

**Parenting in the Best Interests of the Child  
and Support to Parents of the Youngest  
Children with Disabilities**



*Growing up Together PLUS*

unicef 

Edited by Branka Starc

**PARENTING IN THE BEST INTERESTS OF THE CHILD  
AND SUPPORT TO PARENTS OF THE YOUNGEST  
CHILDREN WITH DISABILITIES**

Zagreb, 2014.



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## Preface

With the birth of the child, every parent is faced with a new role in life and a new challenge to his/her personal growth. Parents of the child with disability, developmental delay or risks meet with an additional series of unexpected challenges and many questions that are not easy to answer.

When parents learn that their child has a disability, they start on a different life journey. Throughout that journey they keep questioning themselves and their actions, endlessly digging up for information and services for their child, meeting with different experts and dealing with strong emotions, both their own and those of the close people around them. In that process, many rediscover the sources of inner strength they did not know existed.

Nevertheless, parents often feel isolated and alone, not knowing where to start and how to obtain relevant and useful information and support to their specific needs and those of their child. It is important that each parent have someone they can share their emotions with and say whatever worries and troubles them, what they might be afraid and ashamed of. It is also important that they can rejoice at a success in the development of their child with someone who has a similar experience and understands how one small step is actually a big one for their child.

Knowing how much easier it becomes for the parents to discover that their experience is not unique and that they can get support from professionals and other parents with similar experiences, UNICEF has developed a new programme of workshops with parents, **Growing up Together Plus**, which is intended for the parents of pre-school children with disabilities.

**Growing up Together Plus** workshops offer comprehensive learning about parenting and the child's development, needs, relationships and communication. They provide mutual support, an encouraging and empowering environment, and partnership of the parents and the leaders. Built on the expert knowledge and experience of workshop leaders, this Programme recognizes and nurtures personal strengths, knowledge and capacities of parents. By sharing them with the others in the workshop, parents provide valuable contributions to the joint development and learning.

It is our wish that this Programme and the accompanying handbook become useful to both the professionals and the parents of children with disabilities. Furthermore, we find it extremely important to ensure with our partners that such support services become accessible to all parents and their children, irrespective of where and in what conditions they live. This is because all children, regardless of whether they have a developmental delay or where they live, have the right to be accepted with love and joy and grow into happy people. A support to parents in the fulfillment of their parental responsibilities and to their personal empowerment is the right of each and every child.

To secure these rights for children and their parents, we invite everyone to join us so that together we contribute to the growth of our society into an inclusive and sensitive society capable of responding to the needs of each of its members!

*Đurđica Ivković,  
programme manager of the UNICEF Office for Croatia*



## Introduction

This book is a sequel to *Roditeljstvo u najboljem interesu djeteta i podrška roditeljima najmlađe djece* [Parenting in the Best Interests of the Child and Support to Parents of the Youngest Children] (Pećnik and Starc, 2010a). It is based on the handbook for the implementation of the *Growing up Together Plus* Programme of Workshops with Parents of Preschool Children with Disabilities. The title itself, *Roditeljstvo u najboljem interesu djeteta i podrška roditeljima najmlađe djece s teškoćama u razvoju* [Parenting in the Best Interests of the Child and Support to Parents of the Youngest Children with Disabilities], implies that it is an inseparable continuation of the first book. Only in combination they provide a clear picture of the concept of parenting support and partnership of experts and parents guided by the desire that all children exercise their rights and develop their potential.

The *Growing up Together* workshops with the general population of parents of children aged 1-4 have been conducted over the past four years. The response and the positive experience gained there prompted the development of a programme of workshops for the parents of children with disabilities by taking into account their specific needs and interests. As a result, a "sister" programme of workshops, *Growing up Together Plus*, was developed in 2012 and 2013 under the auspices of the UNICEF Office for Croatia. It is aimed at providing support to parents of preschool children with disabilities.

Why *Growing up Together Plus*? Parents of children with disabilities have a lot of "add-ons" to their parenting – they experience more fear and stress, more challenges and victories, and they need more information, more understanding, more professional work, more care from the society. All these "add-ons" we named a "plus" and the workshops are intended to empower parents and give their add-ons to parenting a positive character.

*Growing up Together Plus* and *Growing up Together* programmes promote the same approach to parenting and parenting support, the same core values and goals. However, in the realisation of these values and goals, we must respect the fact that the parents of children with disabilities experience various additional demands related to their child, family members, wider community and institutions.

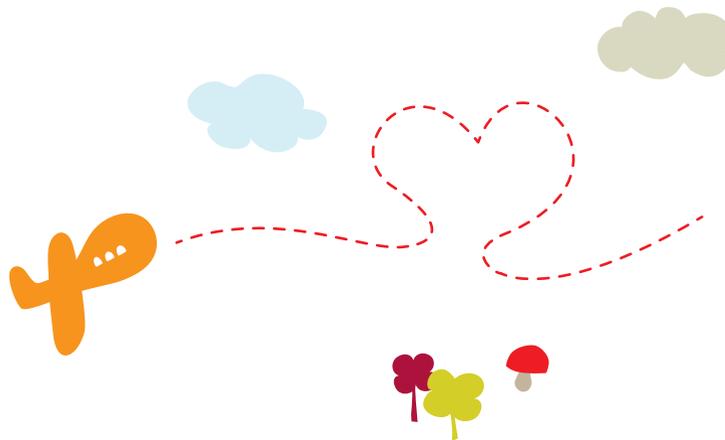
The basic tenets of all *Growing up Together* programmes are already set out in *Roditeljstvo u najboljem interesu djeteta i podrška roditeljima najmlađe djece* [Parenting in the Best Interests of the Child and Support to Parents of the Youngest Children]. Therefore, this sequel conveys only the parts pertaining to the specific features of the Programme of workshops with parents of children with disabilities, with some minor repeatings that were deemed necessary. Given that the *Growing up Together Plus* Programme was created by expanding,



restructuring and adapting the basic *Growing up Together* Programme, we recommend reading both books to acquire a complete picture.

The *Growing up Together Plus* Programme, just like the Handbook or this book, could not have been created without the support of the UNICEF Office for Croatia, especially Ms Đurđica Ivković and Ms Gordana Horvat. We hereby wish to sincerely thank them for providing us with the opportunity to grow into a team of authors that has created valuable contents for the parents of children with disabilities. The provided material was improved owing to the effort and sensitivity of the leaders of the experimental workshops who, in 2013, conducted 13 groups in family centres, kindergartens, rehabilitation centres and parents' associations in Croatia. Mothers and fathers who participated in the first cycle of the *Growing up Together Plus* Programme deserve special credit for its creation. They made fundamental contribution to the development of each workshop, thereby enriching both personally and professionally the experts who participated in the process of creating the Programme and the principles of its implementation. We also wish to thank the organisations that supported the conducting of the first cycle of the *Growing up Together Plus* workshops and its evaluation, and the reviewers who helped us improve the content of the handbook.

*Editor*



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# 1. THEORETICAL FOUNDATIONS AND STARTING POINTS OF THE PROGRAMME

## 1.1.

### Contemporary parenting and parenting support

*Ninoslava Pećnik*

The context of contemporary parenting is characterised by numerous social changes, which set new challenges before parents in fulfilling their parental responsibilities. (Pećnik, 2008). Among them is the change of the child's position in the society which was supported by the affirmation of the rights of the child in the UN Convention on the Rights of the Child (1989). Parental behaviours and attitude towards children have become a matter of public policies, not just in terms of protecting children from parental violence and neglect, but also in terms of promoting parental behaviours and attitudes that foster the child's well-being and optimal development. *Recommendation (2006)19 of the Council of Europe on policy to support positive parenting* defines "positive parenting" as parental behaviour based on the best interests of the child, that is nurturing, empowering, non-violent and provides recognition and guidance which involves setting of boundaries to enable the full development of the child.

This definition of good, socially desirable parenting is based on the notion of the child as a subject rather than an object of parental socialisation influences. It views the parental role in the context of the **relational understanding of socialisation** (Kuczynski and Parkin, 2006, according to Pećnik and Starc, 2010a). In that sense, both the child and the parent are able to initiate a purposeful behaviour and choose the strategies to influence the behaviour of the other side. They are able to reflect on their own behaviour and interpret the messages sent during the interaction. They are also able to take a stand, resist requests that infringe on their autonomy, prevent them from achieving their goals, or that are contrary to their understanding of the social situation. Along with the recognition of the child's active contribution to their own socialisation, a continuous resocialisation of the parents themselves is recognised as well. They, too, develop and adjust their values and educational goals through their interactions with the child in their daily lives. In other words, treating a child as a chunk of clay that can be shaped according to the parents's desire through training, rewards and punishments (Schaffer, 1996, according to Pećnik and Starc, 2010a) has been abandoned. Instead, the respect for the child as a person with their own intrinsic motivation is promoted and the behaviour and opinions of both sides, of both the parents and the child, are taken into account. The child's self-regulation and cooperation are not the consequence of parental disciplinary acts, but rather, the children develop their readiness for



cooperation primarily through early experience of reciprocal cooperation with their parents, and they are motivated to conform to the parent's request due to their "investment" in their relationship with the parent (Kuczynski and Hildebrandt, 1997; according to Pećnik and Starc, 2010a).

In line with the described contemporary understanding of the nature of good parenting is the conceptualization of parenting in the best interests of the child, which constitutes the central theoretical construct of the *Growing up Together* Programme. According to this approach, every child has the right to a caring and nurturing parental behaviour, structure and leadership, respect of their personality, and empowerment (Pećnik, 2007). These categories of parental behaviours and values are the basic principles of parenting that respect and promote the rights of the child in the family. We call them the **four pillars of parenting** in the best interests of the child. (Section 6, Annex "The four pillars of parenting in the best interest of the child").

With the view to empirically substantiating the assumption that the child's well-being and the development of emotional, social and cognitive competences are boosted through a caring parental behaviour, providing of structure and boundaries, respect for the child's personality and empowerment of the child, the "four pillars of parenting" mentioned above have been compared with the recent findings in the developmental psychology and the psychology of parenting (Pećnik and Starc, 2010a).

Along with the right to a family environment that supports the child's well-being and allows a full and harmonious development of their potential, the UN Convention on the Rights of the Child defines the right of every child to their parents' entitlement to adequate and sufficient help from the society in fulfilling their parental responsibilities.

The right of parents to reliable information, counselling, financial and other help in the care for children under the Convention is also promoted by the Council of Europe and its *Recommendation (2006)19 on policy to support positive parenting*. This document points out the extreme importance of "parental work" in the society, but also how demanding it is. Therefore, the European countries are invited to provide universal support to all parents and take special care of the needs of parents who raise their children in more difficult conditions, which includes parents of children with disabilities. *The Growing up Together Plus* Programme of Workshops for Parents gives parents the opportunity to realise some of their rights to support, to which they are entitled simply because they are parents.



Evaluation research with the parents as beneficiaries of the parenting support programmes shows that it is not *what* is done, but also *how* it is done that attracts them to the programmes (Sandbaek, 2007). In other words, the extent to which the parenting support programme will actually strengthen parental competence, self-confidence and satisfaction of the parents depends largely on the manner in which it is implemented. As always, the quality of the relationship between the support provider and the beneficiary of the support is the deciding factor. *Recommendation (2006)19 of the Council of Europe on policy to support positive parenting* lists two basic principles for implementing parenting support programmes:

- 1 They should be characterized by equal focus to strengths, resources, protection factors and risk factors, which means focus on the recognition and evaluation of the strong points of the parents, stakes in the interpersonal relationships and the community and creation of new possibilities of achieving the parents' potential.
- 2 Experts in parenting support programmes treat the parents who participate in them as active participants, persons who make decisions concerning their lives for which they are responsible, who cope with the circumstances in their lives, who are "experts by experience" and holders of social rights (including the right to support to which they are entitled as parents).

A consistent implementation of the described principles requires a change from the approach to parents which has been traditionally based on the deficit model (where the parents are viewed through the prism of their shortcomings) to the approach based on the **empowerment model** (Flett, 2007). In the empowerment model, experts no longer see their role in determining (as experts) the needs of the parents and what they should do to be "better parents". Instead, they view the parents as partners with whom they cooperate so that the parents could find a way to fulfill their parental responsibilities for their child's well-being and their own pleasure. Experts draw on their professional and personal experience to offer to the parent new ideas for verification, inspiration and orientation, and provide feedback and support. They also learn and develop their own competence from the experience and reactions of the parents.

**Partnership** means that the experts and parents are *on the same level* – the former are experts on theories on child development and parenting, and the latter are experts on their children and themselves. If the experts are ready to "let go" of their role as experts in raising children and accept that they do not know best, they will be able to engage in an authentic and sincere dialogue with the parents and be prepared to learn from them. This calls for a non-authoritative approach which enables the expert's personal authority to be established (Breton, 1994).

For the experts implementing it, establishing a parental support programme based on the principles of parenting and empowerment usually means "struggling against the tide", or creating an approach to parents contrary to the one already established. Creating a new understanding of one's own role compared to the parents requires a radical shift from the traditional attitude of experts from social institutions toward parents, characterised by *preaching* and *correcting* parents in how to raise their children.

Therefore, the application of the described principles requires the experts who provide support to parents to have sufficient and appropriate professional support. Just as parental support programmes enable the parents to develop their own competences, so continuous education, supervision and mutual support facilitate the development of the expert's competences in fulfilling their professional responsibilities in the parental support programme.

## 1.2

### Support to parents of children with disabilities

*Marta Ljubešić*

Parenting can be the most beautiful, but also the most challenging life role. Future parents are dreaming about it, anticipating and preparing for it. They covet and hope for the arrival of a child of good health and typical development. However, life teaches us that almost 10% of children, to a greater or lesser extent, temporarily or permanently, will not fit these expectations. Parents will have to face the uncertainty of the outcome, thwarted expectations and painful questions to which they will find answers only gradually. Each parenting role is challenging for many reasons and requires tolerating the uncertainty of future outcomes, especially in the case of parenting a child with developmental risks or disability.

Parenting means living with risk because parents never know what will be the long-term developmental outcome of a disease or condition that has affected their child. Even if their child is healthy, parents have no guarantee against a disease or an accident that may change the child's developmental trajectory. However, parents of children developing typically do not think about possible bad outcomes. And this is good. They intuitively know that problems are not solved efficiently in imagination or in advance, but when they are encountered. Then we address the problem such as it is, in concrete circumstances. The parent of a child with a developmental risk or disability often has an inhibited intuition, loses this intuitive concept, and their parenting has an addition, a "plus": fear in the present, and fear for the future.

Every child, developing either typically or with disability, deserves to be accepted with enthusiasm and to develop into a happy person. On that journey they are accompanied by parents who grow in these difficult circumstances, deal with endless problems, cope with both the expected and unexpected difficulties. This positive addition to their parenting inspired us to name the programme of workshops with parents of children with disabilities the *Growing up Together Plus*. The workshops help the parents grow together with the child. Their chances for better social inclusion, not only of the child with disability, but of the whole family thus grow as well.

In many years of working with parents, we have learned that it is easier for parents if they are not left to their own devices. It is easier when they realise that they are not alone in their fear, that experts are there for them, and that there are many other parents who already went through this and found many ways out. Fulfilled and adaptable parenting does not depend on the characteristics of the child, but on those of the parent. To strengthen their parental skills the parent needs various kinds of support.

However, when talking about the need for support, we must ask ourselves what exactly is the nature of the support that the parents of children with disabilities need, and how and where those needs can be met. This leads to the question of what issues the parents are predominantly preoccupied with. It is also important to choose the right techniques of communication with the parents of children with disabilities in order to successfully provide support.

When we talk about the parental right to support for the growth of parental competences, we must stress that the parents of children with disabilities have even stronger need to realize this right. This kind of support should be provided to parents, but also to children who need parents to encourage them in a way that helps them grow (Roggman, Boyce, Innocenti, 2008).

Parents of children with disabilities raise them in even harder conditions. They must invest additional efforts in the child care, such as frequent visits to specialists, recurrent hospitalisation and medical examinations, more complex daily care because the child is typically less independent, and they need more information. Besides, parents must go through the process of dealing with the fact that their child is different and that the future is less certain than they expected. Therefore, it is particularly important for them to seize every chance they have to realise their right to support. The *Growing up Together Plus* Programme of workshops offers them the opportunity to exercise some of these rights.





A recent research conducted by UNICEF (Pećnik, 2013) warns about the generally low availability of early parenting support programmes. This, of course, has even more serious consequences for the parents of children with disabilities. The same research confirmed what everyone who works with younger children with disabilities or chronic diseases knows. The parents tend to neglect themselves due to preoccupation with the developmental needs of their children. They completely forget that their strength is not inexhaustible. This attitude is also a consequence of the fact that the early support system in Croatia is not sufficiently developed and that the parents are looking for different ways to get the adequate developmental support for their child. They are also aware of the importance of early intervention, and given the fact that the system does not provide sufficient developmental support to children, this becomes their priority. It is not hard to understand why they lack the time to think about themselves. In order to understand the parents of children with disabilities, we will briefly consider the specificities of parenting children with disabilities.

### **Parenting a child with disabilities**

By assuming the role of parents, people do not simply get another life role in addition to the existing ones, but face an exceptional challenge to their personal growth. This is common to parents of all children, including the parents of children with disabilities. Hence, parenting a child with disability has all the features of any other parenting, but it comes with many additional ones. Besides, each parent lives parenting in their own way. We should steer clear of generalizations because the conducted research studies discuss the frequency of the phenomenon, but say little about the actual parents that we encounter and support. This is especially important to keep in mind when meeting parents of children with disabilities because the variability of their parental experiences and reactions is even higher. All parents are meeting their children's emotional, social, cognitive and physical needs. From the earliest age, they encourage them to engage in interaction and to understand the environment and enter the world of learning. Parents organize and equip space, develop closeness with the child, seize opportunities to gain experience, and look after the child's health and safety.

A recent extensive survey of parental actions conducted on young and preschool children has shown that there are no statistically significant differences between the rearing practices of parents of children with typical development and those of children with disabilities (Ljubešić, 2013). However, the research indicates that the parents of children with disabilities have a significantly stronger sense of concern about the behaviour and development of the child than the parents of children with typical development. Sixty-two percent of parents of

children with disabilities and 12% of parents of children with typical development are worried occasionally or often. The survey also found that parents make every effort to compensate for the child's disability so that the behaviour of their children would not be conspicuous. This is why they find the requirements of the parental role to be more burdensome and they report more often that sometimes or often they are unable to cope with them. They grade their stress level higher, and their health poorer than the parents of children with typical development. A particularly difficult situation arises if they have a bad financial situation, which is an extremely threatening circumstance in the child's development. An analysis of parents' answers shows that if we must speak of a special trait of parents of children with disabilities, it is exactly their desire not to be special. Therefore, the approach to their empowerment needs to be subtle because the problem does not lie in their children or in them, but rather in the life circumstances which hardly provide adequate support.

Nancy Miller (1994) believes that parents of children with disabilities go through different stages of adaptation to life conditions and the fact that they are raising a child with disability. During her 25-year long research of this process, which included a direct insight into family relations, she discovered that they manage to find inner strength which helps them adapt to their situation. However, they feel the need for some kind of support. She developed a model that outlines four stages in the process of adaptation. These stages do not necessarily follow one another. Sometimes they overlap or recur. The process of adaptation is dynamic and an individual stage can never be "definitely conquered". Certain events can activate changes in the parental feeling of security and disrupt stability, so that reversal from the already reached stage of adaptation is possible. The process is therefore best described not only as dynamic, but also circular. The support to parents in the particularly sensitive stages of adaptation, the so-called crisis periods, is a strong protective factor of the psychosocial stability of the family life and the family's active inclusion into the community. Also, it contributes to the creation of an environment in which a child is accepted and encouraged.

The first stage begins at the moment of realisation that a child's developmental outcome is connected with high risk, i.e. that the child has a disability. The author calls it "**surviving**". Parents often say that they remember every detail of the moment when they learned something was wrong with their child's development. This moment has been deeply etched in the memory both of the parents who learned this through the medical diagnosis and those who had had suspicions for a long time before their "nightmare was confirmed" (the words of one mother). The entire first stage of adaptation is characterized by strong feelings of helplessness and loss of control over their own lives. Given that every parent goes through the process of "surviving" in his/her own way, the duration of this stage is also determined individually.

However, this process is easier if the parents are informed that difficult feelings are a natural and healthy reaction to what has happened. They should be carefully reminded that as parents they also have to take care of themselves. There is a very strong tendency of parents to completely ignore themselves and their needs and to subordinate everything to what they think might be the needs of their child. The understanding of the child's needs is often narrowed in the sense of giving too much importance to therapeutic treatments of the child's (most evident) problems, e.g. motor skills. If the focus on one area of development grows to the extent that other developmental needs of the child are completely ignored, then the child's development, as well as the sense of parental competence, becomes further threatened.

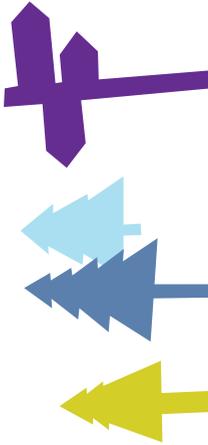
The second stage starts when the parent realises that his/her life will be different than planned. Miller (1994) calls this "**searching**" and it comes in two forms: "outer searching" and "inner searching". The outer searching begins with looking for the correct diagnosis and possible forms of help. In this phase, parents become very active in seeking help, but if they are left to themselves, this period can be very exhausting for them, both financially and mentally. The Croatian experience shows that this phase is significantly extended for parents. Firstly, it often takes too long to make a diagnosis and, secondly, there are no well-organised places where parents can get all the information regarding the needs and rights of their child and their family. Health, social and educational systems are insufficiently linked, both internally and with one another. For the time being, parents learn the most from other parents about all issues that trouble them as their child grows. Workshops and support groups organised to empower parenting skills offer additional opportunities to exchange information. Besides, parents find more and more information on the internet. In their effort not to miss something, they often invest all their time and money in the search for a "cure". Their inner searching is marked by questions such as: "What is the meaning of my child's disability to my life and my relationships with others, for my other children?" Thus begins the search for a new identity that will include parenting a child with disability. The expectations and plans that once existed are now re-examined and new priorities are set. This is a difficult period because in the stage of inner searching parents ask themselves a number of questions that they cannot answer immediately. They may feel depressed, anxious and incompetent for the parental role. For many parents, a large part of the inner searching means creating new expectations from the child with disability and family life. In the agony of searching parents go through a process of accelerated personal growth. Gradually, they manage to integrate the inner and outer searching. As a result, parents often become catalysts of changes that advance the social care of the children with disabilities. They have discovered that there is no answer to some questions, that life has many layers,

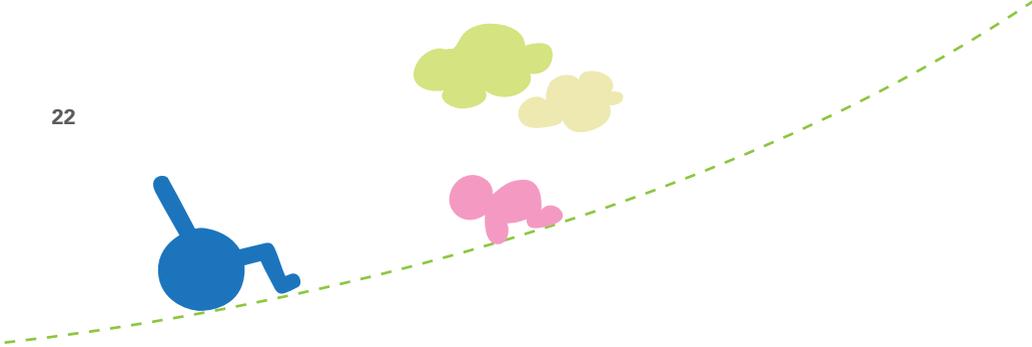
and that unpredictability is a part of many aspects of life. They have also discovered that the continuous progress of science and technology creates new opportunities for the future of their children. Searching never stops completely. It continuously adds new dimensions to parental understanding and gives them a new energy.

The next stage in the process of adaptation is called "**settling in**". The outer searching for various forms of help has subsided, the pace of family life has stabilised, and in most cases the child has been included in a therapeutic system, nursery or school. In this stage parents learn that they have gained new skills and new insights and that they understand many things in a new way. They feel more self-confident and assertive and know the ways of resolving problems. They also know the people and institutions that can help them.

The fourth stage by Nancy Miller (1994) is called "**separating**". Separation is a normal process that does not happen at once, although we are often unaware of that. It begins at birth and goes on in small steps from one day to the next. Gaining independence in an ever increasing number of activities involves separation. In the case of children with disabilities, this process is somewhat altered and slowed. Parents put forth special efforts to help their children become independent and enable them to take care of themselves. Children with typical development leave the parental home and start living on their own when they grow up. In the case of children with disabilities it is the parents who must initiate, plan and support the separation, which makes it a significantly different and more demanding parenting process. Separating is often filled with the same emotions that the parents experienced in the phase when they were faced with the child's disability. Many felt guilt and grief in this period. Making a decision about separation includes an enhanced inner and outer search of what was done or omitted. The end result, as shown by the research and experience of N. Miller, is the new "settling in" and bonding with the life of their child in a new way.

