



Forgotten Families

The impact of isolation on families with disabled children in Scotland, Wales and Northern Ireland

In Scotland,

148 families with disabled children in Scotland responded to our survey (13% of the total).
70% said they experience poor mental health such as depression or breakdown due to isolation.
51% felt so unwell they have asked their GP for medication or have seen a counsellor
64% felt most isolated when their child was first diagnosed.

"I would love to be able to know that I could go anywhere with my son, because everywhere would be set up to cater for the needs of disabled people. My son is desperate to go to the local park and play with the other children but he can't because there are no disabled swings there. I hate walking past the park as he just cries, because he wants to go there more than anything. I dearly wish that I could walk past any park, see all the children playing and take my son in to join them."

"Other parents look at me differently so sometimes we don't go out the house, so the family has lost many of the normal day to day interactions. We are also restricted by all the appointments with the occupational therapist, orthopaedic surgeon, doctors etc rather than seeing friends. Giving up work has had a considerable impact on the family not just socially, but also financially"

As a result we are calling on the Scottish Government to ensure:

- funding to enable parents, carers and families to have a voice, as equal partners in making decisions about services that help them lead a more normal life and feel less isolated.
- funding and support to allow parents to act as volunteer parents so that they can develop peer support approaches to reducing isolation within their own communities, connecting families and sharing common issues and concerns.
- that services offered are responsive to changing needs, lead to the best possible outcomes and are delivered where possible within the home community, as recommended in the Doran Review.
- that carers, including parents of disabled children, are supported to manage their caring responsibilities with confidence and in good health, and to have a life of their own outside of caring as recommended in Caring Together, The Carers Strategy for Scotland 2010-2015.

In Wales,

146 families with disabled children from Wales responded to our survey (12.7% of the total).

71% say they experience poor mental health such as depression or breakdown due to isolation.

48 % felt so unwell that they have asked their GP for medication or seen a counsellor.

60% felt most isolated when their child was first diagnosed

47% felt most isolated during school holidays.

“For the first few years, I felt very isolated, we were forced to move into a rural council estate with no amenities as our original house was too damp. Me and her father split up when she was 18 months old. I would try to take her to parent toddler things but we just didn’t fit in as the gaps between her and her peers grew bigger. She was unable to sit unsupported so couldn’t be on the same level as other children.”

“Cerebral visual impairment is a much misunderstood condition, and has resulted in a lot of self education. To have your baby and very young family to raise and having what seems like nowhere to turn for answers is very isolating.”

As a result, we are calling on the Welsh Government to commit funding to:

- the Early Support programme beyond March 2012.
- implement Section 25 of the Children and Young Persons Act 2008 to increase the duty on local authorities to provide short break services.
- enable health bodies to implement the Carers Strategies (Wales) Measure to provide effective information and support to carers including parents with disabled children to enable them to both continue to care and achieve a more normal life.
- ensure that parent carers have a voice and are partners in making decisions about services that help them lead a more ordinary and feel less isolated.

In Northern Ireland,

47 families with disabled children responded to our survey (4% of the total),

81% said they experience poor mental health such as depression or breakdown due to isolation.

79% felt that a lack of support from statutory services caused their isolation.

79% felt most isolated when their child was first diagnosed.

“Gareth is an only child and despite the difficulties we love him dearly. We do worry about getting older and trust that we remain fit and able to care for him as long as possible. In relation to our own mental health, I think we have become used to living on the edge although we are aware that the stress is bound to take a toll. It is difficult to find ‘me time’ and we are not able to take part in family get togethers as Gareth doesn’t cope well with noisy voices or lots of people. I recently lobbied at Stormont to fight for retained funding for clubs for children and young people with special needs in our area but sadly it fell on deaf ears. Families were able to get a little respite while the club was held however the service sadly ended in March this year.”

We are calling on the Northern Ireland Executive via its Programme for Government 2011–2015 to make a specific commitment to improving outcomes for disabled children and their families by:

- funding a range of early intervention services such as short breaks and specialist family support to help families deal with the impact of caring for a disabled child on family life and minimise isolation and mental ill health.
- improving the provision of integrated and co-ordinated services across health, social care and education
- ensuring that parent carers have a voice and are partners in making decisions about services that help them lead a more ordinary life and feel less isolated.