Rethinking siblings and mental illness

Christopher Griffiths and **Jacqueline Sin** offer support for the brothers and sisters of people affected by mental illness

Siblings of people with mental illness can have a positive effect on their brother's or sister's recovery and reintegration into social environments, through providing emotional and practical support and opportunities for socialisation. However, the experience of having a brother or sister with mental illness can have negative consequences on a sibling's quality of life and mental health. Unfortunately, siblings of people with mental illness remain largely invisible to statutory services. The Siblings Network has sought to address the needs of siblings and raise awareness.

questions

How can we ensure that the needs of siblings are met by services – both statutory and third sector?

How can the importance of the role of siblings in the lives of people with mental illness be highlighted?'

resources

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For the majority of us our relationships with our brothers and sisters are some of the most important in our lives. Sibling relationships can be a great source of meaning, enjoyment and mutual support, but they can also be challenging at times. When someone finds out that their sibling has a mental illness, they must learn to adapt and cope with this, and this adds a new dimension to the sibling relationship. For the brothers and sisters of someone with mental illness, this can be a very difficult and traumatic experience that can negatively affect their own health and well-being (Marsh, 1998), the inter-sibling relationship and wider family relationships (Corrigan & Miller, 2004).

Siblings' experiences have also influenced service development in recent years in the UK as well as worldwide. In particular, we report on the Siblings Network, an innovative mental health campaign for siblings run by the charity Rethink Mental Illness since 2007.

Impact of mental ill-health on siblings

More than 80 per cent of the general population have at least one sibling, and sibling relationships often outlive any other kind of relationships (Smith et al., 2009). Some argue that the quality of sibling relationships, especially during late teenage and early adulthood, is predictive of the long-term relationships between siblings well into their old age. Moreover, the majority of mental health problems, for instance, psychosis and bipolar disorder, typically appear in young people (Department of Human Services, 2005). Therefore, onset of a mental illness in a young person is a major life-event, not only for the individual but also for their sibling/s (Sin et al., 2012).

The mental health and well-being of a person with a sibling experiencing mental illness can be negatively affected by a number of factors (Greenberg et al., 1997; Lukens et al., 2004; Marsh, 1998; Marsh & Dickens, 1997; Riebschleger, 1991). These include:
- increased objective and subjective burden (such as greater responsibility within the family unit);
- possible loss of support (social, emotional, financial, etc.) from their sibling;
- changes in role (such as taking on new supportive roles);
- intense and conflicting emotions (e.g. confusion, despair, hopelessness, anger, and grief);
- interpersonal and intrapersonal difficulties; and
- difficulties in trying to deal with the mental health system.

These factors can contribute to the increased risk of the person experiencing mental illness themselves (Friedrich et al., 2008). The stigma of mental illness can add to the burden that a person faces. It can be a difficult choice: if they tell other people about their sibling's mental illness they might receive support and valuable information, or they might be shunned, lose friends, or experience discrimination. Recent research into siblings of individuals affected by first-episode psychosis has identified that perceived stigma could intensify the siblings' feelings of loneliness and isolation, as many would choose not to share their burden with their close friends or teachers (Sin et al., 2012).

Another negative factor is the impact of their sibling's mental illness on their parents. One of the siblings in the Siblings

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Network said: 'there's so much of a reason to worry about your parents because you just want them to be happy and seeing that they're highly anxious as well... that has an effect on you and your relationship'. Many siblings reported decreased attention from parents on themselves or their younger siblings. Parents often struggle to explain the situation to the younger children, and there can be a heightened sense of negative emotion at home. Some siblings may even feel resentful towards their ill brother or sister, blame themselves for not being empathetic enough and then grow increasingly detached (Sin et al., 2012).

