

Chapter five essay

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However, the influence of these changes is difficult to substantiate. For instance, Finch and Groves (1983) suggested that the care of children with disabilities in the UK almost always means care by another family member, and this family member is nearly always a woman.

Have circumstances changed for families supporting children with learning disabilities? The way in which many services (respite, aids and adaptations, advice on child development, advice on health) in the UK operate necessitates a referral from a G.P. or other professional. Parents with children with learning disabilities are asked in many situations to let professionals into their lives in order to gain access to a range of services. The consequence of this process is the realization that their needs are different from other families and their children may need specialist support.

The constant need to build new relationships with different workers has been a feature of service provision for many years (Dale 1996, Middleton 1998). This chapter will focus on the effective help of parents with children with learning disabilities. Families and Children with Learning Disabilities. It was indicated earlier in this book that some interventions have changed, aiming to build and sustain collaborative relationships with families.

Alongside these changes there has been a shift in the way that some families are depicted in the literature. The main thrust of recent changes relate to a shift from a pathological, atypical parental reaction to a typical, common parental reaction. The pathological view suggests that parents react atypically to a child with a disability. Reactions of parents are well reported in the literature and include denial, anger, sorrow, and over-protection.

Gardner, sky and Turnbuckle (1991) reported that professionals suggest that parents overprotect the child and often seek in-depth information on their child's disability and will often "shop around" for a second opinion. It is claimed that parents deny the reality of the situation and grieve for the loss of the idealized child. Parents who appear to be coping well with the situation are said to be overcompensating to reduce their sense of guilt. Daniels-Mohrinning and Lamb (1993) suggests that the anger that some parents present masks the guilt and sorrow they feel as a result of their child's disability. These claims by researchers are so prevalent that it would appear that all parents experience these range of experiences. Little attention is paid to the influence of economic or cultural circumstances and their influence on the family. Research in the ass's began to challenge the negative view that was a prevalent feature of the research at that time. Furthermore, Sabbath and Eleventh's (1984) found that research focused on parental reactions to disability rarely included control groups of families that did not have a disability.

This prevents any meaningful comparison to other families' sections to children. Vance et al (1980) suggest that when control groups are used in research related to families' experiences of children with disability, the results do not demonstrate marked differences in functioning between families with and without children with disabilities. It has been suggested that the presence of a child with learning disabilities may affect family dynamics (Trivet et al. , 1990). McClellan and Desolated (1993) suggest that specific "stress" affect families with children with learning disabilities.

Intaglio and Doyle (1984) argue that these “ stress” are not experienced by other families.

They are claimed to be caused by, emotional strain, marital discord, sibling conflict, difficult developmental transitions, unresponsive service delivery systems and permanency-planning concerns (McClellan & Desolated 1993). However, the concept of stress is not defined, even though it has become a common term (Mockery 2008). Parents with children with learning disabilities are thought to experience greater stress reactions than other parents (Byrne & Cunningham 1985). There would seem to be few explanations, however, regarding the variations in these reactions, as Grant ..

. Despite the sophistication and considerable et al (1998) noted: explanatory power of some models of stress process, there has been a tendency within the research community to view caring in pathological terms” (P. 59).

Attempts have been made to explore these experiences in more depth by describing parents’ experiences and relating them to stages, similar to grief and mourning (e. G. Parkers & Weiss 1 983, Parkers 2001). These general descriptors have been related to the many reactions parents of children with learning disabilities experience. It is thought that these experiences are sections to the loss of their “ expected” child.

These expectations are generally linked to the expected gender and ability of the child and parents may be disappointed because of their child does not look like the stereotypical “ perfect blue eyed boy’ (Pushed 1991). However these experiences do not always equate to negative feelings towards their children. It is not uncommon, for example, for parents to resent the

impairment, but continue to express feelings Of love for their child (Cunningham & Davis 1985). Davis et al. (1989) focused on mothers' constructions of their children, ND highlighted that parental awareness that their child with impairment is different from others need not be taken to imply “ negativity” from the parents.

