특수교육저널: 이론과 실천
The Journal of Special Education: Theory and Practice
2010. 6. 제11권 2호, pp. 281~309.

Exploring parental experiences and practices associated with disabled children: From a disability studies perspective

Choi, Bogcheon*
Yeungnam University, Adjunct Professor/
Gyeongnam Family Support Center on Disability, Research Director

《요 약》

The aim of this paper is to conduct a critical review of the literature on disabled children and their families, with a focus on the parental experiences of disablement and practices associated with disabled children. Drawing in varying degrees on critical and emancipatory insights developed within disability studies, this paper problematizes the limited notions of disabling conditions of parenting a disabled child and constitutes a direct challenge to the traditional and pathological approaches prevalent in the literature. This paper argues that adopting the social model of disability approaches provides several vantage points in the sense of allowing the broader range of disablement facing families with disabled children to be visible and challenging the orthodox view that the disabled child makes the family disabled. It also argues that parental experiences and practices associated disabled children need to be reinterpreted as social-political matters, not simply psychological ones.

Key Words : disability studies, disabled child, parental experiences of disablement, parental practices, disability embodied parenthood

---

* 교신저자(splbc@hanmail.net)

Ⅰ. Introduction

At a broader level, our approach to disability affects how we understand families with a disabled child. The birth of a disabled child has been traditionally seen as a personal and family tragedy (Shakespeare & Watson, 1998), and research on families with disabled children has tended to adopt a pathological approach, assuming that damaging features in the lives of their families are an inevitable or necessary consequences of having a disabled child. Even though there is increased attention on problems the families encounter, the ideas about the solution of disabled families' problems can be said to be shaped by 'psychological' or 'therapeutic' frameworks (Oliver & Sapey, 2006; Read, 2000). It tends to focus primarily upon the attitudinal and/or behavioral adjustment or maladjustment of the parents and other family members, while material and social circumstance in their lives are neglected or, at best, treated as secondary issues.

Drawing in varying degrees on critical and emancipatory insights developed within disability studies, this paper aims to problematize such limited notions of disabling conditions of parenting a disabled child and constitutes a direct challenge to the traditional and pathological approaches prevalent in the literature. In the first part of this paper, it will discuss critical and emancipatory insights developed within disability studies, with a focus on the fundamental perspectives underpinned by the social model of disability. It will also examine how such perspectives can be applied to parental experiences of disablement. It then provides a critical overview of the research trends regarding disabled families over the last few decades and discussed some of the central themes in the light of the disabling condition of parenting a disabled child. In doing this, I will argue that research on parents of disabled children needs to go beyond the traditional, pathological approaches and consider the wider social and cultural milieus in which they are embedded. In the last section of this paper, I explore the recent literature on the characteristics of disability—parenthood and discuss the parents' practices from a social—political perspective.

In conducting a critical review of the literature on disabled children and their families, this paper tries to discuss the following questions: How do families with disabled children experience disablement?; In what ways are the wider social forces and relations related to their experiences of parenting a disabled child?; How do the parents construct and reconstruct their parenthood through their experiences of rearing a disabled child?

Ⅱ. The Social Model of Disability and Its Implications

There has been a paradigm shift in understanding disability that can be succinctly summarized as a transition from the individual to the social model of disability – in UK terms at least. In this section, I discuss the fundamental perspectives underpinned by the social model, which would serve as a backdrop to analyze the experiences of families with disabled children. These are: (a) a social-relational approach; (b) examining disability as a form of social oppression and as a terrain of resistance; and (c) disabling values and their ideological effects.

1. The social-relational nature of disability

Disability has been defined in many different ways over the years; unsurprisingly, these definitions have been influenced by various historical, social and ideological practices. For many years, professional research and policy have been dominated by the 'medical model' that equates disability with chronic illness and ascribes a 'sick role' to the individual (Barnes et al, 1999). Disabled people are termed and classified in terms of their physiological dysfunction or limitations. It has been assumed that someone with impairment would find it difficult to perform 'normal' activities and, as a consequence, would lack the ability to fulfil normal social roles (e.g. Parsons, 1951). Thus, disabled people's experience of disadvantage and exclusion in important areas of their social lives, such as employment and education, has been viewed largely as an individual problem caused by impairment. From this perspective, the appropriate response is either to 'cure' the problem of the bodily condition or to help the individual to 'adjust' to their circumstances (Oliver, 1990). Closely related to this perspective is the 'personal tragedy' model. Having an impairment is equalized with being 'less than whole person' and, in order to overcome their predicament, disabled people are expected to make efforts to 'rehabilitate' their 'personal defects' and achieve less valued social roles (Oliver & Sapey, 2006).

Disabled scholars and activists have criticised the shortcomings of the traditional, medical and individualistic approaches and been engaged in developing a new, radical reappraisal of disability issues. Undoubtedly, the most significant achievements have arisen from the development of the social-political interpretation or social model of disability. In order to depart from biological deterministic and essentialist notions of disability, the social model approaches conceptually separate impairment and disability. In this model, disability is redefined as the product of complex social structures and processes. The disablement and restriction in disabled people's experience is created by the social barriers and unequal relations between disabled people and the rest of society:

> The experiences of disabled people are of social restrictions in the world around them, not of being a person with a 'disabling condition.' This is not to deny that individuals experience 'disability'; rather it is to assert that the individual's experience of 'disability' is created in intersections with a physical and social world designed for non-disabled living (Swain et al., 1993, p. 2).

Identifying disability as a social construction does not simply replace 'biological determinism' with 'social reductionism' (that is, all restrictions of disabled people are socially caused), as is argued by some medical sociologists (e.g. Bury, 1996). Nor does this undermine the significance of impairment as constituting the embodied experiences of disabled people. Even though 'impairment effects' (that is, restrictions of activities caused by illness or impairment) and disability interact together in the lived experiences of disabled people, it should be noted that there is no essential relationship between having an impairment and being disabled:

> Disability is about restrictions of activity which are socially caused. That is, disability is entirely socially caused. But some restrictions of activity are caused by illness and impairment. Thus some aspects of illness and impairment are disabling. But disability has nothing to do with impairment (Thomas, 1999, p. 39).

