Part-II of this study presents a review of recent research in a number of skill areas. This provides an opportunity to the reader of this study to know the current trend of research in the following skill areas. The areas are: Parental participation in the special education, and care of children with intellectual disability, language interventions for children with intellectual disability, reading skills and cognitive abilities of children with intellectual disability, the mathematical learning of children with intellectual disability, and development of social skills in persons with intellectual disability and autism.
Although the active participation of parents in special education in the United States has received attention (e.g., Lynch & Stein, 1982; McKinney & Hocutt, 1982; Turnbull & Turnbull, 1990), there exists a dearth of systematic studies in this area. Largely influenced by the Head Start movement, this practice continues to be depicted as a necessary endeavor and potentially beneficial to children, their parents, and school personnel.

Despite reported benefits associated with parental participation in the special education context, arguments persist regarding the inherent value of this practice. This chapter traces the evolution of parental participation in special education, examines the extant research, and discusses considerations related to this practice.

Parental participation in special education has a rich history and is governed by law. According to Turnbull and Turnbull (1998) shared decision-making in the schools and other public agencies is referred to as participation-democracy. In essence, participation-democracy pertains to, "...the legal right or political opportunity of those affected by a public agency's decisions to participate in making those decisions". As described below, parental participation has evolved gradually and while the laws surrounding this practice have been enacted, their implementation remains nebulous.

Turnbull and Winton (1984) remarked that from the early to mid-1900's, it was common practice to institutionalize children who were diagnosed with severe disabilities. These children were perceived as a potentially destructive element and an extraordinary burden to their families. Subsequently, at birth, infants with severe disabilities were separated from their parents and institutionalized to reduce the feared pernicious impact on the family system.

By 1954, the National Association for Retarded Citizens (NARC) was established, supported public school programs in community settings, and
advocated for parental participation in decision making within education (Turnbull & Winton, 1984). The educational bill of rights set forth by NARC promoted the role of parents of retarded children as active decision makers on issues pertaining to care, treatment, and training. While NARC was promoting legislative change to ensure active parental involvement in the education of children with disabilities, policy and practice for compensatory education for economically disadvantaged children was evolving.

A major component of proposed compensatory education involved parental participation. Two views of parental participation existed and included a cultural deficit perspective and a political perspective. The cultural deficit perspective recognized parents as needing remediation to improve a child's environment. Consequently, the parental role was that of learner, while professionals dictated the structure and content of such learning. The political perspective, on the other hand, perceived economically disadvantaged parents as disempowered and in need of decision-making power (Turnbull & Winton, 1984).

The Head Start program was based upon a melding of these two perspectives. Public Law (PL) 89-794 was the first legislation to reflect a policy of parent involvement and required parents to participate as learners, teachers, and decision makers (Turnbull & Winton, 1984). Legislation in the 1970s reinforced parents as decision makers and empowered them as advocates to ensure appropriate services to children with disabilities.

The evolution of parental participation policies has created significant expectations for parents. For example, parents are currently expected to (a) assume an active role in a child's education by making informed decisions about the evaluation process, the individualized educational program, and placement; (b) acquire teaching skills in order to extend education within the home context; and (c) assume an advocacy role on behalf of their children. As Turnbull and Turnbull (1990) remarked, "Because parents could be effective teachers, many professionals believed that parents should be teachers". It is important to note that this policy has been significantly influenced by political factors and has not been informed by systematic studies. In other words, whether the implementation of such grandiose policy is realistic, possible, or even acceptable to parents and educators is debatable. Hoover-Dempsey and Sandler (1997) identified three constructs that influence parental involvement in the regular
classroom: (a) beliefs about their roles (b) beliefs that they can help their children and (c) perceptions of opportunities and barriers to involvement. These same constructs can also be applied to special education contexts. In short, parents need to know what is expected of them, whether they can make a positive difference in their child's life, and whether their participation will be endorsed by school personnel.

MacMillan and Turnbull (1983) reported that parental involvement policies of PL94-142 were implemented in a myriad of ways. The Individuals with Disabilities Education Act (IDEA), for example, ensured the provision of public education to individuals with disabilities. Under IDEA, some continue to perceive parent involvement as a requirement while fewer people consider it a choice. Salient considerations pertaining to this practice are outlined and reviewed below.

