

IDEAL, REALITY AND PERSPECTIVES— AN EXPLORATION ON ROLE OF PARENTS OF CHILD WITH SPECIAL EDUCATIONAL NEEDS IN INCLUSIVE EDUCATION

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Abstract

The support and involvement of parents of children with special educational needs (SEN) is vital, which links successful implementation and development of inclusive education. Firstly, this paper analyzes the ideal roles that parents of child with SEN should act in inclusive education, such as advocator, promoter and collaborator of inclusive education and lifelong learner; secondly, it discusses current role conflicts which parents of child with SEN are facing in real life, for example, advocating without clear consciousness of right, promoting inclusive education passively, cooperating with professionals negatively and learning without enough supportive resources; finally, it presents some practical and possible strategies about how to realize the ideal roles of parents of child with SEN in inclusive education.

Key words

Parents of children with special educational needs, role, inclusive education.

A role or a social role is a set of connected behaviors, rights and obligations as conceptualized by actors in a social situation. It is an expected behavior in a given individual social status and social position (<http://en.wikipedia.org/wiki/Role>).

In some countries, education has been seen as largely a matter for professionals. Parents had little part to play, especially parents of children with special educational needs, they have simply received the services provided by so-called professionals. They have not been expected to play any significant roles in the education of their children and they have few formal rights to take part in the decision-making about inclusive education. In countries

which have adopted more inclusive approaches, such as U.S.A, U.K, the involvement of parents of children with special educational needs (SEN) have become central to the process of inclusive education, which links the successful implement and development of inclusive education (UNESCO, 2003).

Without doubt, as the primary, persistent and important place of socialization, family is vital for the development of children with SEN and for children, parents play very important roles nobody can substitute. Comparing with typical children, children with SNE have their own special needs during whole developmental process. Some of these needs can be satisfied via the regulating and implementing related legislations from up to down, but the other needs still need to be advocated and to be strived for by parents and related professionals from bottom to top. So, the role played by parents of children with SEN is different with the role played by parents of typical children in the context of inclusive education. What ideal roles parents of children with SEN should play? We will discuss this as following.

1 The ideal roles that parents of child with SEN should play in inclusive education

1.1 Advocators

As a basic citizen right, children with SEN can choose regular school to receive their education as same as their typical peer. The acquirement of this right largely relates to the persistent and untiring advocacy of their parents and the parents associations with the collaboration of other related professional organizations. For example, in the beginning of 1970s, some advocates of special education in America, including parents of children with SEN, their associations and some lawyers who helped to vindicate citizen right began to implead state and local schools, because these schools' exclusion and mistaken category for exceptional children offended the equal educational right of American constitution (Turnbull & Turnbull, 2000; Yell, 1998). The advocacy was successful. After that, under the support of professionals of association for children with SEN and legislators, many parents of children with SEN took the law as criterion to advance that congress should set up relevant federal law and earmark funds to guarantee the right which exceptional children can get equal education. All these advocacy have contributed for the establishment of *Education for All Handicapped Students Act* (Public Law 94-142) in 1975 and for the other following legislation (Jurnbull; Jurnbull; Shank; Smith & Leal, 2002). Also, the advance and implement of

inclusive education links the remorseless advocacy of parents of children with SEN. The rights and requirements of children with SEN can be recognized, accepted and catered for as equal social citizen by our society when their parents really cognize these proper rights and actively advocate these rights for their children.

1.2 Promoters

Whatever any country, from central government to local school, all kinds of laws and rules about inclusive education have significant influence on implement and development of inclusive education. Who attend the decision-making? Can these persons who participate in the process of decision-making represent the authentic rights of children with SEN?

All these doubts concern one core issue, that's if there are parents of children with SEN to participate in the process of decision-making. As ideal promoter of inclusive education, only can these parents actively participate in the process of decision-making of inclusive education on different administrative levels, the actual requirements of children with SEN and their families can be expressed adequately, and the parents can promote inclusive education successfully in practice.

