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Published in:
Child & Family Social Work

DOI (link to publication from Publisher):
[10.1111/cfs.13000](https://doi.org/10.1111/cfs.13000)

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Publication date:
2023

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):

Laursen, S. H., Nissen, K. B., Udsen, F. W., & Haslund-Thomsen, H. L. (2023). The impact of a respite volunteer 'buddy' programme on behavioural and psychological well-being in young carers. *Child & Family Social Work*, 28(3), 734-752. <https://doi.org/10.1111/cfs.13000>

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ORIGINAL ARTICLE

CHILD & FAMILY
SOCIAL WORK

WILEY

The impact of a respite volunteer 'buddy' programme on behavioural and psychological well-being in young carers

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Funding information

The Department of Nursing, University College of Northern Denmark; The Spar Nord Foundation, Denmark; The Obel Family Foundation Denmark.

Abstract

Young carers often face a great amount of emotional burden and have high practical and social responsibilities. The role of being a young carer is associated with behavioural, developmental, physical and psychosocial problems that may not only affect the individual in childhood but also in adulthood. The aim of this study was to investigate the effect of a Danish respite volunteer programme called *The Buddies for Children and Youngsters Programme* on young carers' ($n = 49$; aged 6–16) social-emotional functioning. A pre-post-design was applied, and data were collected through the parent version of the strengths and difficulties questionnaire (SDQ), here with an impact supplement at baseline and at the end of the programme (after 4 months). The programme showed a positive impact on emotional symptoms, hyperactivity symptoms, conduct problems, peer problems, prosocial aspects and impact aspects, with mean differences values of -2.50 ($p = .000$), -0.62 ($p = .271$), -1.18 ($p = .000$), -0.74 ($p = .008$), 0.62 ($p = .004$) and -0.88 ($p = .007$), respectively. Furthermore, a large effect was found for the total difficulties score: -5.03 ($p = .000$). In conclusion, the programme seems promising considering its effect on young carers' social-emotional functioning. However, future research should include comparative studies with a longer duration.

KEYWORDS

children, mental health, respite programme, strengths and difficulties questionnaire (SDQ), volunteer programme, young carers

1 | INTRODUCTION

It is estimated that approximately 2–8% of children in industrialized countries can be included under the term young carers (Chikhradze et al., 2017; Joseph et al., 2020; Smyth et al., 2011), a prevalence that is rising (Saragosa et al., 2022). Young carers are children (<18 yr) who assist, support or provide care to another family member who has chronic illness, disabilities, mental health problems or another condition that requires support (Becker, 2007; Chikhradze et al., 2017;

Evans, 2014; Joseph, Becker, & Becker, 2009). However, death of a parent can also affect the children's responsibility in the household for instance if a child takes care of siblings to carry out the parental role their parent would have performed if he or she was still alive (Evans, 2014).

Young carers often face a great emotional burden and have high practical and social responsibility. For instance, they may be asked to help with a wide range of domestic tasks, mobility assistance, personal hygiene, talking and comforting, 'being there' for the sick family

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member and looking after siblings (Becker, 2007; Evans, 2014; Joseph et al., 2020; Joseph, Becker, & Becker, 2009; Smyth et al., 2011). According to a comprehensive review, young carers can provide care and support at any age, and their responsibilities increase with age (Sabine & Schnepf, 2007). However, there is a tendency that girls are more involved in all types of caring tasks compared to boys especially in domestic tasks and personal hygiene; a tendency that increases with age (Dearden & Becker, 1995; Dearden & Becker, 2004; Metzger et al., 2020). This tendency may reflect societal expectations placed on the female gender (de Roos et al., 2020; Tucker & Liddiard, 1998) or earlier brain development in girls associated with responsibility and planning (de Roos et al., 2020).

Being a young carer is associated with both positive and negative consequences (Barry, 2011; Bolas et al., 2007; Chikhradze et al., 2017; Cree, 2003; Joseph et al., 2020; Richardson et al., 2009; Sabine & Schnepf, 2007). From a positive viewpoint, the young carer often has a close family bond and an increased sense of self-esteem, with some feeling that the role has made them more prepared for life (Chikhradze et al., 2017). From a negative viewpoint, the role of being a young carer can be associated with behavioural, developmental, physical and psychosocial problems (Chikhradze et al., 2017; Cree, 2003; Sabine & Schnepf, 2007). For instance, it has been found that young carers may experience reduced social capital and social withdrawal and exclusion (little opportunity to socialize with peers) (Barry, 2011; Bolas et al., 2007; Richardson et al., 2009), bullying at school (Cree, 2003; Joseph et al., 2020; Moore & McArthur, 2009), physical injuries, feelings of anger and resentment and suffering from emotional exhaustion (Dearden & Becker, 2000; Hamilton & Adamson, 2013; Joseph et al., 2020; Richardson et al., 2009). Regarding emotional exhaustion, young carers are at risk of compassion fatigue, associated with the 'cost of caring' for another family member in emotional pain. Compassion fatigue or empathy burnout may be explained by emotional, social, physical and spiritual exhaustion that overtakes a person and causes a pervasive decline in her or his desire, energy and ability to feel and care for others (Figley, 2002; Hinderer et al., 2014). Furthermore, it has been well-documented that young carers are often missing out on school, showing poor educational attainment, and that many have difficulty being admitted to or completing a university degree (Dearden & Becker, 2000; Joseph et al., 2020; Kettell, 2020; Richardson et al., 2009). Thus, the difficulties and challenges associated with the position of being a young carer may not only affect the individual in childhood but also in adulthood (Chikhradze et al., 2017; Joseph et al., 2020).

Different programmes and services aimed at supporting young carers exist, such as respite camps and volunteer programmes. However, only a few studies have examined the impact of these services and programmes (Cunningham et al., 2017; Moore & McArthur, 2007; Nagl-Cupal & Prajo, 2019; Nissen et al., 2022; Richardson et al., 2009; Saragosa et al., 2022; Wind & Jorgensen, 2020); this is despite the fact that the concept of 'young carers' has become a social category in many countries (Chikhradze et al., 2017; Joseph et al., 2020; Smyth et al., 2011). The sparse research within the field is problematic as studies are essential to persuade local and national politicians to an effective

commitment in the implementation of prevention and/or interventions programmes for young carers. In Denmark, there is limited focus on programmes and services for young carers, and only one study has evaluated on a respite programme for young carers. This study was carried out in Copenhagen, the capital of Denmark, in 2017–2018 and was aimed at young carers in the age of 5–15 yr (Wind & Jorgensen, 2020). The findings from the Danish study indicate that a respite volunteer programme, where the young carer spends time with a volunteer adult (a 'buddy'), can lead to positive benefits for the young carer because this can provide a place for respite from the emotional burdens and responsibilities in the child's burdened life (Wind & Jorgensen, 2020). In the current paper, another Danish respite programme is evaluated: the Danish programme *Buddies for Children and Youngsters* (BCY). The BCY programme is inspired by the Copenhagen programme but deviates to some extent. For instance, the BCY programme includes children aged 6–16 and has been carried out in the North Denmark region, which includes city, suburbs and the countryside. The aim of the current study is to investigate whether the BCY programme has an effect on young carers' behaviours and psychological well-being from a parental viewpoint. The young carers' experiences and perspectives of participation in the BCY programme have recently been evaluated in another paper (Nissen et al., 2022).

1.1 | The BCY Programme

The BCY programme was a respite programme aimed at healthy young carers between the ages of 6 and 16 yr old who experienced chronic illness, disabilities, mental health problems or death in their immediate family circle or other individuals close to them, that is, parent/parents, sibling/siblings or a close friend. Children experiencing death was included, as death was considered a condition that also requires support and may affect the children's care work and support in the household (Evans, 2014).

The concept of the programme was built on knowledge that young carers have a need to share difficult feelings and a place for respite (Chikhradze et al., 2017; Moore & McArthur, 2007). Thus, the focus was to create a place for respite both physically and mentally for the young carer through time and activities with a volunteer adult—a 'buddy'—based on the child's preferences, time and activities that may lead to spontaneous conversations about more difficult topics. If the topics exceeded the 'buddy's' area of competence, contacts were established between the family and relevant professionals. Table 1 outlines the main elements of the BCY programme.

The programme took place in the North Denmark region between October 2019 and June 2021. Organisationally, the programme was rooted in the University College of Northern Denmark (UCN) within the nursing department.

The programme unfolded in collaboration with municipal and regional institutions and actors including schools, social workers and healthcare workers, who all contributed to the identification and recruitment of young carers and to raising the awareness of young carers. Furthermore, some young carers express a need to participate

TABLE 1 Main element of the BCY programme

- Young carers: Healthy children between the ages of 6 and 16 yr experiencing chronic illness, disabilities, mental health problems or death in a near relation, typically in a parent or sibling
- 'Buddies': Students from University College of Northern Denmark within the areas of nursing, physiotherapist, occupational therapist, teaching and pedagogy
- Recruitment and inclusion of families: The families were recruited through different channels: Social workers, Facebook, schools, flyers and so forth. Then, the parent or guardian had to initiate telephone or e-mail contact to the programme manager to be included in the programme.
- Recruitment and inclusion of 'buddies': The 'buddies' were recruited through different channels: Presentations at school, Facebook, flyers and so forth. The 'buddies' had to go through a personal interview with the programme manager to be included. Moreover, a clean criminal record and child certificate were required.
- Preparation of the 'buddies': The 'buddies' had to participate in a training course before interacting with the families. The course was conducted by the programme managers, a psychologist and researchers related to the field. Course topics included volunteering, grief and cognitive development in children, establishing and ending a relationship, support and the ethical and legal framework of the programme. The students received a course certificate after ending the programme.
- Matching: A 'buddy' and a young carer were matched by the programme managers based on common interests (computer games, football, creativity etc.), gender, age and geography.
- Duration of programme: Minimum 4 months with approximately 10 h of socializing per month
- Supervisions of 'buddies': The students attended one group supervision and two individual supervisions during the programme, which was facilitated by the programme manager, to provide support and ensure discussion of potential dilemmas or problems. If a young carer was identified as requiring therapy, contact was initiated between relevant professionals and the family, as therapeutic measures exceeded the competencies of the buddies.

in community life and thereby have a break from their care responsibilities (Moore & McArthur, 2007). Therefore, the BCY programme enabled activities with the buddy, outside the child's home in the local environment, for example, a visit to the playground, a visit to the school, making ceramics or going to a cafe.