A significant body of literature promotes the widely held assumption that parental involvement is beneficial to children, parents, and the educational system (e.g., McKinney & Hocutt, 1982). Systematic studies substantiating the effectiveness of parental involvement in special education, however, are absent. Furthermore, a bulk of the literature has focused on strategies to increase parental participation (e.g., Goldstein & Turnbull, 1982) and facilitate parent-professional cooperation, rather than examining the effectiveness of such participation.

According to Karnes and Zeherbach (as cited in Bauer & Shea, 1989) school-family efforts serve exceptional children more effectively than school efforts alone. Although these authors reported that an educational program can be enhanced through meaningful parental participation, they failed to provide empirical evidence. Turnbull and Turnbull (1982) underscored the hypothetical basis of parental participation as advantageous to children, parents, and schools. Morgan (1982) also noted that it may be more accurate to state that special educators are merely suggesting that parental participation can be beneficial.

Under IDEA legislation, the role of parents as educators of their children remains vague. However, in contexts where they are expected to serve as educators it is assumed that parents are able to educate their children and that they are interested in pursuing appropriate counseling, consultation, and training
to fulfill this role. What remains questionable is whether children with disabilities benefit from this educational arrangement and the impact of this arrangement on the parent-child relationship. It would be naive to assume that there are no ramifications when parents begin to actively teach their children.

Auerbach (as cited in Bauer & Shea, 1989) contended that by participating in a child's education, parents developed a greater understanding of a child's strengths and needs. It can be argued, however; rather than contributing to a greater understanding of children, parental participation simply affords parents an opportunity to view their children in a different context. In other words, thinking that parents, who lack specialized training and supervision, possess the required skills to observe, identify, and articulate subtle educational needs is a major assumption. Furthermore, assuming that parents can interpret and translate scholastic results into a meaningful educational plan certainly challenges the need for specialized teacher designation or training.

The parental competencies required for direct teaching of the handicapped child at home involve interacting with the child in ways that promote positive behavior, reinforcing desired behavior, establishing an environment that is conducive to learning; setting up and maintaining a routine for direct teaching; using procedures appropriate for teaching concepts and skills; adapting lesson plans to the child's interests and needs; determining whether the child has mastered knowledge and skills; keeping meaningful records, including notes on child progress; participating in a staffing of the child; communicating effectively with others; and assessing the child's stage of development".

Having said this, however; it is conceded that despite a lack of formal training and supervision, there may be parents who are able to identify, articulate, and address the unique educational needs of their children.

Turnbull and Turnbull (1982) contended that expecting parents to become equal participants in the decision making process sets up most, if not all, parents to fail. This arrangement also contributes to educator disillusionment when parents do not satisfy established expectations. In other words, although parents may understand educational objectives, and agree to proposed strategies, they may be unable to actively participate in all aspects involving FAPE (Free and Appropriate Public Education), despite their interest and involvement.
Winton and Turnbull (as cited in Turnbull & Turnbull, 1982) surveyed parents of children with disabilities regarding the parental role in relation to educational decision-making. The findings indicated that parents held special educators in high regard and preferred to defer decision making to these professionals. These data can be interpreted in a number of ways. For example, parents can be perceived either as disinterested and passive adults who prefer to abdicate their responsibilities or well-informed consumers who wisely invite educational experts to make critical decisions in the best interests of their children.

Turnbull and Turnbull (1982) questioned the ability of parents to assume responsibility and collaborate with trained professionals to produce an IEP (Individualized Education Program). In their view, parents may have been ill equipped to understand the complexities of educational programming and the educational needs of children. Although the effort to assign decision-making power to parents is well intended, parents may lack the necessary knowledge and skills to assess and recommend educational planning strategies.

According to research conducted by Turnbull and Turnbull, (1982), typically parents were most comfortable in assuming the role of information giving and receiving. This is in contrast to legislation that recognizes parents in the role of education decision makers. The majority of parents continue to defer to educators for academic decisions. Research findings further suggest that educators expect parents to assume this role. Agreement regarding the parental role may, in turn, form the foundation for a collaborative family-school relationship.

