COOPERATION BETWEEN FAMILY, SPECIAL ADVISOR AND NGO’S AS RELEVANT CONDITION FOR SPECIAL CARE SUPPORTING INTEGRATION

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СПІВПРАЦЯ МІЖ РОДИНОЮ, СПЕЦІАЛЬНИМ РАДНИКОМ ТА ГРОМАДСЬКИМИ ОРГАНІЗАЦІЯМИ ЯК ВАГОМА УМОВА ДЛЯ ІНТЕГРАЦІЇ ПІДТРИМКИ СПЕЦІАЛЬНОГО ДОГЛЯДУ

Народження дитини з тяжкими або численними вадами не тільки перешкоджають життю та розвитку дитини, але й впливають на стан здоров’я та спосіб життя її батьків та найближчих родичів.

Базований на останніх даних про важливість впливу родини на розвиток дитини, спеціальний освітній догляд сьогодні орієнтований на надання допомоги, освіти, створення мотивації та способів раннього втручання в родини з неповносправними дітьми. Умови, до яких потрапляють родини та батьки неповносправних дітей, вельми суттєво впливають на їхні емоції та якість їхнього життя впродовж адаптації до складної ситуації.
Мета цієї роботи — дослідити потреби батьків в особливій ситуації, в якій вони доглядають неповносправне немовля, зробити наголос на важливості співпраці між батьками та спеціальними радниками шляхом підтримки соціалізації та інтеграції дитини. Результативною метою було довести вплив ефективного взаємозв’язку радників державних і громадських установ, а також родин на полегшення батькам адаптуватися до складної ситуації.

Ми хотіли б вказати як підтримка підготовлених умов через всебічну допомогу професіоналів та співпрацю між батьками/родинами, практикуючими лікарями та групою батьків, що самовдосконалюються, може підвищити рівень соціальної інтеграції дитини.

Ключові слова: потреби батьків, стан у родині, соціальна інтеграція неповносправних дітей, спеціальні радники, громадські організації, співпраця.

The complex care of handicapped people includes besides direct individual special educational work support and help to his family.

Integration can be perceived by different views. In this case we will focus in integration and socialization of the handicapped child to the support of the self-reliance and worth life in the society without discrimination and disadvantage.

To achieve this final goal of the whole educational process and nurture of handicapped child, we have to prepare favourable conditions for the situation like this. We have to influence not only the child’s internal conditions, but the other determinants (environment, family) as well.

The birth of the handicapped child is for his/her family an excessive burden and a stressful matter. Difficulty of this situation is based on the fact, that this state is irreversible, so that the family will be exposed also to the time factor of the long-lasting stress. Possibilities of the family to adapt on these conditions are different, depending on possibilities and abilities of entire family members to cope with the difficulties. To stipulate the suitable forms of the help for such family, we have to cope with family and with the handicapped child on multiple levels and analyze their situation. This is connected with the question of how the family perceives and treats the birth of the handicapped child and which roles related to development of such child plays.

From the results of the research performed in Czech Republic in 2008, follows, that most of the help and support is offered to the field of the convenient development, supply of sufficient information related to encouragement of the self-sustainance and the later solving the questions.
referred to education of the child. The advisory system is still oriented more to the solving implications of the handicapped child, than to the advancement of the parents.

From the formulations of the parents as responders in our investigation we assess, that in the counselling and assistance they see the work with the child as well as the intervention and the support of the coping strategies of the parents.

According the parents is the successful solution of different problems related to handicapped child and his/her later integration to the society influenced also by the relationship between the consultant and the parent as the client.

To summarize we would like to present some particular fields, in which the parents see the potential for the support of motivating family environment:

– Support of the parents competence to solve current situations and problems
– Approval of the parents expertness
– Equipollent communication with the advisor as a partner
– Support of effective non-pathological coping strategies of the parents
– Reception of the need of vacation, rest and relaxation and recovery of new energy of the parents.

Requirements of the parents — reliance in parent competence and participation in child care contribute to maintaince of the parent role as well as to decrease their stress, particularly if the parents speak with experts about their participation in the child care. To be «a good enough» parent may be sufficiently stimulating environment for the support of the development oriented to self-reliance. The parent, who feels competent, accomplished and susceptible does not need to manifest his abilities so much. Cooperation with the experts in development of child’s integration will be simpler in such case.

The efficacy and assurance in child care increases, if the parents belong to team of experts, if they fell useful and important. This mutual increasing influence of experts and parents leads to reduction of the syndrome «we and they». It gives to parents an opportunity to share their fear with experts all the more, if the experts taking care of the child accept the parents as the members of the expert team. This way also the communication between them improves. The close cooperation between parents and experts is a fundamental assumption for more effective adaptation of the child and parents to handicap and its consequences.
The need of the **rest and relaxation**, in other words the need of autonomy in spending own time is according several authors very important\(^{10}\), which is confirmed also in our investigation. In our survey 92% parents agreed with implication, that they need a time to relax and recovery the energy, resp. «more time for me and my spouse». There is important not only the consciousness of this need by the parents, but also that they would be able to satisfy resp. ask for the help by his/her satiation. In this regard there is a serious problem. Prevailing sense of blame and the press of professional as well as extra scientific public on parent cause, that most parents who take care of seriously handicapped child do not afford the time for a rest. There is also lack of services (eg. in despite services and respite care etc.), which would enable it them.