The role of being a 'buddy' in the programme was offered to all UCN students in the North Denmark region, but the recruitment was mainly aimed at UCN undergraduate students within the field of nursing, physiotherapy, occupational therapy, teaching and pedagogy because these occupational fields were considered the most relevant regarding interaction and contact with young carers.

Young carers often provide substantial, regular and significant care, and the dimensions of caring tasks vary greatly from practical household chores to emotional support (Becker, 2007; Cree, 2003; Evans, 2014; Thomas et al., 2003). In the programme, no distinction was made in relation to which dimension of caring tasks the young carers provided. Some provided a wide range of tasks, whereas others only provided emotional support. The child's role as a young

carer was determined during the recruitment and inclusion of the families (see Table 1).

Each young carer was matched with a 'buddy' aged between 21 and 45 yr (median 22).

2 | METHODS

The present study was based on the hypothesis that a BCY programme with a duration of ≥ 4 months would have a positive effect on the young carers' behaviour and psychological well-being. The hypothesis was tested from a parental viewpoint.

2.1 | Data collection and setting

The data were collected by telephone through a questionnaire answered by a parent at both baseline (at recruitment) and at the end of the programme, that is, after approximately 4 months. Thus, it was a pre-post-questionnaire study design to evaluate the potential effects on the young carers' behaviour and psychological well-being from participating in the BCY programme.

The validated strengths and difficulties questionnaire (SDQ) was used to assess effects and included the Danish version for parents of 4–11 yr olds (P4–10) and 11–17 yr olds (P11–17), with an added impact supplement (Goodman, 1999; Goodman et al., 2003; SDQ, 2022). The chosen SDQ version was a questionnaire that can be answered by a parent (or guardian) to evaluate the child's social-emotional functioning based on five subscales: a prosocial behaviour scale and four problem scales (conduct problems, emotional symptoms, peer problems and hyperactivity-inattention problems). Each subscale consisted of five items, leading to a total of 25 items. These subscale questions were answered on a 3-point Likert scale: 'not true', 'somewhat true' or 'certainly true'. The impact supplement of the SDQ questionnaire was used to indicate distress, chronicity, social impairment and/or burden for the family, and it included additional questions relating to the impact of difficulties on the child's and family's daily life (Goodman, 1999; SDQ, 2022), where each child's emotional, concentration, behavioural or relational/social difficulties were evaluated on a 4-point Likert scale ('no difficulties', 'minor difficulties', 'definite difficulties' or 'severe difficulties') (SDQ, 2022).

The parent was also asked to answer some background and demographic questions at baseline, including reason for registration, contact and custody information, occupational status, educational level, civil status and questions relating to the child (name, gender, age, ethnicity, interests and number of siblings).

At follow-up, three additional questions were added to the SDQ questionnaire to evaluate whether the parent had experienced that the child's well-being had improved as a consequence of the BCY programme. Furthermore, a question was added to evaluate whether any changes in the family's situation had occurred during the programme, as either a worsening or improvement in the sick family member could potentially influence the results.

Appendix 1 provides a complete overview of the additional questions at baseline and follow-up. The baseline and follow-up questionnaires were pilot tested by a comparable and representative target group and by different questionnaire experts to ensure relevant adjustments and content validity and reliability (Ruel, 2019).

One of the project managers (KBN) familiar to the parents completed all the telephonic questionnaires and entered the answers. The reason for choosing a telephonic questionnaire was mainly based on experiences from the Buddy programme in Copenhagen, which showed a low response rate for an electronic questionnaire.

2.2 | Participants

All families who were included in the BCY programme were considered suitable for inclusion in the questionnaire study. The respondents included 49 parents, that is, a parent from each family, who responded on behalf of themselves, the family and the child. Of the 49 children/families who were included in the study, 34 completed the programme, and 15 discontinued the programme before the 4 months were over (Figure 1). The same parent answered the questionnaire at follow-up.

2.3 | Analysis

The answers obtained from the 25 SDQ items and impact supplement item were scored according to the recommended scoring algorithms on the SDQ scoring site (SDQ, 2022). According to this algorithm, for each of the five subscales and impact supplement, a score ranging from 0 to 10 (if all items were completed) can be calculated from the responses. Furthermore, a total difficulty score (0–40) for each child can be calculated by summing the scores from all the subscales (except the prosocial scale); the scores were assessed and categorized against the SDQ CUT point scale (three-band categorization: 'Normal', 'Borderline' or 'Abnormal'), which indicated if the scores had any clinical significance (SDQ, 2022).

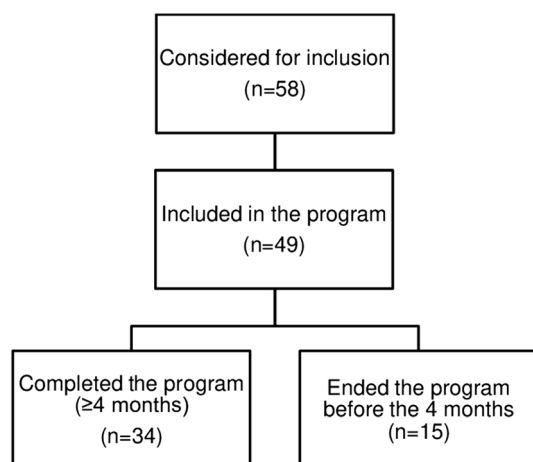


FIGURE 1 Flowchart of participant inclusion and completion

Means and standard deviation (SD) or number of participants (proportion %) were calculated for the demographic data and the SDQ data (the five subscales and impact scale).

All statistical analyses were performed using STATA (StataCorp. 2019. Stata statistical software: Release 16. College Station, TX: StataCorp LLC). The primary analysis was based on complete cases and included data from only respondents who had completed questionnaires at both the baseline and at follow-up. A secondary analysis utilizing multiple imputation was included to report the results for all included participants at baseline to check the robustness of the results. By assuming a missing-at-random (MAR) mechanism, missing follow-up data on SDQ subscales, the total difficulties scores and the impact score were imputed using the *mi impute chained* command with the creation of 30 complete datasets. Predictive mean matching was applied to all missing SDQ scores, and imputation models included SDQ variables, predictors for the SDQ outcomes at both time points and predictors for missing observations in the individual variables. Baseline characteristics and SDQ items were presented as means (standard deviations) or the number of participants (proportions %). Wilcoxon signed-rank tests (non-parametric test for matched pairs) were applied to examine pre-post-group mean differences on the SDQ subscale data, the total difficulties score and the impact score for both the complete case analysis and analysis based on imputed data. A series of post hoc subgroups within the total difficulty score were investigated using the same approach. The alpha level was set to 0.05. Items from the follow-up questionnaire relating directly to evaluating the BCY programme and the family's situation at follow-up were summarized descriptively using frequencies and proportions.

2.4 | Ethical considerations

The current study was approved by the North Denmark Regional Committee on Health Research Ethics (journal number: 2018-000367-102). The study followed UCN legal regulations. This included the fact that the study was in accordance with the General Data Protection Regulation (GDPR) (EUR-Lex, 2021) and followed written regulatory requirements in relation to data responsibility (project-ID: 43500002). In addition, the study followed scientific ethics guidelines based on the principles from the UN Declaration of Human Rights (Universal declaration of human rights, 2022) and the Declaration of Helsinki (World Medical Association, 2014).

The respondents signed a written formal consent form and gave verbal content after receiving verbal and written information from one of the programme managers (KBN) in charge of the data collection. The respondents were assured of confidentiality, anonymity and voluntary participation throughout the process.

3 | RESULTS

At baseline, no missing data were present. At follow-up, 15 participants (31%) did not respond.

TABLE 2 Baseline characteristics

	Included (n = 49)	Completed (n = 34)
The child's gender		
Male	24 (48.98)	13 (38.24)
Female	25 (51.02)	21 (61.76)
The child's age	10.12 (2.90)	9.41 (2.85)
The child's ethnicity		
Ethnic Danish	44 (89.80)	32 (94.12)
Ethnic minority	5 (10.20)	2 (5.88)
Geographical distribution		
Major city (≥100 000 citizens)	20 (40.82)	12 (35.29)
City with 10 000 to 99 999 citizens	5 (10.20)	4 (11.76)
City with 2000 to 9999 citizens	17 (34.69)	13 (38.24)
Smaller city (<2000 citizens)	6 (12.24)	4 (11.76)
Countryside	1 (2.04)	1 (2.94)
Siblings		
No	3 (6.12)	2 (5.88)
Yes	46 (93.88)	32 (94.12)
Number of siblings	1.72 (1.28)	1.77 (1.45)
Reason for enrolment in the programme		
Serious disease in close relations	38 (77.55)	29 (85.29)
Death in close relations	8 (16.33)	4 (11.76)
Both death and disease in close relations	1 (2.04)	1 (2.94)
Other reasons	2 (4.08)	0 (0.00)
Custody of the child		
Both parents	38 (77.55)	30 (88.24)
Father	1 (2.04)	0 (0.00)
Mother	10 (20.41)	4 (11.76)
Mother's highest education		
Primary or secondary school	10 (20.41)	6 (17.65)
Vocational or short tertiary education (2 yr)	9 (18.37)	6 (17.65)
Moderate or long tertiary education (3 to 8 yr)	25 (51.02)	20 (58.82)
Other education (e.g. diploma?)	1 (2.04)	0 (0.00)
Not relevant (e.g. because of death)	1 (2.04)	0 (0.00)
Missing	3 (6.12)	2 (5.88)
Father's highest education		
Primary or secondary school	9 (18.37)	8 (23.53)
Vocational or short tertiary education (2 yr)	24 (48.98)	17 (50.00)
Moderate or long tertiary education (3 to 8 yr)	10 (20.41)	6 (17.65)
Other education (e.g. diploma)	2 (4.08)	1 (2.94)
Not relevant (e.g. because of death)	4 (8.16)	2 (5.88)
Missing	0 (0.00)	0 (0.00)
Mother's employment status		
Employed	17 (34.69)	13 (38.24)
Unemployed	9 (18.37)	7 (20.59)
On leave (incl. voluntary and sick leave)	7 (14.29)	5 (14.71)
Enrolled in an education	4 (8.16)	3 (8.82)
Retired	7 (14.29)	4 (11.76)

TABLE 2 (Continued)

	Included (n = 49)	Completed (n = 34)
Other	4 (8.16)	2 (5.88)
Not relevant (e.g. because of death)	1 (2.04)	0 (0.00)
Father's employment status		
Employed	32 (65.31)	21 (61.76)
Unemployed	2 (4.08)	2 (5.88)
On leave (incl. voluntary and sick leave)	6 (12.24)	5 (14.71)
Enrolled in an education	0 (0.00)	0 (0.00)
Retired	3 (6.12)	3 (8.82)
Other	0 (0.00)	0 (0.00)
Not relevant (e.g. because of death)	6 (12.24)	3 (8.82)
Expectations to the respite programme (5-point scale)*	2.55 (0.87)	2.59 (0.89)

Note: Data are mean (standard deviation) or number of participants (proportion %).

