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14. DEVELOPING PROFESSIONAL RELATIONSHIPS WITH CLIENTS' FAMILIES

Mothers of Children with Disabilities

Families who have children with intellectual disabilities spend a great deal of their time in contact with health professionals. Their children may be at risk of, or experience, chronic or complex physical and mental health issues related to their disability. Due to the demands of caring, parents can also experience a range of physical and mental health issues that may be neglected. They are often confronted with a system that is hard to navigate, a lack of recognition and respect, inaccessible information and educational resources, with limited services when the challenges become too great. This chapter offers health professionals insight into the journey that families undertake and a guide to future interactions with families.

SETTING THE SCENE

In Australia, 18.5% (4 million) of the population has a disability and in 70% of situations the primary carer is female (Australian Bureau of Statistics, 2013). Today, 99% of families care for their children with disabilities within the home. Mothers represent the vast majority (92%) of co-resident primary carers of children aged 0-14 years with a disability.

Primary carers of children with intellectual and developmental disabilities experience changes in their physical and emotional wellbeing. The child's level of core activity limitation is directly proportional to the level of adverse effects on carers' wellbeing. The more profound the impairment the higher the adverse effects on carers' wellbeing. For example, 47% of primary carers of a child with a profound impairment compared to 31% with a severe impairment reported feeling weary with a lack of energy (Australian Human Rights Commission, 2013). The children are also known to experience a range of chronic and complex health issues that require ongoing monitoring and care. Examples include epilepsy, gastro-oesophageal reflux, dysphagia, constipation or contractures (Tadema & Vlaskamp, 2009). Unfortunately, these families' vulnerability to health issues due to the burden of care and subsequent psychological, social and economic sequelae are exacerbated by their invisibility as a consequence of the disproportionate emphasis on health in individuals with acute conditions (Foster & Fleming, 2008, p. 49).

This chapter presents the views of 13 mothers who had children with a range of disabilities and who were interviewed as part of the author's doctoral research exploring their perceptions of the key health issues they faced. The women, aged between 28 and 78 years, not only had experience as mothers but also had insight

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into the health issues of other families across different socioeconomic groups and life stages. The informants included five service providers from professional backgrounds in disability services, psychology, community services, social work and management. Pseudonyms are used for all participants to protect their privacy.

Themes emerging from the data included unrelenting demands, isolation, loneliness and aloneness; invisibility; being time poor; and "build up to a crisis"– all within the context of overwhelming physical and mental health needs. These themes and narratives are integrated into the discussion below, with emphasis on the relationships that health professionals form with families and the priority areas recognised in the National Carer Strategy (Australian Government Department of Social Services, 2011, p. 13) of recognition and respect, information and education, and services for carers.

RECOGNITION AND RESPECT: *WE'RE ALWAYS THERE*

Health professionals meet families in a range of environments including the family home, but regardless of venue it is important to privilege the establishment of rapport with parents or carers of children with a disability. Carers deserve to be recognised and respected, to feel valued, but unfortunately the reverse frequently occurs where they feel "invisible" and "dismissed" (Australian Government Department of Social Services, 2011). Family members have expertise that they bring to their role as a parent. In contrast, as health professionals we "*do not know what we do not know*!" Recognising family members' strengths and demonstrating empathy with an open mind and willingness to work in partnership demonstrates respect for the person and that person's situation and importantly provides the opportunity to "*learn more about what we do not know*".

The circumstances of many of the families involved in this study were complex. They had 48 children between them, 18 of whom had disabilities and were aged between 2 and 40 years. Six families had one child each with autism, and two families had two children with autism. Five families had children with Down syndrome and associated health issues. Gail talked about life with her daughter who had autism with episodes of behaviour that challenged the family for lengthy periods of time. In her reflection on working with professionals Gail highlighted the often temporary nature of professionals' contributions.

