

Families contribute to mental health information portal

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MindEd for Families aims to tackle stigma around poor mental health.

For Julia Ogden, raising her beloved autistic son can be like bridging the gap to an alien world, one that can be difficult to navigate and interpret.

She has had to work hard over a number of years to identify and access networks for information and support for parents and carers. Now, Julia has worked with academics at the University of Exeter Medical School, to contribute to the MindEd consortium creating an "invaluable" online portal to help families with children affected by mental health issues.

Launched today, MindEd for Families, funded by the Department for Education, aims to tackle stigma around <u>poor mental health</u> and to give parents and carers access to information anytime and anywhere. The resource aims to benefit families across the country, including the South West, a region with one of the largest increases in cases of self-harm and



a rapid increase in youngsters being referred to mental health services.

The new portal for families follows the success of MindEd for professionals and volunteers, launched in 2014. MindEd aims to strengthen coping strategies, resilience and to speed up measures to help families.

The resource will cover topics ranging from 'the aggressive and difficult child,' 'self-harm and risky behaviour,' and 'eating problems' to 'the Journey,' 'keeping ourselves strong' and 'child sexual abuse and child sexual exploitation.'

Julia, who lives in East Devon with her 13-year-old son, helped create a section around 'diagnosis', one of 35 new bite-sized e-learning topics, individually tailored to equip families with the skills to identify and support a child with a mental health condition. It also provides guidance on mental wellbeing.

Julia, a former special needs teacher who gave up work to meet the needs of her family, said: "Loving and living with a child who has difficulties, differences or any disability turns life on its head. It can be a bewildering, exhausting, and often terribly lonely place. I hope this resource can reach out and, in some small way, offer families understanding and support. I know too well how deeply it is needed and yearned for."

Julia described how her life had changed through caring for her autistic son. She said: "For me, the autism diagnosis is for my son, and not of him. It should help him but not define him. He is the biggest privilege and I've learned so much from him. Yet there's a massive gulf between us and the rest of the world. Sometimes it has felt like he's on a boat with no oars, drifting further and further away, and I have to swim out to help him. I have to translate for him – to provide a stepping stone so that



he can interact with society. He thinks, feels and perceives a bombardment of information. He has no filtering mechanism on life, and it's exhausting for him. I wouldn't have him different for the world – sometimes I just wish that the world would see him, and others like him, differently. I feel it's my role to try to make that happen."

Julia said the new web portal would provide much-needed signposts to highlight support and information. "It really helps to cut through the fog," she said. "It helps people know they're not alone, and makes it much easier to identify where they can find help."

Exmouth-based teacher Kris Buglass felt isolated when her daughter Holly, now 17, first suffered severe anxiety that disrupted her studies and her life. Kris contacted MindED and became a parent author, advising on a section on "transitions in schools". She said: "Dealing with mental health issues in your children is really hard. You end up blaming yourself as a parent and there was just no information available. MindED is a fantastic resource because it makes it very easy to find strategies that can help, and it's also about the networks. It's really important to know that help is out there."

Professor Tamsin Ford, child and adolescent psychiatrist, said: "There are lots of misunderstandings and suspicions about the use of diagnoses in relation to children's mental health. We wanted to make sure that parents understood what a diagnosis was, what it could and could not do and how to get one if they wanted one."

Dr Ginny Russell, a developmental psychologist at the University of Exeter Medical School, said: "With more and more children being diagnosed with mental health issues, it is important for parents to know why, if, and how, diagnosis is of benefit. This MindEd website will really help parents by creating a simple, practical resource co-authored by academics, clinicians, as well as parents themselves."



Dr Raphael Kelvin, Child Psychiatrist and Clinical Lead for the MindEd programme, said: "We know that up to three children in every classroom have a diagnosable mental health disorder and half of all lifetime cases of mental illness begin by age 14. Left untreated, these disorders have the power to impact on a child's education and their ability to interact with others which can have a knock-on effect on employability and their lives as adults. That's why giving families the knowledge and information to support early effective intervention is essential.

"We would not have been able to develop MindEd for Families without the support of parents and carers themselves. Learning from their experiences and the battles they faced enabled us to identify the key stages of a <u>family</u>'s journey, pin point the information that would be of most use to them and display it in a user friendly format that is most appropriate for parents and families.

"Since its launch in 2014, we had great success with MindEd – the website developed for adults who come into contact with children through the workplace. To date, there have been over 1 million site visits with 24,000 people fully signing up who between them have completed over 60,000 e-learning sessions. We hope that MindEd for Families is equally as successful and most importantly, provides much needed support to families experiencing times of crisis."

Education and Childcare Minister, Sam Gyimah, the first Minister in the Department for Education with specific responsibility for mental health, said: "Growing up in today's world presents all sorts of challenges for our young people – one in ten will experience mental health issues. To stop these issues blighting their life chances it is vital that children get the help they need as soon as possible.

"Parents and families already do a fantastic job of supporting their children but mental illness can be daunting. We want everyone to feel



confident they have the information and skills they need to tackle this issue – that's why we funded this website, which has been designed by families, for families.

"Alongside the government's £1.4 billion investment in children's mental health services and our £3 million project with NHS England to link schools better to those services, we can make sure young people get the help they need when they need it."

Dr Kelvin continues: "To quote Albert Einstein, if we keep on doing what we have always done, we will keep on getting the results we have always got. MindEd for families is a simple tool which if utilised, has the power to help parents to find new and better ways to navigate what's regarded as being a scary or daunting terrain. It's like having a mental health & wellbeing sat nav in your hand, always on and freely available."

Provided by University of Exeter

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