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Raising a child with disability and dealing with life events: A mother's journey

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Abstract

Intellectual disability services recognise people with intellectual disability as a family member and aim to provide effective support that facilitates family cohesion. However, the needs of families and individuals within the family should be addressed in a holistic manner to ensure a seamless service. This article outlines a mother's reflections on her experience of raising a child with autism spectrum disorder and its impact on her life. The article focuses on one mother's feelings, coping or lack of coping and growth during a time of sadness. This article written by a mother, nurse and academic through their shared interest in supporting families of children with a disability all came together to tell this story. It is hoped that this article will assist professionals understand a mother's perspective when raising a child with intellectual disability and support professionals to recognise the importance of listening, coordinated support and working in partnership.

Keywords: autism spectrum disorder, coping, families, listening, mother

Introduction

The availability of literature written by mothers, fathers and other family members of people with intellectual disability has grown over the past number of years. These articles and books assist professionals to develop an insight into what it is like for individuals/families who have a member with intellectual disability (Daly, 2012; Maxwell and Barr, 2003; Rendall, 1997). This article aims to add to the growing insight available on families experiences' by outlining a mother's story and life events that has shaped her experience of raising her child with autism spectrum disorder (ASD). The impact on the mother's life both positive and negative is considered and how she as a person has grown and learned as a result. This article transpired as a result of many discussions between the authors and their interest in intellectual disability research with the concepts of family and support being central. The first and second authors have known each other for 11 years, the second and third authors have known each other since 1 year. Through many shared interests, all authors came in contact with each other. The second author has been involved with the first author (Tina) since her son was a small boy, when the second author worked as a home support and respite manager. Their relationship continued even when the second author left the service and over the years, they met often and spent long periods of time chatting about life, the universe and everything but essentially the conversation would always return to Tina's son, Eddie. These meetings would invariably end with the second author saying to Tina 'someday we will write your story' and Tina saying 'I don't think the world is ready for what I have to say'. Although Tina always expressed a wish to tell her story, she found it difficult to balance her feeling of having to show she is coping and feeling safe to say or admit that it is difficult or that she is not coping. The principal aim of the article is to provide a mother

(Tina) the opportunity to tell her story and experiences as she reflects on her time as a mother of a child with ASD. With this focus, Tina's account of her life with Eddie is presented and was prepared by Tina herself and has been unaltered. Tina's reflection outlines her feelings and how she feels she has grown over the years through the times of sadness she felt as a parent. As this article is a mother's story and her perspective, references have intentionally been confined to the introduction and conclusion.

It is recognised that children with intellectual disability are born into a family and, generally, the family members provide the majority of support and care during their lifetime (Chadwick et al., 2013; Taggart et al., 2012). People with intellectual disability often live at home longer than their siblings, and parents remain an important practical and emotional support during adulthood (Maxwell and Barr, 2003; Barron et al., 2006). Parenting can be for the lifetime of the individual, and this longevity can affect the quality of life of parents. While health, social and educational professionals have a vital role in supporting families (Chou et al., 2011; Hatton et al., 2012; Ward, 2001), fundamental to effective support is an understanding and awareness of what it means to have a person with intellectual disability in the family and the needs of the family (Skinner and Weisner, 2007). While professionals can increase their understanding and insight of intellectual disability and families by reading books and research studies, these, however, are generally written by professionals and researchers, thus running the risk of presenting a particular point of view regarding parents and families.