Adopting the critical perspective underpinned by the social model of disability, I hold the view that disability problems are socially constructed and they arise as a result of social processes and the interaction of social forces, rather than being predetermined by biological factors. This fundamental view is also applied to the understanding of families with disabled children: there is no inevitable causality between having a disabled child and the disablement of the family, as Dowling and Dolan aptly put it:

> Although families with a child with disabilities suffer real inequalities, the concept of these families is nevertheless socially constructed. This is a very different concept from the old fashioned idea that a child with disabilities disables the whole family and that there are handicapped families rather than just handicapped children. What we are saying is that the child dose not handicap the family - society does (Dowling & Dowling, 2001, p. 22).

2. Disability as a form of social oppression and a site of resistance

Perhaps the strongest challenge to the existing ideas about disability is the argument that disability should be regarded as a form of social oppression (Abberley, 1987; Barnes, 1996; Oliver, 1990). Within disability studies, the term ‘disablism’ has been frequently used to denote a specific form of social oppression that differentiates disabled people from others and excludes them from mainstream social activities (Barnes & Mercer, 2003). In order to elaborate its distinctive features, I shall employ Irish Marion Young’s typology of social oppression: exploitation, marginalization, powerlessness, cultural imperialism and violence (1990, pp. 48-63).

The traditional notion of exploitation based on a Marxist perspective was explained according to class structure and labour exploitation in the relations of capitalist production. Of course, the notion of labour exploitation of one group by another within the relations of economic production is difficult to apply directly to the current situation of disabled people who are excluded from the labour market (Barnes & Mercer, 2003). However, if we move beyond a monolithic notion of work by incorporating unpaid and domestic care labour, the exploitation of care work – notably carried by women – is another dimension of the exploitation of labour (Sevenhuijsen, 1998; Tronto, 1993). From a disability perspective, the social assignment of care work to disabled people and their family members can be interpreted as the exploitation of labour in the sense that the social responsibility for 'dependency work' or 'help' is unequally distributed (Kittay, 1999; Shakespeare, 2002).

From the viewpoint of disabled people, marginalization is the most significant feature of social oppression (Linton, 1998). It is important to note that materialization is not simply a lack of life chances or opportunities in an individual sense, but entails 'structured patterns' which hinder disabled people from obtaining and accumulating economic, cultural and social capital (Oliver, 1990). Such marginalization of disabled people directly results in a realization of another form of social oppression, powerlessness. Disabled people and their families have little authority and power to control what to do with their lives, notably in their treatment by medical professionals and bureaucratic policy makers (Morris, 1993; Priestley, 1999). Violence imposed on disabled people is a commonly reported social phenomenon across societies, ranging from direct physical attacks to symbolic abuse (Middleton, 1996). Cultural imperialism, which operates through various forms of cultural representation, is a key oppressive mechanism used to objectify disabled people as 'Other' (Priestley, 1999). I will return to this issue in more detail in the next section.

Employing Young's typology of social oppression, I have discussed briefly the multi-dimensional features of disablism. Following disability theorists' social-political approaches, I maintain that disablism should be understood as a distinctive form of social domination and oppression, which reproduces the existing social arrangements and power relations alongside the binary categorization of the 'abled' versus the 'disabled'. Three further points should be noted. At first, disablism is not only operating according to its own distinctive set of dynamics but is also intersecting with other forms of oppressive mechanism such as sexism and racism. It is often realized as a form of 'multiple' or 'simultaneous oppression' identified by some disability theorists (see Begum, 1992; Lloyd, 1992). Secondly, disablism is manifested in various forms and at different levels. For example, as well as being evident in the forms of institutional practices, it expresses its oppressive power in disabled people's process of self-identity formation. Socially constructed negative meanings, ideas and stereotypes about disability sometimes result in "profoundly exclusionary consequences by working on their sense of personhood and self-esteem" (Thomas, 1999, pp. 47-8). Thirdly, it is important to note that disablism does not express its oppressive power simply in a tyrannical way (Fawcett, 2000). Borrowing Foucault's (1980) ideas, it can be said that disablism expresses their 'productive power' to govern and discipline the disabled, For example, under the social pressure to assign disabled body to a mark of being inferior and deviant, parents of disabled child are likely to perceive it as their parental responsibility to cure or convert him/her into a 'normal' child as possible as they can.

Insofar as the construction of disability is embedded in certain social forces and relations, certain ways of defining and treating disabled peopled in the social world are not a natural but a 'historical invention' (Davis, 1995). Repositioning disability as a form of social oppression provides, in both theoretical and political senses, the space to challenge the social barriers and exclusion that disabled people encounter from the citizenship rights perspectives. At the same time, it enables us to relocate disabled people and their families as significant social agents who interpret, criticise and reshape the existing social orders and relations (Morris, 1991; Oliver & Barnes, 1998). In this context, disability is no longer a fixed phenomenon, but, rather, a social terrain to be reconfigured, struggled against and changed.

3. Disabling values and their ideological effects

I have argued that the social practices of disability can be understood as forms of social oppression which are operating in a number of ways. Here I discuss some of the dominant cultural disabling values in modern societies and their ideological effects in forming and sustaining the existing social relations of domination and subordination.

1) The culture of tragedy

As disability theorists have underlined, the ideas of 'ragedy' seem to be the most common, consistent theme in the cultural representation of disabled people (Barnes, 1992, 1997; Hevey, 1993). The ideas of tragedy have been widely employed as a popular metaphor to depict disabled people as useless, helpless or impotent (Shakespeare, 1994). Contemporary studies suggest that such imagery persists in the mass media representations. For example, Biklen (1987) argues that the U.S. media portray disabled people and their lives as sorrowful, painful, desperate, and defeated. In addition, only a limited number of disability issues are portrayed – such as charity events, fund raising and personal accomplishment stories. A similar picture is found in the media representation of disabled people in Korea. Yi (2001), in his analysis of the main newspapers reporting disability issues, notes that the language used is frequently negative and oppressive, tending to marginalize the day-to-day realities of disabled people. He also emphasizes that Korean newspapers exclusively focus on stories of the 'special achievements' of disabled people. Their high-ranking scores in national exams and success in holding down a professional job are often portrayed under the title of 'overcoming great odds'. The underlying message is that disabled people generally cannot achieve or undertake such ordinary life goals. Similarly, an annual monitoring report (DPF, 2002) shows that Korean TV has two main ways of representing disability issues: focusing either on the exclusively pitiful, stressful, tragic lives of disabled people and their family members, or on the 'heart-rending stories' of non-disabled which portray their assistance as 'angel-like behavior'. The significance of cultural representations of disability as tragedy is twofold. Firstly, its popular negative assumption is frequently reproduced within the professional literature on disabled children and their families. Secondly, it hinders us from apprehending disability problems from a social perspective.

