

## NEW WRITING

### *Parents as Keyworkers*

*Michelle Mould*



I am a parent and my own keyworker. I have a 13 year old daughter with autism. I have an Advanced Certificate in Autistic Spectrum Disorders from the University of Birmingham, have taken a three-day course in TEACCH

(Treatment and Education of Autistic and related Communication-handicapped Children) and am currently studying for a BSc (Hons) Psychology degree. As well as home teaching my daughter I am a parent trainer with the Early Support programme and Right from the Start Programme in Norfolk. I am also the secretary for Norfolk's parent council called Family Voice Norfolk.

#### **Summary**

Michelle's thirteen-year-old daughter was diagnosed with autism ten years ago. Michelle describes how she reached a point of having to take back control because 'I couldn't keep facing the days feeling helpless, useless and with no relationship with my daughter'. She did this by becoming her own keyworker. Michelle argues in this essay that every keyworker should be equipped to empower parents to be their own

keyworker – if and when they want this and are ready for it.

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#### **Introduction**

I am the parent of a 13 year old daughter who was diagnosed with autism at age 3, and of a son of 14 who is the best brother in the world. My son goes to one of the local high schools and is doing very well in all areas of his life. My daughter has been educated at home since the September of 2001. My daughter struggled to access learning at school as well as coping with the social expectations and confusing environment. We tried 4 schools over the years, and are now happy to home educate and see the wonderful progress that she makes. In her words she says quite adamantly, 'No school for (me), just for (my brother)'. However, in the early days life was just another day to get through – a lonely and usually frustrating day in which I was isolated for many reasons.

You see, my daughter had no communication other than a high-pitched scream and tantrums. She never co-operated and hated staying dressed. My plans to make friends at the school gates did not happen. My daughter's behaviour was too bizarre and I made excuses not to have coffee with other mums such as having a pile of

ironing to do or the beds to change. I didn't know how to reach my daughter and she didn't know how to reach me. There was not a real relationship – just a dread every time we had to go somewhere or do something for fear of what would happen next.

We had moved to a new county for my husband's job and we knew no-one. Relatives were many miles away and diagnosis came after the move. In those days Early Support was not around and I found myself repeating everything to all the professionals we met. I also found that help for my daughter was limited and virtually non-existent. This is where I began to take control back. I couldn't keep facing the days feeling helpless, useless and with no relationship with my daughter.

I started by finding a programme to help my daughter interact and communicate. I took a two-year course with the University of Birmingham and gained the Certificate of Higher Education in Autistic Spectrum Disorder, learning how to live and work with a child with autism. Slowly, as my daughter and I made progress, I began to feel more confident and happy with her and our relationship blossomed. Her dad and brother joined in our fun and learning. We would work on her understanding of communication by playing games. One of her favourites was a huge dice that we could write words on instead of numbers. We would take turns to throw the dice and then do the actions for the words on the dice, such as 'run', 'jump', 'skip'. My daughter learned to sight-read, to take turns and to interact with us. We all learned to speak slowly, using a minimal number of those words that we knew she understood to help her understand what we were saying. My son was very good at this and became her best friend. He would use her favourite dolls to play silly games and draw her in to using language and turn-taking. We learnt to give her time to digest what we said and to not answer for her. We could see her growing in confidence as she played with us and especially with her brother. We had to go back to the beginning of playing, communicating and interacting in order to move forward. We were lucky enough to feature in a short documentary that was shown on Channel 5 (the DVD of which is available from the National Autistic Society website, [www.nas.org.uk](http://www.nas.org.uk)). We hope this shows how we

all work together for our daughter. We were on our way to being a family again.

### **Taking control**

I have since taken many courses and am doing a degree in psychology with the Open University. I have my daughter to thank for that. I doubt that I would have had the courage at 40+ to start a degree under normal circumstances.

It was due to the home education that I began to take control of my daughter's Educational Statement Reviews, organising appointments to suit us and gathering reports as and when we needed them. I immediately saw the benefit of organising meetings so that they fitted in with the family and so that I had all the professionals that I felt were needed together at the same time.

Some of the professionals involved in my daughter's life began to be very complimentary of how the home education programme was run. They noted my daughter's progress and appreciated how I had organised meetings, information-sharing and communication between everyone. It was at this point that I heard about Early Support ([www.earlysupport.org.uk](http://www.earlysupport.org.uk)) from the manager of my Children with Disabilities Team. By then my daughter was 11. I phoned their number and asked for more information. It was through this discussion that I became involved as a Parent-Trainer in Early Support. I use the Early Support materials and Family File because I find them so very useful – even though my child is above the age of 5 for which they were designed. From Early Support training came the opportunity to train as a trainer in Right from the Start ([www.rightfromthestart.co.uk](http://www.rightfromthestart.co.uk)). All of this has led to me making a contribution in a local county-wide document about how to manage multi-agency meetings and helping in the training of the use of Early Support's Developmental Journals.

### **Being my own keyworker**

It was through Early Support that I suddenly realised I was in fact my own keyworker. I hope to share that experience with you now and point out some of the pros and cons.

