

Helping Parents of Disabled Children Help Themselves with their Relationship

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tional, mental health and family support initiatives aimed at improving outcomes for children, young people and parents. Prior to joining One Plus One, Justine was Senior Researcher at Opportunity Links in Cambridge working with Children's Information Services and leading on Children's Centre research and evaluations of the Children's Fund programme. She has worked within both secondary and further education, the voluntary sector and directly with both local and central government. Justine has a specific interest and extensive experience in participatory approaches and was involved in the design and delivery of the first DfES Children and Youth Board leading to the appointment of the first Children's Commissioner for England.

Summary

Adjusting to the demands of parenthood is a testing time for all couples. When their child has a disability, parents face increased financial worries, isolation, stress, and the prospect that as their child grows, these problems will not diminish. Research shows that poor relationships affect children. Children with disabilities who grow up with parents who have a strained relationship show evidence of poorer physical and psychological health and behavioural problems. However, their parents may be more likely to struggle on with a troubled relationship than separate. The two key elements to supporting these families are reducing pressure and strengthening their relationship

– which in turn will add to the protective factors for their children. One Plus One, the UK's leading relationships research organisation, has developed a new web service for families called thecoupleconnection.net In this article, Justine Devenney of One Plus One gives an account of the service, of how it helps parents to help themselves, and of its focus on parents of children who have disabilities.

Introduction

One Plus One is the UK's leading relationship research charity. The organisation was founded nearly forty years ago by Dr Jack Dominian who, at the time, was a senior psychiatrist working in a large London teaching hospital. Through his work, Dr Dominian found clear links between depression and relationship problems and observed the damaging effects of conflict on children.

Eager to understand more, he founded a small non-governmental research organisation to explore the causes of family breakdown. From the beginning, the organisation, which later became known as One Plus One, demonstrated a passionate commitment, not only to researching the causes, but also to turning research into practice – using the evidence as a basis for developing effective and ever more innovative ways of providing support.

A new web-based service

In 2008, building on the increased use of social networking and new technology, One Plus One launched its first relationship support web-based service. One of the aims was to effectively reach those parents who were not accessing relationship support services through conventional channels. The website thecoupleconnection.net allowed One Plus One to place its wealth of research and practical experience directly into the hands of parents and couples; thus allowing people to work on their relationship for themselves. Two years on, thecoupleconnection.net

has over a quarter of a million users and the organisation has just launched a companion site for separating parents, www.theparentconnection.org.uk

A particular target audience for **thecoupleconnection.net** was parents of disabled children. One Plus One had published a literature review *Growing Together or Drifting Apart? Children with disabilities and their parents' relationship* (Glenn, 2007) which found that couples caring for a child with a disability are at greater risk of marital problems and divorce. The review also found that parents caring for a child with a disability do so in the face of considerable and varied pressures. These include:

- managing traditional gender roles
- lack of time for one another
- dealing with the grief over the loss of the 'hoped for' baby
- adjusting to changes associated with the child's growing up
- significant financial pressures.

Couples' responses to these pressures were found to vary. However, one important factor was found to be the couple's 'coping style' which affects their ability to draw support from each other as well as their ability to handle the pressures and circumstances of their caring responsibilities.

thecoupleconnection.net is unique in that it aims to help couples develop a coping style and strengthen their relationship – making them better equipped to deal with problems before they become entrenched.

The service is free. Moreover if you have the internet, you can access **thecoupleconnection.net** home. For parents of disabled children who are often under financial pressures and may have difficulty getting to services, this accessibility is essential.

How thecoupleconnection.net is structured
thecoupleconnection.net has three sections:

1. Check it Out.
2. Talk it Out.
3. Work it Out.

Check it Out. This section includes a wide range of articles including short films helping parents to explore common relationship struggles including issues specific to having a disabled child.

Talk it Out. This section is an online forum where parents can share experiences with others. This forum is moderated by the Talk It Out Team – a team of counsellors who have many years' experience of helping couples as they work things out in their relationship. This social support is not to be underestimated. One Plus One's literature review found that supportive

spouses protect one another from many of the parenting stresses and risk of depression associated with caring for a child with a disability. One of the ways in which partners lose the ability to be supportive is if they become isolated and cut off from their local community. The Talk it Out Forum provides an anonymous safe space and the opportunity to be part of an online community. Parents who feel isolated can give and receive valuable peer support or just offload some of the day-to-day strains – and this can make a significant difference.

Work It Out. This section on the site is where parents can access their own 'personal space' and where they are presented with articles and resources relevant to their particular circumstances. It is in this private section that they set goals for strengthening the relationship.

