EMOTIONAL STRUCTURES OF PARENTS WITH SPECIAL NEEDED CHILDREN AND BASIC DYNAMICS IN FAMILY EDUCATION

ÖZEL GEREKSİNİMLİ ÇOCUĞA SAHIP EBEVEYNLERİN DUYGUSAL YAPILARI VE AİLE EĞİTMİNDE TEMEL DİNAMİKLER

ABSTRACT

Having a disabled child is one of the biggest shocks parents can experienced in life, and it leads to the emergence of many different moods. Parents are struggling to fight against life at first because of the emotional destruction caused by having a disabled child and they are working hard to rearrange their family lives according to the reality of disabled children. One of the most problematic points in this situation is the fight against the emotional trauma they experience as well as the concern about how their children will hold on to life. The training processes, which will guide the families towards the solution and will make them gain information, skills and attitudes to facilitate their lives, is a priority. The priority should be the strengthening and foregrounding the family, which should have strong psychological condition. Along with these, every kind of discrimination against the disabled people should be fought, the law-makers should take action, and putting community-based rehabilitation process into action should be a priority.

Keywords: Disability, Parents, Emotional Trauma, Family Training

INTRODUCTION

Becoming a parent is one of the most important events and emotions in the life of humans. The birth of a child leads to radical and structural changes in the life of parents; it changes the outlook on life and perception of parents. It leads to the realization that the realities one knows for sure are actually unreal, and vice versa. Apart from these, another important aspect of the problem is the difficult processes of the family with the disabled children face in psychological, sociological and other similar situations. Parents experience many different and complicated moods after the birth of the disabled children and this leads to a challenging profile of mood states. The mood structure of these individuals is complex (Akkök, 2003: 121-142).

The disabilities and the retardations in some of the abilities of the baby compared to her/his peers may cause shock, denial, and acceptance after a certain period of time on the family (Heiman, 2002; Kandel and Merrick, 2007; Varol, 2010; Ergün and Ethem, 2012; Hatun et al., 2016; Gören, 2016; Gül et al., 2017; Çelik and Ekşi, 2018). The disability, undetectable in any way during the pregnancy, emerges during or after the birth and the joy of birth family experiences is suddenly replaced by deep sadness.
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As the parents are not ready for a child with disabilities, and they don't have physical and especially the psychological strength which is necessary for enduring the disability of the child. This situation paves the way for the formation of serious traumatic events.

Furthermore, the first reaction against this shock process is the question “what will we do now?”. Because the families with children who are disabled and in need of special attention have to face problems, which the families with normal children would not deal with, and they have to take serious responsibilities (Karaçengel, 2007).

With the birth of the disabled children, the perceptions and expectations of parents towards the life will change. These changes occur radically and suddenly, because no family and parent feel ready or prepare for this role.

While the reactions of parents against these situations can be explained with different models, "process model" explains the acceptance and adaptation the parents reach after different processes, following the birth of the disabled child. Process model is consisted of three processes. In the first process, the parents experience shock, grief, denial, which leads to the psychopathological conditions such as depression and anxiety. In the second stage, the individual feels resentment against life, and experience mixed feelings. In this stage, individual experiences guilt and shame. In the last stage, individual passes through the acceptance and adaptation processes about the disabled child, and turn towards the treatment and rehabilitation services (Ataman, 2003: 9-50).

The families with a child with special needs are severely affected socially, psychologically and financially. Parents have difficulty in catering for their own daily needs due to the stress they experience. As the disability of the child will not change in time and it is continuous, the fight of the parents in the process becomes also become continuous, which is tiresome for the parents. In particular, if the disability of the child is severe to the extent that she/he lacks self-care skills, the family members have to take care of the child and make time for the child. At the same time, the problems in the adaptive behavior of the child, which makes it difficult to live together, deteriorates the process (Verep, 2005).

Parents want their children to be in the best state possible, both physically, mentally and spiritually. However, some children are born with special needs and their parents exert intensive effort so the children don't come across with any problem situations through out their lives (Ravindranadan and Raju, 2007: 137-141).

The parents experience a major shock with the birth of the disabled children, and all their dreams for their children are shattered. Furthermore, their structure of ego is threatened, and parents start to threaten each other in time. Having a child with special needs may be a cause of embarrassment for parents and may be an indication of deficiencies in one or both of the parents (Varol, 2009: 353-377).

