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INTIMATELY ABUSED YOUNG PEOPLE'S PERCEPTIONS OF SOCIAL WORKERS

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Abstract

This paper arose out of primary, qualitatively based, research undertaken for my Ph.D., which explored young people's experiences and perceptions of 'intimate abuse'. The definition 'intimate abuse' encompasses all types of abuse, be it of a physical, sexual, psycho-emotional and neglectful nature perpetrated upon young people by known others within the family home and community in the context of intimacy.

The original research looked at seven main areas of intimate abuse as it affects young people: The nature and extent of intimate abuse experienced by the young people and their families; how young people explained the intimate abuse; how intimate abuse affects relationships within the family; young people's reactions to intimate abuse, and how perceptions of and responses to the abuser can change over time; the nature of intervention by family, community and/or professionals; how young people felt about such intervention; young people's perception of the impact of intimate abuse on school performance; their assessment of the long term impact of intimate abuse on their personal development, and their personal concerns and hopes for their future.

This paper wishes to concentrate primarily on some of the main findings relating to these young people's perceptions of, and responses to, social worker approaches and attitudes during intervention and seeks to draw out some of the implications for practice.

Key Words:- Intimate Abuse; young people's perceptions; professional attitudes; implications for practice.

Method

Fifteen young people, aged between eight and eighteen, agreed to be interviewed in one-to-one interviews with me for primary research as part of a Ph.D thesis in Applied Social Studies in UCC during 1995-1996. Respondents were sourced from three types of settings: two refuges, the Al-Ateen self help group for children of alcoholics, and a boy's residential centre. The data for some of the ten young people, aged between fourteen and eighteen, will be included in this paper.

While my focus was on the perceptions and survival strategies of young people, other voices examined in the research included other people directly involved in intimate abuse. These included: Two adult survivors of childhood intimate abuse, four women who had experienced intimate abuse from their male partners, and three men accessed from the MOVE organisation which runs programmes for men wishing to overcome violence. I also interviewed a variety of professionals involved in child care and protection, including a clinical psychologist, the head of care of a boys residential centre, a regional manager for the ISPCC, two GP's, a headmaster of a National school, four social workers and two refuge social workers accessed from three health boards, and also a female gardaí. A balance of gender in the sample was sought wherever possible. Unfortunately, it did not prove possible to source social workers and their clients from the same health board so as to compare their different accounts of the intimate abuse, or intervention processes and outcomes.

One interview conducted with each respondent lasted between one to two hours in duration. The interviews were tape recorded and notes were taken during the process which were later transcribed in full prior to the analysis of the data. Analysis concentrated on selecting the key themes which emerged from each account so as to compare the complementary responses which emerged between them and to contrast any differences. The approach for this research was qualitatively based, and the main themes were presented in a semi-structured interview schedule. Respondents were sourced through the process of 'snowballing' referral between groups and individuals who were contacted by me for research purposes.

The smallness of the sample means that the sample is non-representative of intimately abused young people in Ireland as a whole, nor representative of the communities from whom these respondents were sourced. The intention of the original research was to present in-depth analysis of the accounts of a few individuals so as to highlight the multifaceted and enmeshed issues facing the intimately abused individual. The original research wished to explore how the meaning of these young people's experiences of intimate abuse were further shaped by institutional processes and procedures through the intervention of care professionals.

Aims of the Study

My aim in the original research was, in part, to compare perceptions of social work and gardaí intervention as based on the perspectives of young people and professionals and link this to the literature. I will concentrate in this paper on young people's perceptions of social workers and draw in some of the views of social workers regarding these issues. Young people did not often refer to specific instances of social worker intervention but rather conveyed their overall impressions of, and feelings towards, professionals. In this regard, this paper seeks to further the debate amongst researchers, practitioners and service planners as to how best resolve the real tensions which can arise between professionals and young people as clients.

Introduction

Recent literature on young people's experiences of intimate abuse and intervention processes stress how little is known about how they make sense of and cope with these experiences (Kelly, 1994; Saunders, et al., 1995). Child centred advocates have challenged adult centric attitudes which have traditionally underpinned both policy and practice geared to intervention in child abuse cases (Gilligan, 1994). One major contention in such literature was that the child's voice was lost during intervention processes. There exists a growing body of literature arguing for more child oriented policy formation, management planning and practice in Ireland (see McGrath, 1996; Buckley, 1996; Fagan, 1997; Ferguson, 1997). Individual groups have sought to include young people's voices in their literature, such as that provided by the Northside Inter-Agency Project, Dublin (1994), aimed at adolescents who have sexually abused. However, as a literature review revealed no substantial body of Irish research on the interrelated issues of intimate abuse and intervention practices from the perspectives of young people, I set out to source the voices of some intimately abused young people within the Irish context.

Michael Rutter (1981c; 1985c) proposed the influence of 'protective factors' which provided some 'resilience in the face of adversity' for the developing child. In this context, I wished to excavate how young people themselves accounted for their survival 'in the face of adversity', and what intervention processes and responses they thought had proved helpful or unhelpful to them. I began with the premise that young people who have such experiences are the authority who can best inform policy and practice as regards intimate abuse, and at the very least make more acceptable to them the processes which they go through. Professionals involved in intervention can imbue greater meaning to such processes for young people by their taking real account of the child's voice, and through providing them with support, explanation, and understanding. At present the findings in the literature concerning the UK (see Butler and Williamson, 1994) suggest that most young people perceive that state agency intervention has been rarely helpful for them.

The Literature on current social work practice in the UK

The literature on social work practice (Blagg, 1989; Cloke 1995) indicates that social workers can feel undervalued and misunderstood by the general public, within their own health boards, and in relation to other professionals. In a climate already exacerbated by adverse public opinion in England and Ireland from the 1980s since the emergence of cases like the Cleveland affair (Butler-Sloss, 1988), the Kilkenny incest case (McGuiness report, 1993), and the Kelly FitzGerald case (Keenan, 1996), professional intervention has been seen to put increasing emphasis on child protection work. Parton et al. (1997, p.29) argue that within a legalistic framework, case management 'at interagency, agency and individual case level' has become the crucial aspect of policy and practice for professionals. The legalistic emphasis on improving the identification and protection of children deemed as 'high risk' has been, '... at the expense of other considerations, including those which may be deemed by the professional 'experts' as optimally therapeutic or 'in the best interests of the child' (Parton et al., 1997, p.33). In this context, it is worth distinguishing between current intervention methods which can thus be seen to have become child focused from those which are child centred. Cloke (1995 p.268) argues that one main reason why a 'vacuum' in the creation of child focused policy, and between policy and practice, exists, is that adults 'are not used to thinking about the rights of young people'. For professionals, Cloke (1995, p.272) explains, 'old habits and practices die hard'. While a willingness to become more child focused may be expressed, change involves 'a questioning of one's own system of beliefs and ideals, and this can be both challenging and threatening'. Cloke suggests here that the catalyst for change takes place for many service providers after scrutinising their own practice:

> 'The immediate response of many professionals to the question of 'Do you really listen to children and respect their wishes and rights?' is to agree. It is only when questioning the practice which is necessary for this to happen that an element of doubt enters ... then it is recognised that existing practice may not be as respectful of children as first thought'.

The findings in my research suggest that feelings of being scapegoated and alienated by social workers may contribute what Ferguson (1995, p.37) refers to as 'defensive practice' during intervention practices in cases of child abuse. This paper is mindful of the pressures and constraints upon social workers and other agency professionals, including, as one team leader remarked, the 'lack of legal clout', the lack of managerial support in some health boards, and the lack of adequate resources, facilities and time. The accounts of the social workers in my research indicate that such pressures can only further contribute towards the tendency to practice defensively. However, professional accounts also indicate that individuals invest considerable energy and expend great effort in trying to deal with case work as best they can within the constraints imposed by the bureaucratic organisation of the health board structure. Such efforts are further complicated for social workers where different forms of family based resistance towards intervention exist (Shearer, 1990, p.92; Doherty, 1996, p. 106). The perception of the client towards intervention and the individual practitioner is consequently a crucial determinant of practice outcome.

I will now discuss recent research into young people's perception of social workers. In a recent qualitative study, commissioned by the NSPCC and based in the views of 200 young respondents gathered from three local authorities in England and Wales, Butler and Williamson (1994) discuss the perceived uses and misuses of power wielded by social workers in Britain and the US. They cite the political response to the Cleveland affair including the Butler-Sloss (1988) report as a current indicator of public concern regarding what they see as the professional misuse 'of apparently limitless power' in Britain (Butler and Williamson, 1994, p.15). The authors (1994, p.93) refer to the 'jaded scepticism' of many of the young people interviewed for their research regarding social workers and intervention processes. Common complaints regarding the social work service involved either: the attitudes of the social workers, which were perceived as 'unfeeling'; of false promises made by social workers to help young people; of young people feeling they had not being listened to, were not heard, not believed (Butler and Williamson, 1994, p.77); of inadequate explanations by professionals to young people regarding professional processes and procedures (1994, p.89); and of the inefficacy of the intervention itself (1994, p.95). Many complaints from young people resulted both from the perceived imbalance and misuse of power by professionals in relation to themselves. Interestingly, only half of the sample of young people had experienced intervention directly, though all of the respondents held basically similar, and often negative, attitudes towards social workers whether based on direct experience or not. The findings regarding young people's attitudes towards social workers in Butler and Williamson's work (1994) suggests to me that not only individualised client prejudices but commonalties of attitudes biased against social workers need to be worked with during intervention practices. Alongside this, the actual complaints against social work practice involving the failure to listen to and work with the personal needs, wants and wishes of young people must be addressed by professionals.

Butler and Williamson's (1994) findings are complemented by the work of Saunders et al. (1995). This research is based in part on original research by Saunders and on the data compiled by Epstein and Keep on 126 randomly selected children who called ChildLine in the UK. Of this research Saunders (1995, p.2 - 3) says:

> ' ... the role of social workers with children of abused women must be examined, in particular their overall contribution to the care and support children receive ... I suggest that if refuge workers and social workers are to work effectively with these children they require considerable knowledge and awareness from the child's perspective'.

The data of Epstein and Keep (1995, pp. 55-56) indicates that intimately abused children are reluctant to seek professional help provided by statutory agencies. Although there may have already been involvement by state agencies only seven callers reported their mother having called in the police in the past. Even fewer reported the intervention of social workers. Six children had phoned the social services to be taken into care and only four children who had been physically abused themselves mentioned the involvement of the social services. Fear over the possible consequences of disclosure, which included suspicion and anxiety that they might be taken away from other family members or that they might get their parents into trouble, prevented disclosure of the intimate abuse by children. In one case, the child would not disclose even where a social worker was already involved. The issue of children being given no power or control over events once intervention processes get underway is raised here. In contrast to this situation which children find themselves in during intervention, Epstein and Keep (1995, p. 56) argue:

> 'ChildLine offers children the opportunity of being heard and believed – a new experience for many callers ... when they speak to ChildLine the call is confidential, ... no action will be taken without their consent unless their lives are in danger. Children ... discover that they can talk about their lives without losing control of the consequences ...'.