1.3 Cooperators

Children with SEN can choose regular school to receive education, which guarantees the equality of starting point of education. On the other side, we must consider whether or not regular schools can provide appropriate education and additional supports to meet the needs of their students with SEN, because these appropriate education and supportive service can guarantee the equality of process of outcome of education for these children. Considering understanding children with SEN in an overall way, parents must involve in the process of identification, decision of placement and designing IEP for their children with SEN. Because they possess the knowledge of their children which other professionals can not have and they can represent the benefits of their children. Through the active cooperation with parents, professionals can give proper judgment of placement and present feasible and appropriate IEP for children with SEN. Additionally, as good cooperator, parents will automatically supervise, evaluate children's progress in their daily experiences and routines at home.

1.4 Lifelong learners

Comparing with regular families, families of children with SEN will experience many stages of stress during the lifelong development of their children. Most parents have to experience the following 5 stages for their child with SEN: astoundment, refusing, despair, guilt, acceptance (Gregory & Knight, 1995). After that, most parents try to learn new knowledge, approaches, and methods to promote the development of their children. When they face their children's new situation, problems and difficulties emerging in endlessly, they must learn to know why these new situations will appear and how they will develop, what developmental characteristics of their children, where their children can get service, how to communicate and play with their children and how to communicate and cooperate with professionals working in schools and other professional institutes or centers.

As we mentioned above, family will experience huge stress when parents know their children have some particular requirements for their development, maybe this kind of stress is changeable and will last for very long period even whole life. For releasing family stress and promoting development of their children successfully, parents must become a lifelong learner.

As ideal role of lifelong learner, parents can exert following functions in the context of inclusion:

Firstly, they actively know related law and rules of exceptional children, and advocate for proper rights of their children;

Secondly, they actively learn related knowledge of special education, try to understand their children's special needs and developmental characteristics more, which can help them to carry out family education and rehabilitation for their children;

Thirdly, they learn the skills about how to cooperate with professionals.

2 Current role conflicts which parents of child with SEN are facing in real life

Active parent advocates, promoters, cooperators and lifelong learners, these roles are the ideal ones which we expect parents of children with SEN can play in inclusive education. How are the parents playing their roles in practice? On the basis of analyzing data of questionnaires for parents of children with SEN, we will discuss current role conflicts which parents are facing in real life.

2.1 Lacking clear consciousness of right

When parents advocate for children with SEN they often challenge deep-seated beliefs about disability, special education and inclusive practice. Different beliefs about these concepts will cause different pivot, content and degree of parents' advocacy. The whole and proper right includes equal starting point, process and outcome. In generally, for inclusive education, parents have realized Children with SEN have the right to study in regular school as same as their typical peers, but on the other hand, most of them can not clearly realize that regular schools should offer tailored education and necessary supportive services to their children, only can schools do like that, the education provided to their children's by schools is equal and high quality education. Search to the bottom of unclear consciousness of right, it derives from most of parents' beliefs and values about disabilities, special education and inclusive practice are still vague.

Table1: Parents' recognition of entrance right of education of their children with SEN and current status of knowing related laws and rules

items Note: "I" in the following items means parents of children with SEN	China (Chengdu)					Czech (Olomouc)				
	Sampling amount (N = 60)					Sampling amount (N = 28)				
	SD	D	NS	A	SA	SD	D	NS	A	SA
Children with SEN have the right to study in regular school as same as their intact peers	N = 0 0%	N = 0 0%	N = 4 6.7%	N = 30 50%	N = 26 43.3%	N = 0 0%	N = 0 0%	N = 1 3.6%	N = 14 50%	N = 13 46.4%
I know relevant laws, regulations and social welfares of people with SEN	N = 0 0%	N = 4 6.7%	N = 28 46.7%	N = 18 30%	N = 10 16.6%	N = 0 0%	N = 5 17.9%	N = 16 57.1%	N = 6 21.4%	N = 1 3.6%

Note: SD - Strong Disagree, D - Disagree, NS - Not Sure, A - Agree, SA - Strong Agree

From Table 1, we know most of parents in both countries have agreed their children have right to receive education in regular schools. This clearly shows parents' consciousnesses of right for their children with SEN have been awakening. But table 1 also shows more than half of parents do not know relevant laws, regulations and social welfares of children with SEN. Knowing related laws and rules about children with SEN is the base of proper

advocacy. Parents lack this kind of knowledge will limit the intensity, depth and range of their advocacy for their children with SEN.

