

New Writing: Opinion

Shirley Young



Shirley Young is married and the parent of two adult sons. One son has cerebral palsy and since graduating with a degree in Politics and Social Policy runs the Young Person's Information and Advocacy Service at SNIP, a parent-led voluntary agency based in the Royal Hospital for Sick Children in Edinburgh. The other has arthritis and a rare

specific learning disability syndrome. He is currently studying Law, planning to specialize in Human Rights. Shirley began working in the field of childhood disability 19 years ago, co-ordinating eleven specialist play schemes. She was the Director of SNIP until three years ago when she left to become a freelance trainer and consultant. Shirley also sits on the board of Her Majesty's Inspectorate of Education and the Scotland Committee of the Big Lottery Fund. In April this year she was commissioned by Inclusion Europe to work in Moscow and Samara with parent activists (who are seeking inclusive education for their disabled children), teachers and academics from five regions of the Russian Federation. Shirley wrote the lead article, When parents are in denial, for IQJ Issue Number 1 in April last year.

Resistance in the UK to counselling and other talking therapies prevents families of disabled children making the necessary adjustments and adaptations to their situation

Having lunch today with a neighbour, a retired Occupational Therapist, I was talking to her about my frustration that the psychological and emotional impacts of disability on children and their families still go unrecognised and are rarely proactively addressed. She looked aghast and told me that *forty years ago* this same issue was being discussed!

What then do I feel are the probable reasons behind the lack of progress in this area?

1. Cultural attitudinal issues, whereby needing psychological input is seen as weak and needy – 'We British just get on with it!'
2. Suspicion around therapists and their professional credibility.
3. Lack of trained therapists – despite various government initiatives the promised availability is still nowhere near being reached.
4. A purely Medical Model view of disability, with an over-virtuous ideal of total independence, which assumes that to be unable to do everything for oneself without any support whatsoever is 'less than'. Therefore the main, if not whole, focus being on 'fixing' the child's impairment, rather than the wider aspiration of the next item.
5. Working with the child and family to adjust to the reality of life with that impairment.
6. Assumptions that parents of children disabled from birth are 'different' from other parents and by virtue of parenting a disabled child do not experience the same distress, anxiety, loss of expectations etc as do parents of typically developing children who, for instance,

develop cancer, – i.e. that they get used to it and will not need ongoing psychological support.

7. Lack of recognition that parents bring their own 'baggage' into parenting their children and that failure to explore issues from their own childhood can impact negatively on their ability to parent.

8. Lack of awareness amongst practitioners of the range of mental health issues that parents may have, such as Post Natal Depression, Anxiety, Obsessive Compulsive Disorder, Bi-Polar disorder, Asperger's Syndrome etc.

9. Lack of research into the effectiveness of early psychological interventions.

So why do I feel so strongly about this and how do I feel the situation needs to be tackled?

From my own personal experience, and that of many of the hundreds of parents I have supported over the years, I believe that families are going through a tremendous amount of psychological distress and pain that could be reduced if we introduced counselling and/or other therapies right from the beginning, whether that be the baby's birth or from time of the recognition that the child is going to be disabled. This is also borne out by the positive feedback from parents who have accessed free counselling provided by organisations such as SNIP* and the 3Cs Centre**.

I believe that the Team Around the Child should include a clinical psychologist from the outset. This approach is already in place in some of the Scandinavian countries and on a recent trip, working in Russia I was impressed by parents being given regular access to a weekend of input by psychologists to explore these issues. I believe that this approach would:

- give 'permission' to parents and reduce any stigma they might feel about accessing psychological help – it would just be 'the norm' alongside therapies for the child
- complement and extend on from the emotional support being provided to the family by their key worker (where one is allocated, or other practitioner as applicable)
- reduce the over-prescribing of anti-depressants to parents, often for years and years – whilst medication can be helpful, research shows that without access to talking therapies the long-term benefits to patients are reduced
- shorten the time that some parents remain in 'sub-conscious' denial – so shocked by the situation that they are incapacitated and unable to adequately parent their child or access the appropriate supports available

- improve parents' capacity to maintain their relationship with each other and their relationships with extended family and friends – thereby reducing the incidence of family breakdown
- enable parents to set and maintain appropriate boundaries – this would reduce the over-compensating behaviour and inability to discipline that we know is a feature of many parents' coping mechanisms, usually arising out of guilt and shame. It would also empower parents to maintain their own sense of self and to take care of themselves as well as their children
- help parents to adjust and adapt to each stage and transition of their child's life
- reduce the cost of families reaching crisis point – both in terms of the emotional and economic costs to the family and society
- be a support and resource for the rest of the team to enable them to work most effectively with each family.

What sort of inputs could be made available to parents and what are the benefits?

Psychological assessment of the whole family as a standard process with inbuilt review at key 'transition' stages – inherent permission giving/normalising of occurrence, introduction of ideas, opportunity for practitioners to detect early signs of potential mental health issues, addressing needs of family as a whole and siblings from the outset etc.

Counselling allows a safe place to say the 'unsayable', to work through what the parent feels are 'unacceptable' feelings towards their child and then move on from them. Without these opportunities parents may suppress their anger and grief which might then turn into depression or 'leak' out inappropriately – sometimes resulting in them harming themselves, their partner, the disabled child or other children in the family. Counselling also provides a place for people to explore their own past experiences and how these might be impacting on their relationships with their partner and children. A cohort of counsellors would naturally develop, trained specifically in this area of childhood disability.

Cognitive Behavioural Therapy (CBT) focused and practical based 'brief' therapy to help people to reframe and review their responses and ways of 'coping' and managing. CBT offers a practical short term intervention that can feel more accessible and acceptable, and lead to further therapeutic interventions if required at that time and at later identified stages. Moreover, it can provide a framework for support over an identified period, the knowledge of which can itself

be helpful and supportive.

Disability-specific parenting sessions/courses that enable parents with children of similar ages to support each other using such tools as 'Person-centred Planning' and 'Co-coaching' skills to move to healthier coping mechanisms.***

In my opinion, failure to proactively and systematically address the psychological and emotional impacts of having a disabled child on parents will continue to let down future generations of families. I would therefore urge readers to lobby politicians across all parties and in each of the governments to place psychological support for parents of disabled children firmly in their manifesto pledges for the forthcoming elections, alongside the practical supports that are being developed under Aiming High for Disabled Children and being promoted by Every Disabled Child Matters, for Scotland's Disabled Children and Disabled Children Matter Wales.

* SNIP (Special Need Information Point) funded by the City of Edinburgh and Midlothian councils to provide free counselling to parents living in those Local Authority areas. Go to www.snipinfo.org or e-mail snip@btinternet.com for more information.

** 3Cs Counselling Service is a project of Ealing Mencap and is available to parents of children with special needs living/working in the boroughs of Ealing, Hounslow, Hammersmith & Fulham. Contact: 3cs. counselling@ealingmencap.org.uk

*** The author and a fellow parent/practitioner, Claire Edwards, run workshops for parents using these techniques. In addition to being parents and trainers, Claire is a trained counsellor by profession and both Shirley and Claire have benefited from being in counselling. They have both also trained in the fundamentals of Co-Active Coaching. For more information about the workshops contact Claire Edwards, clairemedwards@hotmail.co.uk or Shirley Young, sayoung@yahoo.com