

Stress and resilience in families of children with specific learning disabilities

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Resumen

El objetivo de este trabajo se centra en el estrés y la capacidad de adaptación que experimentan las familias con niños con necesidades educativas especiales, en especial con familias con niños con dificultades específicas de aprendizaje. Se presentan un conjunto de factores que afectan a las familias con niños con NEE y se explica la importancia de poner una atención especial a la capacidad de adaptación. Puesto que las dificultades de aprendizaje están entre las desviaciones con serios efectos capacidad de adaptación, la atención especial se pone en las familias con niños de estas características. Se ha realizado un análisis de la literatura existente con el fin de identificar los elementos claves relacionados con esas familias.

Palabras clave: estrés, capacidad de adaptación, necesidades educativas especiales, dificultades específicas de aprendizaje, familia, dislexia.

Abstract

The article aims at stress and resilience experienced by families of children with special educational needs (SEN) specially on families of children with specific learning disabilities (SLD). Different factors influencing the level of stress experienced by families of children with SEN are described and the importance of paying more attention to resilience is highlighted. As the specific learning disabilities bare included in the slight deviations with serious psychosocial effects, the main attention is given to families of children with specific learning disabilities. The analysis of literature was made in order to examine the key issues related to these families and the corresponding conclusions were drawn.

Key Words: Stress, resilience, special educational needs, specific learning disabilities, family, dyslexia.

Great consideration is given to the family in the sector of social sciences. But many aspects have not been sufficiently investigated yet. This relates to constant changes of family structure, family goals and family functionality. The functions of a family, which are reproduction, care of the individual, education in terms of individualisation, socialisation and adaptation, social and emotional control among others (Cohen in Kirmayer, 1997), can be more or less disturbed in a family with a disabled family member. In such families we encounter an increased amount of stress and, at the same time, we have to deal with possible strategies of coping with stress in these families.

The objective of the article is to describe the factors influencing the level of stress experienced by the families of children with specific learning disabilities and the coping strategies acquired by these families. Many aspects are common for families with children with special educational needs (SEN) in general; therefore the first part of the article describes stress and resilience in these families. Second part of the article focuses on issues connected especially with specific learning disabilities. Therefore the analysis of accessible journals was undertaken in order to establish the quantity of articles on dyslexia¹ and families and to provide an evaluative comment on the value of the articles in relation to identifying and supporting families of dyslexic children.

Stress and resilience in families of children with special educational needs (SEN)

The birth of a disabled child is a change, threatening the change of the family's functioning. In relation to the child's disability a range of factors affects the family and its ability to cope with this handicap. The single levels are well described using a scheme (scheme 1, author Iva Strnadová).

On the *1st level* the family of the child with special educational needs is influenced by the state's policies regarding people with special needs. The effect of the media, which reflect the state's policies and the society's attitudes, can be assigned to the same level.

The *2nd level* shows the effect of institutions on families with children with special educational needs – meaning school, additional experts that are called, because of the child's disablement, but also society with its attitudes towards disabled people.

On the *3rd level* the second level with all aspects is explained. For example, school influences parents regarding school leadership, the teacher's education, the quality of the cooperation between family and school.