2) The culture of the imperfect and the abnormal body

The cultural construction of disability has been dominated by representations of the imperfect body (Hevey, 1992; Thomson, 1997). The growing dominance of the medical paradigm imposes a "normalizing gaze" on human bodies, defining new boundaries of the pathological and abnormal (Foucault, 1980). The 'politics of scaling bodies' in relation to the bio-medical norms has been the crucial mechanism that constructs the social and cultural categorization of acceptance (Davis, 1995; Thomson, 1997). In this process, the impaired body (and mind) has been represented as 'dangerous' and 'deviant' because it is perceived as being out of control (Wendell, 1996). Not only is it conceived as a violation of the physical norms but also as a threat to the ritualized social behaviors and norms (Thomson, 1997). Hugues also underscores "medical distinctions[of bodies] are powerful cultural distinctions which promote and reinforce social hierarchy" and consequently perpetuate the "aesthetic invalidation of disabled people" (2000, p. 558). Such a medicalization of bodily condition has been particularly significant when set alongside the "late-modern body project" that celebrates healthy, sexy and normal appearances, and enforces self-reflexive control of and responsibility toward our own bodies (Shilling, 1993; Turner, 1992).

In relation to parents with a disabled child, the cultural construction of disability as abnormal body is significant because it has been frequently mirrored in the increased social perception of the parental responsibility to have a 'perfect and healthy' child (Landsman, 1998). As a result, having a disabled child is often regarded as evidence of the lack of 'normal' parenthood (Greenspan, 1998; Gregory, 1991). Furthermore, the cultural principle of 'normality' regarding child development imposes on the parents the moral obligation of fixing or modifying the child's functional performance. As Hillyer (1993) emphasizes, under the dominance of rehabilitation discourse, parents of a disabled child are valued according to the degree to which they help to overcome the child's limitation: the 'good parent' is someone who achieves successful results which approximate to the milestone of 'normalcy'.

3) The culture of dependence

To reify disability as a state of ‘unavoidable’ dependency is one of the most dominant representations in the public culture and policy narratives (Morris, 1993; Priestly, 1999). In popular thinking, disabled people are marked as ‘essentially’ different from the rest of the population, being frequently depicted as embodying an inevitable burden, the loss of adulthood, a lack of competence and autonomy, and the incapacity to manage one’s life (Priestly, 2003). In this context, disabled people are always conceived as inferior, helpless, and, at best, ‘secondary citizens’ in modern societies. Within disability studies, it has been argued that assigning disabled people to a distinctive dependent group is a reflection of the dominant cultural perception of independence, in particular, the idea of being able to do things without the assistance of others, to be self-sufficient and self-reliant (Morris, 1991; Shakespeare, 2002). Oliver comments that:

> In common sense usage, dependency implies the inability to do things for oneself and consequently the reliance upon others to carry out some or all of the tasks of everyday life. Conversely, independence suggests that the individual needs no assistance whatever from anyone else and this fits nicely with the current political rhetoric which stresses competitive individualism. In reality, of course, no one in a modern industrial society is completely independent: we live in a state of mutual interdependence. The dependence of disabled people therefore, is not a feature which marks them out as different in kind from the rest of the population but different in degree (Oliver, 1989, p. 8).

In their research, Fraser and Gordon (1997) underline that the devaluation of dependence and the binary notion of dependency and independency are the creation of modern thought rather than a universal truth. They argue that, in pre-industrial societies, “dependency was a normal, as opposed to a deviant condition [and was] a social relation, as opposed to an individual trait” (Fraser & Gordon, 1997, p. 125). Some feminist theorists of care ethics also point out that the atomistic perception of independence as the ideal self – dominated by ‘work ethics’ – not only obscure the fact that dependence on others is an ontological precondition of human existence but also objectify people needing the help of other as second-class citizens (Sevenhuijsen, 1998; Tronto, 1993; Young, 1995). In a similar way, some disability theorists have suggested that we need to reformulate individualistic, mechanistic notions of competence and autonomy from a social-relational perspective in order to valorize the diversity and difference that disabled people embody in contemporary societies (Jenkins & Angrosino, 1998; Shakespeare, 2002).

Ⅲ. Reinterpreting parental experiences and practices

1. Beyond a pathological approach

Ferguson (2001), in reviewing the literature conducted after World War Ⅱ, argues that the research on parents with disabled children can be characterized as a direct application of the medical model of disability. As already discussed, the view that having impairment is a determinant factor creating personal tragedy is a core assumption in the paradigm. In a similar way, most early research on families with a disabled child adopted a pathological approach, taking the view that “a handicapped child makes a handicapped family” (MaCormack, 1978, quoted in Read & Clements, 2001). Without critical questioning the social construction of disability, most research has tended to treat the disabled child as a ‘pathological property’, assuming that there is a simple, unavoidable causal relationship between having disabled child and family pathology, such as family malfunctioning and the lack of ‘normal’ family relationships (Darling, 1979; Ferguson et al., 2000; Middleton, 1996; Thomas, 1982). This approach has frequently produced biased research in which the impact of a disabled child on the parents’ psychological well-being and family life is described in highly negative terms, replete with examples of parents who are quite unable to manage a disabled child (Ferguson & Asch, 1989). The underlying message in the literature is that a disabled child is undesirable and to be aborted if at all possible (Ferguson et al., 2000; Thomas, 1982). Indeed, where parents have reported the beneficial effects of having a disabled child, these have often been dismissed as evidence of ‘denial’, emotional ‘rejection’ or an attempt to alleviate their guilt (Featherstone, 1981; Hillyer, 1993).

In the 1980s, a number of scholars and patents began to challenge this traditional, pathological approach. Three themes have been most commonly identified. Firstly, the parents’ response towards a disabled child is not always negative, nor is the child’s impairment the sole factor in the parents’ perception of their children (Ferguson, 2001; Ferguson & Asch, 1989). It has been reported that many parents describe their disabled child, like their other children, in terms of love, pride, rewards, and stresses, and emphasize their children’s individuality, personality and achievements (Beresford, 1994; Glendinning, 1983, Goodey, 1991). For example, Beresford observes that “parents do not view their child as a disability. They describe their child as an individual who has limitations and difficulties arising from the disabling condition” (1994, p. 59). It has also been noted that parents’ emphasis of the positive aspects of their children should not be interpreted simply as a ‘denial’ of disability or ‘irrational’ or ‘romanticized’ response (Hillyer, 1993; Read, 2000). Many parents regard it as essential in carving out “defensive spaces in their lives that foster and enhance[ing] the well−being of all family members against oppressive social environments” (Read & Clements, 2001, p. 16).