*Low score equals high expectations.

Table 2 outlines the participant characteristics at baseline for all 49 included participants and for those 34 of the included participants who completed the programme.

At baseline, the average age was around 10 yr, the children's gender distribution was similar (51.02% female), 10.2% were of an ethnic minority, most participants had siblings (93.88%) and the average number of siblings was 1.72. The majority lived in a major city (40.82%) or a city with 2000–9999 citizens (34.69%). Serious disease in near relations was the primary reason for enrolment in the study (77.55%). For the most part, both parents had custody of the child (77.55%). The most frequent highest education among mothers was a moderate or long tertiary education (51.02%), whereas the most frequent highest education for the father was a vocational or short tertiary education (48.98%). Both mothers and fathers were mostly currently employed (34.69% and 65.31%, respectively).

At follow-up, the gender distribution deviated because mostly families with boys dropped out (11 boys vs. four girls). Furthermore, ethnic minority children made up a larger proportion of those who dropped out; 60% ($n = 3$) compared with 18% ($n = 12$) in ethnic Danish children. Regarding the reason for enrolment in the programme, the highest dropout rate was found for the children who experienced death in their nearest relations; 50% enrolled for this reason dropped out. The distribution of the mothers' and fathers' educational level and employment status did not seem to influence the tendency to drop out and neither did the child having siblings or the number of siblings.

Missing data at follow-up were not likely to be missing completely at random (Little's MCAR test 0.0233) and were associated with the child's gender and age, who had custody of the child and whether or not enrolment in the study was because of death or illness, here for all SDQ subscales, impact and total score.

The geographical distribution of the participants was similar at baseline, that is, between those who were included and those who completed the programme.

The parents' expectations of the programme were moderate overall and were relatively similar between those who were included and those who completed the programme.

Table 3 presents the distribution of the answers to the five SDQ questionnaire dimensions, that is, the prosocial and four problem scales at baseline and follow-up. At baseline, five (10.20%) and 18 (36.73%) of the 49 children had SDQ total difficulty scores in the borderline (Barry, 2011; Cree, 2003; Richardson et al., 2009) or abnormal ranges (>16), respectively. At follow-up, the SDQ total difficulty scores for 16 of these 23 children decreased to non-clinically significant levels. At follow-up, three and four children were in the borderline and abnormal ranges, respectively. For the SDQ problem subscales (including the impact scale), there were 40, 18, 20, 19 and 31 children, respectively, with baseline SDQ emotional symptoms, conduct problems, hyperactivity symptoms, peer problems and impact scores in the borderline or abnormal ranges, here based on the clinical cut-off scores (SDQ, 2022). For the children with follow-up data ($n = 34$), there were 15 of 26 (57.7%), six of 11 (54.6%), four of 13 (30.8%), four of 12 (33.3%) and nine of 18 (50%), respectively, with SDQ emotional symptoms, conduct problems, hyperactivity symptoms, peer problems and impact scores that decreased from borderline or abnormal values to non-clinically significant levels at follow-up. For the SDQ prosocial subscale, there were three children with baseline scores at or below the clinical cut-off score of 5. At follow-up, one of the three children had a score within the normal range.

Table 4 presents the mean differences between the SDQ summary scores (including the impact score) from baseline to follow-up for both the primary analysis (complete cases) and secondary analysis (imputed data). At baseline, the average emotional symptoms score and impact score were above the SDQ cut points, indicating challenges here (4.85 and 1.53, respectively) (SDQ, 2022). These results are confirmed by the secondary analysis based on the imputed data (average emotional symptom score was 5.12, and average impact score was 1.90), which also indicates abnormal total difficulties (average total difficulty score 14.06). At follow-up, all scores were in the normal range.

Average improvements were found for all SDQ subscores from baseline to follow-up in both the primary and secondary analysis, and

TABLE 3 Distribution of SDQ items in the survey at baseline and follow-up

	Baseline (n = 49)			Follow-up (n = 34)		
	'Not true' (%)	'Somewhat true' (%)	'Certainly true' (%)	'Not true' (%)	'Somewhat true' (%)	'Certainly true' (%)
Prosocial items						
Considerate of other people's feelings (item 1)	0(0.00)	10 (20.41)	39 (79.59)	0 (0.00)	2 (5.88)	32 (94.12)
Shares readily with other children (item 4)	4(8.16)	9 (18.37)	36 (73.47)	1 (2.94)	4 (11.76)	29 (85.29)
Helpful if someone is hurt, upset or feeling ill (item 9)	0(0.00)	5 (10.20)	44 (89.80)	1 (2.94)	1 (2.94)	32 (94.12)
Kind to younger children (item 17)	0(0.00)	4 (8.16)	45 (91.84)	1 (2.94)	1 (2.94)	32 (94.12)
Often volunteers to help others (item 20)	11 (22.45)	13 (26.53)	25 (51.02)	7 (20.59)	5 (14.71)	22 (64.71)
Hyperactivity items						
Restless, overactive, cannot stay still for long (item 2)	25 (51.02)	5 (10.20)	19 (38.78)	21 (61.76)	8 (23.53)	5 (14.71)
Constantly fidgeting or squirming (item 10)	23 (46.94)	7 (14.29)	19 (38.78)	19 (55.88)	9 (26.49)	6 (17.65)
Easily distracted, concentration wanders (item 15)	20 (40.82)	11 (22.45)	18 (36.73)	12 (35.29)	12 (35.29)	10 (29.41)
Can stop and think things out before acting (item 21)	20 (40.82)	22 (44.90)	7 (14.29)	13 (38.24)	16 (47.06)	5 (14.71)
Sees tasks through to the end, good attention span (item 25)	25 (51.02)	11 (22.45)	13 (26.53)	19 (55.88)	11 (32.35)	4 (11.76)
Emotional items						
Often complains of headaches, stomachaches or sickness (item 3)	22 (44.90)	10 (20.41)	17 (34.69)	30 (88.24)	0 (0.00)	4 (11.76)
Many worries, often seems worried (item 8)	11 (22.45)	4 (8.16)	34 (69.39)	19 (55.88)	8 (23.53)	7 (20.59)
Often unhappy, downhearted or tearful (item 13)	14 (28.57)	22 (44.90)	13 (26.53)	22 (64.71)	10 (29.41)	2 (5.88)
Nervous or clingy in new situation, easily lose (item 16)	12 (24.49)	15 (30.61)	22 (44.90)	17 (50.00)	8 (23.53)	9 (26.49)
Many fears easily scared (item 24)	28 (57.14)	14 (28.57)	7 (14.29)	27 (79.41)	4 (11.76)	3 (8.82)
Conduct problems items						
Often has temper tantrum or hot tempers (item 5)	16 (32.65)	16 (32.65)	17 (34.69)	22 (64.71)	7 (20.59)	5 (14.71)
Generally obedient, usually does what adults request (item 7)	24 (48.98)	18 (36.73)	7 (14.29)	22 (64.71)	12 (35.29)	0 (0.00)
Often fights with other children or bullies them (item 12)	45 (91.84)	3 (6.12)	1 (2.04)	34 (100.00)	0 (0.00)	0 (0.00)
Often lies or cheats (item 18)	33 (67.35)	11 (22.45)	5 (10.20)	29 (85.29)	5 (14.71)	0 (0.00)
Steals from home, school or elsewhere (item 22)	47 (95.92)	0 (0.00)	2 (4.08)	33 (97.06)	0 (0.00)	1 (2.94)
Peer problems items						
Rather solitary, tends to play alone (item 6)	29 (59.18)	10 (20.41)	10 (20.41)	24 (70.59)	5 (14.71)	5 (14.71)
Has at least one good friend (item 11)	44 (89.80)	3 (6.12)	2 (4.08)	31 (91.18)	1 (2.94)	2 (5.88)
Generally liked by other children (item 14)	36 (73.47)	10 (20.41)	3 (6.12)	29 (85.29)	5 (14.71)	0 (0.00)
Picked on or bullied by other children (item 19)	28 (57.14)	11 (22.45)	10 (20.41)	26 (76.47)	6 (17.65)	2 (5.88)
Gets on better with adults than with other children (item 23)	27 (55.10)	10 (20.41)	12 (24.49)	25 (73.53)	3 (8.82)	6 (17.65)

Note: Data are mean (standard deviation) or number of participants (proportion %).