> I must admit I do quite enjoy being involved in this great circus that we live in and I really think it's a circus, because nothing is consistent. You've got different players and actors at you all the time, you've got no one that you're talking to that's in a permanent position and you're the only person that virtually doesn't change. You're always there, you always turn up, always. We're always there, we arrive at every show, every act, we're there, we never let the show down. (Gail, parent)

Although the professionals who were interviewed had worked with families over extended periods, this was not always the case. Families spoke of new graduates working with their child for a year at a time or less. Jane (a parent) found it very difficult to cope with continually changing relationships, with 18 different therapists working with her child over two and a half years. In stark contrast to these temporary relationships, families have their child for life. There is so much involved, the unrelenting demands of caring impacted on the mothers and families. For example, the mothers had to attend various appointments related to early intervention; tests and check-ups with medical practitioners and meetings at schools and disability agencies. As a consequence, Jane reported no spontaneity in life for herself and her partner, who felt that the planning required around managing the numerous appointments impacted on their relationship. The inability to just relax and enjoy life was at times difficult, with Jane stating:

> Can't explain the "ever vigilance", we stop our lives to do whatever it is that we are doing, however vigilance is the constant in our life. What if I was to die? (Jane)

Although not all families experience such challenging circumstances, health professionals can learn much from families and gain great satisfaction from the achievement of positive outcomes. The families wanted to feel respected and to work with health professionals who did not judge them. When family members felt stressed and under continuous pressure they needed to talk, to put the situation into perspective. Initially you, as a professional, may feel that you have to have the answers, or may be scared because you do not know what to say, yet the greatest gift is that of the "*listening ear*".

When a person appears really distressed, sit down (maybe over a cup of tea), ensure that a box of tissues is close and let the person talk and cry (it is often needed). People want to know you are listening and hearing what they are saying without interrupting or offering false hope. Parents may appreciate meeting other families experiencing a similar situation who can empathise with them. This highlights the critical contribution of meaningful health practice relationships to achieving positive health outcomes for families caring for children with disabilities.

REFLECTIVE QUESTIONS

For health professionals:

- Do you go into an environment wanting to "fix" the issues for the family?
- Do you feel that you have all the knowledge?
- What kind of questions would you ask, open or closed?
- Do you acknowledge the parent's level of expertise (their child/condition)?
- How do you respond to parents if they are angry, upset, distressed?
- Do you acknowledge what you do not know?

INFORMATION AND EDUCATION: YOU NEED IT IN WRITING AND SHOWN

When a baby is born with a disability, or when parents come to the realisation that something is wrong with their child, life becomes a journey of discovery. There are times when all is well and the family lives a life that is perhaps similar to that of any other family. However, there is a period of adaptation when parents oscillate between the different stages of grief: these include shock, denial, anger, sadness, bargaining, and depression. Grief and reality can impact on individuals when they least expect it. Jane remembers having panic attacks at the supermarket:

> I could see the car … could not get there … bawling … that was when I knew that I had her for the rest of my life. (Jane)

There are realities concerning the future, the realisation of what life is going to be like with a child who has a disability, and all that it entails. Over the years questions arise which need to be answered in a timely and appropriate way. Jean (service provider) spoke about her perceptions of the thoughts and feelings about their children of families she worked with, offering the following parent's quote:

> I have had a child for 18 years or 21 years, still changing nappies. Am I going to change nappies forever? (a parent via Jean)

Jean spoke about children with disabilities not experiencing the normal rites of passage that children without disabilities go through. The children would not leave home, go to work, they would be forever dependent on their parents and the future did not bear thinking about for Debbie (a parent):

> Other parents find that the children grow older, get married, go away, have grandchildren, all rewards of being a parent, but they will be a parent forever. (Jean, service provider)

> Planning for the future … And that is the greatest fear! (Debbie, a parent)

