

Journal of Social Intervention: Theory and Practice –
2023 – Volume 32, Issue 2, pp. 4–24
<http://doi.org/10.18352/jsi.710>

ISSN: 1876-8830

URL: <http://www.journalsi.org>

Publisher: Rotterdam University of Applied Sciences
Open Access Journals

Copyright: this work has been published under a
Creative Commons Attribution-Noncommercial-No
Derivative Works 3.0 Netherlands License

Ivon Riemersma, researcher and orthopedagogue at

Pluryn. PhD Student. Area of research: Intellectual
disabilities, parental mental health concerns.

ivonriemersma@gmail.com

Floor van Santvoort, researcher at Pluryn. [fsantvoort@](mailto:fsantvoort@pluryn.nl)
pluryn.nl

Karin T.M. van Doesum, researcher at Radboud University
Nijmegen and Impluz. karin.vandoesum@mindfit.nl

Clemens M.H. Hosman, emeritus professor Mental Health
Promotion and Prevention Mental Disorders at Radboud
University Nijmegen. hosman@psych.ru.nl

Jan M.A.M. Janssens, emeritus professor Orthopedagogy:
Family and Behaviour at Radboud University Nijmegen.
j.janssens@pwo.ru.nl

Rianne A.P. van der Zanden, researcher at Erasmus
University Rotterdam. apvanderzanden@xs4all.nl

Roy Otten, professor Clinical Developmental Psychology
at Radboud University Nijmegen. R.otten@pwo.ru.nl

Correspondence to: Ivon Riemersma

E-mail: ivonriemersma@gmail.com

Category: Research

IVON RIEMERSMA,
FLOOR VAN
SANTVOORT, KARIN
VAN DOESUM,
CLEMENS HOSMAN,
JAN JANSSENS,
RIANNE VAN DER
ZANDEN, ROY
OTTEN

YOU ARE OKAY. EXPERIENCES OF PARTICIPANTS WITH THE 'YOU ARE OKAY' PROGRAM

JIJ BENT OKAY. ERVARINGEN VAN DEELNEMERS VAN HET 'JIJ BENT OKAY' PROGRAMMA

ABSTRACT

Many children with mild intellectual disabilities who have parents with mental health concerns suffer from social-emotional problems. The 'You are Okay' program is the first to support these children and their parents. An effect study showed first promising results in decreasing

children's emotional and behavioural problems. The current study was conducted to evaluate the intervention qualitatively using experiences of the participants.

A combination of questionnaires administered to 28 children and fourteen parents and in-depth interviews with three children, two parents and eight professionals were used to evaluate the experiences of the participants.

Children, parents and professionals viewed 'You are Okay,' especially its psychoeducation, mutual recognition, and support, as valuable and useful. However, carefully matching children in support groups and screening for pre-conditions seems to be essential for successful participation. This study concluded that 'You are Okay' supports children with mild intellectual disabilities and their parents with mental health concerns. The findings are also in line with the results of the effect study of the program, which showed that 'You are Okay' supports children by decreasing their emotional and behavioural problems after participating in the program. Together these results strengthen the idea that this family-focused approach is helpful in children's treatment.

KEYWORDS

Family-focused approach, intellectual disabilities, parental mental health concerns, psychoeducation, social-emotional problems, support groups

SAMENVATTING

Veel kinderen met een licht verstandelijke beperking van ouders met psychische klachten hebben sociaal-emotionele problemen. 'Jij bent Okay' is het eerste programma dat specifiek ontwikkeld is om deze kinderen en hun ouders te ondersteunen. Een effectstudie heeft eerste veelbelovende resultaten laten zien om (verdere) probleemontwikkeling bij kinderen te voorkomen. In deze studie is het programma kwalitatief geëvalueerd met de ervaringen van de deelnemers van het programma.

Een combinatie van vragenlijsten, afgenomen bij 28 kinderen en veertien ouders, en diepte-interviews met drie kinderen, twee ouders en acht professionals zijn gebruikt om de ervaringen van de deelnemers te evalueren.

Kinderen, ouders en professionals beoordeelden met name de psychoeducatie, onderlinge herkenning en steun binnen het 'Jij bent okay' programma, als waardevol en bruikbaar. Voor

YOU ARE OKAY

succesvolle deelname is het echter belangrijk om te zorgen voor een goede groepssamenstelling en kinderen zorgvuldig te screenen op de voorwaarden voor deelname.

Deze studie laat zien dat 'Jij bent Okay' ondersteunend is voor kinderen met een licht verstandelijke beperking en hun ouders met psychische klachten. Dit komt overeen met de resultaten van een kwantitatief effectonderzoek dat liet zien dat het programma helpt om sociaal-emotionele problemen bij kinderen te verminderen. Gezamenlijk versterken de resultaten het idee dat de gezinsgerichte benadering 'Jij bent Okay' ondersteunend is in de behandeling van kinderen.

