

Impact of disability on the family

Michael's journey

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A New Child



Michaels disability

- How did it happen
- What was its manifestation
- Clinical description
- Range of medical supports
- Frequency of medical support



A new Child

- Disabled person = disabled family
- Disabled person = special family
- First exposure – Shock !
 - Looking for answers
 - Why did it happen
 - What does it all mean
 - What will we do
 - Am I able to cope

The System Reacts

- Reason
 - Cause unclear, prognosis uncertain, expectations low, viability uncertain
- Poor information
 - What is cause – what can be done
- Two issues
 - Need for info about Person/ child's disability and support
 - Family /carer need for information to manage

Advice is needed !

- **Clinical** – instant nurse skills
- **Support and help** - effective if focus on the real need and not on training staff
- **Relevant and helpful** - sometimes for worn out carer
- **Formal coping and training** - courses are needed - instantaneously

Advice – cont.

- **Care structures- “the team”**
 - not always relevant
 - hindrance if not experienced
- **Need to support the mother as well**
 - main carer

Family

- Family becomes disabled (dysfunctional) to some degree
- Life is centred around the person with the disability
- Limited function and flexibility due to focus
- Priorities become the 'needy one'

Michaels Family



Families need to find their own coping pattern

- Coping
 - Each is unique
 - Different problems/different solutions
- Needs to be a linked services coordination
 - Clinical
 - Educational
 - Support
 - Respite
 - Equipment
 - Financial
 - Progressing stages

Family 'bends' to the disability

- Life patterns adapt
- Sudden explosions of need
 - Seizures
 - Operations
- Slow burn of issues build up
- Wide range of clinical touch points and settings
 - No case conferencing support

Family discovers a beautiful and loving relationship with the disabled child

- Love and dependency bonds build
- Some consequences
 - Some need of other children not met due to time and energy

Early Days





Operations- procedures

- Tube feeding
 - Not able to swallow
 - Tube feeding for several years/nasogastric
- Peg feeding
 - Slow and tedious
 - Getting the right balance

Complex Care

- Medications
 - Poly pharmacy
- Baclofen pump
 - Impact
- Major operations
 - Hips
 - Pain and dystonia distortion
 - Tendons stretching
 - Titanium rods - harrington rods
 - Length of operation (9 hours)



The Journey

- Issues
 - Reason for operation
 - Length of time to plan
- Major operations
 - Length of recovery
 - Level of success
- Alternative treatments-
 - hyperbaric
 - No belief
 - Mothers tale
 - Benefits experienced
 - Botox



Significance of a disabled child

- Total dependence builds a unique bond
- Disabled equals love; draws love and can only give love
- Not always sustainable and has collateral impacts across normal family life
- In Michaels case a beautiful love was expressed through his total dependence
 - His eyes were always alert and he was able to communicate with them.
 - His groans to communicate



Farewell

Michael passed away in his sleep due to aspiration event on 26 April 2007



Reflection-

- How has the experience for families changed
- Birth
- Therapies - difference now
- Equipment
- Financial
- Outcome different - respite