Historically, families have frequently been identified as 'in need' which serves to compound a negative perception. This is evident by the large volume of research studies dedicated to identifying the level of stress/anxiety among either families, parents, fathers or mothers and the difficulties that exist in families with a child with intellectual disability (Blacher et al., 2005; Howie-Davies and McKenzie, 2007). Whilst difficulties may arise, these have too often been accredited to having a family member with intellectual disability without consideration of other possible factors, such as access to services and working with professionals (Todd and Jones, 2003). However, in more recent years, researchers have recognised the positive contributions of a person with intellectual disability to family life (Blacher and Baker, 2007; Grant and Ramcharan, 2001; Little and Clark, 2006). The reality for many parents and families is that they experience a mixture of joy and sorrow with the presence of a child with intellectual disability (Kearney and Griffin, 2001; Little and Clark, 2006; Trute et al., 2007). Other accounts from parents highlight the development of successful coping skills, increased knowledge and abilities and parent's input and commitment to supporting their child (Daly, 2012; Dyer, 1996; Gregory, 2000; Rendall, 1997; Sheahan and DeOrnellas, 2011). In an effort to address negative stereotypes, there is a need to learn how to support families and build existing

knowledge to offer professionals strategies that recognise parents and the wider family situations (Shearn and Todd, 1997; Todd and Jones, 2003; Ward, 2001). Central to developing a greater understanding into the lives of families of people with intellectual disability is supporting and/or encouraging parents, people with intellectual disabilities and other family members to highlight their experience (Maxwell and Barr, 2003).

The following account is an example of a mother's experience that highlights her memories and reflections. This account may not be representative of all parents experience and is not an autobiographical account or an overview of the impact on the family. Rather, it is the thoughts and experiences of one mother, which are presented to provide some further understanding in our endeavour to support parents/families effectively and is presented from one parent's perspective.

A mother's story

I discovered I was pregnant when I was 39 and this came at a time when I was in the process of divorcing my husband. Due to my family circumstances, I did ponder with the idea of having an abortion and discussed it with my husband. He said the decision was entirely mine and he would support my decision. After much consideration, I decided to go ahead with the pregnancy thinking it would be good for my daughter to have a sibling. However, this was a difficult time for me with the divorce and being pregnant, and when the day finally arrived, I found myself burdened further by a sickly underweight little boy who was failing to thrive. I felt this was an extra burden that I was not able to carry, and on occasions in the early stages, I openly said that I regret the decision not to have an abortion. This, however, was met with anger, hostility and disbelief. It is very difficult to explain how I love my son dearly, and at the same time, I wish he had never existed. I have never been allowed to explain this because people do not let me get past the sentence 'I regret not having an abortion' or 'If I could turn the clock back I would have an abortion'.

My son Eddie is a wonderful boy, happy, good-looking, affectionate and very lovable. He has been diagnosed with ASD, but he is not a classic example of an autistic child. I love and protect him with the same ferocity of a tigress with newborn cubs. On numerous occasions, I have angrily confronted people who have been discourteous to him or who do not make allowances for his bouts of unusual or 'bad' behaviour. In a few months, Eddie will be celebrating his 18th birthday, and I still have not recovered from the pain of having a child who has a disability. I feel I will never recover, there is no escape from the 'constant bereavement' and the never-ending 'sadness and worry' about my little baby.

I will always have the same attachment to him as a mother has to a new-born infant. When he is being cared for by someone else, I miss him, and when he is with me, I find that I cannot cope. This see-saw of emotions has continuously invaded my life and took over every aspect of it, and I know these emotions will be with me until I draw my final breath. Over the years, I have not been able to deal with everyday life in the same way as the 'average' person. What might be a minor setback to someone else could plunge me into a deep depression where I have turned to alcohol or tranquillisers.

I began to suffer severe panic attacks when Eddie was only a few months old. I remember taking him for a walk in his buggy when he was a year old and wishing I had the courage to walk in front of an oncoming truck. I thought of my beautiful daughter and luckily the moment was gone. I think Eddie was about 12 years old when I heard in the news of a woman in Humberside who jumped off the Humber Bridge with her autistic son. This seems awful but to me she was a heroine and I wished I could do the same. It seemed to me that people in general were oblivious to the day-to-day difficulties and extreme hardship faced by mothers of disabled children.