TREFWOORDEN

Gezinsgerichte benadering, verstandelijke beperking, psychische klachten bij ouders, psycho-educatie, sociaal emotionele problemen, ondersteuningsgroepen

INTRODUCTION

Children with mild intellectual disabilities (IQ between 50 and 85)¹ often have parents with mental health concerns. Taggart, Taylor & McCrum-Gardner, (2010) reported that 66% of children with mild intellectual disabilities and emotional and behavioural problems have a parent with mental health concerns. Research has repeatedly shown that children of parents with a mental illness (COPMI) or substance use disorder are at risk of developing social-emotional problems themselves (Beardslee, Gladstone & O'Connor, 2011; Havinga *et al.*, 2016; Van Santvoort, Hosman, Van Doesum & Janssens, 2013). In this study, COPMI refers to children of parents with mental health concerns including children of parents with a substance use disorder. In addition, children from parents with mental health concerns, more often have mild intellectual disabilities according to Hay and colleagues (2001), since children of mothers with postpartum depression had lower IQ scores compared to children of mothers without depression. Morgan and colleagues (2012) showed a relationship between mother's mental health concerns (schizophrenia, bipolar disorder, and unipolar major depression) and children's intellectual disabilities. Children with mild intellectual disabilities are already at-risk for emotional and behavioural problems (such as ADHD, depression, oppositional defiant disorder, and autism) due to both child and family characteristics such as low-self-esteem, negative life events, income poverty and poor family functioning (Emerson & Hatton, 2007). Children with mild intellectual disabilities who also have parents with mental health concerns seem to be a particularly high-risk group in developing social-emotional problems (Hatton & Emerson, 2003; Riemersma *et al.*, 2021).

To prevent further social-emotional problems, preventive interventions, such as support groups, have been developed for children with parents with mental health concerns (Reupert, Cuff, Drost, Foster, Van Doesum & Van Santvoort, 2012). 'You are Okay' is the first program that was specifically developed for the high-risk group of children with mild intellectual disabilities (Riemersma, Van Santvoort, Janssens, Hosman & Van Doesum, 2015). The program is based on evidence-based interventions that are already offered to children with average intelligence of parents with mental illnesses (Van der Zanden, Speetjens, Arntz & Onrust, 2010; Van Santvoort, Hosman, Van Doesum & Janssen, 2014). Several studies showed these interventions being effective in preventing mental disorders (Reupert *et al.*, 2012; Siegenthaler, Munder & Egger, 2012; Thanhauser, Lemmer, De Girolamo & Christiansen, 2017).

The 'You are Okay' program consists of a support group for children and an online educational program for their parents. The support group for children consisted of ten weekly sessions lasting 1.5 hours with a booster session after six weeks. Parents were offered an online educational program parallel to the support group for children. They received information on five themes reflecting on their role as a parent and considering the possible effects of their problems on their child.

As shown in Figure 1, the theoretical model underlying the program was based on empirical knowledge about changeable risk and protective factors and working mechanisms of interventions for children of parents with mental health concerns (Riemersma *et al.*, 2015). As the theoretical model illustrates, the support group for children is expected to decrease risk factors and increase protective factors in children, while the online educational program for parents is expected to decrease risk factors and increase protective factors in parents. We expected the program to affect children's emotional and behavioural problems through the intermediate outcomes.

Figure 2 shows the content of the 'You are Okay' program including the themes and aims which are linked to the theoretical model in Figure 1.

In a previous study we analysed the effectiveness of 'You are Okay' (Riemersma *et al.*, 2020). Participants were children with mild intellectual disabilities and at least one parent with mental health concerns. Participants were asked to complete a pre-test, post-test (after 10 weeks) and a follow-up-test assessment (after 6 months). A quasi-experimental design was used to compare the experimental group ('care as usual' and 'You are Okay') with the control group ('care as usual') on the main outcome of emotional and behavioural problems and proposed intermediate outcomes as described above. The results showed a positive effect of the program on emotional and behavioural problems in children based on child-self reports and parental reports. Specifically

