
 1. How many people live in your household?  
 Number of adults: \_\_\_\_\_  
 Number of children under 16: \_\_\_\_\_  
 2. Are there any reasons why your household might have difficulty missing the bin out for collection or returning it to your property? Please tell us about this: \_\_\_\_\_  
 3. Are there any medical reasons why any member of your household might have difficulty identifying which bin is which? (e.g. visual impairment) Please tell us about this: \_\_\_\_\_  
 4. Do you have children in your household under the age of three who use disposable nappies? Please tell us how many: \_\_\_\_\_  
 5. Are there any other reasons why a member of your household generates more rubbish than average (e.g. a medical condition)? Please tell us about this: \_\_\_\_\_  
 6. Please nominate an adult from your household who will take legal responsibility for your bins.  
 Name: \_\_\_\_\_ Age: \_\_\_\_\_  
 Signature: \_\_\_\_\_ Date: \_\_\_\_\_  
 PLEASE BE AWARE THAT BY SIGNING THIS FORM YOU ARE ACCEPTING RESPONSIBILITY FOR ENSURING THAT YOUR HOUSEHOLD CONFORMS TO OUR REQUIREMENTS

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'Despite the challenges, financial consequences and acute lack of services to support disabled children and their families, parents give their time willingly; to them their child remains very special and much loved.'

About Families with Disabled Children – UK  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

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## Key Facts

Over **90% of disabled children** live at home and are supported by their families.

**3 times more expensive** to rear a child with disabilities.

**55% of families** with a disabled child live in, or on the margins of, poverty.

Disabled children are **13 times** more likely to be excluded from school.

**Three quarters of families** with a disabled child live in an unsuitable home.

**Only 16% of mothers** with disabled children are in paid employment (compared to 61% of other).

About Families with Disabled Children – UK  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

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'In realising his academic limitations I realised the loss of my own dream for his future.'

Parent response, Family survey, 2002

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'She was our baby. She was our first. To us, whether there was something wrong or not, she was still a baby. She still needed us, and so we just got on with it.'

About Families with Disabled Children  
 UK  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

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'For most parents the birth of their child is a joyous time. However, nearly 4% of parents receive distressing news about their child's health. In fact, about every 3.5 minutes a parent is told that their child has a serious medical illness, health defect, disability or sensory impairment.'

Barrett, D., Clements, M., Kaplan-Estrin, M., Fialka, J. (2003)

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**'21<sup>st</sup> century families...not necessarily related by blood or kinship, but by a constellation of people offering mutual support.'**

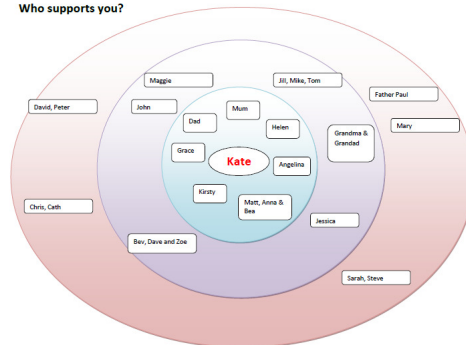
*Dame Philippa Russell  
(October 2009)*



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Who supports you?



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Grandma and Grandad



Kirsty and Helen



Mary



Grace



Angelina



Mat, Anna and Bea



Mum and Dad



Father Paul

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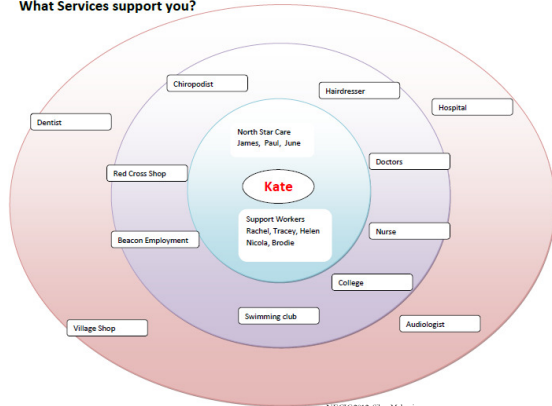
**And a new nephew for Aunty Kate...**



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What Services support you?