Table 2: The status quo of parents participate parents associations

item	China (Chengdu)		Czech (Olomouc)	
	Sampling amount (N = 60)		Sampling amount (N = 28)	
	No	Yes	No	Yes
Are you member of some organizations for parents of child with SEN or do you keep in contact with these organizations?	N = 50	N = 10	N = 27	N = 1
	83.3%	16.7%	96.4%	3.6%

Table 2 shows, few parents participate in some organizations or associations for parents of children with SEN. We can try to explain this situation from two sides. One side is that there are few parents who have realized the meanings of parents association for them. The other side, there are few parent associations, parents have no enough opportunities to participate in. This kind of current status causes great inconvenient of parents' advocacy. Because all we know the voice of group is stronger than single individual's voice and the voice of group is easier to be heard by society than single individual's voice.

2.2 Promoting inclusive education passively

It is parents that know their own child. Parents observe and evaluate their child through daily interaction at home. But parents' special knowledge and contribution to their child are not recognized or utilized by professionals, even are not recognized by parents themselves. Studies indicate that teachers and school professionals make important decisions for students with SEN with little or no parental input (Hoover-Dempsey; Sandler & Howard, 1995).

Allan (1999) has considered that parental contribution is often assigned lower status than those of professionals, parents are more likely to be described as 'opinions', but professionals' judgment are seen been as being objective and therefore more factually based. As result, there are conflicts between parents and school administrators when they discuss how to meet the requirements of children with SEN (Brown, 1999; Ware, 1999; Vincet, 2000, cited from Lindy, Zaretsky (2004)). We can see current status from Table 3.

Table 3: The status quo that parents of children with SEN participate in the school decision-making for inclusive education

item Note: "I" in the following items means parents of children with SEN	China (Chengdu)					Czech (Olomouc)				
	Sampling amount (N = 60)					Sampling amount (N = 28)				
	N	O	NS	S	OF	N	O	NS	S	OF
Representatives of parents of children with SEN can take part in decision-making process of the school policy of inclusion education in my child's school.	N = 16	N = 6	N = 26	N = 11	N = 1	N = 3	N = 2	N = 15	N = 2	N = 6
	26.7%	10%	43.3%	18.3%	1.7%	10.6%	7.8%	53.6%	7.8%	21.2%

Note: N - Never, O - Occasionally, NS - Not Sure, S - Sometimes, OF - Often

Synthesizing the data in Table 3, the rate of parents who often participate in school decision-making for inclusive education is very low. For example, in this investigation, only 1.7 % Chinese parents think there are representatives of them can often take part in the school decision-making for inclusion. There are 70 % Chinese parents are not sure or think there are no representatives of them participate in the school decision-making. As same as Chinese parents, there are 61.4% Czech parents do think so.

2.3 Cooperating with professionals negatively

Parents have knowledge about how their children development which is valuable for understanding their educational needs. Professionals, particularly teachers working in the school can not acquire this sort of knowledge without the help of parents. (UNESCO, 2003). And parents play a key role in facilitating their children's learning through their shared activities and daily routines at home. But usually, the education of children with SEN is thought it should be carried out at school by teachers and professionals. The parents' role is to make sure children go to school on time with the necessary equipment in schools is seen as potentially damaging interference in the efficient education of children (Horby, 2000). Also, it damages the cooperation between families and schools. Research shows, despite the importance of parental involvement in the IEP process, that parents are not actively involved in the IEP process in the United States (Hoover-Dempsey, Sandler & Howard, 1995). Some regular

schools invite parents to go to IEP conference, but just reading pre-prepared professional plan to parents, then handle pen to parents to sign it.