Having a brother or sister with mental illness is not an exclusively negative experience; there can be positive aspects too. For example, a sibling may feel more compassionate and tolerant of others who experience mental illness, or they may constructively reassess their life meaning and values (Jewell, 2000). Some siblings report that their experience led to a closer sibling relationship and a stronger sibling bond (Sin et al., 2008). Siblings have also reported benefits related to the family unit, such as more resilience, more cohesive working and more family supportiveness (Sin et al., 2008).They may also gain coping skills and knowledge through their experience that they can use to benefit their own lives. Additionally it may lead to new opportunities and new life directions. One of the siblings in the Siblings Network stated: 'My twin brother suffers from

A sibling may feel more compassionate and tolerant of others who experience mental illness

schizophrenia... so, I started getting involved and doing voluntary work all last year. I'm set to do a second degree in mental health nursing.'

Coping and recovery

For many people with experience of mental illness their siblings are key people in their lives. Siblings of individuals with first-episode psychosis often act as secondary caregivers and as a valuable resource for their brother or sister in both recovery and normalising activities (Birchwood, 2003) and providing opportunities for socialising (Stein & Wemmerus, 2001). Some siblings view their role as being instrumental in their brother or sister's well-being and recovery (Sin et al., 2012), through engaging and reintegrating them into appropriate activities and roles within their social circle. These activities could be as simple as family gatherings, joining a yoga class together or going to a music festival. One sibling in the Sibling Network stated: 'There's also a lot of inspiration and hope in terms of the great things that you share as a sibling with your brother or your sister. We do have a great laugh... there's a lot of positive things along with, you know, this wave of negative stuff which comes with it.'

The coping strategies that siblings employ when they find out that their brother or sister has a mental illness, and the ongoing consequences of this, are crucial to their health and well-being. Some employ positive coping and adaptation strategies, such as seeking

out information and support, whilst others use negative coping and adaptation strategies, such as dissociation, drugs and alcohol, denial or withdrawal from peers or family (Jewell, 2000).

A long and painful journey

There are a number of books where siblings describe their experience of having a brother or sister with mental illness. *Circles Around the Sun* by Molly McCloskey is a family memoir in which the author seeks to understand her brother's life in the context of his experience of schizophrenia. In this book readers are provided with the author's perspective of her brother's life and their relationship, the connections between them and their family and a mutual sibling love reconstructed and renewed over time. The author seeks to understand her brother as a potential key to unlock a deeper understanding of herself. Throughout the story, you can see the different roles family members take in relation to her brother's care, the effect mental illness has on their own well-being and relationships and the journey of each in coming to terms with what has happened and learning to adapt and cope. Molly McCloskey's journey to a better understanding and relationship with her brother was a long and often painful one; greater access to information and opportunities to connect with other people in a similar situation could have shortened this journey.

Existing projects and the Siblings Network

Research focusing on siblings of individuals affected by mental illness to date is lacking (Sin et al., 2012). Existing research for family-based interventions, such as for psychosis and psychoeducation, often targets parents, especially mothers, as participants. Despite a family-inclusive ethos underpinning community mental health services nowadays, siblings remain largely

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invisible to the statutory services. There can be a number of reasons for this: for example, health services are only designed to meet the needs of primary caregivers, and there is a lack of recognition within mental health services of the role that siblings can play. Healthcare professionals may assume that a person's parents, children or partner are the key people in their lives (Sin et al., 2008). In addition, parents may shield a sibling from contact with mental health services (Sin et al., 2008); there may be a fear of family separation due to child-protection issues (Gray et al., 2008); and siblings may not identify themselves as carers and so do not consider themselves as being able to access health services, even though they may play a significant part in providing support for their brother or sister (Sin et al., 2012).

Whether they have access to support from health services or not, siblings can access information on mental illness, coping strategies and peer support provided by non-governmental organisations. A number of networks for siblings supporting a brother or sister affected by long-term illness or disabilities have arisen across the world over the last decade. For example, The Canadian Mental Health Association has produced a *Sibling's Guide to Psychosis: Information, Ideas and Resources*; Australia has its own national sibling's network run largely online (www.siblingsaustralia.org); and there is a USA-based Sibling Support Project (www.siblingsupport.org). The UK has its own generic sibling support organisation called Sibs (www.sibs.org.uk) that supports siblings of people affected by chronic illnesses and disability.

