

The Role and Place of Parents of Children with Disabilities in Inclusive Education in Serbia

Emilija Lazarević
Institute for Educational Research
Belgrade, Serbia

Emina Kopas-Vukašinović
University of Kragujevac
Jagodina, Serbia

The current *Law on the fundamentals of the education system* adopted in 2009 states that inclusive education is a legal obligation in Serbia, which has resulted in the increased accessibility of education for children with disabilities in regular schools. Numerous challenges have been encountered in the implementation of inclusive education in our country, while the role and place of parents of children with disabilities in inclusive education has remained very important. In spite of the changes implemented so far, solutions for enabling support, procedures and mechanisms for the accomplishment and development of partner relations between teachers and parents in inclusive education have not yet been sufficiently developed in our education system. Parents of children with disabilities in our country are rarely partners in the process of education in which their children are involved. This paper discusses the role and place of parents of children with disabilities from the standpoint of the current situation in inclusive education by reviewing the results and reports of current studies in our country.

Keywords: Parents, children, disabilities, school.

Introduction

Inclusive education demands the creation of an open and flexible education system, in which it is possible to remove the obstacles preventing the optimal development of the potential of all children, including children with disabilities (Lazarević, 2012). Inclusive education should become a generally accepted policy and practice, and not just an individual intervention relating to one or other vulnerable group (most frequently, children with developmental impairments and physical disability or members of certain ethnic minorities). In this wider sense, inclusion is a process of increasing participation and reducing exclusion, where participation is about being recognised, accepted and respected, i.e. being involved in the learning process and social life of the community in such a way as to enable every individual to develop the sense of belonging to society (Booth & Ainscow, 2002). The concept of inclusive education (IE) has undergone significant changes in the Republic of Serbia during the last two decades. The inclusion of children with disabilities (CWD) in contemporary educational courses, alongside the legislative changes, has

initiated a number of reforms in our education system. The current Law on the fundamentals of the education system, adopted in 2009 (The Official Gazette of the Republic of Serbia, 12/72/2009/09), is based on the fairness and openness of the education system. It introduces important changes referring to a fairer enrolment policy, increased access to education for children with disabilities, as well as for children from other vulnerable groups, the adaptation of achievement standards, and the preparation and execution of an individual education plan (IEP) for every CWD. The current Law also envisages the removal of categorisation and the provision of additional educational support to the child/student based on the assessment of an inter-domain committee, introducing a pedagogical assistant for extending support to children and teachers, gradual changes in financing of institutions that support children's inclusion in the education system etc. Additionally, this Law has introduced many changes regarding the place and role of parents of students with disabilities (SWD) in IE. Parents of students from vulnerable and marginalised groups (social deprivation, developmental impairment, physical disabilities etc.) should participate in the preparation of the IEP for their child, propose experts from outside the institution as members of the team in charge of

Correspondence concerning this article should be addressed to Emilija Lazarević, e-mail: elazarevic@rcub.bg.ac.re

the education plan, as well as give their consent for the delivery of the IEP. Parents may also opt to be present during educational activities in order to help the child. Although the general principles of the Law on the fundamentals of the education system point to the necessity and importance of efficient cooperation with the family and parental involvement in the education process, the implementation of the cooperation principle is a very complex and lengthy process.

Educational practice in Serbia has shown that the key stakeholders in the education process, parents and teachers (i.e. the school) are in completely different positions, which brings into focus the question of their cooperation and poses a challenge for the development and maintenance of partner relations (Radivojević & Jerotijević, 2007). In the implementation of IE, the key positions, on the one hand, are given to teachers, who are expected to play very complex new roles adequately. These new roles assume appropriate pre-service education, as well as the acquisition of new knowledge and skills in the IE domain and continuous development (Avramidiset *al.*, 2000). Thus, expectations are imposed upon teachers, and the research findings of many authors internationally and in Serbia that show that teachers do not feel sufficiently competent to respond to the demands they face in inclusive practice (Florian & Rouse, 2009; Villegas, 2007; Macura-Milovanović, Gera & Kovačević, 2010). On the other hand, on the part of parents of students with disabilities, awareness of education as the right of every child, as well as awareness of their active role in the creation of the necessary social and educational support, is still in its infancy. Parents of students with disabilities form poorly structured groups with low social power, who do not have the capacity to shape their relations with the school as partners and usually act as individuals (Radivojević & Jerotijević, 2007).