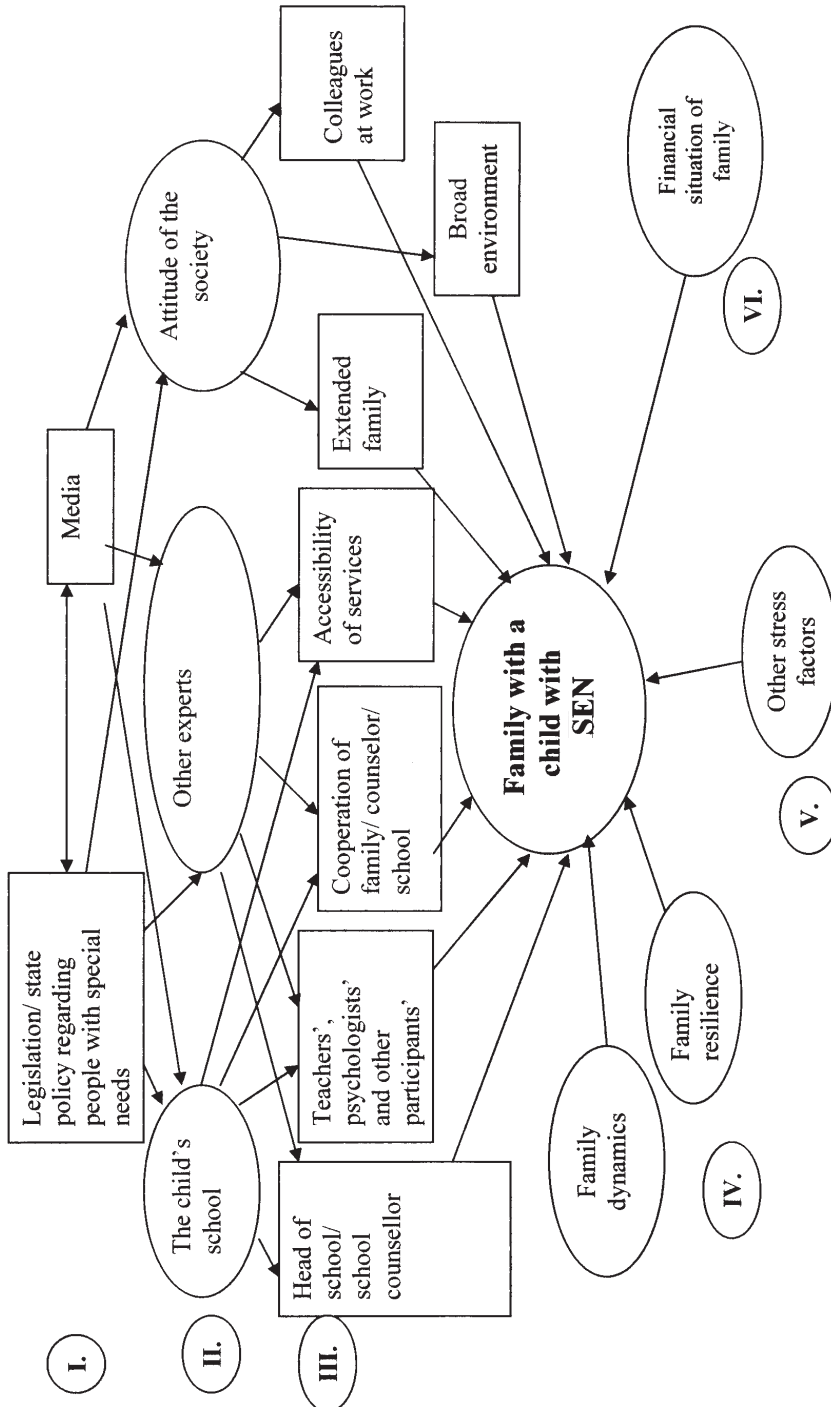
On the *4th level* are psychological factors regarding the parents' ability to cope with their child's disablement and to influence it. Without a doubt family dynamics and family resilience are part of these factors.

The *5th level* indicates the possible existence of other stress factors that, in the end, influence the parental perception of the child's handicap.

The *6th level* expresses the socio-economic background of the family, which plays an essential role as well.

The impacts on families with children with special needs may be even more complex and complicated. The shown scheme tries to indicate the difficult situation for these families and the reasons, why each family experiences the child's disability differently.

¹ The terms specific learning disabilities, SLD and dyslexia are used in the following text as synonyms because of stylistic reasons. This can be justified on the bases of studying the professional literature (see Říčan – Krejčířová 1997, page 132).



Scheme 1. Factors influencing families of children with special educational needs (Strnadová in Lednická, 2004)

Mostly, the descriptions focus on parental reactions to the birth of a disabled child. The time when parents are informed about the diagnosis, meaning the period when the child “officially” started to act deviantly is named “crisis of parental identity” by Vágnerová (2001). More stages, where parents try to cope with the fact, succeed this one.

