

Editorial and Opinion

Peter Limbrick

Parents, professionals and power

When running workshops or seminars about early support I often suggest that there is already happening, or certainly should be, a shift in the balance or power between professionals and the families of babies and young children with disabilities and special needs. In the bad old days, I say, the professional decided the goal for the child and asked the parent to act as a co-worker to practise the work at home between the sessions with the professional. In the modern world of flexible and responsive child- and family-centred services we can switch this around through 180° so that the family decide the goal and ask the professionals to help them achieve it.

The same 180° switch can be applied to the assessment of need: In traditional processes the professionals assess child and family to identify what their strengths and needs are, what goals need to be set and the methods for achieving them. After the switch, an effective assessment can be achieved by simply asking the parents what is needed and then exploring and evaluating all available resources that can be used to meet the expressed needs. In this model, the family 'assess' local services and the professionals within them to see if they are up to the job. This is not really a revolutionary change because any one of us, parent or not, will have to assess other professionals to see if they measure up to our expectations for fixing our teeth or drawing up the plans for an extension to the back of the house.

There is another power play that is changing, or at least ought to change. That is the power relationships *between* the professionals in the

services that support disabled children and families. When there is a child and family involved and when conditions and needs are complicated can it be sensible to operate a hierarchy of opinion and advice with a single professional at the top? When I worked with neurologically impaired babies in the 1990s as a keyworker, the power structure I encountered most often was the team around the paediatrician. This makes no comment about paediatricians individually or collectively, it merely describes the predominating medical model that operated then in early support.

There are undoubtedly hierarchies of authority and power in public services and we will not be able to address them unless we first acknowledge them in our own local services. In this issue of IQJ Carolyn Blackburn (*Making a Difference*) describes a piece of research which, in part, looked at the support preschool staff need from other agencies to enable them to support children with special needs and their families. From this research we learn that preschools 'have commented on feeling undervalued by other agencies, ... Some staff also felt that Portage, for example, had not felt it necessary to observe children within the preschool and this has left them feeling undervalued.' Interestingly, I have long experience of Portage workers reporting that therapists do not trust *them* sufficiently to hand over any work for them to carry out with a child for whom they share responsibility. This just will not do. How can we work together if we judge our colleagues as inept by virtue of their role? OK, some of us are inept with some children at some times, but the way forward is in training and in matching everyone's tasks to agreed

standards of competence, not in unfounded professional elitism and snobbery.

The medical model has its place and this approach suits me fine when I have a gum boil, a rumbling appendix or an in-growing toenail. But families of children who require ongoing multiple interventions have a vastly different level of need. Of course, some new babies and young children will need urgent intervention from doctors and nurses in a medical model, perhaps during and after birth and for ensuing illnesses and emergencies, but a time comes quite soon when everyone has to be weaned off this expert approach in favour of a model which is parent-empowering, family-centred and characterised by partnership. There has to be a move from 'doing to' to 'working with'.

Parents at the beginning of life with their new child need professionals whose toolbox includes established skills in listening, empathy, emotional support, using a whole-child and whole-family perspective, informing, involving, empowering, enabling and in collaborative teamwork. This brings us to the Team-Around-the-Child (TAC) approach which is featured in this issue's Lead Article by Sue Davies. TAC addresses and resolves the problems of unequal power between parents and professionals and between the professionals themselves.

When each child's own individual TAC is formed, the parent is a full member with an equal voice and she meets regularly with the other two or three key professionals at TAC meetings. If, sooner or later, she wants to take the lead then she should. After all, the action plan is for her child and her family. When a professional joins a TAC for one of the children on her caseload, she steps temporarily outside the pyramidal power structure in her own employing agency (in which authority cascades down from a single person at the apex) to join the other professionals from other agencies in a flattened team structure in which there are no bosses or underlings. It is this un-hierarchical structure that creates the space for each member of the TAC, whether therapist, Portage worker, preschool staff, specialist teacher, nurse or doctor, to voice their opinion based on real practical knowledge of, and concern for, the child and family. And, of course, it is the same flat structure that empowers the parent.

TAC is not a chaotic free-for-all, in fact it is the antidote to the chaos that families have had to endure when their professionals have all done 'their own sweet thing' rather than working together. Each professional in the TAC works within her own code of ethics, conforms to her agency's standards and protocols and can demonstrate competence in the tasks she takes on within the action plan. Perhaps there is a paradox here: By working outside the traditional power hierarchies, TAC resolves disorder.

I began this piece by imagining an all-or-nothing switch from the expert professional to the all-powerful parent. While it is a useful workshop exercise that invites professionals and parents to think about power, it is not, in my view, an appropriate way to develop more effective support for disabled children and their families. While I would want to promote parents I would not want, at the same time, to demote professionals to being just contractors who bid for a job of work and then conform to the family's instructions. Professionals have much more to offer and children and families deserve a more skilful approach.

TAC brings parent and key professionals together in a genuinely collaborative team around each particular child to share observations and aspirations, to agree needs of child and family and to create a plan of action. Rather than abandon the new parent to the lonely role of Company Director or Works Manager, all the people who have a close involvement stay together in a mutually supportive team. This recognises the natural role and the expertise of the parent and also recognises the training, skills and experience of each professional. Everyone is valued and everyone is involved. When the TAC is established and has gelled, it becomes the primary source of knowledge, concern, expertise and authority around the child and family.

In their essay in this issue (*Parent-child interaction as a focus for early intervention...*) Andrew Sutton and Wendy Baker tell us that part of the role of Early-age Conductive education is to create 'active parents...confident that they can teach and bring up their disabled children'. We are told in Anna Goldsmith's essay (*Postural Care Provision...*) 'By investing in families to self-manage Postural Care we will reduce body shape distortion...' Michelle Mould in her essay (*Parents as Keyworkers*) tells us that

what parents really want includes '...to be respected for our expertise..., to be trusted to take control when we are able...'

The message is clear. Part of the true role of professionals with these children and families is to help parents learn what they need to learn so that they can help their child as she or he grows up and so that they are equipped to manage all the ups and downs of family life with a disabled baby, child and young adult. When professionals hold on to power they are likely to create dependency and endanger both child and family. We need UK-wide intervention systems that empower families and we are not there yet. Wendy Baker and Andrew Sutton point tantalisingly at movement in USA towards a new '...family-social model for early-intervention planning'. This sounds like a rewarding adventure for professionals in any related field who want to work with families to shape new systems for the future. Exciting times!