Sibs – A day for adult siblings, Manchester

I’ve only recently discovered Sibs (my older sister Alison has Down’s Syndrome), and I was really looking forward to making my first connection with the charity on their Adult Sibling Day. I am so grateful Sibs went ahead with the event on 14 March which, as we now know, was held shortly before the UK went into lockdown. My experience of the day and knowing how Sibs uniquely understands how we, as adult siblings, are coping in this current situation, is somehow making the stresses and strains a little bit more bearable. I can’t visit my sister for the time being and that’s hard, but with Sib’s support I know I’m not alone.

As for the event itself, for the first time in my life I was meeting fellow adult siblings and realising we all shared the same experience: wow! Describing growing up with a disabled sibling to someone who has non-disabled siblings, I have often found difficult to articulate, but was in this lovely hotel conference room filled with people who just “got it. Finally, I felt none of my usual awkwardness. I was particularly moved by the personal stories related by adult siblings Prakesh and Joe. All the speakers throughout the day were insightful and knowledgeable. Afterwards gave me some really helpful advice on my Appointee role. The day finished with a relaxing mindfulness session and a chance to stay and socialise at the close. I finally headed home armed with plenty of food for thought and useful information to further explore.

Thank you for a great and supportive day, Sibs!” Helen Davis, sibling

Sibs are a charity who work to support siblings of all ages. To find out more https://www.sibs.org.uk

BOOK REVIEW

Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion


I recommend this book to people who have an interest in children or adults with profound intellectual and multiple disabilities. It is particularly relevant to teachers, scholars and postgraduate research students. I believe it will also provide interesting and engaging reading for...
students and professionals working in health and social care.

The book has adopted the internationally accepted term ‘intellectual disabilities’ within its title. Readers be aware authors use the terms intellectual disabilities, learning disabilities and also learning difficulties. Despite these terms in the context of this book they refer to the same people (defined on page 1).

The book explores how individuals approach people with profound intellectual and multiple disabilities within education, research and across the wider community. The book is structured into three parts ‘Belonging in education’, ‘Belonging in research’ and ‘Belonging in communities’. Each part explores and challenges policy, legislation, social provision and social and cultural development drawing on contemporary research and personal insight.

The contributing authors, each an expert in their field, include family members of people with profound intellectual and multiple disabilities alongside respected researchers and practitioners from a variety of educational and clinical backgrounds present a vivid multinational story. The inclusion of fellow traveller accounts brings a personal richness to the book. The book begins with its dedication to a wonderful lady Johanna de Haas. Johanna was an immense source of inspiration to all who knew her and a key member of the social history of learning disability community at the Open University.

The structure of the book lends itself to either be read from cover to cover or by dipping into one section or chapter at a time. Whichever route you choose I would urge you to start by reading chapter one and then perhaps chapter eleven.

The contributing authors provide an opportunity for us to scrutinise our practice and how we nurture relationships with others really does push the boundaries in how we approach people with profound intellectual and multiple disabilities.

In summary, this highly readable book provides real examples of how boundaries to inclusion of people with profound intellectual and multiple disabilities have and are being pushed. It challenges us to individually and collectively reshape boundaries to inclusion. I encourage you to push against the boundaries and shape the future.

#Belonging #PIMD #PMLD

Jillian Pawlyn. Registered Nurse (Learning Disabilities) @JillianPawlyn

Oily Cart update

Oily Cart are a theatre company who specialise in creating sensory theatre made for and with children and young people with PMLD. We exist to serve our audiences and artists and are aware of what a distressing me this is for many of the families we work with and have huge respect for. We are sending out our love and solidarity.

Over the next 18 months we will take our inclusive theatre onto streets and into homes, making as much noise as possible to ensure that our young audience and their families are being heard now and as things transition to the ‘new normal’. We will use our resources to respond to what families tell us they need. Shielding should not affect anyone’s right to creativity, their right to connection and their right to play.

To kick this new programme, we’re very excited to share 3 interactive, creative ‘Sensory Sessions’, inspired by sensory moments in our show ‘Jamboree’. Making Shadows, Colour and Movement and Making Noise can be enjoyed individually or all together. The Sensory Sessions was made in collaboration with families during lockdown, and are designed to be used at home and in other settings.

We have also created a private Facebook group especially for families with a young person who has PMLD. We would love you to join us there for sensory ideas and activities, resources from other relevant organisations and to have your say about what you need from Oily Cart at this me. We want to hear from you and your young person!

You can join the Oily Cart Families Facebook group here https://www.facebook.com/groups/OilyCartFamilies/?source_id=151594858186715