These thoughts and feelings over the years lead me to seek help and support from my general practitioner (GP) and health-care services. However, their solution was medication, and I found antidepressants made me act silly and out of character and at a particular stage, I was so drugged and 'out of it' that I barely knew how to get the weekly shopping. With the exception of valium, prescription drugs were not helpful to me, and I am thankful that it has assisted me to get through difficult times in my life. It surprises me that nobody could see my pain or if they could they never told me or asked me to offload or share it in some way. The individuals who tried to reach me left it until I had already gone too far and what was left was only the sedated remains of someone who was once a happy mother of one beautiful little girl. When Eddie was 4 years old and had started school, I stumbled upon a pressure group which convinced me that I needed to push for more services for Eddie. I had not felt strong enough to insist before that he would receive more attention from speech therapists and other therapies. To be quite honest, I was quite accepting of the whole situation and did not realise that things could be better. This led me to a point where almost everything to do with Eddie was dealt with by solicitors or at least I asked their advice on everything. I regret this and the manner in which I dealt with teachers, special needs assistants and other healthcare professionals. I was unable to see anything in a positive way, nothing was good enough for my baby and nobody could do anything right. This came at a time when I was also looking after my mother who eventually died of uterine cancer, and it is important to note that the physical and mental exhaustion of looking after a child with disability left me in a state of mental paralysis, so to speak.

Eddie went to stay at a respite centre with a local service provider, but I felt it was not suitable for his needs. I criticised staff who were doing their best. I alienated them, but to be honest, I never really

was a great communicator and that has nothing to do with Eddie but rather a lot to do with my social phobia and low self-esteem. Life was spiralling out of control. I could not cope and became very depressed, suffered panic attacks and at my lowest point, I was afraid to leave the house without my daughter or my niece. I became addicted to antidepressants and valium. I even turned to bottles of wine. I dealt with everyone in a confrontational manner, whereas in reality, I am a reasonable person. I believe now that people from the pressure group instilled a belief in me that I had to fight. If I did not fight, Eddie would be neglected everywhere, at school, at the hospital, dentist, physio and so on. I am not sure any more about the extent of the lack of services but I am quite sure I was 'obsessed' with the fight for services.

As regards a normal family life, I feel my daughter and I never experienced it or more correctly we felt that our lives were a jumbled confused mess where nothing ever went smoothly. With the exception of my GP, my dealings with all professionals were confrontational as there was always the feeling that I had to fight for things that were causing this 'RAGE' in my head and this rage was killing me. I believe I am lucky the rage did not result in the death of my children and I. I often thought of suffocating Eddie in his sleep and I thought of drowning him in the bath once. If I suddenly found myself back in the situation where I had to deal with health-care professionals, I would refuse to allow them inside my front door, with the exception of one social worker who appeared to quietly understand and accept my suffering. Going from place to place for each different facility caused me so much stress; there were times when I would arrive at appointments ready and willing to be abusive towards health professionals. In the average family, if a child is ill and has to be taken to the GP and subsequently needs to stay in bed and be cared for, or indeed go to hospital, it adds a considerable amount of extra work on the parents (usually the mother). In my case, this featured relentlessly in my dreary day-to-day existence. Dealing with GPs, hospital visits, dentist appointments, occupational therapy, special footwear, emergency situations with seizures and classes for me to attend about helping with speech and behaviour drained me completely. Even going to pick up a prescription was an ordeal and I was 'OVERWHELMED' at the enormity of looking after a child with a disability on my own. I wished the powers-that-be would provide a sort of 'one-stop shop' for parents.

This time was filled by guilt, and blame, I blamed myself for not wanting him to start with and the neglect I felt my daughter was encountering due to my poor mental health and Eddie being in our family. Then, I began searching for a cause of the problem, what I did during pregnancy such as refusal to change my lifestyle, smoking and so on. I have come to a stage where I feel I am at last listened to by health-care professionals and that they are not embarrassed to agree with me. This is a major relief. I once had an extremely helpful, open and honest discussion about possible things I might have done in the early stages of pregnancy that might have caused some of Eddie's health problems. This conversation was very helpful to me. Care staff agree that he is difficult at times and

that they also get stressed but they have a break. It was a huge relief for me to hear this as the intensity of the care, the seizures, the asthma, the behaviour, the trying to do something simple like cook a dinner was damn difficult and no one seemed to acknowledge this before. I was disconnected, invisible and alone, which led me to feel that I could not cope and was doing a bad job, which was causing further stress till it all built-up and I caved in and cracked under the pressure.