Table 4: Cooperation between parents of children with SEN and regular schools

item Note: "I" in the following items means parents of children with SEN	China (Chengdu)					Czech (Olomouc)				
	Sampling amount (N = 60)					Sampling amount (N = 28)				
	N	O	NS	S	OF	N	O	NS	S	OF
I communicate my child's performances in family and in school with his or her teachers	N = 0 0%	N = 8 13.3%	N = 1 1.7%	N = 17 28.3%	N = 34 56.7%	N = 0 0%	N = 0 0%	N = 1 3.6%	N = 1 3.6%	N = 26 92.8%
I actively participate in the activities of my child's family education and rehabilitation	N = 5 8.3%	N = 10 16.7%	N = 2 3.3%	N = 12 20%	N = 31 51.7%	N = 7 25%	N = 3 10.7%	N = 11 39.3%	N = 1 3.6%	N = 6 21.4%
I take part in the process of making Individualized Education Plan for my child	N = 13 21.67%	N = 13 21.67%	N = 9 15%	N = 13 21.67%	N = 12 20%	N = 9 32.1%	N = 3 10.7%	N = 4 14.3%	N = 4 14.3%	N = 8 28.6%

Note: N - Never, O - Occasionally, NS - Not Sure, S - Sometimes, OF - Often

From Table 4, we can know parents of children with SEN in both countries tend to actively communicate with teachers, and Chinese parents more actively involve their children's family education and rehabilitation than Czech parents. No matter China or Czech, there are less than half of parents could participate in the process of making IEP for their children with SEN, that shows parents do not actively involve in inclusive education now.

2.4 Learning without enough supportive resources

In some extent, learning some knowledge about special education, including laws and rules, can alleviate parents' stress brought by their exceptional children, also, it is benefit to parents to advocate proper rights, additional services and supports for their children with SEN, and it make parents more confident when they cooperate with professionals. Parents are eager to

learn some knowledge about their children with SEN. According to Chen Yaohong's (2007) investigation to 51 Chinese families of children with disabilities, 92% parents want to know the knowledge about their children's development and want to know how to teach their children by themselves; 90% parents want to know how to play with their children and how to deal with their children's behavioral problems, 67% parents want to know the problems about their children which will happen in the adolescent period. In practice, there are few public institutes can guide parents to learn, many parents have not gotten or never gotten opportunities to learn the knowledge mentioned above for their children, not to say systematic learning or training. We can further analyze this problem through Table 5.

Table 5: The current situation about parents who have participated in some courses for children with SEN

item	China (Chengdu)			Czech (Olomouc)		
	Sampling amount (N = 60)			Sampling amount (N = 28)		
	Never	Aperiodicity	Periodicity	Never	Aperiodicity	Periodicity
Have you taken part in the course or instruction for children with SEN?	N = 34	N = 22	N = 7	N = 25	N = 1	N = 2
	56.7%	36.7%	11.6%	89.2%	3.6%	7.2%

From Table 5, we can see, the rate of parents who have never received courses for their children with SEN is very high, for Chinese parents, it is 56.6%, for Czech parents, it is 89.2%! The data in this table show it is very necessary and urgent to provide high quality and systematic courses about special education to parents of children with SEN, because it is the base which parents can involve their children's inclusive education actively and cooperate with school professionals and social worker equally and confidently as we analyzed before.