Experts play an important role in all described stages because they assess the length and quality of the process in which the parents have to come to terms with the fact that their child is not what they wished for. This process is experienced by all parents, not just those who raise a child with disability. Imagination and reality do not and should not match in either group of parents. Parents have the right and the need to continue to imagine and wish for their child the kind of future that they consider promising. However, this should in no way be exclusive, but remain open to all possible outcomes. The empowerment of parents also plays an important role here, in that it develops self-esteem and problem-solving skills. Empowerment is possible only if a partnership has been established between the parents and the experts. A partnership approach to parents means that parents have a say





in decisions-making, that their point of view is valued and appreciated, because they are the experts who know their child the best. The experts have professional knowledge and the best decisions can be made only by combining the two fields of expertise.

The empowered parents will maintain contact with the reality as it is. They will see the child and understand what the child wants, needs and can do at a given moment, and support them in every way they can while they are growing up. In the case of parents of children with disabilities this process is more complex due to the demands of the situation and the elevated level of parenting stress. In addition to increased levels of everyday stress, which the parents have felt from the early age of the child (Ljubešić, 2013; Kralj, 2012), the research shows that the needs of the mothers and the fathers are not identical (Kralj, 2012). The mothers feel significantly increased need for personal support (for friends and people with whom they can discuss problems, a time for themselves) and for communication with the environment (for someone's help in explaining the child's disability to family members, friends and strangers). One should always bear in mind that each family has their specific needs. Therefore, the basic rule to remember is that the most important need of a family is the one identified by the family itself and not by an expert (Krauss Wyngaarden, 2000). The needs that should be given priority are identified through conversation. The purpose of the conversation is to provide information and determine what troubles the parents. Conversations generate many sensitive situations that require a high level of communication competence of the support providers.

### **Communication about demanding issues**

Providing support to parents of children with disabilities by discussing their parenting always involves strong feelings and remind parents of the stressful moments when they first learned that their child's development would be different than expected. The goal of communication with the parents is to establish a relationship where parents feel that the professionals are on their side, that their relation is that of a partnership, and that the child's disability to be worked on together is on the opposite side.

Parents of children with disabilities have significantly increased needs for information. Every day they are faced with new and unexpected situations arising from the child's specific developmental and behavioural patterns. Furthermore, to be able to take decisions about the rearing and other practices and find access to appropriate services and programmes, the parents need more information about the child, its disability and the sources of

support. The most frequently mentioned need identified in a study on family needs, conducted on a sample of parents of preschool children with disabilities, was precisely the need for information (Kralj, 2012). A total of 90% of parents reported that they needed more information on the support services and programmes available to their child in the future. Also, more information about the currently available services and programmes was requested by 83% of parents, and more information on the methods of teaching the child was requested by 62% of parents. Given that the workshops aimed at raising parental competences and parental empowerment do not provide this type of information to parents, it is important that parents get them from educators and therapists who work with their children. The workshops should therefore also empower them for communication with experts. However, successful and efficient communication with parents requires knowledge about the parental perspective at all times. This is achieved by monitoring the parents' reactions during communication because every parent reacts in their own way.

Communication with parents of children with disabilities is often additionally challenging because it involves talking about subjects that are emotionally difficult for parents, since they evoke memories of traumatic experiences related to past events. When talking about difficult subjects, such as the diagnosis of disability or the child's limitations, the question is not whether or not to communicate accurate information, but rather how to convey it (Buckman and Kason, 1992). As for informing parents about the child's diagnosis, it was proven that an early diagnosis has long-term positive effects, because it initiates the process of parental coping and adaptation to the child's disability and, consequently, the creation of a supportive environment for the child (Bartolo, 2002). Given that the answer to the question "how to say it" does not entail simple instructions that can be followed consistently, it is important to be aware of communication barriers as they may differ from one case to another. It is also important to avoid and repair possible misunderstandings if needed.

An analysis of the conversations about "difficult subjects" and the communication of results of the child's achievement to the parents shows that it is a process of "negotiation", as it requires an active participation of both the parents and the experts in formulating the problem. It is important because it enables them to look together for solutions. Given that the child learns in a variety of situations, some of those problems are more in the domain of the parents, some others are more in the domain of the experts. One thing that helps is the so-called parent adapted approach, which involves empathy for parental fears and concerns, expressing a positive attitude towards the child, and pointing out to the parents that they already respond well to numerous child's needs in everyday situations. It is important to

actively compare the observations and insights of the expert with those of the parents. Also, all professionals involved should take a common stand on the issues of interest to the parents and make time for the parents to ask questions (Bartolo, 2002). There are some other helpful strategies that can be used when talking with parents about their child's limitations and disabilities; starting with positive results, choosing the words carefully, emphasising the improvement that is expected in the near future and what should be done in order for it to happen. Problems and "undesirable news" should always be incorporated into the information about how to proceed. This opens up a perspective for future actions. In doing so, the child should not be compared to others. Instead, the focus should be put on their progress in relation to a previous point in time. During conversations, it is helpful to ask the parents first what they already know, and then build on what is already familiar to them. In doing so, the child should always be called by name and any kind of generalisation or demonstrative pronouns, such as "that, those, these... children" should be avoided. The success of conversation also depends on many aspects of non-verbal communication: have we offered the parents a place to sit; are we sitting at same eye level; do our non-verbal and verbal reactions match; are we emotionally involved in the conversation; do we show clear signs of interest, etc. This kind of communication helps create a partnership with parents, which is essential for their successful empowerment.





## 2. "GROWING UP TOGETHER PLUS" PROGRAMME OF WORKSHOPS WITH PARENTS

### 2.1

#### Development, purpose and approach of the Programme

*Branka Starc*

The Growing up Together Plus Programme of Workshops with Parents is intended for the parents of children with disabilities aged up to eight years. Similar to the basic Growing up Together Programme, it consists of eleven conceptually and thematically connected workshops led by educated teams of experts in early development support.

After four years of experience in implementing the *Growing up Together* workshops with the general population of parents of the youngest children (up to four years of age) and the messages received from the workshop leaders, we have recognized the need for a programme of workshops that would respond to the specific needs and interests of the parents of children with disabilities. This led to a "sister" programme of workshops, *Growing up Together Plus*, developed in 2012 and 2013 under the auspices of the UNICEF Office. It is aimed at providing support to and empowerment of the parents of children with disabilities.

Why *Growing up Together Plus*? Parents of children with disabilities have a lot of "additions" to their parenting - they experience more fear and stress, more challenges and victories, and they need more information, more understanding, more professional work, more care from the society. We gave all these "additions" a common name: "plus". The workshops are conceived to empower parents by giving a positive character to this "plus" to parenting .

The *Growing up Together Plus* Programme promotes the same approach to parenting, the same basic goals and values as the *Growing up Together* Programme. We took into account the fact that parents of children with disabilities are faced with various additional difficulties in their parenting (in relation to the child, family members, community, and institutions, i.e. the system).

This Programme, too, was developed in collaboration with the leaders and parents who participated in the experimental workshops. Organised in 13 groups, they were conducted in

different cities of the Republic of Croatia in the spring of 2013. The experience and feedback of the leaders and the parents were invaluable to us in shaping the final programme. The *Growing up Together Plus* Programme was also subjected to the qualitative and quantitative evaluation of the results. These results show that the experimental workshops succeeded in achieving the planned objectives, therefore they also qualify this Programme as an evidence-based intervention.

The **purpose** of all Growing up Together programmes of workshops with parents, including the Growing up Together Plus Programme, is to facilitate the flow of information, knowledge, skills and support enabling the parents to fulfill their parental responsibilities and to promote the growth and development of both the parents and their children.

The **main goal** of the programmes of workshops is to create a stimulating and empowering environment in which the parents, together with the workshop leaders and other parents:

- exchange ideas about the ways in which they live their parenting,
- get to know themselves better as parents and
- learn about effective ways to cope with additional burdens in their lives,
- and the ways in which they relate to their child, and
- learn about other possible ways to raise their child.

They also become acquainted with the scientific views:

- on the positive interaction between the parent and the child, and
- on parenting in the child's (and the parents') best interest .



*A mother:*

*Maybe I did not get the answers I expected,  
but I got some answers that I needed.*

The Programme is based on the **approach of empowerment and partnership between the leaders and the parents**. Partnership means that the workshop leaders and the parents are *on the same level*. The leaders are well acquainted with the theories on the child development and parenting, they have experience in working with parents of children with disabilities, and they are experts in conducting the *Growing up Together Plus* workshops. The parents are experts for their children and for themselves and have the experience of living with their children in their own family. Parents seek validation of their competence and, although sometimes insecure, they are indeed experts for their children because they know them the best.

For the parents, the advantage of group work is an exchange of experiences, the knowledge that they are not the only parents with concerns, socialisation, bonding, new friendships, as well as finding the means most appropriate for them and their children, using group creativity and resources. The form of group work is especially useful to the individuals who, given the disabilities they are facing, need additional support. The workshops are primarily educational, but they also provide various forms of support to parents of children with disabilities. This includes emotional support by giving them a chance to express worry and empathy, encouraging support through the process of mutual respect and building of confidence, and instrumental and informational support through the exchange of experiences, information and efficient ways of coping. A specific source of support that alleviates suffering, strengthens and changes the experience of stressful situations is the feeling of belonging to a group of people who share similar experiences, same interests and social activities.

*One couple of parents ...*

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*... commented that they were pleasantly surprised with the workshops. Since they used to attend support groups earlier, they (spontaneously) felt the need to make a comparison - they said that before they had been given more opportunities to speak freely and be heard, but that this structure was also "OK" because it allowed everyone to have their turn and the work was interesting..*





*What the leaders said of married couples in the group:*

- *We had a married couple in the group – it was nice to see how they supported one another and how they "revealed themselves" to each other.*
- *It was very interesting and touching that the parents who came as a couple heard some thoughts and feelings of their partner for the first time.*
- *For the married couple in our group, it turned out to be good that they came together, because they worked out some things right there and with the group, things that they had failed to say to each other until then.*
- *We have three married couples and it is interesting to observe how they communicate as partners. They commented that they would never have heard what their partner thought had it not been for these workshops. Couples also have the need to talk about the changes in their relationship.*

As much as we are aware of the differences between motherhood and fatherhood, the Programme does not address **mothers or fathers** specifically, but rather *parents*. In the groups where only the mothers were present, a strong need for the participation of the fathers was expressed. We observed that married couples who attend workshops together get to know their children in a new way; they begin to talk about them and relate to them in a different way.

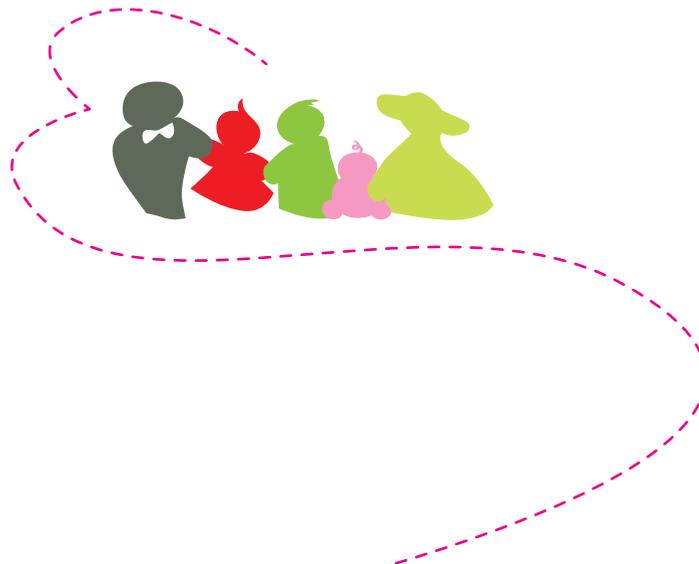
Given that some children with disabilities live with **guardians or foster parents**, who also strongly feel the need for support, their inclusion in the *Growing up Together Plus* Programme is welcome as well.

One of the special challenges to the implementation of the workshops is the diversity of participants and their **different expectations** from the *Growing up Together Plus* Programme. There are parents who seek more efficient ways to "convince" the child to accept a variety of treatments and therapies or to firmly set boundaries. They need encouragement to become more sensitive to their child's psychological needs. Then there are those who are too eager to meet the child's needs and indulge in their whims. They need encouragement to take greater personal responsibility for their own needs and limitations.

Another source of diversity in the group of parents of children with disabilities is their **level of adaptation to the child's condition**. It is a process which requires a lot of time and includes a whole range of reactions. There are significant differences in the level of adaptation reached by each family. This means that the parents in the group will respond differently to certain workshop activities, i.e. their perception of usefulness, attractiveness and suitability of those activities may be influenced by the level of their adaptation to the disability they deal with. It is therefore important to assess the readiness of some parents to participate in certain activities, observe how they feel about a particular situation and offer them support and protection when needed.

The **specificities of disability** and the way each child functions will also determine the way in which the parents respond, so it is important to take these differences into account. This is best noticeable in the activities where examples from everyday life are offered, and those should be adapted to the specifics of a particular group. There may be situations when the leader does not have sufficient knowledge to answer some specific parental questions about the child's disability, treatments, etc. In such situations, parents should be referred to the child's therapist or a counselling centre where they will receive the information they need.

As regards the **level and type of education**, the differences between group members contribute to the dynamics of discussions between parents and do not present an obstacle, since it has been shown that many parental issues are universal, and that they enjoy and worry about similar things concerning their children, regardless of the differences in education. The workshop leaders can also encounter parents of different cultural traditions. Due to all the differences that may be present in a particular group, it is important that the leaders pay special attention when they use their personal norms, values and beliefs. Instead of prejudices and criticism, the situation calls for a dialogue about the differences.



## Inviting parents to participate in the Programme

The *Growing up Together Plus* Workshops with Parents of Children with Disabilities can be implemented in a variety of institutions and organisations, provided that they are conducted by educated experts. The pilot project was conducted in kindergartens, rehabilitation centres, family centres and associations that bring together parents of children with disabilities. The circle of possible organisers may extend to associations that organise groups to educate and support parents, pediatric wards in hospitals, etc. However, we assume that parents will be most comfortable with the Programme leaders who work in institutions or organisations that deal with children with disabilities.

When inviting parents to workshops, it should be kept in mind that parents of children with disabilities have specific needs and expectations. It is important to understand the impacts of disabilities, the process of adaptation and all the problems that a family encounters. Clearly, they go through a lot more stress and suffering, more psychological and social problems. Although each condition generates specific problems, all parents share the need for support to overcome fear and anxiety and find effective ways of coping with stressful situations. This is most easily achieved in a group of people who understand them and share a similar experience and this is what needs to be stressed when inviting parents to workshops.

An important message to the parents of children with disabilities is this: we know the importance of supporting the development of a child; we understand the importance and complexity of the parental role, especially when it comes to parenting a child with disability; we are offering participation in the Programme of Workshops as an opportunity to realise **the right of every parent to support and help.**

Experience has proven that all the usual forms of communication with parents can be used to disseminate information and extend invitations to the workshops.

One of the powerful forms of disseminating information about the Programme to a larger number of parents is by so-called word of mouth. Parents who attended workshops know well their value and they are the best ambassadors of the *Growing up Together Plus* Programme.

Of course, in the "quest" for parents who could be included in the Programme, workshop organisers can turn to a number of institutions which have direct contact with the parents of children with disabilities. These are social welfare centres, first instance bodies for expert

evaluation, associations of parents of children with disabilities, rehabilitation centres, clinics, hospitals, kindergartens that integrate children with disabilities into their programmes, etc.

The experience in the pilot implementation has shown that it is very useful to invite parents to a **meeting** before the start of workshops and explain in more detail the objectives, work methods and duration of the Programme. Parents will then get a picture of what will be happening in the workshops and be motivated to attend. Then they can fill out the questionnaires that are designed to collect information and evaluate the success of the Programme, and the leaders will answer all their additional questions. Such informative meeting can also be arranged on a one-on-one basis.

Some parents may decide to join the workshops because the organizer has offered to provide **organised stay and activities for the children while their parents are attending workshops**, since sometimes parents of children with disabilities may have a problem finding a babysitter. However, we should bear in mind that the presence of their children in the next room could make it hard for them to focus and relax out of concern for their child and a worry that the child might call for them. Such concerns are eased if children know the persons who are looking after them (e.g. in a kindergarten, association, rehabilitation centre).



### What the leaders said about babysitting

- *Babysitting is a very strong motivation for parents and ensures the continuity of their attendance in workshops. In addition, the kids become motivators for coming because they want to attend "their" workshops. It is very important to enable the children to enter the workshop and see what their parents are doing at any time, and the other way around, as we have done. There are also opportunities for the children to spontaneously engage in activities with their parents. That makes the parents calmer and happier, and they do not rush if they do not have to. This flexibility in the approach to parents and their child has further corroborated and increased the credibility of our workshops, which always emphasise the need to take into account the child's needs, but also the needs of the parents.*
- *This is certainly a good motivation for the parents who have no other options. However, we believe that it would be better, if possible, for the parents to arrange the babysitting and come for two hours, which is the duration of a workshop. In the long run, they can benefit more from such an arrangement (use of resources and support from the family and friends; separation; building of confidence in some other important person in the child's life; and last, but not least, the time that parents can "steal" for themselves, their growth and empowerment, and feel that this is a right thing to do and that they are entitled to it, is - in our opinion and experience - a tremendous gain).*
- *This time, too, we organised babysitting. There were 12 children aged from nine months to six years. There were five volunteers and their leader - a speech therapist. They say it was very difficult - many children they did not know at all. On the other hand, the parents say it would be good to organise such workshops on a regular basis, so they could take their children somewhere. We understand both sides - new services are required!*
- *Since all parents expressed the desire (in application forms or personally) for an organised stay of children for the duration of workshops, we have made arrangements with the Bjelovar Organisation of People with Physical Disabilities. The Association will provide us with two to three assistants for each workshop, who will take care of the children (they work in schools as assistants to children with disabilities). We also engaged two of our volunteers and our dear Meri (secretary). We conducted a preparatory course with all of them (awareness of the uniqueness of each child, ways to approach a child/children, choice of activities, change of activities... child safety!!!). We were all very excited before the start because we tried to organise the space in our Family Centre to be as comfortable and safe as possible (we rearranged half of the Centre). Also, we prepared a variety of activities for the children, to make it easier for them to adapt to us and the space - which in the end went great. We thought it would be good to create a joint activity for the children. First we decorated the "Growing up Together Plus boxes" in which the parents placed / will place their evaluations. We must say that the children were very happy and proud of their work, just like their parents, and so were we. And, to make an even better use of the box, the parents can also slip in their initial questionnaires.*



At the same time, the organised stay and activities can be useful for a child in gaining new experiences, meeting and socialising with other children and adults. Of course, the benefits depend on the quality of the conducted activities. The stay should not be stressful for the child because of unfamiliar people or their unwillingness to separate from the parents.

#### *What the parents said about babysitting*

- *The child could play with other children and students for the duration of the workshops; separation from parents into a group of children.*
- *It is good that he went to a workshop with other children and now he plays more in the kindergarten as well.*
- *He plays with other children without my supervision.*

The selection of persons who will be engaged in the babysitting and activities while the parents are in workshops is up to the Programme leaders and their expert judgement. In the pilot project they found among volunteers – students of the Faculty of Education and Rehabilitation Sciences, assistants to children with disabilities in school, unemployed assistants, etc. This kind of activity can also be organised as an internship for students. It is important that the leaders be aware of the specificities and needs of each child (interviews with parents, meeting the child, etc.), so that they can assess whether the volunteers require some specific knowledge and experience to be engaged and/or educated and guided. It is important to ensure they are well informed about the specific characteristics of children and instructed on how to treat them. It is a great advantage if the children know the volunteers or if the volunteers are their educators. In some cases, the ratio of volunteers to children must be 1 : 1, but it should not be greater than 1 : 5, which depends on the characteristics of both the children and the volunteers. This is something to be decided by the leaders. In any case, apart from the volunteers there should also be a more skilled professional to guide and direct them.

It is also necessary to meet some spatial and material requirements for the children's stay and activities while their parents attend workshops. This space must be adapted for children with disabilities, with a special emphasis on maximum safety (many mattresses,



pillows, all sharp edges removed, etc.). Toys and materials should also be selected in accordance with the developmental needs of the children. It is good to organise some common activities in which more or less all children can participate. Perhaps needless to mention, but attention should be paid to the hygiene of the space and toys before and after the stay of children. Since the space has to be adapted and checked, it may happen that the organiser of workshops cannot provide an adequate space. In such case it can be arranged to use the premises of associations or institutions where adapted conditions are available (kindergarten, rehabilitation centre, etc.).

## 2.3

### Who is implementing the Programme

*Branka Starc*

The workshops are led by a team of two (or three) educated leaders. The Programme is highly structured, so that workshops can be conducted by experts with different experiences in this type of work with parents and/or children with disabilities (primarily psychologists and educational rehabilitators, but also speech therapists, social pedagogues, social workers, educators, teachers).

The leaders are experts in the field of early childhood development. They are well acquainted with the characteristics of the development, needs and behaviours of children and have excellent communication skills. It is equally important that at least one of the leaders has the knowledge and experience in working with children with disabilities and their parents. The experience in working with parents and the knowledge of disabilities may be more important than working with children with disabilities, given that workshops are primarily intended to support parenting. Parents and leaders together seek many answers in the workshops.

Equally important is that the leaders have experience in managing workshops, i.e. group work with adults (leadership skills, acceptance without judging, ability to understand the parents' point of view, etc.). It helps if the leaders have previous experience in implementing the basic programme of *Growing up Together* in which they became acquainted with the values of parenting in the best interests of the child, as well as the principles of partnership in working with parents.

When selecting future leaders, i.e. opting for education and implementation of the *Growing up Together Plus* workshops, it is essential that future leaders be truly motivated and ready for education in and conducting of workshops. In other words, their engagement should not be imposed by a principal or some other superior. It is also desirable that team members choose each other and want to work together.

Leaders have a key role and responsibility in the implementation of the Programme. Their knowledge and personalities have a strong impact on the group and its members, therefore they must constantly re-evaluate their own work, study continuously and work on themselves. The leaders are the ones who direct the activities of the group in accordance with the aims of the *Growing up Together Plus* Programme of Workshops with Parents.

### *What the leaders said about teamwork*

*The leader that conducted the workshop for the first time had difficulty controlling the discussion and the amount of relevant information that she had to convey to the parents in limited time. The other leader filled in at the right moments, so the activity went pleasantly.*

It is possible to engage **one of the parents as a co-leader** of certain workshops or individual activities. This option may be exercised occasionally only with an experienced leader, but also a parent with a dual role in life: the role of an expert and the role of a parent of a child with disability. Hearing her/his personal story will make it easier for the parents to tell their own. They will be encouraged by the parent co-leader who experiences the same difficulties as they do. The group will benefit even more if this person if she/he has already come to terms with the child's disability or condition. A parent co-leader may be someone who has completed the whole cycle of workshops. He/she can then become a co-leader in the next group or at a meeting of the Parents' Club. Of course, besides parent's readiness, the most important thing in deciding on the inclusion of a parent co-leader is the assessment of leaders.



## 2.4

### Some characteristics of group work with parents

*Marina Grubić*

Group work with parents is extensively described in the first book, *Roditeljstvo u najboljem interesu djeteta i podrška roditeljima najmlađe djece [Parenting in the Best Interests of the Child and Support of Parents of the Youngest Children]* (Pećnik, Starc 2010a). However, given its importance, we will further build on this subject.

Group work can be defined as a goal-orientated activity with small treatment groups and groups for solving tasks aimed at meeting the socio-emotional needs of its members and accomplishment of tasks. This activity is directed both at individual group members and the group as a whole within the broader system of providing services (Toseland and Rivas, 2001).

The idea was to form small groups in which members would meet their specific psychosocial needs, resolve certain personal and social problems, go through a personal and social change to cope more successfully with problems in their lives, perform work activities better, and develop the knowledge and skills important for a better understanding of themselves, other people and the community in which they live.

A group of parents of children with disabilities includes members who have specific needs and expectations which have to be identified in order to accomplish specific goals. These goals refer to providing emotional and social support and encouraging parents' self-esteem and self-efficacy. It is important to empower parents to take control over events and deal with them, understand and anticipate events and possible problems related to the parenting a child with disability. In doing so, it is important to train them in efficient communication with and support to the child and empower them for their parenting role.