Bruce et al. (1994) compared the experiences of three age cohorts of parents. Their findings suggested that the “ grieving process” should be considered as a continuous aspect of parents' experiences. Additionally, they found that the types of reaction varied considerably amongst the cohorts, “... There is joy and pride in the child's special progress, but for some the continuous strain is almost overwhelming..

. ” (Bruce et al. 1994, p. 49). Some of he literature depicts negative parental reactions to the birth of a child with learning disabilities (Alsations 1 963, Burden 1 986 & Beck et al 2004). These studies report a number of negative feelings, for example, sorrow, guilt and anger, related to the suggested “ shock” associated with the birth or diagnosis of a child. However, there are also studies that discuss different perspectives (Scourge & Sober 2000, Staunton & Bessel 1 998, Hastings & Taunt 2002). Taunt and Hastings (2005) suggest that positive parental outcomes, like personal growth, and negative outcomes, like parental stress, are somewhat independent of each other.

Parents reported positive perceptions of their chi lilled whilst recognizing some of the difficulties they Were experiencing with supporting their child. Equine and Pall (1 991) investigated the effect of specific impairments as causes of stress to families. Their findings suggested that those high levels

of stress correlated with multiple impairments and behavior problems. Stress in parents related to variables that focused on the child and the social and economic circumstances of the family. The most stressful factors affecting the children were, behavior problems, night time assistance, multiplicity of impairments and the child having an unusual appearance.

Economic circumstances of the family included, social isolation, adversity, and worries over money. These reactions are mixed with other factors and also add to parents concerns. Parents are also concerned with the services that would be available when they could no longer support their child. Best Practice – Helping and Helping Relationships. One concept that is held by many as having the potential to change the way services are modeled is the notion of empowerment. Empowerment is a concept that has been embraced by many organizations that work with families.

The concept of empowerment offers frameworks for the exploration and development of new methods, strategies and practices that will contribute to families defining and solving their own problems. However, empowerment still seems to be problematic. It would appear to have widespread appeal, but empirical evidence is lacking of how it can be used to effect sustained change in social situations. It would appear that one of the key elements of the empowerment process is strengthening and supporting families.

One model closely aligned with empowerment is the “ Enabling Practice” model developed by Karl Dunes and colleagues. The foundation of this model focuses on and explores the many different styles that may be utilized by family workers when supporting families. The notion of “ family-centered

services” has been current in the UK since the asses. Central to the complex nature of supporting families are the professionals who provide help.

Families play a vital role in the support of their children and adult family members with learning disabilities. Many families cope independently and require no formal support from family arrives, but some request and require various types of support from formal support services. However, the debilitating effect of certain types of help, and the manner in which it is provided has been well documented (Dale 1 996, Middleton 1998).

Madden (1 995), for example suggests that many professionals are prejudiced, ambivalent and ignorant of the concerns, insights and strengths of parents. This often results in conflict and a breakdown of the relationship between the service users and providers (Fisher et al 1983). The need to alleviate these tensions and harmonies relationships has led any parents/professionals to advocate the use of broad-based family systems that focus on enabling families to build strengths and develop partnerships with workers that offer support, (Dunes 1 989, Dunes, Trivet and Deal 1 988, Murray 2000, Case 2001). The aim of support services should be to strengthen families’ abilities to cope effectively with life events, Dunes et al. (1994). It is thought that this will help families remain in control of their lives and become more self-reliant and less dependent on family workers and services. There are many family support systems that purport to associate heir service practices with effective helping strategies. However, careful analysis would suggest that many are paradoxical in nature. The stated philosophies and aims of these agencies contrast significantly with the experiences that have been reported by parents (Fiske 1993, Cunningham et <https://assignbuster.com/chapter-five-essay/>

al. 1999). It would appear that there is little evidence to support the claims that have been made by many agencies currently offering support.

Additionally, the extent to which parents understand family support systems has not been represented in the literature. The introduction of the Parents ND Disabled Children Act 2000 and “Valuing People” (DO 2001 & 2009) will necessitate evidence related to best practice and continue to review current support services for families. When Parents Make Contact with Professionals Parents feelings associated with seeking and securing help appear to share some similarities with the findings in research by Spots and True (2002).