YOU ARE OKAY

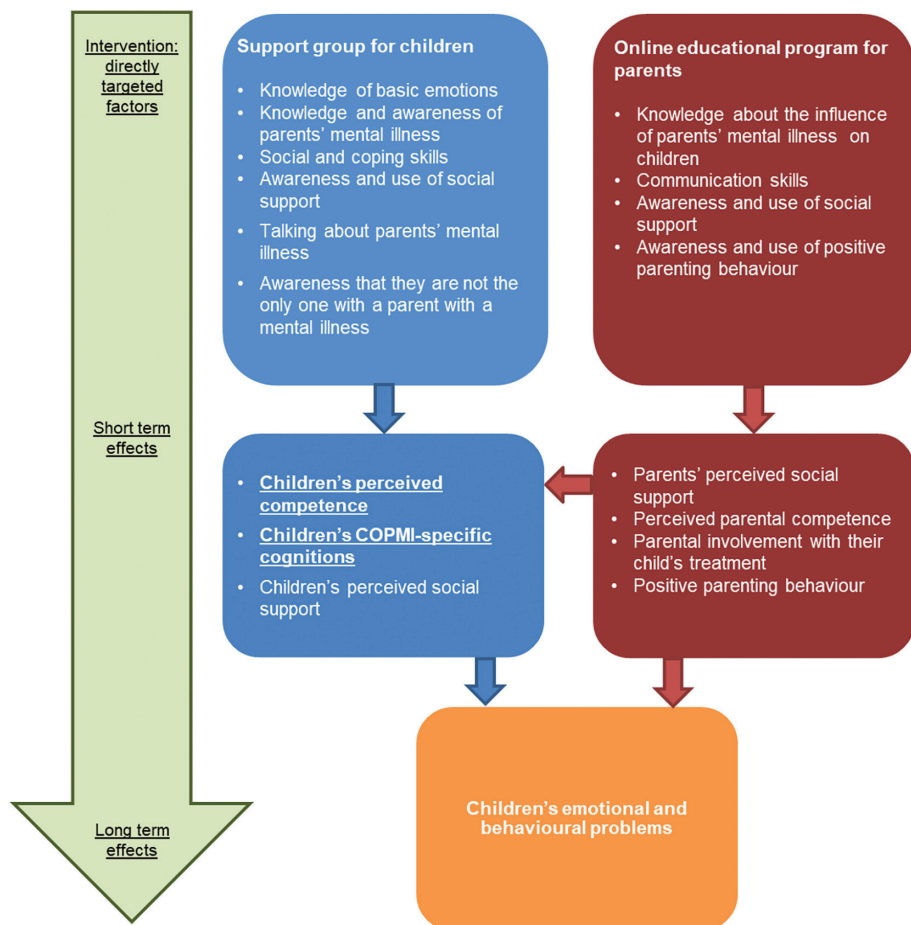


Figure 1: The theoretical model.

children in the experimental group reported larger decreases in externalizing problems between pre-test and follow-up assessment compared to children in the control group. Parents in the experimental group reported lower levels on the total of the child's problems on both the post-test and follow-up assessment compared to parents in the control group. Moreover, parents in the experimental group reported fewer externalizing problems on the follow-up assessment compared to control group parents.

The 'You are Okay' program					
<ul style="list-style-type: none"> Based on the support group for children with average intelligence and their parents with mental health concerns (Van Santvoort, 2013) and on the online educational program for parents ('Kopopouders', Van der Zanden et al., 2010). Adaptations were made to meet the particular needs of children with mild intellectual disabilities and their parents (simplifying language and providing additional sessions on basic emotions) (Riemersma et al., 2015). The changes were discussed with professionals who worked in specialized treatment facilities for children with mild intellectual disabilities and their parents, and they were based on Dutch guidelines for developing interventions for children with mild intellectual disabilities (De Wit et al., 2011). A pilot study (N=4) showed that children with mild intellectual disabilities were able to understand their parents' mental health concerns and to reflect on it. 					
Support group for children			Online educational program for parents		
Session	Themes	Aims	Session	Themes	Aims
1	Get to know each other	Knowledge and awareness of parents' mental health concerns Create a safe environment	1	Negative cognitions	Confidence for being a good parent
2	Recognize problems at home	Awareness that they are not the only one with a parent with mental health concerns	2	Possible influence of problems on the children	Knowledge about the influence of parents' mental health concerns on children
3	Recognize basic emotions	Knowledge of basic emotions	3	Communication	Understanding children and discussing mental health concerns with children
4	Recognize emotions in difficult situations	Recognize basic and other emotions regarding their parent with mental health concerns	4	Positive behaviour of the children	Giving compliments and setting boundaries
5	Show emotions	Recognize, show and talk about basic and other emotions with each other	5	Social network	Awareness and use of social support in and outside the family
6	Understand mental health concerns	Knowledge and awareness about parents' mental health concerns			
7	Use social network	Awareness and use of social support			
8	Cope with difficult situations	Practising social and coping skills			
9	Develop social skills	Practising social skills			
10	Parting session	Evaluating and positive goodbye			
	Booster session	Extra evaluating and positive goodbye			

Figure 2: The 'You are Okay' program.

YOU ARE OKAY

In the current study, we further analysed the 'You are Okay' program using a qualitative approach with experiences of children, parents and professionals. We used a mixed-methods approach by combining evaluation questionnaires administered to the experimental group of the 'You are Okay' effectiveness study with in-depth interviews with selected participants and professionals.

METHOD

Participants

The evaluation questionnaires were filled out by participants from the effectiveness study of 'You are Okay' (Riemersma *et al.*, 2020). These ten-to-twenty-year-old children with mild intellectual disabilities (N=28) and their parents (N=14) were recruited in four Dutch treatment facilities offering outpatient treatment or residential care for children with mild intellectual disabilities and emotional and behavioural problems. Treatment coordinators indicated the presence of mental health concerns in parents based on their clinical judgement formed during the meetings with parents about the treatment of their children. Mental health concerns included both mental health problems (such as depression, anxiety, or schizophrenia) and substance use problems (such as alcohol or drugs abuse). To be included, children had to be able to reflect on their parent's mental health concerns. Children who had been in treatment for at least three months and children who were currently not in a crisis and were stable enough to manage potential emotional responses to the programme were included in the research project. Children were excluded if parents did not give consent and/or refused to be included. The demographic data for this population are shown in Table 1.

