Siblings of Children with Disability

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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







astration for TIME by Arthur



## 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 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





## 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 Service of control

# 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?