**A mother:**

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*Little did I know that these workshops would affect me so much. I normally don't talk that much with people about what is going on in our lives, because they don't understand, so why waste words and time... I just say: Verica has cerebral palsy, and that's it... And I say this in such a simple and joyful manner as if she had the flu that will pass...:) Why bother people?!?! ... At the workshop, when you meet "fellow soldiers" WHO KNOW HOW MUCH IT HURTS, this is something else entirely... Thank you, thank you, I am charging my batteries, which is the most important thing. I will surely learn more with time and I want to thank you two because you are so patient with us... Do not follow literally the UNICEF template because all of us should be allowed (at least now at the beginning) to express our pain. And then when we let everything out, we can take in new information from you...*

One should be aware of the differences between group members due to different personality and disability of each child and the different perception and reaction of each parent to the process of adaptation. On the other hand, the advantage of group work is that those parents are united in their need for support.

Successful leading of a group presupposes the leaders' knowledge of the benefits and values of group work and the ways of stimulating and emphasising them.

The **advantages of group work** stem from the fact that group experience is a fundamentally natural human experience which gives people a sense of reality and, consequently, of predictability and stability. (Benson, 1987).

Group members have similar problems, experiences, feelings and behaviours. Members support one another by sharing them, whereby group processes become a means to achieve the intended objectives and help the members feel less alone in dealing with their problems. The actual experience of another member of the group who is successfully coping with a particular situation empowers others, provides them with hope and a sense of optimism. The group offers the opportunity to learn a new behaviour by observing how other members behave and act. It also provides an insight into their own behaviour, how they see themselves and to what they ascribe their behaviour and the causes of their difficulties.

#### *Values of group work*

- *sharing* – people feel less alone when they see that others feel the same;
- *identification* – people are willing to identify with others in a similar situation;
- *accepting help from "similar people"* – people accept help more easily from those who are in a situation similar to theirs, who understand them;
- *checking* – people in a group can be checked, tested in a variety of important roles;
- *mutual assistance* – people are often able to provide assistance to others who are experiencing the same or similar situations, which raises their self-esteem;
- *social exchange and acceptance* – people need a sense of belonging and acceptance, which is possible to gain in a group of people with the same experience.

One of the most important benefits of group work is the possibility of emotional relief by expressing one's feelings. Emotional relief refers both to the feelings related to current events and the feelings which a member could not express in the past.

Group work also entails the availability of different information from both group members and leaders.

#### What the leaders said about group development

- **After the first workshop:** *My impression is that we were very carefully observed and tested as leaders, and only the future will tell if we passed the test. The majority of parents let go of their reservations with time... There is hope for a positive outcome.*
- **At the fifth workshop:** *Two mothers who had been a little more reluctant about sharing their personal experiences with their children also opened up with the first activities in this workshop. It was nice to see and hear that.*
- **At the seventh workshop:** *All parents are very open, they give us a really great insight into their family life*

#### What the parents said about the gains from the Programme

- *I got a lot of new and very useful information and answers to questions that I had. I am especially glad to have heard the experiences of other parents. I got to know myself a little bit better with regard to parenting.*
- *Gaining new knowledge about children, raising them, the feeling that we are not alone and that everything can be resolved if one only looks for answers.*
- *I learned to be more patient with my child, encourage him to be independent, i.e. to perform as many everyday activities as possible by himself.*
- *I became more aware of work with him, i.e. realised that I have to talk more with my child.*
- *I follow the child's initiative well.*
- *I have become stronger and now my child has a stronger support.*
- *I started going to aerobics – time for myself.*

## 2.5

### Workshop leading skills

*Marina Grubić*

The skills in conducting workshops refer to the specific conduct of leaders which helps a group achieve its purpose and goals. These skills include communication skills that are used throughout the process of interaction between leaders and members and are important for the achievement of group tasks and goals, maintaining the group and establishing good relationships.

#### Directing

Directing the group to the fulfillment of its goals means:

- Paying attention to something that has been said or done and is important for achieving the goal. This is a situation where group members do not see that a certain statement or activity means progress toward goals, so the leader encourages and directs them toward the important things by pointing them out or rewording. The leader should therefore closely follow and listen to each sentence (or non-verbal reaction) of each member of the group, and at the same time take into account the structure and goals of the workshop.
- Returning conversations or other activities to the pre-agreed goal when the conversation turns from the group subject in the direction of casual conversation or some other issue, without the intention to return to the target subject. This skill is especially important in the case of members who talk too much or those who are prone to changing the topic.

#### Requesting and giving information

This is the basic communication skill that comes to the fore when first meeting the members, presenting and resolving problems, and giving and receiving feedback. The differences between group members related to extroversion, communication skills or current emotional state should be taken into account when requesting information. It is important not to expose a silent or introverted group member by insisting on their joining in or expressing an opinion. A helpful question in such situation is, for example: *Does anyone else in the group wish to express their experience or say...* It gives them the opportunity to speak if they want. When giving information, advice or recommendations, it is good to first ask the members to try to find a "solution" on their own, and then add what she deems important after summarising what they said, if necessary.



### Encouraging and balancing

This skill contributes to equal participation of all members in the work of a group. This is achieved by limiting those members who monopolise the conversation and encouraging those who speak little. The leader uses this skill when she notices that one or two members dominate the conversation, when some members do not take part in the conversation at all, or when most messages are directed to the leader and there is not enough interaction between the members. After assessing that a member is talking too much, she should interrupt them tactfully: monitor their speech to avoid interrupting them rudely in the middle of a thought or sentence. Then she should take the opportunity to interrupt them by repeating or emphasising what they said, redirect them by making a brief summary or posing a question to another group member. Interaction between group members can be encouraged by connecting similar experiences and encouraging the parents to help each other by exchanging information. The majority of activities in the workshops are structured to connect group members and encourage them to cooperate.

### Summarising

Summarising is the process of connecting and briefly repeating a certain conversation or an activity of the group by making a single statement. The aim of the summarising is to reach an agreement on what has been done in the group, and to point out what is important to achieve a goal.

When the leader wants all the group members to start from the same starting point, she should summarise previous activities related to the topic of the workshop that is about to begin.

Summarising is also used when someone starts a new topic before the previous has been covered or when one member dominates the conversation and the leader wants to include other members.

It is especially important to use this method when a workshop is near the end and it is necessary to summarise what has been said or done for the purpose of comparison with the initial goals and also to lay foundations for the next workshop.



### Sensitivity and appropriate response to feelings

The group leader can respond to the feelings of the group members in three basic ways:

1. make a mental note of the expressed feeling but without reacting, and continue with the ongoing activity or conversation;
2. indicate verbally that she recognises and understands the feeling, but then continue with the activity of the group;
3. stop the activity and focus on the feeling or on what caused it.

The leader's skill reflects in the appropriate choice of one of the three options, depending on the current activity and the atmosphere, the personality of the member who has expressed emotions, and on what caused a particular emotion. The leader should primarily think of the well-being of the member who reacted emotionally and show understanding and empathy. The leader must be able to recognise the feelings and react in a timely and appropriate manner.

For example, when a parent starts crying, it is good to stop for a while and say something to show her/him understanding and empathy (*I understand that you found it difficult* or something similar, depending on the situation). She should then continue by asking a question as emotionally neutral as possible that will help the parent calm down. The question can be directed to that parent if the leader sees that he or she is able to join again or to another group member if the leader decides that the parent needs more time.

By all indication, the parents of children with disabilities have a strong need to talk in a group of people where they feel like being "with their own kind" because they can say what is in their heart.

#### What the parents said

- *Thank you for helping me, if only to shed a tear.*
- *I have learned to talk about my feelings.*
- *Your workshops help, an excellent therapy that should last longer.*



### What the leaders said about parental empathy

- *The mother of the youngest child (3 years old) commented that she was still mainly focused on the problems and things to be achieved, which is something the other parents remembered from the beginning of their child's rehabilitation. Hearing that she felt reassured.*
- *They were especially empathetic toward one mother who was on the verge of tears every time she talked (throughout the workshop).*
- *When one mother burst into tears, the other parents got involved and said that they had also gone or were often going through the same situations. We encouraged them to say how they manage to defeat that feeling and move on.*

## 2.6

### What is done at workshops and how

*Branka Starc*

The *Growing up Together Plus* Programme of workshops for Parents is divided in eleven broader topics, i.e. eleven workshops. The titles of most workshops are identical or similar to those in the *Growing up Together* Programme:

1. *Every child is special, every parent is special*
2. *Between expectations and adaptation*
3. *The four pillars of parenting*
4. *Psychological needs of the child and parental goals*
5. *All our children and how we love them*
6. *Listening – an important parental skill*
7. *How a child learns about the world around them*
8. *Boundaries: why and how?*
9. *Parental responsibilities*
10. *Being a parent: influences and choices*
11. *The end and a new beginning*

Each topic is a separate unit, but also an integral part of the Programme, which would be incomplete without every one of the eleven workshops. No workshop can be held separately because they build on each other in terms of concept and content.

### Structure of the workshops

As it is common in educational and supportive workshops, each workshop in the *Growing up Together Plus* Programme begins with a "warm-up" exercise or activity, which introduces the topic and supports learning, creating a comfortable atmosphere in the process. The central part usually includes: a short expert presentation (usually with a PowerPoint presentation or handouts for the parents), activities and exercises (often with worksheets or handouts), an exchange of experiences by talking with the whole group or in smaller groups; sometimes a relaxing activity is squeezed in for relaxation between demanding activities.

At the end of the session, the parents receive handouts supplementing the topics discussed. Sometimes they are assigned *homework* which serves to check the newly acquired insights and knowledge in their own families. As a relaxation before the conclusion of the session, there are light games conceptually tied to the topic of the session, which stimulate bonding between the participants and may serve as an inspiration for play with children at home.

Here is an example of a story that the leaders read at the end of a workshop.

#### Street Cleaner (from the novel *Momo* by Michael Ende)

*"You see," the street cleaner said "it's like this. Sometimes, when you've a very long street ahead of you, you think how terribly long it is and feel sure you'll never get it swept. And then you start to hurry. Every time you look up there seems to be just as much left to sweep as before. And you try even harder, and you panic, and in the end you're out of breath and have to stop - and still the street stretches away in front of you. That's not the way to do it." He pondered a while. Then he said: "You must never think of the whole street at once, understand? You must only concentrate on the next step, the next breath, the next stroke of the broom, and the next, and the next."*

***And sometimes look back at what has been swept!***

### What the parents said about the workshops



- *I like the idea that the workshops are not based solely on expert lectures. The materials that we received are helpful, but exchanging experiences was more important to me. Thank you!*
- *Additional information and the knowledge that other parents are facing similar problems, new experiences.*
- *Contact with other parents who have children with different, but also similar disabilities. A new way of communication and direction towards the child's needs and abilities.*

### Size of the group

Workshops should include **from ten to a maximum of 12 parents**. The trust between participants is created more slowly in larger groups, they have fewer opportunities to speak, activities last longer. If a group has less than six members, the group dynamic is lost, the quality of discussions and the amount of constructive exchanges of experience are reduced.

Most leaders in the pilot implementation agreed that a group of eight parents is ideal for quality work.

### Time and duration of workshops

As a rule, the entire eleven-workshop programme should be implemented in eleven weeks, **in two hours once a week**. When inviting parents to join the Programme, it is important to inform the parents of its duration and the need for regular attendance at all of the workshops so that the workshops can achieve their full purpose and impact. The parents are expected to attend regularly.

During the experimental implementation, the parents were occasionally absent from workshops due to different therapies and medical examinations of their child. In such cases, the leaders helped the parents in different ways to compensate for the missed workshop. They sent handouts to parents, invited them to individual meetings, used concise repetition at the next meeting, suggested earlier arrival of parents at the next meeting in order to familiarise them with the content of the workshop which they did not attend, etc.

### What the leaders said about "compensation":

- *In the first cycle, parents were sometimes absent from the workshops for various reasons (especially due to the child's health or previously scheduled medical tests), for which we suggested compensation in the form of earlier arrival at the next meeting in order to summarise the contents of the missed workshop. The few parents who were absent came at the time scheduled for compensation. It was also the time when other parents started gathering, so we seized the opportunity and encouraged the parents who attended the previous workshop to pass on their experience, knowledge and skills with the help of the leaders. So the parents became our assistants.*
- *Compensation is required whenever possible. Individual meetings or meetings with several parents should be arranged (at a separate time, before the next workshop...). At those meetings, we went through some of the activities, retold some others, conveyed the atmosphere of the workshop, distributed handouts. The parents said they found it useful.*

Workshops are usually held in the autumn or spring, depending on the possibilities of organisers. The autumn period usually begins in early October so the last workshop takes place before Christmas. The spring cycle usually begins in early February.

As for the time of day, the leaders adapt to the parents. Workshops are usually held in the afternoon, after working hours (5-7 pm, 6-8 pm). However, we also had good experience with morning groups (8-10, 9-11 am) that were organized during the children's stay in a rehabilitation centre or kindergarten, which also solved the issue of babysitting. Of course, morning meetings are possible if the parents are not employed.

## 2.7

### Preparations for the implementation of the Programme

*Branka Starc*

#### Preparing aids and space

Before the start of workshops, it is necessary to do some practical preparations, both before the beginning of the Programme as a whole and immediately prior to each workshop.

A **room** large enough for the group, preferably with some extra space for exercises and games, should be prepared for each workshop. It can be a room belonging to

a kindergarten group, a meeting hall, teachers' room, meeting room, public library, association premises, etc. The arrangement of the room conveys the message to the parents that they are welcome. The leaders sit in a circle with the parents as equals. If the organiser is unable to provide a laptop computer and a projector, a map with posters that replace PowerPoint presentations is used. Supplies and handouts to be prepared for each meeting are listed for each workshop.

### Preparations of the leader team prior to the workshops

The leaders must prepare for the workshops carefully even if it is not their first time. The entire *Growing up Together Plus* Programme of Workshops for Parents, as well as each individual workshop, are clearly structured to present certain topics and the entire Programme in the most efficient way possible. A good practice is for all leaders to speak for equal amount of time in each session. Alternating between the leaders makes the workshops more lively and the leaders more secure and spontaneous.

#### One leader:

*It is decided who does what, who is "more ready" for a certain part, "which part is easier for whom"; it is important to know who will jump in and where if needed; interaction - verbal and non-verbal - is agreed upon, as each group requires a "different" approach...*



## 2.8 Conducting the workshops

*Branka Starc*

To establish a pleasant workshop process and security in the group, and to “protect” the participants, it is important to agree upon the **rules of group work** at the first meeting with the parents. It is important that everyone accept the rules.

The experience so far has shown that the following rules may be useful:

- Voluntary nature of active participation
- Accepting differences
- Listening to others
- Minding the total time
- Everybody speaks for themselves
- Being discreet

How the participants address each other is also subject to agreement. Although it is commonly suggested to turn off cell phones during workshops, the parents of children with disabilities usually want to be available and may be asked to turn off the sound and leave the vibration. The parents say they prefer to leave their cell phones on so as to be sure that their children at home are well, and to instruct their household members to call only when really necessary. If the children are in the next room with the volunteers, it should be agreed upon that parents can briefly leave the room to calm down both the children and themselves. Since some children are for the first time in a group of children led by an unfamiliar face, the concern of the parents is understandable. The work should begin and end at the prescheduled time. Also, no pictures of the group may be taken without the parents' consent. Naturally, as role models, the leaders have to comply with all the rules and agreements.

Sometimes parents will want to prolong the conversation on a subject, so the leader will have to structure the workshop carefully to enable such conversations. The group can agree to extend the workshops for about ten minutes for those who can and want to stay, or to set aside time at the beginning of the workshop for those who want to share something important with the others. In such case, the leaders will have to reduce the duration of some activities (e.g. those with more detailed handouts or games). If there is a need for additional support, the leaders will arrange individual meetings and discussions with parents or refer them to relevant professionals.



### What the leaders said about conducting the workshops

- *The workshop lasted for 2 hours and 15 minutes. We do not know how we spent those 15 minutes, and it doesn't seem like any activity took longer than scheduled.*
- *Through their comments, the parents would often start a topic scheduled for later. The leaders would then successfully manage to connect the two (discussion with parents and the scheduled activity topics). The leaders had the impression that some parents wanted to continue the discussion and expand it to other important topics, but they tried to summarise the discussion and get back to the topics planned for the first workshop, with the remark that those topics would be discussed more in future workshops.*
- *During the first activities, we spent a little more time than planned on the parents' spontaneous discussion, so we had less time than anticipated on other activities. However, we felt the need to allow the parents to share their experiences and I think this helped them to connect from the outset.*
- *It is more important for parents to be able to talk about specific issues that bother them, rather than to complete the planned structure of the workshop. On the other hand, we think that the structure is a lot more useful than they think. Their need to "vent" is strong, but it can be accomplished outside the workshops as well.*

The leaders must transition from one part of the workshop to another in order to ensure a logical flow between the activities. Each activity should be introduced by connecting it to the previous one; the activity should be summarized and the next one announced.

The speech register should be adapted to the parents present so that the leaders are sure everybody can understand them, regardless of their education level.

Although the workshops and handouts are carefully and thoroughly written and PowerPoint presentations are clear, it is important that the leaders devise as many examples as possible when preparing for each workshop. The examples have to be carefully chosen to suit each particular group of parents. This often depends on the type and degree of their children's disabilities, their limitations of movement, communication and understanding. The Handbook lists only general examples, so the leaders are expected to be flexible and creative, and rely on their knowledge and experience.

In an exchange of experiences, the leader encourages a discussion that enables the parents to better see and understand their own experience. The leader is the one who connects the experiences of the group.

At the end of the workshop, it is important to summarise what has been said and noted, emphasise the main points (in accordance with the workshop goals), and thus wrap up the topic. It also makes it easier for the leaders to link it later with the next topic.

When inviting the parents to join in the play at the end of workshops, it is important to tell them that its purpose is to bring about relaxation and relief before leaving (sometimes in the middle of the workshop), that we are not childish, and that we do not consider them childish. But, given that parents play with their children, this is also an opportunity to learn some new plays. Of course, if they do not want to, parents do not have to join. At the beginning of the Programme, parents may be surprised by the fact they will be playing, but they grow to like playing, and by the end of the workshop they often ask, "What are we playing today?" They also inform the group how their children reacted to the games.

*In one of the groups:*

- The parents embraced the play called "The wind is blowing", and once again confirmed how very similar, and yet so different they are.
- "Planting a garden" - They liked it, it was fun and relaxing. Even those who are usually serious were smiling.
- It was accepted with a lot of laughter and jokes, both the parents and the leaders enjoyed the exercise.

**In the activity named "Three wise thoughts" parents receive three sentences cut into pieces that need to be connected. In search of the solution, they cooperate and begin to know each other.**

- What do / good gardeners do? / They help / a rose become / a rose. / Mothers and / fathers are / like good / gardeners.
- Those / who / conquer / fear / can / scare / even / a tiger.
- There are no / hopeless / situations; / there are / only people / who / feel / helpless / in certain / situations.

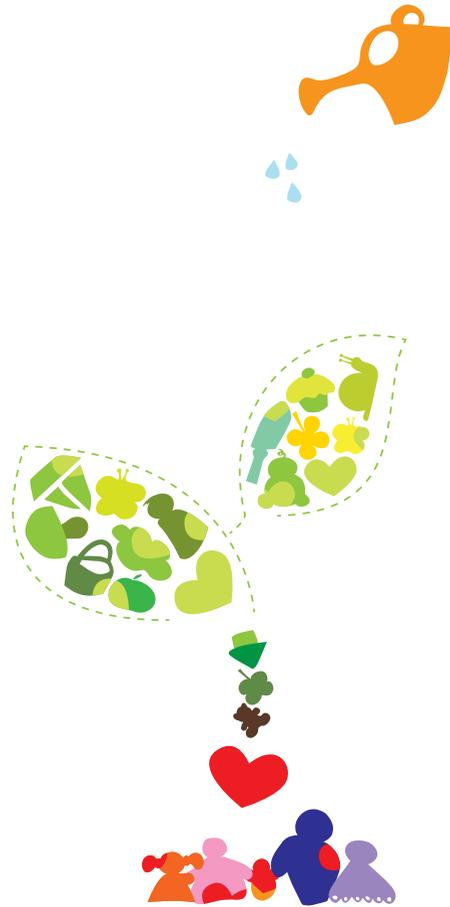
## 2.9 After the workshops

*Branka Starc*

Mutual feedback of the leader team should follow immediately after the session. If this is not possible, then the next day at least a short exchange of impressions after the workshop, a sort of emotional release, for which the leaders should plan to stay for at least 15 minutes after the workshop.

### *What the leaders said about the joint review of the workshops*

- *It is obligatory to sit down after the workshop, first ask how we feel, then how it was with the two of us, how it went with the group members, whether there is anything to comment, point out... then discuss the content, pace, timing, etc. At the end of the meeting we have to discuss the new workshop – divide the roles and arrange to meet before the new workshop to discuss possible traps and concerns.*
- *Review – RIGHT AWAY! This is when we sort our insights, misconceptions and opinions; talk about group dynamics and elaborate leadership strategies for the future workshops – how to encourage the quiet and silence the talkative...*
- *Reviews are extremely important for the leaders to "vent", especially after workshops which can be emotionally exhausting, but also to comment on the course of the workshop and discuss what could or should be different in the structure, what should and in what way be changed or "fixed", which leadership skills the leader thinks are (in)adequate, which parent needed more of something and how to offer it to them in the future.*
- *The best time for a review is immediately after the workshop, when all the details (or at least most of them) are still fresh in the memory. They can be used to plan future changes. This is also a way to establish cooperation and trust between the leaders, "learning" to give and receive feedback. It is important that the leader who conducts the activity hear the observations of his co-leader. Also, it gives an opportunity to the leader who does not currently conduct the activities to learn more about the process.*



# 3. EXPERIENCES IN THE IMPLEMENTATION OF THE PROGRAMME

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## 3.1 Experience of leaders

### What we have learned from conducting the *Growing up Together Plus* workshops

Over a period of one year, through support groups, we worked and met with the parents of the young children diagnosed with deafness or grave hearing impairment at the Association of the Deaf and Hearing Impaired People of the Primorje-Gorski Kotar County. My co-leader Marija and I decided to offer parents a different kind of support in the *Growing up Together Plus* workshops.

More specifically, after a year of meetings, we already became well acquainted with the context in which parenting of "our" parents was happening. Their parenting was characterised by frequent visits to specialists for various diagnostics and therapies. It was burdened with difficult decisions (cochlear implant: yes or no?), everyday challenges of wearing a hearing aid and worry if it was properly tuned, information about the importance of early intervention, and exhausting efforts to make it happen. They were receiving contradictory messages about the sign language (will it cause the child to speak less?), situations where they could not enrol their child in a crèche, or find a babysitter (because of the child's disability), exhaustion caused by waiting for appointments and diagnoses, constant fear that they would not have enough time or money to make the right decisions...

But we also heard that despite this stressful environment they talked about their parenting like all other parents - with a lot of love and some concerns. Basically, they have the same needs for support and information like all the other parents with children of that age.

The group enabled us to open up a wide range of topics related to parenting, which we had not successfully addressed in our previous work. At every meeting we would get questions to which parents expected concrete answers, ready-made recipes and clear instructions, just like they used to get from the professionals to whom they had turned for advice about their child. In one of the comments on the meeting, one mother wrote that as much as she liked to chat, she was looking for answers, e.g. what she should do when her little girl refuses to wear a hearing aid in the kindergarten? Clear and concrete (that was written and underlined on paper) as well as stimulating for us to offer to the group something new through participation in the pilot programme of the *Growing up Together Plus* workshops. Of course,

we knew the workshops would not bring clear and concrete parenting recipes. However, based on the experience in implementing the basic programme of *Growing up Together*, we knew that in the workshops parents would learn how to be more responsive to both the child and themselves and how to look for answers together.

The Association of the Deaf and Hearing Impaired Persons of the Primorje-Gorski Kotar County played a big and important role. During a break of several months when we did not hold meetings the Association kept the group together with a series of activities for children and parents. It took upon itself to enable children and parents to exercise their rights. Also, they were a constant source of information and support in the realisation of these rights. Parents would bring their children to the workshops at the Association to learn the sign language or meet with the educational rehabilitator and the speech therapist. The parents were eager for knowledge, support and companionship, which the Association provided by complementing what the system was unable to provide. The fact that the parents felt good and welcome in the Association certainly contributed a lot to a good turnout at workshops and confidence in what we had to offer. The first meeting was attended by three married couples and four mothers. A total of eight parents finished the entire cycle of workshops.

Although I was an experienced leader of the *Growing up Together* workshops, and Marija had experience in working with "our" parents, the three situations that took place at the beginning of our workshops were our greatest challenges.

We faced our first challenge at the first workshop. The work plan of eleven consecutive weeks every Tuesday for two hours seemed too ambitious and unrealistic to the parents. Until then, our group would meet once a month and even that was too much for some parents. Both they and their children had many obligations. They feared that their tight schedule would not allow two hours per week for workshops. The biggest fear was that their children would be deprived and that they would lose what little time they had for free play. We talked about that fear, about mixed feelings, i.e. their desire to come to the workshops and the fear that this meant loss of valuable time for the child. We believe that we finally "won them over" by recounting experiences of other parents (who completed our basic *Growing up Together* Programme, despite the same initial concerns). But, the parents quickly picked up the pace. They were rarely absent, usually due to their child's illness or work. This group was also initially reluctant and startled about the frequency of meetings, but soon they wondered how the end came so soon and when we would see each other again.



