Siblings of Children with Disability
Paediatrics and Mental Health
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Session Aims

To consider:

• Why siblings are important
• Challenges for siblings (the risks)
• Protective factors, ie what helps
• The role of Paediatrics
How your siblings make you who you are

By Jeffrey Kluger

The New Science of Siblings

Your parents raised you. Your spouse lives with you. But it's your brothers and sisters who really shaped you.

Surprising research reveals how

By Jeffrey Kluger

Services for brothers and sisters of children with special needs.
Why support siblings?

1. They are at risk themselves for mental and other health problems
   - *siblings face challenges too.*
   - *If supported they are more likely to reach their own potential*

2. Siblings have the longest relationship with the child with disability
   - *If supported, siblings are more likely to add to the quality of life of their brother or sister. They have much to contribute.*

*siblings*
Siblings of children with disability

- each experience unique
  - changes over lifetime
  - some enriched, manage challenges well
  - some need more support
- first experiences as children
  - lack maturity to understand
- siblings at risk for mental, social & physical health problems
- very few meet another sibling, or access support
Opportunities for sibs

- tolerance, compassion
- more insight, maturity
- resilience
- reliable, responsible
- high achieving
- pride in achievements of bro/sister
- often work in helping professions
Challenges/risk factors

Can be within family, with peers, at school, or in the community

• Overlooked
• Communication
• Isolation
• Extra responsibility
• Relationship with child with disability
• Others’ reactions
• School
I felt completely isolated. I thought I couldn’t share any of that part of my life with my friends. They didn’t understand and I felt alienated from them. Other kids never had the same responsibility.

Adult sib
Warning signs

- withdrawal
- ‘acting up’ behaviour
- ‘good child’, people pleaser
- perfectionism, overachieving
- anxiety/depression/low self worth
- stomach aches, sleep problems
- school, social difficulties
Factors affecting adjustment

*IS COMPLEX*

- characteristics of sibling
  - eg age, birth order, temperament
- sibling perception/meaning of disability
- sibling sense of competence
- interaction between siblings
- number of siblings in family
- family communication
- parent attitudes
- social support
Factors for resilience

- Family connectedness
- Peer connectedness
- Fitting in at school
- Problem solving skills
- Help seeking skills

Fuller et al. *The Mind of Youth*
What siblings need

• open communication within family
  – information, permission, feel special/listened to
• strong connections with family/friends
• support from school & other agencies
  – problem solving & coping skills/how ask for help
• connections with other siblings
Where can sibs get support?

- Parents
- Community
- School
- Peers
- Extended family/friends
- Other Siblings

SIB
Why siblings are overlooked

• Siblings not a ‘squeaky wheel’
  – Feel guilty, disloyal if complain
  – May not be aware issues are connected

• Parents stretched
  – Many very concerned
  – Others don’t see the difficulties for siblings

• Providers
  – No co-ordination, collaboration, lack funding

• Government
  – Where siblings fit?
  – No data
  – No policy, umbrella of support
Policy

The needs of brothers and sisters should not be overlooked, and they should be provided for as part of a package of services for the child with a disability.

Children Act 1989, UK
Siblings Australia

Our Mission

*Siblings: Acknowledged, Connected, Resilient*

Work in three main ways

- *Direct with siblings*
- *With parents to help them support sibs*
- *With providers to help them support sibs*

Use a ‘settings’ approach

- *family, friends, school, community*
Activities

• Awareness
• Website
• Sibling groups – *SibworkS, Saturday Sibs*
• Adult siblings/adult project
• Parent workshops/DVD
• Professional training
• *SibworkS* facilitator manual/booklets
• School resources
• Research collaborations
• Networking
• Advocacy
Paediatrics

- Acknowledge siblings
- Increase awareness about sibling experience
  - RANZCP
  - Siblings Australia website – reports etc
  - Professional development
- Add to case notes – record impact on sib
- Include in discussions
  - Own needs – ask questions
  - How help interact with child with chronic condition
  - Refer siblings and parents to relevant resources
- Pathways to support?