A fundamental question which has implications for practice concerns the central issue of the function of state intervention. This debate pivots around the dichotomy posed by protection and welfare policies. Within this tension posed for professionals during practice how do interventionist services provide room for 'the voice of the child' to come through, and what importance is given to that voice?

THE FINDINGS

A brief overview of the interview with social and refuge social workers

The overall impression which I gained from my interviews with the social and refuge workers was that they thought that, because of the 'fire-brigade' nature of their work and the lack of resources and facilities, little time was available to give individual attention to intimately abused young people. The senior social worker of one health board, for example, contrasted the social work service with services offered in the ISPCC, so as to highlight the problem of the accessibility of state agency services for young people:

> 'Another constraint on our effectiveness is that I'm not sure how child friendly we are as a service. As regards the children themselves we rely on adults referring them. Services like the ISPCC 'ChildLine' are much more accessible to children. Since it's inception the health board still have had less than ten referrals from the hundreds of calls made to the ISPCC each year'.

The lack of child centred training of social workers was another issue. All the four social workers and both the refuge social workers, for instance, explored the conflict inherent within practice driven by adult centric belief systems and theoretically based training situated within organisational constraints. The senior social worker's response was typical by acknowledging that social work practice was not child centred enough: 'We have tended to work on behalf of children but through adults.... Some social workers find it difficult to get down ...alongside children, because they're so used to dealing with adults'.

All of these professionals admitted that intimately abused young people as clients were often not listened to comprehensively enough and consequently their voice was lost in the system. As the team leader of one of the two health boards summed up: 'Children come out worst in every scenario'. Three of the social workers emphasised their efforts in trying to create certain processes and/ or structures which made it possible for the child's voice to come through the system to some extent. One female social worker also told me that many social workers, including herself, often stayed back voluntarily after office hours to work with children in need. Everyone said that they believed that the service should be improved to incorporate more therapeutic work, and that there should be more specialist team work and networking between professional agencies and with the voluntary sector.

However, these social workers conveyed to me that their main priority was in trying to keep abreast of risk assessment and child protection. The issue of what young people might feel or say regarding their experiences of intimate abuse and intervention often got lost in the process, as professional focus was not geared to the voice of the young person in need as a major component of practice. As one social worker remarked: 'Perhaps we address the physical protection of children very quickly, and only then, we perhaps sit down and try to find out what they're trying to say - what our impressions are'. The question which then arises within the remit of this paper is how current practice is perceived by the young people who come into contact with social workers.

A brief history of the intimate abuse experienced by young people

Four teenage boys, Mark, John, Niall and Brian, were interviewed from a Residential Centre in May 1996, over a period of one morning. All the boys were sourced from one House at the centre, and were aged between fourteen and fifteen years old. They had all had been placed at the centre for about two years, and each had one or two further years to stay there. One of the boys, Brian, had gone to the centre voluntarily. The others had been referred there through the courts because of their continuous involvement in street crime, such as car theft, and/ or physical assault. This included one boy who had attacked his father with a knife so as to protect his mother and sisters from physical harm. These boys came from a working class background. Young people were also accessed for interview from two other sources, a refuge and a branch of the Al-Ateen organisation for children of alcoholics. The interviews took place in various locations over three weeks in early Autumn of 1995. Five of the six teenagers, Bríd, Ann, Una, Noel, and Tom were aged between fourteen and sixteen. Sally, accessed from the refuge, was eighteen years old. The Al-Ateen teenagers came from a middle socio-economic background.

There is not space here to go in to the full range of these young people's experiences of intimate abuse, but many accounts depict their being subjected to extreme physical and verbal abuse by parents, or parent/guardian figures, especially by fathers. Such experiences involved knife and hammer attacks, severe beatings, and for all, the witnessing of attacks upon their mothers. One girl, Bríd sourced from Al-Ateen, and her siblings, witnessed their mother being chased around the kitchen table by her father wielding a chain-saw. Una was raped by her uncle as well as being intimately abused by her mother and emotionally manipulated by her father. A boy from the residential centre, John, along with his brothers and sisters had also experienced sexual abuse by their father. All six boys and one of the girls were the direct subjects of intimate abuse. Everyone experienced chronic psychological, emotional and verbal abuse by the perpetrator/s in their households.

Young people's perceptions of social workers

The issue of the gendered based perception of who perpetrates intimate abuse and who are the victims was an important theme which emerged from my findings. In terms of who abuses, three of the four social workers, for example, stated that they believed that men were the main intimate abusers within the family. One women professional added, however, that while 'women relatives' did abuse children 'there is a gender bias in reporting male violence - it's more comfortable to look at male violence'. That professional perception of victim status was influenced by the gender of the child, is illustrated by the account of John, one of the boy's from the residential centre. Such gender bias may have a profound outcome for intervention around the sexual abuse of the young people. In this instance, parental separation followed the mother's eventual discovery of over a decade of sexual abuse of her daughters, one of whom was disabled, by her husband. However, the children were frequently kidnapped 'off the street' by their father subsequently: 'He used to put us in the car, and bring us down to his house, because he wanted us to stay with him ... so, er, me Ma used to be always trying to get us back off of him ... through the courts'. John, when referring to the social worker his mother was going to in relation to the sexual abuse of his sisters, highlighted for me the dangers of care and legal professional perspectives being slanted in a unitary gendered direction when it comes to the detection and intervention of cases of intimate abuse: '... she said 'if it was girls - that would be a different story, so we'd get the girls back quicker. Since it's boys we can't'. It was during one of those 'kidnapping' incidents that John was sexually abused by his father. After his mother's discovery of John's sexual abuse an older brother admitted that he had also been sexually abused by their father for some years.

John, moreover, linked the intimate abuse he experienced to his acting out at home. He revealed that he used to carry around feelings of anger about the intimate abuse a lot of the time and would behave aggressively towards other members of his family: 'I used to like, lose me temper a lot at home ... Me Ma couldn't control me at all'. John also associated his anger with acting out in the street, where he used to 'get into trouble with the gards ... smashin' windows, ... stealin' cars'. The influence of peer groups and other developmental and socio-cultural factors must be taken into account during the consideration of acting out behaviours. However, the explanations provided by young people regarding their perceptions and responses to intimate abuse and intervention processes add a crucial component to our better understanding the issues involved from the perspectives of those who experience them. The tendency in the recent past for professionals to look for victims of child sexual abuse in the female population, or as may still happen, for professionals to focus on the perpetration of intimate abuse by adult males, are two examples of potential gender bias. Professional intervention being geared to the sexual abuse of females in John's household, for example, missed the sexual abuse of the boys and, therefore, failed to protect them. In terms of the gendered perception of perpetrators, Tom's experiences and perceptions of intervention are also worth examining. He was the only one of the Al-Ateen teenagers interviewed to have experienced long term intervention by health board professionals. Tom's mother had separated from his father, and moved herself and children to her county of origin. Tom believed she was adversely affected 'mentally' through having lived with an alcoholic. He described what he perceived as his being particularly victimised by his mother for while 'she used to literally batter the whole lot of us' he was the focus of her worst verbal and physical assaults.

Tom's account of his perceptions of social workers highlight the dangers of professionals either not taking young people's needs and wishes into account during intervention, or of professionals not being perceived by them of having done so. The extreme frustrations of not being believed and understood are graphically described in his descriptions, and highlight the negative attitudes which young people may form as regards intervention which they do not perceive to be sympathetic or helpful. Tom tried many times to talk to the professionals with whom he came into contact while living with his mother who was intimately abusive to him. When he repeatedly complained to the social work department and they visited his mother '... she'd lie through her teeth and they'd believe her .... Few people gave credit that I was an intelligent being'. In reactions which mirror John's, Tom acted out at home, school, and towards professionals. Tom eventually became so frustrated at the lack of helpful responses by the social workers and the psychiatrist that he was assigned to that he broke some office furniture at the social work department on one of his visits there. As he said of his responses: '... if I couldn't get anyone to listen to me - I'd get very frustrated. I used to shout and roar. I used to let loose on anything near me'.

Tom also attempted suicide on two occasions. The psychiatric services which Tom appeared to have received as a consequence of his 'acting out' made him even angrier. In this context, one of the social work team leader's whom I interviewed discussed the dangers of the professional 'mislabelling' a young person's service needs and their being 'categorised into a conventional slot' based on their acting out behaviours. A young person acting out, as in Tom's case, may become the focus of psychiatric intervention because of their behaviours to the exclusion of effective help and support being provided for the underlying problem. Tom felt great resentment that he was not only a victim of intimate abuse by his mother but that he was further victimised by the system. From Tom's perspective the professional treatment he received at this stage fell into the category of mislabelling, as his expressed needs and concerns were ignored.

Tom experienced intervention through a social workers, child psychologists, a psychiatrist, and a teacher. He only considered one professional, a psychologist to

have really listened to him and to have helped him. Tom maintains that this empathic response and effective therapeutic treatment by the psychologist, along with his attendance of Al-Ateen, has made the difference to his coping with the impact of the intimate abuse, and lead to an alteration of his behaviour:

> 'Before, I thought that the whole world was against me and everything was put in my way as an obstacle.... Now I can let it all out.... It's helped me to control my temper – to see the big picture. It's given me a new outlook'.

I shall now move on to more of an examination of the more generalised responses of young people to professional attitudes and approaches. One girl, Sally, and one Al-Ateen teenager, Tom, had experienced intervention by social workers. Apart from legal intervention through the courts and by the gardaí, the boys from the residential centre had considerable experiences of social work intervention. Butler and Williamson (1994) made the point that preconceptions and biases towards social workers existed even where young people had not experienced intervention directly. The accounts of professionals in my research also open up the possibility that shared and individually held assumptions and pre-judgements regarding clients may negatively affect professional attitudes during practice. Sometimes class based differences, for example, were acknowledged by social workers to influence professional responses to clients. Several social workers referred to the tendency for some social workers to focus on language/ communication differences between themselves and their clients, or the cleanliness of a client family's house, rather than trying to understand the situation more empathically from the client's perspective. This theme strongly emerged within the account of one team leader, who argued that where the professional entered homes where 'no money, little food... different language and mannerisms' were evident 'a social worker sees such a home as exhibiting neglect'. The attitudes of some social workers were consequently seen by clients as 'stand offish, and this effects their relationships.' Both team leaders referred to ethnic differences, such as between professionals and the Travelling community, as another example of the possible prejudices social workers may bring into practice. A third social worker suggested that she thought that such differences are further exaggerated through the nature of the training methods professionals received, which, she believed, encouraged a further 'distancing' from clients.