Hoping that organised babysitting would help them decide whether or not to attend the workshops, we started a discussion about babysitting at the first workshop. The Association was ready to organise the work with children during the workshops. While this practice had been very useful and important in many pilot groups, our parents did not accept it. This was because we combined babysitting and our work when we would meet as a support group. Since the children were babies and/or toddlers, we would all often end up in the hall area or the children would come to us, so the parents now decided to separate the children's activities – to make the work easier.

The transition from the support group to the workshops was another great challenge that we faced early in our work. *Growing up Together Plus* are highly structured 2-hour workshops that leave little time for unstructured free conversations. However, our group had a strong, almost inexhaustible desire for sharing experiences, collecting information and off-topic conversation. Later we found out that this made "our" parents a typical group of parents of children with disabilities, characterized precisely by an increased need for information. In the beginning, it was extremely difficult for us to lead them and keep track of the scheduled content and time. Driven by their need and the past experience, almost every activity encouraged them to start another topic of conversation. We balanced between the need to follow the programme and the parents' need to share their experiences and talk. There were times when we would begin half an hour later than scheduled, especially if a parent with new experience or information came to the workshop. We would let them talk first because the group could not do anything but soak up information (e.g. about how the surgery went), provide support (because the new medical report was worse than expected), or feel happy about a video of the first communication with the child in the sign language. At that time, we balanced the most between meeting the parents' needs and following the Programme and group rules. Through an honest talk we managed to agree that in the beginning they would have 15 minutes for a quick "round" where everyone would briefly say what was new, but without commenting, exchange information on how they were, how the children were and what had happened. We also agreed that we would extend the workshop for 15 min to meet the pace and content of the workshop. They were happy with this agreement. The topics from the first round often continued at the café or one of the parents felt like staying for a while longer and talking to us individually. The transition from the support groups to the structured workshops was not a positive change for all parents. Most parents said that they preferred structure and that they learned something new every time, whereas a few parents said during the evaluation that they lacked the freedom to create topics and the opportunity to talk and listen.

The third challenge waited for us in the second workshop when we talked about learning of the child's disability and coping with it. The fact that they were in our group clearly indicated that they had already gone through the phase of coping, and accepted the child's disability. However, this does not mean that the knowledge about disability diminishes grief, anger, fear and trauma. We knew by experience that for some parents this workshop would be the first opportunity (or the first time they will venture) to talk about what they went through in the early days of parenting. Although we had already been working with parents for a year, this workshop opened the subject of coping in a qualitatively different way and caught us somewhat unprepared for the amount of emotions and traumatic experiences that the parents shared. After this workshop, we, as leaders, thought long about the ways of dealing with emotions in subsequent workshops. Fortunately, the leaders are never alone at workshops. All group members were always ready to provide support and empower the members in need. This was an encouraging thought that we embraced later on in our work.

As the workshops continued as planned, the group and the two of us as leaders continued to grow. We began to notice more and more that the workshops went easier, in terms of both content and time, as the parents became closer to each other and more relaxed. We noticed that they started to socialise outside the workshops as well.

Today we are happy about the fact that we have successfully overcome the first challenges and completed our first (pilot) group of the "Growing up Together Plus". We are even more thrilled to see that these workshops had multiple benefits for the parents, since most of the group members still meet spontaneously (a year and a half after our work together) at children's birthday parties, joint excursions, have coffee together... In light of the knowledge that parents of children with disabilities have a relatively poor support network of relatives and friends, the fact that they made friends and support each other is maybe one of the greatest achievements of this Programme for its participants.

*Sonja Pribela-Hodap*

### **How we became leaders *Plus***

The "Vrbik" kindergarten has a long tradition of enrolling children with disabilities in the regular groups. It has three teams implementing the *Growing up Together* Programme of Workshops. The parents of children with disabilities also participated in this Programme. During the workshops we became aware of the special needs of these parents and were



happy to accept the invitation to participate in the implementation of the pilot programme of workshops for parents of children with disabilities, the *Growing up Together Plus*. We are one of the two kindergarten teams in Croatia that took part in the pilot project.

The *Growing up Together Plus* Programme promotes the same approach to parenting and support to parents as the *Growing up Together*. They share core values and goals. Given that parenting of children with disabilities imposes additional efforts, challenges and fears, we can certainly call it parenting *plus*.

Does parenting *plus* require leadership *plus*?

The workshops in the *Growing up Together Plus* Programme are led by a team of two leaders and not three, as in the *Growing up Together*. In our case, this is a well-tuned team (affectionately known as 2M) that has conducted a lot of workshops together. As a team of leaders we feel competent, trust each other and are compatible in almost all situations, one could say – we understand each other without words. We were happy and truly motivated to start the workshops with parents of children with disabilities.

We thought about which parents to invite to workshops. Should we invite only the parents of children with disabilities who have medical reports and opinions? Should we also invite the parents of children with incomplete reports? What about the parents of children who are still in the diagnostic process, and the parents who are in denial of their child's disability? What about the parents who are not even aware of the child's disability?

We decided to invite the parents who were aware of the child's disability (regardless of medical records).

We spent a lot of time devising a way to invite, inform and get them interested in workshops that last for 11 weeks. We usually present the *Growing up Together* Programme at the parents' meetings of kindergarten groups. Our tactic for inviting the parents of children with disabilities to the *Growing up Together Plus* Programme of workshops was quite different. We made a list of parents and invited them individually. We jokingly called this "ambushes" as we would wait for the parents in the kindergarten halls and invite them to the expert team's room. We explained to them the purpose of the Programme and pointed out that participation was voluntary. At the end of the conversation, each parent received a letter with brief information about the Programme and the time and venue of the workshops.

We also invited a few other parents whose children do not go to our kindergarten, but friends and acquaintances told us about them.

Seven parents accepted the invitation (including one married couple). The parents who joined us had children with different disabilities.

The workshops were conducted in the educator's room of one of our facilities. There was always some coffee, juice and cookies. Coffee was a particular source of joy for the parents because, as they said, they could finally "have it in peace" after several years.

Preparing workshops, dividing activities, arranging the room, sorting materials – it all required the same amount of time and energy as in the *Growing up Together* workshops.

The past experience with the *Growing up Together* workshops helped us a great deal in conducting the *Growing up Together Plus* workshops. We were familiar with most topics, we knew the routine, the course and changes of activities, so we could focus on the emotions and reactions of parents. Our knowledge of certain types of disabilities, the experience of working with children with disabilities and our almost daily communication with their parents was also extremely useful.

During the entire cycle, the communication between us as leaders and the parents was positive and supportive. We were on the same footing and our relationship was based on mutual respect.

The specificities of the group became apparent to us very quickly. When defining group rules at the first workshop, it turned out that the same rules did not apply!

Mobile phones had to stay on because of their constant worry about the child's condition (and the babysitter)!

Although the parents did not know each other, a genuine emotional charge was present, which made the group homogeneous very quickly. By the second workshop, they knew the names of all the children and asked each other (and us) about them before each workshop.

The parents were happy to share their experiences and opinions on their own, and they usually did not have to be further encouraged. They told the group about the most personal things in their lives in full confidence, and the group was very warm, supportive and discreet. It was obvious that they had a tremendous need to talk, share experiences and "vent". The parents recognized the opportunity and the chance to share their concerns in front of the group that would pay attention, understand, support them, propose new ideas.

Due to their need to share experiences, it was difficult to handle the time. As a result, the structure and dynamics of the workshop often differed from the one set out in the

Handbook. Sometimes it was hard to stop the parents and remind them of time because their conversations were so substantive, useful and necessary. Occasionally, we would let the parents talk and devote less time to other activities.

*Once it happened spontaneously that we just talked with the parents for the entire duration of the meeting. They told us about their children and the way they applied what they learned at the workshops. They were happy to have the opportunity to share their thoughts and fears, as well as listen to other parents who were in the similar situation. It was important for them to hear how other parents dealt with the obstacles that they encountered every day. It suited them that they could express thoughts and feelings in the workshops, not just listen to instructions. They mentioned that these workshops were their only outing without the children, because they were so preoccupied with the developmental needs of their children that they neglected their own needs.*

In comparison with the parents in the *Growing up Together* Programme, the parents of children with disabilities were more involved in all the activities and topics in the workshops. They were a much more dynamic and involved group. Additional explanations were rarely necessary. After each activity they gave feedback on the self-insight they had gained and explained how they would apply these lessons to their relationship with the child (e.g. closer observation of the child's non-verbal messages, taking into account the child's reactions and acting accordingly).

*In the activity called "Following the instructions" the parents of children with disabilities were a lot more careful and focused on the instructions. Their parenting plus taught them to carefully follow instructions and adhere to them.*



One mother in particular stood out with her optimism, her way of coping with problems, good communication, quick self-insights, great reflections and conclusions. She often helped us summarise the activities and further motivated the parents to think and reflect and try out the techniques they learned. We see this mother as a potential parent co-leader in some of the workshops in the future cycles.

Parents were more often absent from workshops in the *Growing up Together Plus* cycle, mostly due to the child's condition. The parents made up for their absence by coming to talk to one of us during the week or by arriving earlier at the workshop. Then we would briefly retell them the content of the previous workshop.

During the fourth workshop we conducted an activity in which parents were assigned to imagine their child in the future. We feared this activity knowing that their children were different and that their future was more uncertain. Generally, the parents in the *Growing up Together* Programme had an idealised image of their children's future. They fantasised about their children as successful athletes, businesspeople and family people. By contrast, parental expectations in the *Growing up Together Plus* Programme were not focused on external achievements, but on the child's personality. They were positive and happy and imagined their children as honest and happy adults.

We also had a dramatic situation when one parent had to leave a session due to the child's condition.

### Our gain as leaders

Each group is a new experience. And this was a great experience *plus*!!

We have noticed a significant improvement in the communication with the parents of children enrolled in our kindergarten who participated in the pilot programme of *Growing up Together Plus*. Now they talk to us more frequently and extensively and it is much faster and easier to arrange for individual work with a child or make changes to the programme. They continue to inform us about the child and the family. They share with us both their joy and sorrow, and sometimes they just come to say hello and ask how we are doing!

Now we understand much better the challenges of such parenting. In the past we did not think about how a child with disability can be entertained while waiting for hours to see a doctor, how to take them to the store or on a trip, how to find a babysitter, how it feels when your own sister will not invite you to her child's birthday because of your child.

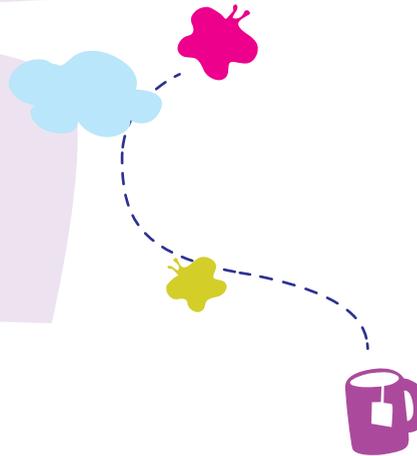
When we now meet new parents of children with disabilities, we ask different questions, give more support and encourage them to find time for themselves. Due to our increased sensitivity to parenting *plus*, more and more children with disabilities are being enrolled in our kindergarten.

We feel enriched by the knowledge of what these parents encounter, of the fears, love and courage that they generously shared with the group. This was also our personal and individual growth.

Conducting the *Growing up Together Plus* workshops was the conducting *plus*. Although it was more emotionally demanding, we felt more fulfilled. We see the satisfaction of the parents, hear their positive feedback and a desire for further cooperation and meetings. This makes us feel useful and workshops are now the best part of our job.

*We are thankful for the opportunity to be a part of the Growing up Together Plus workshops.*

*We wish to thank all the parents from our Growing up Together Plus group for their trust and for everything that we received and learned from them.*



*Minja Jeić and Martina Smiljanić*

## 3.2

### Experience of parents

#### **The workshops have connected us. They are no longer an obligation, but a chance to socialise**

The first thing that comes to mind at the mention of the UNICEF *Growing up Together Plus* workshops is the slight initial discomfort that I felt thinking how I would have to spend two hours each week with other parents of deaf children for three winter months of 2013. In the invitation, I noticed in particular the accounts of the parents who attended similar workshops and made progress in communication with their child, which was a priority for us and our daughter at the time.

During the period when the time for personal needs seemed like an unattainable luxury, my husband and I were reluctant to spend several hours on education with an uncertain outcome. In the end, we concluded that UNICEF was a respectable organisation, and we also had a lot of confidence in the workshop leaders that we had met in the previous activities of the Association of the Deaf and Hearing Impaired Persons of the PGK County in Rijeka.

Our girl was almost 2.5 years at the time. She had been wearing a cochlear implant for 12 months, she responded extremely well to auditory stimuli, and to the satisfaction of myself and my husband, she spoke better and more frequently.

Nevertheless, our everyday life was still full of challenges. The hardest thing for us was the fact that she grew used to our availability at all times – either to play or for vocalisation – which brought her pleasure and progress, but we were pushed to the limits of exhaustion. It seemed to us that she was turning into a little tyrant and that, instead of becoming more independent, she was increasingly relying on us. We decided to come together.

The practical value of the workshops soon became evident. They would usually start with playing, which was not so great (we had enough of that at home). However, it was interesting and fun to share concerns, joys and an occasional vivid anecdote with other parents. At first, we were all a bit skeptical and only sympathised with one another, but later we opened up and shared experience and advice without reservations, whether or not it was required from us.

With a lot of laughter and the unforgettable wafers, the workshops were no longer an obligation and soon they turned into socialising, almost outings. Quite a few participants have remained a part of our lives even after the workshops ended. We continue to see

most of them, call each other to trips and family gatherings, celebrate children's birthdays together. This proved to be an invaluable gain.

In addition, we got a lot of written material in the workshops which my husband and I have consulted to this day, whenever we feel we have returned to our old patterns of behaviour, and walk (again) the path of impatient and authoritarian parenting. Personally, I can always use the recipe that proved useful and good that winter: set clear expectations, adhere to agreements, give feedback, criticise the behaviour and not the child, differentiate the child's needs from desires, remember that we are not perfect so why expect that from the child.

The workshops have made us a living proof that perfectionists like the two of us can do something right even without hard work (planned activities) in the relationship with the child, just by following her (good) impulses. We have learned that we must show her our love even when we are angry. The principle of reciprocity soon became manifest – she knows that we love her even when we are not always available or when we don't allow her something, won't give her something, etc. Not a single day passes without negotiation, pouting and tears, but everything always ends in hugs, kisses and with a statement that even an imperfect parent can never get enough of: "Mum/Dad, I love you!"

*Aleksandra Filipović, Tara's mother*

### **Formulating and expressing fears and questions was very helpful**

UNICEF's *Growing up Together Plus* workshops designed for parents of children with disabilities and led by Marta Ljubešić and Branka Starc were a great experience for my husband and me. They helped us in many ways exactly at the moment when we needed such help the most.

Families whose child develops differently from other children are in a truly demanding situation. Uncertainty, fear and anxiety emerge from the moment they notice that their child is different from his or her peers. They grow deeper until an assessment in a specialised institution confirms their fears. Choosing the right therapy, organizing life within and outside the family instills only more fear.

I speak from the perspective of a parent of a child with an autistic spectrum disorder. Our family life changed; ordinary things like shopping, going to the movies or for a walk in the park became more difficult, more complex, less accessible. Even when we managed to organise them, it took us more strength to carry them out, and afterwards we often

felt completely defeated, desperate and hopeless. We were angry, guilty, sad, mad, tired, exhausted. Communication changed between family members, between my husband and me, our daughter and us, us and friends. Our priorities, life goals and expectations changed... Our whole life was suddenly in a vacuum and chaos, and it was at that moment that we came to the workshops. They were extremely useful in several ways.

The workshops are very well balanced with respect to the ratio between theory and reflection, so that they gave us the theoretical knowledge on some important issues, such as different approaches to raising the child, the stages of parenting a child with disability, possible strategies for coping.

We also got the opportunity to analyze our situation and relationships through the prism of the new knowledge. It was useful to hear that everyone went through similar periods, to know what was happening to us at the time it was happening, and that hard times pass. It was difficult for me to recall Leon's worst moments, but the hardest of all was to figure out and put on paper my expectations of him as an adult. Such reflexive activities were extremely emotionally challenging for all of us, since we did not dare to go to these painful places until then. I think the despair of about a dozen of us parents was almost palpable. However, this was followed by the activity of sharing and talking with other parents. Skillfully facilitated by the leaders, this activity ended up with changed emotions and a relief from anxiety. Such processes were the backbone of the Programme and its greatest value. A particularly good activity was the one with the puzzle of personal growth as parents, which served as an indicator and a milestone of our development through workshops from one week to another.

Finally, it was very difficult, but also extremely liberating to share our innermost thoughts with other parents. The carefully planned workshop processes came to the fore here. Reflection was usually extremely challenging for us and required looking for answers in difficult places. It was followed by the activity of sharing with others - here we profited on several levels. We were able to formulate and express our fears and questions, which was very helpful; become aware that we are not alone because all parents have similar fears; hear other parents' answers or solutions (or simply "we went through this stage, and so will you") and give someone a useful advice about something that we had already been through. All this made us stronger and brought us closer.

In a different way, it also connected me and my husband in an entirely new context. As "students in the same class", we spent a long time talking about the things from the workshops and commented on each meeting until the next one.

The atmosphere in the group had to be especially convivial if we were to carry out all the demanding tasks, and still return to the workshop the next time. It was relaxed and we felt safe; we could laugh, cry, participate or not participate. Right at the beginning, the leaders started with a high-risk activity that succeeded and gave a relaxed tone to the entire Programme.

The fact that we, the parents, attempted in the end to "negotiate" an extension or a certain continuation in the form of at least one meeting speaks for the quality of the Programme. After the isolation and separation from the majority of "normal" families we all found a place where we felt comfortable, where people understood us when we talked about our children and lives, and where we could get the right information and answers to our questions and problems. The Programme addressed precisely those areas that are of the greatest importance and use to the parents of children with disabilities. Most importantly, it addressed them in the best possible way – practical guided reflection – the way that helped parents the most in their development and empowered them to make personal changes, overcome the current life crisis, reshape their families and create healthy family relationships.

One particularly good aspect of the Programme was a one-time attendance of a mother of a child with disability as a co-leader. She covered an emotionally demanding and difficult subject. We left the session empowered by that insight into the experience of a parent as we could identify her emotional states and feel the power of the solutions and strategies based on the direct experience that she offered.

It was very nice to see a mother who was at the point where we are now, who has managed to overcome anxiety, fear and disorientation, get back to work, perform well at work, and resume her normal life, be cheerful, optimistic and able to help others. And happy. Ana-Marija has helped me a lot, both through her advice and examples.

I think that the Programme would benefit from the participation of parents as facilitators, co-leaders in certain workshops, provided they are educated (in the basics of communication, group dynamics and the content and processes of workshops), which is important given the sensitive subject of this course and emotionally sensitive participants, and the extremely important effects of the Programme.

*Natalija Andraković Kostanjevac, Leon's mother*



### Proud climbers

When we learn that we will become parents, we feel that every segment of our lives is about to change. Certainly, our expectations always go (and should go) in a positive direction. We expect the delivery to be easy, that our baby will be eating well and immediately begin to sleep, that we will have enough time to take care of our other children, pursue a career, have leisure time, etc. This does not happen so easily, but most of us survive these little disappointments because parenting can in fact accomplish all of the above, but it takes *time* to learn how to harmonise desires with capabilities.

When we find out that we will become parents of a child who is at risk for disability or this disability is already established, all the expectations from the introduction sink to the deepest depths and it often seems that there is no way out. Luckily, there is! But the *time period until everything mentioned in the introduction falls into place* doubles, triples, quadruples... even centuples sometimes.

During this time, we atypical parents search for useful therapies, accurate diagnoses, go "to the end of the internet and back" to find if somewhere in the world there was a child identical to our own that "got away", we cry, fret, despair and exhaust ourselves to the ultimate limits - physically and mentally.

And we typical experts try to shorten and lessen this *initial difficult time period* in order to speed up the establishment of a good everyday routine and the harmonisation of our expectations with our capabilities. The question is what helps? How can this transition to the good phase be cut short? One should bear in mind here the diversity and uniqueness of each parent. But this is what strengthens, encourages and guides: useful information on disability, good examples of overcoming everyday challenging situations with atypical children, information related to parenting as challenging as it may be. And all of this is important to experience through the living word, from another parent in a similar situation. This is exactly what one can experience in the *Growing up Together Plus* workshops with parents.

Almost all topics of the workshops are typical parenting topics. All parents should know about the four pillars of parenting and think about which pillar is shaky. They should learn how to listen because listening is one of the most important skills in the modern times of noise. It was a relief for me to learn that I, as a parent of my atypical son, have the same concerns as my neighbour Ana who has a typical daughter. This meant that although we are different, we are also the same - we are both mothers. As for the dear "fellow soldiers" in the workshops, it is very encouraging to hear examples on how to lull a child more easily,

how to deal with the environment, or how to tell a story so that the child can understand and experience it.

As for myself, I developed a sense of pride during the "Climbers" activity. It is actually a sketch of a tree and climbers. Some are sitting at the base of the tree, some are hugging, some are very high looking down, some are standing on the side, some are waving, some are falling... The task was to indicate which climber we were at the time when we learned about the child's disability and where we are now. I selected my climbers very easily. At the moment when I learned that my son was seriously ill, immediately after his birth, "I held on tight to the trunk", feeling that if I let go just a little, everything would fall apart. That period required strength. And now, I am more relaxed, I am "sitting on a branch and waving" because that time from the beginning is now behind me. My husband and I have survived it (that is why I also circled the climbers who are hugging) and we know that hard times will come again, but we know how to cut them short and go through them as painlessly as possible. It is precisely in these workshops, with these climbers, that I became aware of this and that is why I am proud of our family.

*Ana-Marija Bohaček, Jakov's mother and educational rehabilitator*





# 4. EVALUATION OF THE GROWING UP TOGETHER PLUS PROGRAMME

Ninoslava Pećnik

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## Introduction

Evaluation of the effectiveness of the Programme in achieving its goals is one of the assessment criteria for the quality of the parenting support programmes (Oates, 2010). It reflects the growing demand for the evidence-based psychosocial interventions. When developing the *Growing up Together Plus* Programme, we tried to meet the high quality standards of support programmes for parents which are, *inter alia*, set forth in the Council of Europe *Recommendation (2006)19* on the policy to support positive parenting and in the guidelines for the development of prevention and treatment interventions aimed at protecting children from violence (Åsmussen, 2011).

The evaluation of outcomes of the experimental implementation of the *Growing up Together Plus* Programme was aimed at establishing whether this Programme serves its proclaimed purpose, i.e. whether it facilitates the exchange of information, knowledge, skills and support that help the parents of young children with disabilities in fulfilling their parental responsibilities, and promote the development of competence of parents and children.

To accomplish this purpose, two versions of the Programme were created, the abridged and the extended version. They consisted of six and eleven workshops, respectively. The abridged version was intended for the parents who were assumed to be more willing to join a programme which required less of their time. The goals and activities of the workshops were quite similar in both versions, except that almost half of the content was left out in the abridged version.

The *key question* to which we sought answers in the evaluation study was whether (and how) participating in the Programme made a difference to the parents' experience, their need for support, certain parental behaviours, and the realisation of desirable changes in both the parents and the children.

The outcomes of the Programme were evaluated on the basis of the "pre-post intervention" model. It involved the group that did not participate in the Programme and the *two-arm quasi-experimental design with an uneven and untreated group* (Milas, 2000). The data was collected from the extensive survey that included either holistic or adapted measures of: parental stress (subscales: Lack of support, Incompetence and limitations to the parental role; Profaca and Arambašić, 2004), parental morale (Trute & Hiebert-Murphy, 2005), family needs (subscales: Need for information, Need for personal support, Need for



support in communication with the close and broad environment; adapted from Bailey and Simeonsson, 1988), interactions with a young child (Pećnik and Starc, 2010) and measures of the desirable and achieved changes in close relations, designed for the purpose of this study.

The efficacy and relevance of the new *Growing up Together Plus* Programme was examined in the spring of 2013 through the collaboration of the experts who participated in the programme development project (as workshop leaders or coordinators of the control group) and the parents (as workshop participants or members of the control group). The abridged version of the Programme was implemented in five groups of parents in the kindergartens “Radost” in Crikvenica and “Cekin” in Slavonski Brod, the Rehabilitation Centre of the Faculty of Education and Rehabilitation Sciences and “Mali Dom” in Zagreb. The control group comprised parents from the kindergartens in Zagreb, Rijeka, Opatija, Šibenik, Zadar, Osijek and Slavonski Brod.