Secondly, the impact of a disabled child on family life should not be interpreted in pathological terms, even though the difficulties that parents experience in rearing disabled children are different from those experienced by parents of non−disabled children. It has been acknowledged that, without neglecting the social pressure that they are under, many parents experience numerous benefits and positive outcomes through parenting their disabled children; for example, family harmony(cohesiveness), spiritual growth and a deep understanding of the lives of others (Bower and Hayes, 1998; Reinders, 2000). Rather than characterize the relationship with their disabled children as a burden to be shouldered, many parents tend to describe their relation ships as ‘mutual’, ‘reciprocal’, and ‘inter−subjective’ (Ferguson & Asch, 1989; Gray, 1997; Hillyer, 1993; Landsman, 1999).

Thirdly, in general, the professional literature on the disabled family has been shaped by the legacy of psychoanalysis, tending to focus primarily upon the attitudinal and/or behavioral adjustment or maladjustment of the parents and other family members, while the significant needs and circumstances in their lives are neglected or, at best, treated as secondary issues. As a result, policy derived from the traditional research is concerned with ‘fixing’ the personal and family qualities which are identified as the barrier to adjustment, rather than with a ‘context−changing’ approach to the social environment (Ferguson, 2001). The therapeutic intervention that psychological and other traditional disciplinary works offer may help the parents to cope with certain emotional problems. However, limiting our understanding of the experiences of disabled families to ‘intrapsychic and intrafamily issues’ has perpetuated the conventional idea that disability is a problem to be solved through individual or family intervention (Philip & Duckworth, 1982; Read, 2000). More problematically, much of the psychological literature has contributed to pathologizing the parents by attributing the problem of the child and family to the parents’ deficiency or failure (Ferguson et al., 2000; Hillyer, 1993). This dominant research paradigm has been challenged in recent years through the development of disability studies. A growing number of studies has suggested a reappraisal of what had been identified previously as ‘pathological’ features by addressing environmental contingencies. A shift from a child/family−specific focus to environmental contexts lets the disabled family being understood in terms of the broader social, cultural and political contexts, as well as in relation to the support systems (Read, 2000; Read & Clements, 2001).

2. The Disabling Conditions of Good Parenting

There are contested ways of representing the problems that parents encounter in rearing a disabled child: firstly, through a representation of the child’s impaired body, and, secondly, through the representation of the disabling barriers that impact on parenting. Without neglecting the parents’ particular experiences and their constitutive nature of parenting, a number of disability theorists have argued that we need to move the analytical focus from a child’s impairment or his/her parents’ characteristics to the social conditions which disable them (Dowling & Dolan, 2001; Middleton, 1996; Shakespeare & Watson, 1998). Here, I briefly review central issues that emerge from the research on the disabled family, and discuss them in terms of disabling condition of parenting a child with an impairment.

1) Material, financial and practical problems

It has long been established that the presence of a disabled child makes a significant financial impact upon a household. As widely noted, this results from two main factors: the cost of meeting the special needs of the child is high and therefore the expenditure increases; at the same time, the child's needs for extra care reduce the opportunity of the parents, especially the mothers to participate in the labour market (Baldwin, 1985; Baldwin & Carlisle, 1994; Glendinning, 1983; Twigg & Atkin, 1994). As a result of these factors, the living standards in households with a disabled child are lower than those of comparable families in the general population (Read & Clements, 2001), and a family with a disabled child is at a likelihood of being poor (Ball, 1998; Daly & Leonard, 2002). Some recent research has drawn attention to the particularly vulnerable groups among families with disabled children; for example, families with more than one disabled child and lone-parent households. It is reported that in these families there is an increasing rate of parental unemployment, greater hardship in balancing income and expenditure, and a greater risk of poverty (Lawton, 1998; Tozer, 1999).

The restricted financial resources also magnify other major material problems in the lives of families with disabled children. The families often find themselves living in housing conditions that are restrictive and unsuitable for disabled child (Sloper & Turner, 1992). Given the lack of suitable public housing, the families frequently experience great financial pressure due to moving house or undertaking adaptations at their own expense (Oldman & Beresford, 1998). In addition, the rate of ownership of ordinary consumer items is lower among the families of disabled children than the general population (Baldwin & Carlisle, 1994). For example, a national survey in the UK reported that only half of the families with a disabled child had access to a car, compared with two-thirds of those in the general population (Beresford, 1995). When there are serious shortfalls in the public support designed to offset the costs of using special equipment and other facilities to meet the child's needs, rearing a disabled child imposes great hardship in terms of managing the household budget and other the family members' needs are often sacrificed. Some Korean research on families with disabled children has reported that, on average, a third of household income is spent on purchasing these services or basic items that are essential to the children's well-being (Lee & Lee, 2000).

A consideration of these financial and practical problems encountered by families is important in its own right, but it is also important to be aware that these inadequate material conditions for rearing a disabled child frequently cause psycho-emotional damage to the parents. Research has provided evidence of a clear association between high levels of parental stress and concerns about their fragile financial position and other vital material assets (e.g. Beresford et al., 1995). Furthermore, restricted financial resources and other material problems can undermine the parents' attempts to engage in 'good parenting', and consequently damage their sense of morality and self-esteem as parents (Hillyer, 1993).

2) Disabling services and professionals

Information is one of the most significant factors that impacts upon parents' ways of planning, managing their family life and coping with the problems that they encounter. In addition to general knowledge about child rearing, the presence of a disabled child demands parents to learn and absorb special kinds of information; this can be about the child's condition, welfare benefits, educational system, practical services to aid the child's development and other social services. While the parents' demographic and social attributes influence the accessing of information, most parents commonly experience substantial difficulties in identifying and obtaining crucial information throughout their life spans (Beresford, 1995; Sloper & Turner, 1992). Recent studies have reported that many parents still have to make extraordinary efforts to access basic information that is directly related to their child's well-being (Ball, 1998; Read & Clement, 2001).