TABLE 4 Differences in SDQ summary scores between baseline and follow-up

	Range	Cut point*	Baseline		Follow-up		Difference		
			Mean	SD	Mean	SD	Mean	SE	P-value#
Complete case analysis (n = 34)									
Hyperactivity symptoms	0–10	6	4.03	3.55	3.41	3.05	−0.62	0.36	0.271
Emotional symptoms	0–10	4	4.85	2.38	2.35	2.09	−2.50	0.43	0.000
Conduct problems	0–10	3	2.24	1.91	1.06	1.41	−1.18	0.26	0.000
Peer problems	0–10	3	2.21	2.25	1.47	2.06	−0.74	0.26	0.008
Total difficulties (without prosocial)	0–40	14	13.32	6.69	8.29	5.97	−5.03	0.72	0.000
Prosocial	0–10	5	8.41	1.74	9.03	1.42	0.62	0.20	0.004
Impact	0–10	1	1.53	1.93	0.65	1.20	−0.88	0.34	0.007
Analysis based on imputed scores at follow-up (n = 49)									
Hyperactivity symptoms	0–10	6	4.24	3.60	3.47	2.87	−0.78	0.29	0.032
Emotional symptoms	0–10	4	5.12	2.36	2.33	1.80	−2.80	0.35	0.000
Conduct problems	0–10	3	2.29	1.93	1.00	1.26	−1.29	0.21	0.000
Peer problems	0–10	3	2.41	2.47	1.49	1.78	−0.92	0.26	0.002
Total difficulties (without prosocial)	0–40	14	14.06	6.81	8.20	4.97	−5.86	0.76	0.000
Prosocial	0–10	5	8.55	1.56	9.10	1.25	0.55	0.14	0.000
Impact	0–10	1	1.90	2.17	0.51	1.04	−1.39	0.32	0.000

Note: #Wilcoxon signed-rank exact test.

*Cut point indicates borderline for raised number (or lowered when prosocial).

all improvements were statistically significant, save for hyperactivity symptoms ($p = 0.271$). In the primary analysis, the total difficulties score improved from the baseline follow-up (−5.03). Emotional symptoms improved the most from baseline to follow-up (−2.50) compared with the other subscales (conduct problems −1.18, hyperactivity symptoms −0.62, impact −0.88, peer problems −0.74 and prosocial behaviour 0.62). The results are supported by the secondary analysis (imputed data), which sees an improvement in total difficulties of −5.86, with emotional symptoms exhibiting the largest effect (−2.80) compared with the other subscales (conduct problems −1.29, hyperactivity symptoms −0.78, impact −1.39, peer problems −0.92 and prosocial behaviour 0.55).

Table 5 presents the mean differences in total difficulty scores between baseline and follow-up across subgroups for both the primary analysis (complete cases) and secondary analysis (based on imputed data). Both the primary and secondary analyses show statistically significant similar results for gender, place of residence, mother's employment status and expectations of the programme. For both genders, the mean difference score improved, but more for males (−7.38 for males vs. −3.57 for females) in the primary analysis (complete cases), which was confirmed in the secondary analysis (−8.21 for males vs. −3.60 for females). The results relating to place of residence showed a statistically significant improvement in children who came from a larger city ($\geq 100,000$ citizens) compared with children who came from a city with 2000 to 9999 citizens in both the primary (−6.00 vs. −4.85) and secondary analyses (−6.45 vs. −5.35). Considering mother's employment status, improvements in total difficulties score were the highest for unemployed mothers compared with

employed mothers (−6.86 vs. −3.00) in the primary analysis, which was confirmed in the secondary analysis (−7.56 vs. −3.82, respectively). Furthermore, parents who indicated 'Moderate' or 'Low' expectations of the programme at baseline had a greater improvement in total difficulties score than those who indicated 'Very high' or 'High' (−6.25 vs. −3.29), which was confirmed in the secondary analysis (−6.07 vs. −5.57).

Across age groups and mother's or father's highest education, the results from the primary and secondary analyses were more ambiguous. The total difficulties score improved approximately the same between younger and older children (−5.00 for ages < 10 yr and −5.06 for ages ≥ 10 yr) in the primary analysis but with a higher effect for ages ≥ 10 yr in the secondary analysis (−5.56 for ages < 10 yr and −6.23 for ages ≥ 10 yr). When it comes to the highest education of fathers, the most pronounced effect on the total difficulty score was found for fathers with primary or secondary school (−7.25) compared with those with vocational or short education and moderate or long tertiary education (−3.76 vs. −5.83) in the primary analysis. However, in the secondary analysis, the highest effect was found for fathers with a moderate or long education (−7.70) compared with fathers with primary or secondary school and vocational or short tertiary education (−7.00 and −4.17). For mother's highest education, similar effects on the total difficulty score were found within vocational or short education and moderate or long tertiary education (−4.67 vs. −4.70) in the primary analysis. However, in the secondary analysis, the highest effect was found for mothers with a vocational or short education (−8.44) compared with mothers with primary or secondary school and moderate or long tertiary education (−4.60 and −4.36).

TABLE 5 Differences in the total difficulties score between baseline and follow-up across subgroups

Complete case analysis (n = 34)				Analysis based on imputed scores at follow-up (n = 49)												
	n	Baseline		Follow-up		Difference		P-value#	n	Baseline		Follow-up		Difference		P-value#
		Mean	SD	Mean	SD	Mean	SE			Mean	SD	Mean	SD	Mean	SE	
The child's gender																
Male	13	15.54	5.75	9.15	6.17	-7.38	1.35	0.000	24	16.83	6.23	8.63	4.54	-8.21	1.20	0.000
Female	21	11.33	6.57	7.76	5.92	-3.57	0.65	0.000	25	11.40	6.38	7.80	5.42	-3.60	0.70	0.000
The child's age																
<10 yr	17	11.71	6.84	6.71	4.66	-5.00	1.11	0.000	27	12.74	6.39	7.19	4.09	-5.56	0.91	0.000
≥10 yr	17	14.94	6.33	9.88	6.81	-5.06	0.94	0.000	22	15.68	7.11	9.45	5.73	-6.23	1.28	0.000
The child's ethnicity																
Ethnic Danish	32	13.41	6.82	8.31	6.11	-5.09	0.76	0.000	44	13.45	6.48	8.25	5.20	-5.20	0.71	0.000
Ethnic minority	2	12.00	5.66	8.00	4.24	-4.00	1.00	0.500	5	19.40	8.11	7.80	2.39	-11.60	3.34	0.063
Siblings																
No	2	17.00	7.07	14.50	10.61	-2.50	2.50	1.000	3	18.33	5.51	12.33	8.39	-6.00	3.79	0.500
Yes	32	13.09	6.72	7.91	5.62	-5.19	0.75	0.000	46	13.78	6.85	7.93	4.69	-5.85	0.78	0.000
Place of residence																
Major city (≥100 000 citizens)	12	12.33	7.36	6.33	4.40	-6.00	1.58	0.002	20	13.55	6.75	7.10	3.81	-6.45	1.12	0.000
City with 10 000 to 99 999 citizens	4	15.00	5.94	11.25	7.46	-3.75	1.49	0.250	5	18.00	8.46	12.00	6.67	-6.00	2.52	0.125
City with 2000 to 9999 citizens	13	13.77	7.17	8.92	7.19	-4.85	0.90	0.001	17	13.71	7.13	8.35	6.50	-5.35	0.87	0.000
Smaller city (<2000 citizens)	4	14.75	5.32	10.25	4.27	-4.50	2.47	0.250	6	14.67	5.01	9.50	3.73	-5.17	1.74	0.063
Countryside	1	7.00	-	4.00	-	-3	-	1.000	1	7.00	-	4.00	-	-3	-	1.000
Reason for enrolment in study																
Serious disease in close relations	29	13.83	6.88	9.00	6.03	-4.83	0.79	0.000	38	13.82	7.12	8.79	5.27	-5.03	0.86	0.000
Death in close relations	4	9.00	4.55	2.50	0.58	-6.50	2.25	0.125	8	13.63	6.23	5.25	3.11	-8.38	1.66	0.008
Both death and disease in close relations	1	16.00	-	11.00	-	-5.00	-	1.000	1	16.00	-	11.00	-	-5.00	-	1.000
Other reasons	0	-	-	-	-	-	-	-	2	19.50	3.54	7.50	0.71	-12.00	2.00	0.500
Custody of the child																
Both parents	30	13.53	6.97	8.70	6.13	-4.83	0.78	0.000	38	13.21	6.85	8.58	5.43	-4.63	0.77	0.000
Father	0	-	-	-	-	-	-	-	1	19.00	-	9.00	-	-10.00	-	1.000
Mother	4	11.75	4.35	5.25	3.86	-6.50	1.85	0.125	10	16.80	6.37	6.70	2.71	-10.10	1.69	0.002
Mother's highest education																
Primary or secondary school	6	14.17	7.88	9.17	3.97	-5.00	2.29	0.094	10	13.20	6.68	8.60	3.06	-4.60	1.67	0.025
Vocational or short tertiary education (2 yr)	6	15.00	6.99	10.33	6.74	-4.67	0.33	0.031	9	18.11	7.64	9.67	5.43	-8.44	2.04	0.004
Moderate or long tertiary education (3 to 8 yr)	20	12.30	6.74	7.60	6.48	-4.70	0.97	0.000	25	12.08	6.42	7.72	5.78	-4.36	0.91	0.000

TABLE 5 (Continued)