The contemporary concept of education, quality education for all, not only implies the inclusion of students with disabilities in regular schools, but also readiness and positive attitude towards solving specific learning-related problems (Rajović & Jovanović, 2010). The reform of the curriculum, education plans and standards, an individualised approach, reformed schools and a formative assessment are only some of the issues that need to be adequately resolved in order to provide students with disabilities with quality education (Kovač-Cerovićsar., 2004). In

the opinion of some authors, although IE is present in our schools, there are still numerous problems in its implementation (Radó, 2009; Radó & Lazetić, 2010). It often happens in current educational practice that the beginning of education of the SWD and the beginning of school-family cooperation are marked by confusion, tension, a lack of openness and distrust (Radivojević & Jerotijević, 2007), which further hinders the development and progress of these students. The immediacy of these problems in the implementation of the modern concept of IE was an incentive to deal with the issue of the importance of the role and place of parents in solving specific learning- and behaviour-related problems in students with disabilities.

The family of children with disabilities: problems and needs

The cooperation of teachers and parents of students with disabilities implies various complex contextual, cognitive and personal variables and affects somewhat the quality and course of the child's education. A systemic approach to the issue of the development of cooperation between the school and the family of a SWD presumes knowledge and understanding of the structure and functioning of the families of these students. The family system, as a very complex entity, passes through different phases in its development, sometimes relatively continuously, and sometimes interrupted by different normative and non-normative stressful events. The usual problems that occur in the family grow more complex in the case of the family of a SWD. In their initial phases of development, such families face a life event that is unexpected, massive, chronic, and stressful, and which is perceived as difficult to solve, undermining all the expectations and notions formulated about family life. Finding out about the child's disability brings parents into an existential crisis, since it seriously disrupts their basic beliefs about life, the basic feeling of safety and trust, and activates various ambivalent and unresolved feelings (Dragojević, 2008). For the family, a child's disability is one of the most difficult accidental or paranormal events that can be experienced. Parents of students with disabilities often express emotional reactions in the form of guilt, loss of self-respect, chronic sorrow, feelings of separation, etc., which can lead to the isolation of the family and the setting of rigid boundaries towards their environment

(Hrnjica, 2007). Such reactions can partly be explained by the attitudes of society, which are often, at least implicitly, negative. Divorce is more frequent in families with a CWD than in families that do not have this kind of problem. Even when the family remains whole, the father is often absent from home and communicates with the child less (Hrnjica, 2007). Analyses of problems encountered by families with a CWD show that their problems can be grouped into three levels:

- the family level, i.e. the problems and difficulties of functioning within the family (facing the disability; problems of childcare and fulfilling the basic needs of the child and other family members; organisation of family life; exhaustion and fatigue in parenting and parental-partner relations etc.),
- the level of the relationship of the family and its surrounding, i.e. within-family/environmental problems (the disability in the context of poverty; lack of time, energy and necessary knowledge for encouraging the child's abilities; the problem of single mothers and foster families with a disabled child et al.),
- the level of the environment (insensitivity; the problem of the acceptance of the child; fear; rejection of differences) (Polovina, 2003).

Families with a CWD are under specific kinds of pressure, and in order to achieve their optimal functioning, it is first necessary to determine the specific characteristics of these family systems and the effect of the child's disability on the functioning of parents and individuals, on the married couple and on the family system. In addition, when it comes to the successful establishment of partner relations between the family and the school, it should be borne in mind that children with disabilities and their parents come to the school with various unpleasant, traumatic experiences of discrimination and stigmatisation in society. The analysis of opinions and attitudes of parents of children with disabilities has shown that organised activities (parental education, cooperation with kindergarten/school employees and other parents) can have a positive effect on overcoming fears and concerns about the

inclusion of their children into the regular programme (Vujačić, 2003). The needs of students with disabilities and their parents in IE are varied, and they are also conditioned by the type and characteristics of the disability. However, regardless of the type of disability, the main need is for parents of these students to become active and responsible participants in the education process in which their child is involved.

