

## **Literature Review on the Needs of Families and Carers of People with Learning Disabilities**

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### **Abstract**

*Basic condition of a National System of health is the production of high quality of health services. The purpose of this study is to review theoretical aspects and empirical data about the satisfaction and needs of families and carers of people with learning disabilities, which are qualitative indicators of provided mental health services. Research has shown that pressure of parenting a child with learning disability can be multifaceted including different practical, financial and social difficulties that constitute of a significant emotional burden. Thus, families and carers of people with learning disabilities consist of a different population with significant needs that should be addressed. The present literature review presents the specific needs of families and carers of people with learning disabilities and it points out limitations and anomalies in the service provision for this population. These limitation and omissions clearly lead to a low level of satisfaction with the services.*

**Key words:** Learning disabilities, Family and carers, needs, Greek mental health system.

### **1. Introduction**

Families and carers of people with learning disabilities face significant difficulties not only in the family life but also they face an uncertain future that affects their personal, emotional and social life (Redmond & Richardson, 2003). The impact of caring for a person with learning disabilities, especially a person with profound and complex learning disabilities has proved to be multifaceted, encompassing different aspects of the lives of those primarily involved in such care (Baldwin, 1985).

### **2. Learning disabilities**

#### **2.1. History of learning disability**

Until the 1970s interest in the domain of learning disability was not a common issue, while disabled children and their families consisted of a largely invisible group population with respect to policy and research (Social Policy Research Unit, 2007). Until that period the problems, difficulties and challenges faced by the disabled children as well as the persons related to them were considered only as private challenges rather than issues of public and collective responsibility (Richardson, 2005 cited in Grant, Goward, Richardson & Rachmaran, 2005). After the 1970s, changes in the domain of learning disability begun to appear, demonstrating an increased awareness and interest for the neglected minority of people with learning disabilities (Read, 2000). Until that period, the eugenics movement reinforced the discrimination between people who deviated from the ideal "normal". The concept of difference and stigmatization controlled the services that provided accommodation, care and education of people (McPhail & Freeman, 2005). Significant but not necessarily efficient achievements have been developed resulting in policy and practice responses that supported inclusion and increased awareness (Department of Health, 2001). During the past two decades an unprecedented development in the organization and delivery of health, education and social care services has been designed but still the needs of people with learning disabilities are not significantly addressed (Read, 2000).

Despite the changes, important challenges for service development and delivery have been posed and remained unanswered. As a possible explanation it has been suggested that damaging and stereotypical perceptions regarding the nature of learning disability and the needs of learning disabled persons and their families led to unsatisfactory and limited service provision (Baldwin & Gendinning, 1981). Recent research has documented that people with learning disabilities experience poorer health compared to the general population (Krahn, Hammond & Turner, 2006). Krahn and Drum (2007) reviewed literature from the last decade regarding the health care and health promotion for people with learning disabilities and their families and highlighted the emerging need for improvements in surveillance and measurement of quality of health services, as well as increased participation of persons with learning disabilities and their families in the service planning. The present study can be considered as an attempt to fill the gap in the research and support the active participation of families of people with learning disabilities in the service design.

## **2.2 Families and carers of people with learning disabilities**

During the attempts and social efforts that led to changes regarding social inclusion of learning disabled people and service development, the interest was generally focused on the person presenting learning disabilities (Redmond & Richardson, 2003). Relatively, the acknowledgement of the families' needs remained limited and was not satisfied in the policy strategies and professional literature (Burke, 2008). While child development research demonstrated the influence of interactions and relationships between the parents and child to the child's cognitive and emotional development, this influence has frequently been overlooked by the professionals and the service providers (Dale, 1996). Additionally, apart from the lack of social and emotional support towards the parents of children with learning disabilities, powerful and stereotypically frozen ideologies have been developed by professionals regarding families and persons related to children with learning disabilities contributing to a limited awareness of parents' needs (Dale, 1996). Read (2000) presents some historical evidence demonstrating a judgmental tendency towards family members of disabled children and implying that learning disability was a result of family dysfunction. This evidence clearly demonstrated a negative and pathologizing attitude and perception towards the family members and carers of disabled children, a tendency that strongly influenced the service provision and the satisfaction of their personal needs. This judgmental tendency led to misconceptions and well established concepts of guilt and victim blaming being attributed to family members of learning disabled children (Roll- Petterson, 2001).