Complete case analysis (n = 34)										Analysis based on imputed scores at follow-up (n = 49)									
	n	Baseline		Follow-up		Difference		P-value#	n	Baseline		Follow-up		Difference		SE	Mean	SD	P-value#
		Mean	SD	Mean	SD	Mean	SE			Mean	SD	Mean	SD	Mean	SE				
Other education (e.g. diploma)	0	-	-	-	-	-	-	-	1	21.00	-	6.00	-	-15.00	-	-	-	-	1.000
Not relevant (e.g. because of death)	0	-	-	-	-	-	-	-	1	19.00	-	9.00	-	-10.00	-	-	-	-	1.000
Missing	2	16.00	1.41	6.50	4.95	-9.5	2.50	0.500	3	17.33	2.52	7.00	3.61	-10.33	1.67	-	-	0.250	
Father's highest education																			
Primary or secondary school	8	15.25	7.81	8.00	5.98	-7.25	1.77	0.016	9	15.00	7.35	8.00	5.59	-7.00	1.58	-	-	0.008	
Vocational or short tertiary education (2 yr)	17	12.65	5.49	8.88	6.34	-3.76	0.72	0.000	24	12.83	5.49	8.67	5.31	-4.17	0.80	-	-	0.000	
Moderate or long tertiary education (3 to 8 yr)	6	11.00	7.77	5.17	2.40	-5.83	2.52	0.031	10	14.00	9.38	6.30	2.36	-7.70	2.53	-	-	0.016	
Other education (e.g. diploma)	1	26.00	-	21.00	-	-5.00	-	1.000	2	23.00	4.24	14.50	9.19	-8.50	3.50	-	-	5.000	
Not relevant (e.g. because of death)	2	12.00	5.66	7.50	4.95	-4.50	0.50	0.500	4	15.00	5.35	7.50	3.11	-7.50	2.53	-	-	0.125	
Missing	0	-	-	-	-	-	-	-	0	-	-	-	-	-	-	-	-	-	-
Mother's employment status																			
Employed	13	10.69	6.40	7.69	6.98	-3.00	0.76	0.004	17	11.59	6.48	7.76	6.06	-3.82	1.00	-	-	0.001	
Unemployed	7	15.86	8.40	9.00	6.08	-6.86	1.87	0.031	9	16.11	7.56	8.56	5.36	-7.56	1.71	-	-	0.008	
On leave (incl. Voluntary and sick leave)	5	16.00	7.00	7.80	5.26	-8.20	2.63	0.063	7	16.14	5.79	7.86	4.34	-8.29	1.90	-	-	0.016	
Enrolled in an education	3	12.33	4.62	6.33	4.93	-6.00	3.00	0.250	4	14.25	5.38	6.75	4.11	-7.50	2.60	-	-	0.125	
Retired	4	12.25	3.30	8.25	4.11	-4.00	2.00	0.125	7	12.00	5.51	8.14	2.91	-3.86	1.95	-	-	0.078	
Other	2	18.50	7.78	14.00	8.49	-4.50	0.50	0.500	4	18.50	10.41	11.25	5.85	-7.25	4.77	-	-	0.250	
Not relevant (e.g. because of death)	0	-	-	-	-	-	-	-	1	19.00	-	9.00	-	-10.00	-	-	-	-	1.000
Father's employment status																			
Employed	21	14.48	6.29	9.48	6.87	-5.00	0.76	0.000	32	14.72	6.79	9.00	5.58	-5.72	0.95	-	-	0.000	
Unemployed	2	15.50	12.02	7.50	4.95	-8.00	5.00	0.500	2	15.50	12.02	7.50	4.95	-8.00	5.00	-	-	0.500	
On leave (incl. Voluntary and sick leave)	5	10.40	9.76	5.00	3.39	-5.40	3.49	0.250	6	10.83	8.80	5.50	3.27	-5.33	2.85	-	-	0.125	
Enrolled in an education	0	-	-	-	-	-	-	-	0	-	-	-	-	-	-	-	-	-	-
Retired	3	11.33	1.53	8.33	3.21	-3.00	1.15	0.250	3	11.33	1.53	8.33	3.21	-3.00	1.15	-	-	0.250	
Other	0	-	-	-	-	-	-	-	0	-	-	-	-	-	-	-	-	-	-
Not relevant (e.g. because of death)	3	10.67	4.62	6.00	4.36	-4.67	0.33	0.250	6	14.67	5.65	6.84	3.06	-7.83	1.85	-	-	0.031	
Expectations to the respite programme																			
Very high or high	14	10.57	7.10	7.29	7.31	-3.29	0.83	0.002	21	13.05	7.65	7.48	5.93	-5.57	1.19	-	-	0.000	
Moderate or low	20	15.25	5.81	9.00	4.90	-6.25	1.00	0.000	28	14.82	6.15	8.75	4.14	-6.07	1.00	-	-	0.000	

Note: #Wilcoxon signed-rank exact test.

The results relating to the child's ethnicity, sibling status, reason for enrolment in study, custody of the child and father's employment status included only one subgroup with significant results, making subgroup analyses less meaningful.

Table 6 provides information on the parent's reported experiences with the BCY programme at follow-up. The parents were overall positive about the cooperation between the child and 'buddy'; only the options 'Good', 'Very good' or 'Excellent' in relation to cooperation were chosen. Most parents (87.51%) also found that their expectations of the programme had been met 'To a high extent' or 'To a very high extent'. Furthermore, the parents fairly agreed that 10 h a month were appropriate but found that the programme was too short (84.38%).

At follow-up, 88.2% ($n = 34$) indicated that their child's well-being had improved during the programme, and 13.33% (of the 88.2%) assigned the improvement to the child's participation in the programme. A total of 62.5% found that the programme provided respite in the child's daily life 'To a high' or 'To a very high' extent; only one indicated 'Not at all'.

The average monthly number of hours spent between the child and young carer ($n = 32$) was 8.59 (± 2.42 SD).

Table 6 provides information on the parent's reported experiences with the BCY programme at follow-up. The parents were overall positive about the cooperation between the child and 'buddy' because 26 respondents (81.25%) indicated that the cooperation was

'Excellent' (and only the options 'Good', 'Very good' or 'Excellent' in relation to cooperation were chosen). Here, 28 parents (87.51%) also found that their expectations of the programme had been met 'To a high extent' or 'To a very high extent'.

Twenty parents (62.51%) indicated that the young carer had been provided respite in daily life 'To a very high' or 'To a high extent' during the programme. More than half of the parents thought the improvement was because of the programme 'To a very high' or 'To a high extent'.

The average monthly number of hours spent between the child and young carer was 8.59 (± 2.42 SD), which was found appropriate by 23 parents (71.88%). However, the 4-month duration of the programme was deemed too short by 27 parents (84.38%).

4 | DISCUSSION

The BCY programme showed a large positive impact from baseline to follow-up, here considering the four problem scales, the prosocial scale, the impact scale and the total difficulty score. Emotional problems showed the greatest improvement from baseline to follow-up. This result may be explained by the possibility of respite through conversations and activities with the 'buddy', which helped bring about temporary relief from the difficult thoughts and emotional burden that

TABLE 6 Reported experiences with the BCY programme at follow-up

	Follow-up ($n = 34$)					
	Excellent	Very good	Good	Less good	Bad	Do not know
The cooperation between the child and young carer ($n = 32$)	26 (81.25)	3 (9.38)	3 (9.38)	0 (0.00)	0 (0.00)	0 (0.00)
	To a very high extent	To a high extent	To some extent	To a small extent	Not at all	Do not know
Extent to which expectations have been met ($n = 32$)	15 (46.88)	13 (40.63)	3 (9.38)	1 (3.13)	0 (0.00)	0 (0.00)
Extent to which the respondent think the programme is the cause of improvement during the programme ($n = 30$)	2 (6.67)	16 (53.33)	8 (26.67)	3 (10.00)	1 (3.33)	0 (0.00)
Extent to which the young carer provided respite in daily life ($n = 32$)	9 (28.13)	11 (34.38)	8 (25.00)	3 (9.38)	1 (3.13)	0 (0.00)
	Marked worsening	Worsening	No change	Improvement	Marked improvement	Do not know
Change in the family's circumstances because of illness or death during the programme ($n = 30$)	0 (0.00)	6 (20.00)	16 (53.33)	6 (20.00)	2 (6.67)	0 (0.00)
	Too short	Appropriate	Too long	Do not know		
The duration of the programme (4 months) ($n = 32$)	27 (84.38)	5 (15.63)	0 (0.00)	0 (0.00)		
	Too many	Appropriate	Too few	Do not know		
Assessment of the 10-h spent per month between child and carer in the programme ($n = 32$)	2 (6.25)	23 (71.88)	0 (0.00)	0 (0.00)		

often come with being a young carer (Becker, 2007; Joseph et al., 2020; Nissen et al., 2022). Emotional relief through conversations and time with the adult 'buddy' was outlined as a positive experience from the children's viewpoint in both the BCY programme and the Buddy programme (Copenhagen) (Nissen et al., 2022; Wind & Jorgensen, 2020). The opportunity for respite has also been pointed out as one of the important benefits in studies evaluating peer camps for young carers (Cunningham et al., 2017; Nagl-Cupal & Prajo, 2019). These positive results may be explained by the continuity/cognitive model associated with adult and peer relationships. In this model, having a balance of peer and adult support has both a positive and an additive influence on the well-being of adolescents (Buchanan & Bowen, 2008) meaning that, both adult and peer programmes could have the potential in terms of providing support to young carers. However, peer camps deviate from initiatives such as the BCY programme and the Buddy programme. Thus, camps are time-limited and rare events that focus most on group-based peer support and socializing, whereas programmes such as the BCY programme and Buddy programme are more continuous and adaptable approaches that provide the opportunity for adult support integrated into the young carers' everyday lives (Cunningham et al., 2017; Nagl-Cupal & Prajo, 2019; Wind & Jorgensen, 2020). In the BCY programme, the adult support approach was chosen because the children should have the opportunity to talk to an outside adult about potential difficult topics that peers might not be able to or expected to accommodate. The adult support was not intended as a therapeutic approach as the buddies simply supported through everyday conversations with the opportunity to approach difficult topics on a non-therapeutic level. In this context, attention should be drawn to the fact that young carers are a vulnerable group who may need professional therapy (Cree, 2003; Moore & McArthur, 2007; Sabine & Schnepf, 2007). If it was considered that professional therapeutic support was needed, the programme managers could arrange the contact. This underlines the importance of the training course and the ongoing supervision of the buddies, to identify such needs. According to the continuity/cognitive model, it can be suggested that future respite programmes focus on encouraging young carers and their (adult) buddies to meet other young carers (and their buddies), for example, through some joint events organized by the programme managers.

The large positive impact from baseline to follow-up may also be explained by different family constellations across countries. For instance, inter-generational sharing of care is known to be higher where family cohesion is stronger (Bettio & Plantenga, 2004). In Denmark, family cohesion across generations is often rather weak, and the individual family often has to fend for itself without or with little help from grandparents (Bettio & Plantenga, 2004). Thus, in a country like Denmark, where the BCY programme was held, there may be a tendency that the children become more involved in caring tasks than in countries where the family cohesion is stronger.

