International Journal about Parents in Education
2007, Vol..1, No. 0, 145-150

ISSN: 1973 - 3518

Parents of disabled children.
The educational system and the everyday challenges

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The purpose of this presentation is to present how parents with disabled children view and understand the existence of their disabled children through the lens of special education professionals and also how professionals experienced and are affected from this understanding.

After a lot of discussions and also after the completion of a questionnaire it had been discovered that parents of disabled children seemed to be a great issue for the professionals who work with their disabled children in case of Cyprus. Thus the Ministry of Education and Culture decided to organize a program which its aim will be to evaluate the difficulties that the professionals faced and secondly it will provide them with the right skills in order to make them able and ready to come across those difficulties. This program consisted of two meetings during the school year 2005-2006 and six meetings during 2006-2007. Parents of disabled children seemed to be a big issue to professionals, since their behaviour sometimes caused lot of difficulties in the everyday life of a school. The group of professionals was made of 22 “special” education teachers who work in the Ministry of Education and Culture. The group was closed for everyone else apart from the two educational psychologists who were responsible for the program and the representative of the Special Education Department. All the information that was mentioned in those groups could not be shared or discussed anywhere else apart from the specific group. It was decided from the organizing team as well that those meetings must be held in places other than school places, since this will provide the participants the chance to talk freely in a much different environment than their everyday environment at work. The analysis on the results is based on qualitative methods, since the group of professionals acts as a focus group.

Introduction

The purpose of this paper is dual. Firstly to present the way parents of disabled children view and understand the every day reality of their disabled child, through. Secondly to mention how professionals experienced and affected from this every day relation.

The results that will be presented came after a series of workshop that had been held from the Ministry of Education and Culture, during the school years 2005-2006 and 2006-2007. It was very clear from the beginning that parents of disabled children seemed to be a great issue for professionals who work in Special Units (a class with disabled students which is situated to a primary school or to a kindergarten). Thus the Ministry of Education and Culture decided to organize a program which its aim will be to evaluate the difficulties that the professionals

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faced and secondly to provide them with the right skills in order to make them able and ready to come across those difficulties.

The group of professionals was made of 23 "special" education teachers who work in the Ministry of Education and Culture. The group was closed for everyone else apart from the two Educational Psychologists who were responsible for the program and the Special Education Counselor. All the information that was mentioned in those groups could not be shared or discussed anywhere else apart from the specific group. It was decided also from the organizing team that those meetings must be held in places other than school places, since this will provide the participants the chance to talk freely in a much different environment than their everyday environment at work.

Literature Review

All parents develop expectations about their child's education based on their own experience and informal networks for parents (Russell, 2004). Parents typically expect high quality of teaching, their child's academic progress and happiness, homework, fair discipline and information (Crozier, 1999). Goodnow and Collins (1990) suggest that parents, ideas will not automatically change as a result of receiving information about heir child's "special" educational needs. If parents disagree with professional opinion about their child this may mean they change their expectations, ignore the information or change their reference group. The parents of a disabled child will react in a similar way as a result of their expectations not being confirmed (Russell 2004).

Lake and Billingsley (2000) believed that the main causes of conflict between school and the parents of a disabled child is the discrepancy between the respective views of the child and their needs. When the school describes the child it is often from a deficit perspective: children's needs are connected to their "disability" and not to their "ability" The approach of the social model of disability provides a better way forward. According to this approach focus is put on the child's strengths, the parent's aspirations and opportunities to achieve. This would involve parents and professionals having ongoing opportunities to share information about what they need and expect. As a result more equal relationships can be developed between the family of the disabled child and the professionals.

High achieving well-ordered schools are characterized by good home-school relationship (Kelly-Laine, 1998).

Inclusion gives us the chance to work in co-operation with the parents in different settings, which we have to continue improving by hearing the voices of parents of disabled children and young people, who can provide us with very useful information. In the past as Solity (1992) mentioned parents of disabled children and young people had been seen as 'consumers' within the education system, even though it was important that parents and teachers establish an effective rapport with each other. Following this model Hornby (1995) came up with a new model 'the partnership model' in which teachers are viewed as being experts on education and parents are viewed as being experts on their children and young people.