In terms of the attitudes which professionals are perceived to bring into their practice, the theme of suspicion, resentment or disbelief that social worker intervention could or would help, emerged in the accounts of the young people. Eighteen year old Sally, accessed from a refuge, also spoke of the way that some social workers who came to her family home would 'fish around the house to see if it's a clean house'. Sally was afraid that if she called these professionals in 'they would interfere.' The issue of 'trust', and concerns over the loss of control over matters once the intervention process started, came up here. Though Sally related that she had desperately wanted to talk to someone and receive effective, co-operative help to stop the intimate abuse in her family home, she did not believe that she would receive the kind of support she was looking for from social workers. Because of her fears of social worker attitudes and actions being unsympathetic to her family situation, Sally said that when social workers came to visit she 'would try to hide the problems [as the] social workers would be no good'. In the context of talking to professionals I asked if Mark, from the residential centre, had ever tried to confide in any of the social workers with whom he had come into contact. Mark's responses paralleled the way many young people perceived social worker's attitudes, according to the research conducted by Butler and Williamson (1994) in the UK: 'The social worker? Well I didn't try and talk to him – he was talkin' to me!'.

Mark's comment opens up the issue of age and development which may prevent young people talking to adults. Butler and Williamson (1994, p.76-77) found that many young people believed that the generation gap between social workers and themselves inhibits professional understanding, a situation which leads the professional to try and impose their own views of 'what is best' for their young clients. Such responses invariably leave young people being talked down to and resentful where they feel that their situation is "distorted' ... by adult misinterpretation' (Butler and Williamson, 1994, p.77). Professional attitudes seemed to be an important issue for the young people in my research also. From their perspective many intimately abused young people have had very negative experiences of adults and adult centric processes and procedures. Such experiences include those of intimate abuse, adversarial legal systems and sometimes apparently unsympathetic social workers. As indicated by Tom and John's accounts, some victims of intimate abuse can be seen to have become further victimised through interventionist systems which focus on and appear to reinforce their acting out behaviours. Niall's strong response to this issue is a further case in point: 'I don't like social workers. My own is a snobby bitch. I nearly hit her the last time. She thinks she's the best!'.

However, professionals may find that, even with their best efforts, trying to talk with traumatised young people may prove extremely difficult (Connolly, 1997), especially where severe communication difficulties within the family are present (Brandon and Lewis, 1996). In this context, the male team leader referred to the particular difficulites of communicating with adolescent boys. Teenage resistance to talking with social workers is indicated in my research. John said that he'd 'met a good few' social workers while being remanded in court before being sent to the residential centre, as well as when being assessed for three weeks in another residential centre: 'They're all right ... I didn't really talk to any of them. I just used to say ... 'Yeh, yeh, yeh.' I just didn't want to know ... I didn't want them to talk to me.' When asked, 'Do you think it was any of their business?' he reiterated 'I didn't really care, I just didn't want to talk'. In contrast to three of the four boy's unwillingness to talk with social workers, all of them talked positively of their trusting and confiding in the house staff at the residential centre. I, therefore, asked John 'So what made it different about talking to people here?' to which he replied of social workers ' ... you're only meant to be meeting the people, d'you know what I mean. Here you're livin' with them like'. An important issue raised for me in John's comments on what he thought of the social services, as in the studies of Butler and Williamson (1994, p.91), Connolly (1997, p. 50), and Fagan (1997, p.21), concerns the need for individual professionals to build up trust over time between themselves and young people in order to provide a meaningful service for them.

A further issue which may arise for practice involves recognising and working with the cynical fatalism intimately abused young people have evolved as part of their coping strategies. They disbelieve that any type of adult intervention can create changes for the better (see Butler and Williamson, 1994, p.107). At the same time, however, many young people in Butler and Williamson's study stated that adult understanding could be better. Their views are reflected by Brian, a fourth boy from the residential centre. His opinion was that the social workers, by 'letting things get worse' within his family, did not intervene effectively to stop the conflict or ameliorate its impact on the children. Brian, suggested that he would have liked to have been given more positive support and guidance from social workers, including the difficulties he was experiencing at school at the time: 'I think they didn't help much. Me mother thought they didn't, and I thought they didn't .... They only go so far ...' In contrast to Brian and his mother, he remarked that his married sister felt positively about intervention, and kept applying for help to the social services when Brian informed her that another intimately abusive crisis was occurring in her family of origin: 'She thought that they were doin' some help'.

Mark raised an issue voiced by some of the other teenagers concerning social worker attitudes and behaviour during practice, when asked if he would talk to social workers: 'No, not really .... Social workers - I think they're too nosey.' When I then enquired 'Don't you think that's their job?' he replied:

> 'Well they don't really have to know what's happening in the family now, and what happened ages ago. If they're trying to find out about you – that's all right. But if they're trying to find out about your family, like, ... they'll ask me about me Ma, ... if I don't want to speak about me Ma – they can ask her'.

Respondents of all ages in my research often expressed the view that social workers and other professionals can trespass too far into private family matters. While professionals in the social services must have a working knowledge of case histories and operate within a legalistic framework, a better relationship with the young client based on an intimate knowledge of their family case history, alongside a real understanding of their personal concerns and needs (see Connolly, 1997, p.50) may cause less resentment and suspicion.

For the Al-Ateen respondents, four of the six reported a positive example of favourably perceived intervention by an individual professional at some point in their experience. Help came for Sally in the form of a refuge social worker. For Noel, some solace was afforded through disclosure to a teacher. Tom found help and support through a psychologist, and Bríd through a member of the gardaí. Una accessed therapeutic help from a Rape Crisis Centre. For the boys in the residential centre, an understanding of their personal concerns was provided by their house staff. The attitudes and interventions of health board and refuge social workers were viewed positively, furthermore, by two of the three women whom I interviewed in one refuge and some of their children. Unfortunately, such positive experiences of intervention seems to have been the exception in each teenager's case rather than the rule.

In terms of social work intervention, the findings of Butler and Williamson (1994) may shed some light on young people's perceptions of social workers. Butler and Williamson (1994, p.84) state that many young people were adamant that they would talk to no-one about their problems, or else only those they knew well. Their prevailing suspicion of social workers often involved the beliefs that they did not: 'listen, explain or understand ... were disinterested, unreliable and not in sufficiently regular contact with young people to secure a proper grasp of their feelings and their situation' (1994, p. 94). Those social workers who did make efforts to get to know young people, tended to be viewed in a more positive light (Butler and Williamson (1994, pp. 96-97).

Discussion:

In his summary, Saunders (1995, p. 41) reflects:

> 'For social workers the impact upon child witnesses of violence against women converges with child protection issues, but in a much broader sense than is being currently recognised ... research ... suggests that a great deal of harm may beset children living with years of violence, fear and guilt.... Policy and practice ... must be underpinned with a greater adherence to children's rights.'

In terms of the accounts of the four boys from the residential centre, I would like to emphasise these boys status as victims and survivors of intimate abuse and contrast this with their perceptions of intervention. According to their accounts professional focus was on their criminal acts and antisocial behaviours. Their personal needs were, apparently, rarely responded to therapeutically and little chance seems to have been provided for them to heal during much of their experience of intervention. The issue of attendance to children's rights, in the sense of the professional getting to know the young people they work with, of offering the young person real choices and alternatives, of giving realistic appraisals of the current situation, of only making promises which are realistic, of being reliable and accessible, may help to address some of the issues implied in these findings. As Butler and Williamson (1994, p.85) argue: 'Striking the balance between professional distance and personal affinity is perhaps the critical foundation for effective intervention.' A genuine and personal response by professionals was valued by young people in their study, even where they did not believe the social worker could really improve their family situation. Respondents in my research conveyed the impression that where professional empathy and support was offered it, in itself, provided a form of therapy.

The accounts of the young people in my research indicates that if a young person has feelings of being listened to, being believed, understood and communicated with by adults, such interaction will provide gateways for disclosure. While the findings from the residential centre show that the building up of trust over time with the staff is conducive to young people revealing their concerns, several of the respondents stressed that they felt relief in talking to me as 'someone who understood'. The understanding, or lack of, by adults of young people's perspectives was a key issue in the findings of Butler and Williamson (1994) and for purposes of this paper, affected how professionals, including social workers, were perceived and responded to.

Tom's comments on the issue of not being heard and understood brought to mind a common complaint by young people of their perceived attitudes of social workers in the Butler and Williamson study (1994, p.79). Tom stressed that social workers need to take young people more seriously and do something about their present attitudes in relation to listening to, and acting on behalf of, young people. My findings complement the literature which indicates that the voice of all types of children can often get lost in a system which is based on a 'doing-to' as opposed to a 'doing-with' approach. Whatever arguments may be made for a lack of resources as directly inhibiting to the development of child centred practice, what comes across in these accounts is that the attitude of the professional can make intervention meaningful and acceptable for young people.

The findings in this research indicate the need for a comprehensive and integrated approach to intimate abuse which would move on two main fronts: Firstly, many respondents in my research (professionals, survivors and abusers) argued for the creation and enforcement of stronger preventative and protective legal measures for victim/survivors of intimate abuse. Secondly, professionals (social workers, refuge workers and the clinical psychologist) argued for the provision of more child care social workers to work alongside those involved in protection. All professionals involved in intervention stressed the need for the establishment of multidisciplinary services based on specialist teams, and the need for state and voluntary sectors to network effectively. Such systems, the three social workers in senior positions felt, must offer more comprehensive support structures within and between departments and from management in terms of the needs and requirements of individual professionals, as well as from professional to client. The need for more therapeutic services being made available for young people through state agencies and the voluntary sector emerged as a strong theme in the accounts of professionals involved in child care and protection, and from the Al-Ateen respondents themselves.

