PMLD LINK
sharing ideas and information

Communication

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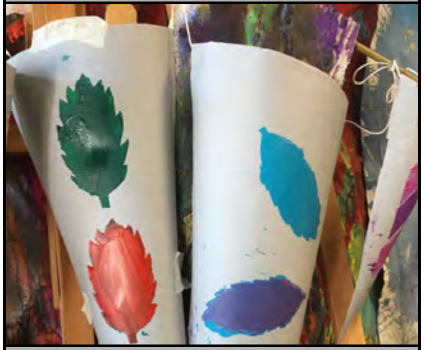

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Cover picture: provided by Jenny Buckland

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Losing control

Rachel Wright

One of the first things to evaporate, when parenthood to a child with complex needs arrived uninvited, was my sense of control. That and sleep – sleep became a long distant memory. Foolishly I once thought I was the master of my own destiny. With rose tinted glasses I can fondly remember a time when, if I needed some groceries, I could pick up my wallet, keys and walk out the door. I remember a time when cleaning a midnight tide of poo and wee would have turned my stomach rather than be a normal Monday night.

Caring for a child with complex needs, meant my life and my diary was skewed by a growing list of professionals and their lengthening to-do lists. While my home became a collecting ground for specialist (and often ugly) equipment.

Loss of control is the same for anyone hearing the carefully crafted words of bad news.

In the beginning, there is a life-changing diagnosis or trauma. This defining moment splits life into before and after. Everything changes; perspective, hopes, dreams and expectations for the future.
Suddenly you are in the middle of a whirl wind of activity you barely understand, never mind determine. The best option becomes hunkering down in the eye of the storm as people buzz around like bees on illicit drugs. All the while, life ticks by with the slow monotonous pace of a midnight clock; relentless, persistent and unfazed by tragedy.

Then comes the invasion. Professionals, therapists, specialists and practitioners (even your sister's hairdresser), walk into your life to give advice, instructions, options and varying levels of fear or hope. In the midst of overwhelming change, you are left standing in the present.

The rope of life once clung on to, ruthlessly slips through fingers, no matter how tightly it is gripped by hands. Instead of climbing, slump to the ground deflated and tired, hands raw and throbbing we look up to watch everyone continue to climb.

The past seems so immaterial and the future uncertain. Professionals swarm about using language and rules not fully understood, like playground friends who have written a new code they aren't letting you in on. A rabbit warren of disability jargon and medical liturgy slowly builds a dark and impenetrable maze that I like to call the vulnerability labyrinth.

Soon the complexities of disability swell and consume, out sprinting the simplicity of ordinary life.

In the wee small hours of the night, Google flicks from ally to arch enemy. One minute a lifeline of hope is caught with a therapy, drug or personal story. But before long the stark truth flashes up in front of my eyes whether I am prepared to see it or not. Compounding this sense of confusion is the lingo, language, secret policies and protocols that frame the social, healthcare and educational world.

"This life changing therapy can't happen until you've seen Doctor Important."
"You can't access this opportunity until you've got this diagnosis."
"Yes, you need to see this specialist, but that professional has to refer you and they have a three-month waiting list."

As a parent, or simply someone trying to determine their own destiny, contributing to a decision could feel liberating. I don't necessarily want the weight of responsibility to lay heavy on my shoulders. Rather parents like me long to be part of a team of specialists determined to make the best decisions. Like everyone one else on this planet we simply want to be seen and heard, to belong and have purpose.

Thankfully there is hope. There actually is a magic wand that can help loosen the fear of the vulnerability labyrinth and bridge the gap between families and practitioners.

Effective communication

Practically every professional body, clinical guidance and credible research related to those with profound and multiple learning difficulties, recognises the importance of effective communication with families (National Institute of Clinical Excellence, 2017; Jones et al., 2014; Nursing and Midwifery Council, 2010; Learning Disability Professional Senate, 2015; and Ofsted, 2018). A parent's perception of the quality of care their child is receiving will be directly related to effective communication and the quality of relationship they have with a professional (Konrad, 2008). Effective communication allows the opportunity for relatives to engage in the lives of their loved ones. It is an essential ingredient for partnership and co-production (Stephens, et al., 2008). But first we must recognise the natural gap between each individual's priorities and perspectives whilst acknowledging parents and practitioners are experts in their own right. Relatives and carers are experts by experience, with the skills and knowledge necessary for 'best practice' to be provided. But the gap needs to be bridged with effective communication.