These misconceptions consisted of stereotypes clearly influencing the attitude, and the behaviour towards families with children with learning disabilities within the professional discourses (Grant 2005 cited in Grant, Goward, Richardson & Rachmaran, 2005). These professional perceptions of parents and carers viewed as dysfunctional or deviant have been under changes in conjunction with the whole attitude towards learning disability. During the last two decades these perceptions of deviance and the attitude towards the parents and carers of disabled children have been seriously questioned and challenged (Roll-Petterson, 2001). This change and challenge can be viewed in the direction of research as well as the nature of support and service delivery (Rolph *et al.*, 2005). Recent national policies and strategies support the involvement of parents and carers of people with learning disabilities in their care, development and education (Russell, 2008). *"Families are the bedrock of society and the place for nurturing happy, capable and resilient children. In our consultation, parents made it clear that they would like better and more flexible information and support that reflects the lives they lead. Our Expert Groups emphasised how important it is that parents are involved with all policy affecting children and that we need particularly to improve how Government and services involve all family members, including fathers. To achieve this, we must put parents' views at the heart of Government and find new ways of engaging parents as active citizens"* (Department for Children, Schools and Families 2007)

More recent work highlighted the importance of engaging with families of people with learning disabilities in ways that promote their 'normality' and explore family voices in order to lead to policy and service improvements (Redmond 2003; Shearn & Todd, 2000). Thus, the value of recording and exploring such family voices was well documented in different research studies demonstrating the significant needs of carers of people with learning disabilities (Weiss, 2002). Recent studies as the present study, aim to identify the needs of families and carers of people with learning disabilities and focus on them as change agents in the service development and planning.

## **2.3. Needs of families and carers of people with learning disabilities**

### **2.3.1. Practical needs**

The practical tasks of caring for a person with learning disabilities especially with profound disabilities include all aspects of daily living as well as commitments such as washing, dressing, feeding and lifting in parallel with general housework (Twigg & Atkin, 1994).

Heron (1998) describes these practical tasks as limitations that affect the quality of every day life and cause a significant emotional impact. Research focusing on the experiences of carers of people with learning disabilities and especially people with profound/severe learning disabilities, describe the stresses and strains of every day life using terms such as ‘daily grind’ (Stalker, 2003)

### **2.3.2. Housing needs**

Unsuitable housing affects families with children with a wide range of impairments including children with learning disabilities (JFR Findings, 1998). In the same study the vast majority of families described their housing conditions as unsuitable, making the task of caring harder and causing more anxiety. With respect to the amount of space and safety parents and carers underlined that these unsatisfying parameters consist of significant barriers to normality and have a negative impact to independence and the task of caring (Grant, 2005 cited in Grant, Goward, Richardson & Rachmaran 2005). Further research is needed in order to explore the perceptions of parents and carers of people with learning disabilities regarding their difficulties and support them to voice these perceptions by using them as change agents.

### **2.3.3. Financial needs**

Carers of people with learning disabilities highlight the significant difficulties they have to confront during their caring role (Social Policy Research Unit, 2007). The additional financial costs of bringing up and caring for a person with severe disability have been estimated as twice as much compared to the carers of non-disabled children (JFR Findings, 2001). The additional costs cannot be confined only to the early years of parenting since over the life course, parents and carers of people with learning disabilities would encounter a number of unexpected situations and financial challenges that will require new coping strategies to be found (Todd & Shearn, 1996a). An additional burden for carers of people with learning disabilities is the fact that their employment levels are greatly reduced (Shearn & Todd, 1997). In a different study, Shearn and Todd (2000) presented the perspectives of mothers of children with learning disabilities with respect to their employment. The mothers who participated in the study encountered unusual time demands and felt that their employment opportunities were restricted by social attitudes towards parents of children with disabilities. Different studies have tested the psychological cost of the employment of parents – carers of people with learning disabilities (Todd & Shearn, 1996b; Stephens, Franks & Atienza, 1997).