Because of this is a very complex topic, there is impossible to point herein all the fields participating on the support of the functional family environment.

There is important to know, how essential the cooperation between family and consultant, no mater if he is an expert in advisory institution or a consultant in non-profit organization.

In our opinion, the ready —willing and enlighten family environment is one of the most important determinant of the successful integration of the child to the society. By the birth of the handicapped child, his/her family is the most vulnerable and at the same time is the influence of the family on the child’s development the greatest and long-continuing if positive or negative sense. This influence may be substantially modified by the support of consultants devoted the family.

The range of the services offered by the consultants in municipal (state-owned) institutions to the family with handicapped child is often negatively determined because of orientation of the institution as well as by legislative, economic and personal characteristics. The advisors in the state institutions may offer the support and intervention to family particularly by individual consultations. The relationship and communication between the advisor and the parent is often interfered by accustomed partition of the roles: professional expert and lay parent. In such atmosphere is the cooperation realized in a more difficult way. On the other hand offers the counselling in such institution enough information and contacts on additional experts in the field of health care, social work, or psychology etc.

\(^{10}\) Compare eg. Wittke a Solf, 2007, Lampmann, 2008, etc.
The support of the abilities and adaptation for the parents may be replaced eg. by services provided by non-profit organizations, particularly by community league. Therein the counselling supplies in two basic ways. One of them is a pattern of individual consultation with advisors who are less restricted by the institutional orientation, because most of these institutions include wider range of care of their clients. The applied knowledge may be less special and more general, but on the other hand more detailed in particular fields of the support of the client.

The second model is the group encouragement from other parents, who live in similar conditions and who solve similar problems. This way of counselling is more temporarily oriented, but provides psychical and social benefit, improves the family atmosphere and facilitates the family to return to «normal life».

These two patterns of counselling — state and non-profit organization have been working in our country for several years. The activity each of above mentioned institutions positively influence the survivance of the family and consequently the development and integration of the child. In spite of that the impact of complex care of the family with handicapped child is a well-known theoretical anticipation, the interconnection of these two fields is still very rare.

Therefore the encouragement of advisors in both types of institutions to start a close cooperation by satisfying the needs and requirements of the families with the handicapped child is in our opinion very needful. Hereby the equalization of the roles of the advisors and parents will improve the cooperation, the effective solution the problems of the parents and consequently to maintenance of the integration of the handicapped child to the society.

The certain type of supervision by the cooperation of family, advisors in state institutions non-profit organizations, which is inevitable, will be a warranty of a good practice. The complex approach will rise from more deep knowledge of the family and child’s needs. This will also reflect in the adapted offer of the services and in the personal approach of the advisors, which will create a good atmosphere for the effective collaboration.

*The birth of a child with severe or multiple handicap influences the life and development not only of a child, but also the situation of its parents and near relations.*

*Based on the latest information on the importance of an impact of a family on the child’s development, nowadays the special educational care is*
oriented to afford assistance, education, motivation and early intervention to families with a handicapped child. Conditions, in which the family and the parents of the handicapped child at the beginning of its development fall into, eminently influence their emotions and the quality of their life during the adaptation on a difficult situation.

The Aim of this work was to investigate the needs of the parents in a special situation, in which they breed a handicapped infant, accent the importance of the cooperation between parents and special advisors by supporting child’s socialization and integration. Consequent intention was to prove the influence of the effective interconnection of Advisors in governmental and NGO institutions and families on facilitating Parents inhere in adaptation to difficult situation. We would like to point out, how the support of prepared conditions through comprehensive approach of professionals and cooperation between parent/family, practitioners and bootstrap parent groups can predict level of child’s social integration.

Key words: parent needs, family situation, social integration of handicapped child, special advisors, NGO organizations, cooperation

References


REFLECTIONS ON STUDENT LEARNING
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ВИВЧЕННЯ РЕАКЦІЇ СТУДЕНТІВ НА НОВІ ПІДХОДИ У ВИКЛАДАННІ

Метод оцінювання «Складні питання» спонукає студентів ставити анонімні питання щодо найбільш складних моментів заняття. Метою викладача є використання цієї інформації для поліпшення процесу викладання матеріалу. Анонімність спонукає студентів до більш чесних відгуків. Вони дають можливість переконатися, що заняття такі є корисними. Особливо це стосується студентів, які мають вади здоров’я.

Introduction

After working as a teacher and school administrator for over thirty years in the United States, I took a position at Southern Illinois University Edwardsville (U.S.) in the Department of Special Education and Communication Disorders as assistant professor.

Southern Illinois University Edwardsville is located in the Midwest United States, close to the city of St. Louis, Missouri. It is a metropolitan university on a campus of approximately 2,660 acres with about 13,500 students. The student to faculty ratio is sixteen to one. The university is