The normal lives of the parents change with the birth of the child with special needs. Families don't know what to do, what to say, or how to solve the problems and these lead to their confusion (Mowbray et al. 2000).

The causes of this anxiety may be questions and concerns such as how the disabled child will adapt to the society and how the child will live independently (Prime Ministry Report, 1995).

The resulting concerns cause radical changes in the quality understanding of family and affect the family from psychosocial aspects. How the parents will handle the disability is a serious question. In addition, the future problems, as well as seeing themselves as faulty for the disability reveal their inadequacies of social support. The mothers are the ones who give serious reactions in the face of difficult situations. There actions of mothers arise as the anxiety processes; this anxiety arise due to the fact that mothers assume full responsibility for the child (Başgül et al., 2013).

The studies conducted on the parents of the disabled children revealed that the disabled children cause a traumatic situation in the family. Psychological breakdown reveals itself as inability to concentrate, forgetfulness, hallucinates and crying with unknown causes. At the same time, negative physical problems also emerge in parents. Parents suffer especially from stomach problems, muscle tension, headaches and blood pressure in the long term. Considered in terms of gender, the studies on the mothers have revealed that especially the mothers feel shame, despair, guilt and burnout (Keskin et al., 2010; Bilge et al., 2010).

** These Centers provide that; protective, preventive, supportive, developmental services and guidance and counseling services to children, young people, women, men, disabled people, elderly people, martyrs, veterans and their families.
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Models about the Emotional Responses of Families
Different models have been introduced to explain the emotional reactions of the families with disabled children. These models are categorized as “process model”, “continuous model of grief”, “personal structuring model”, and lastly “despair - powerlessness and insignificance model”.

- Process Model
Family goes through various stages until it accepts the situation (Darica et al., 2000).

Shock: This is the first reaction the family gives when parents learn about the disability of the child. It generally emerges as crying, unresponsiveness or despair. The shock may take a few hours or a few days (Campbell et al., 1999).

Denial: Families are unwilling to accept the disability of their children. They even think that the diagnosis of the physicians is wrong. This is a typical denial state. They try to find evidence by assuming that their own thoughts are true. They visit different physicians and try to prove that their child is not disabled (Baltaş and Baltaş, 2002).

Anger - Depression: When parents have a child with special needs, they feel angry at the physician who diagnosed the disability, or the physician who is inefficient in the treatment process of the child. However, the important detail here is the fact that the anger is actually oriented towards the disabled child. This anger mood reveal itself with thoughts such as “Why could not you be like normal kids?”, “Do you have to be disabled?” etc. In some families, parents show anger both to themselves and to their spouses. This situation can be interpreted as the inability of both the parents to have a normal child. This anger of the parents may turn into depression and it may last a lifetime in some families (Lerner, 1997).

Guilt: Generally, the mothers are more likely to feel guilty. In addition, the mothers usually carry thoughts beginning with “I wish” in their head (Kurt, 2001).

Indecision: While parents easily adapt to the disability of their children, for some parents this process takes a lot of time. The indecision about acceptance of the disability of the child stems from the accusations of family members towards each other and from the negligence they show.

Shame: Parents regard their children as a copy or a different version of themselves before they are born. However, they see the disability of the child as their own fault or they see the disability as originating from themselves, and they don't want to be with their children. They think that the people will mock them, which leads to shame (Akkök, 2003).

Bargaining: The family does not accept that the child is disabled, and the families who accept the disability try to eliminate this adverse situation of their children. In order to achieve this, they bargain with the teacher, with the physician, and even with the God, if the parents are believers (Duran, 2018).

Adaption or acceptance: At this stage, the most important point for the family is the beginning of the treatment process of child. The family accepts the disability of the child and the tendency to gather information and create solution about the problem gain importance (Doğan, 2001).

- Continuous Grief Model
According to this model, the families live in a state of continuous grief due to the social influence and situation. This is a natural phenomenon for the parents which arise in the natural process; thus a psycho pathological condition shouldn't be sought in these types of situations. Parents may feel enormous grief as well as they may struggle for their children (Akkök, 2003).