The work of Wolfendale (1999) helps to move forward the discussion surrounding parental involvement. Wolfendale (1999) sets out a methodological framework that places parents in a central and powerful role as research partners. Listening to parents and considering the perspective of parents, are ways in which professionals can support the development of educational provision that are sensitive and effective and that meet the needs of a diverse groups of people. Duckorth and Kostell, (1999) state that one method for acquiring specific disability awareness information is through the use of Parent Panels to organize meetings between parents and educational staff in order to share information and discuss associated issues and concerns. Ward et al. (2004) found parents valued being listened to, feeling that their views had been heard, participating in discussions about future opportunities for their son or daughter, being kept informed or even feeling that they were driving the process. Other parents mentioned that they appreciated being backed up by the school in helping to secure the future provision of their choice.

Levy and Allen (1988) reported that mothers and fathers of disabled children and young people they involved in research used to blame everyone and everything for what is happening to their disabled child. A teacher admitted that sometimes they thought that teachers are bringing up their children instead of them. A mother of a disabled child though added by saying that "we cannot do anything with them and this is the reason why we rely on the school to do it and they let us down" (Levy and Allen, 1988). Some parents of disabled children and young people believe that since professionals are 'experts' they can make the difference to their children and young people. Sometimes though, the difference is not an easy task to be made.

Also the difference and the progress in professional terms can be different than in terms important for a parent of a disabled child.

Some research suggests parents believe that the most important educational area for parents is the communication, the independent living and the various types of therapies (Coffey, 1997). Coming now to the concerns that parents have for their disabled children and young people, it was found from research that the most common concern expressed by parents was the need for more staff and also for staying in school after the age of 18 (Coffey, 1997). Also in another related research the main concern of parents of the elementary school children and young people was related to social difficulties, isolation and their child's self esteem (Pivik et al. 2002).

Stages of Emotional Reaction

Every parent wants to have a healthy child. The fear of lot of mothers is that they may give birth to a different child. When this fear becomes a reality a sense of quilt, feelings of rejection and a determination to make up, almost to atone to the child for what has happened to him are all present in various degrees (Younghusband et al, 1970).

Much had been written about "chronic sorrow" and the so called |grieving process" that parents undergo when they discover that they have failed to produce the "perfect baby" (Olshansky, 1962). The discovery that they have a disabled child generally leads to parents experiencing similar feelings and thoughts to those, which are typical of any major trauma or loss.

Hornby (1995) had developed a model for the process of coming to terms with loss. This model is similar to the stage model, that had bee proposed by Kubler-Ross (1969) and stage models of adaptation to disability described by several writers (Bickwell, 1988, Hornby, 1992). In the following model it is suggested that the process of adaptation to a significant loss can be viewed as a continuum of reactions, beginning at the time of the initial discovery of the loss, through which people pass in order to come to terms with it (Hornby, 1995).

The initial reaction of most parents on being informed of their disabled child is typically one of shock. The shock reaction usually lasts from a few hours to a few days. Shock is typically followed by a phase that is characterized by denial or disbelief of the reality of the situation. As a temporary coping strategy, denial can be quite useful in giving parents time to adjust to the situation. Following denial, when they are beginning to accept the reality of the situation, many parents experience anger about the loss. They may search for the cause of the problem or for someone to blame.

Sadness typically follows anger and is a reaction which more than any other, pervades the whole adaptation process. This sadness can be due to parents grieving for the lost of the healthy child which they thought they had or it can be due to sadness about the loss of the opportunities and ambitions which their children many not be able to fulfill. Following sadness parents typically experience a sort of detachment, when they feel empty and nothing seems to matter. Life goes on from day to day but it has lost its meaning. Reorganization is the reaction that follows detachment. It is characterized by realism about the situation and hope for the future. Finally parents are considered to reach a point when they have come to terms with the situation and exhibit a mature emotional acceptance of the loss. They are fully aware of their disabled child needs and they are strived to provide for these.