The extended version of the Programme was implemented with eight groups of parents in the “Vrbik” Kindergarten in Zagreb, the Association of the Deaf and Hearing Impaired People in Rijeka and the family centres in the Bjelovar-Bilogora County, Dubrovnik-Neretva County, Istria County, Primorje-Gorski Kotar County, Šibenik-Knin County and Vukovar-Srijem County. The control group included parents from the “Latica” kindergarten for children with disabilities in Zadar, kindergartens “Duga” and “Vladimir Nazor” in Zagreb and the kindergartens in Rijeka, Opatija, Šibenik and Osijek.

As we anticipated that regular attendance in the workshops would be important for the efficacy of the overall Programme, the evaluation study included the parents who participated in more than 80% of the Programme workshops. This was the case in 75% of the parents participating in the abridged Programme and 58% of those participating in the extended Programme. The evaluation study also included the parents who participated in two-thirds of the Programme (18% of the parents from the abridged and 33% of the parents from the extended version of the Programme).

The parents who did not participate in the Programme were also included in the evaluation study along with those who did. The control group consisted of the parents who stated they would definitely (N = 24) or probably (N = 35) participate in free workshops for parents of children with disabilities, and the parents who responded that they did not know whether they would participate (N = 8).

The evaluation of outcomes of the Programme showed that most of the expected changes were not achieved (Pećnik and Ljubešić, under review) so that only the extended version of the Programme, with the results shown here, was selected for further implementation.

## Data collecting procedure and participants in the evaluation study

The survey was anonymous, with a code that enabled matching the surveys completed prior to the first workshop and after the eleventh workshop. The untreated parents from the control group and the Programme participants took part in the survey at the same time. The data collected from the Programme participants and the control group was analyzed in accordance with the appropriate statistical procedures. Those procedures were aimed at establishing the differences, if any, in the results of both groups at two points in time. The full report on the effectiveness assessment of the *Growing up Together Plus* programme is available in Pečnik and Ljubešić (under review) while the main findings of that research are summarized herein. In addition to that, this chapter provides results of an analysis of qualitative data provided by the Programme participants regarding impact of the programme on various domains of parent's or child's experiences.

The evaluation is based on a sample of participants in the Programme which comprised mostly the mothers (90%) with secondary school (63%) and university (24%) education, aged 36.6 years in average, from two-parent families (90%) with two children. The average age of the child with disability was slightly over five years. A total of 40% of them attended a kindergarten, and 40% did not, while there was no data available for 20% of children. One half of the parents received the confirmation of their child's disability more than two years ago, for a quarter the diagnosis was established between two years and six months ago, and for a quarter it was established less than six months ago. The most common disabilities of children of the parents who participated in the Programme were genetic syndromes (28%), impairment of speech and voice communication (25%), motor impairment (25%), hearing impairment (18%), hyperactivity (15%), impairment of other organs and organ systems (15%), intellectual disability / mental disorder (13%), visual impairment (13%), autistic spectrum disorder (12%), multiple impairments (12%) and other disabilities.

The comparison of the characteristics of the Programme participants (treatment group) (N = 67) and the parents from the control group (N = 60) showed that the two groups did not differ in terms of their sociodemographic features. However, some differences were found in the type of disabilities of their children. In the treatment group, there were more parents whose children had a genetic syndrome, hearing impairment and impairment of another organ or organ system, and fewer parents of children with impairment of speech and voice communication or autistic spectrum disorders. Also, fewer children of parents in the treatment group were enrolled in a kindergarten.

### Results of comparing the participants and the non-participants before and after the Programme

The first group of performance indicators in the Programme related to the **experience of parenting** a child with disability.

The parenting morale index (Trute & Hiebert-Murphy, 2005) measures the frequency of emotions (or affective states) that parents most often experience every day in their role of the parents of children with disabilities. This includes uncomfortable / difficult emotions (e.g. anger, anxiety, loneliness, guilt), as well as affective states that represent psychological resources of coping (e.g. optimism, fulfillment, happiness).

The results of the comparison of *parental morale* before and after the participation in the Programme indicate that it *strongly shifted towards a higher level*. This change was not found in the parents who did not participate in the Programme, and whose score did not differ from that of the participants in the Programme at the first measurement point. The established difference was interpreted as a probable consequence of the efficacy of the Programme in strengthening parental morale, and thus increasing the parental psychological well-being and coping resources with the demands of parenting a child with disability.

The assessment of parental experience also involved measurement of the intensity of parental stress arising from the lack of support from the environment, the feeling of incompetence in fulfilling the parental role and to the limitations of the parental role. The content of the original incompetence scale of (Profaca and Arambašić, 2004) was adapted to the parents of children with disabilities. The compared results of the treatment group and the control group of parents, did not indicate any statistically significant differences, and there was no evidence of decreased intensity of parental stress related to the investigated sources. This finding did not match the expectations, and the indicators related to parental stress should be tested in the future implementation of the Programme. However, it should be noted that the qualitative data collected from parents after the Programme do point to the experience of increased level of parental competence and decreased level of parental stress.





The second group of the Programme performance indicators related to the **needs** of the parents who have children with disability. Among the needs for support, significant differences before and after the participation in the Programme were established in regard to the need for personal support in coping with the demands of the parental role, and the need for support in communication with the close environment. It was shown that the parents who participated in the Programme *had a more pronounced need for personal support in parenting after the Programme than before the Programme*, especially in regard to the need for more friends that they could talk to, and the need for more time for themselves. Since these changes were not found in the parents from the control group, we attributed them to the efficacy of the Programme in raising parents' awareness of the importance of taking care of their own personal resources and the sources of personal support in their environment that help them cope with parenting a child with disability. It should be noted that the comparison of the Programme participants with the control group showed that the need for personal support was significantly more pronounced in the Programme participants than in the control group. A significant difference was also found in regard to the need for support in explaining the condition of the child with disability to close persons. *The need for support in communication with the close people was weaker after the Programme than before the Programme* in the Programme participants. This is attributed to the impacts of the group work, particularly the exchange of experiences between the parents and acquisition of new knowledge on how to build relationships with other children in the family. As regards the pronounced need for information, there was no significant difference in the results before and after the Programme.

Given that the ultimate purpose of the Programme was to influence the **frequency of parental behaviours** experienced by children with disabilities, an important indicator of the Programme's efficacy was the data on possible changes in the frequency of the parents' desirable and undesirable forms of interaction with the child in a seven-day period before completing the questionnaire. The participation in the workshops indicated a more significant shift towards improvement in the area of undesirable parental behaviours, than in the case of desirable parenting behaviours.

The results have shown that *after the Programme the parents reported significantly lower frequency of yelling at and hitting their child with a disability on the hand or bottom* in comparison to the frequency of these behaviours over the seven-day period prior to the Programme. These changes were not identified in the control group of parents. No difference was found in the frequency of undesirable behaviours after the workshops between this control group and the Programme participants, whereas higher incidences

of yelling in the Programme participants were found before the cycle of workshops. It is concluded, these changes are ascribed to the effects of the workshops and we consider them as a confirmation that the Programme contributes to the reduction of verbal and physical violence of parents toward children with disabilities.

In total, the changes in the parental feelings and behaviours in their role of parents of children with disabilities indicate an increase in “parental morale”, the need for personal support and a decrease in the need for support in explaining the condition of the child with disability to the close environment. Also, they indicate lower frequency of undesirable behaviours, such as yelling and hitting the child with disability after participation in the Programme.

Since no such changes occurred in the parents who did not participate in the Programme, we believe that they are most likely the effects of the Programme due to the methodological limitations to the evaluation study which does not allow for causal inference. The generalization of results is also limited by the fact that the data was collected on a double selected sample of the parents who participated in the workshops and attended regularly until the end.

Also, expected changes were not identified in regard to some indicators where they were expected in line with the goals of the Programme. However, the evaluation of outcomes of the *Growing up Together Plus* Programme is not based only on the previously presented results obtained by comparing the changes between the participants in the Programme and the non-participants, but also on the additional data collected only from the participants in the Programme. They include information on the **desirable and realised changes** as a result of participating in the Programme.

When asked, prior to the first workshop, what they wanted to change in their lives through participation in the *Growing up Together Plus* workshops, most parents (45%) reported “the relationship with my child with disability”. After the eleventh workshop the parents were asked to what extent they accomplished changes in certain areas. *Most of them responded that their relationship with the child with disability had changed* (for 37% “a lot” and for 41% “moderately”), while only 5% responded that it remained unchanged.



Before the Programme, a relatively large number of parents (38%) stated that, through participation in the workshops, they wanted to change how they felt as parents of children with disabilities. The responses after the Programme were as follows: *for most workshop participants the personal experience of parenting a child with disability changed a lot (35%) or moderately (36%), for 21% it changed a little, and for 9% it did not change at all.*

Before the Programme, nearly one third of the parents wanted to change something in the behaviour of the child with disability, with the help of the workshop leaders and other parents. The parents' answers after the Programme indicated that twice as many participants noticed positive changes in the behaviour of their children. Specifically, *the behaviour of every other child with disability changed a lot (26%) or moderately (24%), while for 15% it changed a little.* The changes in the child's behaviour included greater satisfaction and joy, independence, composure and attention, increased cooperation with the parent (more obedience), more negotiation with the parent, better communication and better control of aggression. Finally, 35% of the parents responded that the behaviour of their child with disability did not change at all.

Before the Programme, over one quarter of the parents said that they wanted the workshops to help them achieve changes in their relationship with other family members: another child (28%) or partner (27%). After the Programme most parents noticed a significant (33%) or a moderate number (35%) of *changes in their relationship with another child*, and 45% recognized these *changes in relationship with their partner.*

At the end, parents could also add if they wanted to change anything else through their participation in the Programme. Before the Programme, 17% of participants said they wanted changes in the category of "something else", while after the Programme twice as many

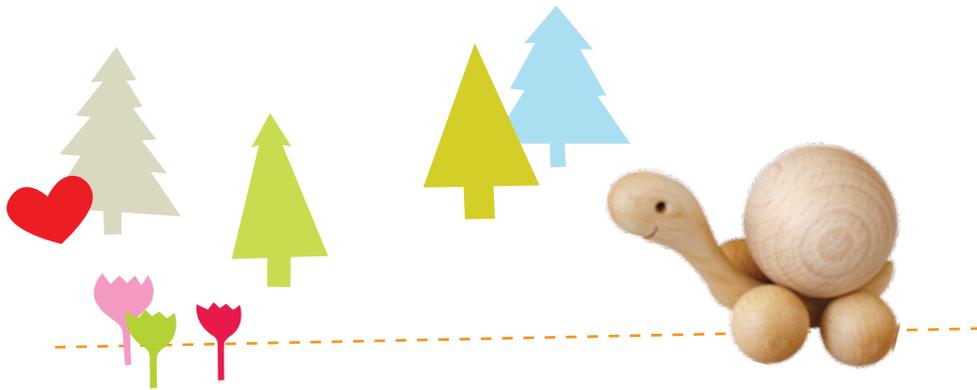


participants reported that changes in this category were achieved to a great or moderate extent.

“What questions do you want answered by the workshops?” gave us an insight into **parental needs**. The questions that they listed were grouped into several thematic areas: facing new challenges (e.g. How to achieve a balance between caring for a child with special needs and *normal* life?), focusing on the child and optimal response to the needs of the child (e.g. I would like to talk to other parents and see how they function and if I can do even more for my child in specific areas of development.), increasing the feeling of confidence (reducing insecurity) in their rearing practices (e.g. I would like confirmation of my behaviour, what is good and what is not.), empowerment and understanding of the child (e.g. How to develop the child’s self-esteem?).



After the Programme, more than a half of the parents (54%) stated that they had found an answer to their initial question. An additional 43% said they had received a partial answer, while 3% had not found the answer to their question(s) in the workshops. Since it is evident from the sample questions that some cannot be answered through workshops, the results indicate considerable efficacy of the workshops Programme in meeting parental needs for support – the ones that they defined themselves.



## Responses to open-ended questions after participation in the Programme

The evaluation of the efficacy of the Programme was complemented by qualitative data collected through answers to three open-ended questions that the parents gave in the evaluation survey at the end of the Programme.

The analysis of content was made on the basis of the parents' answers to the request to state the **changes that were prompted by participating in the Programme** of workshops, *Growing up Together Plus*. It showed that the majority of parents (every other parent) reported the *changes in their relationship and behaviour towards the child with disability* – in terms of greater involvement, better understanding of the child, greater appreciation of their needs and problems, more patience and more listening to the child.

- One in five parents stated that the Programme brought about *changes in the personal experience of parenting and an increased insight and confidence in their own internal resources*.
- One in eight parents *realised the value of exchanging experiences and of group support* as a change prompted by the Programme.
- Participation in the Programme was reflected in the relationships with other family members as well. One in ten parents stated that they noticed *changes in the relationship with another child or partner*.
- Finally, several parents mentioned that participation in the Programme encouraged them *to seek or use resources in their environment for the child's or their own empowerment*.

Parents also stated where they **personally benefited the most** from participation in the workshops. The majority of them (42%) stated that the *support from the group, the opportunities to exchange experiences and making new friends* was the most useful for them.

- The next benefit related to *new knowledge and information about the relationship with the child*. It was reported by 20% of parents which was half the support of other parents that they identified as the most important benefit.
- The most tangible benefit from participation for nearly one fifth of parents was *personal growth, opportunity for personal development and time for themselves*.
- One eighth of the parents in the Programme benefited the most from the *acquired knowledge and skills or parenting "tools"* (listening skills, setting boundaries, I-messages and other communication skills).

- Another eighth of parents saw the opportunity for *reflection and raising awareness of their own parenting and life situation* as the main benefit from participation in the workshops.
- Finally, a small number of parents reported *an improved understanding and appreciation of their child as a person* as their personal benefit from the Programme.

In order to get an insight into the possible effects of the Programme on the child's experience, we asked what parents thought was the **most useful benefit for the child ensuing from the parent's participation**.

The most common answers were in the first three categories, and each was mentioned by almost one quarter of the parents.

- In the opinion of the parents, their participation in the workshops made them understand and appreciate their child better and come closer to the child's perspective.
- *Progress in the child's development and independence*, partly related to the socialisation with other children during the supporting activities organised for the children of parents in the Programme, was seen as the child's most useful gain from the parent's participation in the Programme.

The benefits for children who accompanied their parents and attended the "children's Programme" while the parent was at the workshop were especially emphasized here.

- In addition to having a parent who has become more sensitive to the child's perspective, the parents believe that the child's greatest gain from the Programme is an *empowered, happier and more patient* parent.
- One sixth of the parents believe the child's greatest benefit from their participation in the workshops is that *parents can now meet the child's needs (and solve problems), including setting boundaries more appropriately*.



- One sixth of the parents believe that the child's greatest gain is that they got a *parent who has more knowledge*. A small number of parents think that, owing to their participation in the Programme, the child's main benefit was that they *spend more time with the child in activities that are (also) fun*.
- Finally, one answer mentioned the discovery of new sources of support for the child (finding experts, joining the Autism Association of Istria).

Overall, the results of the content analysis of the parents' answers to questions about what the Programme meant for them and their child with disability clearly show that these benefits are consistent with the determined goals of the workshops.

## Conclusion

If the results of parental subjective views on the effects of the Programme on them and their children are combined with the results of the analysis of the quantitative indicators of changes in the experience of parenting and parent's interaction with the child with disability (Pećnik and Ljubešić, under review), it is possible to conclude that they provide an initial confirmation of the efficacy of the *Growing up Together Plus* Programme in achieving the goals related to the empowerment of parents and enhancement of the conditions for promoting the well-being and development of children with disabilities.

Finally, considering the results of testing the efficacy and adequacy of the new parenting support programme for parents of children with disabilities, it can be concluded that the Programme was effective in achieving some, but not all of the goals. More specifically, the expected changes in regard to the measures of parental stress were not achieved. Further improvement of the Programme and its evaluation are our future challenges.





# 5. DEVELOPMENT AND EXPANSION OF THE PROGRAMME

*Branka Starc*

Without doubt, the future development and expansion of the Programme depend predominantly on well educated leaders. There is a training plan for all *Growing up Together* Programmes, including *Growing up Together Plus*, on how to implement workshops, monitor their implementation, and maintain their quality.

Organisations (kindergartens, family centres, rehabilitation centres, associations, etc.) that are willing to implement the *Growing up Together* or *Growing up Together Plus* workshops should have a team of leaders, i.e. two or three educated experts.

The training of workshops leaders includes:

- initial training seminar,
- conducting of the first cycle of workshops with supervisory support, and
- evaluation seminar.

Experts associates in the helping professions, such as psychologists, educational rehabilitators, social pedagogues, speech therapists, social workers and pedagogues, can be trained in conducting the of the *Growing up Together Plus* Programme of workshops. Educators with extensive experience in conducting the *Growing up Together* workshops, those with experience in working with the parents of children with disabilities and those who are highly motivated, can also be trained for the *Growing up Together Plus* Programme.

During the three-day initial seminar each leader receives a *Growing up Together Plus* Leader Handbook. At the end of the seminar the newly trained leaders sign the *Declaration on the Programme Protection of Integrity*, whereby they agree to implement the Programme in keeping with the guidelines and values set out in the Handbook and not to use either this Programme or any of its parts for other purposes and especially not for commercial purposes, as they understand that the Programme was created through citizens' donations to UNICEF to be available to all parents and used for the common good. They also undertake to join the Leader Network in order to ensure the quality of the Programme implementation.

The training is conducted by the authors of the Programme and appointed regional leaders. It is recommended that the seminar participants have already completed the training in the basic *Growing up Together* Programme and that they have conducted at least one cycle of this Programme (at least one team member). The professionals who commence the training

with no prior knowledge of the *Growing up Together* Programme should have expertise and experience in group work or counselling with parents of children with disabilities (see section 2.3).

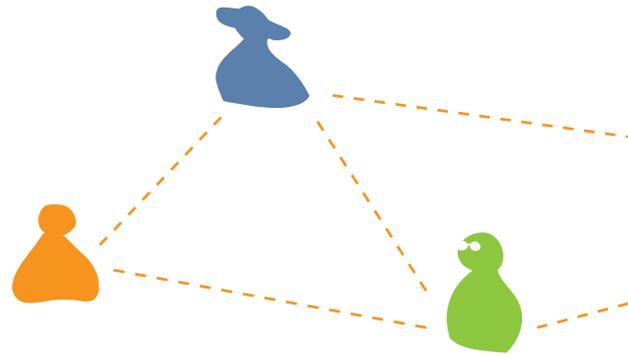
Training of each new group of leaders entails a supervisory meeting organized with the authors of the Programme and/or regional group leaders, in the middle of the first cycle of the workshop programme, and an evaluation seminar at the end of the first cycle of workshops, all members of the leader teams attend the. An additional support to new leaders is provided through network reporting via e-mail, i.e. by submitting and reading each other's reports (on available forms) for each individual workshop. In this way, all leaders and regional leaders have the opportunity to receive and give feedback on workshops during the first cycle. These types of support to the leaders during and after the first implementation of the Programme proved important for alleviating initial insecurities, obtaining additional explanations, instructions and feedback, and exchanging experience regarding the implementation of the Programme.

At the evaluation seminar after the first cycle of workshops with parents, leaders receive feedback on the effects of the workshops that they conducted in the form of quantitative and qualitative analysis of the measuring instruments used (questionnaires for parents and for leaders). It is only after this seminar that leaders will become certified.

Two kinds of activities have been designed to ensure the lasting effects of the Programme, both for parents and the leaders, as well as the latter's further education. They imply the continuation of the Programme in the *Growing up Together Plus* Parents' Club as support to the parents, and the obligatory membership of the leaders in the *Growing up Together* Leader Network.

Furthermore, to ensure quality, it is necessary to evaluate the outcomes and processes of the Programme implementation systematically and continuously, like we did during its experimental implementation. The evaluation of all *Growing up Together* Programmes is conducted by the *Growing up Together* Centre for Parenting Support.





## 5.1.

### Ensuring the quality of the Programme and continuous support to its leaders: Growing up Together Leader Network

The organisation that provides continuous peer support to the leaders after the completion of the first cycle of workshops is the *Growing up Together* Centre for Parenting Support in cooperation with relevant institutions. The purpose of this organization is to ensure quality and improve sustainability and accessibility of the *Growing up Together Plus* Programme to as many parents as possible.

The *Growing up Together* Leader Network consists of all professionals involved in all *Growing up Together* Programmes of Workshops with Parents (authors of the Programme, regional group leaders and workshop leaders). It was founded at the first conference held in 2010 as a form of peer support and further training. We consider it to be a key guarantee of the quality of all programmes. Regional leaders in that network are the vital link between the authors of the Programme and workshop leaders.

The task of the regional group leaders is to train new leaders and provide peer support for the implementation of the programmes. Peer support can be group/regional or individual for each leader team. Supervision should be done on a regular basis, which the leaders themselves see as important and necessary. The regional peer support leader groups consists of several “neighbouring” teams (or teams of the same organiser) who meet at the regional peer supervisions to exchange experiences, provide mutual support and seek answers to questions arising from the work with parents.

Since the leaders evaluated as very useful the peer support by way of electronic networking and exchanging of reports, we believe that the continuation of such reporting can be mutually beneficial in the future cycles. Of course, the form of this exchange develops in accordance with the needs of the leaders who implement the Programme over a certain period. At the end of each cycle, the leaders send the final report to the *Growing up Together Centre for Parenting Support*.

A meeting of all the leaders is organised annually at the *Growing up Together* conference, for the purpose of evaluating the implementation of the Programme and further education of the leaders.

We believe that the *Growing up Together* Leader Network and the *Growing up Together* Centre for Parenting Support are a good response to the leaders’ need to be affirmed as competent experts, to continue education and gain further experiences of personal and team growth – to grow together both personally and professionally.





## 5.2.

### Ensuring continuous support to the parents: Growing up Together Plus Parents' Club

As a continuation to the support to parents, it is possible to organise a *Growing up Together Plus* Parents' Club. In this way, we let the parents know that they are not on their own after the Programme, now that they have begun applying new behaviours and changing the relationship with their children, family, etc.

The parents' testimonies show that they are very satisfied with the workshops, that their expectations were met, but that they still need more time to discuss and resolve their own issues connected with the upbringing of their children and coping with the problems related to parenting a child with disability. Also, they think that the workshops should last longer or should at least have some form of continuation after the conclusion of the Programme. They also valued socialisation and the possibility of sharing with other parents, which they could do at the meetings in the *Growing up Together Plus* Programme. They want more.

#### What some parents said



- *I would like to thank the leaders for their relaxed approach and expertise which made us continue working on ourselves.*
- *The workshop was excellent and I hope for a new meeting.*
- *I'm sorry that this is the last workshop. I really got used to these gatherings.*
- *I'm happy to have met new people and hope that we will remain in contact. Thank you!*
- *I'd like another workshop!*
- *It would be nice to attend some other workshops.*

At the meetings of the *Growing up Together Plus* Parents' Club, the leaders choose discussion topics with input from the parents. This should be done in advance, so that the leaders can adequately prepare for the next meeting and motivate the parents to attend. It could involve repeating of some activities from the Programme related to a topic that the parents consider important or further discussion on what the parents think was not discussed sufficiently at the workshops or about the things that trouble them, etc. Sometimes it is enough for them to be together. They have always a lot of common topics to discuss.

*What the leaders from a rehabilitation centre said*

*Our parents have the need to socialise, to support each other, exchange experiences, useful information about their rights, services in their communities, methods of communication with the child, their therapists, doctors and so on. They see the Growing up Together Plus Parents' Club as one way to achieve this in our Centre. They have ideas about what could be done in the Club and suggest that we occasionally invite guests to hold lectures (e.g. guest therapist, speech therapist, occupational therapist, etc.)*

The meetings can be held bimonthly, quarterly, semi-annually – depending on the interest of parents. Sometimes the initial enthusiasm wanes, so the parents should be motivated by suggesting topics that they find important and interesting and by inviting them via mailing list, Facebook group, telephone or personal contact.

The parents can join the Club after each new cycle. Some parents will give up over time, some will not come every time, new parents will join in. The Club is seen as an open group with its own rules in terms of discretion, but there is a possibility of including new parents who have completed the Programme.

Several groups have continued with the meetings in the Club. The first experiences are positive and new ideas are born. The parents' spontaneous meetings outside the organised premises show their need for continuation and support.

*In one family centre, three meetings of the Club were held after the completed cycle:*

1. Topics: expectations from the Club and the leaders; agreement on the frequency of meetings; comments on the completed workshops; events that followed...
2. Topics: repetition of adopted concepts through Pantomime Quiz (activity from the 11th workshop)
3. Topics: Focus group - expectations and gains from the community...



### 5.3. Expanding the availability of the Programme to parents in the community

Since the ultimate purpose of this Programme is to improve the well-being of the child with disabilities and facilitate the development of her or his potential, one of its aims is to increase the availability of the Programme to as many parents of children with disabilities as possible, in other words **to bring the parents closer to the workshops and to bring the workshops closer to the parents.**

The experimental implementation of the *Growing up Together Plus* Workshops with Parents started in kindergartens, rehabilitation and family centres and associations of parents of children with disabilities. The Programme can also be implemented by other organisers under the aforementioned condition that it be implemented by trained experts, and who are members of the *Growing up Together* Leader Network.