In addition to the direct care work, parenting a disabled child necessitates contact with a number of specialist services designed to aid the child's development and secure the child's interests. Parents consistently argue that the presence of appropriate, supportive services is a significant factor that makes a very big difference to their disabled child's life, as well as their family as a whole (Darling & Darling, 1982; Seligman & Darling, 1997). It has been well documented that a good service that meets the family' needs is not only an important resource, helping them to copy with the practical problems in their daily lives, but also a powerful mediator of stress (Sloper et al., 1991). However, a range of studies reports that very many parents experience substantial difficulties in receiving appropriate, timely services. It has also been documented that there are substantial levels of dissatisfaction with the existing services in terms of both in quantity and quality (Read & Clements, 2001; Sloper & Turner, 2002). Indeed, obtaining the services that the parents perceive as necessary for their child's well-being is the most stressful part of bringing up a disabled child. For example, a UK national survey in 1995 found that about half of the parents complained that they had to fight for everything that their disabled children needed (Beresford, 1995).

In addition to the problems of the unmet needs for services, the parents of disabled children have continually reported difficulties regarding the ways in which the services are operated and their relationships with the service providers. In her study of parents caring for children with intellectual disabilities in Austria over five decades, Stehlick (2000) identifies the parents' relationships with the health and other social service professionals as "sites of struggle". She reports that, from the moment of diagnosis and across the whole of childhood, parents complain of a subordinate power relationship with the professionals. Despite the family-centered and family empowerment models have been adopted by the health and social care organizations, research studies still confirm that parents identify their relationships with the professionals as unequal and non-collaborative (Case, 2000; Murray, 2000).

3) Isolation and exclusion

It has been widely documented that families with disabled children experience unequal opportunities to participate in mainstream social activities and are frequently isolated from their peers and the wider community. In addition to the extra caring demands in relation to their child's specific mobility and behavioral difficulties, the parents of disabled children consistently has reported that the unavailability of appropriate care services and/or the inaccessibility of mainstream childcare provision is the most significant problem which constrains their aspirations for social participation (Beresford et al., 1996; Seligman & Darling, 1997). The parents, particularly the mothers are frequently compelled to withdraw from their previous social career and social relationships because childcare becomes the sole responsibility of the parent. In addition, transport problems, a restricted household income and an inaccessible built environment have been frequently cited by parents as barriers preventing the family from participating in mainstream social activities (Ball, 1998; Read & Clement, 2001). Most particularly, the restriction of financial resources constrains the possibility of engaging in leisure and other meaningful social activities that are taken for granted by others in the population. Together, these factors often make it difficult for disabled families – especially vulnerable groups, such as lone-parent families – to escape from their household and so lead to a feeling of "being ghettoized" (Hillyer, 1993).

It has been widely illustrated within disability studies that disabled children encounter a variety of forms of exclusion and discrimination, ranging from negative attitudes to systematic segregation (Middleton, 1999; Morris, 1998; Shakespeare & Watson, 1998). Social hostility toward disabled children also induces discriminatory responses towards other members of their family. For example, Atkinson and Crawforth (1995), in their study of siblings of disabled children, reported that almost three-quarters of them experienced bullying or teasing at school. A number of writers have examined how the prevailing negative perceptions of their disabled children make the parents 'Others' – being treated by others as 'less than whole parents' and impose on them a sense of social isolation (Green, 2003; Greenspan, 1998; Gregory, 1991; Landsman, 1998, 1999). As Glendinning puts it:

> The reactions of members of the public in the street and other public places, and reports in the press and on radio and TV all communicate to parents the dominant response of society to severe disablement in children. In different

> ways these messages seemed to lead to the development and reinforcement of a sense of social isolation: an awareness of the many ways in which their particular experience of parenthood diverged from the patters of those around them (Glendinning, 1983, p. 225).

3. Disability Embodied Parenthood

1) Extended Parental Practices and Disability Work

Inequalities based on disability add to the complexities of family dynamics and challenge many of the assumptions about parenthood and parenting. Given that society is designed for non-disabled people, parenting a disabled child is not like parenting a 'normal' child.

Kittay (1999), a feminist philosopher and mother of a daughter with a severe impairment, draws attention to particular features of disability-parenthood by reappraising what is commonly identified as essential parental work – that is, preservative love, socializing the child for acceptance, and fostering the child's development. Regarding "preservative love", Kittay notes that the parental responsibility to preserve the severely impaired child's life is often accompanied by a life-long commitment to his/her day-to-day physical care. The protracted dependency of the child can be a threat to the 'normal' phase of parenting. However, as she underscores, this alteration of the parents' life course is a product of an able-body-focused society, where dependency (and the distribution of care work) is omitted from considerations of social justice. In relation to "socializing the child for acceptance", she addresses the double-sided nature of the parents' activities. The parents of disabled children have not only to encourage their child to prepare for a world larger than the family but also to 'socialize the world' so that it will accept the child despite his/her difference. Finally, Kittay points out that parenting a disabled child entails the work of "enabling" as well as fostering the child's development, because the development of many children with severe impairments is not given. This demands the parents of disabled children to undertake more 'specialized' and 'intensive' parental work than the parents of non-disabled children, and the task of dealing with health, education and other professionals constitutes an integral component of parental work.

Some scholars have paid attention to the new or extended roles that the parents of disabled children have to fulfil in order to secure their child's welfare. Darling (1988) notes that parents adopt an "entrepreneurial role" when they continue to encounter needs which are unmet by the existing societal resources. This role includes seeking information, seeking control and challenging authority. In her recent study of mothers in England, Read (2000) explored the "mediating role" of mothers who acted as "buffers" between their children and various professionals and institutions. She argues that the job of mediator becomes an almost inevitable extension of their roles as parents under the social circumstances that are unfavourable to disabled children. She writes:

> As they modify and augment their view about their children, their children's place in the world and the need to safeguard their interests, they find themselves increasingly and irrevocably drawn into the role of go-between and the buffer state. Many do not take to the role easily but feel that they have no alternative (Read, 2000, p. 115).

In their study of the mothers of children with profound impairments in Canada, Mckeever and Miller (2004) also explored the multiple roles and tactics that those mothers had to develop over time, including the manipulation of the child's appearance. By eliciting the mothers' perspectives and meanings, they found that these parental practices were a kind of strategic invention to enhance the children's social position and to augment resources in many fields of social life.

Several authors have attempted to explicate the terrain of the parents' practices in terms of careers which they have embarked upon in trying to get their own children's needs met, which then broadened into disability work (Darling 1988; Traustadottir, 1991, 2000; Wickham-Searl 1992a, 1992b). For instance, Traustadottir (2000) examines the activities through which mothers extend their caring beyond their child to embrace advocacy and lobbying and underscores that such work is more like that associated with a professional career than traditional motherhood. Similarly, in her study of mothers of disabled children in the USA, Wickham-Searl (1992a) reports that the mothers initially devoted their lives to their own children's welfare, but gradually extended their roles to assist other families in similar circumstances and to conduct other disability-related public work.