System theory

It had been decided that the whole approach that it would be use for those workshops would have been system theory. System theory is the transdisciplinary study of the abstract organization of phenomena, independent of their substance, type, or spatial or temporal scale of existence. It investigates both the principles common to all complex entities, and the models which can be used to describe them. System theory is basically concerned with problems of relationships, of structures, and of interdependence, rather than with the constant attributes of object (Katz and Kahn, 1966). Webster defines a system as a "regularly interacting or interdependent group of items forming a unified whole," which "is in, or tends to be in, equilibrium". Negandi says that "a system's attributes, which are the interdependence and interlinking of various subsystems within a given system, and the tendency toward attaining a balance, or equilibrium forces one to think in terms of multiple causation in contrast to the common habit of thinking in single-cause terms".

Types of Systems: The three major perspectives of organizations are a rational system, a natural system and the open system. The rational system and the natural system tend to view the organization as a closed system, that is, separate from the environment. In contrast to closed systems, in the open system, organization is open to and dependent on the environment, especially, connections with external and internal components. These three system perspectives will be briefly described in following section.

For the case of this paper school had been seen as an open system and parents of disabled children consisted of a part of that system.

Methodology

The results that will be presented above had been collected during the various workshops (six workshops during 2006-2007). Those workshops had been organized from two psychologists coming from the Educational Psychologist Department of the Ministry of Education and Culture. The Special Education Counselor had been participated as well at those workshops and her role was to keep detailed notes. After the completion of each workshop those detailed notes had been sent to the two psychologists whose analyzed the findings.

The participants were 23 professionals who worked in Special Units in Cyprus. The vast majority of those professionals hold academic degrees in the field of special education and they work from 1-8 years in the specific setting. Most of them are working in primary school since the Special Unit they are responsible for is situated in the primary school and only three of them work in a kindergarten setting.

All the workshops had been held in the same place, a place outside the school system and they used to start at 11.00 and completed at 14.00. It lasted three hours approximately.

The findings had been collected from all the workshops that had been done. Not a specific method of data collection was used. The organizing committee decided that it will be more beneficial if several methods had been used. Scale items and questionnaires helped us to understand the participants. Also we had used drama and working-discussing in groups in order to help them reveal and understand the way the system works and also understands the value of parents of disabled. Lot of personal experiences had been mentioned from the participants.

Results

In order to analyze the data, we decided to use grounded theory. This method is designed to serve as a flexible guide for researchers in their course to reflect on the data, to generate effective theory that fits the reality of the situation it originated from. Grounded Theory provides an analytic qualitative approach explicitly concerned with seeking out theoretical explanations (Goodley et al, 2004).

The aim according to Glaser (1995) is to discover the theory implicit in the data. Grounded Theory has is responsive to the situation in which the research is done. There is a continuing search for evidence which disconfirms the emerging theory. It is driven by the data in such a way that the final shape of the theory is likely to provide a good fit to the situation (Glaser, 1995).

The first result that came up to the surface, was that all the professionals who work at Special Units, experiences in a way the feeling that parents of disabled children is a major sub-system to the whole system we name educational system. This system affects and is affected from various sub-systems. It had great power though and it can create easily negative feelings to the professionals.

When the professionals asked to answer the question what mean to be a parent of a disabled child in small groups, the results were very interesting. The first group said that when you have a disabled child in your family, then the whole family change and the identities of the members in this family also change. They added that the feeling of insecurity is spread among their lives, since someone from the family will have to be responsible for the disabled person.

The second group said that those parents have a “negative energy” and image and they are very depressed because of the existence of the disabled child in their family. They added that those parents are left alone, since the society stigmatize them a lot. There are no services for them in order to teach them cope with the new situation. They had to discover everything by themselves until the day their disabled child will start attending a school.