One important consideration in terms of child centred intervention services must be that of case management, which involves a periodic review of structure. Unrealistic expectations of both professional and client as to what can be achieved through social work intervention may create a context for failure. Social workers may try to take on too much when dealing with families who experience intimate abuse and delegate too little. Perhaps social workers could more often utilise other existing services in both the state and voluntary sectors? Such backup services could provide help for clients on an interpersonal or therapeutic basis which is otherwise hard to provide. Young people may feel less suspicious of social workers if their approach included explanations of professional intentions, including realistic expectations and outcomes in relation to practice. Up-to-date advice on what other services may be out there for young people may be reassuring, even of help to some. An expressed willingness of professionals to be accessible and willing to listen, if the young person so wishes, seems of key importance to young people according to the Butler and Williamson study (1994). Finally, in line with Butler and Williamson's study, the accounts of young people in my research show how teenagers felt much resentment around what they perceived as the patronising attitudes of some professionals. It must be emphasised, however, that the views of young people as service users can be utilised constructively by professionals. Professionals should take heart in socio-historical evidence which shows that for over the past hundred years they have managed to protect increasing numbers of children (Ferguson, 1996a, p.215). The perception of young people regarding professional approaches can create the basis from which to construct more effective and accessible child driven programmes.

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TOWARDS A SOCIOLOGICAL UNDERSTANDING OF SOCIAL CARE WORK IN IRELAND

by Carmel Gallagher and Jacqueline O'Toole

Abstract

Social care work in Ireland emerged from the voluntary residential child care services which date back to the 19th century. A qualifications base has only been developed since the 1970s. Due in part to the relative newness of the discipline in Ireland, it has been subject to little critical analysis. Emanating from a sociological perspective, the authors have sought to address this by an initial attempt to explore the social actors and social processes involved in the social construction of social care work in Ireland. The article is based on documentary and qualitative research carried out by the authors in 1997. The key social actors were identified. The authors explored the social processes involved in the negotiation of a shared understanding of the role and occupational location of social care work. In the closing years of the 20th century the authors would contend that social care work is an emerging profession.

Key words:- Social care work; Professionalisation; Actor networks.

Introduction

Social care work in Ireland is an emerging profession. Notwithstanding its growing importance in the delivery of personal social services, particularly child care services, it has been subject to little critical analysis. The authors contend that social care work can be seen as a social process of social negotiation[1]. The present article suggests that operationalisation of the term social care work itself requires a clear understanding of the contexts within which care work is carried out and an understanding of the multiple meanings that co-exist amongst practitioners, educators, policy makers and employers. The article is based on documentary and qualitative research carried out by the authors in 1997. It represents an initial attempt to explore the social actors and social processes involved in the social construction of social care work in Ireland.

Theoretical Overview

The purpose of this paper is to generate a sociological understanding of social care work in Ireland through outlining a number of ways in which social care work has been and continues to be socially constructed. Social care work is an organised activity within many societies. The meanings and practices associated with social care work have developed over time to embrace a discipline which, while central to the delivery of many personal social services for both children and adults, appears to lack academic recognition, professional status, a clear public identity and internal unity (Lorenz, 1994).

In this article, the emergence of social care work is located mainly within the context of the development of child care services[2]. While social care work can be conceptualised as ranging on a continuum from informal care through to voluntary provision to state services, in this article the focus is on paid social care work. Social care work, similar to social work, is part of a complex theoretical, occupational and service network (Payne, 1991). Within sociology, a theoretical approach that appeared particularly useful vis-à-vis understanding the development of social care work in Ireland is that of social constructionism. Berger and Luckmann (1967) emanating from a sociological tradition, articulated a social constructionist position which emphasised both objective influences and subjective meaning. Payne (1991) adapted Berger and Luckmann's (1967) theoretical approach in his analysis of social work in Britain.

His summation of the key theoretical insights is important:

> ... 'reality' is knowledge which guides our behaviour, but we all have different views of it. We arrive at shared views of reality by sharing our knowledge through various social processes which organise and make it objective. Social activity tends to become habitual, so that we share assumptions about how things are and behave in accordance with social conventions based on that shared knowledge (Payne, 1991:8).

Over time, conventions become institutionalised and people come to share similar understandings. These, in turn, are legitimised by processes which attach meanings to behaviour, conventions and institutions. These meanings are organised into social understandings which are seen to be objective as people are immersed in, socialised within and internalise such social understandings (Payne, 1991). In a complex fashion, people are both creative and simultaneously a product of the society in which they find themselves.

Sibeon (1991a, 1991b), employs such an approach in his analysis of social work in Britain. He emphasises concepts such as actor, strategy, and unintended consequences. Actors may be individuals or social actors [organisations]. Only actors have the capacity to act or take decisions. Sibeon (1991b) also utilises the concept of actor network which could involve, as in the case of social work, the interlocking of various political, administrative and personal actors. The actor network embraces a number of actors whose activities revolve around certain focal [for example occupational] concerns and activities in ways that can be continually reproduced temporally and spatially (Sibeon, 1991a). The author acknowledges that actors in an actor network may be able to shape the outcome of interaction in their favour: the conditions of action are fluid and shifting. Actors are not, however, unconstrained agents but are bound up with the social relations of power (Sibeon, 1991b). In a similar vein to Sibeon (1991a, 1991b) and Payne (1991), the authors suggest that the social construction of social care work can be viewed as a process of negotiation amongst relevant actors for a meaningful and acceptable role within the occupational structure of the social professions.

The Development of Social Care Work in Ireland

Social care work has developed within the occupational structure of the social 'professions' in the last three decades. It is pivotal in the delivery of a range of residential, day and community social services particularly child care services for children at risk, services for children and adults with disabilities and other support services for marginalised groups. The historical development of social care work in Ireland is located within the residential child care services particularly the Reformatory and Industrial School system established in the second half of the nineteenth century to care for and control children who were orphaned, neglected or deviant. The industrial schools which catered for the largest category of children in need of care and the reformatories which catered for criminalised children were managed by religious orders and subvented and inspected by the Department of Education (Gilligan, 1991; Robins, 1980).

The residential child care system remained underfunded and staffed by untrained child care workers until the 1970s when a government committee made far reaching recommendations for change. Gilligan (1991) argues that the Kennedy Report (1970) was a watershed for the development of child care services in terms of both philosophy, models of practice and service provision. In particular, the report called for the introduction of formal training for child care workers. In 1971 the first training course in child care was initiated as a one year full time residential course. From the mid 1970s, the in-service training of social care workers became part of the mainstream higher education technological sector and in the mid 1980s pre-service training was introduced.

The National Council for Educational Awards Report on Caring and Social Studies (1992) recommended that the primary qualification for social care workers should be based on a three year course of study, a vital element of which is supervised placement practice. A further recommendation was that add on degrees and other post-diploma qualifications be provided. The first degree course in social care was introduced in 1995.

A major research study into the residential child care system[3] in Ireland twenty five years after the Kennedy Report (Focus Ireland, 1996) found that there was a small number of untrained staff in the system. While training provision is improving nationally the situation in Ireland is that an unqualified person (academically untrained) can be described in the same way as a qualified person (academically trained). The diploma in social care was the most common qualification among the staff of the residential units surveyed. Other qualifications included psychology, social work and nursing (Focus Ireland, 1996). The location of social care education and training within the non-university higher education sector and its relatively recent origins in Ireland may be contrasted with the development of social work education and training within the university sector in the 1930s (Darling, 1972).

Courtney (1999) argues that the European dimension of social care work has come to the fore during the past decade. A European Association of Training Centres for Socio-Educational Care Work was established in Strasbourg in 1989 and through various EU programmes extensive communication and exchanges have been established between Irish educational institutions and their counterparts in other European countries.

An important development in 1995 was the establishment of ECSPRESS, a consortium for education and training across the social professions, which was recognised as a thematic network. While there is great disparity in job titles among European Union countries there are great similarities in philosophy, values and methods of practice (Courtney, 1999). Further, although the profession is still unregulated by statute in most European countries, considerable work has already been carried out on harmonising the qualifications. The criteria for professional recognition on a European wide basis are in place in the relevant Irish training colleges [Dublin Institute of Technology, Institutes of Technology Athlone, Waterford, Sligo, Cork, Tralee and St. Patrick's College, Carlow] (Kennedy and Gallagher, 1997).

A significant expansion of the role of the social care worker occurred in the context of the development of community based child and family services. The Kennedy Report (1970) heralded a developmental model of child care and emphasised the prevention of family breakdown and the use of residential care as a last resort (Focus Ireland, 1996). The emphasis on preventative services was reinforced by the recommendations of the Task Force Report (1980) on community services for children at risk and underpinned in legislation by the Child Care Act (1991). This Act provided the state through the Health Boards with a stronger regulatory role in relation to child protection and a more proactive role in relation to the promotion of child welfare within the community. Reports by the Health Boards on the adequacy of their child care and protection services reveal that in most cases the increased funding for the implementation of the Act has gone into community care services including community child care workers (Focus Ireland, 1996).

Accompanying this development of services has been a dramatic decline in the number of places in residential children's homes and some diminution of the involvement of the voluntary sector. While child care units managed directly by the health boards have increased in number since the Child Care Act (1991), approximately two thirds were still managed by voluntary bodies or religious orders in 1995 (Focus Ireland, 1996).

Administrative and legal changes have been introduced during the 1990s, which have had a major impact on the work of child care professionals. These changes arose from inquiries into child abuse scandals (Ferguson, 1996). The inquiries addressed both inter-agency and inter-professional communication systems at community level (Report of the Kilkenny Incest Investigation, 1993; Joint Committee on the Family, 1996) and inadequacies in the management of children's residential homes (Department of Health, 1996b). Various initiatives have been undertaken by recent governments to achieve more coherent and coordinated policies in relation to the welfare of children. These include more interdepartmental cooperation, the appointment of designated officers in the health boards to coordinate inter-agency approaches to child protection at community care level, and the appointment of regional and local Child Protection Committees to enhance cooperation between the various agencies (Department of Health, 1996a).

Historically, it is clear that child care services in Ireland have been conceptualised within a highly selective model of welfare provision where state services have been seen as an adjunct to the role of the family which is seen as the ideal institutionalised means by which the needs of children are met (Murphy, 1996). While this ideology of familism has been criticised as too narrow a basis for public child care policy needs (Murphy, 1996), child protection and family support services are provided primarily as a compensatory measure for those children who are at risk or whose needs are being inadequately met. It has been argued that an over emphasis on child protection work has led to a bureaucratic, investigative approach to working with children and families to the neglect of preventive services (Ferguson, 1996; Murphy, 1996). Wells (1999) argues that the emphasis on child protection has had an opportunity cost effect in terms of lack of service provision for children and adolescents with major psychiatric problems.

Methodology

The key research question that emerged from the literature concerns the process of professionalisation within social care work in Ireland. Specific questions are

- what is the nature of social care work
- what are the perceived boundaries with related social professions
- what is the degree of conceptual unity within the discipline
- what are the status and location within the state bureaucracy of social/ welfare services
- what are the levels of education and training.