Thus, while employment may have a positive impact on carers, evidence demonstrate, that without effective support, the psychological pressure of the dual role parent- employer can be heavy (Shearn & Todd, 2000). Concerns regarding the nature and the combination between these different roles of parents- carers have been expressed in different studies and underline a significant challenge for the delivery of more effective forms of service support to carers (Todd & Shearn, 1996a; Felce *et al.*, 1998 ). Shearn and Todd (2000) in their study demonstrated that the lack of employment opportunities can lead to feelings of isolation and low self-esteem. Additionally, employment difficulties can cause significant social restriction that aggravates the pressures of caring.

### **2.3.4. Emotional needs**

Parents and carers of people with learning disabilities face different challenges that have a significant impact on their emotional well- being (Sloper, Greco, Beecham & Webb, 2006). Research has shown that pressure of parenting a child with learning disability can be multifaceted including different practical, financial and social difficulties that constitute of a significant emotional burden (Baldwin, 1985). It is well documented that even the practical tasks of parenting a child with learning disability can cause increased levels of stress and anxiety (Beresford, 1995). Parents and especially mothers facing all these daily routines of care can be socially isolated and restricted by social attitudes concerning appropriate roles for women, especially mothers of children with profound learning disabilities (Shearn & Todd, 2000). The lack of opportunities to engage in employment can lead to feelings of depression and increased levels of stress (Social Policy Research Unit, 2007). Mothers face significant lack of personal contact, mentioning they have no one ‘to talk to’ and a gap in their social networks (Redmond & Richardson, 2003).

The multifaceted psychological needs of fathers of children with learning disabilities were described in different studies (Carpenter & Towers, 2008). Their parental role tended to be easily ignored, as fathers were reported by researchers as the “peripheral parent” (Herbert & Carpenter, 1994). However, the Green Paper, Every Child Matters clearly demonstrates the vital role of fathers in the parenting of children with learning disabilities (Department for Education and Skills, 2003). Fathers described the frustration and difficulty to receive the news of their child’s diagnosis and the emotional impact of being a support to their families (Graungaard & Skov, 2006). Parents can react and respond differently to the diagnosis of the learning disability.

Parents are experiencing great emotional stress during the diagnostic process and significant dissatisfaction with disclosure (Fidalgo & Pimental, 2004). Emotional reactions to the learning disability can vary demonstrating the life-transforming impact of learning disability (Carpenter & Towers, 2008). This variation can include a challenge to confront the situation or significant stress and disorientation regarding personal goals (Bray, Skelton, Ballard & Clarkson, 1995). Different studies have underlined the lack of social networks and support that parents receive and the importance of the relationship between the two parents (Carpenter & Towers, 2008). The emerging need to address and explore these emotional needs of parents and carers of people with learning disabilities consists of an important aim for the successful delivery of national policy across public mental health services.

### **3. Satisfaction and services**

#### **3.1. Contact with services**

With respect to services, the parents and carers of people with learning disabilities expressed their needs for a sense of partnership with services and confidence in services used by their child (Policy Research Unit, 2007). Different studies have demonstrated that parents wanted to have their expertise on their child recognised, to feel valued and respected by services, and to be involved in decision making (Herbert & Carpenter, 1994; Lloyd, 2000). Significant features of a quality service included services able to meet the needs of people with learning disabilities, to be a positive experience and to offer respect and reliability (Graungaard & Skov, 2006). Morris (1999) refers to the evaluation of care suggesting that although professionals use pathologizing terms such as complex health and support needs for families and carers of people with learning disabilities, actually it is not the needs that are complex, but the effort, lengths and barriers they have to go in order to obtain the appropriate help. Studies focused on parents needs clearly demonstrate that the social and genuine inclusion of these families still remains a myth and professionals often fail to provide a sensitive individualized personal care (Rooney, 2002).

In contrast to the historical evidence which stereotypically described parents as deviant and peripheral, recent findings underline the active role of parents, their need to be co-operating partners with professionals, the importance of being acknowledged as the experts for their child as well as their expressed disappointment for their exclusion from the assessment and from the service planning (Scourfield, 2005). Studies measuring the contact between the families and carers of people with learning disabilities present evidence of low level of support provided and the lack of co-ordination between services and families (Social Policy Research Unit, 2007). This lack of co-ordination with the families and carers can be viewed as a continuum of the pathological model, considering the parents and carers as dysfunctional and inappropriate to participate to the decision-making of the person with learning disabilities (Krahn & Drum, 2007). The use of the pathological model in the service provision regarding families with children with learning disabilities can be viewed in the domain of resilience. Indeed, professionals often fail to consider the factors related to resilience and focus only to the pathological factors (Bayat, 2007).

