

NEW WRITING

Parent Power? Parent Power!

Mary Camplin

Summary

In this article, Mary Camplin, a parent of a child with special needs, (who does not wish to identify herself to IQJ readers in the interests of maintaining good relationships with the powers-that-be) relates her recent experiences as a Parent Consultant and founder of a Parents' Forum. She discovered that professionals have a much more positive attitude to parents groups that are led by professionals than to parent groups that are led by parents and carers. She also discovered that it is felt appropriate for parent groups to discuss decisions that have already been made, but not for them to make their own decisions.

Introduction

How a group of inexperienced urban mums have been getting parent participation off the ground and onto council agendas – much to the horror of local key disability players. An article in diary format.

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March 2008

I'm at the Child Development Centre (CDC), but for once, I haven't brought Freddie with me. He's three and was born prematurely, which has caused some developmental delay, epileptic seizures, and challenging behaviour. He's creating havoc at nursery while I sit in an ugly meeting room helping a committee of health professionals understand the parent perspective on getting assessment appointments. Feel uncomfortably like I am telling them how to suck eggs. Haven't they heard other parents talking about the impact of their arrival in special needs world?

The clinicians listen intently as I explain (tearfully at one point) how those dreadful early weeks felt – post hospital, pre-diagnosis and prior to the first appointment with the CDC paediatrician, which led to the beginning of a routine encompassing occupational therapy, physiotherapy, speech therapy, Portage etc.

'I was in such a mess, I couldn't retain any information, and would have benefited from someone like a health visitor, or frankly, any named person to contact in those first few days, who could guide me through what was going to happen when we got home,' I said, 'but, if you take that route, you must be realistic: that person (unlike our local health visitors) must be available to get back to a parent when they leave messages, and (also unlike the HVs) be

used to working with children and families living with disabilities.'

'That was so useful,' enthuses a speech therapist afterwards, 'when can you come back?'

'Tomorrow – if you pay me for my time like you're being paid for your expertise', I think to myself, knowing that I've had to pay the nursery *and* take a morning off work to attend the meeting – a rough cost to me of around £70. But I am a lot more assertive on paper than I am in the flesh, and I would never say it. It's a big boost when I hear that, in part because of the meeting I attended, the whole assessment procedure is to be speeded up and a named professional with dedicated contact telephone number supplied to new families. I even get a call, offering to refund my childcare costs.

September - December 2008

At a time when I felt pretty powerless, attending that meeting and being listened to really helped my confidence. It's good to feel I've got something to contribute after all the help Freddie and I have received from the doctors and therapists who look after him. So I applied for a temporary job as a Parent Consultant (PC), and got it.

I am now part of a group of six parents who've been asked to find out what other parents think about respite care, soon to be officially renamed 'short breaks'. We are plunged into designing a questionnaire which must be circulated very soon. We have been given no training, and have no clear information about what short breaks are (I had never heard of them – Freddie's never been offered anything), who gets short breaks in our area already, who isn't claiming them, or, indeed, what the potential eligibility might be.

Immediately, one group member drops out because she'll lose her income support if she gets paid. One member appears to have no special needs experience, fails to show up for meetings, refuses to answer her phone, and replies to about one email in 20. One struggles with English to such an extent that she can't grasp what we're on about in meetings. Three of us soldier on, consulting with other parents, cobbling together the questionnaire. During this time my printer breaks and I can't afford a new one, and the computer catches a virus and decides it dislikes email. Spend a (non-

refundable) fortune on text messages to my fellow PCs.

January 2009

Attend a meeting for parents/carers of children with disabilities in our area. The chairperson works at a charity that supplies play opportunities and the organising committee is made up of lots of different people from different disability organisations. There are two interesting speakers (one health professional from the psychology department, and one speech therapist). People ask pertinent questions about accessing services, but I'm left wondering what the follow-up is going to be – will there be a report back at a later date about whether parents' suggestions have been taken up?

February 2009

It's 2 a.m. and I'm entering data from our questionnaires onto the council's survey-analysing software. 'I don't know what these "short breaks" are,' says one form. 'I can't transport my child to a short break at the adventure playground as he does not cope on buses and we don't have a blue badge for the car,' explains one form. 'I think my child's too disabled for after-school club,' says another. 'I don't think my child is disabled enough to get a short break,' says yet another; 'Nobody explains anything to us in our language so we don't claim anything,' says one form translated from Gujarati and another from Urdu. Form after form tells the same story. Parents aren't accessing information, don't know where to find out which short breaks are right for their child, aren't being told about breaks by health professionals, and aren't sure what the eligibility criteria are. They also don't like having to be assessed by the overworked and sometimes less-than-tactful social work team either, but for some families, that's the only way they're going to get a break. That is, if the social work office ever returns their calls, reads their emails or manages to retain their files.