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**North Star Care**



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Paul



June



Steve



James



Kate

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## Beacon Employment



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## College



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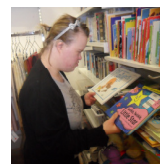
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## Red Cross Shop



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## Swimming Club



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## Drama Club



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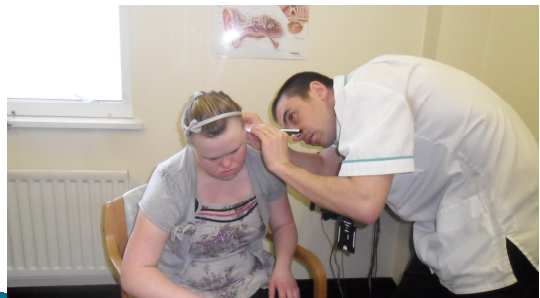
## Doctors



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## Audiologist



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## Chiropodist



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## Hairdresser



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## Living with children with complex learning difficulties and disabilities – the stories and the narratives

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### A mother speaks...

'She was attached to monitors for blood pressure, heart rate and respiration. A tube was inserted through her nose into her stomach to feed her, and another into her mouth to provide oxygen if she stopped breathing during seizures...

'I reached out to touch her hand. I looked for life. A triple cocktail of medications, two anti-convulsives and morphine kept her from us. She was in La-La Land.'

*Stacie Lewis*

*Blog - mamalewis.wordpress.com*



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'I watch the parents: no empathy, no attachment [to their child], no realisation of the path to self-destruction the child is on.'

*Teacher in a BESD school*



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'Twenty years ago, I saw 'at-risk' families in poverty, where the only food they had for a month was potatoes and cabbage.

'Now I see 'at risk' families whose poverty is a 'poverty of relationship'.'

*A Portuguese Social Worker (2009)*



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'I see parents parenting beyond their capacity.'

*Teacher in an SLD school*



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'My son was born at 24 weeks: he is now five years old, and commenced a mainstream school in September 2009. He has been diagnosed with global learning delay and has difficulty with his behaviour and attention.

'I often dread picking him up from school to be informed of his antics. I dutifully go through the motions of discussing his behaviour with him and the teacher, but I feel really very sad for him because it is not his fault. The teachers do not understand that sometimes he just cannot help his behaviour.

**He is definitely wired differently to his peers!'**

**A Mother (January 2010)**



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'The knowledge about the significant influences of the environment on cognitive, social and emotional child development is a key factor for economic success and wealth of nations in a globalised world.'

'It is a must for policy to invest in...children and family'.

*Peterander, F. (2009) 'Environmental influences on young children's Mental Health', Interdisciplinary Early Childhood Intervention Conference. Madrid, Spain (November).*



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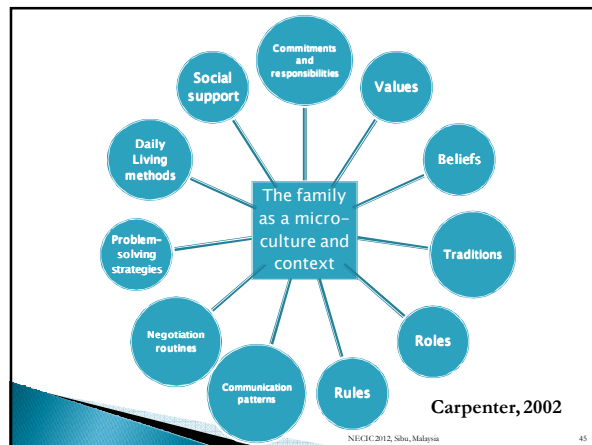
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## Influences on Family Structure

- ▶ Ethnic and cultural background
- ▶ The stage of the family life cycle
  - ▶ Environmental events
  - ▶ External factors
- ▶ Individual relationships
- ▶ Personal and collective experiences

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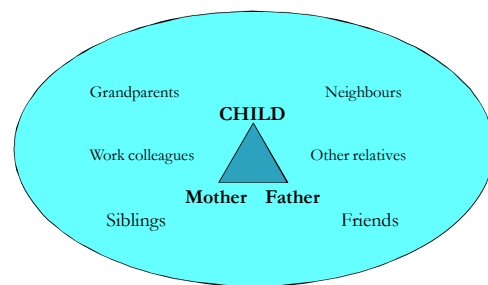
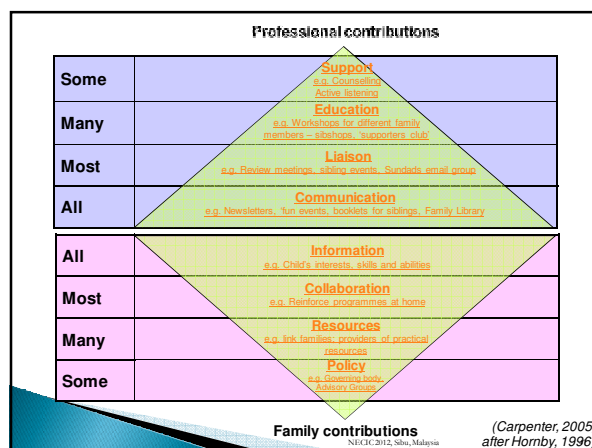


