4. EVALUATION OF THE *GROWING UP TOGETHER PLUS* PROGRAMME

Ninoslava Pećnik

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 (Asmussen, 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 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 Pećnik 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 conclusion, 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.

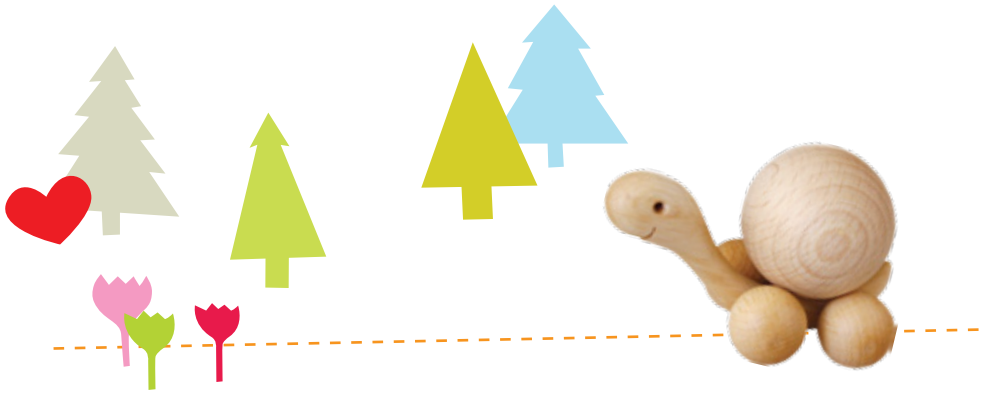
Before the Programme, over one quarter of the parents said that they wanted the workshops to help them achieve changes in their relationship with other family members: another child (28%) or partner (27%). After the Programme most parents noticed a significant (33%) or a moderate number (35%) of *changes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