Grace (service provider) commented that families' levels of stress and vulnerability varied across their children's lifespans. Initially, she felt that parents with young children (under 6 years) experienced difficulties, sometimes with no diagnosis or support, that made it harder for all involved, especially when parents were grieving. At this time the emphasis was on therapy, the child was the focus. Parents turned to each other for support as they shared a common bond and felt they understood one another at a time when they were overwhelmed:

> Parents are grieving, in denial, professionals say to them: you need to do this, have therapy, go to specialist services – they [parents] don't want to know anything is wrong with their child, there is pressure then. (Grace, service provider)

These families needed access to appropriate and timely information, to enable them to gain the most suitable information. Early in the child's life parents may require referral to a grief counsellor or psychologist, education about their child's disability, and later they may need respite services to enable them to have a break or spend time with their other children. But parents often found it difficult to navigate the system when looking at services for their child and wondered where to begin, when it resembled a maze (Australian Government Department of Social Services, 2011). Many parents experienced a range of mental health issues. Jean (a service provider) felt that there was so much that families were confronted with:

> What compounds that frustration that leads to the depression is the fact that there is nowhere to go to find out what you need, you have to begin a journey like a jigsaw puzzle, always pieces missing. Families wear out trying to find services out there. That's a huge issue. (Jean)

Lack of services and supports and ways to navigate existing services resulted in parents struggling on their own, especially with lifting and moving the child with a disability. Families highlighted back and neck pain and joint problems. Service providers witnessed these issues, along with tendonitis, use of wrist straps or support bandages, and even instances of arthritis in young parents. A number of mothers commented that their back pain worsened as time went on, especially as the child became heavier with age.

> Lifting him [son] my whole body aches, my back, just everything is hurting from carrying him around … 12 or 13 kg. I actually need to go to a physio 'cause I've got this pain up here [points to back] that is constant, yeah … just a matter of me making the time to do it. (Kristie, a parent)

Hoists were not often used to lift children out of wheelchairs because the house was not equipped for them. Amy (a service provider) spoke of a parent who managed alone with her child, and how lifting was a constant activity for parents. Written instructions were required, or needed updating, for safe lifting and positioning of children. Families had forgotten or disregarded a physiotherapist's instructions, often provided in a quick training session long ago, if at all. The families wanted to be shown quick and easy approaches, with follow-up.

REFLECTIONS: WHAT CAN BE DONE

The families found themselves in situations they could never have predicted, with no preparation prior to the event and so much to learn, often through trial and error. They cared for their children 24 hours a day, managing complex physical, behavioural and mental health issues including complex seizures and eating difficulties with limited education and support. These mothers all came from English-speaking backgrounds. Imagine how these challenges would amplify if they were from a different cultural background, new migrants or refugees. When accessing information there is often an assumption that everyone has a computer and the internet, and has time to search for information. The mothers were "time poor". They spoke about the trauma of opening unknown websites that displayed graphic images of the worse possible scenario with regard to disabilities – late at night and with no support. The families appreciated being offered up-to-date information; they attended seminars and conferences when there was timely notification and child care available. They appreciated professionals who were approachable, insightful and empathic. The mothers wanted to know as much as possible, to be able to ask questions without being made to feel inadequate, because this helped them to make informed decisions about their child.

SERVICES FOR CARERS: BETWEEN A ROCK AND A HARD PLACE

The mothers perceived that the real scenario, their “lived experience”, was invisible to everyone except themselves. Attitudes of service providers had a huge impact on some mothers who felt they were not taken seriously or treated as equals. These mothers felt ignored, that their feelings were not understood and that they had to “make a noise” to be heard. Others felt exposed and vulnerable:

> You’re naked to all of these people who are involved with your child and you want to be trusting of them and hope they’re not going to abuse you but you know that they talk about you behind the confidentiality. You do feel very, very vulnerable. So when somebody around a committee meeting patronises me I shrink instead of looking up to them and saying, “Look, you haven’t got a clue”. (Jane, a parent)

Service providers often appeared unaware of the plight of families. While parents described services provided to the children as “great”, their needs as parents were invisible. One family placed the child in a respite service for a break but were called out four times in a week as the child kept absconding. The parent had provided staff training and behaviour management plans, but still issues remained.