Sometimes information will be hard to hear. Sometimes hard conversations need to happen.

Trust between parents of children with additional needs and professionals can be difficult to build for many reasons (Avis and Reardon, 2008). In addition, communication can be emotional and tiring for parents (Young, et al., 2013). The professional/parent imbalance of power means the family is expected to reveal every little detail of their life whilst the professional maintains boundaries which prevent them from sharing simply where they live. Although there are very good reasons for this, the gap and imbalance it creates must be recognised in order for effective communication to flourish.

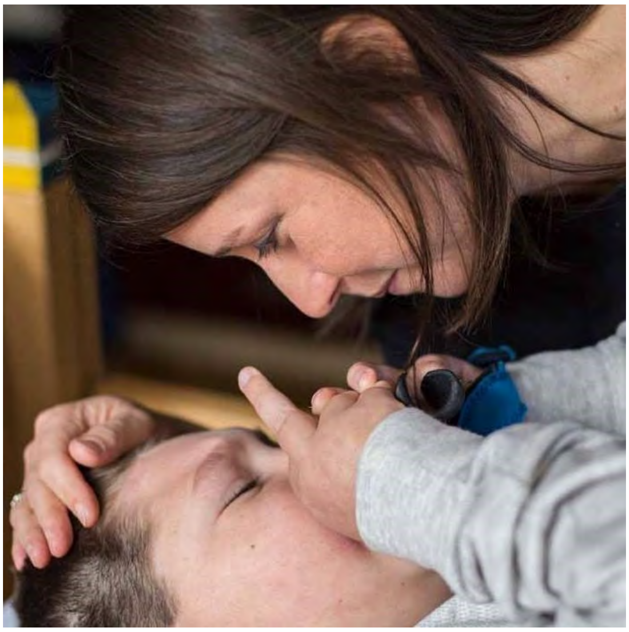
Small things can make a big difference.

But the way a professional builds trust, supports and listens will directly impact the feelings a person, parent or relative has when they leave a conversation. One small detail that can make a very big difference is using a parent's chosen name. Simply using 'Mum' or 'Dad' rather than a parent's name doesn't foster the attitude of partnership most professionals are keen to employ. Looking someone in the eye, saying, "Hello my name is …. and you are?" initiates an atmosphere of reciprocal respect and engagement.

In many instances, as the parent of a child with complex needs, I might not like what is being said to me. But if I feel heard, if I build trust with the person speaking to me, if I know they have me and my loved one's best interests at heart, then the sting of hard news is easier to bear.

I am passionate about dispelling the shadow of the vulnerability labyrinth with effective communication and co-production.

Simple practices like 'Don't call me Mum' demonstrates a practitioner's determination to communicate effectively, promote partnership and co-productive working.



As the parent of a child with complex needs and a nurse, I have experienced the positive benefits from both sides when all parties are heard and work in partnership. That is why my work is now focused on helping parents and professionals understand the impact of a family's story, their perspectives, priorities and the impact of effective communication. Through parent workshops, training professionals and speaking at conferences I believe we can learn to hear each other and bridge the gap. With effective communication and co-productive working, together we can change the lives of those with profound and multiple learning difficulties and their families – and it doesn't cost a penny.

Contact Details:

Rachel Wright is a nurse, writer, public speaker, trainer and mum living in Essex with her husband and three sons; one of whom has severe disabilities. Through her website, Born at the Right Time, you can read her blog and find out more about her training for professionals and workshops for parents. Her three passions are communication, community and facing life's challenges.

Website: https://www.bornattherighttime.com
Photographs by Nicola Parry Photography'

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Apology for Angelika Hild

We try very hard to ensure that what we print is correct. Unfortunately, within the winter issue, Health and Wellbeing, a mistake was made. We would formally like to apologise to Angelika Hild, who with Guillaume Jacquinot wrote the article on a new task force on people with complex support needs, for the misspelling on her first name within the winter issue. This mistake will be corrected in the online winter issue on our website.

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