1. *Shock and denial* – this is the first stage, the first reaction to the diagnosed disablement. Parents, who have naturally prepared themselves for the birth of a healthy child, whose ideas are connected to a healthy descendant, are shocked. It is experiencing a stress situation that gradually “develops to a deprivation of the need of self-realisation as parents, of an open future and of a secure feeling” (Vágnerová, 2001, 78).
2. *Gradual acceptance of reality, coping with the problem* is a stage of indefinite length. It does not always result in the parent’s acceptance of the child’s disablement. If the parents are not able to accept reality then “different mechanisms of protection evolve” that aim at “maintaining the psychological balance at least in the minimum achievable degree” (Vágnerová, 2001, 79). Two ancient mechanisms are the basis for these protection measures – attack and flight. Which one to choose depends on the temper, other individual dispositions and experiences.
3. *Realistic attitude* is the stage during which parents accept their child’s disablement and its consequences. All parents do not reach this stage.

Stress within the family with a disabled child usually starts before the handicap is even diagnosed. Parents often suspect that “something is wrong” with the child. Often the parents request a psychological examination and are not taken serious with their fears. The next stressful stage is the diagnosis of the disablement. In technical literature we often find a description of stages that parents live through, when they find out about their child’s disablement.

The beginning of school attendance is usually a very straining period of life for parents of children with SEN. At this time they are fully confronted with the corresponding handicap. Fears regarding the child’s future, opportunities to study and professional career are added. Often parents fear the heredity of the disablement, they fear that their grandchildren may have the same handicap.

For unmarried or single mothers, raising a disabled child turns out to be even more difficult. Additionally, a disabled child can be a burden for his or her siblings. Increased attention to the disabled child can become a problem as well as protective behaviour of a sibling.

The social environment, particularly the relations to grand-parents and friends, play an important role regarding mastering a stress situation. To be a parent of a challenged child, without any doubt, belongs to such stressful situations. Where parents face non-acceptance and a lack of understanding, social contacts are reduced. This is reflected in the forms of coping with stress.

But not only parents experience stress. Challenged children also are susceptible to psychological stress (Fawcett, 1995 in Reid, 1996). Fawcett (in Reid, 1996) credits this fact to these children's high probability of failing in the corresponding schooling system. One of the sources of stress cited for children with special needs is their family. That's why stress prevention should be part of the societal priorities, because the increased stress level in families probably causes an increased stress level in children. This leads to more failures at school. A vicious circle develops.

Preventive programmes, practical neighbourly help, economic help, educational help, crisis services, counselling, educational programmes, therapeutical services, respite care and palliative care belong to the basic forms of accompaniment and support (Vágnerová, 2001).

Prevention within a family with a child with SEN can take place differently. Individual conversations or joint activities with parents and child can be organised. Experts, devoted to familial accompaniment and support, have to be aware of the difficulties, brought along by a counsellor's interventions in the family. Basic ones are risks, caused by the intervention in family life. A key difference is the idea that accompaniment and support do not regard the family as an object of special educational care, but as an equal partner with competences (Vítková, 2003).

When speaking about prevention and support offered to families with disabled child, we cannot omit resilience. Resilience plays the key role in dealing with the challenging life situations – to which undoubtedly belongs the disability of one's child, relatively new term in psychology and education.

The term of family resilience according to Sobotková (2004) relates to the coping strategies and adaptation processes of the family. Rather than a stable characteristic of the family, it is a dynamic family property. Sobotková (2004) accurately describes it as a renewable power that helps to keep up or to renew harmony within the family. Family resilience is not a new concept, but was introduced to stress theory relatively late. According to Copan, who is specialised on the problem of family, resilience expresses the idea according to which “some individuals or families have the physical strength, psychological repartee and interpersonal abilities, which allow reactions to serious challenges and to grow on the basis of this experience” (in Boss, 2002, 4).

By this definition Copan agrees with Hauser and Walsh, who indicate two important indicators of resilience, which is the fact that resilience is a process that implies growth –one becomes stronger “thanks to the experience” (in Boss, 2002, p. 4). Thus, resilience is not just surviving an incident, an experience– resilience is coping with that experience.

