

Issues for Practitioners in Supporting Grandparents

Ray Murray



Ray Murray is an educational psychologist and was previously the Director of the Centre for Special Education at Auckland College of Education (now the Faculty of Education at the University of Auckland, New Zealand). He has lived in Ireland for the last five years where he has been a research associate (part-time) at The National Institute for Intellectual Disability, University of Dublin, Trinity College and a part-time Disability Consultant. He is the grandfather of Evie (7) who has Rett syndrome.

Summary

Grandparents and parents are likely to experience similar reactions to the diagnosis of disability. Grandparents also grieve for their own child – one of the parents. While grandparents have significant roles within the family they are also a potential source of significant support for parents. Practitioners may provide support for grandparents in a variety of ways. An important role for practitioners is to encourage parents to be aware of the emotional needs of grandparents and of the benefit of involving them in the care of the child. Such involvement has the potential for grandparents to become a significant resource for the family.

Introduction

When a child is born with a disability or health concern it is a time of readjustment for the parents and indeed the extended family including the grandparents. The reactions of parents at the time of diagnosis have been well documented (Ferguson, 2002; Simpson, Hornby, Davies & Murray, 2006; Kingston, 2007) but less has been written about the feelings and reactions of grandparents as they too struggle to come to terms with the changed reality for them and the extended family.

Practitioners who support parents at the time of diagnosis need to be aware that grandparents and members of the extended family also need support. In a similar way to parents grandparents may be experiencing feelings of shock and confusion, denial, anger, sadness and bewilderment. Grandparents are likely to be grieving for the newly diagnosed child and for their own child – the parent.

If parents are invited to attend information and guidance sessions it may be helpful to include grandparents so that practitioners may foster a supportive relationship between grandparents and parents. Practitioners may set up and facilitate support groups for grandparents. Such groups provide opportunities for the exchange of information and experiences. Through such sharing grandparents may be helped by feeling less alone and bewildered and more emotionally secure when interacting with their grandchild.

Practitioners may feel they do not have time to attend to the needs of grandparents because they need to focus on the needs of the parents. But if grandparents are helped and supported at this early stage they may well become not only a great source of practical and emotional support, but also one of the greatest advocates for the child. Research (Prudhoe & Peters; Sandler, Warren, & Raver, 1995) has indicated that support from grandparents and other members of

the extended family is more important for a positive adaptation to the diagnosis of disability than intervention from professionals.

In 1986 Vadasy, Fewell and Meyer reported that when grandparents feel they lack the knowledge and skills to care for and support their disabled grandchild they are more likely to experience feelings of despair and helplessness which in turn may result in rejection or denial of the child's condition and may hamper their ability to support the child's parents. At the most basic level grandparents, like the parents, need accurate, factual information about the child's condition and how to intervene. If practitioners do not have direct access to the grandparents because they live in a different town to the family then practitioners could leave extra copies of any printed material with the parents to be passed on – with a suggestion that parents and grandparents talk together about the material. Practitioners may also encourage parents to involve grandparents in the care of their disabled grandchild from the earliest stage on the understanding that they, too, need to bond with the child.

The role of grandparents

The roles of grandparents have been listed by Katz and Kessel (2002) as historian (a link with the cultural and familial past); guide; role model; mentor; storyteller; nurturer; substitute parent and/or provider of social, emotional, intellectual, and financial resources (p.114-115). For the well-being of the child and the whole family it is important that this rich source of natural support is fostered and encouraged.

Practitioners may need to suggest to parents that they need to be mindful of the feelings of their own parents (the grandparents) and of the fact that grandparents also need factual information about the child's condition. Parents may need to be encouraged to educate grandparents and coach them in ways in which they can be supportive.

The need for support will vary as the child grows and matures. As grandparents become older they may wish to be less actively involved while still supporting emotionally. As the child becomes adolescent, the siblings of the parents may step forward and be willing to be members of a circle of support around the young person (Forest & Pearpoint, 1997). Hence anything that practitioners do to encourage families to embrace a team approach to providing support may result in lifelong benefits.