The significant omissions of service provision and service delivery for people with learning disabilities are being demonstrated in different studies voicing the families' and carers perceptions regarding the characteristics of services and service providers (Roll-Pettersson, 2003; Thompson, 1998). The parents' assessment regarding the quality of care and services, has been intensively studied and the results demonstrate a lack of comprehensive and useful information available to parents from the services, leading to conflicting situations and causing further emotional pressure (Read, 2000). Additionally, studies focused on the level of parental satisfaction regarding the quality of service provision demonstrate a low level of satisfaction and the inability of services to meet the parents' emotional and support needs (Tunali & Power, 1993). More than 50% of the mothers are dissatisfied by the communication process between doctors and parents during the disclosure of the diagnosis (Pearson, Simms, Ainsworth & Hill, 1999). Lack of personal contact with the service personnel had a significant impact in the social isolation and discrimination of these families (Shearn & Todd, 2000). Additionally, feelings of anxiety and worry were described when the services were not able to meet the child's particular needs or were inadequate and inappropriate (Graungaard & Skov, 2006). Professional counseling support combined with positive and supportive relationships with professionals were viewed as vital by the parents but this aim is not still achieved by the services (Shearn & Todd, 2000). Thus, while parents face a long period of despair, uncertainty, and hope often feel very frustrated and their emotional needs remain unmet by the professionals (Bromley, Hare, Davison & Emerson, 2004).

#### **3.2. Research on satisfaction with services**

An increasing interest regarding the improvement of quality of care provided is observed in the U.S.A and Europe.

This interest remains in accordance with the improvement of quality assurance provided by the health services (Donabedian, 1989). Despite the significant research work focused on the satisfaction of patients with service provision, a clear and widely accepted definition of satisfaction does not exist. Satisfaction with services was described as an attitude or a perception or a view in different studies. Curry and colleagues (1997) described patients' satisfaction as a variable that affects the results of the offered services and can contribute to identification of limitations and to the amelioration of service provision and delivery. It can also be described as the amount of personal perceptions regarding service provision before, during or after the offered services (Tselepi, 2000). According to Donabedian (1980) patient's satisfaction can be viewed as the perception regarding the quality of care provided and reflects the patient's values and expectations. Weiss (cited by Theodorou, 1993) referred to two different groups of factors that affect the level of satisfaction:

a) *The material, technical infrastructure and the administrative services*

This group includes factors such as: hygiene services, safety, sufficiency of staff, the procedures followed during the contact with the services, the duration of treatment, the management of financial issues and other practical difficulties that can arise.

b) *The relationship between the patient and the professionals*

This relationship is strongly associated with the communication and the trust. The relationship between the patient and the professionals consists of a significant parameter regarding the quality of offered services and a variable that strongly affects the level of satisfaction with the services. More analytically, this relationship has been and remains a keystone of care and the medium through which health information is gathered, diagnoses and treatment plans are being designed, compliance is accomplished and patient activation and support are supported (Goold & Mack, 1999). A relationship between the patient and professional based on communication and trust can control the negative feelings of fear and anxiety that develop when a patient contacts a health service.

International studies have been conducted in order to provide information regarding the limitations of quality of care, activate the different systems for better service planning and reinforce the active participation of professional as well as patients in the service development (Priporas, Laspa & Kamenidou, 2008; Crawford *et al.*, 2002). The level of satisfaction of patients has been described as a significant indicator regarding the quality of care and can be considered as a parameter that affects the effectiveness of care and the development of service provision (Wolf, Putnam, James & Stiles, 1978).

In the domain of learning disability, research findings point to limitations and anomalies in the way support to parents and carers of people with learning disabilities is provided by services and a low level of satisfaction is being referred (Rooney, 2002). Traditionally, the control and decision making regarding the provision of care has been the domain of professionals neglecting the expertise of parents and carers (Selingman & Darling, 1997). More recent work highlighted the importance of active participation of family members and carers in the planning and the delivery of services on formal and informal levels as well as the exploration of family voices for policy and service improvements (Redmond, 2003; Scourfield, 2005). Thus, the value of recording and exploring such family voices was well documented in different research studies demonstrating the significant needs of carers of people with learning disabilities (Weiss, 2002).