In-depth interviews were performed with selected participants and professionals who participated in the effectiveness study of 'You are Okay'. We approached all children (five) and parents (four) who consented to be contacted for future research and who participated in the program within the last year. We expected that those who participated earlier might experience difficulties remembering the details. Three children and two parents agreed to participate in the in-depth interviews. The other children and parents could not be reached or did not agree to participate (for example because they were not interested or did not have time). Professionals in two of the four treatment facilities agreed to participate, which led to the inclusion of eight professionals with diverse backgrounds (trainers of the child support group, social workers who guided the online educational program for parents and behavioural scientists who were involved in children's treatment). More detailed information regarding the participants' characteristics is depicted in Table 2.

Table 1: Demographic data of children and parents who participated in the effectiveness study on the 'You are okay' program.

	Experimental group
Child characteristics (n=28)	
Mean age	13.79 (2.11)
Female/male	11/17
Type of health care	
Residential care	19
Part-time treatment	9
Intelligence quotient (IQ)	
Total intelligence quotient (TIQ)	70.50 (9.03)
Verbal intelligence quotient (VIQ)	74.40 (9.37)
Performance intelligence quotient (PIQ)	70.64 (9.87)
Parent characteristics (n=14)	
Mean age	43.52 (7.31)
Female/male	12/2
Participating parents had mental health concerns themselves	13
Family characteristics	
One-parent family	5
Both parents with mental health concerns	4

Table 2: Characteristics of participants in in-depth interviews.

	Age	Gender	Location	At home situation	Parental mental illness
Children					
1	17	Male	C	Living with father (4)	ADD
2	16	Male	C	Living with both parents	PTSD
3	13	Male	A	Living in residential care (mother 5)	Depression
Parents					
4	49	Male	C	Single parent	ADD
5	37	Female	A	Remarried	Depression

Procedure

The researchers contacted children and parents by phone, inviting them for an in-depth interview. The researchers visited children and parents who agreed to participate in their homes; professionals were visited in the health care facility or were interviewed by phone.

To enhance the reliability of data collection, an interview protocol was used. The researchers who performed in-depth interviews were master students of psychology and were trained by the first

YOU ARE OKAY

and second author. All interviews were voice recorded. Furthermore, we used triangulation of sources by combining and comparing information that was derived from the in-depth interviews with children, parents, and various professionals.

Intervention

The themes and aims of the ‘You are okay’ program are explained in Figure 2. Each support group session starts with a warm-up exercise. After this introduction, the experiences of the previous week and homework assignments are discussed. The program continues with exercises, including role-playing games, psychoeducation, videos and practising coping and social skills. At the end of each session, the session is summarised, and the homework assignment is explained. The sessions of the support group were at the treatment facilities for children with mild intellectual disabilities.

Figure 2 shows the themes of the online educational program for parents that help them reflect on their role as a parent and the potential effects of their problems on their child. In our study parents completed the educational program online at home. A social worker involved in the family system visited each parent three times and assisted him/her with completing the online educational program individually.

Measures

Evaluation questionnaires

The list of topics included in the evaluation questionnaires of the ‘You are Okay’ program is shown in Table 3. Children answered twelve questions about experiences, usefulness, perceived outcomes, ambiance, the difficulty of the used materials, the workbook, and recommendations to other

Table 3: Topic list for evaluation questionnaires.

Children	Parents
Experiences	Best part of the program
Usefulness	Worst part of the program
Perceived outcomes	Material comprehensibility
Ambiance	Missed topics
Material comprehensibility	Recommendation to others
General remarks	General remarks

children on 4-point Likert scales. Two open-ended questions were also included, one about the used workbook, and one to provide general remarks about the support group.

Parents were asked to rate nine questions about separate sessions, the videos, the animations, and the assistance of the professional on a scale from 1 (very bad) to 10 (very good). The overall score reflected their experiences with the online educational training. Two open-ended questions asked parents about the best and worst parts of the program. Another four 3-point Likert scales questions asked parents whether they were able to understand the information in the written text, the assignments, the videos, and the animations. They were also asked to report whether and what they had missed in the program and whether they would recommend the program to other parents with open ended questions. Lastly, they were encouraged to provide general remarks about the online educational program.

In-depth interviews

The participants in the in-depth interviews were interviewed about their experiences with the intervention individually following an interview protocol. The list of topics is depicted in Table 4. The interview protocol included open ended questions and suggestions for probing when answers were not clear. Different interview protocols were used for children, parents, and professionals with diverse backgrounds. The average duration of the interviews was 30 minutes.

Analysis

The quantitative data of the evaluation questionnaires were analysed using SPSS by calculating means, standard deviations, and percentages.

Table 4: Topic list for in-depth questionnaires.