A review of the development of social care work in Ireland revealed a number of key social actors currently involved in the social construction of social care work.

Included in the actor network are social care workers, managers, employers, educational and training institutions, and the statutory sector. Seven individuals were selected within the actor network which we argue represented the key interests involved. We contacted the interviewees and arranged to meet them in their respective places of employment. All agreed to participate in the research. The interviewees were:

- Chairperson of Irish Association of Care workers [IACW]
- Assistant Principal Officer, Special Education Section, Department of Education
- Principal Officer, Child Care Division, Department of Health
- Assistant Head of School of Social Sciences, Dublin Institute of Technology [DIT]

- Chairperson of Resident Managers Association [RMA]
- Strategy Manager, North Western Health Board who is also a former community child care worker
- Director of Child Care and Family Support Services, Eastern Health Board [EHB].

In order to explore the specific research questions with the interviewees, the unstructured interview with topic guide was utilised. Patton (1980) in his discussion of qualitative interviews, notes that the general approach involves outlining a number of issues which are to be explored in the interview.

According to Marshall and Rossman (1995:80):

> typically, qualitative in-depth interviews are much more like conversations than formal events with pre-determined response categories. The researcher explores a few general topics to help uncover the participant's meaning perspective, but otherwise respects how the participant frames and structures the responses.

May (1997:112) asserts that depth interviewing allows the interviewee to draw on ideas and meanings in terms of his/her own frame of reference. In-depth interviews, using the topic guide are useful tools which permit the generation of rich data. The interviews lasted approximately one and a half hours. The responses were recorded manually and written up immediately following the interview. Topics discussed were the role of the social care worker, education and training, job titles, pay and conditions, perceived status, promotional opportunities, management structures, patterns of communication between social actors and current policy issues.

Qualitative data analysis is a continual process that permeates the data collection stage. Much of the rigour attached to coding, classifying and developing concepts has been influenced by Glaser and Strauss (1977). The authors advocate grounded theory and analytic induction, whereby the theory emerges from and is induced from the data. We applied categories and labels to the various segments of data enabling linkages to emerge thereby generating key concepts (Dey, 1993; Bailey, 1996).

Professionalisation of Social Care Work

Since the establishment of a training course in child care in 1971, the issue of professionalisation of social care work [child care] has become increasingly important (see, for example, O' Connor, 1992). However the concepts of profession and professionalisation are laden with definitional difficulties. Drawing from symbolic interactionism, the authors examine professionalisation as a negotiated outcome of the interactions amongst relevant actors (see also, Sibeon, 1991b). Professionalisation of social care work involves dealing with the difficulties inherent in conceptualising the nature of the work, devising an adequate job title, educating the public about social care work to improve its societal status and providing appropriate education and training.

Multiplicity of Job Titles

The multiplicity of job titles may serve as a difficulty in establishing a recognised unified profession. This is the main reason why the term social care is currently favoured in the context of training. A survey of graduates from the National Diploma in Child Care in 1990, found that thirty five different titles were used by them to describe their work situations, even though almost 90% were employed as child care workers (NCEA, 1992). Other titles included care workers, training officers and residential social workers. With regard to job titles, all the interviewees were more familiar with the title child care rather than social care.

Education and Training

Education and training remain at the core of increasing professionalisation of social care work. Differences emerged between the two Department representatives and the remainder of the interviewees in relation to education and training. Both the Department of Health and the Department of Education suggested that the Leaving Certificate is the minimum qualification required. They noted that at interview level, however, most candidates possessed some form of third level qualification. The IACW, DIT, RMA representatives and the strategy manager all argued that at a basic level, a national certificate [2 years] should be a minimum but the ideal is a national diploma in social care or applied social studies. The introduction of degree programmes in social care was generally welcomed. However the IACW representative expressed the view that the quality of care services will depend more on the standards of the certificate and diploma courses and was concerned that degree programmes should not be too far removed from the coalface.

An adequate practice placement as a central component of training programmes was emphasised by all the interviewees. The benefits of both pre-service and in-service models of training were also endorsed. However, there were some differences amongst the interviewees in the emphasis placed on each type of training. The DIT representative believed that there should be more emphasis on pre-service training since this corresponds with the training model of other professions. She also observed that the increased legal obligations affecting the work demanded pre-service training. The IACW representative argued that in-service training would continue to be important because it would be too restrictive not to employ people with experience but who needed further formal training. The EHB representative was also strongly in favour of in-service training to enable people with skills and experience to remain within the field. In this regard, the EHB representative expressed an interest in devising new models of in-service training, which would be less academically driven and more flexible in terms of methods of assessment and delivery. The Department of Education representative stated that in-service training was a useful model for the special schools for young offenders.

Status and Pay

The IACW, DIT and RMA representatives argued that the increasing level of education and training, the adoption of professional values and practice techniques and a gradual improvement in status vis-a-vis other health and socio-educational professions, all indicate the gradual emergence of a professional base within social care work. However there was also widespread recognition amongst the interviewees that professionalisation is fraught with difficulties.

The strategy manager suggested that in terms of pay, conditions and status, social care work is not widely perceived as a profession. This combined with the lack of statutory registration, he argues, belies the existence of a profession of social care.

The IACW representative argued that poor conviction amongst social care workers themselves hinders acceptance of social care as a profession. The DIT representative identified a number of reasons as to why social care work might not be perceived to be a profession: it is frequently seen as skills based similar to a good mother, the issue of untrained staff and the general lack of assertiveness among practitioners themselves. Differences emerged within the statutory sector with regard to perception of social care work as a profession. The Department of Education stated that social care work is a profession on the basis that it is a specialist area not covered by any other group. This is reflected in its salary scales, which are linked with teachers and are higher than those in the Department of Health. The Department of Health representative does not view social care work as a profession. The interviewee explained that historically from an industrial relations point of view, social care work does not come under the definition of a profession with regard to qualification requirements. As a result, the pay has been linked to clerical/administrative scales. However a review group is examining the pay and conditions of social care workers following industrial action in 1996[4].

Formal Regulation

Statutory registration is bound up with the notion of professionalisation. Differences emerged between the Departments and the other interviewees over this issue. The Department of Education representative stated that little thought had been given to statutory registration but that it may in fact prove to be restrictive.

The Department of Health explained the history of the issue for child care work and felt there would be little progress in the immediate future. She noted that the IACW, as a 'professional' body, is not as developed as other professional bodies and this may negate its attempts to push registration. The strategy manager argued that legislation would dictate progress in the area. The remainder of the interviewees felt that registration was essential but were unsure when it would occur. In 1999, a Social Services Inspectorate was established. At present in the health board sector, the interests of social care workers are represented by social workers within the management/reporting relations of community care teams. The National Social Work Qualifications Board was established in 1997 to regulate entry to the social work profession. This will have ramifications vis-à-vis regulation of social care work.

There is a distinct awareness amongst the social actors interviewed that the development of social care work is moving towards professionalisation. However the responses indicate that there are difficulties involved in terms of who defines what professional attributes are required, what the skills and expert knowledge should be based on and what exactly is self-regulation. Political and administrative responsibility for child care services is divided across three government departments and is reflected in differing job titles, qualification requirements and pay scales. Lorenz (1994) suggests that this diversity and fragmentation serve to hinder the development of a social care work profession in Ireland. The analysis suggests that the development of social care work and its conceptualisation as a profession is still under negotiation internally, by the IACW and the RMA, and externally, by the Departments of Health and Education and the educational institutions.

This process is ongoing and would seem to contradict O'Connor's (1992) view that professionalisation of child care [social care] will remain an unlikely development. The climate has changed and the issue of professionalisation is central to the development of social care work.

Role of the Social Care Worker

At the root of the difficulties in conceptualising the role and determining the status of the social care worker lies the ideologically based distinction drawn in countries like Ireland between paid and unpaid caring work. This can be contrasted with Scandinavia for example where the term 'care-giving work' encompasses all types of work where the care-giver provides consistent and reliable care for a person who, through age, infirmity or youth is unable to care for herself (Walmsley, 1993). In the market place different values are placed on similar skills according to who is using them, the criteria frequently being the gender and power of the workers (Walmsley, 1993). It has been observed for example that within the residential child care sector in Ireland the salary scale for child care workers is considerably higher within the special schools (operated by the Department of Education and Science) than within group homes which come under the remit of the Health Boards (O'Connor, 1992). This is despite the fact that the level of unqualified staff is higher in the special schools, a fact which, it has been suggested, may be related to the gender pattern of employment which is predominantly male in the special schools and predominantly female in the group homes (O'Connor, 1992).

The key social actors identified in this research have internalised the 'received' ideas about social care that have evolved historically. The idea of sharing life-space on a regular basis is one of the key principles of social care work and is a feature, which distinguishes it from social work. According to Marcon (1988), this involves the care worker and client sharing various situations of daily life, either in a residential institution or a service or in the setting of normal living through continuous interaction with that person. The respondents shared this understanding. The IACW respondent compared the role to that of a good parent, providing all round care in both day to day situations and in more difficult situations. The DIT respondent expressed it in terms of the creation and maintenance of a continuous and intensive relationship through sharing life space and enrichment of the lives of those in care situations. The respondents contrasted this with the more legalistic and administrative role of the social worker who has larger case loads and shorter inputs into the lives of those in care. The European literature supports this understanding of the role of the 'social educator' as involving close, regular contact over a relatively long period of time, in a milieu with which the client is very familiar. This can be contrasted both in terms of time extension and location with traditional methods of field social work (Kennedy and Gallagher, 1997). The dynamic role attached to the residential care worker illustrates the complexity of the tasks and the considerable demands on practitioners in terms of knowledge, skill, integrity and stamina (Gilligan, 1991).

Graham (1994) identified a complex, intertwined combination of maintenance, nurturing and therapeutic roles. The author expressed concern at the very small percentage of residential care workers' time, which was spent, on therapeutic tasks (Graham, 1994). The report into the running of Madonna House (Department of Health, 1996b) was critical of the excessive amount of time residential care staff were required to devote to domestic duties.

The extent to which personal care tasks are part of the role of the social care worker was discussed with the interviewees. Contrasting views were expressed by the IACW respondent and the strategy manager. The IACW respondent advocated the importance of personal care tasks in making a child or client feel better and argued that it was an 'enobling' aspect of the care worker's role. The strategy manager argued that the performance of such tasks had diminished in importance as social care work became more professionalised. The Department of Education and DIT respondents stressed the purposive use of personal care tasks to enhance the relationship between care giver and care recipient or to promote independent living skills. The RMA representative emphasised that training should help the worker to appreciate the value of personal care tasks as 'therapeutic interventions'. The DIT respondent stressed that in her view housekeeping tasks should not form any part of the role of the social care worker. She recognised though that cooking and personal care tasks as methods of relationship building or self development might form part of the role. The strategy manager and the EHB respondent pointed to the introduction of the 'family support worker' in the EHB area who performs a range of domestic duties including cooking and personal care tasks in respect of families who are experiencing extreme difficulties in coping. In relation to special schools for children with disabilities, the Department of Education respondent differentiated between the tasks of the child care assistant and those of the child care worker in terms of personal care tasks undertaken.

