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RESEARCH ARTICLE

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Exploring long-term outcomes of a peer support programme for parents* of children with disability in Australia

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Abstract

Peer support groups can offer parents of children with disability, positive well-being outcomes. Peer support groups not only provide opportunities for connections with others with similar experiences but also provide resources and information, emotional support, a sense of belonging and may help reduce stress and isolation. Peer support groups are an established form of support existing within family centred practice. However, it is unclear whether peer support groups achieve the outcomes that they aim to deliver. Further, little is known about the longer-term outcomes for parents attending such groups. This study aimed to explore the medium- and long-term outcomes and experiences of parents who participated in a peer support programme (the Now and Next programme) for parents of children with disability. Well-being data were collected at three timepoints (Ts): prior to commencing the programme (T1), immediately after completion of the programme (T2) and 6–30 months after completion of the programme (T3). Results of the study showed empowerment and well-being improved from T1 to T2, with gains maintained at T3. Hope scores did not significantly change over time. Participants continued to set and achieve goals over time using resources from the programme. Improvements in parents' well-being and empowerment scores were maintained in the longer-term. Our study contributes to evidence confirming sustained long-term outcomes of peer support programmes and demonstrates that building parent capacity, empowerment and well-being has a lasting effect on the parents of children with disability.

KEYWORDS
caregivers, children, disability, parents, peer support

1 | INTRODUCTION

The challenges that parents' face when raising a child with disability are far-reaching, affecting hundreds of thousands of families in Australia (Australian Bureau of Statistics, 2018). These parents experience loss of occupation and increased caregiving responsibilities

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Please note: * The term parents is inclusive of all primary caregivers of children with disability in this manuscript.

which affect their individual and family quality of life (Bhopti et al., 2020). Given the demands of providing specialised support for their developing child, parents repeatedly seek services to help them care for their child's specific needs. One option for parents is to connect with peer parents in a similar situation.

Peer support refers to support provided through social networks by other people who share similar experiences. Peer support groups help parents of children with disability cope with the stresses they face by providing emotional support, belonging and skill development (Chakraborti et al., 2021; Law et al., 2001; Shilling et al., 2013). Peer facilitators are able to relate and empathise with parents through their shared experiences (Bourke-Taylor et al., 2021). Through creating a shared experience, education, supporting social opportunities and the cultivation of optimism, empowerment, a sense of belonging and self advocay, peer support groups build strength and resilience in families (Chakraborti et al., 2021). Fung et al. (2018) provided a peer led programme for parents of children with Autism ($n = 33$) and found significant improvements in parent's flexibility and cognitive fusion. A systematic review found parents's well-being and quality of life significantly improved when they participated in a peer support group (Lancaster et al., 2022). Programmes containing peer support have had positive effects for parents of children with disability on decreasing parental anxiety and depression (Martin et al., 2019) and increasing well-being and quality of life (Mills et al., 2021).

Despite the identified benefits of peer support programmes, several gaps exist. Methodological issues used in published studies make the outcomes of peer support unclear (Chakraborti et al., 2021; Sartore et al., 2021). The length of follow-up typically ranges from immediately postintervention to 3 months. Little is known about the longer-term outcomes of peer support programmes or what specific programme factors were helpful for meeting desired outcomes.

We present results from the long-term data from one such peer support programme known as Now and Next, a peer support programme that assists parents of children with developmental delay or disability to set goals for the child and family, identify strengths and increase parents capacity (Janson et al., 2018). The programme was co-designed by parents of children with disability and is built upon systems informed positive psychology principles (Kern et al., 2020). The approach develops well-being literacy in participants to shift perspectives from seeing ‘disability as a disadvantage’ and that ‘experts know best’ to the perspectives that ‘we will start with our strengths’ and ‘we've got this’ (Mahmic et al., 2021). The programme uses unique tools, such as the goal setting planning tool called Pictability. N&N is facilitated by peer leaders and is run via weekly group sessions for 8 weeks, and this evidence informed programme has been shown in the short-term to building parents' sense of empowerment and well-being (Moore et al., 2018). The N&N programme has been providing peer support to parents and collecting feedback since 2015, but medium- to long-term outcomes of the programme are unknown, thus making this programme well-suited to answer our research questions.

This study aimed to explore the medium- and long-term outcomes and experiences of parents who participated in N&N peer support programme for parents of children with disability. We addressed the following research questions:

- Are improvements in empowerment, well-being and hope maintained 6–30 months after completion of the programme?
- What proportion of participants are still setting and achieving goals for themselves, their child and their family 6 to 30 months after completion of the programme?