When considering parental involvement, it should be recognized that the severity of a student's disability may directly impact parental time, responsibilities, and energy. According to Bauer and Shea (1989), support from school personnel served to provide respite for parents and helped them from becoming overwhelmed. For this group, extensive involvement in a child's educational program deserved special attention and may not have been feasible. What needs to be recognized are the repercussions associated with elevated parental stress when parental limitations are not acknowledged (e.g., Albrecht, 1995; Rolland, 1994). For example, additional demands placed on parents may contribute to tension within the parent(s)-child relationship. Turnbull and Turnbull
(1990) elaborated, "The impact of the parent-as-teacher role on parent-child relationships has received negligible professional attention. Anecdotal accounts from some parents indicate unintended consequences, such as guilt and anxiety if they are not constantly working with their son or daughter".

Parents may find themselves in a precarious position when defining personal limitations that will affect their level of participation. On one hand, parents may seek direction and support from school personnel. On the other hand, they may fear jeopardizing their relationship with school personnel (and their child's educational services) when exercising their right to disagree or limit their involvement. Such apprehension may emerge when there is a perceived clash between school and parental expectations.

To avoid erroneous generalizations, it is imperative to distinguish parental involvement in the educational process from overall parental involvement. In other words, parental choice to be minimally involved in a child's educational program should not be contiguously equated with parental disinterest in a child's life. MacMillan and Turnbull (1983) suggested that the encouragement of parent involvement be tempered by an appreciation of the possible beneficial or detrimental effects on parents and children respectively. For example, parents may at times choose not to be involved in their child's educational program in order to sustain their parental effectiveness or maintain a balanced commitment to other family members.

Turnbull and Turnbull (as cited in Bauer & Shea, 1989) asserted that a model for parental involvement should include the option of non-involvement. Underlying this view is the belief that parental non-involvement may be a reflection of the stresses imposed by children and parental coping abilities. Furthermore, Bauer and Shea (1989) remarked that parental activities must reflect the degree to which parents are comfortable and capable of being involved. Interestingly, although this option is extended to parents of children without disabilities, there appears to be less willingness to accommodate personal preferences of parents who have children with disabilities. MacMillan and Turnbull (1983) contended that decisions concerning the degree of parental involvement in their child's educational program should be based on individual preferences rather than on generalized expectations. Lynch and Stein (1982) reported that, similar to children with disabilities, the unique needs of parents must be honored.
When considering a model for parental participation, a continuum of involvement based on parental time, commitment, and level of self-disclosure warrants consideration. The continuum would range from minimal time and commitment to extensive participation. Turnbull and Turnbull (1982) further suggested that the needs, abilities, and preferences of parents in regards to the demands of their children and school expectations must be considered.

Despite appearing logical and reasonable, parental participation in special education continues to be a complex and controversial issue. The dearth of systematic studies in this area compounds the problem and, subsequently, professionals are left with personal testimonials and anecdotal descriptions upon which to base their decisions of how to effectively involve parents in special education. The notion that parental involvement benefits all students, parents, and school personnel remains unsubstantiated and denies the uniqueness of individuals and can inadvertently contribute to unnecessary conflict within families and between parents and school personnel. It may be suggests that a balanced view of parental participation is lacking and several considerations related to parental participation deserve attention.

PARENT - PROFESSIONAL RELATIONSHIP

As many of the objectives of welfare provision become increasingly reinforced and underpinned by family carers, the profile of parents of people with intellectual disabilities, as of family carers in general, has become ever more significant and visible to academics, health and social care professionals and policy makers alike (Twigg & Atkin 1994; Heaton 1999). Thus, while early reform-orientated policies referred to families only in passing, more recent policies view the families as both providers and consumers of care. Not only the needs of families but also carer participation have become central concerns in policy making and service development arenas, as both advocate for their own children and for parents of disabled children in general (Knox et al. 2000). The latest development in policy in the UK to reflect these trends was the 'Carers (Recognition and Services) Act 1995' (Department of Health 1995). For the first time, carers became an exclusive focus for policy, reflecting a growing view that carers had needs independent of those they cared for (Department of Health 1996; Nolan et al. 1996). Family carers are seen as both consumers and
participants in the delivery of care, and as a result, have become drawn into and embedded within an extensive, sometimes changing (MacLachlan et al. 1987), professional network of care.