The role of parents in inclusive education

There is a range of varying factors that influence the establishment of parent-teacher cooperation, and these include cultural, linguistic, socio-economic (Reay, 2009) and historical factors (Tomlinson, 1996; Wolfendale, 2000). Various authors have posited parental participation in education figures as one of the most important aspects of current educational reforms in many countries, and also as the fundamental principle of the contemporary concept of IE (Tassoni, 2003; Farrell & Jones, 2000). Parents are thus facing increased demands related to the process of their children's education. Such demands, an opportunity or a challenge in the life of today's parents, collide with others, such as work (providing the means of existence) and efforts that have to be invested to cope with the fast pace of life, and an omnipresent increase of uncertainty (Gidens, 2005, according to Karić, 2008). The readiness and motivation of parents and teachers to form a partnership is a starting point in the fulfilment of parental roles in the education of their children. Establishing trust between parents and those who provide help for the child, the school team monitoring and supporting the child's development (a class teacher/teacher, a pedagogue, a psychologist) is an important precondition for the beginning of cooperation (Dejvis, 1995). The preconditions for establishing good cooperation between parents and educators comprise parental satisfaction with their level of involvement in the preparation of individual education programmes, a realistic assessment of the child's abilities, accepting responsibility for the children, successful communication, the stability of relations and well-organised bureaucratic support.

Parents play an important role in the development of successive inclusion programmes and hence many countries provide guidelines for the active participation and involvement of parents in their children's education

(Leyser&Kirk, 2011). True cooperation implies partnership in the planning and implementation of the decisions made, the same norms of behaviour and commonly accepted goals. The success of cooperation between the school and the family depends largely on the communication competence of both subjects, including parents as important partners in the encouragement, and the maintenance and enhancement of this cooperation. Setting boundaries between home and school becomes an important precondition for establishing satisfactory cooperation (Reay, 2005), while the blurring of boundaries and the lack of clearly defined roles have an unfavourable effect on the development of partnerships (Todd, 2003).

The beginning of partnership with the school is burdened by numerous fears experienced by parents of children with disabilities: How will the school accept the child? Will the child manage to master at least one part of the curriculum? Will he/she be accepted by the teacher and peers? Will the child begin to resent school commitments when he/she encounters the first problem? (Hrnjica, 2004). Unfortunately, most of these fears are justified since, even before the child starts school, parents have had many negative experiences (in their surroundings, healthcare institutions, playing with peers in the kindergarten). Still, notwithstanding the fears, parents of children with disabilities think that inclusion in regular education proves useful for them and their children. Inclusion enables them to solve or mitigate existing problems, to form a realistic perception of the child and his/her abilities, to establish quality mutual relations in the family, to exchange experiences with people who have similar problems and to find relief from everyday burdens and anxiety (Vujačić, 2006). Parents of students with disabilities think that inclusion helps their children to "become aware of their potential", "socialise", "find friends", "become useful citizens" and "acquire the necessary experience for developing friendly relations with typically developed children". They also mention that their children need a model for learning speech and social skills, and this opportunity is provided by inclusive education (Hanson *et al*, 2001).

Connecting the school and the family is a very important component of the school policy. The foundations for building successful cooperation between parents and the school include the establishment of equal, appreciative and student-

oriented communication between parents and school, psycho-social support, the enabling parents for active involvement in the education of students with disabilities and an active attitude towards educational contents and educational policy. Various kinds of parental involvement in school life help them understand the way in which the school functions, its structure, organisation and curriculum, and encourage the development of competences for cooperation with the school (Cotton, 2000). Todd (2003) and Porter (2008) have emphasised that schools view parents as "homogenous groups" with similar values, while in reality parents are diverse individuals who vary in beliefs, values (Brassett-Grundy, 2004, Bynner, 2004), ethnicity, language (Harry, 2008), cultural background (de Carvalho, 2001), educational and socio-economic status (Reay, 2009), as well as individual life experiences. Observing parents as a broader group, differences arise between parents of students who have no disabilities and parents of students with disabilities (Ollison Floyd & Vernon-Dotson, 2009; Porter, 2008). Parents of students with disabilities face specific challenges relating directly to their child (Lake, & Billingsley, 2000). Many parents of students with disabilities are required, if the need arises, to cooperate with teachers and have a different relationship with schools than other parents (Todd, 2003).