The ambiguities and contradictions in caring roles have been analysed through the concept of 'love labour', an emotional form of work which challenges materialist concepts of unpaid work and which is emerging as a new field of scholarly thought (Lynch and McLaughlin, 1995). The distinction between 'caring for' tasks and 'caring about' tasks which is examined through the concept of 'love labour' has implications for the definition of the role and tasks of the social care worker. The extent to which 'caring for' tasks such as personal care or cooking can be used to express the 'caring about' role or indeed hinder that role is an important question. A further question concerns whether the same person should necessarily perform both sets of tasks.

Community Child Care Worker

The role of the community child care worker within community care teams of health boards was discussed. The IACW representative and the strategy manager expressed their concern at the absence of a clear definition of the role. Their perception was that tasks were assigned on a rather ad hoc basis by social work managers who themselves had varying levels of knowledge of social care work. This led to an unsatisfactory situation for some community child care workers who were regarded as general social services workers to whom a wide range of residual tasks could be assigned at the behest of social work managers. This concern led the IACW in 1996 to establish a working party representative of community child care workers in all health boards to examine, review and make policy recommendations on their role.

Confusion was evident at official level in relation to the qualifications required for the position of community child care worker. The Department of Health stated that Health Boards could make appointments as community child care worker at any of the three grades of house parent[5]. The EHB representative stated that persons who held the Diploma in Social Care/Applied Social Studies could only fill the position.

Documentation provided by community child care workers in two of the Health Boards was examined. The community child care workers indicated that inconsistencies existed in relation to working conditions, reporting relationships, salary scales and job descriptions. In general their role is a preventative one and involves working with children, young people and their families in order to reduce the risk to individual children and to promote positive interaction between children and their parents. Their duties, formerly carried out by social workers, have raised problems with regard to the boundaries between social workers and social care workers. The IACW representative expressed concern at 'a lack of understanding' between social workers and social care workers.

Consultation and Policy Formation

Networks and patterns of communication exist between the significant social actors. These are frequently informal and sporadic. Extensive links existed between the IACW and RMA. Educational institutions involved in training, including the DIT and the other Institutes of Technology are in the process of developing formal links. In addition, all are currently members of the European Association of Training Centres in Socio Educational Care work.

The representatives of the Departments of Health and Education noted the institutional procedures between their departments and management of agencies, which acted as a channel of communication between policy makers and practitioners. The recent proliferation of reports around specific policy issues in the child care system has resulted in the formation of tenuous networks and the opening up of more channels of communication. The Department of Health respondent observed that when the previous Minister for Children invited a debate on the issue of mandatory reporting, formal consultations took place between the Department and all interested parties. The RMA respondent confirmed that consultation had taken place in relation to mandatory reporting. However, he also stated that a recent survey by the Department of Health/EHB on specific child care needs had not engaged in adequate consultation with the voluntary sector.

All of the interviewees concurred in their assessment of the importance of networking. The DIT respondent delineated a number of key actors that are consulted: advisory boards, IACW, European networks and placement contacts. Informal contacts were in place between the DIT and both the Department of Health and the EHB. The strategy manager suggested that there was inadequate communication between the colleges and the caring organisations and the colleges and the advisory boards. Conferences and research were also highlighted as being useful in encouraging networking. Social care workers themselves have not been to the fore in instituting networking for policy making. In the light of mounting public and political disquiet about allegations of abuse, the IACW respondent noted the demoralising affects of such allegations on the energies of care workers to engage in self promotion.

The DIT respondent argued that the two critical factors in shaping social care work were the ad-hoc nature of the policy response to social care needs and the European influence. The first factor can be understood in terms of the fragmentation of services that permeates social care work delivery. The Department of Health respondent also suggested that child care services have exploded without having an overall guiding strategy and that consolidation of services would be their priority. The second factor, European influence, has involved social care workers in Ireland making linkages with the profession of social pedagogy in other European countries. This has enhanced the identity of social care work in Ireland as a distinct area of professional practice.

Key Policy Issues

Social care work involves a broad spectrum of specialised interventions in peoples' lives. This was recognised by all respondents as they sought to explicate specific and immediate policy issues. Of major import was the status of the social care worker vis-à-vis other health care professionals and within the personal social service organisational structures. Important policy issues[6] mentioned by the interviewees were:

- the involvement of social care workers in policy formation
- evaluation of education and training
- the withdrawal of voluntary groups and increasing bureaucratisation
- statutory registration
- a structured initiative to deal with abuse allegations
- gender imbalances
- short term contracts and opportunities for promotion
- adequate resourcing.

O'Connor (1992) argues that the state through the Departments of Education and Health has directly and indirectly inhibited the professionalisation of child care work [social care work] while facilitating the professionalisation of social work. She further suggests that the state has an interest in maintaining child care as a low paid activity as this fits easily within a socio-cultural context where child care is linked closely with dominant definitions of femininity. The gender imbalance within social care work and the lack of debate around wider issues of gender and social care work requires further investigation.

CONCLUSION

This article represents an initial attempt to explain in the sociological sense, the development of the discipline of social care work in Ireland. The authors argue that the meaning of social care work is negotiated. Since the inception of specialised training courses, social care work has progressed along the professionalisation trajectory: improved education and training, increased job status and a recognised location within the social professions. Preliminary investigations revealed that a number of social actors are significant in the evolution of social care work: educators, employers, policy makers, practitioners and their representatives.

Social workers were not included in our research design. However, they emerged as an important social actor involved in negotiating the meaning of social care work.

Professionalisation is one of the central social processes affecting the development of social care work at present. This process is not without its contradictions. A lack of internal unity, fragmentation across qualification level, diverse client and administrative settings, a changing role and exclusion from key policy making structures within the bureau professional hierarchy of state welfare services impact on the development of a coherent professional identity. Furthermore, the perceived lower status of social care work vis-à-vis related professions can be linked with ambiguities and contradictions built into the concept of 'caring'.

Our research indicated gaps in communication and networking among the social actors. The implications of this for social care practitioners are particularly acute and are frequently expressed in feelings of being undervalued and excluded from the policy arena. Significant matters that could be considered by all the social actors include the absence of a forum involving employers, policy makers, educators and practitioners where social care work practice can be evaluated and disseminated and institutional barriers which limit the ability of practitioners to shape policy.

At present, a negotiated strategy amongst various social actors to consider common training needs, appropriate resource allocation, appropriate sharing of responsibility and decision making has not formally emerged.

At the European level, EU funded research has begun to explore the common linkages among related social professions: social care work/social pedagogy, social work and youth and community work (Courtney, 1999).

The future direction of social care work will depend upon the strength of individual and collective key social actors, including the state, voluntary sector, social care workers and educational and training institutions to explicitly generate a coherent vision for the identity and role of the social care worker.

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Footnotes

[1] For an interesting discussion of social negotiation processes and unemployment, see McCullagh (1985).

[2] The development of services to meet the needs of other groups such as people with disabilities has also significantly impacted on the development of social care work. Factors which have shaped social care work in a general way include the development of anti-poverty strategies involving partnership approaches to community development and enterprise, increased emphasis on the rights of service users and continuous efforts to locate services within the ordinary settings of family and community.

[3] The residential child care system includes group homes operated by the health boards, special schools operated by the Department of Education, adolescent units funded from a variety of sources and probation hostels funded by the Department of Justice.

[4] The Review group was established following a labour court recommendation in 1997. It is examining a number of paramedical occupations including social care work. The terms of reference include inter alia the role of the profession, training and education requirements and problems related to recruitment and retention.

[5] The three grades of house parent are: house parent, assistant house parent, trainee house parent.

[6] Since the field work was carried out, there have been some developments in relation to these policy issues.

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POSITIVELY COPING[1]: A STUDY OF THE COPING STRATEGIES AND RESOURCEFULNESS OF PARENTS WITH A CHILD ON THE AUTISTIC SPECTRUM

by John Sharry

Abstract

Following the emerging research tradition which moves away from studying the 'burden' of caring for a child with a disability, this study using semi-structured interviews, documents the coping resources and strategies adopted by a group of thirteen parents, who have a child on the autistic spectrum attending a special school in the South Dublin area. The study involved parents of higher functioning children on the autistic spectrum, that is children with average or borderline cognitive ability, as the distinct experience of this group is often lost within general studies of families with autistic or disabled children.

The distinct stressors reported by parents in the sample were the ongoing behavioural problems and lack of support caused by the 'invisibility' of their child's difficulties. Parents who felt they were managing these problems described adopting firm and consistent management strategies, positively focusing on progress, seeking support from front-line staff caring for their child and from meeting other parents with similar children. Blame was sometimes a block in receiving support from extended family members and the parents often had to assertively ask for the support they needed.

The study highlights the need for positive service provision which complements parents' coping ability and questions the universal application of a 'bereavement' model of adjustment, finding that for some parents the adjustment to caring for their child was straight-forward or at least no different to the care of a non-disabled child.

Introduction

In a theoretical review concerning children with a mental handicap, Byrne and Cunningham (1985) described how, up until the mid-1970s, most of the research which examined the effect on family functioning adopted a 'pathological' approach which assumed that such families are 'subject to high levels of stress which cause psychological impairments among some if not all, family members' (p. 847). They identified three trends in the literature that reflected a move away from these pathologising models of the past. In the first group, the assumption that stress was inevitable was discarded and the focus changed to identifying factors which made families more vulnerable to stress and problems. The second approach is based on the assumption that it is not the presence of a mentally handicapped child that causes stress but the lack of adequate services available to the family.

The final paradigm, and the one which concerns this project, is based on the assumption that while the presence of a disabled child does place the family under more stress, the parents develop resourceful and adaptive ways of coping in response to this. Families with disabled children are often coping successfully and often more than professionals credit them. Some studies have found that professionals predict more adverse effects on families than parents actually report themselves (e.g. Blackard & Barsch, 1982; Sloper & Turner, 1991).