Redmond (2003) has argued that the attachment of a network of service agencies and professionals to parents provides a unique and distinguishing dimension to their lives, perhaps as much as having a child with disabilities does. Without doubt, dealing with the professional network is an integral component of being the parent of a child with intellectual disabilities. Although service intervention might be assumed to ease parental work, it can also generate work of its own (Shearn & Todd 1998). The work of families in dealing with professionals and service agencies has often been understated in a research literature, which assumes that professional and service support is unproblematic. Although the growth and development of a service network around parents (see, for example, Todd et al. 1993; Evans et al. 1994; Perry et al. 1998) are ostensibly positive changes, there are also good reasons why this might also be experienced as problematic. Parents may find such relationship marked by inconsistencies and discontinuities in points of contact (McLachlan et al. 1987), by an acute asymmetry of power (Knox et al. 2000) or even by conflict (Williams & Robinson 2001). There also exists a wide sociological literature, which suggests that such relationships will be problematic in terms of professional dominance, exclusion, service rationing, stereotyping and surveillance (Nettleton 1992; Coyle 1999; Viisainen 2000). Professional encounters always involve more than the application of scientific or value-free expertise, and moral judgments seem to be figured significantly within them (White 2002). As satisfaction with services and the extent to which carers feel supported are seemingly strongly related to the social dimensions of the support provided (Green 2001; White 2002), the intended benefits of any support can be blunted by the range of factors outlined above. There is, therefore, a need to continually examine the quality of these relationships as well as to pay attention to the number and frequency of contact that parents have with professionals (Grant et al. 1994).

While professional support can make a positive contribution to the lives of people with intellectual disabilities and their families, there are risks that seem to go with these. Interestingly, family carer and professional relationships can be a struggle for both sides and not just for carers. Allen (2000), for example, showed
that nurses are uncertain about how to work alongside longstanding and
experienced family carers. She claims that carers' participation in caring within
hospital settings is perceived as threatening the competence and identity of nurses.
Allsop & Mulcahy (1998) found that patients can be perceived as a potential risk for
doctors in as much as their competence and identity can be the subject of much
scrutiny. Their account of how doctors feel if a complaint has been raised against
them is not unlike those that describe how carers might feel about how they are
treated by professionals. Allsop & Mulcahy (1998; p. 819) wrote:

... that doctors, when they receive a complaint, feel afraid, vulnerable, hurt and lonely.

The increasing presence and participation of families and professionals in
the activities of each other can, therefore, be seen as highly problematic for both
parties. Professional-carer encounters can be seen as the ground for the tussle
of 'identity politics' (Giddens 1991). Certainly, the research on professional
perspectives of such encounters suggests that such relationships can be viewed
in terms of the identity threat they provoke. Coyle (1999) has, also argued that
behind much of the dissatisfaction health care consumers experience lays a
concern that their personal identity is at risk. The concept of identity has been
one that seems to have some importance in understanding the lives and
concerns of mothers of disabled children (Todd & Shearn 1996a,b; Felce et al.
1998; Shearn & Todd 2000). The focus, there, has been on the way non-
maternal aspects of self are frequently overlooked as important potential
dimensions of well-being. It has been argued that the identity of mother is super­
ordinate and that other aspect of identity, for example friend or worker, struggle
to find expression, and to detriment of some, over the life-course. The identity of
mother may be, therefore, both highly visible and potentially exposed aspects of
self in such encounters with professionals.