- Personal structuring model
This model gives importance to the mental processes and perceptual processes rather than their emotional processes. Parents, who experience some intense emotional states after the birth of their disabled children, enter into the re-framing and configuration process both for themselves and their children, in the subsequent process (Akkök, 2003).

- Despair - Powerlessness and Insignificance Model
This model has a more pessimistic viewpoint for the parents. Disabled children cause a trauma in the family, together with the influence of social circles. Desperation- powerlessness and insignificance is a situation all parents may experience under normal conditions, but with their fluence and reaction of the social circles, these emotions (despair, powerlessness and insignificance) may be felt drastically (Doğan, 2001).
Behavior and Attitudes of the Parents Towards the Disabled Children

Attitude, as a concept, expresses the emotions, thought and behavior tendencies of an individual towards an object, an event or phenomenon. It prepares individual to show any behavior (Kağıtçibaşı, 2008). The attitudes of the parents towards their children arise generally in four different styles. These are generally expressed as democratic, authoritarian, overly protective and indifferent. While the attitudes of parents considerably influence the personality development of their children, parents may exhibit different attitudes towards their children after learning about her/his disability (Özgür and Zan, 2004). These attitudes can be analyzed as follows:

- **Overly protective attitude of parents towards the children with special needs**
  The main purpose of overly protective structures the parents of children with special needs build is to have their children to live in a safe environment and to allow them to fulfill their needs independently. Children may be condemned, ridiculed or humiliated by other people. Thus, this type of parents tends to keep their children indoors. Parents stay with children in her/his all kinds of needs. This situation causes the children to be dependent on the family in her/his later life (Aral and Gürsoy, 2012).

- **Privileged attitude of parents towards the children with special needs**
  The disability of the children has made her/him the privileged children in the family. This may lead the family to neglect other children, who don't have any disability (Duran, 2018).

- **Overly interested attitude of parents towards the children with special needs**
  Parents exceed their normal living standards because fulfilling the needs of the disabled children becomes their priority. All attention is given to the disabled child. Sacrificing for the disabled child in the house is important for all family members.

- **Denying attitude of parents towards the children with special needs**
  The acceptance of the disability of children is very hard for the family. The family and their social circles want to get rid of this child. According to family child is healthy. Thus, in order to prove this, the parents collect evidence from the physicians, etc. (Canarslan, 2014; Özşenol et al., 2003).

- **Parents’ attitude of benefiting from the disabled children**
  The aim is to get help for the child from others. In order to achieve this, they try to make others pity the disabled children.

- **Normal attitude of parents towards the disabled children**
  Parents with normal attitudes accept the disability of their children. They benefit from all the opportunities their children can be provided and they contribute to the development of their children (İçmeli et al., 2008).

The Stress Sources Emerging in the Family with the Birth of Disabled Children

1. The dreams of parents are shattered with the birth of disabled children; they experience problems and difficulties in accepting the children and overcoming the emotional crises (Güllüpınar, 2013).
2. The problems parents face when explaining the disability of the children.
3. Lack of information and inconsistent behaviors of parents in the disabled child's rehabilitation, care and other issues.
4. The financial and emotional needs emerging with the birth of disabled child, the parents’ inability to pay attention to each other and other members of the family.
5. Social pressure from the external environment directed to the disabled child, establishing social distance.
6. Problems in finding experts with skills and information oriented towards the disabled individuals.
7. Efforts in the minds of the parents for providing the children with healthy education.
8. The concern of the children for the future (Neely-Barnes and Dia, 2008; Akçamete, 2009; Gülşen and Gök-Özer, 2009).
The View of Siblings on Disabled Children

Perceptions of siblings towards the disabled children have parallels with the reactions of the parents; namely, the reactions of the siblings are shaped by the reactions of parents. Identically to the reactions of the parents, the siblings also feel joy with the birth of baby, but with the disability, this joy is replaced with sadness and complex emotions (Sarı, 2007). The reactions of the siblings after the birth of the children with special needs are as follows:

**Ignoring, not realizing:** This is a natural situation arising with the birth of a sibling with special needs. At the same time, as both parents exert a lot of effort to fulfill the needs of the disabled children, and the pressure of environment becomes visible, this mood emerges (Sarı, 2007).