The service is built on One Plus One's tried and tested five-stage Helping Process:

Exploring > Understanding > Making plans > Making changes > Review

This is how it works:

1. When we are worried, unhappy or unsure about something, it helps to use general information, expert relationship advice and the experiences of other people to explore what might be going on for us.
2. As we explore our situation, we start to get a clearer understanding of what's really going on. We begin to recognise our feelings, how they shape our needs, and how those feelings influence what we do.
3. Acknowledging feelings is a critical basis for working things out and making changes because we begin to recognise why we behave as we do and how that is helping or hindering us from achieving what we want.
4. Talking and listening to others whom we trust because they know us well or have experience of dealing with kinds of relationship problems we are going through helps us to plan what we want to change, and how. The hardest part of the process can be putting your plans into action and making changes to your relationship.
5. Being able to **review** the different stages in the helping process and see what has changed not only gives us a sense of achievement but it makes us better able to cope the next time a problem arises.

So in summary, the helping process allows us to take a different perspective on our daily lives. This

clearer view allows us to make plans and effect positive change in our lives which helps in avoiding relationship issues.

Negative cycles of behaviour

Specific disabilities involve different caring demands and this could explain differences in how well couples cope. Where couples cannot manage these pressures or lack sufficient support to deal with them, the relationship often breaks down. In some cases, couples stay together but get caught up in negative cycles of relating that exacerbate, and are exacerbated by, challenging child behaviour. In particular, mothers who feel unsupported may be more critical of their partner, resulting in conflict and the father withdrawing from family life, leaving the mother feeling even more unsupported.

There is a growing body of evidence showing that children who grow up with parents who have a poor couple relationship are more likely to have poorer physical health and behavioural problems compared with peers whose parents get on well.

thecoupleconnection.net has a range of short animations called Relationship Insights that couples can use to gain a deeper understanding of what might be going on in their relationship. Some of these films explain negative cycles of behaviour and what happens when a partner feels unsupported – whilst others help couples understand when to seek support and demonstrate the difference it can make.

As a web-based service, **thecoupleconnection.net** does not seek to replace the need for face-to-face practitioner support – rather it aims to complement and add value to the specialist support many practitioners give.

A new guide for practitioners

Practitioners play a significant part in families' lives. Where support works well, practitioners co-ordinate the range of services that parents deal with, and are an important source of emotional and practical assistance. However, when it comes to supporting couples with relationship issues, many practitioners say they feel anxious, uncomfortable and unsure how best to help.

One Plus One has recently produced guidance on how practitioners can use **thecoupleconnection.net** effectively as an aid to their work. This guidance will be disseminated through PCTs, Children's Centres, and local authorities. We hope this will help practitioners know where to turn when they need additional resources and be a trusted service to which they can signpost parents for them to use in their own time.

One Plus One's survey

In January 2010, One Plus One conducted the first survey of **thecoupleconnection.net**. This is what we found:

1. 73% of users said they valued being able to get relationship advice any time of the day.
2. 81% of users said that they were now more confident in dealing with relationship issues.
3. 92% of users said they could see that the real reason behind a relationship problem was not what they originally thought.
4. 94% of users said that knowing the Talk it Out Team checked all posts and comments made them feel more comfortable when using the website.

The survey findings are encouraging, however, three years on from launching the service and publishing the review, One Plus One would argue that more needs to be done to understand the relationship dynamics of couples caring for a child with a disability. Different forms of data are needed, including: longitudinal data to look at risk and protective factors as well as the 'lifecourse' of these families; in-depth accounts of the experiences of parents and other family members; and information on what makes a supportive intervention.

In these uncertain times and with cuts in those services that support parents of disabled children, there is great need now to:

- ease the financial burdens under which many parents operate
- extend supportive services beyond the early years and make them available to children with a range of disabilities throughout the lifespan
- enhance the skills and co-working of those offering support
- break down professional disciplinary boundaries
- ensure support is available at times of change, challenge and crisis.

Many parents with a disabled child say they feel isolated and find they are faced with a range of unexpected financial, social and emotional pressures – so it is hardly surprising that many relationships break down. Whilst some couples find these difficult issues bring them closer together, others find it really hard to stay connected. One Plus One, through **thecoupleconnection.net** is committed to helping parents stay engaged with each other by giving them a structured approach to strengthening their relationship.

Further information

More information on One Plus One's services including our new service for separating parents:

visit www.theparentconnection.org.uk or go to www.oneplusone.org.uk, or contact One Plus One at info@oneplusone.org.uk

A downloadable copy of the Practitioner Guidance is available from One Plus One.