Furthermore, and with good reason, this chapter focuses on the
experiences of mothers of adolescents with intellectual disabilities. The role of
parents in the lives of their disabled children is an enduring one. Grant & Whitnell
(2000) have argued that research on family-professional relationships needs to
be sensitive to life-course concerns. They found, for example, that young carers
were less confident than older parents, although older parents wished they had
been more assertive in the earlier years of their careers. They further argued that
special attention should be paid to transitional points in the lives of families when there are interruptions in service provision. The data reported in this paper deal with the middle years of parenting or the years of parenting an adolescent with an intellectual disability. These years have been seen as critical ones for family members (Riches 1996), and involve considerable disruption and change in service provision (Simpson 2000). During this phase in the family career, there are significant changes taking place in this professional network as well as there is a growing need for support from it. Over time, families may come to rely more on formal services for support and to take on roles or tasks that may have been previously performed by friends and/or other relatives (Grant 1993; Todd & Shearn 1996b). Interestingly, it is significant for mothers themselves as a time of normative transition (Gergen 1990), the mid-life transition, when there may well be considerable changes taking place in their own personal lives.

Families are increasingly becoming drawn into a professional network. Although it was noted that this network was often characterized as seeking to provide and develop positive benefits for families, the data suggest that mothers look upon it as also containing risks for themselves. The general tone of mothers' comments was largely negative in as much as they felt they could be stereotyped, devalued and judged. However, it was argued that their comments could not be taken as generalizable or as representative of mothers' dealings with professionals. Nor should they be seen as being as straight-forward truths. Rather mothers' perceptions of those relationships tell us more about how they wish to be seen and supported and how they feel important aspects of self-identity can be threatened. They inform us more about themselves, and it is from this that there are implications for professionals and service agencies. That is, mothers wished to be seen and taken as 'ordinary mothers' whose motivations are driven by the needs of their children and are not the product of pathological personalities. In that 'motherhood' seems under scrutiny; the concept of identity would seem to provide one means of contributing to developing research and practice in this area. It has already been suggested that 'identity' might provide a basis to understand the support needs of mothers (Todd & Shearn, 1996a). It also seems, as the data suggest here, to provide a basis for understanding something of the quality of carers' experiences of their encounters with health and social care agencies (Coyle, 1999). The professional network around
families seems to neither un-problematically facilitate nor affirm mothers' sense of identity. There is, then, an on-going need, as Grant et al. (1994) have argued, to take into account the perceived quality and the nature of parents' contacts with this network, as well as its size and scope to ensure that the maximum benefits of support are realized, that is, to develop a feeling of being supported. There is also scope for further research in this area that could supplement measures of satisfaction with measures or dimensions of identity, and ones that would recognize gender as a critical issue (Traustadottir 1991). In addition, there is an obvious need, as highlighted in the introduction, to understand how encounters with families are viewed and perceived by professionals.

One of the difficulties mothers face is that they considered that their qualities as mothers are under surveillance and this colours how they approach and conduct themselves. It is felt to be a longstanding and recurrent feature of their dealings with professionals, extending back to the period of disclosure. This is a phase of the parental career that has been considered to have been badly managed in the past (Featherstone 1980; Bicknell 1988; Quine & Rutter 1994), and it is of some interest to continue to examine how this process is being managed and experienced. This is of interest in terms of not only the immediate emotional consequences of disclosure but also positive adaptation. Annandale and Hunt (1998) have argued that initial encounters with professional set the foundations and expectations for subsequent ones, as the data here also suggest. It is also during this phase that mothers begin to sense they are not being treated as 'ordinary' mothers. Across their years of involvement with professionals and services, mothers felt it was a struggle to have the sense of self as 'mothers' affirmed and valued by them. The general essence of their concerns is perhaps best captured in the rhetorical device; "What kind of mother do they think I am?"

The study confirms that mothers are tenacious in their resistance to being labeled or typified as pathological or incompetent mothers. As others have found, mothers are not passive participants within this network (Williams & Robinson 2001). The challenge or resistance to the professional voice seems, at least to mothers, and as far as the lives of their children are concerned, to be taken as a legitimate expression of motherhood. It is a part-and-parcel of what mothers do, as they themselves appeal. However, the data also suggest that
adopting a 'what mothers do best' framework also exerts a constraining influence over them. As Williams & Robinson (2001) have also revealed, mothers tend not to discuss their own needs with professionals. The data here indicate that their reluctance centres around a desire to deflect a potential judgment that they are 'bad mothers'. As White (2002; p. 429) describes, a cultural definition of bad parent is one who may have willfully neglected or deliberately abused their child, have put their own needs first, or have acted in an evasive or deceitful way: Whilst they embraced advocacy, it seems that they also embraced a deeper and wider cultural ambivalence about the role of mothers inside and outside the family. For example, mothers felt they could not discuss their own support needs in relation to their employment needs. There exists a growing body of research that highlights that mothers of disabled children find paid employment difficult (Traustadottir 1991) although it is salient and desired by many, but importantly not all, such mothers. Their aspirations, however, remain very much an example of 'private worries' (Mills 1959) at a price of being 'selfless'. If, as Heaton (1999) suggested, the professional network around mothers can be understood as a 'disciplining gaze', then mothers are also very much self-disciplining.