**Jealousy and ill-treatment:** The fact that the attention and love of the parents, to some extent, go to the disabled child, the siblings may experience jealousy. The child may show various behavioral problems in order to regain the parents' attention, which is switched to the disabled sibling. The most common form of these behavioral problems is aggression or in difference towards the disabled sibling (Ahmetoğlu, 2004).

**Fear:** Individual may fear that the same problems may occur in her/his own future family. Besides, after realizing the disability of her/his sibling, the child may pity the disabled sibling, try to protect and take care of her/him (Yavuz and Coşkun, 2014).

**Shame, embarrassment:** Feeling ashamed of the disabled sibling, not mentioning about the sibling in the friend circle and restricting the social relations are the reactions the siblings may give (Ahmetoğlu and Aral, 2008).

On the other hand, there are positive emotions and experiences arising from having a disabled sibling. Increased susceptibility to human relationships and differences, being more tolerant, and having a higher sense of responsibility are among these positive experiences (Özsoy et al., 2006).

Possible Trainings for the Families

- **Psychological Consultation**
  While working with families of the children with special needs, making sure that family members think about future and have positive expectations may indicate that their complex and pessimistic views and thoughts have made advance towards positivity. The main objective of the psychological counseling session is providing support to families for achieving the aforementioned advance. Here, the aim is to re-frame the mental schema of the family members. Besides, in the psychological counseling based sessions, the determined goal-directed behaviors constitute a starting point in order to develop the desired and positive behaviors especially in the mother, who assumes the primary responsibility for the disabled child. Psychological counseling can be organized individually or as in groups. 8 to 12 people can participate in the group counseling. Parents and siblings continue the process with the guidance of a specialist (Voltan-Acar, 2001).

- **Participation of the Families and the Features of Family Training**
  Families go through the psycho-mediation by means of psychological counseling as well as training processes. In particular, the movement from basic to complicated, from small steps to bigger steps, which is among the basic principles in the education process, is a good evidence of strong training processes.

  The education and training process of an individual with special needs is shaped by some basic principles. One of these is the principle that teachers, students, administrators and parents all participate in this process. The main objective is transporting the skills, knowledge and gains of students learnt in the school environment to the house environment and reinforcing them. Here, emphasis should be given to the consistency between house and school (Keskin et al., 2010).
The main reasons for the participation of families to the education and training processes of their children with special needs can be summarized as follows:

1. First and foremost, as the parents concern most about their children, they need to know their children very well. This is why the education and training processes proceed best when the parents participate in (Neely-Barnes and Dia, 2008).

2. Mothers are usually the closest individuals with their children in the house environment. The most important issue concerning mothers is the fact that females usually receive less education than males. Hence, mothers should be taken to the forefront in the education and training processes of their children and they should actively participate in these processes (Ersoy Quadır and Temiz, 2018).

3. Another important point in the participation of the family in the education and training processes is the fact that this situation gives the family the opportunity to know the school better; and family feels as a part of the school, which makes it easier for school to ask for funds from the parents. Thus the academic performance of the disabled individual will improve and her/his living standards will increase (Cavkaytar et al., 2012).

4. The participation of family in the education and training environment contributes to laying the ground for the formation of a common culture.

5. Thus families find the most efficient and best way for the development of their children (Mohsin et al., 2011).

6. The participation of family in the education process contributes both to the parents and the children.

7. The children have a successful personality development. As a result, the academic success and social skills improve, thus there is a positive increase in the emotional development. At the same time, teachers take advantage of this process and they meet the educational needs of their students more easily (Cavkaytar et al., 2012).

8. Families may develop a positive attitude perception for both school and education and training process (Kanık, 1993).

9. At the same time, the participation of families in the education and training process also increases the quality of the education. In this way, the multifaceted development of children is achieved and positive developments may occur (Cavkaytar et al., 2012).

10. The participation of families in the education and training process has made it easier for the school to support children in the house. For the education to be permanent in the children, it must be supported by parents in the house (Törster, 2001; Turan, 2013; Doğan, 2015; Ertürk Mustul et al., 2016).

Considering all these reasons, other contributions of the participation of family in the education processes can be summarized as follows: holding face to face meetings with families, creating an environment for the discussion of education programs, creating opportunities for the development of various academic skills and communication skills by preparing various programs for house.