	Children and parents	Professionals
Implementation	Recommendation to others	Inclusion criteria
	Positive evaluations of the program	Recruitment of participants
	Negative evaluations of the program	Experiences with the program
	Suggestions for improvement	Suggestions for improvement
		Train-the-trainer program
Effects		Further implementation
	Learned knowledge during the program	Perceived effects on participants
	Improvement in skills	Differences in effects between participants

YOU ARE OKAY

The qualitative data of the evaluation questionnaires and in-depth interviews were transcribed and coded using ATLAS.ti (version 8). The interviews were analysed using a general inductive approach (Thomas, 2006). This method helps discover participants' experiences without prior assumptions, theories, or hypotheses. The first step included reading all transcriptions of the interviews. Second, the first author coded all interviews. Decisions concerning coding were discussed among the first and second author. Finally, the interview data were clustered into themes and subthemes.

RESULTS

This section reviews the themes that emerged from the analysis of the participants' experiences with the program, perceived results, the working mechanisms, suggestions for improvements and further implementation. An overview of the derived themes and subthemes is given in Table 5.

Table 5: Derived themes and subthemes from the interview contents.

Themes	Subthemes
Children's support group	
Experiences with the 'You are Okay' program	Communication Individual versus group program Content of the program Organisational aspects Combination child and parent program Workbook Matching of participants Recommendation to others
Perceived results	Openness about parental mental health concerns Openness about emotions Understanding parental mental health concerns Less feelings of loneliness Less feelings of guilt
Working mechanisms	Session with psychologist Psychoeducation Recognition and sharing stories
Online educational program for parents	
Experiences with the 'You are Okay' program	Recommendation to others Difficulties in using the program Support by professional at home Content of the program
Perceived results	Child rearing skills
Working mechanisms	Psychoeducation Support from professional

Information from the evaluation questionnaires and data from the in-depth interviews were combined to report about the child support group and the online educational program for parents.

Child support group

Experiences with the 'You are Okay' program

From the 28 children who participated in the support group, 75% experienced the support group as good to very good. Most children always or often dared to say what they wanted to say (89%) and understood the given information (93%). More than half of them (57%) would probably or certainly recommend other children to participate in the intervention. Additionally, 57% evaluated the workbook in general as good to very good and 86% often or always understood the information in the workbook. All participating children reported at least one of the evaluation questions positively.

These findings largely corresponded with the findings from the in-depth interviews. In general, the three interviewed children and eight professionals evaluated the program positively. Watching videos introducing the difficult and burdensome topic of parental mental health concerns was generally considered as pleasant. Two children reported the group meeting with an external psychologist to be especially useful because they were able to ask all their questions about parental mental health concerns. In this 'expert meeting,' an invited expert (a colleague psychologist) provided psychoeducation about mental health concerns and other topics by answering the children's questions.

The children reported that some of the assignments were childish, for example throwing over a ball. Professionals also concluded that they felt the urge to adapt some of the assignments to fit the needs of the children. One child experienced the homework as a lot of work while another child experienced the homework as useful. The professionals expressed that homework assignments were not always completed. Children and professionals felt positively about the workbook for children and professionals liked the manual for professionals. The overall content of the program appeared to include a good variety of exercises with both easily accessible games and more difficult themed conversations.

The professionals stressed the importance of safe and pleasant group interaction, as was also stated by the children. Two children observed a nice and safe group while another child noticed

YOU ARE OKAY

some arguing and irritations in the group. However, both children and professionals believed that it was useful for children to share their home situation and recognise each other's stories.

Children and the professionals who were not directly involved in the online educational program for parents appeared to be scarcely informed about the parent program. Most children knew their parent also participated, but they had no further information. The professionals involved in the child support group missed to have contact with the parents, and they were not informed about the participation of the parents and the content of the online educational program.

The three interviewed children would recommend this program to other children with parents with mental health concerns.

Perceived results

From the participating children 82% affirmed to have learned from the program. The other 18% of the children reported that they dared to say what they wanted to say and understood the given information but did not report any changes or results due to the program. In more detail, most children (61%) affirmed that participating in the support group helped them communicate with their parent with mental health concerns. Discussing the parental mental health concerns with the affected parent was helpful for 50% of the children. Furthermore, 61% of the children showed increased knowledge about parental mental health concerns. Overall, 46% of the children stated that they now understood their parent with mental health concerns better than they did before, whereas 39% of the children had the same understanding before and after the program. Worries about their parents decreased in 32% of the children, in 50% they remained the same, in 4% worries increased and 14% answered that they did not worry about their parent.

In general, children and professionals participating in the in-depth interviews mentioned improvements after participating in the support group. The three children reported having learned to talk more about their situation at home with others. Five professionals and one of the parents reported that children asked them questions during and after the intervention about diverse topics, including the mental health concerns of the parent. According to them, this also positively affected the family environment, with more openness and calmness.

Two children reported that they had learned to recognise and show their own emotions and those of others. One of the children also reported having gained more insight into the mental health

concerns of the parent, which was also observed by three professionals. One parent and one professional also observed an increase in one child's understanding of the parent (regarding the same child). Professionals reported that children experienced fewer feelings of guilt as children realised, through the psychoeducation, that parental problems are not related to their own behaviours.