The degree of resilience according to Sobotková (2004) is influenced by the type of familial functioning, by the form of evaluation of a stressing situation in the family, by the problem solving skills, by the coping strategies, by the parents' personality and the source of familial durability. There are external and internal sources of familial durability. External sources in this case are for example the socio-economical stability of the family or the social network of support. Internal sources according to Sobotková (2004) are categorised in familial system sources (meaning cohesion

and flexibility of the family, mutual intellectual orientation and others) and personal, individual sources (meaning intelligence, knowledge, self esteem and others)

But one cannot assume that resilience depends on personal characteristics and familial properties only. Masten and O'Connor emphasise that the "*ability for resilience may also have its roots in genes and the individual's environment, the influence of which still goes on*" (in Boss, 2002, 5).

When studying resilience we rather focus on protective factors that cause resilience. According to Boss (2002, 76) in families the following factors lead to resilience:

- *style of adjudication and ascription* – includes the blame of external and internal powers
- *reaction style* –expresses considerations regarding a situation or, for example, the offensive position in the environment
- *cognitive style* –shows, for example, whether a person is optimistically or pessimistically minded
- *social skills* –include the connection as well as the isolation to others
- *problem solving skills* –are, for example, seeking expert advice or personal search for solutions without consulting others

Regarding counselling practice it is encouraging that protective factors can be taught. But as much as children can learn resilient behaviour from their parents, they can also acquire dysfunctional strategies in coping with stress. If the father, for example, learns to solve his problems by coming home and yelling at all family members until he feels better, it is very probable that his child copies this behavioural pattern. For the parents this may be one of the most important arguments to learn resilient behaviour. At this point it is important to realise that if we want to understand resilience, we have to contemplate the family members' characteristics as well as the characteristics of the family as a whole.

In the past years more and more scientists have been giving attention to the impact of spirituality and faith regarding coping with familial stress. In case of an emergency people, who look for comfort in their religious denomination during times of stress; turn to local representatives of their faith and to families and friends who share their beliefs. This form of problem solution is positive, but spirituality and faith may not always offer positive methods of coping with stress.

Studying resilience factors brings about certain difficulties. If we only concentrate on what makes an individual resilient, we may miss a more important task – which is the prevention of negative incidents within the society that are, without a doubt, prejudices against people with special needs in the field of education, racism, poverty or child abuse among others. According to Boss "*we may not accept the status quo when change is possible*" (2002, 82)– that's why it is not always the best choice to stay resilient.

As a conclusion one can state that in mastering such situation, like a child's disablement, the cooperation between parents and experts plays an important role. Con-

necting both perspectives, a sufficiently profound idea of the problem can be achieved. The companions have to be aware that parents of more or less severely disabled children dispose of more rights than the ones granted by law, as, for example, Gorgon states (in Černá, 1997, 178): the right to remorse and dolefulness, to self-remorse and self-torture, the right to be convinced to do the best for their child, not to be intimidated by experts and not to be blamed for their children's failures, to always be informed about what is happening to the child, to be able to accept help without a feeling of gratefulness and dependence, to make decisions for themselves and for the child, to spin tales occasionally, to "retouch" reality, to expect wonders.

The couples, at the same time, have the right to be respected as experts, they have the right to get real and non-distorted information about the child, the right to the conviction that they also do the best for their students, which can be done at that moment, the right not to be blamed for the child's failures in learning and behaviour.

If we succeed in identifying the sources of stress that most families with a disabled family member suffer from, this will help considering changes. Studying the "secrets" of resilient families is just as important as other aspects and deserves much more attention than in the past. At first we have to change the changeable and only then we can search for coping strategies for the unchangeable.

Families of children with specific learning disabilities

"Slight deviations of mental development are gaining ever greater social importance" (Matějček, 1995, 8). Specific learning disabilities (SLD) are a prototype of such slight deviations with serious psychosocial effects. They concern the family and family life importantly; they are reflected in educational attitudes to the child and retrospectively influence not only his own attitude to school, but the whole of his further psychosocial development.

The value of education from the overall social point of view has increased considerably. Simultaneously the ambitions of parents are likewise increasing. The school success of children is today, more than ever before, a sign of the educational (but also generally reproductive) success of their parents.