**Characteristics of Effective Family Training**

- The family members of the disabled children are interested in and concerned about the education, development and education methods of the children.
- The parents may have different backgrounds, skills and characteristics.
- It is necessary to prepare creative and flexible programs which are suitable for the needs of the family. Family expectations, roles and responsibilities should not be ignored.
- Parents should be able to share their views, thoughts and experiences with teachers.
- In addition, the relationship between children and parents should be taken into account in the education and training process. Programs should be shaped accordingly. In particular, the attitudes of democratic, overprotective or indifferent parents should not be overlooked.
- The family should have an active role as decision-makers in the process. In addition, the opinions of parents should be taken into consideration in making decisions about the children. Apart from these, parents should be more solution-oriented, rather than emphasizing the problems (Sen and Yurtseven, 2007; Konuk and Doğru, 2012; Özel and Zelyurt, 2016; Doğan, 2015).
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The most important limitation about the education and training programs is drawing the attention of family to this type of environment. Families may not want to participate in these types of activities, by making excuses. The reasons for this type of behavior can be listed as follows:
- Not being able to find time for participation
- The situations arising due to their emotional nature
- Problems with their self-confidence
- Inability to fully understand the importance of family training (Türkdoğan et al., 1998; Kaytez et al., 2015; Çamlıbel Çakmak, 2010).

Fundamental Aims in the Family Training
- Informing and guiding families in fundamental subjects
- Drafting realistic expectations about the disabled children
- Crystallizing the place of children within the family
- Developing basic skills in children
- Evaluating the interaction between parents and children
- Making parents recognize the changes that may arise in the behaviors of children (Tezel Şahin and Özbey, 2007; Öztop and Yılmaz, 2015; Çömert and Güleç, 2004).

a) Informing and guiding families in fundamental subjects
- This process begins with medical and educational diagnosis of the children.
- First of all, parents should be informed about the disability of the children. This is because the parents may feel anxious if they don't know about the effects of disability on the life and development of their children. The disability should be explained in a way that parents can understand and perceive, that leaves no questions in their minds. The possible effects of disability on the development of children should be explained.
- In the second step, the families should be informed about the education institution which is suitable for the characteristics of children and constitutes a priority for the needs of children. The families should be insistently directed to these institutions without wasting time (Özyürek, 2015; Özdemir, 2010).

b) Drafting realistic expectations about the disabled children
- It is not a right thing to expect the realization of realistic expectations about the children. Families should be first prepared psychologically for this situation.
- Families expect fast developments and changes in their children and may experience disappointment when these changes don't occur, which leads them to leave all their efforts aside.
- Even the minor changes in the children should be explained to parents with positive examples and they should be made recognize these changes (Canbeldek and İşıkolu Erdoğan, 2016).

c) Crystallizing the place of children within the family
- Parents may neglect both themselves and other individuals in the family after the birth of children with special needs. Therefore, the siblings may be seriously troubled by this change. Thus, the siblings should be informed on the status their sibling with special needs.
- The responsibilities of parents may be heavy; however, they still have to behave equally towards their children (Bedel, 2017).

d) Developing basic skills in children
- The needs of children should be determined and the works which are needed most should be taught to parents. Then, the parents should implement what they have learned on their children with special needs.
- The acquisition of basic skills should be demonstrated to parents by the specialists during the training and parents should be asked to continue this process in the house (Yavuz Konokman and Yokuş, 2016; Çömert and Güleç, 2004).
e) Evaluating the interaction between parents and children
   • During the evaluation of the family interaction, the steps should be taken to maximize the comfort and satisfaction both for parents and children, and to minimize the anxiety (Bağçeli Kahraman et al., 2017; Tezel Şahin and Cevher Kalburan, 2009).

f) Making parents recognize the changes that may arise in the behaviors of children
   • One of the most common situations faced in the education of individuals with special needs is that their development progress is low and the changes may be hard to perceive compared to their peers (Tezel Şahin and Cevher Kalburan, 2009; Bağçeli Kahraman et al., 2017; Özyürek et al., 2015).
   • Thus, the morale and motivation of families should be kept at the highest level during the education process of children with special needs. Even the minor changes in the children should be explained to the family, and they should be made recognize these changes (Yıldırım and Conk, 2005).