Working mechanisms

According to the professionals, recognising and sharing each other's stories was an important working mechanism for children in the intervention. It helped them talk about their home situation and decreased feelings of guilt and loneliness. The children also reported positive experiences with sharing their stories.

Another working mechanism that children, parents and professionals reported was parents' recognition of their mental health concerns through the psychoeducation on parental mental health concerns. According to one professional: *"I think the recognition is important. Children need to be told that it is not their fault, but that the parents have their problems and that's why things do not always work out."*

Online education program for parents

Experiences with the 'You are Okay' program

The fourteen parents who participated in the intervention evaluated the program with an overall mean score of 7.9 and the sessions were rated from 7.0 to 7.8 on a scale from 0 to 10. The videos regarding experiences of other parents were rated 6.8 and the animations with psychoeducation 7.2. The professional who supported the parents during participation was rated 8.3. The best part of the program was psychoeducation about parentification. Most parents (69%) did not report a worst part of the program, the other 31% of the parents labelled the videos and animations as the worst part. The comprehensibility of the diverse materials was good: 81% of the parents understood the text of the program, 91% understood the assignments, 75% understood the videos and 82% reported the animations as understandable. Most parents did not feel that they had missed anything during the program. Two of them missed contact with the professionals of the child support group. Parents generally liked the option of rereading the materials online. One parent reported that there was no aftercare after the program ended. Most parents (75%) would

YOU ARE OKAY

recommend participation to other parents. All participating parents reported at least one of the evaluation questions positively.

The positive experiences from the evaluation questionnaires highly corresponded with the experiences from the in-depth interviews. The two parents who were interviewed recommended other parents to participate in the intervention. One parent believed that the program was very useful. The other parent noticed that the professional had difficulties using the program on the computer. Although the practical issues hindered the program's usefulness, he valued the aim of the program. Both parents viewed the professional support offered at home as a very helpful and necessary part of the program.

The content of the online program, with its varied materials (videos, assignments, animations), was evaluated positively. Professionals also reported that it was beneficial to discuss good enough parenting and that no parent is perfect. It helped discuss difficult topics in an easily accessible way without parents feeling blamed.

Perceived results

One parent reported having learned to take back control in the family situation. The psychoeducation helped this parent reflect on her role as a parent, improve her child-rearing skills and increase her knowledge of the influence of parental mental health concerns on children. It facilitated the discussion about the difficulties within the family as reported by both the parent and professionals. The other parent reported to have learned to have more patience with his child and that his knowledge of mental health concerns had increased.

Working mechanisms

According to the professionals, psychoeducation helps parents reflect on their role as a parent. It also helps them realize that they don't have to do everything perfectly. Psychoeducation teaches parents about the influence of their mental health concerns on their children, which decreases feelings of guilt and increases feelings of competence. According to the professionals, the videos showed stories of other parents, which decreased feelings of loneliness in parents. According to both parents and professionals, the support of the professionals was another important part of the program. Discussing how to deal with difficulties in their own family situation with a professional was an added value for parents.

Suggestions for improvements and further implementation

The interviewed children, parents and professionals gave multiple suggestions for improvement:

- Experienced professionals may tailor the intervention to the needs of children (such as adapting or skip sessions and include more in-depth conversations) and parents (with or without support from a professional, offering after-care)
- The formation of support groups is considered a difficult but essential part of this program. Matching children with similar needs (e.g., do not select children with acting out behaviour together with very shy children) and screening for pre-conditions as children's motivation, children's understanding that parents have their issues and parental acknowledgement of their mental health concerns, is important in creating support groups with enough safety among group participants and therefore essential for successful participation.
- Professionals should consider the possibility to enhance the integration between the support group for children and the online educational program for parents (for example with a shared session with children and parents).
- Treatment facilities may consider further implementation by discussing the program in standard procedures during the start of the treatment of children and inclusion in standard lists of available interventions.

DISCUSSION

We concluded that most children, parents and professionals experienced 'You are Okay' as a useful and valuable program. The main perceived results included an increase in children's and parents' knowledge and understanding of parental mental health concerns and an improvement in communication and understanding between children and parents. The reported working mechanisms in the child support group were the session with the psychologist, psychoeducation, recognition from other children in comparable home situations and talking with others about the difficult topics they experience. In the online educational program for parents, the experienced working mechanisms were psychoeducation, recognition from other parents by videos and support by the involved professional.

Moreover, the family-focused approach of this program has been highly valued by most participants, although integration of the child and parent part of the intervention was reported as a suggestion for further improvement. Further recommendations included options for tailoring the intervention to the family's needs, carefully match children and their pre-conditions in forming support groups and to further implement the program in treatment facilities.