Based on the complete case analysis, only hyperactivity problems did not show a statistically significant improvement from baseline to follow-up. This could be explained by the dropouts in the study because a significant result was found based on the imputed score

analysis. Another explanation could be an undetected diagnosis, such as attention deficit hyperactivity disorder (ADHD), in some of the children (Madsen et al., 2018). ADHD is reasonable to assume because it has a fairly high prevalence (7% in childhood) (Sayal et al., 2018) and because the condition is underdiagnosed in many European countries (French et al., 2019). Thus, it may be difficult to assess whether the child's hyperactivity symptoms are signs of the family's situation of an actual disorder or both.

The subgroup analysis showed some differences in effects from the total difficulty scores. The most pronounced difference was found between boys and girls, indicating a higher effect on boys. This result seems surprising considering the tendency that girls are more involved in caring tasks compared to boys (Dearden & Becker, 1995, 2004; Metzger et al., 2020) and that girls are more likely to be more concerned and emotionally involved than boys (Cree, 2003; de Roos et al., 2020). Thus, the expectation was that the girls could be more in need of respite compared to the boys as they are typically more burdened in their everyday life and at higher risk of compassion fatigue (Figley, 2002; Hinderer et al., 2014). The higher effect on boys may be explained by individual differences in the rather small sample. However, the average age (baseline 10.12 yr; follow-up 9.41 yr) of the children may also partly explain the result, as the difference between gender regarding caring tasks is more pronounced when children get older (Dearden & Becker, 1995, 2004; Metzger et al., 2020). Also, it should be considered that the programme was carried out in Denmark, where the caring burden is less gender specific than in most other European countries (Bettio & Plantenga, 2004). In future studies, a special focus could be directed at retaining more boys in the entire duration of a study considering the high dropout rate in the current study. Some families with boys in the BCY programme explained that the cause for dropout was that they preferred a male 'buddy', which was only possible in four cases (only four male 'buddies' available). Thus, it could be relevant to aim the recruitment more directly at male 'buddies' in future programmes. We also found that ethnic minority children were more likely to drop out of the programme than ethnic Danish children. The pre-mature termination in ethnic minority groups is consistent with studies of other intervention programmes aimed at children and adolescents (de Niet et al., 2011; Kazdin & Mazurick, 1994; Kendall & Sugarman, 1997; Zeller et al., 2004). Language barriers and cultural differences have been mentioned as some of the causes of the high dropout rates in ethnic minority group children (de Niet et al., 2011). These reasons were also pointed out by the buddies in the BCY programme during supervisions.

Because of the large effect across all outcomes, at least some of the effect might be attributed to a Hawthorne effect (REF), which would be because of limitations of the study. First, the study was without a control group and with a relatively short follow-up of 4 months. Second, the programme may have been in high demand among the parents, here considering that young carers constitute a rather overlooked group of children, leading to a lack of interventions within the field (Becker, 2007; Joseph et al., 2020; Kavanaugh & Stamatopoulos, 2021; Saragosa et al., 2022). Third, the choice of having the project manager implementing the telephonic questionnaires,

which were known to all parents, could have resulted in the tendency to answer more positively than if the interviewer had been a more neutral person.

Despite the relatively short follow-up of 4 months, it should be emphasized that the findings from the qualitative study that evaluated the children's experiences with the BCY programme were generally consistent with the scores found in the current study (Nissen et al., 2022). Furthermore, a comparative study with a longer duration was not feasible because of ethical considerations. It was also challenging to accommodate a longer duration because the 'buddies' in the BCY programme were volunteers and, therefore, not a sustainable solution. In this context, some of the children in the qualitative study evaluated that the 4 months period was too short (Nissen et al., 2022). However, in the study of the Buddy programme in Copenhagen, based on reports from a parental viewpoint, it was concluded that the young carers did not seem to be negatively affected by the programme ending and that it might have been harder on the child if the programme had continued longer (Wind & Jorgensen, 2020). This finding is consistent with those from another study that concluded that even a short-term positive relationship can have a significant impact on an individual's personal development (Gilligan, 2000). Despite such findings, further research is required on the young carers' well-being after the ending of respite programmes and if such endings contribute to further losses to the child.

Questionnaire data could also have been obtained electronically, but telephone questionnaires were chosen for ethical reasons because of the sensitive position families were in. Consequently, it was considered important to choose an interviewer whom the parents knew and trusted. Also, electronic questionnaires often lead to an insufficient response rate because it may be difficult to fill out for instance due to insufficient technical competencies, lack of resources, language barriers and lack of understanding of the questions (Hollier et al., 2017; Roster et al., 2004).

Another limitation might be the potential for generalizing the results because of the relatively small size and attrition rate (30.6%). Despite recruitment efforts through oral presentations, awareness at schools, paediatric wards, flyers, posts and on social media, it was not possible to include more participants in the programme. The difficulty of recruiting young carers is not an unknown problem (Fives et al., 2013; Kennan et al., 2012). One explanation is that young carers may be hard to reach if their situation is sensitive and parents or guardians fear they will be considered at risk of a child protection intervention if public attention is drawn to them (Kennan et al., 2012). Another explanation may be the lack of understanding and awareness among parents regarding the implications of caring for their children (Kennan et al., 2012; Morrow, 2005); from the child's perspective, an explanation could be that young carers often fear being bullied at school if attention is drawn to them, so they do not want to be identified as different (Aldridge & Becker, 2003; Kennan et al., 2012; Morrow, 2005). Furthermore, in the late recruitment phase of the study, COVID-19 resulted in restrictions and limitations in starting activities in the programme and might have also affected the dropout rate. The implication here is that larger cities ($\geq 100\,000$ citizens) and cities with 2000 to 9999 citizens may have been over-represented in

our sample, whereas the remaining geographical locations may have been underrepresented (40.82% in cities with $\geq 100\,000$ citizens included compared with 20.19% in the North Denmark region as a whole and 34.69% in cities with 2000–9999 citizens compared with 25.73% in the North Denmark region as a whole). Finally, it could have been considered to use a more controlled approach when identifying and including the children in the programme as young carers. For instance, questionnaires such as The Multidimensional Assessment of Caring Activities (MACA YC-18) and/or the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) could have been used as guidelines in the definition and selection process (Joseph, Becker, Becker, & Regel, 2009). A more controlled approach would have made it easier to infer clear results about the success of the programme. This would have made it more transparent if the effect of the programme was greater in young carers subject to specific caring tasks and whether the psychological effects of caring would have an impact on the benefits of the programme. However, some distinctions were made in the study relating to the 'young carer' situation. Thus, reason for enrolment was considered where we distinguished between serious disease in close relations, death in close relations or both. No clear differences in effect between these subgroups were found from the analysis.

In conclusion, the BCY programme appears to be a promising intervention that can consider young carers' social-emotional functioning, especially focusing on the young carers' emotional well-being. Thus, it could be relevant to implement the BCY programme or similar programmes at other university colleges or similar educational institutions within relevant educations, that is, educational fields targeted work areas that include interaction and communication with children. If possible, future research should include comparative studies with a longer duration. In this relation, a special focus could be directed at testing if a more pronounced effect can indeed be found in boys compared to girls, and what significance the child's age may have in relation to whether there is a difference in the effect between boys and girls. In such studies, it should be considered how to retain more boys in the entire duration of a study. For instance, it could be relevant to aim for the recruitment more directly at male 'buddies' in future programmes.

Finally, it would be relevant to do further research on the young carers' well-being after programme termination, for example, evaluating whether ending the programme adds further losses to the child because the child continues being a young carer but in a new situation without a buddy.

DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data are not available.

