

Programme helps parents become effective advocates for their children with disabilities

By Julie Costello

Killygordon mum of two Clare Temple has started exercising again, a sure sign that for the first time in two years she is feeling fully herself once more.

The event that jolted Clare so profoundly out of her usual interests and habits occurred in November 2014, when her then 2-1/2 year old son was diagnosed as having autism.

“We were thrown into autism,” Clare said. “We didn’t know anything about it, so it was a complete shock. It has taken me two years to come back into myself, to be fully, fully accepting of it.”

One key to this acceptance, Clare said, has been her recent participation in a six-session “Empowering Parents Programme” run by the national Disability Equality Specialist Support Agency (DESSA).

The free programme offers information and support for parents of children with any disability to become effective advocates on their child’s behalf.

“When the group first started I thought it was a very positive forum for parents,” Clare said. “It provides invaluable information for parents that mightn’t have the time or be in the right head space to search it out on their own. It lets you know you’re not the only one that believes in your child.

“As a parent you can feel like the only one fighting for your child. The services in general are very quick to put your child in a special category and pigeonhole them using the medical model rather than the social inclusion model, which is why I think it’s very powerful to have an organisation like DESSA behind you.”

Approximately 40 parents in Donegal are among 500 nationwide who have participated in the Empowering Parents Programme since it started in 2007. Over the past two years the programme has run in Dungloe, Falcarragh, Kilcar, and Letterkenny with support from Social Inclusion Community Activation Programme (SICAP) funding provided by Donegal Local Development

Company (DLDC).

“If we’ve enabled one parent to have a sense of empowerment to advocate for their own child, that’s a success for us,” said Margaret Doherty of DLDC. “It’s so easy for self-doubt to come in unless someone gives you the confidence to say you are entitled to that, your child is entitled to that.”

Offering information about disability-related entitlements – and the national and international laws which underpin them – is a core aspect of the Empowering Parents Programme.

“Its purpose is to provide parents with the information and confidence they need to critically challenge the services on behalf of their child,” said DESSA Manager Alice Griffin, the programme presenter. “It also offers them the space to receive support from other parents and to hear how other parents are dealing with similar situations to the ones they are experiencing themselves.

“Many parents are still at the grieving stage...they haven’t had the chance to reflect on the impact of having a child with a disability, so the programme offers a supportive space for allowing that to happen.”

The first two sessions of the programme discuss parents’ own understanding of disability within the framework of existing equality and human rights legislation, including the Education for Persons with Special Educational Needs (EPSEN) Act 2004 and the Education Act 1998.

“It’s heavy going, but it’s really important for parents to know the legal information, especially when they’re challenging schools around supports,” Alice said. “They need to know that they’re not asking for anything special, just the opportunity for their child to be treated as an equal citizen. That attitudinal piece is key.”

From there the course moves on to discussing the practical skills that parents need to advocate for their children as effectively as possible.

“We look at things like how organised parents’ paperwork is and how able they are to prepare for and participate in meetings with the different service providers,” Alice said. “I also show them what a good IEP (Individual

Education Plan) looks like, as it's hard to know how good your own child's IEP is if you have nothing to measure it against."

Empowering Parents participants said the equality focus and personal support that they'd experienced on the programme had been extremely helpful to them.

"My son is 16 years old and I'm just sorry I didn't do this course 10 years ago," said Deirdre McCormick of Kilmacrenan. "You used to feel so grateful anytime someone was taking time to help your child, but Alice has made you realise: Why shouldn't they? Equality, equality, equality was drummed into us.

"Alice also gave me her number and said to call her any time. That one sentence – 'Call me any time' – changed my life. You'd be knocking on so many doors but nobody wants to listen. From the bottom of my heart I appreciate getting a chance to do the course."

Participant Angie Gallagher of Letterkenny said the information she learned on the programme this Autumn has already helped her in addressing an issue involving one of her two children with disabilities.

"Because of the course, I know I have every right to say that the system the school has in place for supporting my child needs to be updated," Angie said. "I wouldn't have known that otherwise."

She added: "The course was very good, I have to say. Knowing the laws and acts that are behind you gives you the confidence to say, 'You know what? I'm not asking for anything my child isn't entitled to. I'm just asking for what's needed for my child to be equal to other kids.'"