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SPECIAL VIRTUAL ISSUE

Families and children with disabilities: making the best of both.

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The electronic age provides many innovative opportunities for sharing knowledge internationally as to how the disabilities can best be ameliorated. The concept of Virtual Special Issues in journal publication is another welcome development and I am especially pleased to be invited to write this introduction to the first such issue of this journal.

It is very appropriate too that the focus is on children and families. Despite the vast material differences in service provision around the world, families remain the common bedrock for children's development as they have done in generations past and will likely do so well into this century and beyond. A priority must be to further our understanding of how to make the best of families and of children with disabilities. The collection of articles in this Virtual Special Issue gives us some pointers as to how this can happen.

Professional wisdom allied with common sense has long appreciated the extra burden placed on families when there is a child with a disability and truth be told, much of this is borne by women—mothers and grandmothers. Indeed there is a remarkable concurrence across international studies in the way women the world over are affected by their caring roles. The literature reviews contained in these journal articles usefully summarise the main conclusions. Mothers tend to have poorer physical and emotional health, higher levels of stress and experience difficulties in communication among family members. Financial worries, inadequate housing and the needs of other children often exacerbate the burdens they carry. Mothers may adopt ineffective coping strategies that add to the strains they experience. They often feel socially isolated. Overall the family's quality of life suffers.

What is perhaps less appreciated is that the sources of stress extend beyond the physical demands of caring for children who are dependent on others for their basic needs or whose behaviours are difficult to manage. *Chang and McConkey* in their study entitled "The Perceptions and Experiences of Taiwanese Parents who have Children with an Intellectual Disability" highlight the impact on these mothers of cultural attitudes and expectations both from within the family and the wider society. For instance, grandmothers can be a source of stress rather than a support for parents if they believe the child's disability is the fault of the mother, and worse still if they judge it results from her past sins. These themes are echoed too by *McCabe* in her paper centred on Chinese mothers entitled "The Importance of Parent-to-Parent Support among Families of Children with Autism in the People's Republic of China" and by *Oh and Lee* in their study of Korean mothers entitled "Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea".

Cultural influences on parenting behaviours are often not factored into research studies. Indeed how can they be when so many investigations are carried out in mono-cultures? It is presumptive to say the least,

to believe that the findings from one culture, albeit a dominant one in terms of research and service delivery, can be applied to other cultures. Worse still is the converse that researchers in the dominant culture feel they have little to learn from studying other societies. The solution may be simply stated—let's have more cross-cultural research. But there are formidable obstacles to achieving this of which the matching of samples is a prime example. Meantime we must hope that journals such as this one, continue to nurture research endeavours across a diversity of countries so that we can build a deeper and richer appreciation as to how culture intersects with the parenting of children who have special needs.

One of the most remarkable cross-cultural achievements of the 20th Century was the commitment from the world's nations to international declarations of the Rights of Children and of People with Disabilities (United Nations 1999; 2009). Perhaps in generations to come, these statements of Rights, allied with national legislation, will drive changes in national attitudes. But this may be a vain hope and in any case today's families need help now. An encouraging finding from many research studies that is repeated in the pages of this journal too, is the value of informal supports in helping mothers to cope better with the stresses and strains of their life. These supports can come from members of the immediate family—fathers, grandparents, siblings—as well as from friends and allies in the wider community, notably support from other parents of children with disabilities.

This is a most hopeful message for those families who live in less developed nations in which professional supports are sparse. *McCabe*, for example, demonstrates the value of parent-to-parent support to Chinese families whose children had autism. But these low-cost initiatives can easily be overlooked in emerging economies as they strive to take their place among the developed nations with their sophisticated health and education services. Arguably the professional solutions that dominate service provision in affluent nations have not delivered the types of support that families the world over require in order to really improve the quality of their lives. To a large extent this failure results from a focus on assessing and remediating the children's impairments with scant consideration given by therapists and teachers to supporting the families in which children spend most of their time. But even when the need for family support is recognised, often no one shoulders the responsibility for this key function. When anyone *could* be doing it and everyone *should* be doing it, then ironically no one does it!

