

Life on the Edge of the Cliff

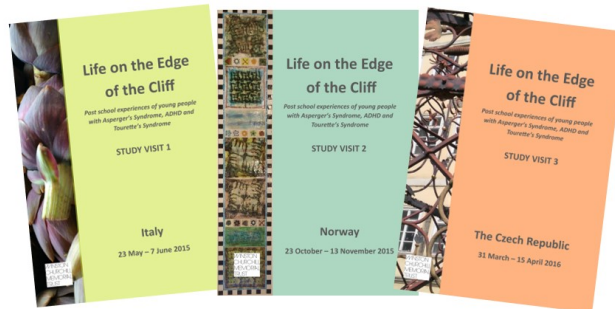
Supporting the transition to adulthood: the experiences of parents, carers and family members

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“I always need to take the hand of my child, and one day my dream is to let him go, for him to be as independent as possible. This is the goal, the real target.”

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Transition – what’s the big deal?

- Changing relationships
- Developing sense of independent self
- Less structured settings
- Unpredictability
- Open choices, far reaching decisions
- Planning and organisation challenges



What families said

- NO CHANGE in level of parental support required
- Sometimes, demands can increase
- Too often support is not effective because it doesn't address need
- Their knowledge, expertise and support role not formally recognised or validated
- Too much focus on theory, not enough on making a practical difference
- Lack of long term thinking



“Sometimes ... someone doesn’t have parents, or doesn’t want mummy and daddy doing this when they are adults ... parents have been parents for a long time and maybe they’ve tried and tried. They need other people to help them.”

Roles families were playing

- Autism expert
- Employment consultant
- Life coach
- Advocate
- Finance provider
- Medic
- Counsellor
- Emergency contact
- Housing agency
- Social network
- Domestic manager
- Support worker



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Care at a cost

- Financial impact
- Pressure on relationships
- Physical and mental health
- Employment
- Future proofing
- Dependency

“I still have to focus on problems all the time and I hate it. This is just bringing us down.”

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DO...

- DO respect the young person's view on family involvement and appropriate boundaries
- DO take time to assess the role(s) family members are currently playing in a young person's life
- DO include families on the same basis as professionals wherever possible, particularly in planning
- DO prioritise communication and information sharing
- DO identify the best person to manage and coordinate support
- DO plan support using ability to manage everyday tasks as a benchmark



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DON'T...

- DON'T make assumptions about the capacity of family members to deliver support. Review this to reflect changing circumstances
- DON'T assume one person's barriers are the same as another's. Assess each person individually
- DON'T ignore the experience and background knowledge of families
- DON'T underestimate challenges related to the condition
- DON'T be afraid to manage expectations



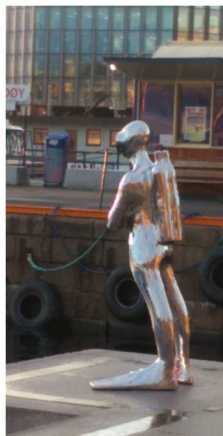
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“I feel the only person who sees how vulnerable my son is now at this moment of transition is me. I see if we don't get it right now we might never ... this is his life at stake. That scares me ... if this fails now his experiences will be connected to therapists, very dependent. So the doors are closing.”

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