The contemporary concept of education ensures the parents of a SWD the right to choose the school where their child will be enrolled. The new role and place of parents of students with disabilities implies their active participation in the preparation of the IEP, proposing members of the team which will prepare the IEP, monitoring the learning process, and involvement in curricular, extracurricular and after-school activities, as well as participation in councils and the management structures of the school. The parent as a partner in the expert team is an irreplaceable source of information about a CWD. Parental experiences and knowledge about the peculiarities of the impairment, early development and socio-emotional developmental status, as well as about the child's preserved potentials and strengths, are invaluable for positive educational outcomes. Recognising the preserved potentials as well as the abilities that can be built upon them helps class teachers and teachers to determine the direction they should pursue in further work with the child (Lazarević, 2012). All members of the team preparing the IEP, including parents, are

given clear tasks, as well as explanations of how to accomplish them. In addition, well-planned short-term and long-term programmes can provide parents of these children with quite varied types of activities they can be involved in according to their preferences, commitments and abilities/skills. This opens up the possibility of various forms of participation, starting from the simplest, such as informing and consulting the parents and their active participation in parent-teacher meetings, to attending classes, helping the teacher in working with children or working with children at home, participation in the preparation of school development plans and participation in various school teams dealing with the organisation of curricular and extracurricular activities.

The findings of numerous studies indicate that parental involvement in various school programmes has significantly contributed to their children's educational progress, higher motivation and self-respect, the alleviation of behavioural problems and reduction of expulsions from school, the progress in general care of the child, as well as to the improvement at many other levels within the family (Barnes & Weikart, 1993; Rockwell *et al.*, 1995, cited in Karić, 2008). It has also been noted that there is a correlation between increased parental involvement and positive achievement in literacy and numeracy domains, increased attendance and reduced absenteeism (Deslandes, 2009), as well as improvements in behaviour management in school and classes (Smit & Dreisson, 2009). The development of successful cooperation in IE largely depends on the class teachers'/teachers' work in the team, together with parents, experts and other professionals. It is hence important for the teacher to build the skills and abilities necessary for teamwork, such as: communication skills, cooperative skills, responsibility, exchange of opinions, appreciation *et al.* (Lazarević, 2012). Some class teachers/teachers think that parental involvement is efficient, while others are of the opinion that it is a source of conflict and hence avoid it (Grolnick *et al.*, 1997). Researchers in the United Kingdom have identified certain typologies of parental involvement in their children's education. According to Vincent (1996) these include parents as consumers, as participants, and as independent parents. In the United Kingdom, after the 1988 Education Act, the emphasis was on parent-school partnership. This empowered parents belonging to the well-off

middle class to gather more information about schools, to select schools, to get involved in school governing bodies *etc.* (Reayet *al.* 2011). The consequences of these changes have led to tensions in parent-school relations since teachers have felt that parental involvement is a form of supervision and that their professionalism is being called into question, challenged and undermined (Crozier 2000; Vincent 1996). However, teachers have different attitudes towards students with disabilities, which consequently leads to differences in the readiness for cooperation with parents of students with disabilities. Teachers expressed positive attitudes towards the joint education of students with disabilities and their peers, but more than half of the teachers who participated in the study thought that a selective approach was necessary, adapted to the type and severity of the impairment. They supported inclusion from the humanitarian aspect, but the majority expressed doubts about the academic achievement of the class that included a SWD (Đević, 2009).