This study suggested that help can lead to the parent feeling that they should be grateful for the support they are offered. Moreover, they suggest the parent is likely to feel indebted to the worker if they have to ask for rather than being offered help. It could be assumed that if parents paid for the service/help then they might react differently when asking for help. These debilitating effects can be reversed by what Dunes & Trivet (2008) refer to as a process of creating opportunities for competencies to be acquired as part of meeting needs, solving problems, or achieving aspirations.

The promotion and the enhancement of competencies that permit an individual or group to become better able to solve problems, meet needs, and achieve aspirations would be a crucial part of the support offered to parents at this stage of the eloping process. Parents’ reactions to the discovery that their child has learning disabilities are well represented in the literature and discussed earlier in this chapter. These views as to the likely

impact of a child with learning disabilities on the family may explain why some of interviewees in a study experienced emotional issues when deciding they needed support, (Summers 2009). It could be argued that by asking for help you expose yourself and your family to the judgment of professionals. Summers (2009) claimed that it was the difficulties that the parents experienced with purporting their children that confirmed their thoughts about their child's needs. None Of the parents in this study had been given a formal diagnosis for their child before they decided they needed support (Summers 2009). The turning point for these families appeared to be the realization that they were unable to cope with their current situation, typically represented by the physical and/or emotional issues of supporting their child having an effect on their situations. Although it is recognized that families' experiences cannot and never will be " typical", the difference in this study was that their children ere developing alongside their peers.

This often resulted in parents in this study asking or being asked questions (by family, friends or workers) about their child's development. Moreover, parents of children without learning disabilities would be exposed to these experiences but would not have to deal with any of issues related to their child's delayed development. As well as coming to terms with the possibility that they needed help, the parents in this study also dealt with the realization that the help required was related to their child's developmental delay. Given that these experiences could be Hellenizing for parents, a number of them found it difficult to continually relate ' their story' about their child to numerous workers. It is clear to see that these children did not just suddenly acquire learning disabilities. The identification of learning

disabilities is a progressive cultural practice it is the socio-economic conditions and disabilities that contribute to the exclusion that the child and parents experience. As it is difficult to make any firm conclusions about how parents react to the birth of a child with disability, or news that their child has learning disabilities, it would appear appropriate to offer choices related to support at this stage.

The important lesson to learn of the helping process is that there is not a standard family and that each family experiences events and react to this news according to their values/culture/ beliefs and resources. It is also important for services to be responsive to family requests for help to enable parents to begin to build early relationships with workers that promote the acquisition of effective behavior that decreases the need for help, thus making the family more competent and more capable (Dempsey & Dunes 2009). Securing Help Following the decision that they required help, many parents find it difficult to make contact with services. When help is established it is difficult to ascertain the effects on the parents of continually having to tell ‘ their story” to different workers, (Summers 2010). There is little written about the effect (if any) of parents being continually asked by workers and others to explore their child’s developmental history. However, parents are likely to tell different stories to different stake holders/professionals/helpers/providers.

Parents do not have one story to tell. A parent may for example tell a different story to a portage worker (these are usually home teaches that work with pre-school children) social worker. Parents appear to be telling us that they find it intrusive and difficult to convey personal information to so

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many different workers offering help, as they find it difficult to build relationships with so many different professionals. Making the decision to seek help from a professional would be seen as one of the many transitions parents face as their children grow and develop. These transitions include the birth of a child, the news that the child has an identifiable learning difficulty, working through the emotions related to a diagnosis, establishing the need for various kinds of support and supporting the child into education. Each of these transitions may give rise to various support needs. To meet these needs parents may need to find and move into formal and informal networks of support. Moving into these networks will again mean sharing intimate details about their family with many different people.