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REFERENCES

- Aldridge, J., & Becker, S. (2003). *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals*. The Policy Press. <https://doi.org/10.46692/9781847425676>
- Barry, M. (2011). "I realised that i wasn't alone": The views and experiences of young carers from a social capital perspective. *Journal of Youth Studies*, 14(5), 523–539. <https://doi.org/10.1080/13676261.2010.551112>
- Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on "young carers" in the UK, Australia, the USA and sub-Saharan Africa. *Global Social Policy*, 7(1), 23–50. <https://doi.org/10.1177/1468018107073892>
- Bettio, F., & Plantenga, J. (2004). Comparing care regimes in Europe. *Feminist Economics*, 10(1), 85–113. <https://doi.org/10.1080/1354570042000198245>
- Bolas, H., Van Wersch, A., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology and Health*, 22(7), 829–850. <https://doi.org/10.1080/14768320601020154>
- Buchanan, R. L., & Bowen, G. L. (2008). In the context of adult support: The influence of peer support on the psychological well-being of middle-school students. *Child and Adolescent Social Work Journal*, 25(5), 397–407. <https://doi.org/10.1007/s10560-008-0143-z>
- Chikhradze, N., Knecht, C., & Metzger, S. (2017). Young carers: Growing up with chronic illness in the family - a systematic review 2007-2017. *Journal of Compassionate Health Care*, 4(1), 1, 12–16. <https://doi.org/10.1186/s40639-017-0041-3>
- Cree, V. E. (2003). Worries and problems of young carers: Issues for mental health. *Child & Family Social Work*, 8(4), 301–309. <https://doi.org/10.1046/j.1365-2206.2003.00292.x>
- Cunningham, L. C., Shochet, I. M., Smith, C. L., & Wurfl, A. (2017). A qualitative evaluation of an innovative resilience-building camp for young carers. *Child & Family Social Work*, 22(2), 700–710. <https://doi.org/10.1111/cfs.12286>
- de Niet, J., Timman, R., Jongejan, M., Passchier, J., & van den Akker, E. (2011). Predictors of participant dropout at various stages of a pediatric lifestyle program. *Pediatrics*, 127, e164–e170. <https://doi.org/10.1542/peds.2010-0272>
- de Roos, S., van Tienen, I., & de Boer, A. (2020). *Bezorgd naar school [Delivered to school]* [Internet]. Sociaal en Cultureel Planbureau (pp. 1–77). [cited 2021 Aug 9]. Available from: <https://www.scp.nl/publicaties/publicaties/2020/02/12/bezorgd-naar-school>
- Dearden, C., & Becker, S. (1995). *Young carers: The facts*. Reed Business Publishing.
- Dearden, C., & Becker, S. (2000). Young carers transitions to adulthood. *Childright*, 167, 8–10.
- Dearden, C., & Becker, S. (2004). *Young carers in the UK: The 2004 report*. Carers UK.
- EUR-Lex. —Access to European Union law [Internet]. [cited 2021 Aug 5]. Available from: <https://eur-lex.europa.eu/>
- Evans, R. (2014). Children as caregivers. In *Handbook of child well-being—Theories, methods and politics in global perspective*. Children as Caregivers. (pp. 1093–1916). Springer. https://doi.org/10.1007/978-90-481-9063-8_173
- Figley, C. R. (2002). Introduction. In *Treating compassion fatigue* (1st ed., pp. 1–17). Brunner-Routledge.
- Fives, A., Kennan, D., Canavan, J., & Brady, B. (2013). Why we still need the term 'young carer': Findings from an exploratory study of young carers in Ireland. *Critical Social Work*, 14(1), 49–61.
- French, B., Sayal, K., & Daley, D. (2019). Barriers and facilitators to understanding of ADHD in primary care: A mixed-method systematic review. *European Child & Adolescent Psychiatry*, 28(8), 1037–1064. <https://doi.org/10.1007/s00787-018-1256-3>
- Gilligan, R. (2000). Adversity, resilience and young people: The protective value of positive school and spare time experiences. *Children and Society*, 14(1), 37–47. [https://doi.org/10.1002/\(SICI\)1099-0860\(200002\)14:1<37::AID-CHI564>3.3.CO;2-N](https://doi.org/10.1002/(SICI)1099-0860(200002)14:1<37::AID-CHI564>3.3.CO;2-N)
- Goodman, R. (1999). The extended version of the strengths and difficulties questionnaire as a guide to child psychiatric caseness and consequent burden. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40(5), 791–799. <https://doi.org/10.1111/1469-7610.00494>
- Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. (2003). Using the strengths and difficulties questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *International Review of Psychiatry*, 15(1–2), 166–172. <https://doi.org/10.1080/0954026021000046128>
- Hamilton, M. G., & Adamson, E. (2013). Bounded agency in young carers' lifecourse-stage domains and transitions. *Journal of Youth Studies*, 16(1), 101–117. <https://doi.org/10.1080/13676261.2012.710743>
- Hinderer, K. A., VonRueden, K. T., Friedmann, E., McQuillan, K. A., Gilmore, R., Kramer, B., & Murray, M. (2014). Burnout, compassion fatigue, compassion satisfaction, and secondary traumatic stress in trauma nurses. *Journal of Trauma Nursing*, 21(4), 160–169. <https://doi.org/10.1097/JTN.0000000000000055>
- Hollier, L. P., Pettigrew, S., Slevin, T., Strickland, M., & Minto, C. (2017). Comparing online and telephone survey results in the context of a skin cancer prevention campaign evaluation. *Journal of Public Health (United Kingdom)*, 39(1), 193–201. <https://doi.org/10.1093/pubmed/fdw018>
- Joseph, S., Becker, F., & Becker, S. (2009). *Manual for measures of caring activities and outcomes for children and young people*. London. Carers Trust.
- Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child: Care, Health and Development*, 35(4), 510–520. <https://doi.org/10.1111/j.1365-2214.2009.00959.x>
- Joseph, S., Sempik, J., Leu, A., & Becker, S. (2020). Young Carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolescent Research Review*, 5(1), 77–89. <https://doi.org/10.1007/s40894-019-00119-9>
- Kavanaugh, M. S., & Stamatopoulos, V. (2021). Young Carers, the overlooked caregiving population: Introduction to a special issue. *Child and Adolescent Social Work Journal*, 38(5), 487–489. <https://doi.org/10.1007/s10560-021-00797-2>
- Kazdin, A. E., & Mazurick, J. L. (1994). Dropping out of child psychotherapy: Distinguishing early and late dropouts over the course of treatment. *Journal of Consulting and Clinical Psychology*, 62(5), 1069–1074. <https://doi.org/10.1037/0022-006X.62.5.1069>
- Kendall, P. C., & Sugarman, A. (1997). Attrition in the treatment of childhood anxiety disorders. *Journal of Consulting and Clinical Psychology*, 65(5), 883–888. <https://doi.org/10.1037/0022-006X.65.5.883>
- Kennan, D., Fives, A., & Canavan, J. (2012). Accessing a hard to reach population: Reflections on research with young carers in Ireland correspondence. *Child & Family Social Work*, 17, 275–283. <https://doi.org/10.1111/j.1365-2206.2011.00778.x>
- Kettell, L. (2020). Young adult carers in higher education: The motivations, barriers and challenges involved—A UK study. *Journal of Further and Higher Education*, 44(1), 100–112. <https://doi.org/10.1080/0309877X.2018.1515427>
- Madsen, K. B., Ravn, M. H., Arnfred, J., Olsen, J., Rask, C. U., & Obel, C. (2018). Characteristics of undiagnosed children with parent-reported ADHD behaviour. *European Child & Adolescent Psychiatry*, 27(2), 149–158. <https://doi.org/10.1007/s00787-017-1029-4>
- Metzger, S., Ostermann, T., Robens, S., & GaLiatsch, M. (2020). The prevalence of young carers—A standardised survey amongst school students (KiFam-study). *Scandinavian Journal of Caring Sciences*, 34(2), 501–513. <https://doi.org/10.1111/scs.12754>

- Moore, T., & McArthur, M. (2007). We're all in it together: Supporting young carers and their families in Australia. *Health & Social Care in the Community*, 15(6), 561–568. <https://doi.org/10.1111/j.1365-2524.2007.00719.x>
- Moore, T., & McArthur, M. (2009). Attendance, achievement and participation: Young carers' experiences of school in Australia. *Australian Journal of Education*, 53(1), 5–18. <https://doi.org/10.1177/000494410905300102>
- Morrow, R. (2005). *Profile of known young carers and identification and snapshot of the ones who are hidden*. Curtin University of Technology.
- Nagl-Cupal, M., & Prajo, N. (2019). It is something special: How children and their parents experience a camp for young people who care for a parent with a severe physical illness. *Children and Youth Services Review*, 107, 104560. <https://doi.org/10.1016/j.childyouth.2019.104560>
- Nissen, K. B., Laursen, S. H., & Haslund-Thomsen, H. (2022). Young carers' experiences of having a “buddy” on the buddies for children and youngsters programme in Denmark—A qualitative interview study. *Health & Social Care in the Community*, 30, e2849–e2857. <https://doi.org/10.1111/hsc.13728>
- Richardson, K., Jinks, A., & Roberts, B. (2009). Qualitative evaluation of a young carers' initiative. *Journal of Child Health Care*, 13(2), 150–160. <https://doi.org/10.1177/1367493509102475>
- Roster, C. A., Rogers, R. D., Albaum, G., & Klein, D. (2004). A comparison of response characteristics from web and telephone surveys. *International Journal of Market Research*, 46(3), 1–9. <https://doi.org/10.1177/147078530404600301>
- Ruel, E. (2019). How can pretesting and pilot testing improve reliability and validity? In *100 questions (and answers) about survey research*. SAGE Publications, Inc.. <https://doi.org/10.4135/9781506348803.n59>
- Sabine, M., & Schnepf, W. (2007). Children and adolescents as caregivers: Who they are and what they do. An international literature review (1990–2006). *Pflege*, 20(6), 323–330.
- Saragosa, M., Frew, M., Hahn-Goldberg, S. O.-C., Ani Abrams, H., & Okrainec, K. (2022). The young carers' journey: A systematic review and meta ethnography. *International Journal of Environmental Research and Public Health*, 19(10), 1, 5826–25. <https://doi.org/10.3390/ijerph19105826>
- Sayal, K., Prasad, V., Daley, D., Ford, T., & Coghill, D. (2018). ADHD in children and young people: Prevalence, care pathways, and service provision. *Lancet Psychiatry*, 5(2), 175–186. [https://doi.org/10.1016/S2215-0366\(17\)30167-0](https://doi.org/10.1016/S2215-0366(17)30167-0)
- SDQ. - Information for researchers and professionals about the Strengths & Difficulties Questionnaires [Internet]. [cited 2022 May 7]. Available from: <https://www.sdqinfo.org/>
- Smyth, C., Blaxland, M., & Cass, B. (2011). “So that's how I found out I was a young carer and that I actually had been a carer most of my life”. Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145–160. <https://doi.org/10.1080/13676261.2010.506524>
- Thomas, N., Stainton, T., Jackson, S., Cheung, W. Y., Doubtfire, S., & Webb, A. (2003). “Your friends don't understand”: Invisibility and unmet need: In the lives of “young carers”. *Child & Family Social Work*, 8(1), 35–46. <https://doi.org/10.1046/j.1365-2206.2003.00266.x>
- Tucker, S., & Liddiard, P. (1998). Young carers. In A. Brechin, J. Walmsley, J. Katz, & S. Peace (Eds.). *Care matters: Concepts, practice and research in health and social care* (Vol. 1998). Care Matters: Concepts, Practice and Research in Health and Social Care. (pp. 54–65). SAGE.
- Universal declaration of human rights. [Internet]. [cited 2022 May 20]. Available from: <https://www.un.org/en/about-us/universal-declaration-of-human-rights>
- Wind, G., & Jorgensen, G. K. (2020). “It has been fun. Super-duper fantastic”: Findings from a Danish respite programme to support young carers. *Health & Social Care in the Community*, 28(1), 100–109. <https://doi.org/10.1111/hsc.12844>
- World Medical Association. (2014). World medical association declaration of Helsinki: Ethical principles for medical research involving human subjects. *The Journal of the American College of Dentists*, 81(3), 14–18.
- Zeller, M., Kirk, S., Claytor, R., Khoury, P., Grieme, J., Santangelo, M., & Daniels, S. (2004). Predictors of attrition from a pediatric weight management program. *The Journal of Pediatrics*, 144(4), 466–470. <https://doi.org/10.1016/j.jpeds.2003.12.031>

How to cite this article: Laursen, S. H., Nissen, K. B., Udsen, F. W., & Haslund-Thomsen, H. (2023). The impact of a respite volunteer ‘buddy’ programme on behavioural and psychological well-being in young carers. *Child & Family Social Work*, 28(3), 734–752. <https://doi.org/10.1111/cfs.13000>

APPENDIX: ADDITIONAL QUESTIONNAIRE QUESTIONS

Additional questions at baseline

Who has custody of the child? ☐ Both parents ☐ Father ☐

Mother ☐ Other guardian.