Therefore this article is aimed at families of children with specific learning disabilities, specifically at recognizing the way in which these families of children with SLD adapt psychologically to this relatively "light" handicap of their children. For this purpose the analysis of (for the author accessible) literature was undertaken. The objectives were:

- to establish the quantity of articles on dyslexia² and families,
- to establish the specific themes that provided the focus for the research reported in those articles,

² Due to stylistic reasons the terms "specific learning disabilities" and "dyslexia" are used as synonyms in this article. This strategy can be judged on the basis of reviewed literature (see Krejčířová, Ričan, 1997, p. 132).

- to identify the current social and emotional needs of families of dyslexic children and
- to provide an evaluative comment on the value of the articles in relation to identifying and supporting families of dyslexic children.

Table 1 below indicates the journals studied and the number of articles relating to families and specific learning difficulties.

Journal	N° of articles in total	N° of articles ref. to families	Percentage of total
Annals of Dyslexia, An Interdisciplinary Journal of The Orton Dyslexia Society, USA (now IDA)	19 Volumes since 1983- 285 articles	5 articles referring to issue of family	1.8%
Australian Journal of Learning Disabilities, Educator's Association, Australia	21 Volumes since 1996 - 126 articles	4 articles referring to issue of family	3.2%
Bulletin of the Orton Society, USA	11 Volumes since 1967 - 132 articles	5 articles referring to issue of family	3.8%
Dyslexia: An Internacional Journal of Research and Practice, UK	30 Volumes since 1995 - 120 articles	3 articles referring to issue of family	2.5%
Journal of Learning Disabilities, USA	33 Volumes since 1999 - 264 articles	3 articles referring to issue of family	1.1%
Perspectives, The International Dyslexia Association, USA	25 Volumes since 1996 - 150 articles	4 articles referring to issue of family	2.7%
Thalamus, A Journal of the International Academy for Research in Learning Disabilities, USA	13 Volumes since 1985 - 65 articles	3 articles referring to issue of family	4.6%
Total	1,142	27 articles referring to issue of family	2.4%

Table 1. The number of articles in the journals studied relating to families and specific learning difficulties (Strnadová in Lednická, 2004)

These results are highlighted in fig 1 below.

Average number of articles in the above mentioned journals - contributions concerning family (N=27) present 2.4% from the total number of articles (N=1142).