Figure 1: A model of the self-defining family  
Carpenter, 2000

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(Carpenter, 2005, after Hornby, 1996)

## SUPPORT

e.g. Counselling / Active listening / family library



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## EDUCATION

e.g. Workshops for different family members  
– sibshops, 'supporters club'



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## LIAISON

e.g. Review meetings, sibling events,  
Sundads email group



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## COMMUNICATION

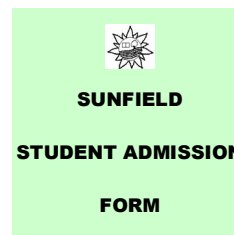
e.g. Newsletters, 'fun' events, booklets for  
siblings, Family Library



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## INFORMATION

e.g. Child's interests, skills and abilities



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## COLLABORATION

e.g. Reinforce programmes at home



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## RESOURCES

e.g. link families; providers of practical resources



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## POLICY

e.g. Governing body, Advisory groups



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## Mothers (of children with disabilities) Findings from a cross-Nordic study

- Amendment of 'Life Project' goals
- Increased 'caretaking responsibilities
- Dreams that are realised differently
- Restricted leisure opportunities
- 'Emerging feelings of restriction may promote stress'
- Work (employment) patterns
- Illness from work

*Hautamäki, A.  
In Carpenter, B. 'Families in Context'  
London: Fulton*

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'If you are a sole parent it is important to take on board the principles of taking care of the most important relationship in your life – with yourself.'

'Through grief to self-care'  
Justine Watson, Australian Autism Handbook

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'Our lives fell into a black fog – this news that our baby had a disability. They called it a diagnosis. For us, it was like a stab in the heart; your whole body filled with searing pain. Then hoards of professionals entered into our lives – people with titles we had never heard of. This was not how it was meant to be, our lives, our little family, controlled and directed by others.'

Father quoted in Carpenter, 2005  
PMLD Link, 17, (2), 51

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There are over 200,000 young people in Australia with a severe or profound disability. If we assume an average of one sibling per person with special needs there is at least a comparable number in the target group.

Strohm, K., Nesa, M., (2005)  
Sibworks: Facilitator Manual  
[www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

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## Concerns of siblings

- Mental health needs
  - Anxiety
  - Depression
  - Low self-esteem
- Relationship difficulties
- Physical health problems
- Unable to express feelings (in relation to disabled sibling)
- Feelings of isolation
- Anger / resentment
- Shame and guilt
- Pressure to achieve
- Concerns for future

Strohm, K., Nesa, M., (2005)  
Sibworks: Facilitator Manual  
[www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

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### Characteristics of supportive parent –grandparent relationships

**Practical support**

- Baby-sitting
- Child-minding
- Household chores
- Financial support

**Emotional support**

- Following diagnosis of disability
- Sharing of feelings
- Being non-judgmental
- Being 'a Life Line'
- Allowing space to talk

From a study by Mirfin-Velich & Bray (1997) Dunedin, New Zealand  
These findings support the studies of Beresford, 1994 and Sonnek, 1986  
Conflicting studies, demonstrating an inability to adjust to a grandchild's disability or offer practical support: George, 1988; Mever & Vadsav, 1986; Simons, 1985; Turnbull & Turnbull, 1990

An Australian study reported grandparenting of a child with disabilities...

‘through a veil of double grief’

‘as an intense, emotional experience’

Woodbridge et al., 2009  
Cited in Carpenter, B. (2009)  
***Think-piece: The family journey.***  
South Australia: Department of Education and Child Development.

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### Responses of 'significant others' to children with disabilities and their families

Support available to families particularly in the locality in which they live is 'crucial in determining their quality of life': (p. 51)

**Families' varied experiences**

- Isolated by neighbours (Family Maro, Tanzania)
- Encouragement from friends and offers of child-minding (Family Murthy, India)
- Sympathy received from friends (Family Chawdhury, Bangladesh)
- Attacked by members of their neighbourhood (Family Eed, Jordan)

From an International Study undertaken by Helle Mittler

- Family supporters
- Neighbours
- Friends
- Work colleagues
- Church members
- Teachers and assistants
- Link families
- Volunteers (from charitable organisations)

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‘Friends and neighbours might turn away because of their own attitudes to disability and because they are afraid they will not know what to say or how to help!’