March 2009

Our paid work is complete. We've written a report, with an appendix and an executive summary of our findings. We estimate that we (the three who worked the most) have spent about 150 hours each – but we'll be paid for 40. I

wish we were able to carry on our work, there's so much to do. We have 20 recommendations covering things like: reaching out to those communities who never seem to claim short breaks; providing reliable transport; ensuring that teenagers have suitable short breaks too; and keeping a consistency of venues and staff, so that children who find change challenging will keep the same worker.

Some parents are concerned that the commissioning process will put finance above all other criteria and families will end up with short breaks run like a fast food franchise – producing low-priced goods and staffed by cheap, indifferent and unmotivated teenagers.

April 2009

We've heard something very interesting. Aiming High finance to the tune of £10,000 is available to fund parent participation! In our area, parents do sometimes get to give an opinion on decisions made about our kids' services and treatment, but it's very haphazard, like when I went to the meeting about assessments. The word on the street (according to my source in the CDC) seems to be that it's OK to consult with parents on decisions that have already been made, but it's not good to get parents involved in actual decision-making. We're too chaotic about making a regular commitment, fail to understand what the meeting is for, or use the time to bang on about our children's medical issues. We're incensed by this attitude. Parents we know that have managed to participate in formal decision-making have found few committees willing or able to provide proper background briefings, training, or even expenses to parents. Then they complain that parents don't come back!

'What if there was an organisation run by and for parents which provided training for those parents wanting to help make decisions?' we mused, 'with its own website to give out information, running its own events to increase parent participation in the area, and linking with other parents nationally? It wouldn't be a support group, more like an action group...'

May 2009

We've run into a slight problem. The council's children's services department dislikes the very idea of our group. Meanwhile the voluntary

groups that run the meeting I attended for parents back in January think they already do enough 'for' parents and don't buy the idea that we want to do it ourselves.

We attend a fraught meeting (which we nearly missed because we didn't get the chance to check email the night before) explaining that the grant is for parent-led groups, not groups run by other people on parents' behalf. We secure agreement to work with the existing group as their 'political wing' and come along to their planning meetings. Council man – who is very much of the old school when it comes to parents – says well done, but warns that "other people" (i.e. his mates on the council) will say we have no 'constituency' and that we cannot claim to represent parents. We say, of course we can't. We haven't formed yet, but when we do, we will be able to formally recruit parents from the membership of the existing parents' group. We assure him that we are not setting up in order to disrespect the council's services, but to help make them work even better. We produce precedent documents to back up our case. We also secure a venue, interpreters and crèche facilities for our launch meeting. Council man looks suspicious, but what can he do? We're part of a national network, not just a local bunch of troublemakers.

Beginning of May 2009: Launch meeting is attended by a small number of interested parents who give their opinions on the kind of topics we should tackle and offer their skills to work with us once we have funding. We talk about holding meetings on different days of the week, keeping tabs on what is happening with summer play schemes, making our local hospital more accessible, and offering training to parents who don't yet use the internet. Meeting is also attended by two non-English speakers who sit with their interpreter through the whole thing. One of them pipes up at the end, 'Do you know where we can get good insurance because my daughter has tantrums and keeps smashing up the car?' Feel worried that this parent has just wasted her afternoon thinking she is at a support group meeting. Oh, and I get elected as Chair – a job nobody else wanted. Think I will do it for a year. Part of me hopes we don't get our funding – I might have bitten off more than I can chew!

Mid-May 2009: I have no idea how to plan a budget – my personal finances are appallingly run. The other two have no experience either. But I do know we're going to need to communicate quickly with one another, especially if we are being asked to quickly provide information or read documents. So, as our 'office' will be whoever's on phone-duty's handbag or buggy, I say we need a Smartphone and a laptop. Council man sees the draft budget and is heard to splutter, 'But even my staff don't have BlackBerry phones!' We say, 'Yeah, but you've got an office and a secretary to keep you abreast of meetings, documents and developments – and we will be doing this work as volunteers, with one eye on our children.' Talking of which, we note that none of our recommendations about short breaks has yet been taken up by the council. Parents still don't know their entitlements for the summer holidays, less than a month away.

June 2009

Disaster! Our funding has been refused. We haven't explained ourselves properly and there is a worry we have just been set up to be a thorn in our local disability service providers' sides. As if! We hastily rewrite, casting ourselves as encouraging parent participation rather than organising demonstrations, rallies and picketing sessions. Although, as parents are still clueless about what's happening to their short breaks this summer, that might have to be an option.

July 2009

Phew! Funding is to be granted. We don't have the money in our bank account yet but we've already set up our next meeting, to discuss how we'll get our website off the ground. We're also committed to helping train the next generation of health professionals at the CDC. We've forged a good working relationship with the professional-led parents group. And we're still chasing that pesky short-breaks team about what's happening this summer and beyond.

Parent power is here to stay!