This appears to be the area that has the potential to cause emotional trauma and conflict for the interviewees in this study. If these events are attached by negative perceptions about the availability of appropriate support, these negative emotions could be unresolved (Summers 2010, Redmond et al. 2002) and are also entangled with the realization that by asking for help parents are revealing themselves and their feelings to the outside world. A possible way of alleviating these concerns would be to: Help families write a FAQ sheet about themselves that they can send to professional prior to the first meeting. Ensure that the helper read previous data that organizations keep or discuss this information with previous helpers.

Prevent repetitive information gathering by writing to parents before a visit suggesting information that they may need to know about families. Ensure that this information is passed onto other workers (sometimes known as a handover). A local, consistent and organized network of formal and informal

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services is needed to support the individual needs of families moving through these transitions.

The need to build a consistent relationship with a worker appears to be an important source of support to parents. Adaptation to the news that their child has learning disabilities can be prolonged and difficult, with parents often moving in and out of different stages of this process. Summers (2010) found that the availability of such services was not a feature for many caregivers in his research.

Caregivers were not offered any choices in relation to professional type, gender, age or expertise of workers. Us emmer (2009) found that there was evidence of strengthening bonds in families, despite the often stressful emotional experience. Caregivers described a deeper “love” and “devotion” to their children during this time. Parents also reported that despite increased levels of physical demands (as a result of caring for their child) they perceived changes associated with personal growth and maturity as a result of their experiences. These findings contribute to the increasing body of evidence that supports the view that care giving can be satisfying and rewarding (Hastings and Taunt 2002). One of the factors that may have influenced caregivers’ experiences was the relationship some had developed with a particular worker. Summers (2009) identified that parents found the emotional support offered by workers at the time when they were experiencing reactions to the needs of their children as beneficial in helping them remain positive about their children. Much has been written about the perceived shift in worker approaches associated with different models of

service delivery (Middleton 1998, Barnes & Oliver 1995, Case 2001, Dunes et al. 2002).

This shift is typified by a move away from the medical model towards different theoretical and conceptual models which underpin the way workers approach the support of families. In Summers (2009) study parents talked in more general terms about what it felt like to be helped and what the helper was like and the impressions they made. The ease with which parents were able to build relationships with workers appeared to be an important aspect of the relationship dynamic, Summers (2009). The strong personal characteristics (e. G.

, “caring” (Mrs. Z), “comfortable” (Mrs. Q), “easy to get to know” (Mrs.

IF)) of the workers were also thought to be key to the success of the career/worker relationship. These general impressions are important since they felt it was important that workers were able to use them when building relationships with families. However, these general impressions are difficult to quantify and generalist.

How, for example, can workers ensure that they are “easy to get to know” and are comfortable to be with? These attributes are not specifically linked to a particular, conscious approach adopted by a worker, but appear to be personal traits that are thought to be helpful by parents when building relationships. It is interesting to note that some careers identified negative personal characteristics that weakened or resulted in a breakdown in relations with workers. Workers who were “unfriendly” or “difficult to get to know”, who appeared not be interested in families or were “uncomfortable”

to be with manifested attributes that interviewees felt awakened and damaged their relations with the workers. It could be argued that workers who did not build strong relationships were not able to connect on a personal level with parents.

Parents did not identify specific approaches that influenced the relationship but more subjective personal characteristics. Careers found it difficult to build new relationships when long term workers were replaced or left the service. Activity helpful strategies and behaviors Parents suggested in Summers (2009) that they want staff who are caring easy to get to know However these characteristics are not always easy to annuity. Thinking about yourself, how would your behaviors and ways of working show that you are 'caring, what would you do to ensure you are 'easy to get to know' had 'good communication skills, and 'gave accessible information? How would you terminate a long term professional relationship to best support the next professional in developing an effective relationship? You may have suggested that when people seeking help have strong emotional links with the person providing help these relationships are more likely to be successful. Summers (2009) findings pose potentially difficult scenarios for services that employ workers to support parents.

It is difficult to embed personal attributes into job roles and equally difficult to employ workers who have or have the potential to develop such characteristics. Conversely careers reported dissatisfaction with the workers who were perceived as judgmental, not good listeners and poor at communicating ideas to families. Some parents felt that their parenting style

was being challenged when workers advised them how to manage the behavior of their children.