### **3.3. Satisfaction with mental health services**

The quality of mental health care remains the keystone of mental health care. The quality of mental health care signifies the identification and management of the personal difficulties as well as the inclusion and support of families of people with mental health difficulties and the reinforcement of familial cohesion (WHO, 2001). The service providers are obliged to offer services that not only treat and ameliorate the mental health problems but consist of protective and maintaining the mental health factors (WHO, 2001). The use of policy strategies that are based on the needs and perceptions of this population can consist of a significant parameter for the success of these policies.

Quality of mental health services refers to:

- a) respect of the individuality and the personal needs and difficulties of people with mental health difficulties
- b) offer of the most suitable and evidence – based clinical or non- clinical plan and treatment in order to reduce the effects caused by the mental health difficulties in the quality of life of people with mental health problems
- c) use of strategies that reinforce independence and social inclusion
- d) ensure that the quality of mental health care is generalized to the different domains of health care including early intervention, treatment and community- based programs ( Department of Health, 2001).

### 3.4. Satisfaction with mental health services in Greece

The satisfaction with mental health services in Greece is being explored mainly after the “Mental Health Act” which started after 1983 and lasts till nowadays. The “Mental Health Act” led to the amelioration of the quality of mental health services and the development of inclusive policy strategies and the design of community- based programs and services for people with mental health difficulties and their families (Mpilanakis, 2004).

According to the law 2716/1999 entitled as “Development and Renewal of Mental Health Services”, the context of the mental health service provision is supported and community- based programs are being designed for sensitive populations such as children and adolescents. For the first time community – based interventions are being implemented for children with mild learning disabilities and autistic spectrum disorders.

Since 1997 a new program, the “Psychargos” program, founded by the Greek Government and the European Union is implemented in the domain of mental health services design and provision (Department of Health, 1997). During the period 1997- 2001 the first phase of the program was conducted and different services were created. These services involved people with chronic mental health disorders and their inclusion in the community and the employment. Interest was focused on people with moderate learning disabilities and especially children, with special education playing a central role. The second phase of “Psychargos” program included the design of services and strategies for a number of 3.000 persons with mental disorders (Department of Health, 2000). The studies measuring the level of satisfaction of service users demonstrate a positive level of satisfaction but an emerging need for generalization of these strategies to different domains of mental health care such as early intervention. The significant role of the use of families of people with mental health disorders as change agents in the service planning was documented (Simpson & House, 2002). With respect to people with learning disabilities inclusive educational strategies were utilized and the participation of their familial environment in the service provision was supported (Department of Health, 2000).

Interest was focused on people with profound and complex learning disabilities, permitting them to use community- based mental health services for the evaluation of their intellectual ability and the satisfaction of their financial needs (Department of Health, 2000). According to “Psychargos” program, people with learning disabilities can obtain financial benefits given they provide evidence supporting their learning disability. Satisfaction with the Psychological sector of the Psychiatric Department of “Vostaneio” (Lesvos, Greece) General Hospital was measured in a large study conducted in the Psychological sector by one of the clinical psychologists who work in a full time base in the Psychological sector (Spyrou, 2009). This study clearly demonstrated the serious omissions and limitations of this community- based mental health service in a frontier island region, Lesvos island. One of the significant limitations of this study was that did not manage to identify the needs and the perceptions of families of people with learning disabilities regarding the quality of care provided by the Psychological sector.

### 4. Discussion

Given the significant inability of services to satisfy the families’ and carers’ needs as indicated above, significant challenges are raised. Translating the evaluations and perceptions of the family members and carers into practice is one of them. In aiming the particular challenge it is essential that practitioners and service providers build upon the evaluations and views of family members and carers. The present literature review suggests that services should begin to think more broadly and flexibly about what constitutes satisfaction for the service users. It is important, therefore, that they capture family members’ and carers’ perspectives on the quality of new services to provide a sound evidence base about the effectiveness and continuing helpfulness of support (Seddon *et al.*, 2009). Further research studies should focus on the participation of this population in the service planning and on the greater collaboration between the practitioners and service users.

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