I didn't become my own keyworker overnight. It was a gradual process, possibly a necessity due to home-educating my daughter. In the early days my health visitor was the one that I would always turn to when I needed help. Later on that key role was taken by the speech and language therapist as my daughter's communication progressed and became one of our main goals. I realised early on that I needed to hang on to my trusted professionals who had begun to understand our family, the home education programme and most importantly my daughter. I began to see the logic in organising meetings and sharing information with them all so that we all knew where we were. I felt that I had to do that if we were to keep moving on. I felt that I had to try, but didn't know if I would end up overloading everyone with paper and e-mails. People often ask me incredulously, 'How do you find time to do all this?' – as if it should be impossible, or as if I shouldn't be able to cope. I usually answer that a busy person is the best one to ask to do something. In truth I cope very well most of the time. However I do have a wonderful team around me to support me and help out when necessary.

At first it was quite hard and meant extra work. Seeing the results was the motivator. If everyone knew we wanted the meeting to discuss walking problems as a priority then they came prepared. Relationships with the professionals have grown from strength to strength. Most professionals are still with us after 8 years but some have moved on. However, any new professional to the team has the advantage of being in a team around the family where everyone gets on, shows respect for each other and works as a team. I feel very honoured and special to have this wonderful team who understand that I like to do the organising and the information-sharing and who trust me to do it. They have also supported me in times of crisis and have not belittled me when my usual coping skills have gone to pot. A little while back my husband and I decided to separate. This was a huge shock to me and my coping skills vanished for a while. I was lucky to have my good team around me who visited and phoned and kept me sane. Thankfully their support helped me get back to being my usual self.

At our latest Statement Review, whilst completing the boxes for attendance, I was jokingly asked if I wanted to act as Head Teacher

or SENCO (having neither as a home educator) and because the forms do not cater for 'Home Educator'. I have chaired some meetings myself and chosen for others to chair sometimes. It has depended on what the meeting was for. I am now asked if I would like to chair and I feel confident that I can choose to do so or decline – and everyone is OK with that.

### **Feeling like 'mum' again**

So the major benefit of being my own my keyworker has been to put me back in control as a parent, as I am for my son. I make choices with my son and I now feel that I can do that with my daughter too. I am not waiting for someone else to do that for me. In short I feel like mum again. The trust and respect of the wonderful team around our family has been another huge benefit. They have given me back faith in professionals and shown me respect for my knowledge of my child. I feel being my own my keyworker is part of my parenting job and I am very happy to do it.

The crunch, though, is that I had to work it all out on my own. What I would want for other parents is that their keyworker supports the family but also empowers them, and enables those that wish to take on some of the role. It can start with small things like choosing who they would like to attend a meeting and making their list of priorities for the meeting. These priorities can often be different to the professionals' priorities. Many a time, a professional's first priority to address has been my daughter's lack of social contact in home education. My answer has been different on each occasion. For example, toilet training was the priority at one point and then later being able to walk to various places. What the professionals presumed was that my daughter missed company of her own age. This was in fact not correct. My daughter feared other children who lacked the knowledge of how to interact with her, and who spoke too fast for her to understand. She also lacked the understanding of body language and could never tell if someone was coming towards her to ask her something, or push her. She couldn't work out their intentions. This frightened her. So you can see that the professional view was not that of the child. Further down the line we are now looking at more contact with peers as she has developed more skills to cope in these kinds of situations.

However, I am well aware that being your own keyworker is not the answer for everyone. Some families have many more difficulties than mine that involve many more professionals and many more trips to hospitals and clinics. I can see that it is essential for them to know about keyworking and to be able to ask for a professional to take the role on for them. Early Support training is now covering workshops to empower parents in this. These workshops celebrate the family and the child and help to empower parents – whether it is to ask for a keyworker or to ask for support to enable them, as parents, to organise life in a way that is better for the family.

### **My message for professionals and parents**

I hope that professionals reading this story will recognise the need for parents to be just that – parents. This can take many forms and will necessarily differ from family to family. What we really want is to be listened to, to be respected for our expertise (just as we respect professionals for theirs), to be trusted to take control when we are able, to be supported when we need it and, lastly, to be reassured that we are all working together. Early Support is about all of these things. The role of the keyworker must be seen as empowering parents as well as supporting them. Keyworkers should be able to offer support when it is needed and then, when appropriate, to help empower parents and give control to them – whether completely as in my case, or in part.

I hope that some parents who read this will feel inspired to take the lead role in the team around their family. The keyworker's role then is to support, encourage and enable them in this. This doesn't mean parents have to do it all or do it all of the time, but there may be times when the parent is the right person to take the lead – and has the right qualifications by being the parent. Keyworkers should get to know their families well enough so that they can both support and empower. I also hope that parents will speak out and ask for a keyworker. There are too few schemes running at present and parents' voices need to be heard to encourage local children's services and health services to work together to provide this very vital, supportive and empowering role.

**Editor's note:** To learn more from Michelle or to access the DVD about her daughter please e-mail: [mouldfamily@tiscali.co.uk](mailto:mouldfamily@tiscali.co.uk)

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