In 2006 Rethink Mental Illness undertook a survey of nearly 300 siblings of individuals affected by mental illness (Rethink/Canning, 2006). The survey findings identified a gap in support and information for siblings of people who experience mental illness. In particular, siblings themselves expressed a need for a dedicated webspace for information, a discussion forum and peer support amongst siblings. Siblings interviewed stated that they wanted information about their brothers' or sisters' diagnosis, about how to cope practically with symptoms such as psychosis, about services and about how to help promote recovery. They said advice on how to deal with hallucinations and delusional beliefs would be particularly helpful. Rethink Mental Illness also drew on research (e.g. Landeen et al., 1992) that reported that siblings expressed the desire for phase-specific information on mental illness and to know about prognosis, problem solving,

symptoms and treatment. Based on this identification of needs Rethink Mental Illness submitted a bid to set up the Siblings Network, and gained funding from the Big Lottery Fund.

The Siblings Network has two main aims: to provide the siblings of people with mental illness with the tools to support their unwell sibling and family to better cope with the challenges mental illness can bring; and to provide them with support in order to improve their own health and well-being. To achieve these goals the project offers a variety of resources. It provides the option of joining an online sibling forum to engage with other siblings in conversation, joining a sibling support group to meet with other siblings to share experiences and advice,

Siblings may not identify themselves as carers

attending workshops, being part of the project steering group, writing a blog or sharing their story online and downloading sibling-focused videos and advice and information factsheets. These resources are accessed via the Siblings Network website and they continue to be shaped by the feedback obtained from siblings. The Siblings Network also ran two national events for the adult brothers and sisters of people affected by mental illness. So far there have been over 50,000 unique visitors to the website.

Rethink Mental Illness also surveyed health professionals in relation to support for siblings. It was found that 27 per cent said they were never in contact with siblings, while 23 per cent said they were in contact with siblings in only 1 out of 10 cases. However, 90 per cent agreed that siblings should receive emotional support in family intervention work, and 75 per cent identified a need for siblings to be involved in support groups. In order to engage professionals in the goals of the

project and encourage the sharing of best practice and ideas, the Siblings Network has set up an information network for mental health workers and organisations, which includes an online forum and a quarterly newsletter. This has brought forward some great examples of best practice. For example, the Worcestershire Early Intervention Service demonstrates how to include siblings in all family-inclusive service provisions.

Feedback has been gained from people using the resources provided. A sibling reported that the network positively impacted on their identity: 'I have felt invisible for years as a sibling and this network and support has given me my sense of identity back.' One person attending a support group said: 'I shared things with the group that I had never been able to say before, and got a lot of helpful advice from people who had gone through the same things on how they coped.' Another person who attended a Youth Mental Health First Aid course for siblings commented: 'It feels great to have connected to such supportive, insightful and friendly people. I feel like I can cope a bit better and also keep a healthy space for myself as well as keep helping my sister'. Another relayed that their brother was 'touched' that they went along to a workshop and that they were showing an interest in their experience of mental illness.

In conclusion, siblings can be greatly affected by the mental illness of their brother or sister. Despite this, there can also be positive outcomes that can be maximised through resources provided by projects such as the Siblings Network. Siblings are a highly vulnerable, ostracised and marginalised group: their experiences and views need to be taken into consideration in research and in making key decisions in policy and building supportive relationships in healthcare practice.

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We are specifically looking for someone who is able to take forward two key workstreams. Firstly, the successful candidate will have an interest in international education in psychology and in collaboration with psychologists working outside of the UK, and will be able to draw on this to support the development of our accreditation process to accommodate international provision. Secondly, we are looking for someone who will be able to review the ways in which our present governance structure supports the delivery of the accreditation process, with a view towards enhancing member engagement in our work. Overall, we are seeking an individual who will be able to champion our work and help us work with our partners to develop it further.

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