From a practice point of view it is arguably more useful to discover the resources families access and the coping strategies they use, so that practice can be adapted and services designed which support and enhance these resources and strategies. As Beresford (1994a) states:

> 'It cannot be disputed that parents of disabled children face a great deal of stress. However it is now important for investigations to move away from describing these stressors and their adverse effects. Instead research should focus on exploring the ways that such families cope, with varying degrees of success, with the care of a disabled child. Such work has far greater implications for understanding and improving the ways that these families can be helped [emphasis added] (p. 171).'

Studies of Coping

In order to condense this article to a manageable size, I will keep this section short, briefly describing the models underpinning much of the coping literature and then identifying some of the consistent themes which have emerged, before later exploring them in relation to the findings of the current study. For a fuller discussion of themes I refer readers to the full manuscript (Sharry, 1997).

In one of the first studies to look at stress and coping within families with disabled children, McCubbin *et al.* (1983) surveyed a group of parents caring for a chronically ill child. They discovered three patterns of coping which were related to positive adjustment:

> '(a) maintaining family integration, co-operation and an optimistic definition of the situation; (b) maintaining social support, self esteem and psychological stability; and (c) understanding the medical situation through communication with other parents and consultation with the medical staff.' (p. 359)

Building on McCubbin's work recent studies have used models of stress and coping that define stress as a transactional process between the environment, the availability of resources, and the individual's cognitive appraisal and patterns of coping (e.g. Folkman *et al.* 1986). These models discard the simple notion of cause and effect between a stressor and stress. For example, how parents cope with disabled children is determined by how they view their situation, what access to resources they have, and critically by what coping strategies they employ. Recent studies have attempted to identify which coping strategies are effective in reducing stress and in increasing parental well-being.

Both quantitative and qualitative methodologies have been employed. In a typical quantitative studies, parents are asked to list their coping responses by filling out an index such as the Ways of Coping Questionnaire (Folkman *et al.*, 1986). In addition they fill out a standard questionnaire aiming to measure the level of stress they experience such as the Malaise Inventory (Rutter, Tizard and Whitmore, 1970). These measures are then correlated statistically to see which coping strategies result in less stress and greater well-being for the parents. Qualitative methodologies (e.g. Furneaux, 1988; Beresford, 1994b; Redmond 1996) which record and analyse parents' narratives about their experience of having a disabled child, and how they have coped in response, provide meaning and clarification to many of the general quantitative results.

While there are variations, a number of consistent results emerge across many different studies. Firstly, active coping strategies, that is strategies which involve parents taking active steps to remedy or ameliorate the problems they are facing tend to result in greater well-being and less stress for parents (e.g. Sloper *et al.* 1991; Quine and Pahl, 1991; Brown and Hepple 1989). These strategies include activities such as planning, problem solving, actively seeking support and information seeking.

Secondly some positive cognitive strategies are also correlated with greater well-being (e.g. Brown and Hepple 1989, Beresford, 1994b). For example, self-praise, the ability to focus on the positive aspects of their child's progress and on their life situation can all contribute to parents feeling less stressed. Some problems can not be overcome but they can be viewed in a different way which gives rise to less distress (Beresford, 1994a).

Thirdly, while many studies have noted strong similarities between fathers' and mothers' experiences and coping patterns (e.g. Redmond, 1996), a number have noted specific differences. For example, Sloper *et al.* (1991) found that fathers were less stressed than mothers and Kravetz, Nativitz and Katz (1993) found that mothers and fathers had different coping styles in that mothers were more likely to use emotion-release coping strategies such as catharsis.

Not all coping strategies have been shown as effective in the literature. For example the use of 'wishful thinking' has been shown as counter-productive strategy by Sloper *et al.* (1991) and Sloper and Turner (1993). Other strategies such as 'using social support' have had conflicting results. For example while many studies have found that parents' use of social support (that is social contact with friends and family) is related to increased parental well-being (e.g. McCubbin *et al.*, 1983; Reddon *et al*, 1992; Sloper & Turner, 1993), a significant number of large-scale studies have found no such correlation (Sloper *et al.*, 1991; Quine and Pahl, 1991). At issue here is the quality of the social support as some further qualitative studies suggest. For example, Beresford (1994b) in her study based on interviews with 20 parents of a severely disabled child found that while most enjoyed supportive relationships with their family some experienced these as undermining especially when there was a different opinion about discipline approaches or the origin of the child's problems. As we shall see, this finding is replicated in the current study.

Methodology

Population and Sample

The parents asked to participate in the study were caring for a child on the autistic spectrum who was attending a special school for children with emotional and behavioural problems in the South Dublin area. Following Berseford's (1994b) methodology only children who were attending the school for at least 1 year were included, so as to avoid those families where diagnosis is a relatively new event and where their child has not yet settled into education. Beresford in her study had interviewed the parent who was the main carer, but in this study the choice was given to the parents about who should be interviewed and the option of being interviewed together. This approach was adopted after feedback from the pilot interview (with a married couple with a disabled child outside the school) who suggested that it would be difficult for some parents to select the main carer, and that many couples would prefer to be interviewed together. It was considered whether to offer separate interviews to both parents, but this was abandoned due to time constraints.

Of the eleven families who fitted in the above categories, nine agreed to take part in the study. In four of the families both mother and father were interviewed and in the other five the mother was interviewed alone, giving a total of thirteen parents altogether. Within all the families the mother was the main carer of the child. Of the ten children (two from the same family), seven were tested within the average range of cognitive ability and three had a mild learning disability. All the children were on the autistic spectrum indicating that they had significant difficulties in social communication and interaction, thus affecting their ability to relate to their parents, other children and adults.

Data Collection

Given the exploratory nature of the study, the small numbers in the sample and the inclusion of the participants 'voice' in the findings a qualitative methodology was used. In particular a semi-structured interview was designed to elicit parents' narratives about their coping resources and strategies. This approach was similar to comparative studies (e.g. Brown and Hepple 1989; Beresford, 1994b), though with a different client group.

The topics covered in the interview were: (1) Diagnosis process of finding out about child's disability, (2) Formal support, (3) Informal support (4) Financial support (5) Keeping going (6) Acceptance/ Coming to terms (7) Stresses and Coping Strategies (8) Coping with change and the future. A single interviewer completed all the interviews following a loosely structured schedule of questions. Each interview lasted about one and a half hours each. Parents were given the choice about whether the interview took place in the school or in their home.

This article concentrates mainly on the findings from topics 3, 5, 6 and 7. A complete description of the study's other findings and of the methodology is contained in the full dissertation (Sharry 1997).

Data Analysis

All the interviews were audio-taped, before being reviewed individually and a summary transcribed. The content was categorised into the topic sections laid out in the interview schedule. When all the interviews were completed a comparative analysis, informed by the results of the literature review, was carried out to look for common themes existing across the parents' responses. Attempts were made to draw general conclusions about coping patterns but attention was also given to exception cases – that is parental experience which did follow the norm and which therefore delineated the bounds of any generalisations. The analysis focused on, as much as possible, using parents' own words to describe any themes and conclusions.

Key Themes and Findings

Day to Day Stressors

> 'I have had hair pulled, being kicked, had doors damaged, walls scribbled on.' (Mother 1)

> 'You would be worried going to the shops that he would start "I want I want" and throw a tantrum ... He might refuse to wear certain clothes and there would be a tantrum getting ready for school ... If he was in a bad mood he would upset the household for the whole day.' (Mother 5)

All parents in the sample cited behavioural problems as the biggest source of stress they encountered on a day to day basis. For some parents these were on-going and for others they had occurred in the past. The problems included tantrums, hitting out, over-activity, feeding and toileting problems. There was also concern over the child's stereotypical, and socially withdrawn behaviour. Such problems are reported in other studies of families with autistic children (e.g. Bristol 1984) and contribute greatly to the stress experienced by the parents (Holroyd and McArthur, 1976; Cutler and Kozloff, 1987). Being towards the more higher functioning end of the autistic spectrum the children in the sample appeared 'normal' and this in itself could be the cause of extra stress. As one mother in the sample reported:

> 'The problem is that Sam looks normal and then he does really weird things or he says strange things. Sometimes a child with a mental handicap or Down's syndrome looks different so people expect problems, they have a warning. But Sam who can behave quite bonkers, yet who looks normal, so people think he is just being naughty.' (Mother 8)

Coping Responses to Behavioural Problems

Responses of Parents

> 'We worked very hard at it. We thought if we let him away with it he would always be like that. My husband was firmer than me. He said we must treat him like an ordinary child.' (Mother 5)

> 'Once they know that wherever they throw the tantrum, that you are not going to throw in the towel. Because once you give in you lose any ground you have made. If you are out on the road or in the middle of the shop you have to see it [discipline strategy] through - and they soon learn to give it up.' (Mother 7)

The parents who felt they had made some progress with their children's behavioural problems put it down to being extra firm and consistent. Indeed many parents described how they opted for the easy life early on and lived to regret it - wishing they had been more consistent in the past. It seems that what works is not entirely different from the standard skills used in parenting, though they must be more consistently applied to gain results. Equally success can be slow and gradual and many parents coped with this by being realistic and focusing on small gains. One mother described the gradual shaping of her child's behaviour:

> 'I would think to myself maybe one [target behaviour to change] a week, or I would lead her up gently. For example we would approach the shop and only look in the door and then go out. But eventually we would go in and it wouldn't be traumatic for her.' (Mother 7)

Another family described how they felt it was important for families to take responsibility for solving problems themselves, rather than depending on professional help:

> 'The main mistake people make is waiting for someone to guide you and make it better. It [the problem] is something you have to solve yourself. There is no magic wand.' (Mother 3)

Dealing with their child's difficult behaviour in public was often difficult for parents. Some coped with it by avoiding trigger situations. For example one family described how they had recently stopped going into restaurants because of their daughter's anti-social eating habits (Family 3). One mother reported how she used to be self-conscious about her child's bizarre behaviour in public which would make her feel very stressed, but then she learned to ignore not only the behaviour but also the disapproving reactions of the critical audience (Mother 8). Interestingly, Tunali and Power (1993) found that mothers of autistic children when compared to a control group placed less value on other people's opinion of their child's behaviour.

Many parents had to balance their desire to improve their child's behaviour against the limits on their own time and energy:

> 'It's to get the balance between constantly fighting with him, not letting him walk all over you and then not to drive yourself crazy by having a row with him over every single thing.' (Mother9)

Howlin and Rutter (1987) noted that while many elaborate behavioural programmes may work to a great degree, one has to be careful that the implementation of the programme doesn't become an even greater stress than the original problem.

Equally for many parents it was not clear which behaviours they should target for change, especially as many of their child's stereotypical behaviours were not dangerous but merely unusual or unsocial. Parents agonised over how much to intervene to change this: If they did then the child could learn more pro-social ways of relating but also they ran the risk that such a move would cause a tantrum and thus more stress for child and parent.