Limbrick, 2005

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The main types of support offered (i.e. Reported by more than five families in the sample) were:

- Baby-sitting and child-minding
- Transport
- Respite care
- Social Activities
- Meals out for child and/or family
- Practical help in the home (household chores, maintenance tasks)
- Empathetic listening

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## Working with children with special educational needs and their families

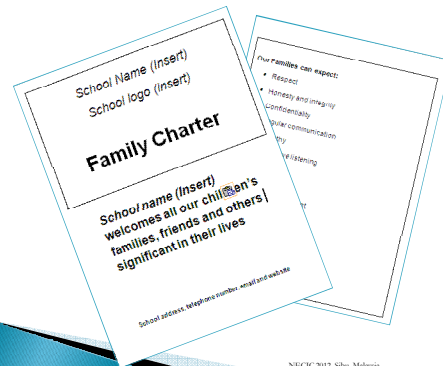
- Nurture the uniqueness of the child
- Respect the individuality of the family
- Develop flexible working patterns
- Build a collaborative partnership based upon equal, if different, expertise
- Identify a key support worker whenever possible
- Articulate an inclusive philosophy
- Maintain high expectations
- Balance adult support against peer interaction
- Work positively and creatively

(based upon: Carpenter, 2002 in 'Enabling Access', London: Fulton)

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## Family Charter



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## Our families can expect:

- › respect
- › honesty and integrity
- › confidentiality
- › regular communication
- › empathy
- › supportive listening
- › information
- › partnership
- › a safe environment

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## We fulfil this by:

- › Valuing your opinion and knowledge of your child
- › Respecting your need for privacy and confidentiality
- › Make regular contact
- › Care and concern for your parenthood
- › Being non-judgemental and giving time
- › Working together for the benefit of your child
- › By providing a private space for a family to spend time together

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## Our practical support of the Family Charter takes place through the following:

- › Providing the family centres
- › Letters to family members from your child
- › Introductory invitations in to class
- › Updates on your child's progress
- › Photographs or video film of your child (with parental permission)
- › Provision of a family library / resource centre
- › The preparation of a family profile for your child which includes photos of family, friends, neighbours, pets etc.
- › Reports on your child's progress at home and at school
- › A family newsletter each term
- › Family days / open days
- › Links between existing and new families
- › Events for siblings e.g. Sibshops

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## The Tangibility Factor

- › How would families know there were services there for them?
- › How would they (literally) touch these services?
- › How would they feel the impact in their lives?

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## Family Values as an instrument of change

'We didn't just want to talk about values superficially; we wanted values to become intrinsic to school life'

Ellis, G (2012)  
Special Children 205, 20-21

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## How were the values demonstrated

- Consultation with the School
- School Assemblies
- Displays
- Reward schemes
- Personal behaviour/role models

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## Outputs seen in children

- Improved attendance
- Improved behaviour
- Positive attitudes to school
- Increased engagement in learning
- Pleasure in practising values
- Reflected in language of younger children

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### Family-School partnerships should:

- ▶ View each partner as making equally valuable contributions
- ▶ Respecting student needs and preferences
- ▶ Address barriers to involvement in schools by families, in particular indigenous families
- ▶ Create better programmes, opportunities and learning for students
- ▶ Give families appropriate opportunities to contribute to school decision-making and governance
- ▶ Contribute to professional satisfaction for Principals and teachers

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' Good communication with school makes life much easier for everyone...The first thing I try to do is actually ask the teacher how they would prefer to communicate.'

O'Reilly & Berrison (2008)

Some responses:

- ▶ Home /school communication book
- ▶ Diary
- ▶ Monthly appointments
- ▶ Notes in reading folder
- ▶ A 'remember all' schedule
- ▶ Phone calls
- ▶ Email
- ▶ Skype!

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## Shifting the focus...from parents to families

Carpenter, 2003  
Australian Journal – Special Education Perspectives

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'We live in a society that sees people like my daughter as worthless.'

Why then, would it be one that delivers high quality services?'

A mother, UK survey by Mencap, 2001

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Together in Partnership.

1. Be honest with each other
2. Be willing to learn from each other
3. Treat each other with respect and dignity
4. Be willing to admit you make mistakes
5. Work collaboratively and co-operatively
6. Be yourself

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'We need a whole community to develop a child. We are that community, and these are our children.'

*Nigerian Proverb*