2) Transformative experiences

When the existing literature is explored in an effort to discover what is known about the lives of the parents of disabled children, one immediate problem presents itself. While there are exceptions, researchers have tended to focus primarily upon the seemingly negative results of having a disabled child. Scorgie (1996) argues that ways of interpreting parental responses in the professional literature have been biased due to two fundamental problems. Firstly, sharing one's life with a disabled child is predominantly described in terms of coping with stress, which is informed by notion that the lives of families with such children are characterized by a deficit. Secondly, investigators have conventionally examined only short-term responses, assuming that initial reactions evident at a certain crisis moment constitute the overall picture of the lives of the parents of disabled children. By eliciting the parents' perspectives, Scorgie (1996) argues that, in order to understand how parents manage their lives, one has to include the potential benefits of being involved in such a task and the transformational outcomes they experience:

> In fact, parents seemed to be describing their experiences as a journey - a journey from the devastation which accompanied the initial diagnosis to a place where they were beginning to discover, and often to their surprise, not only that they were able to manage life effectively, but they were also being enriched along the way. (Scorgie, 1996, p. 7)

In a recent study, Scorgie and Sobsey (2000) identify a range of transformational outcomes associated with parenting disabled children. According to them, parents of disabled children experience "personal transformations" in terms of acquired roles or acquired traits; "relational transformations" regarding family, advocacy, new friendship networks and attitudes towards people in general; and "perspective transformations" which refer to changes in attitudes towards life and acquiring a different view of living with a disabled child. They underline that although challenging events or circumstances tend to produce negative results initially, “positive outcomes are usually slower to be realized, enduring and of a higher order” (for instance, a change in values or the ability to form satisfying relationships).

Several writers have also suggested that, in order to understand how parents regain their strength and resilience against a background of social barriers and restricted circumstances, one has to appreciate the transformative experiences that they undergo over time and consider these experiences as a crucial part of the development of disability-parenthood (Greenspan, 1998; Landsman, 1998, 1999). The writings of parents of disabled children themselves certainly support this line of approach (e.g. Bérubé, 1996; Curry, 1995). Parents frequently describe living with a disabled child as a “journey” to emphasize their on-going process of learning from and sharing with their disabled child. According to their stories, the goals of parenting a disabled child is not simply to adjust their child and themselves to the existing social arrangement; nor is it to follow certain principles of ‘normalization’ that society imposes (Hillyer, 1993). In the process of continually encountering circumstances that they regard as unfair to their children and of struggling to secure their children's welfare, many parents come to develop moral-political judgments about the social treatment of their children and forge their identity as “allies” of their children to enhance the children's position in society (Murray & Penman, 1996; Read, 2000). The following parent's narrative captures the essence of such parental transformative experiences:

> We are learning that the journey begins in our homes - in our own lives. We are learning to challenge the set of beliefs we grew up with. We are learning about being allies to our children. We write from a human rights perspective. We do not accept the medical or charitable models of disability which present our children as defective. They are models which we, as parents, are expected to accept and collude with against our children. To collude in this way would mean seeing our children in the negative way society at present sees them. This would fundamentally damage our families[…] Our children are the ones who reach us about the issue. They give us the opportunities to learn and understand. They

> give us determination and confidence[…] Our children are teaching us how to be their allies (Murray & Penman, 1996, p. ix).

Read (2000) emphasizes that parents should not be seen simply as a passive conduit for handing down socially acceptable values. She argues that it is helpful to see parents as 'active subjects' who are involved in interpretive processes. On the basis of her own research on mothers' experiences of rearing disabled children, Read (2000) argues that, as they get to know their children, parents learn to see their difference in novel ways, which generally changes their prior perceptions of disability, and reconstructs their identity beyond the prevailing notions of 'normal' parenthood. She also suggests that parents develop the critical understanding of their own and their children's problems as part of their everyday experiences of inequality and injustice. Through these processes, many parents gradually change their views of the world of disability:

> In their own particular ways, in their own words and as their own pace, very many start to make a distinction between their child's impairment and the negative things that all too often go along with it in our contemporary society. Women become convinced through their own experience that many of the most restrictive features of their own and their children's lives are not an inevitable or necessary consequence of impairments (Read, 2000, p. 117)

Ⅳ. Conclusion

Research on families with a disabled child, as knowledge production, is one of the social forces in shaping how we perceive disability problems and how the lives of disabled children and their families are understood. The purpose of this paper was to conduct a critical systematic review of the literature on disabled children and their families, particularly focusing on the parental experiences of disablement and practices associated with disabled children. In doing this, It first and foremost aimed to constitute a direct challenge to the conventional or orthodox view that the disabled children make the family disabled. Drawing in varying degrees on critical and emancipatory insights developed within disability studies, this paper tried to reinterpreted what had been identified previously as 'pathological' or 'deficient' features by addressing environmental contingencies.

Throughout this paper, the social model of disability has been used as an 'heuristic device' to understand the parental experiences of disablement and their practices associated with disabled children. It is suggested that research on parents with disabled children needs: (a) to give more weight to the parents' own accounts of their lives beyond a pathological assumption; (b) to pay attention to the disabling conditions in which the children are reared; (c) to acknowledge the parents' experiences with regard to the social contexts in which they are embedded; and (d) to reinterpret parental practices regarding their disabled children as social-political matters, not simply personal/familial ones.

Reference

Abberley, P. (1987). The Concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society, 2*(1), 5-19.

Atkinson, N., & Grawforth, M. (1995). *All in the family: Siblings and disability.* London: National Children's Home / Action for Children.

Baldwin, S. (1985). *The costs of caring: Families with disabled children.* London: Routledge & K. Paul.

Baldwin, S., & Carlisle, J. (1994). Living with disability - the experience of parents and children. In G. Allan (Ed.), *The sociology of the family.* Oxford: Blackwell Publishing.

Ball, M. (1998). *Disabled children: Directions for their future care.* London: Department of Health

Barnes, C. (1992). *Disabling imagery and the media: An exploration of media representations of disabled people.* Belper: British Council of Organizations of Disabled people.

Barnes, C. (1997). A legacy of oppression: A history of disability in western culture. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future.* Leeds: The Disability Press.

Barnes, C., & Mercer, G. (1996). *Exploring the divide: Illness and disability.* Leeds: Disability Press.

Barnes, C., & Mercer, G. (2003). *Disability.* Cambridge: Polity Press.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction.* Oxford: Polity.

