Supporting Disabled Parents:

Community of Practice

Summary and Resources Document

Week 3

Our third session of Supporting Disabled Parents: Community of Practice took place on the 24th of March, introducing Leann a mother of two with an Acquired Brain Injury (ABI), that she acquired in adulthood. Leann spoke of her lived experience recovering from a stroke while pregnant and the implications it can have on family life and mental health. We were also joined by Dr Phil Butler who works with the National Rehabilitation Hospital (NRH) and who has developed resources to support rehabilitation teams focusing on the lived experiences of mothers living with ABI and the needs of families affected by ABI.

At age 31, Leann was working as a dental nurse while pregnant with her second child when she suffered a stroke. When she first presented in hospital Leann was given a CAT scan before being left in a corridor for 24 hours, when a nurse noticed the position of her hand Leann was only then given an MRI. As a result of the stroke Leann had limited vision in her left eye and a marked tremor in her arm. As she was pregnant at the time, Leann could not access pain medication and was told that she would have to wait until after she had given birth before any interventions were possible. After having her baby, Leann spoke about 'being on a high' meeting with The National Rehabilitation Hospital (NRH) and having a short discussion about having a newborn, however she stated that reality was six months

away when the baby started to move around and she struggled to adapt. During the discussion following her presentation, the issue of **changing needs** was brought up highlighting how different kinds of support may be required by a person or family at different times.

Managing stroke fatigue, with reduced sight in her left eye, and a marked tremor, Leann sought help from a stroke team who attributed her concerns to anxiety. Through her own research Leann found that her symptoms were like that of the Holmes tremor, but her medical team dismissed her concerns and discouraged her from liaising with other neurologists. Leann eventually contacted a neurologist from Vancouver, who validated her experience and confirmed her diagnosis. She subsequently had Deep Brain Stimulation (DBS) surgery in London, and this has reduced tremors significantly and improved her quality of life.

As creches were closed throughout Covid, Leann was mentally and physically drained having no time for respite during the day, she spoke about how much difference an hour of help would have made. Told that she 'looked well' as her symptoms were hidden, Leann found that she was plastering on a smile to get through each day.

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As mentioned in previous sessions Leann said that her children were extremely independent and aware of her emotions, and she was conscious of letting them be children free from stress and able to enjoy things that other children do. Leann reflected on the differences between having a child with no disability and having a child with an acquired brain injury.

Dr Phil Butler developed a study on the best practice considerations for the health service: **Working with Mothers with Acquired Brain Injury, including Stroke**. Through conducting narrative interviews with 10 women who were mothers before their brain injury, both practical suggestions for Healthcare Professionals (HCP) and broader suggestions for health and social policy were developed. The document reflects the specific needs and unique situations of mothers with ABI and can be used by HCPs when working with this client group. A pdf of the guidance document accompanies this summary.

The following practice and policy recommendations were made by the group in terms of recognising the unique experience of mothers with an ABI, and their subsequent support needs:

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- HCPs should be mindful that mothers may feel the need to mask hidden impairments or sequelae and, bearing this in mind, should strive to ensure that a thorough assessment of support needs is conducted.

- HCPs should acknowledge the challenges for mothers at all stages of their children's life cycle. For example, mothers of toddlers may need support with performing childcare tasks while mothers of teenagers may need support with providing emotional support to their children.

- HCPs should consider running a support group specifically for mothers with the following criteria:

◊ Available to mothers who are at least six months post-injury;

◊ Open group – people can join at any time;

◊ Ongoing long-term group, run fortnightly or monthly;

◊ Hybrid – in person and virtual options;

◊ Facilitated by 2 members of an interdisciplinary team;

◊ Have 'experts by experience' available to speak to the group;

◊ Have an educational session on the compassion focused model to encourage self-compassion.

The group also recognised the need for ongoing rehabilitation support after the acute phase and the need for supports for other members of a family where the mother has ABI, particularly the children. With regards to policy considerations the group felt that there is a lack of awareness and understanding by healthcare professionals particularly in acute hospital settings of the impact of hidden sequelae of ABI. The group proposed Education and training for healthcare professionals through their training and as part of their Continuing Professional Development (CPD). Modules on brain injury should be made available to healthcare professionals and should be included in their training.

The group noted the lack of awareness in the public in understanding hidden challenges such as fatigue and information processing difficulties and recommended public awareness campaigns on the hidden nature of ABI, as well as making suggestions for both the support of mothers and support in returning to work.

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Peer Support Department of Children What Works Fund

The What Works initiative, led by the Department of Children, Disability and Equality supports evidence-informed prevention and early intervention services for families, young people and children, including the **Parent Peer Support** initiative, launched under Goal 2 of Supporting Parents: A National Model of Parenting Support Services (2025/26 Parent Peer Support Fund). Peer Support offers an informal and non-judgemental environment for individuals who can share experiences and struggles with others in similar situations. Peer support groups complement professional mental health services in offering emotional support and connecting individuals with a community who can help reduce feelings of isolation and loneliness. Engaging in a network can strengthen a person's sense of belonging through forming social ties and maintaining relationships, while also offering practical tips and normalising the reality of daily life. The benefit of peer support groups is that it is low tech, addressing both psychological and social needs. Throughout our sessions so far, our participants have reiterated that **support makes a difference** and connecting with others living with similar circumstances can help with confidence in managing the challenges that come with disabled parenting.

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