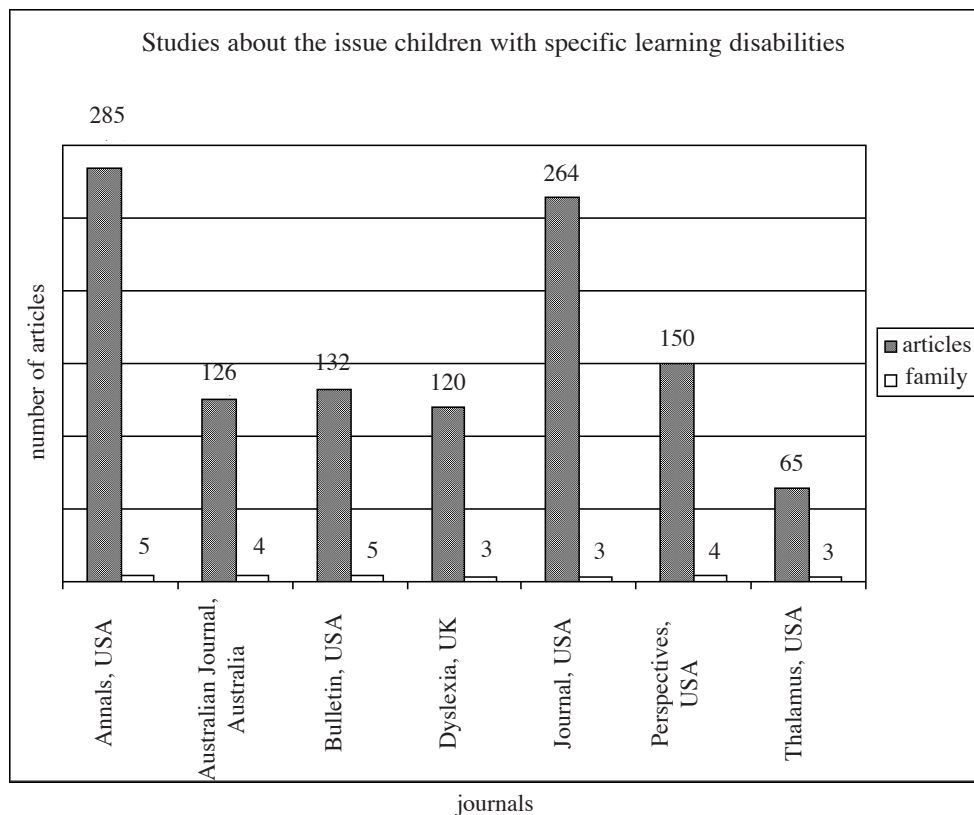


Figure 1. Studies about the issue children with specific learning disabilities in the journals studied (Strnadová in Lednická, 2004)

The analysis involved dividing the articles dealing with the issue of families with dyslexic children published in accessible journals focused on specific learning disabilities into three basic categories (see figure 2).

1. Articles written *by parents* of children with specific learning disabilities
2. Articles about the *issue* of families of children with specific learning disabilities
3. Articles written *for families* of children with specific learning disabilities.

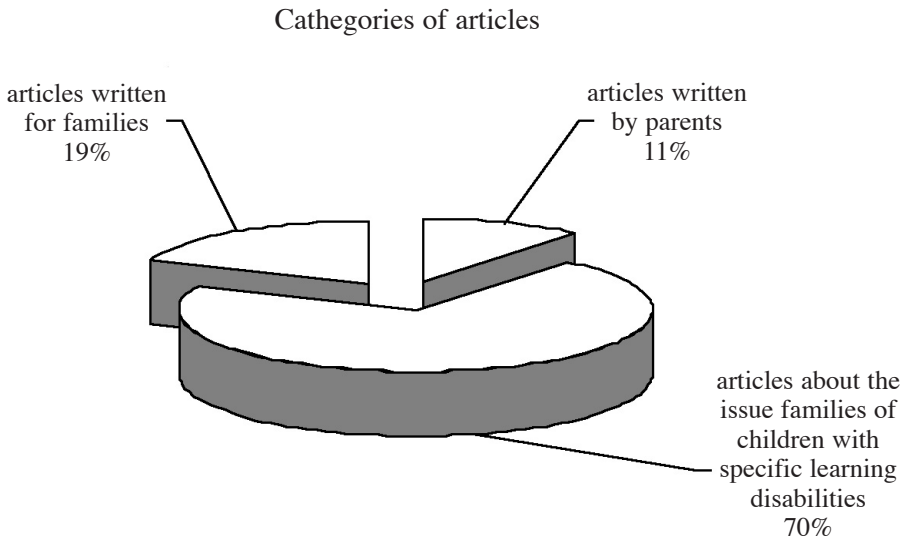


Figure. 2: Categories of articles in the journals studied (Strnadová in Lednická, 2004).

Interestingly enough, majority of articles involved in the analysis were written by authors from non-European countries.

Concerning the time of publishing the articles, we can see that while during 1967–1987 only 8 articles about families with children with specific learning disabilities, between 1992–2004 it was already 19 articles (see table 2). This seems to reflect the increased interest in families in general.

Type of article	Number of articles	Year	Journal	Country
1) Articles written by parents of children with specific learning disabilities	3	1967	Bulletin of the Orton Society	Idaho, USA
		1970	Bulletin of the Orton Society	New York, USA
		1984	Bulletin of the Orton Society	Maryland, USA
2) Articles about the issue families of children with specific learning disabilities a) Articles dealing with genetic aspects of specific learning	19	1986	Annals of Dyslexia	Ohio, USA
		1992	Annals of Dyslexia	Washington, USA
	4	1993	Annals of Dyslexia	Florida, Lousiana, USA
		2001	Journal of Learning Disabilities	Israel