3. Some practical and possible approaches and strategies about how to realize the ideal roles of parents of child with SEN in inclusive education

Without doubt, if the ideal roles of parents of children with SEN can be realized completely have huge influence on the development of inclusive education. Inclusive education can not realize without the active involvement of the parents of children with SEN. How to resolve current role conflicts of

the parents of child with SEN are facing in real life? We will discuss possible and practical approaches and strategies as following:

3.1 Changing social concepts about disabilities, special education and inclusive practice

Basically, the realization of ideal roles of parents of children with SEN is severely restricted by social concepts about disabilities, special education and inclusive practice. After experienced the movement of normalization, mainstreaming, integration and inclusion, social attitudes towards persons with SEN have been changed in some extent since 50s of 20th century. Gradually, people begin to realize disabilities and special needs is one form of human being's diversity. On some extent, the appearance of disability reflects that our society only provides available and appropriate environment for typical 'majority', but does not consider to provide such environment to 'minorities'. When individuals with special needs interact with typical environment, conflicts appear. So, on the one hand, we must provide all kinds of interventions to the individuals with special needs to boost up their abilities which can help them adjust themselves in different environments; on the other hand, we need modify our environments, including educational environment to cater for people's diversity. Both sides can promote realization of individual potentials and well-being.

Persons with special needs are not minority who need to be commiserated by public, but part of social citizens. Our society should provide appropriate environment to them in which individuals with special needs can realize involve society and make maximum contribution to society as same as other typical citizens. Also, when we realize the nature of education is to teach students in accordance with their aptitude and respect human being's diversity, we will carry out complete educational reform to cater for every student's special needs and will regard active involvement of families in education. when most of people change their concepts and beliefs about disabilities, special education, inclusive practice, nature of education, and when schools, families, children with SEN and communities can develop harmonious partnerships and work together to contribute to children's equal and high quality education, definitely, all the conflicts of concepts about inclusive education will reduce and inclusive education can be realized.

3.2 Empowering—assuring realization of ideal roles of parents of children with SEN from enhancing setting up related laws and rules

Either the American public law *Education of All Handicapped Students Act* (PL94-142) issued in 1975 or English *Warnock Report* issued in 1978. We can see policy makers had recognized the importance of parents' involvement of their children with SEN and set up the policy frameworks to guarantee the rights of parents. All these laws promoted the quick development of special education in their countries and contributed much for the development of special education all over the world. So far, there are so still many countries have not concrete and practical laws and legislations of special education to guarantee the rights of parents to participate in their exceptional children's education, such as China. That heavily hinders the development of inclusive education in these countries. We must quicken our steps to set up related laws and legislations about special education for parents of children with SEN to recognize, guarantee and encourage their advocacy and contribution to their children's family and school education.

3.3 Enabling—promoting parents' knowledge of their children with SEN and strengthening their skills and confidence in the cooperation with professionals

Firstly, offering curricula relating to family education to students in middle schools, colleges and universities, such as *good prenatal and postnatal care, family education* and so on. These curricula must include content about how to educate children with SEN. On one side, this kind of curriculum can help reduce birth rate of baby with disabilities, one the other side, it is important for adolescents and youths to prepare some knowledge and skills for playing proper roles of parents for their children in the future. Additionally, this kind of curriculum can make more people know children with SEN more and have proper understanding about human being's diversity.

Secondly, promoting establishment of all kinds of parents associations and strengthening the collaboration and communication between parents associations and other professional organizations.

Thirdly, accelerating the function transition of regular schools. Except the function of cultural diffusion, school has to change its roles and functions to adapt to the requirements of change of modern society. We can utilize school's human and material resources; link all kinds of community resources to make schools become multifunction center through providing one-stop

services to the residents such as the cultural, counseling services, educational and occupational trainings in its community. Parents and their children with SEN can easily get services in this kind of school in their community such as diagnosis, identification, making IEP, annual review and regular evaluation for their children's progress and so on. And parents can participate in some courses for children with SEN in their spare time. The multiple, convenient and comprehensive services of this kind of school will benefit for developing good partnerships between schools, parents of children with SEN and their community and encourage active participation of parents in their children's education.

Finally, making good use of all kinds of resources to facilitate parents' learning about special education. Except regular schools in community, we still need utilize special education centers, special schools, counseling institutes, voluntary organizations of social workers and charities to offer systematic courses and necessary supportive services to parents of children with SEN under the coordination of local educational authority. All these will release parent's stress and promote their confidence to face continuing difficulties and new problems their children with SEN will experience and keep growing up together with their children.

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