Hornby and Ashworth (1994) in their study found that a significant percentage (25%) of the grandparents of the families they interviewed were considered to have added to the parents' problems. Such negative perceptions may be prevented if practitioners are mindful of this possibility and intervene early to sup-

port grandparents and foster positive relationships between parents and grandparents – while also encouraging parents to be aware of grandparents' emotional needs and of the need to coach them in ways to care for their grandchild.

Research studies investigating the kinds of involvement and support provided by grandparents of children with disabilities highlighted financial aid, shopping, babysitting, and help with household chores (Hornby & Ashworth, 1994; Sandler, Warren & Raver, 1995; Seligman & Darling, 1997). A disabled child may also benefit from a warm relationship with their grandparents who believe in the child's potential to improve and who focus on the positive aspects of development, rather than on the limitations of the disability (Levitt, Weber & Guacci, 1993).

Part of my work in Dublin over the last five years has been to co-facilitate, with a parent, a programme for parents of disabled children. This programme aims to empower parents, to encourage them to be as effective as possible for the demanding role they have and to give them the skills to support other parents. The programme acknowledges the considerable expertise of parents and seeks to promote:

- **self-care** in order to prevent burn-out
- **stress management** as a means of reducing stress
- mutual support for accessing support for self and others
- **listening skills** as a means of enhancing relationships (both within the family, with service providers and practitioners)
- **assertion skills** as a way of claiming rights and having needs met
- **information** to ensure awareness and confidence (Hornby, Murray & Davies, 2001)

From time to time when involved in the delivery of this programme I have been struck by the anguish that some parents expressed when they felt they did not receive the support they anticipated from their own parents or even from their own brothers and sisters. Katz and Kessel (2002) report:

One of the most significant findings in determining the quality and quantity of involvement of the grandparents in the life of their grandchild was the dynamics of the intergenerational relationships between the grandparents and their adult child and his/her spouse.

(p.122)

If intergenerational relationships are to be positive and become really supportive then, at the time of diagnosis, practitioners may need to be ready to give

some sensitive guidance to parents about informing grandparents and about involving them as soon as possible in the care of the child. Such guidance can help realise grandparents' potential as a significant resource for the family.

References

- Ferguson, P. M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education*, 36, 24-30.
- Hornby, G. & Ashworth, T. (1994). Grandparents' support for families who have children with disabilities. *Journal of Child and Family Studies*, 3, 403-413.
- Hornby, G., Murray, R. & Davies, L. (2001). *Basic helping/ supporting skills. Facilitator's Manual*. Auckland: Auckland College of Education.
- Kingston, A. K. (2007). *Mothering special needs: A different maternal journey*. London: Jessica Kingsley.
- Levitt, M., Weber, R.A. & Guacci, N. (1993). Convoys of social support: An intergenerational analysis. *Psychology and Aging*, 8, 323-326.
- Forest, M. & Pearpont, J. (1997). Life is either a daring adventure or nothing at all! In O'Brien, P. & Murray, R. (Eds), *Human services: Towards partnership and support*. Palmerson North: Dunmore Press.
- Prudhoe, C. M. & Peters, D. L. (1995). Social support of parents and grandparents in the neonatal intensive care unit. *Pediatric Nursing*, 21(2), 140-146.
- Sandler, A. G., Warren, S. H. & Raver, S. A. (1995). Grandparents as a source of support for parents of children with disabilities: A brief report. *Mental Retardation*, 33, 248-250.
- Seligman, M. & Darling, R. (2007). *Ordinary families, special children, Third Edition: A systems approach to childhood disability*. New York, NY: The Guilford Press.
- Simpson, J., Hornby, G., Davies, L. & Murray, R. (2005). Positive parent-professional relationships: Allies who emancipate one another. In O'Brien, P. & Sullivan, M. (Eds), *Allies in emancipation: Shifting from providing service to being of support* (199-211). Melbourne: Thomson/Dunmore Press.
- Vadasy, P. F., Fewell, R. R. & Meyer, D. J. (1986). Grandparents of children with special needs: Insights into their experiences and concerns. *Journal of the Division for Early Childhood Education*, 10, 36-44.