I feel compelled to explain that on the one hand, if Eddie is hurt in some tiny way, for instance, if he stubs his toe, I feel it just as a mother jumps to help an infant who falls over while he is learning to walk. I feel the same pain. There is a connection between mother and child, which does not fade away in the same way as the connection between a 'normal' child and his/her mother. I cannot seem to let go of him, I worry about his future and the support that will be available, and I worry that he may not be able to properly communicate when he does not feel well. I even worry about when he is an old man and does not have me to look out for his welfare. He does not have the ability to communicate with people in the same way that he can with me. People either do not believe that he can communicate properly or they do not stop to try and understand. Even my own siblings do not believe that Eddie can tell me which popular music he enjoys. To some family members, Eddie's ability does not extend past sitting staring at the fire or watching his Postman Pat videos.

Eddie and I no longer go out in public together unless we are accompanied by someone who can help with tantrums. I am always fearful that we will meet someone who will criticise his behaviour and I will either end up feeling angry or upset. We have on countless occasions come across people who vary from being intolerant, uncaring and unhelpful to downright abusive. It is also true to say that we have met kind, helpful people and these people usually intervene in a crisis saying they have a relative with a disability. Another issue that affected me deeply and more than I realised at the time was the plentiful supply of people with strong religious beliefs. Comments such as 'it's a terrible cross', or 'he's a special gift from God' were not helpful in any way. It seemed ludicrous to suggest that 'God' decided that my son should have a disability when it is obvious that genetics and/or environmental factors are the cause. It seemed obvious that health/social care professionals and educators should keep their religious beliefs to themselves. I sometimes still get annoyed that my son takes part in religious rituals like a performing monkey. However, it is not one of my most important concerns because Eddie does not understand it all anyway. It seems to me that instead of projecting religious beliefs onto my son, it would be better if he could do something that would be helpful to him in his daily life. Eddie would derive greater pleasure from watching Postman Pat than learning to go to Holy Communion.

The achievements of my 17-year-old son have surpassed the expectations I had when he was 4 years. Every tiny achievement creates a sense of extreme pride. When he first said 'Eddie loves Mum', it

was my proudest moment. When he first offered to make me a cup of tea, I felt as proud as a parent watching their child graduate from university. I remember a friend once saying that she thought of me and Eddie when her grandson started mainstream secondary school. She said she felt so sorry for me because my son would not be doing the same. To be honest, I felt nothing at all when she said this. I never made comparisons between my son and other boys of his age. To me, Eddie's happiness is all I care about, and it seemed silly of people to make comparisons and to assume that I would be envious of other people's children. To me, it is rather like comparing having a gorgeous red-headed daughter to your neighbour's blonde daughter, or being envious because your son is going to study Art History when your neighbour's son is going to do Chemistry. The very basic maternal instincts that most mothers feel when they have an infant are still very much a part of my existence and therefore I have never at any time wondered what it might be like to have a 'normal' son. I love Eddie as he is and while my journey through life with Eddie has had a few ups and many downs, I accept him and had never actually thought what my life would have been like if he was 'normal' until this moment, when I was writing this article.