Cooperation between the school and the family in the context of IE: experience from educational practice

The contemporary concept of the parental/family contribution to a child's work at school entails new strategies of parental involvement. They are based on the philosophy of comprehensive and supportive partnership between the family and the school. Parents play a central role in this vision of cooperation, and the platform has been extended and deepened (Polovina, 2007). However, research findings point to a discrepancy in the perception and conceptualisation of cooperation on the part of school principals, teachers, parents and students, what is most prominent in the expectations related to the roles created in different contexts (Polovina, 2007). The results of a study on parental involvement in school conducted in 2008, which comprised 2273 school principals from South East Europe¹ (Albania, Bosnia and Herzegovina, Macedonia, Montenegro, Moldova, Romania and Serbia), point to the readiness of principals in all seven countries to involve parents in school life. They

¹The international report of the project "Advancing Educational Inclusion and Quality in South East Europe".

expressed the belief that such involvement could contribute to the quality of learning and school surroundings. At the same time, however, the research results showed that in practice there were very few quality opportunities for parents to be involved in school work and school management (Durbin, Miljević & Pop, 2009). The findings of a study² conducted among 200 primary school principals in Serbia on their attitudes towards the possibilities and practice of parental participation in school showed that principals thought that parental participation was an important part of the school life, which contributed to a positive atmosphere in school, the motivation of other parents for participation and to students' success. However, in Serbian schools, participation is mostly reduced to subsidiary activities that are not related to the process of education in a narrow sense or to school organisation. Parents of students with disabilities take part in extra-curricular activities (field trips, excursions, school pageants et al.), the renovation of school premises (i.e. cleaning up the school and the surrounding area), as well as in various charity events. Principals perceive parents themselves as the greatest obstacle to parental participation in the process of education, more specifically, their lack of interest in, and lack of readiness and competence for, participation. Parental participation in this study referred to the level of parental information about different aspects of school life, consultation with parents and appreciation of their opinion in making decisions, as well as to parental participation in the process of decision-making in various areas of school life (mostly through the School Board and the Parental Council) (Vranješević, 2008).

It is most certain that parent-school cooperation is conditioned both by the type and degree of the impairment of students with disabilities. Research findings about the way in which cooperation takes place between parents of children/students with autism and the school are discouraging. Parents of these students see cooperation as mutual appreciation, a constant exchange of information, the school's acceptance of the child, accepting parents' suggestions, the possibility of being involved in making decisions related to

their child, and the possibility of being involved in the preparation of the IEP. According to parents' statements, teachers regularly characterise them as parents who do not accept their child's problem and who hold unrealistic expectations regarding the child's educational achievements. The dominant feeling of parents about cooperation with the school is that they are not accepted as partners whose suggestions and information about the child are considered relevant and credible (Radivojević & Jerotijević, 2007).

The findings of the study "Inclusion between desires and possibilities"³ on the status of the implementation of inclusion in the Republic of Serbia, which take into account the fact that the formal, official part of the introduction of inclusion was the school year 2010/11, point to the necessity of extending support not only to the persons who work with children in the inclusive process, but also to the children themselves and their parents. Class teachers/teachers and associates from 117 schools in the Autonomous Province of Vojvodina claimed that the team for the execution of the IEP most frequently comprised: a school principal, a pedagogue, a psychologist, a homeroom teacher and a teacher teaching the particular subject, and less frequently: a parent/caregiver, a special education teacher and a speech and language therapist. These findings, which offer an insight into the manner of preparation of the IEP and parents' readiness to give consent for its execution, are not encouraging. Only a small number of parents were involved in the preparation of the IEP for their children from the beginning. The most frequent opinions were that parents of a SWD participated in the process of preparation of the IEP in some way, that they were involved from time to time or that they did not take part in its preparation at all. The preparation and execution of the IEP is possible only with parental consent. The following are the reasons most often cited for parents not giving consent for the execution of the IEP: lack of information; non-acceptance of the fact that due to developmental impairments their child needs a different mode of education; the association of the IEP with special education

² The national report is part of the project "Advancing Educational Inclusion and Quality in South East Europe".

³Inclusion between desires and possibilities, Report of the Provincial Ombudsman of the Autonomous Province of Vojvodina, 2011

schools; the misconception that the child will be stigmatised and discriminated; their own shame because their child is different from other children; concern that the child will be isolated and rejected from the environment; lack of understanding of the advantages of education guided by the IEP and the low level of education of parents. However, if the parents do not give their consent for the IEP even after the measures undertaken by associates, the student's class teacher/teacher or the expert team dealing with inclusive education, the individualised method of work is applied, without the preparation and execution of the IEP (Muškinja, 2011).