> The staff are not in touch with the journey that the person has travelled, families not acknowledged for what they do. (Tanya, service provider)

One of the most poignant moments arose when one mother talked about her role on advisory committees for a number of organisations that provided services to children with disabilities (early intervention, respite care). Jane felt she had to be on these committees in order to bring about change and support for her daughter. Jane had to find the money to cover childcare while on these committees as a volunteer, while professionals were being paid. Her husband had to work two jobs for the family to survive. There was no acknowledgement of her situation as a mother of a child with a disability. She realised that she was

> … supporting everyone else but not being supported. (Jane)

Families who had children with mental health needs often experienced difficulty gaining access to services to meet those needs. Service providers felt that the families were denied access to services because of the confusion about actual needs and who should provide or was prepared to provide the service, either mental health or disability services. The service provider felt torn:

> That [situation] puts us between a rock and a hard place, whether to service them and how that looks to other families. (Jean, service provider)

Children and young people with severe challenging behaviours were singled out by the services as too hard and too complex for them to work with. When the parents sought help, the responsibility was put back on them. The family felt that they had no choice but to carry on caring for their child. If they did not, they felt that the services would be taken away altogether.

> The service providers threaten to take services away, the family becomes silent, withdrawn, complete anxiety. [The parent] hears threat [from the service provider] become silent and withdrawn, anxiety escalates. (Tanya, service provider)

REFLECTIONS ON THE REAL PICTURE

I reflect on my thoughts at the time of interviewing these mothers. Jane initiated communication with me at one of the workshops. She was vibrant, intelligent, educated, and had a put a lot of energy into ensuring that services were there for her daughter and others in a similar situation. Yet Jane was one of the only mothers to cry and on more than one occasion. She spent her time supporting others but not receiving or accepting support, even when this was offered by her friends. This situation is repeated weekly as families advocate for their children. We were able to raise awareness of Jane's scenario with the organisations and she was reimbursed for child care costs when attending meetings. In this way, albeit through research, the establishment of an authentic relationship led to meaningful health experiences and outcomes for Jane.

THE IMPORTANT ASPECTS OF LIFE

Although this chapter has illuminated many negative and challenging health issues for families there is much that can be done. There are positive aspects of each family's journey that tell us what is important to them and can guide health practices. This selection of narratives comes from mothers of young adults looking back on their lives and emphasising the value of key relationships.

> Having a child with a disability also gives life a purpose. (Noelene, a parent)

> Husband is my best friend, we've worked really hard to create and maintain that. (Debbie, a parent)

> It's always been my friends who have been my sanity, they're the ones I cry with, they're the ones I laugh with. (Julie, a parent)

> What I said today I have not told my closest friends, but I've told Julie my friend [a carer parent] and the interviewer, but I don't tell my friends outside

> the disability area because they would be concerned about me and try and treat me. But with Julie I don't have that fear. And … unfortunately we probably always come together in a crisis time. (Gail, a parent)

CONCLUSION

In this chapter I have explored the issues of families who have children with disabilities from the perspective of the mothers and key workers. Families' needs for recognition and respect from health professionals from the beginning of their child's journey have been highlighted. Access to empathic professionals, grief counsellors and support groups will offer the families assistance at the onset. Education and information ensure that families are at reduced risk of injury or ill health when caring for their children. Addressing these areas can reduce the relentless demands on the parents (mainly mothers), the loneliness and aloneness of caring, and the subsequent isolation and invisibleness of their situation. Finally, it is often the families who are there for each other, passing on their wisdom and support, sharing resources, the joys and heartaches. We are the visitors in their lives, with a duty of care to do no harm.

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