Conclusion

The diagnosis of disability is most often considered to be a traumatic experience for families, which influences the lives, emotions and behaviours of family members (Ergün and Ertem, 2012; Yıldırım et al., 2013). Most parents expect to have and raise a normal child and possess hopes and expectations for the future of their child. In contrast, parents of a child with a disability may experience dramatic changes in social life, expectations, family plans, work life, financial status and emotional well-being. This is the case in Tina's story where she expresses that 'I will never recover, there is no escape from the constant bereavement'. While several studies have established that parents of children with a disability, particularly mothers experience more stress, higher levels of anxiety (Esdaile and Greenwood, 2003; Estes et al., 2009; Seymour et al., 2013) increased sadness, a sense of denial and guilt (Ergün and Ertem, 2012), and there is a need for health and social care professionals to proactively support families and listen to and value what they say and their knowledge of their child as this is essential to an effective working relationship (Blacher et al., 2005; Keen, 2007; Tomasello et al., 2010).

Within Tina's story, she often felt isolated and alone and left feeling that the professionals avoided addressing the issue of her coping 'it surprised me that nobody could see my pain'. This pain and stress lead to the spiral of medication and drinking to create a 'sedated remains of someone who was once a happy mother'. 'In reality, through looking back on my life and events, I have also to take some responsibility for not saying I was struggling and not coping'. However, as a parent this is difficult, and as a parent of a child with a disability, it is more difficult, as this can be seen as not

wanting your child or resenting the life you now have and thereby resenting your child. While professionals may feel they have detailed knowledge on disability, they do not know the individual child and their family nor do they live families' daily reality (Biswas et al. 2009). Professionals need to gain a deeper awareness and understanding beyond theory or book knowledge to enable them to work more effectively with families, identify crisis and understand that other normal life events can escalate and intensify the stress at any given time. However, professionals often do not effectively engage and listen to the individual stories of people with intellectual disability or their families and often feel unprepared to respond or support that person by failing to encourage the person to open up and tell their story. It was this aspect along with the comments of other families who had a child with a disability that drove Tina's desire to tell her story. Too often, we are afraid to say it is difficult as one feels it will be interpreted as saying 'my child is difficult'. While this article only highlights one mother's story, it may draw attention to professionals implementing policy principles of supporting people with intellectual disability and their families that a relationship of partnership and listening effectively is a key starting point (Barr, 2007; Ward, 2001).

Tina like many others in society is a lone parent, and it is recognised that lone-parent families are at greater risk of experiencing poorer health and quality of life (Emerson, 2004; Kelly et al., 2009), stress and emotional difficulties in caring for their child with intellectual disability, especially when behavioural problems exist (Kelly et al., 2009; McConkey et al., 2008). It must also be acknowledged that different families react differently to the demands placed upon them (Hewitt-Taylor, 2005).

Given that the emphasis of current policy in many countries is on family-centred care and supporting carers (Department of Health and Children, 1999, 2004), we need to develop a collaborative family-professional partnership. To facilitate collaborative family-professional partnership, Blue-Banning et al. (2004) propose six interrelated themes in the context of childhood disability including communication, commitment, equality, skills, trust and respect. True family-centred care implies a readiness to consider the needs of the family unit as a whole where the inclusion of families in the planning, implementation or delivery of care is paramount.

When working with families, professionals need to operate from a base of trust and respect (Fereday et al., 2010), and for this to occur, each party will have to be open and feel safe to clearly articulate their thoughts and feelings. Within a single parent family, this openness is essential to support the parent and assist them care for their child when they are also dealing with many other social, emotional and stress issues. This open and honest relationship has to be a two-way process with the parent and professional both willing to admit and acknowledge their difficulties. This was essential for Tina to move beyond the stress as when this relationship existed 'I feel I am at last listened to' and 'staff agree that he is difficult at times and that they also get stressed but they have a break'. These statements of admittance and acknowledgement enabled Tina to feel she was no longer 'invisible and

alone', which she feels was compounding the 'feeling I could not cope and was doing a bad job'. Without this relationship in the past, it had caused Tina grave difficulty 'I caved in and cracked under the pressure' and she spiralled onto a double-edged sword where antidepressants were prescribed but the issues behind her stress/depression were not dealt with. Professionals have to take a more proactive role in listening to what is said and what is not spoken but still communicate and pick up on and respond appropriately to the cues that clearly communicate, such as parents/families joy, sorrow and concern on both verbal and non-verbal communication (Karst et al., 2012; Rao and Beidel, 2009).