The results of N. Polovina's (2011) research into the way in which parents of students with disabilities perceive the inclusive potential of Serbian schools point to difficulties that have been analysed on the macro-, meso- and micro-level, their interpretation and consequences. Parents of students with disabilities relate the majority of their difficulties to macro-system factors (questions of marginalisation, solidarity, social justice). They emphasise that there is no system of continuous support, especially in the domain of finances, and they face prejudice and lack of understanding in the very institutions that should provide help to the child. Parents relate many difficulties to meso-system factors (the functioning of institutions in the local community): they encounter "incompetent associates" whose activities cause damage both to the child and the family, lack of understanding for the behaviour of a CWD, proclamations about accepting diversity while showing prejudice and rejecting those who are different. Parents of these children feel lonely and marginalised and are often considered responsible for the child's condition. The micro-system factors that pose difficulties to parents include the many different demands placed upon them (special organisation and life regime, finding solutions for the problems they are facing on their own), and half of the parents stated that they had not managed to overcome the trauma of birth/facing the child's handicap, that is, were unable to accept the fact that they cannot provide a normal childhood to their child (Polovina, 2011a).

Discussion and concluding remarks

Parent-school cooperation in the system of inclusive education has been a focus of research in recent years. The findings obtained indicate

that there are advantages and benefits to be gained by all participants in education (parents, the school and students). Still, this cooperation is not satisfactory in educational practice. When it comes to Serbian educational practice, the cooperation of parents of children with disabilities and the school abounds with problems, ranging from the lack of readiness and motivation on the part of parents and teachers to establish a partnership, and insufficient or inadequate parental involvement in the process of preparing an IEP, to partial mutual understanding and support. The experiences and results of the studies on IE in the transitional circumstances in Serbia indicate that its current implementation is far from satisfactory. There are still numerous obstacles to the implementation of the inclusive process, and parental experiences tell us that the school and the local community still do not perceive parents as active and equal participants in making decisions about their children's education. Additionally, they are not adequately and satisfactorily involved in the education process itself, regardless of their legally guaranteed right to be so. In the declared intensification of the involvement of their children in the flow of regular education, parents see yet another cycle of "optimistic rhetoric", which is not accompanied by a thorough or comprehensive preparation of the key stakeholders, and which carries the risk of unfavourable consequences for their children (the lack of preparation of the environment, including teachers and other students)" (Polovina, 2011b). The findings of the studies conducted in Serbia enable us to perceive different views on this problem on the part of the school and parents. On the one hand, the school management emphasises the importance of parental involvement in education, and, on the other, parents of students with disabilities state that they have been involved only in subsidiary activities. Based on such indicators, it can be argued that schools tackle the issues of the involvement of parents of students with disabilities in the education system mostly on the declarative level. Although the new Law has envisaged that parents should be involved in the preparation of the IEP for their children, in practice parents are involved in these activities very rarely, and only in certain phases, although the adequate participation of parents and cooperation with class teachers/teachers might be a good start and an example of good practice in cooperation between parents of students with

disabilities and the school. This cooperation requires different forms of participation of parents of students with disabilities in expert teams and educational activities, which might benefit the child in various ways (parents as a source of information about the child, their knowledge and experiences about the child's developmental peculiarities, potential and behaviour etc.).

The development of such partnerships entails the continuous education and training of teachers who implement inclusive practice, but it is also vital to educate the parents, who are very important factors in the contemporary concept of education. Raising the awareness of all the stakeholders in this process should be the primary objective of the creators of education policy since it demands a very complex process of continuous education, as mentioned above. Studies show that parents of typically developed children and parents of children with disabilities are ready to accept the inclusive system of education when it is well-founded and when

experts are trained to understand children's needs and adapt their working methods and teaching aids (Elkins, Kraayenoord&Jobling, 2003).

When it comes to the role and place of parents of children with disabilities in inclusive education in Serbia, it can be argued that this area of the school system has not yet been fully researched, and that there are a number of research questions that should be examined in the future in order to enhance the educational and social conditions of the development of children with disabilities. An especially important issue among them is the development of the concept of continuous institutional support for parents of children with disabilities provided by the system, followed by the issue of the development and nourishment of partner relations and teamwork between parents and school experts, who will provide mutual support for the involvement of children with disabilities in the education system.

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