This is a common experience of parents, and workers need to be tactful and diplomatic in the way they communicate their advice and recommendations about managing aspects of their children's behavior with parents. When workers adopt approaches that present themselves as experts, parental involvement can be limited. The worker as an expert can take control of the relationship using their perceived expertise to control and take responsibility away from the parent. Although taking control away from parents can be useful when parents want/need expert opinions (this may be as a result of emotional confusion), this approach can result in a conflicting worker/parent goals for the child (Case 2001 Activity 2 Try and reflect on some of the unhelpful strategies explored in the previous paragraph. For example thinking about yourself, what biases influence your own relationships with parents, what negative ideas do you hold about parents of children with learning disabilities? Practical skills of workers are also valued by many parents and this was a highlight of the findings in Summers (2009). Activities related to respite activities for example play schemes and respite holidays, swimming sessions and other social events are very important to parents but are often "riddled" with administration requirements, like liability insurance and volunteer training.

One of the knock-on effects of workers taking responsibility for the child on such outings and play schemes appeared to be a stronger working relationship with families. Relationships with children and families can be strengthened as a result of the worker getting to know the child better on

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such activities. This corresponds with evidence of the importance of workers getting to know children, from other parents who have reported dissatisfaction with this aspect of their relationship with workers, (Case 2001). The parents' perception that a worker wants to, can and ought to build a " closer' relationship with the child appears to be an important feature of supporting families. It could be argued that parents that perceive strong relationships between the child and a worker can contribute to them feeling that workers are part of their " struggle". However, Dowling and Dolan (2001) reported that one career suggested that their worker was easy to get to know and friendly but did not meet the perceived needs of the family.

It is difficult to measure how much these factors influence the parent/worker relationship UT they appeared to be highly valued by almost all families.

What does emerge from the literature is a link between a strong worker/parent relationship and workers who clearly stated what they could and couldn't do with and for families. Additionally, workers who are realistic and honest with parents about resources and aspects of their child's development were likewise valued in some of the literature (see Summers 2009, Dowling and Dolan, Dempsey and Dunes 2009). However, what is not clear in the literature are the factors cause conflict in worker/parents relationships.

Parents report mineral factors and are not specific about the causal factors related to conflict. It was not clear, for example, whether areas of conflict are specially associated with workers approach or the characteristics of that approach. If, for example, a worker was utilizing an expert model (Case 2001 <https://assignbuster.com/chapter-five-essay/>

) which is criticized for taking away the control from parents, but that worker was seen to be open and honest, would these attributes counter the areas of conflict? Additionally, working for the best interest of the parent may not always address the child's needs. Moreover, parents appear to value the personal heartsickness of workers more than any particular approach, (Summers 2009). They value the “softer” aspects of relationships often associated with personal rather than professional contacts.

Although Summers (2009) findings are difficult to generalize it could be suggested that it is essential that workers have or develop personal characteristics that will help them to build and sustain relationships with families. Additionally, it could also be suggested that workers in this study were skilled and were utilizing both a professional approach and personal characteristics that strengthened worker/career relationships. I can identify situations as a practitioner when it was more important for me to befriend families rather than simply be a professional. If workers, for some families, are their only contacts to discuss family issues, it may be important for workers to step outside of the professional boundaries that often shape worker approaches. In the previous chapter the problems of appropriate support are discussed so I will not explore them here other than to reiterate that isolation is linked to poverty due to employment changes and opportunities, appropriate transport and skilled and accessible child care. The Education of Parents Linked to the help received and resources for careers is the need to offer education to parents with children with learning disabilities.

Summers (2009) found that parents wanted to maintain and develop new skills that would help with the care of their children. It was apparent from the earlier discussion that parents sought information from workers about their child's needs in and around the time that they were given a clear indication that their child had a disability. Parents want to continue to develop their knowledge base and used various avenues in these pursuits. Read (2002) indicated that parents with children with disabilities in her study developed “expert” knowledge, skills and perceptions about their children's needs.