> 'I didn't want to push her, I didn't want to make her life a misery, because she was quite happy in her own little world once you let her do what she wants.' (Mother 7)

Support from Services

It was practical day to day support and help which parents seemed to value most in their contact with pre-school and school staff and which was most instructive in managing behavioural problems.

> 'They would tell me what she was doing and what they were trying to do with her. They would say to me "try and get her to do this" bring her on in a certain way - what "bribe" would work.' (Mother 7)

> 'Seeing the care workers on a daily basis really helped. They told you what to try with him - how to handle his difficult behaviours and fed-back on what they were doing. They weaned him in very slowly.' (Mother 6)

For many parents the school day was welcome respite for themselves and sometimes represented the only place they felt their child was well looked after without them being present.

> 'It's nice when he is in school to take a break, to take a breather, go into town or whatever...In the early days I would be at my wit's end and I'd go out for the day over to my sister.' (Mother 7)

Informal Support

One of the key indicators of how a person copes with stress is how they access and use support from family and friends. Most parents in our sample described support from their spouses, grandparents, extended families and friends as been very helpful to them, in roughly this order of importance. This was both emotional and practical support (in the form of baby-sitting). As we have seen in the literature review, though generally social support is indicative of successful coping, this is not the case if the contact is experienced as undermining or inaccessible. In our sample this finding was replicated: While the majority of parents enjoyed supportive relationships with their families a significant majority did not, either currently or at some time in the past:

> 'Initially it was quite difficult, because most people felt that the problems of the children was due to bad parenting...They'd say "you're too soft; if you dealt with them this way you wouldn't have a problem; give me the child for a week and I will sort him out.' (Father 8)

> 'My mother was a thorn in my side. She never accepted that there was anything wrong with Paul. She'd ask "why don't you send him to an ordinary school?"' (Mother 1)

Blame seemed to be one of the biggest factors, which prevented many relationships from being supportive. This affects not only the spouse relationship but also relationships with grandparents and extended family (as well as inhibiting the functioning of professional relationships as well). This blame is perhaps particularly acute for higher functioning children on the autistic spectrum as their disability is less visible and manifests itself in specific behavioural problems identical to 'naughty' or oppositional behaviour. It seems however that once people understand the nature of the child's problems and specific requests are made about the support needed, these relationships can be transformed:

> 'He [father] didn't want to admit initially to himself that Paula had problems, but when he did he was very supportive.' (Mother 7)

For some families gaining support was not straightforward, and time had to be spent 'recruiting' and encouraging family members to help out. Often all that was needed was an explanation about their child's needs and a request for specific help. One mother explained to her brother the specific management programme she was adopting with her daughter, so he could re-produce it, when he took her on trips out (Mother 7). Another mother had noticed that her father was spending more time with her disabled child's brother (as he more easily returned affection). She sat down and spoke to her father about this and they agreed that he would set aside a special time for the disabled boy as well (Mother 8).

Support From Other Parents of Disabled Children

> 'It was a great relief that it's not just you that other people have been through similar situations, for example very difficult tantrums. Parents with normal children don't understand.' (Mother 1)

> 'It's very helpful to have the support of other people in the same position. At times, they will come up with an idea to a particular problem which might work for you.' (Mother 9)

Most parents in the sample described how they derived great support from meeting other parents of disabled children, especially those who had similar experiences to their own. All but one of the parents had attended a parent's support group at the school or pre-school, and described this as a benefit to them. The mother who had not attended described how she found it difficult to speak in a group. She also stated:

> 'I think that if I met a parent with a much bigger problem than Paula it would upset me, knowing what they were going through and what I have been through.' (Mother 7)

Another parent described how she used to feel this way when her child was younger:

> 'Now, I find meeting parents with similar children, very helpful, but I used to find it difficult - quite depressing as I hadn't fully accepted James had a problem.' (Mother 4)

Some parents attend groups for a period and then drop out of them. One father stopped attending a national support group as it became too much of a responsibility with other parents looking to him for answers (Father 5). Another mother felt she no longer needed to attend a group as she had developed her own support network in her local neighborhood (Mother 5).

The unique importance of support provided by other parents of disabled children is well documented in the literature (e.g. Beresford, 1994b; Furneaux, 1988; Brown and Hepple 1989).

Focus on Progress

> 'The fact that he's come on so well has been a big reward. It could have been much worse, he could have had no speech, we are very lucky' (Mother 5).

> 'It's very hard sometimes not to give into despair, if you don't see light at the end of the tunnel. Tangible examples of progress make all the difference' (Father 9).

Central to adaptive coping is the experience of positive progress. Parents of disabled children often have many experiences of their child failing, or not reaching certain standards relative to another child. A focus on such experiences can lead to stress and sadness. In contrast, the witnessing of their child's progress can be very rewarding. For this reason it is important that the child is in the right school placement, and parents have access to the right services which help the child progress according to their ability:

> 'I found the tutor absolutely marvellous. She more or less showed me how to interact with him, showing me how to start at his level and bring him on, it was all very positive.' (Mother 4)

Sometimes the simple fact of progress and positive change being noted and discussed by family and professionals can make all the difference:

> 'My two sister-in-laws only see her infrequently, and they point out progress like they notice when they phone that she will talk to them and tell them she misses them or whatever...The first time she had a conversation with her Dad on the phone, you would think we were after winning the pools' (Mother 7).

> 'I think he has come on very well than since a year ago, they [school staff] are very happy with his progress' (Mother 2).

For most parents to experience progress in the relationship with their child was particularly important. Given their child's social disability, affection or emotional contact was slow in coming so that when it did come it was a breakthrough and something very precious to them.

> 'When she first started coming up and giving me a cuddle that was a breakthrough. It had been very hurtful before that.' (Mother 3).

> 'You get the odd moment with Simon. One time last year he said "thanks Mum" I was quite touched' (Mother 9).

Brown and Hepple (1989) found that for parents, adopting a philosophical view which allowed them to see their child and their situation in a positive light was an adaptive coping response. They argued that such a positive view 'seemed to be infectious and helped others in the family and those in the community to be more understanding and to see the child with a mental handicap as normal person' (p. 67).

Process of Acceptance

Historically authors describe the response of parents to the disclosure that their child is disabled as similar to the grief reaction experienced by the death of a non-disabled child (Furneaux, 1988; Brown and Hepple, 1989). Classically this is characterised by a stage of shock or denial, followed by a period of mourning, moving through a period of adaptation, to a final stage of adjustment or acceptance (Furneaux, 1988). Middleton (1996) criticises such a model for its negative emphasis on grief. She argues that though the diagnosis of disability can mean loss to a parent, likening it to the death of a child is inappropriate, as no one actually has died. She attacks the prescriptive nature of the bereavement models, which argue that parents pass through the various stages with certain time-scales, when many do not. Equally she points out that though parenthood for a parent of a non-disabled child can be experienced as very stressful and requiring parental adjustment, bereavement models are never suggested as appropriate or thought helpful.

Brown and Hepple (1989) noticed that as well as reporting anxiety, shock and disappointment, many parents commented on some positive benefits of their adjustment process following disclosure of their child's handicap.

The parents in our sample gave a broad range of descriptions of what the process of adjustment was like for them, which is reflected by following comments from three families:

> 'I have always been reasonably relaxed and happy about James.' (Father 4).
>
> 'At the beginning it was upsetting, I wished he was normal, but after a year or two I accepted him for what he is. Then I just got on with it, otherwise you'd just be worrying yourself sick, and there's nothing you can do.' (Mother 5).
>
> 'You never get over it, you always face each day his disabilities.' (Mother 6)
> 'It's like the grief following a death.' (Father 6)

As we can see the first parent is describing how there was very little adjustment for him; the second describes a very discrete period followed by resolution; the third couple describe the process in terms of a grief following a death. As their child is youngest of the three, this indeed could be a process through which they eventually will pass. Interestingly the mother herself also says in the interview that she hopes to reach a level of acceptance. When asked by the interviewer 'What have you learned as a parent?' She replied:

> 'I know what I should have learned: "God give me the serenity to accept the things I can't change, courage to change the things I can and wisdom to know the difference"...That's what I aspire to.' (Mother 6)

Other parents described how the process of acceptance was a dual process for them in the sense that balanced against their acceptance of their child's special needs was the hope that a 'cure' could be found. This hope remained important to them to hold on to:

> 'We have adjusted but we are still at the phase where we haven't fully accepted. We are always hoping - like winning the lottery - that something will fall into place...but not as much as before.' (Mother 2)

> 'I still say to myself who knows what the future holds. There is still a chance of some miracle improvement in Simon. I still hope for this though I don't pin all my hopes on it.' (Father 9)

It seems difficult to have any prescriptive model, which describes the process of adjustment for all parents of disabled children. As Middleton (1996) argues, we must not work with clients with a fixed model in mind, but rather be open to the reality of as experienced by individual parents. The broad range of responses given by this group of parents seems to support this conclusion.

Conclusions

This article documents some of the active and creative ways parents with children on the autistic spectrum cope with the problems they encounter. Though the study was small scale and exploratory (and would need to be replicated and corroborated with further research), a number of tentative conclusions and suggestions for social work practice, can be drawn.

Parents in the present study described their child's behavioural problems as one of the biggest challenges they coped with. As practitioners we could support how they manage by providing regular contact with front-line staff, respite, access to supportive parent's groups, help in building their own support networks, and help in implementing behavioural programmes which are collaboratively designed and which complement their own resources.

A positive focus to professional support and service design, which emphasises progress and strengths seems to be strongly indicated in the study. Parents welcomed contact with services which not only gave their child an opportunity to progress according to their ability, but which allowed the positive qualities about their child to be noticed, reflected upon, and discussed with them. The ability to notice and enjoy good times (even if infrequent) was a key aspect to coping.

While parents of disabled children in general and children on the autistic spectrum in particular, do face sadness and challenges in their lives, this is not the whole story and certainly should not be the only aspect of their lives focused on by professionals. There is also the alternative story of progress, joy and responding to adversity which can be as valuable for parents to share and be as useful for professionals to hear and encourage. Though the 'bereavement' model of adjustment may be helpful in some situations it can hardly be universally applied. Above all it is important to be flexible in working with parents of disabled children. We should listen more and prescribe less. We should be less led by a fixed theory or model but more led by the individual parent's experience and reality, consulting with them about how we can be helpful in supporting them.

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Footnotes

[1] This article summarises the key themes of the full study that was submitted as a Masters dissertation (authors own, 1997).

[2] All names used in the article are fictitious to maintain confidentiality.

Biographical Note

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