Type of article	Number of articles	Year	Journal	Country
b) Articles dealing with family background of children with specific learning disabilities	15	1970	Bulletin of the Orton Society	USA
		1973	Bulletin of the Orton Society	USA
		1995	Dyslexia	Netherlands
		1996	Australian Journal of Learning Disabilities	New York, USA
		1997	Australian Journal of Learning Disabilities	NSW, Australia
		1998	Thalamus	Canada
		1998	Thalamus	Israel
		1999	Journal of Learning Disabilities	Finland
		2000	Australian Journal of Learning Disabilities	South Australia, Australia
		2001	Dyslexia	Netherlands
		2001	Australian Journal of Learning Disabilities	South Australia, Australia
		2002	Thalamus	Israel
		2002	Dyslexia	Queensland, Australia
		2003	Journal of Learning Disabilities	Finland
		2004	Perspectives	USA
3) Articles written for families of children with specific learning disabilities	5	1976	Bulletin of the Orton Society	Ontario, Canada
		1987	Annals of Dyslexia	Maryland, USA
		1996	Perspectives	UK
		1997	Perspectives	USA

Table 2: Details about articles in the journals studied relating to families and specific learning difficulties (Strnadová in Lednická, 2004)

Stress and resilience in families of children with dyslexia

The most frequented common features in families of children with specific learning disabilities are:

- higher level of experiencing stress (AlYagon and Margalit, 2002),

- frequent occurrence of anxiety (AlYagon and Margalit, 2002) and feelings of guilt (Brock and Shute, 2001),
- lower level of satisfaction from one's life experienced by individual members of family (AlYagon and Margalit, 2002),
- over protectiveness of children (AlYagon and Margalit, 2002),
- fear for the future (Brock and Shute, 2001),
- difficulties with accepting reality of specific learning disabilities of own child (Brock and Shute, 2001) and though resulting higher level of emphases on the development of siblings of the child (AlYagon and Margalit, 2002),
- higher emphasis on structure and control of family system (AlYagon and Margalit, 2002),
- conflicts within the frame of family systems, insufficient mutual support between members of family and lower encouragement of free expressions of emotions (AlYagon and Margalit, 2002).

It is obvious that families of children with SLD experience significant difficulties. Some authors speak about "parental stress" in these families.

One explanation of this phenomena is offered by Dyson (2001 in Brock and Shute, 2001, s.15), who supposes that stress is in this case connected with "invisible and seemingly benign nature" of specific learning disabilities. These hidden factors can result in delayed diagnosis and subsequently delayed intervention.

Brock and Shute (2001), speak about three sources of stress in families of children with specific learning disabilities:

- problems children with specific learning disabilities (SLD) have, that retrospectively influence parents - these include lower levels of social skills, social isolation, difficulties of child when dealing with SLD, inability to concentrate for longer period, and hyperactivity of the child,
- outward factors which family cannot influence so much (e.g. cooperation with educators, system of education or lack of social support from surrounding environment),
- the ability of parents to manage their parental role in demanding situations - common factors are feelings of guilt, exhaustion, sad feelings or difficulties with accepting the disability of own child.

Brock and Shute (2001) came to conclusion that the most important sources of stress for 57 mothers of children with SLD are some characteristics of their children, such as moodiness, unadaptiveness, diffusiveness and hyperactivity. More than 80% of mothers mentioned as a source of stress frustration of the child, time spend together when doing school homework and problems with self-esteem of their child. Around 68% of mothers mentioned as the source of the stress the school or the teacher of their child.

Another area of importance is the differing ability of parents to cope with stress. Some parents reach higher level of resilience than others no matter what they are going through. While some families experience significant difficulties with having child with disabilities, other families are able “cope effectively with difficulties and turn them into challenges” (AlYagon and Margalit, 2002, 41).

On the contrary resilience in the families does not have the space in research it would deserve. This topic has been discussed only in one article in terms of the “Resilient Family Model”, which is according to Snow (in Nichols, 2000) characterized by a well structured environment, effective use of time and positive emotional climate.

Nichols (2000) mentions three factors that parents take into account when dealing with SLD within the family:

- a) difficulties in the cognitive area – parents mention especially problems with concentration, auditory perception, short-term memory and understanding language. These parents come out of professional diagnosis, which is often source of pessimism to them;
- b) level of development –some parents consider the difficulties of dyslexic origin as those connected with immaturity and therefore they suppose that difficulties of their children are only of temporary character;
- c) level of motivation –some parents suggest that SLD of their children are more question of motivation of their child than disorder. They are convinced that difficulties of their child result for example from the fact that he prefers to play football rather than to read. Some parents consider SLD as laziness, not disability.