The second set of articles in this issue looks at how families can bring out the best in children. Although *Nunes and Hanline* describe a single case study of enhancing the non-verbal communication of a child with autism, their research encompasses some very key messages that have much wider applicability for families internationally. First, every child is



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a natural communicator and therapists should assist families—parents, siblings and grandparents—to devise novel means for a child with communication difficulties to understand the family's communications and to help the child to get his or her message across. This often means relying on some form of non-verbal, augmentative or alternative means of communication; "low tech" (e.g., picture boards) as well as "high tech" (e.g., voice synthesisers). But often it is not the means of communication that makes the difference but rather how and when it is used! Second, interventions have to be embedded within the naturalistic settings of the home and community and not just used in clinics and classrooms. This means undertaking home-based assessments of the family environment with training and guidance being provided—preferably in situ—to all the family; siblings as well as parents! Third, our teaching strategies to enhance the child's communication should be centred around their personal needs and on what is feasible for the family caregivers to undertake. This means shared, creative, person-centred planning but the investment of time and effort in promoting effective communication will reap rich dividends as this is the foundation for all of the child's future learning.

Bennett and Hay take this research on family communication one stage further by demonstrating how healthy family relationships and especially high levels of parental involvement with schooling led to greater social skills development in Australian children with physical disabilities. By contrast, *Shandra and Hogan* identified how low parental expectations are associated with increased likelihood of adolescents with mild and serious disabilities failing to graduate from high school education in the United States. Perhaps there is one simple message from both these studies that is not novel but bears repetition: schools cannot bring out the best in children unless we bring out the best in families. Family-centred approaches are the solution—challenging though that may be in modern technological societies.

Parental engagement with a child's learning has long been recognised as advantageous and in longitudinal studies, this variable is a better predictor of educational achievements than schooling. Why you may ask? Parents can provide the individualised assistance that teachers struggle to give in classrooms but more crucial perhaps is the emotional support offered by parents in overcoming the child's poor self-esteem or a lack of self-confidence. The latter can be especially important for pupils assessed as having "special educational need" and who from a young age, fare worse in comparisons with their brothers and sisters, and even their classmates. But family support can not be assumed nor taken for granted. In many affluent nations, families are under added pressures with more single parenting, increased numbers of working mothers and the break-up of extended families with a concomitant reliance on formal child care arrangements. With imagination and renewed efforts, modern society could find ways through these changed times and I would like to think that researchers would live up to their name in re-searching and evaluating possible solutions.

Finally, another value of this Virtual Special Issue is to remind us of what we have yet to learn about families bringing up children with disabilities. Three questions in particular strike me.

How can we mobilise community resources to support families? In this respect, we might have more to learn from community-based

rehabilitation strategies that are being pioneered in the poorer countries of the world rather than finding answers in the so-called more advanced nations. When professional resources are sparse, greater reliance has to be placed on equipping available personnel to act as family supporters in either a paid or voluntary capacity (O'Toole & McConkey, 1995). Building local networks of support for vulnerable families is an attainable objective but requires personnel with different talents than those traditionally recruited to work with "disabled" children. Among the core attributes I would identify, is a capacity to forge relationships with people from a wide range of backgrounds and to energise and educate local people to develop their talents and those of children with disabilities.

Why are some families more resilient than others? We lack the longitudinal studies that would give us the insights into why some families seemingly thrive while others flounder; a phenomenon found across all cultures I believe. These insights may well change the way we professionals approach the issue of disability from our earliest contacts with families. I suspect it means focussing more on the child's talents rather than their impairments and doing the same with parents—boosting their talents and toning down the criticisms! We use terms like "empowerment" and "coping" too glibly without trying to define the dimensions underpinning them and how they can be nurtured. Too often we resort to circular arguments—"the parents cope better because they are empowered", "they are empowered because they are better at coping!"

How best can we support families who are struggling to cope? The glib response is to repeat the mantra of partnership working across disciplines and agencies. But what does this mean in practice? I suspect we have to radically review the training provided to professionals involved with families who have children with special needs—therapists, teachers and social workers to name but some. The focus needs to be as much on working with families as it is with children, on designing and implementing interventions for parents and not just for the child, and on nurturing the family's social inclusion through the use of local community resources. Remember too that disability is not just an issue for health and education. Other sectors have a role to play too—housing, employment, transport and leisure. One of my favourite quotations when faced with an uncertain future is this. "A journey of a thousand miles begins with a single step". Thankfully we are quite a few steps down the road to building more effective child and family support services as the studies in this Journal issue testify and they provide yet further signposts for the directions we need to journey. The really big question is not how far we have come but rather, have we the energy and determination to keep travelling. Have you?

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