Responding appropriately to both verbal and non-verbal communication enables the professional to look below the surface and public image and become more alert to the loneliness that can be present in some people's lives and enable them adjust to their new situation (Barr and Miller, 2003; Maxwell and Barr, 2003). Professionals need to engage parents and recognise their strengths, limitations and concerns and facilitate their continued growth (Keen, 2007; Rouse, 2012). Through building trust with the family/parent based on respect, professionals can effectively engage with the parent/family in a partnership manner (Turnbull et al., 2010). This is an ongoing challenge and professionals need to be cognisant of providing clichéd answers and broad reassurances, which the parent/family interpret as a failure to listen and a reluctance to engage (Turnbull et al., 2009). Professionals cannot work with the individual with intellectual disability in isolation from their family, nor can parents and family members be viewed purely as a means of providing support and care, with little attention to how they feel and the fact their lives are intimately intertwined (Doody, 2012; Maxwell and Barr, 2003). Failure to recognise the unique relationship in providing care and support to both the person with intellectual disability and their parent/family only increases the isolation felt by the parent/family. This relationship is lifelong as one is a parent to a child with a disability all their life 'I worry about his future, I even worry about when he is an old man and does not have me to look out for his welfare'. A partnership approach provides an opportunity for all parties to exchange views and learn from each other and extend beyond the parent/family to include effective partnerships with other professionals (O'Halloran and Doody, 2013; Maxwell and Barr, 2003). This partnership relationship has to recognise the unique understanding between the parent and or family members and the person with a disability, which is based on knowing the person and/or intuition 'he does not have the ability to communicate with people in the same way that he can with me'. This recognition needs to be held by all professionals as in some circumstances several professionals can be involved in similar areas of work with overlap, confusion, inconsistent advice and perceived role and boundary conflicts (Maxwell and Barr, 2003). Thereby, an effective key worker role is important as it can support families, by providing a clear point of contact and minimise confusion and conflict between professionals, leaving families to focus on their activities (Williams and Robinson, 2001).

This article has taken all three authors on a journey of discovery, from the initial conversation by Tina expressing her wish and desire to tell her story and show that it is ok to say it is difficult and that sometimes she did not cope, to now, where she is in a better place and has learned to work more effectively with professionals in an open and honest manner and face the future. For the second author, who has worked with Tina and her family over the past number of years, Tina's story has created mixed feelings of regret in that the service she was providing could not meet all Tina's needs to feelings of privilege that Tina wanted her to be part of her story and that she choose her to be the first person to read it on paper. The third author, as an academic, struggled with the desire to support Tina to tell her story and the difficulties leaving Tina's story untouched and not be influenced by the conventions of academic publications as well as trying to protect Tina from the potential disheartening reviews that can occur within the publication process.

The concerns regarding the ethics of telling one's own story and the right to tell one's own story were not easy to balance or justify as this was uncertain territory and within this 'no man's land', all authors trusted the guidance that would be offered by the editor as to whether to submit for consideration and the judgements of the blind reviewers during the publication process. As this process was supportive of the value of this article and Tina's willingness and wish to allow her true identity was revealed, we proceeded and hope this article may give other parents, siblings and people with a disability the confidence to tell their story outside of the traditional research study format.

Overall, this article has tried to portray the voice of a mother, and for Tina, if she knew what she knows now when she started out on her journey she would say 'try to take one day at a time, admit when you are not able to cope and seek help but do not necessarily expect your family and friends to understand your needs. Find at least one friend who will support you when you are making important decisions. Never ever allow others to judge you or make you feel guilty. Accept and take care of yourself'. The final words go to Naomi Judd who in an interview said, 'when you're a carer, you need to realise that you've got to take care of yourself, because, not only are you going to have to rise to the occasion and help someone else, but you have to model for the next generation' (Judd, 2013).

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