YOU ARE OKAY

The findings of this study are in line with the results from the effect study of the program which showed that 'You are Okay' supports children by decreasing their emotional and behavioural problems after participating in the program (Riemersma *et al.*, 2020). The results are also in line with other qualitative research in which participants with mild intellectual disabilities experienced a group intervention as beneficial in for example support and sharing of experiences (Croom, Chadwick, Nicholls & McGarry, 2021; Grové, Reupert & Maybery, 2015; Marston *et al.*, 2016).

Strengths and limitations

The current study has several strengths and limitations. One of the strengths is that we derived perspectives from diverse participants (children, parents and professionals) which created a wider overview of experiences with the program than when we would have interviewed a more homogeneous group of participants. Moreover, the qualitative approach of this study complements our quantitative effectiveness study as it provides more detailed information regarding participants' experiences underlying the effectiveness of the 'You are Okay' program.

One of the limitations concerns the small number of people who participated in the in-depth interviews. Therefore, we should be tentative to generalise conclusions about their experiences with the program. It is possible that participants agreed to take part in the in-depth interviews *because they were positive about the program compared to the entire group of participants*. To further assess the program and generalize conclusions to the broader population of children with a mild intellectual disability, future research may include children who do not receive treatment themselves and incorporate different moderating variables (e.g., age, gender, IQ level). Another limitation pertains to the reported difficulties in remembering details, as some interviewees participated some time ago and some of them had an intellectual disability causing working memory problems (Douma, 2018). Furthermore, the semi-structured interviews did not incorporate open-ended questions only. This may have prevented interviewees from providing their ideas about the topics that were discussed. On the other hand, children with mild intellectual disabilities may have difficulties answering open questions and therefore closed questions may be more appropriate.

Recommendations for practice

The participants reported several critical issues regarding the current program, which may positively influence the program's effectiveness. For example, since the participants experienced the inclusion of both children and parents as highly valuable, the integration of the support

group for children and the online educational program, should be more thoroughly considered. A joined session with both children and parents or a personalised after care session could, for example, be added to the program. This is in line with earlier studies showing that interventions involving children as well as parents have larger effects than interventions that address just one of them (Hay *et al.*, 2001; Thanhauser *et al.*, 2017; Van der Zanden *et al.*, 2010). Also, the option for tailoring the program to the needs of the family should be taken into account in further implementation. However, further implementation should be carefully considered, since recruiting children for prevention programs for children of parental mental illness can be problematic (Van Doesum *et al.*, 2016).

Although treatment facilities increasingly focus on a systemic approach, professionals have traditionally focused more on child characteristics and less on parent- and family characteristics. When professionals do not adequately consider the home situation of children with mild intellectual disability and their parent(s) with mental health concerns, they may underestimate the effect of parental mental health concerns on children's emotional and behavioural problems. This information may be included in health care facilities' policies, education and training. Professionals may therefore openly discuss with parents the possible effect of mental health concerns on their children. Preferably, professionals can involve parents more intensively in children's treatment and frequently talk with parents about the effects of their mental health concerns on their children's behaviours. This may also stimulate parents in acknowledging mental health concerns to professionals and to their children which will help children to understand their at-home situations. Furthermore, when parents talk about their mental health concerns with their children more openly, it may also encourage children to talk about their at-home situations with others.

Although more research of the 'You are Okay' program is needed, the present study shows that the program has the potential to contribute to the 'care as usual' offered by specialised institutes. In the long term, this may also help social and health settings improving their treatment and therefore shorten expensive forms of treatment. Future research should include a larger study sample and focus on the working mechanisms to support the current findings.

FUNDING DETAILS

This work was supported by ZonMw; under Grant number 729111011; and Antonia Wilhelmina Fonds; under Grant number 131031.

DISCLOSURE STATEMENT

The authors declare that they have no competing interests.

NOTE

1 In the Netherlands mild intellectual disabilities also includes borderline IQ.

REFERENCES

- Beardslee, W. R., Gladstone, T. R., & O'Connor, E. E. (2011). Transmission and prevention of mood disorders among children of affectively ill parents: A review. *Journal of the American Academy of Child and Adolescent Psychiatry*, 50, 1098–1109.
- Croom, S., Chadwick, D.D., Nicholls, W., & McGarry A. (2021). The experiences of adults with intellectual disabilities attending a mindfulness-based group intervention. *British Journal of Learning Disabilities*, 49, 162–178.
- De Wit, M., Moonen, X., & Douma, J. (2011). *Richtlijn Effectieve Interventies LVB [Guideline effective interventions mild intellectual disability]*. Landelijk Kenniscentrum LVB.
- Douma, J. (2018). *Jeugdigen en (jong)volwassenen met een licht verstandelijke beperking: Kenmerken en de gevolgen voor diagnostisch onderzoek en (gedrags) interventies* [Youth and Adolescents with Mild Intellectual Disabilities: Characteristics and Consequences for Diagnostics and (Behavioural) Interventions]. Utrecht: Landelijk Kenniscentrum LVB.
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191, 493–499.
- Grové, C., Reupert, A., & Maybery, D. (2015). Peer connections as an intervention with children of families where a parent has a mental illness: Moving towards an understanding of the processes of change. *Children and Youth Services Review*, 48, 177–185.
- Hatton, C., & Emerson, E. (2003). Families with a person with intellectual disabilities: Stress and Impact. *Current Opinion in Psychiatry*, 16, 497–501.
- Havinga, P. J., Boschloo, L., Bloemen, A. J. P., Nauta, M. H., De Vries, S. O., Penninx, B. W. J. H., Schoevers, R. A., & Hartman, C. A. (2016). Doomed for disorder? High incidence of mood and anxiety disorders in offspring of depressed and anxious patients: A prospective cohort study. *Journal of Clinical Psychiatry*, 78, e1–10.