Nowadays, there are various media forms that can be used for the popularisation of the Programme in public and promotion of the values, knowledge and skills of all those who take care of children and raise them. They include articles, interviews, information about the start/end of the cycle of workshops announced in the media, on websites of the organiser, on social networks, in the associations of parents of children with disabilities, on websites of the *Growing up Together* Centre for Parenting Support.

The professional public should be informed about the value and efficacy of the Programme through participation in professional and scientific meetings, the *Growing up Together* Leader Conference, debates, etc.

*The merits and a wider need for the Programme are evident in the testimonies of parents who went through the Programme, gave it high ratings and said:*

- *I think that the workshops of this kind should be organised more often.*
- *An experience that I would recommend and love to repeat.*
- *The workshops are an opportunity to grow as parents, share experiences and support with other parents, for pleasant and useful socialising.*
- *All my expectations were fulfilled and more!!!*
- *Thank you for the workshop. These workshops are very important and useful to parents of children with disabilities.*
- *Finally something for us, this is what we needed!*



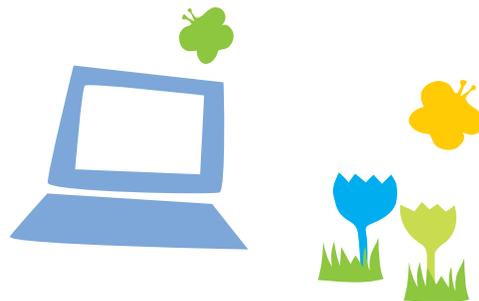
In the development and expansion of the Programme, it is important to make it available and interesting enough to attract all parents of children with disabilities regardless of their education, to both mothers and fathers, and irrespective of the types and degrees of children's disabilities. Therefore, additional efforts should be invested to encourage a wider population of parents to participate in the workshops.

The *Growing up Together Plus* Programme of Workshops with Parents has proven to be applicable, efficient and well-accepted by the parents and leaders, and therefore has to be developed and expanded further, i.e. made available to as many of parents as possible, which would contribute to the well-being of a largest number of the children with disabilities.

#### **5.4.** **Guidelines for media relations**

Finally, here are some concrete information about the cooperation with the media.

With the help of the media it is possible to communicate with the entire local community and present the *Growing up Together Plus* Programme of Workshops with Parents to the general public. It is necessary to ask the representatives of the local newspapers, TV network and radio stations to continuously cover the organisation and implementation of the Programme. This might encourage the entire community to promote responsible parenting and care for children with disabilities.





### Sample media announcement for the local media

(Organiser's letterhead)

## PRESS RELEASE

### Short title conveying the general idea

(in five or six words, preferably containing a verb)

**Place, day / month / year**

**Most important information** (the obligatory "who" and "what" - followed by the most important parts: when, where, why and how) should be stated in the first paragraph, no more than a few sentences long. This paragraph should attract the attention of journalists in the most efficient way, and provide them with relevant information.

The second paragraph can begin with explaining why parenting a child with disability is so important and different in many ways.

This may be followed by several chapters describing in more detail the activities related to the implementation of the *Growing up Together Plus Programme of Workshops with Parents*. Such an announcement should not be longer than a single page.

Examples of titles:

- New: Workshops with parents of children with disabilities at the "Sunce" Rehabilitation Centre
- Parents of children with disabilities exchange experience at the "Svijet" Association
- New programme for parents of children with disabilities at our Family Centre
- The "Radost" Kindergarten invites parents of children with disabilities to the *Growing up Together Plus* workshops



Example of an announcement

## Parents of children with disabilities exchange experiences in the “Svijet” Association

Zadar, 10 September 2014

Starting 10 October of this year, the “Svijet” Association of Parents of Children with Disabilities will organise Growing up Together Plus Workshops for Parents, established under the auspices of the UNICEF Office for Croatia to support parents of pre-school children with disabilities. At the workshops parents will seek answers to questions about raising children, problem solving and everyday situations through sharing experiences with other parents and experts.

Why are our workshops called Growing up Together Plus? A parent of a child with disability has a lot of “additions” to their parenting – they experience more fear and stress, more challenges and victories, and they need more information, more understanding, more professional work, more care from the society. All these “additions” have been called “plus”. Therefore, these workshops are designed to empower parents and to give their addition to parenting a positive character.

The “Svijet” Association brings together parents through various programmes, and Growing up Together Plus workshops have been conducted by our experts for two years. The Programme of workshops lasts for 11 weeks and is free of charge for the parents. So far, 56 satisfied parents have participated in the workshops.

We invite all interested parents to learn more about the workshops. You can register by calling xxx or e-mail at xxx. Details can be found on our website [www.udrugasvijet](http://www.udrugasvijet).

For more information, please contact:

**Name, position** (Ana Anić, psychologist)  
**Organisation** («Svijet» Association)  
**Telephone and/or e-mail**

signature



After such a media announcement journalists can request more information and an interview with the leaders and the parents. The consent of all participants must be obtained for any filming of the workshops.

At the end of the year, it is recommended to notify the media of the number of parents attending the workshops that year, quoting their statements on how the workshops helped them with their children and coping with the difficulties of parenting.



## 6. HANDOUTS ACCOMPANYING THE PROGRAMME IMPLEMENTATION

The *Growing up Together Plus* Programme of Workshops is accompanied by a number of handouts for parents to be studied at home, and revisited, if needed.

In addition to the contributions published in *Roditeljstvo u najboljem interesu djeteta i podrška roditeljima najmlađe djece [Parenting in the Best Interests of the Child and Support of Parents of the Youngest Children]* (Pećnik and Starc, 2010), the *Growing up Together Plus* Programme edition contains some new or expanded professional articles.

- The four pillars of parenting in the best interests of the child
- Parenting requires constant adaptation
- Possible adaptation strategies
- Parent traps
- Three types of parental responsibility
- Family relations
- Parents' frequently asked questions
- Ten tips as support to parents of children with disabilities
- Development and needs of younger children
- The basic psychological needs – how to meet them in a child with disability
- Play –tips for parents



# The four pillars of parenting

## IN THE BEST INTERESTS OF THE CHILD

### 1. FIRST PILLAR

#### Nurturing behaviour

- Responds to the child's need for love, emotional warmth, security, belonging, bonding, acceptance. The child needs their parents' nurturing behaviour as a safe base from which they can explore the world, and to which they can return when they feel fatigue, fear, sadness or some other uncomfortable state or emotion.
- This requires the parents to be sensitive to their child's messages, and to respond to them appropriately, to show warmth and love, to provide comfort and protection, to accept the child and to provide support. The parent can show affection and happiness to the child, comfort them when the child is sad or shaken, talk to the child about the child's worries and interests, maintain a positive emotional environment at home and provide security.
- Consistent emotional warmth and response to the child's needs represent the basis for the development of a safe, stable and emotionally warm bond with the parent. Such a bond enables the child's emotional needs to be satisfied, and the child feels valuable and accepted as a result.

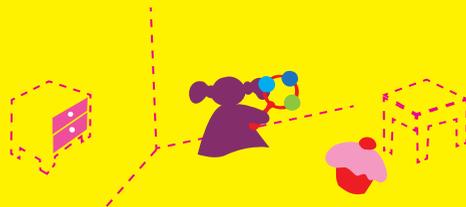


# 2.

## SECOND PILLAR

### Structure and guidance

- Respond to the child's need for security, predictability and competence.
- Structure means directing the child's space, time and guidance.
- A structured space is a safe space in which the child is protected from potential dangers, both inside their own home and outside it. Besides, for a small child it is important to keep the layout in a known space unchanged.
- Structured time and activities mean a consistent (but not rigid) daily schedule with regular times and patterns of family activities. Routine and predictability offer a sense of security to a small child. At the same time, a flexibility enabling the routine to adapt to the current needs of the child is also important (e.g. we do not wake the child up for a snack). Flexible time structure also enables more agreements with the child as it grows and matures.
- The structure also consists of boundaries of acceptable and unacceptable behaviour, as well as other forms of directing and guiding the child – such as expressing one's expectations or explaining a request. It enables the child to learn to manage his or her own behaviour. The parents serve as the role model of appropriate behaviour, expressing emotions, and interactions with other persons. The child learns from them and develops his or her own moral values, conflict resolution methods and pro-social behaviour. In order to achieve that, the parent helps the child understand what is and what is not acceptable, and sets reasonable and appropriate limits and expectations. In that process, it is necessary to consider the child's opinion and direct him in a positive way, while setting clear limits, offering reasonable explanations, and refraining from corporal punishment and psychological pressure.



# 3.

THIRD  
PILLAR

## Acknowledging or recognising the child as a person

- Satisfies the need and right of the child to be seen, heard and respected as a person – with their own understandings, ideas, plans, preferences and human dignity.
- For the development of the child’s self-awareness, the parent needs to notice, acknowledge and confirm the child’s personal experience of themselves and/or of the world (e.g. I see you like sticking the branch into the mud; You’re sad because you’ve lost your toy; You’re worried about when Dad is coming home, etc.).
- This requires the parent to spend some time with the child, and to express interest in the child’s daily activities and experiences (e.g. what the child likes and dislikes doing, his sources of worry, fear, joy or excitement). All this requires from the parents to listen to their children, try to understand their point of view, and help them express their thoughts and feelings. When parents show that it is important for them to hear and understand how the child truly feels and what he thinks, the child feels he is valued for what he is.
- Appreciating the child as a person involves respect for the child’s limits and making decisions appropriate for their age and maturity (e.g. whether the child is [still] hungry). It is also important that the parent take into consideration the child’s opinions and needs when making decisions that concern the child and the family. “Appreciating the child as a person” does not mean fulfilling all of their wishes, but rather recognising, accepting and “seriously considering” how the child sees themselves or a certain situation (e.g. I see you’d prefer to wear your green shorts, but unfortunately they’re wet. Here are blue and red shorts. Come and pick the ones you want to wear until the green ones dry. But I want the green ones! Yes, I know you like them best. I’m sorry you can’t wear them right now...).



# 4

FOURTH  
PILLAR

## Empowering the child or enabling the child to be empowered

*It is not the noise that makes the baby laugh; it is the fact that she rattles the rattle. (Seligman, 2005)*

- Responds to the child's need to feel personal control, competence and the ability to affect other people and the world around them. In other words, empowerment implies the parents' support to their child's autonomy.
- This requires parental sensitivity, openness for the child's influence, and mutual cooperation (e.g. You're pointing your finger there – you'd like to turn on the light – I'll lift you up so that you can reach the switch.). The parents support the child's strengths, they encourage the child and express confidence in the child's abilities, they follow and support the child's initiatives.
- The parents empower the child when they follow the child's idea with interest, when they join the child's activities if the child allows it, and when they refrain from directing and helping when the child can achieve their aims alone. When the child is determined to realise a self-assigned task (e.g. get a glass of water, bring a plate to Mum, focus on an interesting device), instead of saying: You'll break it, you'll ruin it, you'll fall down; see, you can't do it, the parents can empower the child by saying: Oh, that looks interesting, have you discovered how to open it, you're carrying it very carefully, you'd like to learn how it works already, etc.)
- Furthermore, the parents may create opportunities in which the child can learn and gain new experiences. This involves broadening the child's experience and acquainting the child with the world, responding to the child's questions, supporting play and enabling the child to experience success.
- When they see how their actions have an effect on their environment, the child experiences the feeling of efficacy, which encourages them to be active and to act in accordance with their needs and in new situations. On the other hand, if the child is never successful in affecting their environment, he or she may become passive and withdrawn.
- In supporting the growing independence of their child, the parents should not forget that development is not linear. The child may sometimes express the need for autonomy, and later again for a greater protection and presence of the parents (e.g. when they try to put on their shoes by themselves in the morning, and when the parent comes to pick them up in the afternoon, they want the parent to put the shoes on for them, etc.).



## Parenting requires constant adaptation

Being a parent has a lot of meanings. One of them implies constant readiness to face new challenges: they have barely resolved a problem when another one arises. There is nothing unusual to it, because the parents did not just give birth to the child – they observe and love the child, nurture, rear and teach them. The child changes with each day and each day brings something new. Parents also change as a result. Therefore, parenting requires courage and strength for constant adaptation, i.e. balancing between what they carefully planned and what life brings. Life proves them to be extremely skilful at that, because they intuitively recognise what is in the best interest of their child and they adapt accordingly. However, in the process they do not feel just happiness but also fear, worry, anger, pain and grief or have mixed feelings which include strange combinations of pleasant and very unpleasant feelings.

Being a parent to a child with health problems, developmental risks or disabilities is additionally demanding. The parenting itself is not different. The difference, however, is primarily in the amount of stress and the new, unexpected duties, the intensity of fear and uncertainty. Nancy Miller (1994) believes that parents of the child with disability go through different stages of adaptation to their life conditions and the fact that they are raising a child with disability. Throughout her 25-year long research of this process, which included a direct insight into family relations, she discovered that parents manage to find inner strength which helps them adapt to their situation. However, they feel the need not to be left to their own devices, but to receive some kind of support. Based on her observations and years-long experience in working with parents, the process of adaptation has four stages. These stages follow one another, but not linearly, since there is always some overlapping or going back to one of the previous stages. This is a dynamic process and an individual stage is never “definitely conquered”. Certain events may set in motion changes in the parental feeling of security and disrupt stability, which may reverse the once reached stage of adaptation. Adaptation is therefore best described as a dynamic process which lasts as long as the parenting itself and in difficult moments the process goes back to one of the earlier stages.

The support provided to parents in the particularly sensitive stages of adaptation is a strong protective factor of the psychosocial stability of the family life and the family's active inclusion into the community. We will briefly describe the stages Nancy Miller identified through her work with parents and then the parents will see for themselves to what extent they find them useful. Every parent is unique and experiences parenting in his/her own way. An insight into other parents' experience gives them a new perspective which often helps them see their own parenting more clearly.

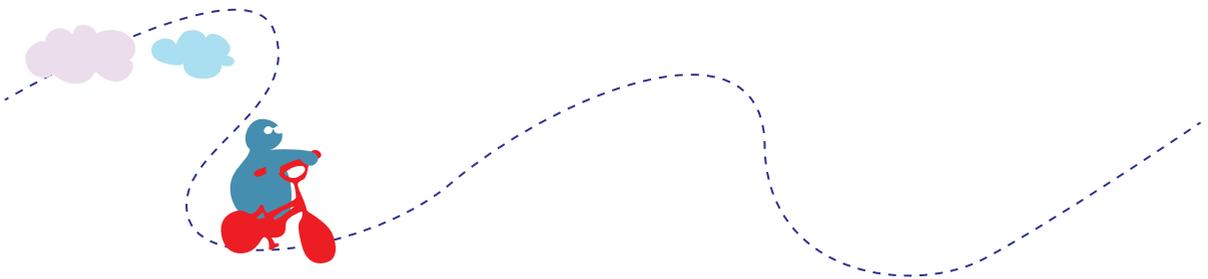
According to Miller (1994), the first stage begins at the moment of realisation that the developmental outcome of the child is connected with high risk. The author calls it **“surviving”**. It is characterized by strong feelings of helplessness and a complete loss of control over their own lives. Every parent goes through the process of “surviving” in their own way. However, this process is easier if parents are informed of the fact that those difficult and unpleasant feelings are a natural and healthy reaction to what has happened. Also, they should be made aware that this is precisely the way any person is preparing to face undesirable events that may occur in the process of parenting. It is important for the parents to know in this stage that it is their duty to take care of themselves. The parents have a very strong tendency to neglect themselves and their needs, and give absolute priority to the needs of their child. The child’s needs are often narrowly understood and excessive emphasis is placed on the role of therapies thus ignoring what every child needs, and that is a cheerful and interactive parent who reads and responds well the child’s signals but who also gives enough structure and guidance to the child’s behaviour. In order to ease and overcome the first shock as quickly as possible, it is necessary to help them find a support network, which usually means parents’ associations and extended family.

The second stage Miller calls **“searching”** and it comes in two forms: “outer searching” and “inner searching”. The outer searching begins with the search of the right diagnosis and possible forms of help. The inner searching raises questions such as: “What is the meaning of my child’s disability in my life and my relationships with others, my other children?” In this stage parents actively seek help. But if they are left to themselves, this period can be very exhausting for them, both financially and mentally. Our experience shows that this stage is significantly extended in the case of the parents in our country. Firstly, it often takes too long to make a diagnosis and, secondly, parents are unable to get at one place all the information regarding the needs and rights of their child and their family. Health, social and educational systems are insufficiently interconnected, both internally and among each other. Therefore, parents most often receive information on diagnostic and therapeutic possibilities from other parents.

The next stage in the process of adaptation is called **“settling in”**. The outer searching for various forms of help has subsided by now, the pace of family life has stabilised, and in most cases the child has been included in some kind of treatment or kindergarten. In this stage parents learn that they have gained new skills and new insights and that they now understand many things in a new way. They feel

more self-confident and assertive and are already familiar with the simplest ways of problem solving. Now they are also acquainted with the people and institutions that can help them.

The fourth stage is the stage of “**separating**”, as called by the author. Separation begins with birth and continues in small steps from one day to the next. In the case of children with disabilities, this process is somewhat altered and slowed. Parents put forth special efforts to help their children become independent and enable them to take care of themselves. Children with typical development leave the parental home on their own initiative when they grow up. In the case of children with disabilities it is the parents who must initiate, plan and support the separation, which makes it a significantly different and more demanding parenting process. Separating often brings back the same emotions that the parents experienced in the stage when they were faced with the fact that their child was different. Many felt guilt and grief in that period. Making a decision about separation includes an enhanced inner and outer search of what was done or omitted. The end result, as indicated by the research and experience of N. Miller, is the new “settling in” and bonding with the life of their child in a new way.



## Possible adaptation strategies

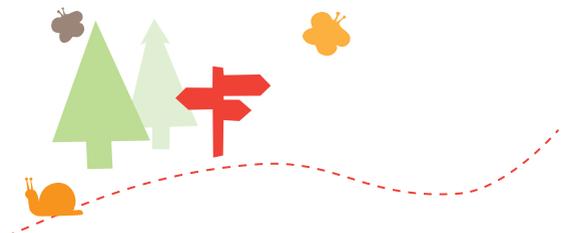
In the challenging and unpredictable parenting they should be frequently reviewed (sometimes daily, weekly or monthly), so keep them where you can always see them.

**1. Taking care of yourself** (Think of the oxygen mask on the plane where the first rule is to put it first on your face and only then on the child's. Taking care of oneself also means going to the hairdresser without feeling bad about it or thinking how this money could have been used for a therapy. It is also perfectly fine for the father to go to a football match with his friends once in a while despite the fact that his child might never walk. It is also fine if the mother goes out and chats with her friends over a cup of coffee about trivial things or fashion ... Even if we are atypical parents, there is no reason why we should not enjoy typical things.) ”

**2. Take care of your partner** (Whatever our children turn out to be eventually, the time will come when they will be gone and we will grow old and be on our own, directed to each other. Having been focused on the child our entire lives, there is a risk that we would no longer recognise each other. As much as it happens to typical parents, this risk is even higher with us.)

**3. Developing “marathon” skills** (sometimes we wish so much to see our child reaching the level of his/her peers and we focus so hard on exercising and work to achieve that, that we end up in a vicious circle of resentment – all of us – Mum, Dad and the child; what should be always kept in mind here is that we must endure till the end of the marathon and under no circumstances give up after ten kilometres. There are times when the best you can do is stop and just lie down next to the child and cuddle – without any therapy – except the typical parental one – “the therapy of love!”)

**4. Accepting means saying “It’s not important to me”** (I found it a very important strategy; to me it means saying: my son is 3,5 years old and he has just begun to walk and he can say only five words. But, this does not make me sad all the time and I do not wake up every morning thinking about it. I love my life, my path and I can handle it. Also, I think that our family life is still worthwhile and that life in general can be beautiful and good. That means not to give up on your child but rather accept their limitations, and some limitations are immanent to every child and every human being. It is a tough strategy and yet, the very thought of its existence and the fact that I should strive for it, makes it easier for me to adapt.)



**5. Always keeping in mind that we are not just teachers to our child, but also their support and partners** (This means adapting to the child's disabilities. I used to watch my son through a number of professional instruments for assessment and diagnostics and teach him only academic skills, while forgetting to give him support in the things that he already could do and rejoiced in those he was good at. A good partner is the one who adapts and follows you on your path and not the one who keeps correcting something. This is because things are not "corrected" at the pace and with the intensity that we as parents expect, despite all our efforts, training and teaching. Child is a person, just like us and their developmental pace must be respected. We as parents should be their support, as all other parents in the world are.)

**6. Acknowledging the fact that we as parents are not to be blamed in any way for what happened** (Whatever the disability of the child may be, and I stand firm here. Many parents have a hard time dealing with this fact. Personally, I tortured myself with guilt thinking why I was so patient while in labour and why I stopped screaming; why I let the amniotic fluid run for 15 hours without contractions so that the intrauterine bacteria spread all over the baby. My husband, and he is a physician, could not get it off his mind either. I write about this in the past tense because in the meantime I have learned that not all the things depend on our free will.

**7. When you feel sad – cry, cry, cry ...** (We all pretend to be strong. But, what a relief it was for me to get a permission to feel sad and cry.)

**8. Bearing in mind that we are equally worth as all other parents and equally capable of performing all the activities that we had performed before we found out that we were not typical parents** – for example, at our workplace. (I used to have this inferiority complex. I was cautious about my pregnancy, about my child, so am I not worth having a healthy child? We are equally worth it as all those parents we see in the park with their healthy children. It is just that our duties are more challenging and more difficult. But, the fruits are that much sweeter!)

So, these are the strategies that may be self-understood, but the fact that I became familiar with them before my special parenthood (as an expert) made it so much easier for me to adapt. That is why I deemed important to share them with other parents.



*Ana-Marija*

## Parent traps

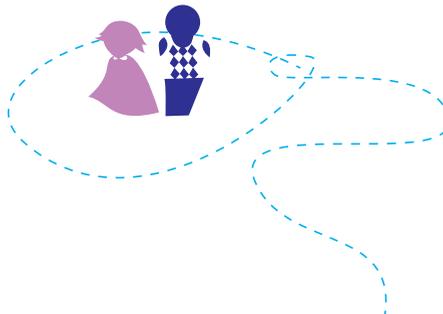
The most frequent parent **traps** that contribute to parental stress and make raising children more difficult rest on erroneous beliefs and expectations.

- **THE VILLAIN PARENT** – is frequently in a power struggle with the child; often demands and expects from the child what she cannot or does not want to do; yells, warns, tries to persuade, negotiates with the child. They do not enjoy the things the child can do. They are in danger of falling into the trap of noticing only negative behaviours of their child, and of giving them only negative attention.
- **THE BLOCKER** – similarly to the villain parent, demands from the child more than she can do; exercises a lot with the child and urges her to exercise, but in doing so demonstrates great enthusiasm and positive feelings; this parent is immensely attentive. Never stops assessing the child's progress and scrutinizes her every behaviour. It is hard for the child to deal with the parents' high expectations and ever present message that they are not good enough, that their parents want a better child. As a result, the child becomes passive and blocked. They do not cooperate. It is easier for them because the pressure is gone.
- **LEAVE THEM ALONE/DON'T TOUCH THEM/DON'T WATCH THEM** (while they are behaving well) – ignores the child as long as he/she behaves well and plays. The trap: ignoring reduces the probability of good behaviour to be repeated.
- **THE PERFECT PARENT** – this trap results from the desire to be an excellent, not just good parent who is up to the challenge. All parents are human beings – and they make mistakes. What matters is not to repeat the same mistakes. Since there is no perfect parent, trying to be one only leads to stress, disappointment, frustration and guilt. The burning desire to satisfy all the requirements and heed all advice takes all the joy from parenting at the moment, as parents expect future success or failure.
- **THE PERFECT CHILD** – it is not realistic from parents to expect their child to be perfect. All children are sometimes "whiny", upset, messy, angry. The way the parents react decides whether those problems will remain the same, worsen, or be reduced in time.
- **IT'S ALL MY FAULT** – sometimes parents blame themselves for all their child's issues. It is possible to guide/direct the child to learn values and social skills, but it is impossible to control everything that affects the child's behaviour. Parents are sometimes depressed because they believe they are to blame for their child's behaviour, which makes it more difficult for them to be calm and patient with their child.