Studies dealing with families of children with SLD are not limited only to family background of these children, but they also focus on the matter how families experience the social environment of their children. A good example is study from Toronto University (Wiener and Sunohara, 1998), who researched how mothers experience “friendship” of their child (children) with SLD. The results are interesting – many mothers mentioned their children do have difficulty relating to the concept of “friendship” and they described their children as “socially immature”. This does not mean that their children are socially isolated– they have friends, but mothers have often to intervene to construct, develop and encourage peer group friendships for their child (children). To these parents it appeared like another responsibility they had to undertake and manage.

Other topics related with families of children with dyslexia

The stress and resiliency where not the only topics covered in studied articles. Unfortunately the articles dealing with the theme families of children with specific learning disabilities are not commonly frequented. This may raise the question -

Why? It might be suggested that the most highly circulated journals are academic ones and it might be argued that the experiences of parents seem not scholarly enough to the publishers? Yet of course conventional wisdom would indicate that parental experiences are of key importance. Particularly in order to obtain some insights of the difficulties families face on a daily basis.

The general approach of the articles written by parents appears to focus on questions that may occur to parents once their child has been diagnosed dyslexic. For example parents often mention how they would have changed their behavior towards their child if they could turn back the clock. This applied particularly to parents who obtained a diagnosis for their child after 15 years or more.

Experiences of parents are not the only source of information for professionals within the field of specific learning disabilities, but they are a primary source and can offer advice and encouragement for other parents.

Articles written primarily for parents of children with SLD are not frequented either. Integral components of these articles are usually suggestions on how to develop the skills of dyslexic children and how to help them cope with the demands of school.

Cicci (1987) highlights the importance of both the parents being engaged with the child with SLD indicating that it is necessary that both parents understand the problem and jointly support intervention. She suggests that the translation of professional jargon is a key aspect in making articles accessible for parents. She also suggests that parents need to emphasize to their child the value of them as an individual. Children need to know she maintains that every success is valuable and not only success in school. "We need professionals in education, medicine and law, but our lives are also immensely enriched by artists, musicians, poets and sportsmen. We need builders, but also dreamers" (Cicci 1987, s.206).

This is important as many children with SLD suffer from low self-esteem. Parents, who by themselves fight with the feelings of disappointment on their child underachievement, can be transferring their disappointment and fears to the child that further deepen any feelings of inferiority.

Conclusions

The literature highlights the importance of addressing the social and emotional needs of children with dyslexia. Children however are usually part of family units and the disability literature identifies the effect on families of a child with disability within the family (Reid, 2004, Frude, 1990).

Compared to other dyslexia related themes such as educational, neurological and cognitive factors relating to dyslexia, family related issues seems to be given less prominence in the literature. This may be because of the variation in cultural and contextual settings within different countries that can influence the prominence or otherwise of family related issues. This may make international research less valua-

ble. The author of the article as well as other professionals (e.g. Reid, 2003), however, believe that irrespective of culture and context there are common issues and common themes that can have impact on families. This means that theoretical perspectives and practical solutions can have universal application.

This view is supported by research carried out in different countries –for example in United Kingdom by Gavin Reid or in the Czech Republic by the team of researchers³. These researches confirm the assumption that dyslexia is the source of stress for families of children with this disability and that the identification of individual source-of-stress categories can help to improve the level of support provided to families of these children. The results also showed a need for more precise cooperation among teachers, parents, special educators, psychologists and counselors who participate in the care of children with dyslexia. A successful example of such cooperation can be –among others– project supported by European Union, “DYPATEC –Dyslexia– Parents’ and Teachers’ Collaboration”⁴.

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⁴ This Grundtvig2-project is funded by the European Commission and focuses on the interaction between professionals and other adults, particularly parents, who share the responsibility of supporting children and young people with dyslexia. For more information see: <http://www.dypatec.org/en/>

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