The third group of professionals said that those parents have no choice, and they feel insecure. The road of their life is too difficult.

The fourth group named those parents as correlated with failure. They feel embarrassed and insecure and sometimes they seemed that they have a grief. The realization of the situation takes them lot of time, if they finally made that.

As it can be seen clearly all the professionals mentioned negative characteristics about the parents of disabled students, since their reality is strongly connected with such feelings and behaviors. The way the system works, the everyday pressure, the difficulties in terms of their disabled students make them have this negative picture about parents of disabled children and this picture came up from all the professionals.

Professionals were asked also about the difficulties they face with the parents of disabled children in their everyday practice. The vast majority of the professionals mentioned that the parents did not and can not listen about the difficulties of their child. Parents often appeared to have a lot of demands, which sometimes can not be done, not because of the inability of the professional, but because of the way the system works. The feeling of no appreciation also appeared to be spread out. Parents of disabled students can not understand the effort that the professionals made in order to educate their disabled child and they believe that this is their right and that professionals are responsible and obligated to do this.

Sometimes they can not follow the program and the rule of the Special Unit and sometimes they even use the excuse that their child is disabled and can not follow a strict program. There were times when professionals face lot of anger on behalf of the parents. The professionals themselves tried to understand this, by saying that the professional has several roles for the parents. The professional may be a special teacher on the one hand, but on the other hand he/she had to be transformed to a psychologist, or a social welfare officer, or in some cases a part of their family. This though seemed to create several misunderstandings and confusions to the school-home relation.

A group of professionals, (those with the least experience) mentioned that the difficulties they have with the parents of disabled children make them realize how lonely they are in their class. They desperately ask for support but unfortunately the given support is not enough. Even though parents want to be informed about everything that happen in the Special Unit or in the school in general, when the professionals tried to inform them they discovered that their interest is very low. They believe that they can not be the professionals and they prefer to let themselves out of the learning procedures of their lives. There were though lots of examples from professionals that the parents used to criticize and judge a lot.

It is obvious from all that had been mentioned above that the parents of disabled children face various difficulties and those difficulties have a serious impact on professionals.

Suggestions

As it can be seen from the results mentioned above, parents of disabled children affect a lot the special education professionals. The negative and depressed feeling that lot parents of disabled children have, had been transformed to the negative feelings that professionals have as well. Parents face lot of difficulties in order to cope with their child disablement. The Cypriot society is not a society which welcomes and celebrates the diversity, thus everything that does not belong to the norm is something strange and it creates the feeling of insecure.

It is amazing how professionals name what parents of disabled children are. All that had been mentioned have a negative input and they spread the feeling that disablement is something looking like a curse. The professionals as it is argued by Lake and Billingsley (2000), used to characterize a disabled child through a deficit approach.

They never start with what the child can do and then how there are going to built up in the future. This attitude is no welcomed from the parents of disabled children, since it reminds them the inability, it is not strengthen the abilities that their disabled child may have. This cause conflicts and real problems between professionals and the parents of disabled children.

It is also very clear from the results, that parents face serious difficulties in order to accept their disabled child. This is why they used to ask for so much things, and feel insecure. The absence of a support system for parents of disabled children creates lot of problems. Parents of disabled children in Cyprus, in most cases they are left alone until their child will attend a school. Then parents are so overwhelmed with negative experiences, they are so tired, thus they can not appreciate the guidance and the help that professionals offer them.

The existing educational system as a system had been affected from various sub systems like the professionals, the non disabled students, the parents of non disabled students, the law, the educational policy etc. They can not understand though easily that their attitude affect the relationship with the professionals and that the enthusiasm and the willingness that professionals have will be minimized, thus their disabled child will not gain as much as he/she can.

The way the system works worked as a barrier towards a better relationship among professionals and parents of disabled children. The existing educational system with all the difficulties to the evaluation procedure, the bureaucratic practices, the absence in the employment of more professionals, make parents of disabled children frustrated and this frustration is usually transformed to the person who represents the system which is the professional who they can see everyday.

In order then, to change the existing situation we need an educational inclusive policy which will be based to a national inclusive policy. Inclusion is not a matter of educating the disabled. It is about the convergence of the need to restructure the public education system, to meet the needs of a changing society. It is about the development of the unitary system that has educational benefits for both non disabled students and disabled students. It is about a system that provides quality education for all children and young people (Lipsky and Gartner, 2000).

We need to inform parents about inclusion and about how inclusive techniques can be transformed and applied in the cases of their children as well. Parents of disabled students need to be educated not only to accept their child but also to understand how they will help in depth either their disabled child nor then. Disablement today is nothing to be ashamed of. Parents need to understand and accept this. They need first of all to through away the feeling and the label of being special and they have to understand that in an inclusive society each person counts and this is appreciated.

Programs that will be aimed to inform parents to various aspects have to start after the birth of a disabled child. This support must continue until they feel ready and secure. The government had to make the policies that will base those changes. Parents of disabled children need to try, but it is the responsibility of the government to make all the inclusive settings.

On the other hand professionals need also to be supported and appreciated for what they did. They need to be informed as well about inclusion, its philosophy and its application into the everyday life of the school and the society in general. They need to leave the deficit model they use and try to use a more social model of disability, where disability is not connected to physical impairment, but to social exclusion and labeling.

Special Education Professionals need to be supported. Thus the role of the Special Education Counselor and also the role of the Connecting Officials have to be re-designed and more time must be give in order to support. Also the design of such programs like that one must be organized more often, in order for the professionals to express their views, share their difficulties and their worries. Finally a combine program between parents of disabled children and professionals seemed to be an excellent idea. This program will aim to bring together professionals and parents and minimize the barriers among their relationships.

References

Crozier, G. (1999) “Is it a case of: We know when we’re not wanted?” The parents’ perspective on parent-teacher roles on relationships. *Educational Research, 4(3),* pp. 314-328.

Duckworth, S. V. and Kostell, P.H. (1999) The parent panel: Supporting children and young people with special needs. *Journal for the Association for Childhood Education International, 75(4),* 199-203.

Goodnow, J. and Collins, W. (1990) *Development According to Parents-the nature, sources, and consequences of parents’ ideas.* Hove: Lawrence Erlbraum.

Hornby, G. (1995) *Working with parents of children and young people with special educational needs.* London. Cassell.

Hoy and Miskel. (1978) *Educational Administration, Theory, Research, and Practice.*

Katz and Kahn. (1966) *The social psychology of organizations.*

Kelley-Laine, K. (1998) Parents as partners in schooling: The current state of affairs. *Childhood Education, 74(6),* pp. 342-345.

Lake, J. and Billingsley, B. (2000) An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education, 21(4),* pp. 240-251.5

Levine and Fitzgerald. (1992) *Analysis of Dynamic Psychological Systems,* vols. 1&2.

Levy, G. and Allen, P. (1998) “Selfish Parents, Spice Girls and children and young people of 10 Obsessed with Sex**”.** *Daily Mail, Friday February 6, 1998*, p.17.

Pivik, J., McComas, J. LaFlamme, M. (2002) Barriers and Facilitators to Inclusive Education. *Exceptional Children and Young People, 69(1),* pp 97-107.

Russell, F. (2004) The expectations of parents of disabled children and young people. *British Journal of Special Education, 30 (3),* pp. 132-137.

Solity, J. (1992) *Special Education.* London: Cassell.

Tanner and Williams (1981) *Educational Planning and Decision Making.*

Ward. L. Mallett, R. Heslop, P. and Simons, K. (2004) Transition planning: how well does it work for young people with learning disabilities and their families? *British Journal of Special Education,30 (3),* pp. 132-137.

Wolfendale, S. (1999) Parents as partners in research and evaluation: methodological and ethical issues andsolutions. *British Journal of Special Education, 26(3),* pp 164-170.