

**YOUR CHILD HAS A DISABILITY:
PERSPECTIVES ON LEARNING THAT A CHILD HAS A DISABILITY**

SUSAN COLMAR (Ed.), 1995

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This monograph of parent and professional perspectives on child disability is based on a panel discussion at the Eleventh Conference of the Australian Early Intervention Association (NSW Chapter). Two parents of children with disabilities provide insights into their emotional response upon learning that their child has a disability and during the early stages of coming to terms with what that means for them and for their families. A psychologist and a paediatrician who work in the area of early intervention outline the types of issues that are relevant to professionals who are involved in diagnosis and intervention with children with developmental disabilities and their families.

Mothers Debra Dunn and Carol Dwyer describe the extreme vulnerability and disempowerment felt by parents faced with the distressing news that there is something “wrong” with their child. Professionals who have worked in this area probably will be unsurprised by parental stories about the insensitivities of particular professionals and the seemingly callous ways in which they were told of their child’s disability or some concerning aspects of their child’s development. It did me no harm, however, to be reminded by the accounts of Debra and Carol of their early experiences in finding that their children had been either born with or, after an accident in Carol’s case, been left with a significant disability.

The parental perspectives are also important in that they provide the reader with an outline of some of the individual responses that can be experienced during the “finding out” phase. Carol speaks of the feeling of wanting to run away, reminding professionals that what is uppermost in their mind may not be what is at

the forefront of the thoughts of the parent in front of them. She also talks of the stage which may follow the initial shock, of wanting to know “everything” about the disability and how it may affect the child. My response, on reading this, was to be reminded of the value professionals have in providing parents with information. Debra comments on our need to do this in a positive way that demystifies the disability.

The need to minimise jargon and to clarify issues confusing for parents was taken up by all four contributors. Each mentioned the issue of “control”, pointing out the powerlessness of parents when they are so dependent on the service providers for information about what they, their child, and their family will face in the future.

It may seem trite to remind those of us who work in this area of the need to provide time to listen to parents. Professional training should be sufficient to ensure that this is always the case. Yet it seems that not all of us do listen. Perhaps at times we think we have the answers to all of our clients’ problems or perhaps we feel we should have. Whatever the reason, psychologist Rosemary Flavell highlights probably the most important point in interactions with parents at this time, when she reiterates what all of the other contributors have emphasised, and that is the need to actively listen to parents, so that we can provide them with the information that they need to hear at any particular time.

Rosemary also makes some valuable reflections about the grief process that parents go through. Psychological training generally involves developing an understanding of the normal grief process, but special factors may serve to confound the grief process for individuals whose

child has a disability. As Rosemary also points out, parents may need to come to terms with more than one diagnosis, and the diagnosis may also have changing implications that may recur, moreover, throughout the early childhood period, with each recurrence very like a new diagnosis. Thus, parents in this situation can face the dilemma of accommodating news of more than one disability or implication of the disability over a relatively short space of time. Recognition of the effects of shock and the inability of parents to hear what is being said is a point made by everyone in the monograph. Moreover, the implications of these issues are drawn for all of those who work across early intervention settings.

Rosemary also expands an extremely relevant point for psychologists who work in early intervention: how to deal with emotional reactions and interpretations of parents that can be varied and at times focused on the psychologist. A psychologist who is part of the diagnostic process can be one of the people who contributes directly to counselling the family soon after they've received a diagnosis. This dual role raises issues that may be difficult to resolve at times. For instance, parents are likely to feel anger as part of their grief, and this anger may well be at times directed, whether appropriately or inappropriately, towards members of the diagnostic team. The news about a disability can evoke different responses from individuals, families, and members of different cultural communities, and Rosemary warns about making assumptions about the meaning of a particular disability or degree of disability for different individuals.

Paediatrician Sandra Johnson's comments on the process of informing parents of a child's disability mirror many of the views expressed by both parents and by Rosemary Flavell. This thematic unity is certainly pleasing because, as we know, it is often the doctor who will have first contact with the family after the diagnosis is made. It is a pity that Sandra had not been involved in the training of the medical personnel who dealt with both Debra and Carol's families. Hopefully, Sandra and other paediatricians like

her will influence other members of their profession to maintain an all-important sense of hope for families who must deal with the issue of having a child with a disability.

Doctor Johnson's comments generally reflect a sensitive approach, which all of us working in early intervention would do well to emulate. However, I have one criticism about the possible ununderestimation of self-fulfilling prophesy. Sandra calls for caution in predicting what children with a disability may or may not go onto achieve in their life, but she rightly points out the need to be realistic in the prognosis (based on experience) that is offered to parents. Her example of informing parents that a child may need to attend a special school, however, is not a small or straightforward issue to me. As an educational psychologist myself, I have seen many examples of children whose parents were told early that their child would only be able to attend a special school. I have seen many such children go on to survive quite well with support within the regular education system. Sandra herself points out that the realm of prediction is fraught with difficulty, and I feel that extreme care should be taken in making predictions for young children about what form of education will be appropriate in the future.

In summary, this monograph is an excellent resource for psychologists, as well as other practitioners in the field of early intervention. Its readability is excellent for both parents and professionals. Professionals can find timely reminders of issues that we may sometimes fail to remain as aware of as we should in our roles as diagnosticians and interventionists. Parents can find useful information on how others in similar positions have dealt with the process of coming to terms with their child's disability, survived the early stages of "finding out", and gone on to realise the hope that can exist for all who find themselves in such circumstances.

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