Who? _____.

Gender of the child? ☐ Girl ☐ Boy ☐ Other.

Comments:

What is the child's birthday? _____.

Do the child have siblings/half-siblings/step-siblings ☐ Yes ☐ No.

- If ‘Yes’, how many? _____.

What is the reason for contact?

- Serious illness among the child's nearest relations ☐
- Death among the child's nearest relations ☐
- Both ☐

Comments:

Which close relation to the child is dead?

(You may choose more than one)

The cause of contact is not because of death ☐.

The child's mother ☐.

The child's father ☐.

Child's sister ☐ number ____.

Child's brother ☐ number ____.

The child's grandparents ☐ number ____.

Other: ☐.

Write _____.

Which close relation to the child is seriously ill?

A **close relation** refers to the family and nearest relations

Serious illness is when a person is threatened in relation to their everyday life and the illness causes major changes and role changes. These can be major physical and mental disabilities and/or be a life-threatening illness. It also matters whether the disease is acute or chronic and what degree of complex needs it involves. Reference: Sundhedsstyrelsen, ANBEFALINGER TIL SUNDHEDSPERSONERS MØDE MED PÅRØRENDE TIL ALVORLIGT SYGE. 2012 page 14.

(You may choose more than one)

The cause of contact is not because of serious illness ☐.

The child's mother ☐.

The child's father ☐.

Child's sister ☐ number ____.

Child's brother ☐ number ____.

The child's grandparents ☐ number ____.

Other ☐.

Write: _____.

What serious illness does the close relation have?

(Only fill in if the cause of contact is because of serious illness)

Serious illness is when a person is threatened in their everyday life and the illness causes major changes and role changes. These can be major physical and mental disabilities and/or be a life-threatening illness. It also matters whether the disease is acute or chronic and what degree of complex needs it involves.

Reference: Sundhedsstyrelsen, ANBEFALINGER TIL SUNDHEDSPERSONERS MØDE MED PÅRØRENDE TIL ALVORLIGT SYGE. 2012 page. 14

Write:

_____.

Comments:

To what extent does the illness and/or death affect your family's everyday life?

To this question, you must answer to what extent the illness and/or death has an impact on your family's everyday life regarding their activities and chores.

Choose one option below:

Not at all ☐.

To a lesser extent ☐.

To some extent ☐.

To a large extent ☐.

To a very high extent ☐.

Do not know ☐.

Comments:

To what extent do you consider that the illness and/or death affects your child's everyday life?

Choose one option below:

Not at all ☐.

To a lesser extent ☐.

To some extent ☐.

To a large extent ☐.

To a very high extent ☐.

Do not know ☐.

Comments:

What option do you have for relief in relation to your child now?

(You may choose more than one.)

Friends of the family ☐.

The family, e.g. grandparents ☐.

Paid babysitter ☐.

Offers from the public sector ☐.

No options (no network) ☐.

Local environment (neighbour) ☐.

The child's network ☐.

Other:

Write _____.

What interests does the child have?

The child's interests are relevant in relation to being able to make the best match (with a 'buddy'). Interests can be football, board games, horse riding and so forth.

Write _____.

The marital status of the child's parents/guardians

(You may choose more than one.)

Married ☐.

Divorced ☐.

Boy/girlfriend ☐.

Single ☐.

Widow or widower ☐.

Other:

Write _____.

What is the child's ethnicity? (Ask, if necessary, about where the parents were born).

Choose one option below:

Ethnic Dane ☐.

Ethnic minority ☐.

Other: ☐.

write _____.

What is the child's mother's highest level of education?

Choose one option below:

Not relevant can be checked if, for example, the child does not have a mother.

Not relevant ☐.

Studying ☐.

Primary school ☐.

Secondary school ☐.

Vocational training/education ☐.

Short tertiary education ☐.

Moderate tertiary education ☐.

Long tertiary education ☐.

Other: ☐.

Write _____.

What is the child's father's highest level of education?

Choose one option below:

Not relevant can be checked if, for example, the child does not have a father.

Not relevant ☐.

Studying ☐.

Primary school ☐.

Secondary school ☐.

Vocational training/education ☐.

Short tertiary education ☐.

Moderate tertiary education ☐.

Long tertiary education ☐.

Other: ☐.

Write _____.

What is the guardian's highest level of education?

Choose one option below:

Not relevant can be checked if, for example, the child does not have a guardian.

Not relevant ☐.

Studying ☐.

Primary school ☐.

Secondary school ☐.

Vocational training/education ☐.

Short tertiary education ☐.

Moderate tertiary education ☐.

Long tertiary education ☐.

Other: ☐.

Write _____.

The child's mother's occupational status?

Choose one option below:

Not relevant can be checked if, for example, the child does not have a mother.

Not relevant ☐.

Employed ☐.

Job training (e.g. light job, flexible job) ☐.

Reported sick ☐.

Sick leave benefit ☐.

On leave ☐.

Unemployment benefit/seeking for a job ☐.

Cash benefit ☐.

Seeking education ☐.

Student/trainee ☐.

Early retirement ☐.

Optional retirement ☐.

Old-age retirement ☐.

Other: ☐.

Write _____.

The child's father's occupational status?

Choose one option below:

Not relevant can be checked if, for example, the child does not have a father.

Not relevant ☐.

Employed ☐.

Job training (e.g. light job, flexible job) ☐.

Reported sick ☐.

Sick leave benefit ☐.

On leave ☐.

Unemployment benefit/seeking for a job ☐.

Cash benefit ☐.

Seeking education ☐.

Student/trainee ☐.

Early retirement ☐.

Optional retirement ☐.

Old-age retirement ☐.

Other: ☐.

Write _____.

The occupational status of another guardian?

Choose one option below:

Not relevant can be checked if, for example, the child does not have a guardian.

Not relevant ☐.

Employed ☐.

Job training (e.g. light job, flexible job) ☐.

Reported sick ☐.

Sick leave benefit ☐.

On leave ☐.

Unemployment benefit/seeking for a job ☐.

Cash benefit ☐.

Seeking education ☐.

Student/trainee ☐.

Early retirement ☐.

Optional retirement ☐.

Old-age retirement ☐.

Other: ☐.

Write _____.

Where have you heard about the programme?

(You may choose more than one.)

Friends/acquaintances ☐.

Family ☐.

The hospital ☐.

The programme's website ☐.

Flyers ☐.

School ☐.

Municipality ☐.

LinkedIn ☐.

Facebook ☐.

Other: ☐.

Write _____.

What are your expectations for your child's and family's benefit from the programme?

Choose one option below:

Very high ☐.

High ☐.

Moderate ☐.

Low ☐.

None ☐.

Do not know ☐.

Comments:

Additional questions at follow-up

Do you experience that your child's well-being has improved overall during and/or just after the programme?

(Choose one option below:)

☐ Yes ☐ No ☐ Do not know.

If yes, to what extent do you assess that the improvement in the child's well-being is because of participation in the programme? (Choose one option below:)

Very high extent ☐.

High extent ☐.

Some extent ☐.

Lesser extent ☐.

Not at all ☐.

Do not know ☐.

Comments:

What difference has it made for your child to participate in the programme?

(Choose one option below:)

Very positive ☐.

Somewhat positive ☐.

No difference ☐.

Somewhat negative ☐.

Very negative ☐.

Do not know ☐.

Comments:

To what extent do you experience that the volunteer has been a relief in everyday life?

(Choose one option below:)

To a very high extent ☐.

To a large extent ☐.

To some extent ☐.

To a lesser extent ☐.

Not at all ☐.

Do not know ☐.

Comments:

How do you assess your collaboration with the volunteer (the 'buddy')?

(Choose one option below:)

Excellent ☐.

Very good ☐.

Good ☐.

Less good ☐.

Bad ☐.

Do not know ☐.

Comments:

How many hours do you estimate that the volunteer has spent on average with your child per month?

Write in full hours (e.g. 10 h): _____.

Comments:

What changes have occurred in your family's situation in relation to illness and/or death since the beginning of the programme?

(Choose one option below:)

Marked worsening ☐.

Worsening ☐.

No change ☐.

Improvement ☐.

Marked improvement ☐.

Do not know ☐.

Comments:

To what extent has the programme lived up to your expectations in relation to your child's benefit from the programme?

Benefit can be that the child has gotten better physically, mentally, socially and so forth.

(Choose one option below:)

To a very high extent ☐.

To a large extent ☐.

- To some extent ☐.
- To a lesser extent ☐.
- Not at all ☐.
- Do not know ☐.

Comments:

How do you experience the duration/length of the programme of 4 months?

(Choose one option below:)

- Too short ☐.
- Appropriate ☐.
- Too long ☐.
- Do not know ☐.

Comments:

How do you assess the 10 h per month on average, in relation to the volunteer's time with your child?

The programme has stipulated that the volunteer should spend, on average, 10 h a month, with the child.

(Choose one option below:)

- Too many hours ☐.
- Appropriate number of hours ☐.
- Too few hours ☐.
- Do not know ☐.

Comments:

How satisfied are you with the start of the programme (contact with the programme management/first meeting with the volunteer).

(Choose one option below:)

- To a very high extent ☐.
- To a high extent ☐.
- To some extent ☐.
- To a lesser extent ☐.
- Not at all ☐.
- Do not know ☐.

How satisfied are you with the end of the programme (parting with the volunteer)?

Comments:

(Choose one option below:)

- To a very high extent ☐.
- To a high extent ☐.
- To some extent ☐.
- To a lesser extent ☐.
- Not at all ☐.
- Do not know ☐.

Comments:

Do you have suggestions for how we can improve the programme?

Comments:
