

# Providing disabled parents with a place, a voice and a space to belong

**Sarah Fay** has combined her occupational therapy background and her lived experience of complex needs to set up a charity that aims to understand, support and address the unique challenges of parenting with physical disability and other complex conditions

I am an occupational therapist and disabled parent and I have combined my occupational therapy background and lived experience of complex needs to navigate my own parenting journey to set up a registered charity, Enabled2Parent.

My experience showed me that I received the best, most holistic care when I was willing to engage with professionals from many different agencies with honesty and openness. This helped me to create and

maintain positive relationships with professionals, who then helped me create and maintain a safe environment for my daughter.

Enabled2Parent has been founded and designed as a service specifically for disabled mothers and fathers and those parents with additional support needs. I believe it is the first organisation of its kind that can provide clinical as well as social and functional assessments in relation to the life role of being a parent.

Townsend (2002) defines a life role as a 'culturally defined pattern of occupation that reflects particular routines and habits'.

The charity is there to protect and represent the interests of its service users and to promote and increase understanding of the specific life role of parenting for disabled mothers and fathers. The scope of practice extends from planning for a baby right through pregnancy and beyond.

The underlying philosophy of the charity is that of enablement.

According to Townsend (2002), enabling is the processes of facilitating, guiding, coaching, educating, prompting, listening, reflecting, encouraging or otherwise collaborating with people so that individuals, groups, agencies or



organisations have the means and opportunity to be involved in solving their own problems.

Enabling is the basis of occupational therapy's client centred practice and a foundation for client empowerment and justice.

In recent years, there has been a drive to fund studies and create services within the NHS to provide specific services that seek to hear the voice of disabled mothers in relation to their pregnancy, birth experiences and the ways and means they will adopt to care for their children after birth. This has led to collaborative working between obstetrics, occupational therapy and midwifery.

A recent DRILL (Disability Research on Independent Living and Learning) press release announced a research project carried out at the University of Bedfordshire about disabled parents in 2019 (<https://bit.ly/3mKWbQJ>).

The research team were shocked to find that many disabled parents were 'often too scared' to ask for help from social services for fear of being judged unfit to look after their children.

They identified that greater collaboration between adult and children's services was essential to ensure disabled parents could access the vital help they needed to fulfil their parenting role and keep their families together.

With this in mind, Enabled2Parent has deliberately chosen to position itself within the charitable sector. This is to provide disabled parents with a place, a voice and a space to belong and receive tailored assessments, advice, information, advocacy and support within an atmosphere of empathy, encouragement and hope.

The charity aims to achieve this by building a bridge between a disabled person's human right to be a parent and rear their own children and the reality of becoming and being a resilient and independent parent with the right personalised support.

Other ways we hope to support people include:

- providing an email facility to refer, chat and offer advice;
- providing an assessment about the impact of a disability on their parenting role, their needs and help map out the journey from pregnancy onwards;
- helping to identify and trial any equipment they might need to care for their baby or child;
- supporting them in their transition into their role as a new mother or father; and
- supporting them in their liaison with adult and children's services.

Enabled2Parent also seeks to work with professionals in health and social care, the third sector, as well as agencies and

organisations who link with the baby and parenting industry. This is achieved through a number of things, including the commitment to working with professionals to enable disabled parents to look forward to the birth of their child with hope and excitement.

Also, providing the relevant assessments, reports and risk assessments that relate to the functional and adaptive aspects of baby care and parenting, and supporting clients and families to understand the roles of different services and organisations involved with the family and helping them form meaningful and positive relationships with their children.

The charity also provides education and training courses and service development workshops about adaptive parenting that are tailor made to suit a service, organisation or business, and forms partnerships with existing services to provide a needs led, co-ordinated and prompt response to parents with additional support needs.

The charity provides long and short-term support to clients and conducts the majority of its assessments online, while both parents or professionals can make a referral or request information.

With a growing community of disabled parents on its Facebook page and a growing peer support network for both mothers and fathers, the charity's peer support is open to perspective clients regardless of whether they need a full occupational therapy assessment or not. It is provided by two disabled parents who are part of the charity's leadership team.

This is because Enabled2Parent recognises it is important to understand, support and address the unique challenges of parenting with physical disability and other complex conditions (Wint et al 2016) and to endorse the fact that having and raising children is highly valuable for many people with or without disabilities (Cureton 2016).

## References

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- Wint AJ, Smith DL and Lezzoni I (2016) Mothers with physical disability: childcare adaptations at home. *American Journal of Occupational Therapy*, 70(6): 1-7

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