- Hay, D. F., Pawlby, S., Sharp, D., Asten, P., Mills, A., & Kumar, R. (2001). Intellectual problems shown by 11-year-old children whose mothers had postnatal depression. *Journal of Child Psychology and Psychiatry*, 42, 871–889.
- Marston, N., Stavnes, K., Van Loon, L.M.A., Drost, L.M., Maybery, D., Mosek, A., Nicholson, J., Solantaus, T., & Reupert, A. (2016). A content analysis of Intervention Key Elements and Assessments (IKEA): What's in the black box in the interventions directed to families where a parent has a mental illness? *Child & Youth Services*, 37, 112–128.
- Morgan, V. A., Croft, M. L., Valuri, G. M., Zubrick, S. R., Bower, C., McNeil, T. F., & Jablensky, A. V. (2012). Intellectual disability and other neuropsychiatric outcomes in high-risk children of mothers with schizophrenia, bipolar disorder, and unipolar major depression. *The British Journal of Psychiatry*, 200(4), 282–289.
- Riemersma, I., Van Santvoort, F., Janssens, J. M. A. M., Hosman, C. M. H., & Van Doesum, K. T. M. (2015). 'You are Okay': A support and educational program for children with mild intellectual disability and their parents with a mental illness: Study protocol of a quasi-experimental design. *BMC Psychiatry*, 15, 318.
- Riemersma, I., Van Santvoort, F., Van Doesum, K. T. M., Hosman, C. M. H., Janssens, J. M. A. M., Van der Zanden, R. A. P., & Otten, R. (2020). 'You are Okay': Effects of a support and educational program for children with mild intellectual disability and their parents with mental health concerns. *Journal of Intellectual Disabilities*, 26, 70–89. <https://doi.org/10.1177/1744629520953765>
- Riemersma, I., Van Santvoort, F., Van Doesum, K. T. M., Hosman, C. M. H., Janssens, J. M. A. M., Weeland, M., & Otten, R. (2021). Social-emotional problems of children with mild intellectual disabilities having parents with mental health concerns: A quantitative comparison study. *Journal of Intellectual Disabilities*, 26, 811–823. <https://doi.org/10.1177/17446295211030092>.
- Reupert, A. E., Cuff, R., Drost, L., Foster, K., Van Doesum, K. T. M., & Van Santvoort, F. (2012). Intervention programs for children whose parents have a mental illness: A review. *The Medical Journal of Australia*, 1(1), 18–22.
- Siegenthaler, E., Munder, T., & Egger, M. (2012). Effect of preventive interventions in mentally ill parents on the mental health of the offspring: Systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51, 8–17.
- Taggart, L., Taylor, D., & McCrum-Gardner, E. (2010). Individual, life events, family and socio-economic factors associated with young people with intellectual disability and with and without behavioural/emotional problems. *Journal of Intellectual Disability*, 14, 267–288.

YOU ARE OKAY

- Thanhauser, M., Lemmer, G., De Girolamo, G., & Christiansen, H. (2017). Do preventive interventions for children of mentally ill parents work? Results of a systematic review and meta-analysis. *Current Opinion in Psychiatry*, 30, 283–299.
- Thomas, D. R. (2006). A general inductive approach for analysing qualitative evaluation data. *American Journal of Evaluation*, 27, 237–246.
- Van Doesum, K. T. M., Riebschleger, J., Carroll, J., Grové, C., Lauritzen, C., Mordoch, E., & Skerfving, A. (2016). Successful recruitment strategies for prevention programs targeting children of parents with mental health challenges: An international study. *Child & Youth Services*, 37(2), 156–174. <https://doi.org/10.1080/0145935X.2016.1104075>
- Van Santvoort, F., Hosman, C. M. H., Van Doesum, K. T. M., & Janssens, J. M. A. M. (2013). Children of Mentally Ill Parents Participating in Preventive Support Groups. *International Journal of Mental Health Promotion*, 15, 198–213. <http://doi.org/10.1080/14623730.2013.851816>
- Van Santvoort F., Hosman C. M. H., Van Doesum, K. T. M., & Janssens, J. M. A. M. (2014). Effectiveness of preventive support groups for children of mentally ill or addicted parents: A randomized controlled trial. *European Child & Adolescent Psychiatry*, 23, 473–484.
- Van der Zanden, R., Speetjens, P., Arntz, K., & Onrust, S. (2010). Online group course for parents with mental illness: Development and pilot study. *Journal of Medical Internet Research*, 12, e50.