Resilience in the Families of Disabled Individuals
Resilience is a concept gaining importance in the academic studies. Resilience is the process of individuals' adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress-physiological problems or psychological-based depression or tensions. Individual can adapt and cope with negative conditions. For example, an unexpected death of a family member may cause psychological imbalance, and the fact that family members recover quickly with minimal influence against this imbalance can be viewed as a healthy reaction and as an example of resilience. The risk factor facing the individual and the protective factors that seek to eliminate it are very important in the resilience. Risk is vital in the development of the resilience in the individuals. However, at the same time, risk can be defined as the fusion of the factors leading to negative situation with conditions that would make the situation worse. On the other hand, the protective factors may reduce the negative consequences of the risk, or even eliminate them (Oz and Yılmaz, 2009).

Resilience is a characteristic of individual, protecting her/him from the environmental risk factors. Acquired attitudes and skills allow the reduction of environmental risk factors and introduction of protective factors. The protective process consists of four stages in the resilience. These are:
   • The ones lowering the risk exposure and the risk impact,
   • The ones lowering the negative conditions after the negative experiences,
   • The ones increasing the self-esteem with performance,
   • The positive interactions mediating the needs in the life.

The aim of individual to have a successful and efficient life in the future is the most important motivational tool. At the same time, resilience helps the individual in keeping the hope alive (Oktan, 2012: 1691-1693).

The literature review reveals that families of the children with special needs feel serious concerns about their children. They may give negative first reactions due to their concern for the disability of the children and they may continue this situation in the future. Within the process, after a certain cycle, families may overcome this situation and may be involved in the process of affirmation. The families of children with special needs face more risk situations which create more stress, compared to other families. Thus, positive adaptation and supportive external programs should be activated in order to increase the resilience and robustness of the families when they face this type of situations (Keskin et al, 2010).

The families of the handicapped individuals face more risk situation which creates stress, compared to families with non-handicapped children. The future of their children and what will happen to their children when the parents are not with them exemplify these risk situations. Therefore, when families face this type of situations, they should put themselves into the positive adaptation process and the supportive programs for families can positively affect this process (Heiman, 2002).
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DISCUSSION AND CONCLUSION

Disabled people consists 12% of population in Turkey. This ratio equals to 9.5 million people. The family lives different moods with birth of children with disabilities. The most important wishes of the parents is that his/her child stay on his/her own two feet, be a well regarded citizen in the future; in other words, parents want their children to be able to “earn his/her life” alone (Danış 2009: 92). They usually feel anxious about what will happen to their children after their own death. Measures should be taken as state policy and should be implemented with continuity in order to relieve this anxiety. As a first step, increasing the health services before, during and after the pregnancy will partially decrease the number of people with disabilities. Counseling and awareness services for women who are pregnant may be taken to forefront. In order to decrease the disability risk after the birth, the pregnant women should be given education, provided with preventive health care (about the importance of vaccines), and explained about intervention channels in case of risky situations that may occur during this period.

Families have usually difficulty in accepting the disability of their children. In this respect, the earliest intervention of families towards their children depends on the early medical diagnosis. The duties of the state in this respect are providing the needs of the families, and helping the families financially so that they can apply to the health and educational institutions. These can be achieved after the health screening are given priority in the early diagnosis, the family medicine system proceeds efficiently and home health care and social care services towards the disabled children and their family members taking care of the children are activated without wasting time.

Other important services for the disabled people are the development of educational possibilities and vocational training opportunities. Disabled people are often perceived as mere consumers and not producers, which creates problems their educational possibilities. The thoughts prevailing in the society such as “disabled people will work futile even when they study”, “they need no school, they don't understand anything”, “what good will happen when they study?” hinder the disabled people from beginning to work.

Considering all of the aforementioned situations, improvements should be made in order to eliminate the negative mood of the families of disabled individuals. In order to achieve these, the family training should be given priority. Above all, the disabled people should be considered as a part of the society and they shouldn't be marginalized. Discrimination against people with disabilities should be eliminated completely; their exclusion should be ended.

In this context; it is necessary to create contemporary social policies for the improvement of social perceptions and attitudes towards people with disabilities, to provide equal opportunities for disabled people, to improve education and employment opportunities, to develop family education programs for disabled families.
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RESOURCES


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