At one level, their silence can be attributed to the moral risk and assessment that they feel provide the subtext of interactions with the service world, and that these, in turn, centres around the meaning of 'motherhood'. Our culture appears to have a troubled relationship with mothering. Although perceptions of the role of women and mothers in society are beginning to change, cultural contradictions have deepened rather than diminished, as more and more women enter the workforce (Hays 1998). It remains the case that mothers are still largely responsible for ensuring that work commitments and ambitions do not interfere with child-rearing (Garey 1999). Mothers have to integrate their work-related identities with their identities of mothers, by both valuing work whilst at the same time preserving cultural norms about what it means to be a 'good mother' (Maushart 2000). Thus, working mothers can feel that they are failing to live up to their own expectations of what makes a good mother, and this balance probably becomes more difficult to achieve for some mothers, and for mothers of children who might be seen as requiring more 'intensive mothering' (Hays 1998). Given their own subscription to a view of motherhood, the extent to which they feel it is not easily credited to them and the
lack of encouragement to look beyond it, an idealized version of motherhood is upheld. This does not necessarily act in the longer term interests of some mothers of disabled children (Todd & Shearn, 1996b).

Despite appearing logical and reasonable, parental participation in special education continues to be a complex and controversial issue. The dearth of systematic studies in this area compounds the problem and, subsequently, professionals are left with personal testimonials and anecdotal descriptions upon which to base their decisions of how to effectively involve parents in special education. As demonstrated in this paper, the notion that parental involvement benefits all students, parents, and school personnel remains unsubstantiated and denies the uniqueness of individuals and can inadvertently contribute to unnecessary conflict within families and between parents and school personnel.

Although the participation of parents in planning services is becoming increasingly acknowledged (Department of Health 1995), the movement towards bringing more and more of carers' lives into a growing and more coordinated professional network through independent assessments may only heighten their suspicions of the power, scope and purpose of the professional gaze. Without effective support, mothers of disabled children may be unable to give voice to, let alone exercise, their personal lives. Yet obtaining a sense of the private day-to-day struggles mothers encounter seems important for researchers, health and social care professionals and the designers and planners of policy makers to include some recognition of the private struggle between self and society. This has to be done carefully and with consideration. It will have to involve empathy as an essential ingredient, and once earned, they will have to be maintained. Empathy has been considered to be an aspect, which is most thought to be missing from carers' dealings with professionals but contributes significantly to parents' sense of feeling supported (Grant et al. 1994). Added to this, must be legitimation so that mothers may feel that their own aspirations are important not only to themselves but also to others. However, the pressure to bring this about may not come from or be led by mothers themselves. The increasing involvement of parents in the professional network, as McConkey et al. (2000) have highlighted, has led to further promoting and advocating for the rights of people with intellectual disabilities. However, the question of who advocates for the rights of parents, and for mothers in particular, within this network remains largely unasked. The data suggest here that mothers are capable of the former but may be unable to even consider the latter.
CONCLUSION

Despite appearing logical and reasonable, parental participation in special education continues to be a complex and controversial issue. The dearth of systematic studies in this area compounds the problem and, subsequently, professionals are left with personal testimonials and anecdotal descriptions upon which to base their decisions of how to effectively involve parents in special education. The notion that parental involvement benefits all students, parents, and school personnel remains unsubstantiated and denies the uniqueness of individuals and can inadvertently contribute to unnecessary conflict within families and between parents and school personnel. It may be suggests that a balanced view of parental participation is lacking and several considerations related to parental participation deserve attention.

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