- **IT'S ALL MY CHILD'S FAULT** – this belief blames the child completely for behavioural problems (e.g. She's so stubborn, she never does what she's told.). Such beliefs may prevent the parents to realise how their own behaviours contribute to the child's misbehaving – many issues are the result of how the children and their parents communicate and treat one another.
- **THE MARTYR** – when parents are so preoccupied by parenting, sometimes they neglect their own needs for intimacy, socialisation, recreation, privacy / alone time and fun. When they “afford” some of that, they do not feel content, and their relationship with their partner worsens. Quality parenting is only possible when adults live balanced lives. Martyrdom does not result in quality parenting.
- **STAYING TOGETHER FOR THE SAKE OF CHILDREN** – children growing up in families with serious relationship issues and conflicts are more likely to develop emotional issues and behavioural problems.
- **THEY WILL GROW OUT OF IT** – parents often see a problem in their child's behaviour as something short-lived, something that the child will grow out of in time. Undesirable behaviour must be addressed early to prevent it from escalating into serious difficulties. The belief that problematic behaviour will go away on its own may prevent the parents from looking into the cause of that behaviour, resolving it, changing something or seeking help.
- **THE MULTI-PURPOSE PARENT** – these parents take care of everything; there is nothing they cannot do, nothing they do not know – they drive children to therapies and various activities and back, do motoric and logopedic exercises at home, do the cooking, washing, cleaning, and follow the news on the Internet forum...
- **THE THERAPIST** – does not waste time but takes every chance they can get to practice with the child (thinking that only devoted work brings results). The child thus has one more therapist in life, but loses the parent.

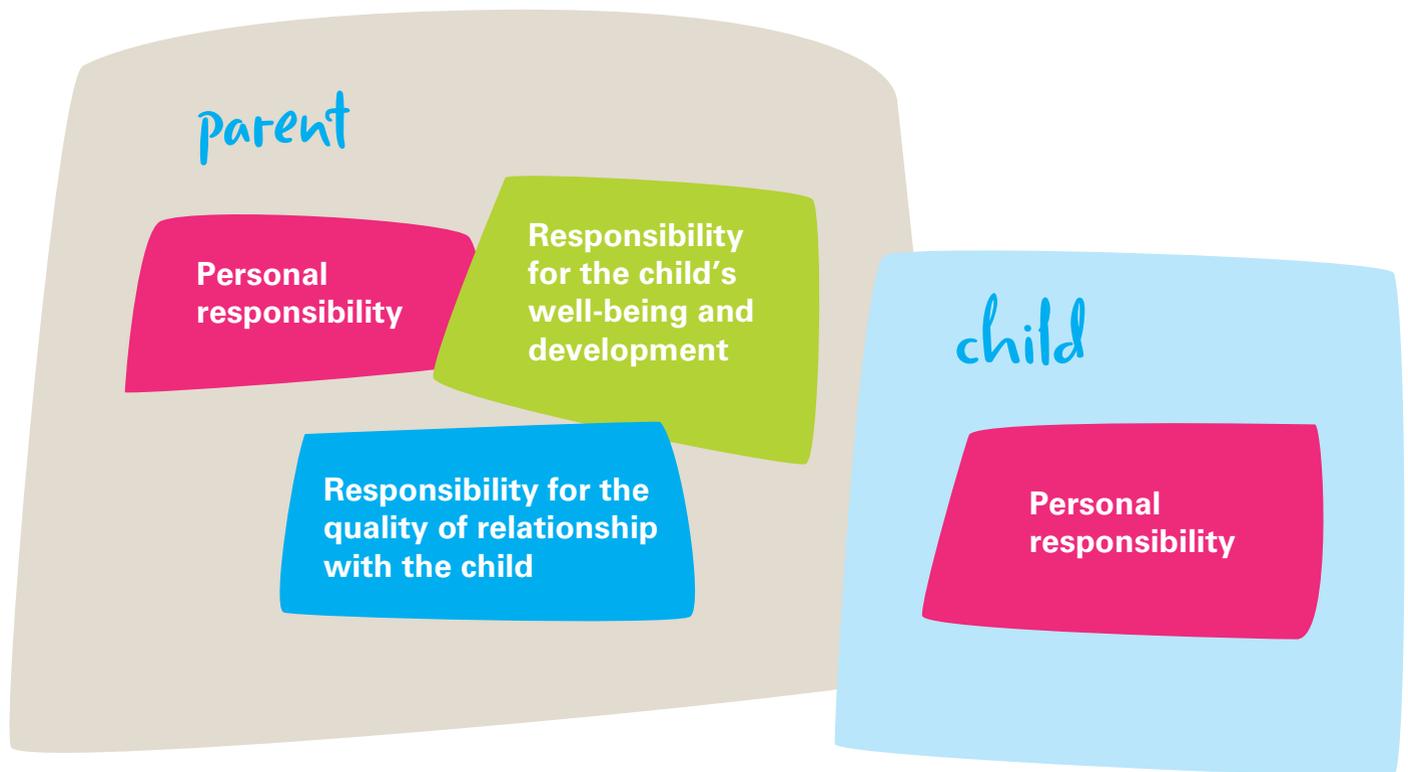
Read about all these traps and choose the one(s) in which you recognise yourself, or which your family members have connected with you. If you recognise yourself in some of those traps to some extent, reflect on our eight meetings and think about whether you have learned, discovered or gained something that you think may help you “extricate” yourself from the trap in which you have fallen.

Adapted from the leaflet titled “Positive Parenting Program”, n.d.



## THE THREE TYPES OF PARENTAL RESPONSIBILITIES

### What are the parent's responsibilities and what are the child's



### Communication:

- Personal expression
- I - messages*

- Listening to the child
- passive/active*

- Personal speech
- I want/I don't want  
I like/I don't like*

**Personal responsibility** – it encompasses self-awareness (awareness of what I think [don't think]; what I feel [I don't feel]; what I want [I don't want]; what I like [I don't like]; what I need [I don't need], etc.) and self-representation, both in word and deed, i.e. through conduct and actions.

Every adult person is responsible for themselves and their conduct, for meeting their needs and respecting their own limitations. Parents assume personal responsibility by making choices, taking decisions and by acting in accordance with their own needs and limitations (i.e. I need [I don't need]; I want [I don't want]; I like [I don't like]...)

Children, too, have personal responsibility – from their birth onwards they are aware of their condition and needs and they represent themselves (express their condition and needs) by producing sounds and by gestures. The child with developmental disability sometimes demonstrates his/her limitations either less explicitly than other children or through unacceptable behaviours (e.g. aggression, auto-aggression, learned helplessness). That happens because they do not have a socially acceptable communication system, so they just fight for themselves.

In that early stage, children do not represent themselves in deed, i.e. action because they lack ability and knowledge for that. It is the parents/adults who respond to the child's need which is expressed by action; they are temporarily the child's "extended arms and legs" and they take care of the child's needs. The more relaxed and calm they are, the better they identify the signals coming from the child and recognize the immediate needs to which they must respond.

Over time, children will be able to help themselves with a glass of water when they get thirsty or to remove wet diapers that bother them. They become more and more able to represent themselves not only in word but also in deed, i.e. to meet their own needs because they become more independent, better understand the consequences of their and other people's behaviour and have more life experience.

**Responsibility for relationship** – Parents also bear full responsibility for the quality of the relationship with the child and the family. The adults are those responsible for the atmosphere (e.g. a tense, frowning expression that scares the child as opposed to a serene and relaxed expression, full of understanding), the way of communication and the values (e.g. we take care of each other, we help each other, we do not hurt each other; the feelings of family members are important; acceptance of differences, tolerance; relationships are founded on equal dignity, which means that the needs, wishes and feelings of each family member should be taken seriously, regardless of age or gender ...).

**Responsibility for the well-being and development of the child** – In addition to the personal responsibility for their self, their needs and limitations and the responsibility for the quality of the relationship with the child and the family, parents also have the responsibility for the well-being and development of the child. As mentioned earlier, the child bears personal responsibility for their own needs and limitations, how to express and satisfy them to the extent their abilities allow. However, this responsibility does not rest solely on the child, but on the parents as well. The parent is responsible for taking decisions that ensure the child's safety and health, and meeting their needs (but not all their wishes).

Being responsible for the well-being and development of their child, the parents sometimes take decisions that are contrary to the child's wishes and feelings. It is important that even then parents respect the child's personal responsibility for their self, their needs and limitations. To put it in the terms of the four pillars of parenting – parents should perceive and respect the child as a person who is competent enough to know what they want and what they do not want (e.g.: I can see you want to play on the swings, but I won't let you because it's for older children; I hear you want to watch TV a bit longer, but I will turn it off now because I don't want you to watch it for more than an hour a day...).

The parent of the child with disability has to look after his/her limitations and well-being even more closely. The limitations of the child are very fragile due to biomedical problems on one hand, and their contacts with a number of other persons, on the other hand. The child meets a lot of people from the early age and more often than other children. Sometimes these people are not aware enough of the child's limitations or tend to ignore them due to lack of time or excessive workload.



# Family relations

## Relations between partners

One of the most common misconceptions regarding the destructive impacts of the child's illness or disability on the functioning of a family is the one about increased marital problems and higher probability of parents' divorce. However, a large amount of researches have proven that there is no difference in the general extent of marital satisfaction between the family with a healthy child and the one with a child with disabilities. The latter, as it turns out, should be perceived as a "normal" family that is exposed to a demanding, disturbing and lasting series of stressors.

Some time or other, every family experiences a serious conflict or crisis caused by a family interaction or by a certain event in the life of an individual. This always calls for adaptation of regular habits, routine and values to a new situation. In the case of the family that has a child with developmental problems, the interaction between family members is constantly exposed to stress. As a result, the intervals in which crises occur may be shorter than in the majority of families.

It is necessary for the spouses to keep the balance between their roles of parents and partners, between the need to take care of their individual needs and limitations and the need to adapt and make compromises, or to give up on themselves. In the process of adaptation it is often the mother who takes the role of both parents, whereas the father takes care of providing for the family. The mother look after the child 24 hours a day, just like nurses do, and is therefore likely to forget or suppress her needs and those of her partner. It may happen that in such situation partners shut out their feelings, talk less about personal things and focus on their duties. This results in poor communication and vague expectations with regard to the distribution of responsibilities concerning the child. It happens that one of the parents, most often the mother, believes that nobody can replace her in the round-the-clock care for the child. As a result she completely loses touch with her own needs. She often takes full responsibility for the well-being of the child and the family as a whole, whereas the partner is just an assistant. The problem here is not the amount of duties and obligations but rather the way the partners address them. What is important is that partners should be able to rely on each other and that they both know what, when and how something needs to be done. To be able to bear the responsibility, a person must be given the opportunity to formulate and accept the responsibility and be sure that the other side recognizes and appreciates their efforts.



A good communication is what helps when parents have to establish a balance between parenthood and partnership and when it is important to maintain the ability to see and respect one another.

Conversations between partners are of great help because the only way to get closer to their selves and each other and to avoid estrangement is to express themselves and their feelings. Although some of the problems may not be resolved, by discussing them on a regular basis it is possible to prevent them from draining all the energy from the partners. Partners can help and support each other only if they know what makes the other side happy or sad.

## Siblings

The relationship between siblings implies closeness as well as rivalry, and no family is an exception. The researches show that growing up with siblings contributes to a faster social and cognitive progress. The birth of a child with disability may be considered as another opportunity for the personal growth of other children in the family. However, this does not happen on its own, but requires full parental focus on other children, especially on their feelings as they grow. They are likely to hear all kinds of strange comments about their brother or sister with disability or find themselves in situations where they will not understand or where they might feel too responsible or guilty.

A child with disability demands a lot of parental attention so that other, healthy children of the family are often pushed on the back seat. The presence of a child with disability changes many things in the family dynamics. The past family routine becomes disrupted, priorities change and parents change because they are worried, overburdened and under stress.

There is no universal way in which siblings respond to a brother or sister with disability. Their reaction is often impacted by the interaction of their temperament, the way they cope with the difficulties and the changes in the family.

Some children may react by a demanding behaviour because this is the only way to attract their parents' attention which is now focused on the child with disability. Siblings of a child with disability struggle for time and attention not because they are jealous but because their past experience tells them that their parents tend to overlook their needs due to all the needs of the sibling with disability. Sometimes other children react by becoming almost invisible because they do not want to

become another burden to their parents. As a result, they withdraw and feel lonely in their family.

The child's reaction is not caused by the lack of their parents' love for them. It is a logical consequence of how the child perceives the actual functioning and priorities of the family.

The presence of a child with disability may stir up different emotions in his or her siblings:

- Feeling neglected, because their parents devote a lot of time and energy to the sick child
- Reacting inappropriately (showing impatience and lack of understanding) due to exhaustion, frustration and stress
- Feeling bad in the company of peers, unable to explain their sibling's disability
- Feeling mocked and rejected by peers, ashamed of their brother or sister
- Feeling unloved and unaccepted in the family
- Feeling guilty because they sometimes wish their sick sibling did not exist
- Feeling ashamed because their family is not like other families.

But, they may as well feel more mature, happy and proud because they can help their parents with the sibling.

**All thoughts and feeling mentioned above are natural, common and healthy** and there is no reason to worry about them. The problem arises when these emotions are not discussed. Since it is not easy for a child to clearly articulate his or her emotions, say what they think and feel, they should be encouraged to do so.

Parents should give them a good example by expressing their thoughts and feelings, by openly encouraging the children to talk (e.g. ***You must feel neglected sometimes because we are always busy with your brother/sister. Has it ever occurred to you that life would be better if he/she were not around or if he/she were perfectly healthy?***)

When siblings demonstrate responsibility by offering help and discretion, it is important that the parents show them their appreciation, i.e. that they do not take that responsibility for granted. Also, they should encourage the siblings to hang out with their friends and play freely, be irrational and irresponsible. Parents must understand that when the children react by being difficult, demanding or arrogant they just need attention. The spontaneity which they demonstrate should not be judged or criticised.

## Extended family and friends

Families with a child with disability need much more help and support from their extended families, friends and wider social networks. There is a number of issues related to the realization of that support.

Parents are not sure how much information about their child's condition they should share, and how they can avoid being perceived as special and maybe even difficult members of the family and the circle of friends. It is nice to meet with interest and compassionate understanding of other people. But, it is not so nice to see that tragic and pathetic look on their faces every time they meet.

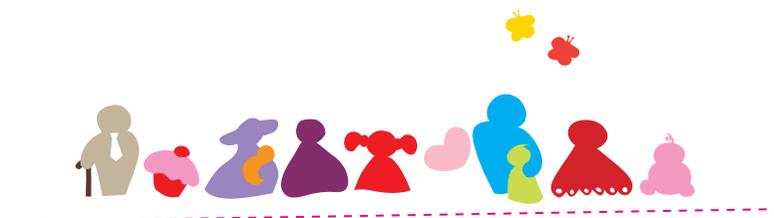
Experience shows that it helps to give the family accurate information on the child's condition, seriousness of the illness and prognoses. This will prevent myths and prejudices from spreading and, at the same time, give the family and friends a basis on which they will make their own decisions and opinions.

A great many people have a hard time facing pain and difficulties. Thus, the people in our cultural setting tend to withdraw even from the close family relations and years-long friendships. In most cases it happens not because of their bad intentions, but because they feel helpless. That is why parents of a child with disability should help their family members or friends stay in touch with them by keeping them informed and talking to them about their own feelings, anger, insecurities and helplessness.

There is one more reason for distancing from the rest of the family. The parents have fallen into the trap of making their child and their disability their major project, which has then become the only topic they think or talk about. There is not a single relative or friend who can stand for a long time such preoccupation with oneself. It also happens that other people withdraw because of the way in which the parents cope with their situation. If they behave as martyrs, expecting others to feel sorry for them and therefore owe them consideration and compassion, then their relationship with other becomes unbalanced. They end up in the most humiliating situations of all – they become collectors of alms.

Open talks with family members and friends help parents clearly define their needs and set boundaries to the offers of help.

Sometimes parents do not ask for or accept help because they feel the awkward balance between receiving and giving. It is good to know that other people feel well when we let them give us what we need.



## Parents' most common questions

The *Growing up Together Plus* workshops offer plenty of opportunities for talk and asking questions. Some of the frequently asked questions and possible answers which provide guidelines on how to respond in a specific situation are listed here. Parents' questions should be listened to attentively, as they often hide their fears and the desire to protect the child from future disappointments or feelings of failure. Questions give a good opportunity to hear what really bothers parents, and to help them articulate it in a conversation. It is not uncommon that a parent thinks something troubles the child, when in fact it troubles only the parent. The way the workshop leaders listen to the questions and answer to them also helps the parents **to see their child more clearly**: what worries that child, what he wants, what interests him.

The parents should be told that there are no simple, routine answers, so-called recipes, to most questions. It is therefore perfectly fine if the parents admit that they have no answers to the questions their children may ask about their disability or condition. It may be helpful to ask the child first what he/she thinks would be the right answer. This will enable the parents to learn more precisely what the children are interested in, but also what they actually know about the issue that preoccupies them. The parent can then respond better to what really bothers them and to what the child needs an answer. Children, like adults, hear a lot of bizarre and wrong interpretations and strange comments in their environment. A conversation with children is likely to reveal what they think, what they heard and how they understood what they heard. This will give the parents the opportunity to provide accurate and honest information focused on the essence of what bothers the children.





# 1

## *How to talk to the child about their disability*

Parents often find it difficult to answer the child's question about their disability. It is best to tell the parents to give a direct and honest answer, and to provide only as much information as the child requests. The leaders can tell parents that they understand these questions are difficult for them because the answers often sadden the children. It is not easy for any parent to see their child sad, but avoiding answers or ignoring sadness, anger and similar feelings that go with the child's coping with the disability will make the child feel isolated and excluded, and send her a message that it is not right to be sad or to cry. This is exactly the opposite of what the child needs to be shown and taught. Parents need to give the children hope that even with obvious limitations and disabilities they can be successful, loved and happy people. Parents' "job" is to teach the child that dealing with what we can do, and even more with what we cannot do, is a part of life.

For example, if a child is interested in why he cannot draw like other children (e.g. due to hemiparesis), the parents should be instructed to answer only that question and avoid long and lengthy explanations. One can start with saying: "Nobody can do everything because no one is perfect. Drawing is difficult for you. Your hand cannot hold a pencil in the right way for now, but you have discovered that we can make up for this by using a very thick, special pencil." It is important to always tell the child that there are many other children who are also doing some things worse than they want, but they still work hard and make progress. The parent can then remind the child of the thing that they do well (e.g. singing). It is good to remind parents that they are in many ways role models for their children, so they can say that even they are not good at some things and explain how they deal with it (e.g. take more time, ask someone for help, change a goal, find something equally interesting, etc.). Parents should convey the message that children are worthy just the way they are and that we need to accept ourselves as we are.

If the child wants to know whether their condition will improve in the future (e.g. if they will be able to walk), the parents should be honest, but also tactful. It is good to practice with them an answer that is consistent with both expert knowledge and parents' beliefs. However, the answer must leave some hope as no one knows what the future brings. For example, one can say to a child whose medical prognosis does not indicate the ability to walk: "Doctors so far think this will not be possible.

But in the past they thought many things were not possible, and then they truly were not, but time has shown they were wrong. I think that the most important thing is that you can move around and reach what you need. This is why you got a wheelchair. It is true that it is not quite as convenient as walking, but it gives you a lot of opportunities that you still have to discover and use."

## 2

### *What to tell the environment about the child's disability and how?*

It is widely accepted that an open discussion about the child's disability with the environment helps both the children and the parents. Hiding or concealing information about the child's condition further increases the anxiety of the parents and adversely affects their view of the child's disability (if something is hidden, it must be negative, bad, ugly...). It also has a bad influence on the relations with the environment because it hinders communication. Insufficient information increases the likelihood of prejudices and inadequate approach to the parents and the child.

The extent and the way in which the parents will inform the environment about the child's disability depends on the person they are talking to. Family members and close friends should be given accurate information about the child's condition. In addition, the parents should tell them what kind of support they need and expect, i.e. how they are expected to help. As for those who do not ask any questions or do not notice anything, this subject should not be discussed at all, let alone in an apologetic manner. Children's disabilities occur beyond our will and responsibility, therefore the parents cannot be blamed and should not justify themselves.

A particularly important part of the child's environment if they attend a kindergarten, are the educators and the expert team. They take care of the child and should know if the child has some additional health or educational needs. This is why the workshop leaders should encourage parents to make expert reports and information about the child available to the responsible persons in the kindergarten, even if parents may know of a case where that did not have a positive effect.



## 3

*Will my child feel different, deprived?*

The child's attitude towards their condition depends on the attitude and behaviour of the parents and other people from the close and broad environment. If they behave in an overprotective or lenient manner or directly express pity toward the child, the child will feel less worthy, sick... If they encourage the independence and competence of the child, if the child's needs are met, they will be confident and cope more easily with the limitations of his/her disability. The child will not feel deprived due to his/her disability unless the environment assumes a negative attitude and imposes on the child a value judgement that the disability is not the child's special quality, but a sign of deprivation and inferiority.

## 4

*How to explain to the children with typical development that the children with disabilities also have feelings and do not want to be isolated, although they lag behind when they play together?*

Generally, children react to differentness with curiosity. Open and age appropriate information about the condition of the child with disability, their behaviour and the way they experience things will result in understanding and acceptance. It is important to give specific information about what the child can and cannot do, how they will behave in a given situation and how they can be included in playing and socialisation. Children love to help and if they are given a model, they will compete who is going to do more for the child with disability. This would give them additional opportunities to practice their skills, but also to develop empathy and patience.



## 5

*How to prepare a child for a painful examination or medical procedure?*

In the case of a pre-school child, the preparation should be done on the day of the procedure. If the preparation starts too early, the child's anxiety can deepen. One must be honest, explain the course and duration of the procedure, how painful it could be. It is good to explain that the unease through which they must go lasts a limited time, and the ensuing benefit will be long-lasting and valuable. One should be very specific and give examples and explanations that are close to the child's experience and that she can understand. It may also help to promise an additional reward to which the child will look forward and thus endure the procedure more easily. Their best solace will be the assurances of their parent's presence. It is important that the parent does not further upset the child by their own behaviour (excessive worry or tension), but rather helps the child by behaving calmly.

## 6

*Should every moment be dedicated to new "exercises and learning" of the child with disability, or should a smaller portion of strict "exercises" be combined with other "regular" activities such as "disguised exercises"?*

Learning and exercising should be subtly incorporated into regular everyday activities whenever possible. In this way, it is less likely that the child will experience them as imposed. Learning through play and various activities is effective because the child is highly motivated to willingly participate in the activities that are meaningful to them and are a part of their daily routine. Besides, "exercises" built into a daily routine gradually become a part of everyday functioning and increase in number. Insisting on exercises when the child is not in the mood, results in resistance and further negative reactions. The intensity of pain and discomfort in more strenuous exercises will be higher due to the negative emotions that the child associates with the exercise. Therefore, during the habilitation procedure, it is important to take into account how the child feels, what time of day is more suitable for exercise to them, which therapist makes them feel the best, what kind of preparation for the procedure suits them best, for how long they can "endure" or retain attention. This means respecting the child's limitations and building their cooperation and their consciously made efforts.



# Ten tips on support to parents of children with disabilities

01. Don't avoid conversations about our child. We may not say much in the beginning. Then again, you might hear a spate of words. Both ways, we remember those who asked and we cannot forget those who did not.
02. Touch us, touch our child. Your hug, look and touch send us a message that you care. A gentle pinching of our child's cheek will tell us that we are "normal". At the beginning, we feel so lonely and different from others.
03. Don't tell us how we should or should not feel! We feel as we feel and that's it! In our first days and months we struggled with strong emotions and often felt we were at the end of our rope.
04. Don't tell us that one gets as much burden in life as one can carry. We take it one day at a time, especially at the beginning. Therefore, this sentence is nothing but yet another burden to a person who is about to lose all control.
05. Don't say *I admire you* or *You are such a generous person*, unless the parents adopted the child with disability. We did not want this to happen. We do not see us as more generous or better than other parents. Moreover, on a number of occasions we feel trapped.
06. Offer help. Come over, sit next to our child, play with him/her. If you do, we can take a break that we need so badly. Cook a meal and bring it over sometimes. Take our child's sibling out for an ice-cream or pizza. Make it clear to us that we can always call you. And call us to hear how we are doing.
07. Be patient with us. Our everyday life is hard to go through. Early on, we only see what our child cannot do or what he/she will never be able to do. It will be difficult for us in the beginning to accept your help. But, please, insist! One day we will accept it.
08. Always be considerate towards siblings of the child with disability. He/she may get lost in the thicket of check-ups and diagnoses. Bring them a little something when you visit. Greet them first and talk to them. Only then ask about the child with disability.
09. Please, don't stare! We are well aware that our child does not look "normal" and that he/she is acting strangely. At the beginning, this is the only thing we see. Think of something positive to say, like *How beautiful eyes/thick hair he/she has*. Such remarks are music to our ears.
10. Remember that whatever disability our child may have, he/she is still just a child and feels the need to be loved and accepted, to be happy and to belong. He/she needs hugs, laughter, music, friends. He/she needs you – just like we do!