Begum, N. (1992). Disabled women and the feminist agenda. *Feminist Review, 40,* 70-84.

Beresford, B. (1994). *Positively parents: Caring for a severely disabled child.* London: HMSO.

Beresford, B. (1995). *Expert opinions: A national survey of parents caring for a severely disabled child.* Bristol: Policy Press.

Beresford, B., Sloper, P., Baldwin, S., & Newman, T. (1996). *What works in services for families with a disabled children.* Essex: Barnardo's.

Bérubé, M. (1996) *Life as we know it: A father, a family, and an exceptional child.* New York: Pantheon Books.

Biklen, D. (1987). Framed: Print journalism's treatment of disability issues. In A. A. Gartner & T. Joe (Eds.), *Images of the disabled, Disabling images.* New York: Prager.

Bower, A. M., & Hayes, A. (1998). Mothering in families with and without a child with disability. *International Journal of Disability, Development and Education, 45*(3), 313-322.

Bury, M. (1996). Defining and researching disability: Challenges and responses. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability.* Leeds: The Disability Press.

Case, S. (2000). Refocusing on the parents: What are the social issues of concern for parents of disabled children. *Disability and Society, 15*(2), 271-292.

Curry, R. (1995). The exceptional family: Walking the edge of tragedy and transformation. In S. K. Toombs, D. Barnard & R. A. Carson (Eds.), *Chronic illness: From experience to policy.* Bloomington: Indiana University Press.

Daly, M., & Leonard, M. (2002). *Against all odds: Family life on a low income in Ireland.* Dublin: IPA.

Darling, R. B. (1979). *Families against society: A study of reactions to children with birth defects.* Beverly Hills: Sage Publications.

Darling, R. B. (1988). Parental entrepreneurship: A consumerist response to professional dominance. *Journal of Special Issues, 44*(1), 141-158.

Darling, R. B., & Darling, J. (1982). *Children who are different: Meeting the challenges of birth defects in society.* St. Louis: C. V. Mosby.

Davis, L. (1995). *Enforcing Normalcy: Disability, deafness and the body.* London: Verso.

Dowling, M., & Dolan, L. (2001). Families with children with disabilities – inequalities and the social model. *Disability and Society, 16*(1), 21–35.

DPF. (2002) *Annual monitoring report of media.* Seoul: Disabled People First.

Fawcett, B. (2000). *Feminist perspectives on disability.* New York: Pearson Education.

Featherstone, H. (1980). *A difference in the family: Life with a disabled child.* New York: Basic Books.

Ferguson, P. M. (2001). Mapping the Family. In G. L. Albrecht (Ed.), *Handbook of disability studies.* Thousand Oaks: Sage.

Ferguson, P. M., & Asch, A. (1989). Lessons form life: Person and parental perspectives on school, child, and disability, In D. Biklen (Ed.), *Schooling and disability: Eighty–eighth yearbook of the National Society for the study of education.* Chicago: The University of Chicago Press.

Ferguson, P. M., Gartner, A., & Lipsky, D. K. (2000). The experience of disability in families: A synthesis of research and parent narratives. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights.* Washington, DC: George University Press.

Foucault, M. (1980). *Power/Knowledge.* Brighton: Harvest Press.

Fraser, N., & Gordon, L. (1997). A genealogy of dependency: Tracing a keyword of the US welfare state. In N. Fraser (Ed.), *Justice interrupts: Critical reflections on "Postsocialist" Condition.* New York: Routledge.

Glendinning, C. (1983). *Unshared care: Parents and their disabled children.* London: Routledge & Kegan Paul.

Goodey, C. (1991). *Living in the real world: Families speak about Down's Syndrome.* London: The Twenty–one Press.

Gray, D. E. (1997). High functioning autistic children and the construction of normal family life. *Social Science and Medicine, 44*(8), 1097–1106.

Green, S. E. (2003). What do you mean "what's wrong with her?": Stigma and the lives of families of children with disabilities. *Social Science and Medicine, 57*(8), 1361–1374.

Greenspan, M. (1998). Exceptional mothering in a "Normal" world. In C. Coll, J. L. Surrey & K. Weingarten (Eds.), *Mothering against the odds: Diverse voices of contemporary mothers.* New York: The Guilford Press.

Gregory, R. J. (1991). Challenging motherhood: Mothers and their deaf children. In A. Phoenix, A. Wollett, & E. Lloyd (Eds.), *Motherhood: Meanings, practices and ideologies.* London: Sage.

Hevey, D. (1993). *The creatures time forgot: Photography and disability imagery.* London: Routledge.

Hillyer, B. (1993). *Feminism and disability.* London: University of Oklahoma Press.

Hughes, B. (2000). Medicine and the aesthetic invalidation of disabled people. *Disability* *and Society, 15*(4), 555-568.

Jenkins, R., & Angrosino, M. V. (1998). *Questions of competence: Culture, classification and intellectual disability.* Cambridge: Cambridge University Press.

Kittay, E. F. (1999). *Love's labor: Essays on women, equality, and dependency.* New York: Routledge.

Landsman, G. H. (1998). Reconstructing motherhood in the age of "perfect" babies: Mothers of infants and toddlers with disabilities. *Signs: Journal Women in Culture and Society, 24*(1), 69-99.

Landsman, G. H. (1999). Does god give special kids to special parents?: Personhood and the child with disabilities as gift and as giver. In L. L. Layne (Ed.), *Transformative motherhood: On giving and getting in a consumer culture.* New York: New York university press.

Lawton, D. (1998). *Complex numbers: Families with more than one disabled child.* University of York: Social Policy Research Unit.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York: New York University Press.

Lloyd, M. (1992). Does she boil eggs? Towards a feminist model of disability. *Disability, Handicap and Society, 7*(3), 207-221.

McKeever, P., & Miller, K. L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science and Medicine, 59,* 1177-1191.

Middleton, L. (1996). *Making a difference: Social work with disabled children.* Birmingham: Venture Press.

Middleton, L. (1999). *Disabled children: Challenging social exclusion.* Oxford: Blackwell Science.

Morris, J. (1991). *Pride against prejudice: Transforming attitudes to disability.* London: Women's Press.

Morris, J. (1993). *Independent lives? Community care and disabled people.* Basingstoke: Macmillan.

Murray, P. (2000). Disabled children, parents and professionals: Partnership on whose terms. *Disability and Society, 15*(4), 683-698.