(Michele Stiefel)

## Development and needs of younger children

### 1. Comprehensive approach

All children are first of all children and they need our full devotion and acceptance. Albeit indisputable, this fact is too often ignored when it comes to children whose development is not typical. Attention is focused on delays and the pursuit of methods that would mitigate or eliminate those delays, as if all the rest will go away by itself. That is why development standards are left out here as well as instructions on the methods of determining to what extent the child differs from their peers.. We will focus on the foundations of early childhood and the things that every child needs in order to develop his/her potential and grow into a complete and happy person. When reflecting on the development and how to support it most effectively, we know that a child cannot develop a healthy personality and acquire knowledge and skills without emotional support and cooperation with others. An old Chinese proverb comes to mind here. It says: ***Grass does not grow faster if you pull it.*** Every gardener knows very well what grass needs time to grow. We are going to discuss what is it that every little, fragile being, each of our children needs.

A lot of infants and young children develop in the way that is ***typical*** for their age. And then we discover that they are different. Some children may have developmental difficulties and lag behind in reaching certain developmental turning points. Some may be “at risk” of delay leaving their parents uncertain of what to expect. Some children may have specific health related problems which require special care. Some infants and young children need an extra time and technical aids to complete activities that other children complete easily. It is important to know that **the same basic developmental principles apply to both children whose development is typical and those with developmental difficulties because development is based on the interaction between the biological basis and the impact of environment.** All children are curious but each in their own way. They are all motivated to learn about and act upon the world around them. However, every child goes through developmental stages at a different pace and every child needs an individual approach, “tailored” precisely to fit their developmental profile. Parents feel and intuitively know that. They also know that every child develops in its own, unique way, as part of their family, community and culture.

Physical growth and development, emotional development, cognitive abilities, speech, social skills, desire to learn – they all happen simultaneously. Developmental areas are not chronologically divided in the life of a child; **a child develops simultaneously in all areas.** Each newly adopted ability or skill upgrades the previous ones and helps the child develop in more than just one area. For the needs of research and description, development was divided into physical and motoric, emotional and social,

communication, linguistic and cognitive. However, there is no such division in the child. We should therefore always see the child as an integral human being, and keep in mind that our acts may affect their overall development.

Experts will help parents determine the level of the child's development. This is important for the parents to know in order to enable them to choose the right strategy of support in the next developmental steps. It does not mean that we ignore the "calendar of development." We just do not use it with the view to making comparisons, but **with the view to understanding developmental needs and further steps**. Consequently, comparisons in terms of age standards do not make too much sense in the case of children with disabilities. Their development should be stimulated in accordance with their developmental needs, i.e. the child should be exposed only to the challenges and in the way that the child is able to accept and build in his mind and acts. Most often, parents of children with disabilities cannot do it alone. They need professional help focused on both the child and the parents. This help brings results only if it is built in the everyday routine and this is where parents need guidance.

For example, a young child learns how to capture her mother's attention by making noise with her new toy. She does it frequently to show the mother that she trusts her and feels safe with her (emotional and social development). The child can also learn the toy's name while watching and listening to her mother talking about the toy (linguistic development of speech and communication). This happens long before the child begins to talk. Before the first birthday, the child also knows if her mother's face or body language tells her **Take this toy or Don't touch this toy**. This knowledge will help her to remain safe and healthy in new situations (health and physical development). Each simple child's activity provides the parents with a whole range of opportunities to impact on the child's development in a number of areas. Such overlapping has its purpose and shows us that the child's development in one area is connected with the development in other areas. Parents are intuitively aware of that and they always attend to their children taking into account their integral development.

However, parents of children with disability get scared and often confused with their child's reactions, which are sometimes different from what they expected. As a result, they have fewer opportunities to act intuitively and spontaneously. Since this makes it more difficult for them to raise their special child, they look for the way out by seeking information. Our message to them is: always ask professionals to help you integrate the specific information that you gathered yourself or received from them into a comprehensive approach that you practice with your child.



## 2. Child's progress

Every child develops at his/her own pace. One ability or skill develops earlier than some others. Earlier achievements become the foundation for what comes later. There is no need to rush: some children need more time to build certain foundations, some less. But, we must give them the time they need: if we encourage them too much by exposing them to the next thing for which they are not ready yet, we are sending them a message that they are incapable or not good enough. Giving them assignments that are too difficult for them could be disastrous for their motivation and self-confidence. For example, most children sit up on their own, crawl, get up on their feet and "cruise" around the furniture, and only then they start walking. But, they differ greatly from one another in how and when they reach a certain stage of development. One baby may make a fast progress from crawling on its "tummy" to walking. A baby of calm temperament will be happy just sitting and exploring the toys at his/her reach, and start walking rather late. A baby with a physical disability may need physical therapy and special equipment to help him/her walk. All three children eventually make progress in walking, each in their own way and time. And, even if we are certain that the child will never walk due to their motoric disability, we can make it possible for them to experience movement and what it implies: reaching for new objects and places, gaining independence in changing locations and movement in general. This can be achieved by providing different aids, such as prams.

## 3. How young children learn

Children of different ages learn in different ways. The more mature they become in terms of cognitive abilities, the more independent they get in gaining experience. But, even then they need adults to learn more and progress better. An important trait of the mankind is that parents teach their offsprings with great dedication from the very moment they are born, but not always in the same manner. Parents have a special "talent" to recognize the child's current intentions, their so-called "plan". Parents then join in by encouraging learning through the activity or play that corresponds to the child's needs and intentions at a given time. This is important because the child still does not understand adults' intentions so they cannot join them. That is why parents join the child and it is their responsibility at that early age to initiate cooperation, common routine and rituals.

Infants learn through interaction with people close to them. Studies show that integration and communication abilities start developing early, owing to genetic background of the child and equally important stimulation coming from the parents. This interaction grows into a routine which become predictable to the child and gives them a feeling of security because now they know what follows. Predictability is very important for the child to be able to participate. When disturbed, it produces surprise, which the

child also finds amusing and then focuses on the adult who has sprung the surprise at them. Such early interactions stimulate learning and psychological development.

A child learns best in the safe environment where they actively participate in whatever may be a source of their interest and enjoyment. That is why they should not be kept for too long on the swing, in highchair, or playpen. Infants and young children learn when they actively participate in the daily routine. For example, at meals they experience various looks and smells of food, learn to separate the remains of food from the pans or set the table and later remove the cutlery, etc. It helps if the space is arranged so that they are allowed to touch and explore everything that is within their reach and thus enrich their experience. Dangerous or valuable objects should be placed out of their reach and sight. Children gradually learn to control their behaviour and parents should be careful not to surround them with too many “challenges” that they cannot resist and when all they hear is ***Not this, not that, no ... no ...***

However, arranging the space and going through routine is not enough. The child learns more when adults play with them. It is important that adults observe closely what infants and young children do and that they respond to their interest. Also, we should show the young child how they can play with other children or resolve a conflict. For the child with disability it is more difficult to explore and play, so we should bring them various objects, show them new possibilities and skills and encourage other children to play with them. Children are “teachers” to other children. Children are less adaptable than adults and for that reason their adaptation to other children is for them a greater challenge than adaptation to adults.

Parents start to think very early about school and how to prepare their child for school, especially if they have developmental difficulties. Some believe that the best way of preparation is to start early with learning. However, researches show that active exploration and play are the best preparation for school. What contributes to the future learning and success is the child’s emotional and social development, health and attitude towards learning rather than adoption of information, facts and skills required later in school. This also applies the child’s cognitive development, basic skills and communication. The best way to acquire them is through play, exploration and socialization with adults close to them and their peers. The child should therefore be given adequate support and structure and this is the responsibility of parents and professionals.



#### 4. Therapies should be built in daily routine

A child with disability usually gets some kind of therapy: physiotherapy, speech therapy, work therapy, maybe some professional support at home, i.e. a professional who visits the child at home and stimulates them to learn in the familiar environment. It is neither pleasant nor beneficial for a child of young age to visit too many professionals. His/her ability to adapt and to integrate the newly acquired knowledge into experience is still too fragile. The newly acquired knowledge must be built in the daily routine in order to preserve it and make it functional. It is therefore very important that the professionals share with the parents their methods of individual work with the child and explain to them which stimuli and strategy are to be used at a given time. It is not enough to just hear that they are necessary, but also why they are necessary, i.e. place them in the context of the child's interests and their learning capacity. Then the parents can include them in their daily activities with the child, and not as therapists but as parents. Professionals engaged in individual work with children may help parents become more efficient if they teach them how to use and implement certain strategies that are useful to the child. For example, in his interaction the child does not pay enough attention to the parent's face and does not look right in the eye. The professional may suggest a different strategy when the child asks to be given certain object: the parent should not just go to the shelf and put the object in his hand. Instead, she should hold it for a while in front of his face. Focused on the object, the parent's face will be in the child's field of view together with the object. Their eyes will meet and contact will be established in a natural situation. The child will notice that his parent's eyes shine a different light when their eyes meet and that those eyes are sending a message **Here, take it**. Of course, to discover this, the child needs to go through a number of similar situations (repetitions) which will make sense to him. That can only happen in a natural situation interesting to the child, and not through "drills". Such strategy is far more effective than parental instruction: **Look at me!** The child will look at the parent to get hold of the desired object, but he will not understand what exactly he is supposed to look at on that face. He will look to get what he wants and not to establish contact. If they hear a good explanation of the method and purpose of the strategies, the parents will build it into their parental behaviour and cleverly use it in a number of daily situations. As for the children, they will make an important discovery without duress or exercising in which they see no point.



# Basic psychological needs

Every child and every adult have the basic psychological needs – they are universal (Ryan and Deci, 2000). Satisfying them is important for personal well-being. Parents of children with developmental difficulties and risks sometimes must invest special efforts in order to make sure that all basic psychological needs of their child are harmoniously met. The rhythm of various exercises and check-ups leave the child little time for bonding, freedom of choices and mastering of knowledge and skills at the child's own pace and in the way that makes them feel capable and efficient in what they do. A lot of things are and must be imposed on the child, and that is not simple. However, parents are resourceful and they should make use of it by giving their child enough opportunities to meet their basic psychological needs.

The basic psychological needs are the following:

- **The need for connection with important person/s in the environment, for love, acceptance, close relationships, a "safe base" and for security, predictability and stability of this connection.**
- **The need for autonomy, independence, appreciation, freedom of choice.** It relates to experiencing self- initiative, freedom of choice, feeling that I am the one directing my own behaviour and making decisions important for my life (rather than behaving under duress and extrinsic pressure).
- **The need for competence, the ability to have an effect on the people and things that surround the child and to master knowledge and skills.** It concerns the need to feel efficient and successful in their interaction (efforts) with people and things around them.

The parents' attitudes and behaviours play a role in the fulfillment of the child's psychological needs to a lesser or greater extent (Grolnick et al., 1997).

## How the parent facilitates fulfillment of the child's need for connection

By being a part of their child's life and world!

**The parent's personal involvement** concerns the parent's interest for the child and the knowledge of them, and how much the parent participates in the life of the child. Showing personal involvement implies surrendering oneself to the child in the emotional and material sense (e.g. spending time in activities together, paying attention, showing warmth, being present in the child's everyday life).



## How the parent supports fulfillment of the child's need for autonomy

By encouraging the child's autonomy!

**Parental support to the child's autonomy** involves active support to the child's initiatives and projects, offering choices (in line with the child's age, maturity and interests), and encouraging the child to resolve their own problems. Opposite to encouragement of the child's autonomy is the use of duress and pressure to motivate the child, and resolving problems instead of them. This is not an easy task because the child with disability is forced to do things they do not like more often than other children. Therefore it is good to discuss this issue with the professional who works with the child to make sure that everything that is useful and necessary is done but that, at the same time the child gets the support to his need for autonomy.

## How the parent supports the fulfillment of the child's need for competence

By providing structure and guidance!

**The parent's providing structure and guidance** means ensuring stability and predictability in the child's life and surroundings (e.g. daily routine, rituals, safe space), and expressing their clear expectations, rules and feedback to the child on desirable and undesirable behaviour. These parental behaviours help the child to acquire the experience of competence and also to experience the feeling of achievement and success.

The child sees parental involvement and providing of structure as positive or negative, depending on the measure in which the parent supports the child's autonomy.

Too much parental involvement may be seen by the child as imposing, meddling and overwhelming if the parent does not acknowledge the child as an individual and does not support their autonomy.

Likewise, structuring and directing the child's behaviour may be perceived by the child as something negative if the parent does not respect the child's autonomy and his/her participation in decision making.

Of course, how the child will see parental support to their autonomy, providing structure and directing, depends on whether the child feels the parent's personal involvement, acceptance and emotional warmth.

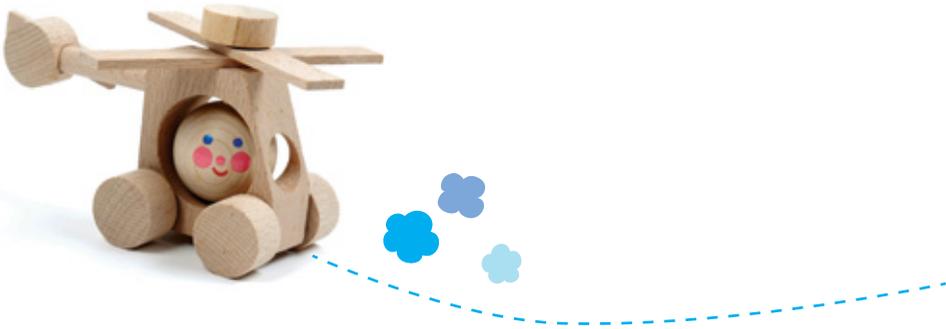


## PLAY – Tips for parents

- Take some time to play with your child every day – let this be a time when your attention is focused solely on the child.
- Follow the child's interest in the choice of plays.
- Keep your focus not on teaching academic skills (graphomotor skills, adoption of terms), but on the child's and your own fun, good feelings and good communication.
- Include as many family members as possible in the play.
- Let playing become your family ritual.
- During the play, stress the child's skills and virtues, commend the initiative of the child, thus encouraging the child's sense of competence.
- Teach your child to accept victory and defeat as a normal part of the play and activities.
- If the play must end, allow the child a transitional period, e.g. warn the child that playing is possible for another 15 minutes, then another five minutes, after which playing must stop.
- Try to organise the child's obligations as a play – tidying the room can be fun as well.
- PLAYING IS IMPORTANT, if you have questions, contact the experts!

You are your child's  
best, most valuable toy!  
– So play!





## 7. REFERENCES

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- Asmussen, K.** (2011) *The evidence-based parenting practitioner's handbook*. New York: Routledge.
- Bailey, D. B. and Simeonsson, R. J.** (1988) Assessing needs of families with handicapped infants. *Journal of Special Education*, 22, p. 117 - 127
- Bartolo, P. A.** (2002) Communicating a diagnosis of developmental disability to parents: multiprofessional negotiation frameworks. *Child: Care, Health & Development*, 28 (1), p. 65 - 71
- Benson, J.F.** (1987). *Working More Creatively with Groups*. Tavistock Publications.
- Breton, M.** (1994) On the meaning of empowerment and empowerment-oriented social work practice. *Social Work with Groups*, 17 (3), p. 23 - 37
- Buckman, R. and Kason, Y.** (1992) *How to break the bad news: a guide for health-care professionals*. London: Papermac.
- Flett, M.** (2007) Supporting mothers: Enriching the learning environment for young children. *Early Childhood Matters*, 11, p. 45 - 50
- Grolnick, W. S., Deci, E. L. and Ryan, R. M.** (1997) Internalization within the family: The self-determination theory perspective. In Grusec, J. E. and Kuczynski, L. (Ed., *Parenting and children's internalization of values: A handbook of contemporary theory*, p. 135 - 161 New York: Wiley.
- The UN Convention on the Rights of the Child* (2001) Zagreb: State Institute for the Protection of Family, Maternity and Youth.

- Kralj, T.** (2012) Opterećenje i potrebe roditelja male djece s razvojnim teškoćama [Burden and needs of parents of young children with disabilities]. *Unpublished master's thesis*. Zagreb: University of Zagreb, Faculty of Humanities and Social Sciences.
- Krauss Wyngaarden, M.** (2000) Family assessment within early intervention programs. In: J. P. Shonkoff and S. J. Meisels (ed.), *Handbook of early childhood intervention (2nd edition)*, (p. 290 – 308). New York: Cambridge University Press.
- Kuczynski, L. and Parkin, M.** (2006) Agency and bidirectionality in socialisation: Interactions, transactions and relational dialectics. In: Grusec, J. E. and Hastings, P. (ed.) *Handbook of socialisation*, p. 259. – 283 New York: Guilford Press.
- Ljubešić, M.** (2013) *Roditelj i dijete s teškoćama u razvoju [Parenting a child with disability]*. In: Pećnik, N. (ed.) *Kako roditelji i zajednice brinu o djeci najmlađe dobi u Hrvatskoj [How parents and communities care for the youngest children in Croatia]*. Zagreb: UNICEF Office for Croatia, p. 84 – 97
- Milas, G.** (2005) *Istraživačke metode u psihologiji i drugim društvenim znanostima [Research methods in psychology and other social sciences]*. Jastrebarsko: Naklada Slap.
- Miller, N. B.** (1994) Nobody's perfect. Living and growing with children who have special needs. Baltimore: Brookes.
- Oates, J.** (2010) Supporting Parenting. *Early Childhood in Focus, 5*. Milton Keynes: The Open University.
- Pećnik, N.** (2007) Towards a vision of parenting in the best interests of the child. In: Daly, M. (ed.) *Parenting in contemporary Europe: A positive approach*, p. 15 – 36 Strasbourg: Council of Europe Publishing.

- Pećnik, N.** (2008) Suvremeni pogledi na dijete, roditeljstvo i socijalizaciju [Contemporary views of the child, parenting and socialisation]. *Dijete i društvo*, 10(1/2), p. 99 - 115
- Pećnik, N.** (ed.) (2013) Kako roditelji i zajednice brinu o djeci najmlađe dobi u Hrvatskoj [How parents and communities care for the youngest children in Croatia]. Zagreb: UNICEF Office for Croatia.
- Pećnik, N. and Ljubešić, M.** (under review) Supporting parents of young children with disabilities: A program evaluation. *Infants and Young Children*.
- Pećnik, N. and Starc, B.** (2010) *Rastimo zajedno, program radionica za roditelje najmlađe djece: Priručnik za voditelje [Growing up Together Programme of Workshops with Parents of Youngest Children: Leader Handbook]*. Zagreb: UNICEF Office for Croatia.
- Pećnik, N. and Starc, B.** (2010a) *Parenting in the Best Interests of the Child and Support to Parents of the Youngest Children*. Zagreb: UNICEF Office for Croatia.
- Recommendation 19** (2006) of the Committee of Ministers to member states on policy to support positive parenting. *Dijete I društvo*, 10 (1/2), p. 463 - 470
- Profaca, B. and Arambašić, L.** (2004) Upitnik izvora i intenziteta roditeljskog stresa. *Suvremena psihologija [Questionnaire on sources and intensity of parental stress. Contemporary Psychology]*, 7(2), p. 243 - 260
- Roggman, L. A., Boyce, L. K. and Innocenti, M. S.** (2008) Developmental parenting. A guide for early childhood practitioners. Baltimore: Brookes.
- Ryan, R. and Deci, E.** (2000) Self-determination theory and the facilitation of intrinsic motivation, social development and well-being. *American Psychologist*, 55 (1), p. 68 - 78
- Sandbaek, M.** (2007) Supporting parenting in the best interest of the child In: Daly, M. (ed.) *Parenting in contemporary Europe: A positive approach*, p. 15 - 36 Strasbourg: Council of Europe Publishing.

- Shonkoff, J. and Phillips, D.** (2000) *From neurons to neighborhoods: The science of early childhood development*. Washington, DC: National Academy Press.
- Toseland, R. W. and Rivas, R. F.** (2001). *An introduction to group work practice*. (4th ed.). Boston: Allyn & Bacon.
- Trute, B., Hiebert-Murphy, D., Benzies, K. and Levine, K.** (2009) Three Measures for Family-Centred Practice in Children's Services: *Family Impact of Childhood Disability (FICD), Parenting Morale Index (PMI), and Professional and Parent Alliance Scale (PAPAS)*. Calgary, AB: University of Calgary.



# 8.

## LIST OF ORGANISATIONS AND ASSOCIATES WHO PARTICIPATED IN THE EXPERIMENTAL IMPLEMENTATION AND EVALUATION OF THE PROGRAMME

We would like to thank all the leaders who conducted the *Growing up Together Plus* Workshops with Parents of Children with Disabilities in the spring of 2013 and made a valuable contribution to the creation of the Programme and its evaluation. The experimental implementation of the Programme took place in the following organisations:

- 1. RADOST Kindergarten, Crikvenica**  
Sonja Pribela-Hodap  
Tea Petek
- 2. VRBIK Kindergarten, Zagreb**  
Minja Jelić  
Martina Smiljanić
- 3. CEKIN Kindergarten, Slavonski Brod**  
Vesna Jerković  
Maja Ereiz
- 4. MALI DOM, Day Care Center for Rehabilitation of Children and Young Adults, Zagreb**  
Sabina Šimić  
Mirjana Marojević
- 5. Rehabilitation Centre of the Faculty of Education and Rehabilitation Sciences, Zagreb**  
Marta Ljubešić  
Branka Starc
- 6. Association of the Deaf and Hearing Impaired Persons of the Primorje-Gorski Kotar County, Rijeka**  
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- 7. Family Centre of the Vukovar-Srijem County, Vinkovci**  
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Ines Puhar  
Irena Krajecar



We extend our thanks to the professionals who made the evaluation of the Programme possible by working with the parents who did not attend the workshops and made a so-called “control group” in the following organisations:

1. **OPATIJA Kindergarten, Opatija**  
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2. **VEDRI DANI Kindergarten, Zagreb**  
Martina Mikac
3. **OSIJEK, Centre for Preschool Education, Osijek**  
Gabrijela Hajba  
Tatjana Mikloš
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Ivana Vukšić
5. **RIJEKA Kindergarten, Rijeka**  
Darko Sambol
6. **DUGA Kindergarten, Zagreb**  
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7. **VLADIMIR NAZOR Kindergarten, Zagreb**  
Vesna Marušić
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Renata Belas
9. **LATICA Kindergarten, Zadar**  
Božica Dušević
10. **Down Syndrome Association – Zagreb**  
Natalija Belošević



## Excerpts from reviews:

“First, I would like to express my satisfaction with this extremely valuable and useful material intended for the work with one especially vulnerable group of parents. In addition to all the challenges that go with the contemporary parenting, this group is faced with increased demands of encouraging the growth and development of children with disabilities. Every effort to empower parents is a direct contribution to the well-being of children, which is important for every child. The very fact that “children are children” is often forgotten in the context of children with disabilities. ... The handbook for leaders of the Growing up Together Plus workshops with parents of children with disabilities is aimed at ensuring support to the empowerment of parents in these difficult conditions. In addition to providing a clear theoretical framework for the challenges of the contemporary parenting, the handbook describes a series of structured workshops aimed at arming parents with information, skills and support that they can use to fulfill their parental responsibilities. Also, it promotes the development of parents and children and offers information on the evaluation of the implemented programme. ...

In conclusion, the Growing up Together Plus Programme is extremely valuable both to the leaders of the Programme and the parents of children with disabilities as beneficiaries.”

**Tamara Martinac-Dorčić, PhD**

Faculty of Humanities and Social Sciences  
of the University of Rijeka  
Department of Psychology

“One of the main features of all aspects of the contemporary society, including parenting, is the access to information and the possibility of choice, but also the responsibility arising thereof. In their need for a variety of information, parents form groups, communities and associations, because the living word and experience are the most authentic instruments. Parents of children with disabilities have an even greater need for information and action. However, in their quest they do not receive systematic and science-based support in our country. The Growing up Together Plus Programme of Workshops with Parents and its sister programme of workshops, Growing up Together, have precisely this purpose – to provide support to the parents of children with disabilities by offering general, science-based information about parenting and education through practical work in groups, but taking into account all specificities of such challenging parenting. ...

Furthermore, the examples which are abundant in this handbook and contain the quoted experiences and reflections of the leaders and the parents who took part in the pilot project of the Programme are also very valuable. This is what makes this handbook original and shows openness to genuine cooperation between the parents and the experts. ...

One of the insights from the Programme evaluation is that the parents of children with disabilities do not want to be considered “special”. By emphasising that the principles of positive parenting apply to all parents, that doubts and bad stages are a part of everyday life of all parents, and that the parental need for support is universal, this Programme makes adaptation easier and strengthens their, unfortunately still shaken, equal position in the society. ...

In conclusion, this is one of the most comprehensive programmes for parents of the youngest children with disabilities which meets the criterion of being based on evidence, and its practical workshops offer parents information that empower them and help them to overcome and cope with all stages of the challenging parenting, always considering parents as active partners.”

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What do good gardeners do?  
They help a rose become a rose.  
Mothers and fathers are like  
good gardeners.

Those who  
conquer fear can  
scare even a tiger.

### Three wise thoughts

There are no hopeless  
situations; there are only  
people who feel helpless in  
certain situations.