Murray, P., & Penman, J. (Eds.) (2000). *Let our children be: A collection of stories*. Sheffield: Parents with Attitude.

Oldman, C., & Beresford, *B. (1998).* Homes unfit for children: Housing, disabled children and their families. The Policy Press/Community Care.

Oliver, M. (1989) Disability and dependency: A creation of industrialised societies. In L. Barton (ed.) *Disability and dependency.* London: Falmer Press.

Oliver, M. (1990). *The politics of disablement: A sociological approach.* New York: St. Martin's Press.

Oliver, M., & Barnes, C. (1998) *Disabled people and social policy: From exclusion to inclusion.* London: Longman.

Oliver, M., & Sapey, B. (2006). *Social work with disabled people* (3rd ed.). New York: Palgrave Macmillan.

Parsons, T. (1951). *The social system.* New York: Free Press.

Philip, M., & Duckworth, D. (1982). *Children with disabilities and their families: A review of research.* Berkshire: NFER-Nelson Publishing Company Ltd.

Priestley, M. (1999). *Disability politics and community care.* London: Jessica Kingsley Publishers.

Priestley, M. (2003). *Disability: A life course approach.* Cambridge: Polity.

Read, J. (2000). *Disability, the family, and society: Listening to mothers.* Buckingham: Open University Press.

Read, J., & Clements, L. J. (2001). *Disabled children and the law: Research and good practice.* London: Jessica Kingsley.

Reinders, H. S. (2000). *The future of the disabled in liberal society: An ethical analysis.* Notre Dame, IN: University of Notre Dame Press.

Scorgie, K. (1996). *From devastation to transformation: Managing life when a child is disabled.* Unpublished PhD Thesis. University of Alberta.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation, 38*(3), 195-206.

Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children: A systems approach to childhood disability* (2nd ed.). New York: Guilford Press.

Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality and politics.* London: Routledge.

Shakespeare, T. (1994). Cultural representation of disabled people: Dustbins for disavowal. *Disability and Society,* 9(3), 283-301.

Shakespeare, T. (2002). *Help.* Birmingham: Venture Press.

Shakespeare, T., & Watson, N. (1998). Theoretical perspectives on research with disabled children. In C. Robinson & K. Stalker (Eds.), *Growing up with disability.* London: Jessica Kingsley Publishers.

Shilling, C. (1993). *The body and social theory.* London: Sage.

Sloper, O., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's Syndrome. *Journal of Child Psychology and Psychiatry, 32*(4): 655-676.

Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development, 18,* 259-282.

Swain, J., Finkelstein, V., French, S., & Oliver, M. (1993). *Disabling barriers - Enabling environments.* London: Sage.

Thomas, C. (1999). *Female forms: Experiencing and understanding disability.* Buckingham: Open University Press.

Thomas, D. (1982). *The experience of handicap.* London: Methuen.

Thomson, R. G. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature.* New York: Columbia University Press.

Todd, S., & Jones, S. (2003). Mum's the world!: Maternal accounts of dealing with the professional world. *Journal of Applied Research in Intellectual Disabilities, 16,* 224-229.

Tozer, R. (1999). *At the double: Supporting families with two or more severely disabled children.* London: National Children's Bureau / Joseph Rowntree Foundation.

Traustadottir, R. (1991). Mothers who care: Gender, disability and family life. *Journal of Family Issues, 12*(2), 211-228.

Traustadottir, R. (2000). Disability reform and women's caring work. In M. H. Meyer (Ed.), *Care work: Gender, labor and the welfare state.* New york: Routledge.

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care.* New York: Routledge.

Turner, B. S. (1992). *Regulating bodies: Essays in medical sociology.* London: Routledge.

Twigg, J., & Atkin, K. (1994). *Carers perceived: Policy and practice in informal care.* Buckingham: Open University Press.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability.* New York: Routledge.

Wickham-Searl, P. (1992a). Careers in caring: Mothers of children with disabilities. D*isability, Handicap and Society, 7*(1), 5-17.

Wickham-Searl, P. (1992b). Mothers with a mission. In P. M. Ferguson, D. L. Ferguson & S. J. Taylor (Eds.). *Interpreting disability: A Qualitative reader.* New York: Teachers College Press.

Yi, I. Y. (2001). Media: Making distorted imagery of disabled people. In *2001 annual report of news media.* Seoul: DPF(Disabled People First).

Young, I. M. (1990). *Justice and the politics of difference.* Princeton, NJ: Princeton University Press.

Young, I. M. (1995). Mothers, citizenship and independence: A critique of pure family values. *Ethics, 105*(3), 535-556.

장애아동의 부모경험과 실천에 관한 탐색적 연구: 장애학적 관점에서

최복천
영남대학교 겸임교수/
경남장애인가족지원센터 정책연구실장

<국문초록>

본 연구는 ‘장애학’적 관점에서 장애아동 및 가족을 대상으로 수행되어 온 연구들에 대한, 특히 장애아부모의 장애경험과 부모역할수행에 대한 비판적 문헌고찰을 수행하였다. 장애아부모에 대한 지배적인 경향은 의료/기능적 모델로 지칭될 수 있는 장애문제에 대한 전통적인 이해방식을 직간접적으로 반영해 왔다고 할 수 있다. 무엇보다도 장애를 가지고 있다는 그 자체가 일반적인 생애사적 과업을 수행할 수 없게 된다는 가정 하에서 행해져 왔던 대부분의 연구들은 장애아동이 가족에게 미치는 부정적인 측면들에 집중해 왔으며, 암묵적으로 장애아가족을 소위 ‘정상적’인 가족으로부터 일탈된 문제가족으로 간주하는 경향을 보여 왔다. 본 연구는 사회적 모델 혹은 사회정치적 관점으로 집약될 수 있는 ‘비판적·해방주의적(critical and emancipatory) 관점’에서 장애아가족이 경험하는 다양한 어려움과 문제점이 장애아동에 의해서 결정되는 것이 아니라 그들을 둘러싼 사회·환경적 요인에 의해 생성된다는 점을 강조하고자 하였다. 또한 본 연구는 장애아부모가 겪게 되는 이차적 장애경험의 특성을 살펴보는 한편 이들이 장애아동 양육과정에서 발전시켜나가는 다양한 형태의 부모역할 및 부모성(parenthood)의 특성을 고찰하고자 하였다.

주제어 : 장애학, 장애아동, 장애아부모, 부모역할 및 부모성

논문 접수: 2010. 05. 05 **심사 시작:** 2010. 05. 10 **게재 확정:** 2010. 06. 16