Key Messages

- Peer support interventions are associated with increased well-being and empowerment for parents and caregivers.
- There is a need for further research and a controlled trial study to further understand the factors contributing to sustained impact of peer support programmes.

2 | METHOD

2.1 | Study design

The well-being outcomes of N&N programme participants were tracked across three timepoints (Ts): prior to commencing the programme (T1), immediately after completion of the programme (T2) and 6–30 months after completion of the programme (T3). Outcome measures were collected by programme staff at T1 and T2, with additional data collected at T3 for this study. The study was approved by La Trobe University Human Research Ethics Committee (HEC20223 & HEC21285).

2.2 | Participants

Participants included parents of a child with a developmental delay or disability, who completed the N & N programme between December 2018 and April 2021 ($n = 242$). Participation in the programme was online or in person with groups of approximately 8–12 people. Each session runs for 2.5 h and topics include visioning and goal setting, identifying strengths, circle of control, empowerment, working with professionals and well-being. Participants were included if they consented to their information being used for research purposes and completed the T3 survey (see Figure 1).

2.3 | Measures

Participants completed online surveys that included basic demographic information, goal setting, empowerment, well-being, hope and other information (see Table 1).

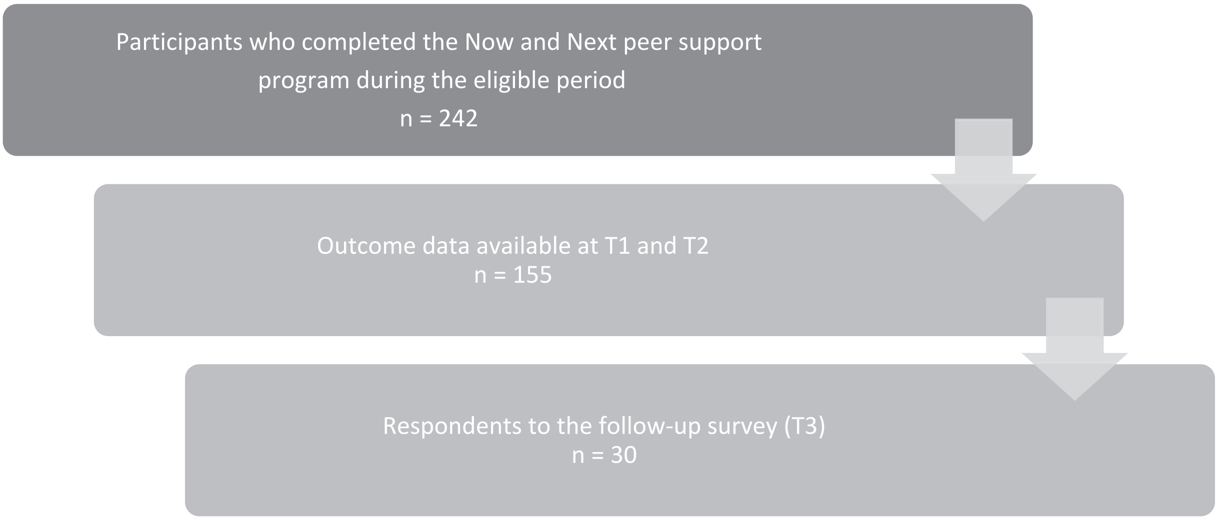


FIGURE 1 Study recruitment.

TABLE 1 Summary of outcome measures.

		When collected		
Outcome measure	**Source**	**Preprogramme (T1)**	Postprogramme (T2)	**At 6–30 months follow-up (T3)**
Empowerment: Psychological Empowerment Scale (PES) for families of children with disability (Akey et al., 2000) (see Appendix A.1)	Online survey	✓	✓	✓
Well-being: PERMA-Profiler (PP) (Butler & Margaret, 2016) (see Appendix A.2)	Online survey	✓	✓	✓
Hope: The Adult Hope Scale (AHS) (Snyder et al., 1991) (see Appendix A.3)	Online survey	✓	✓	✓
Goal setting: Whether goals had been set and achieved (see Appendix B)	Online survey			✓
Programme information (start date, mode of delivery, location)	Routinely collected service data	✓		✓
Demographic information (age, sex, ethnicity, education) (see Appendix B)	Routinely collected service data	✓		
Continued involvement in programme (see Appendix B)	Online survey			✓
Participant experience of the programme (see Appendix B)	Online survey			✓

Note: **Preprogramme (T1)**: data collected by Plumtree prior to participating in the Now and Next programme; **postprogramme (T2)**: data collected by Plumtree after completing the Now and Next programme; **Online survey (T3)**: participant data collected in November and December 2021.

2.3.1 | Empowerment

Sense of empowerment was assessed using the Psychological Empowerment Scale (PES), a 32-item measure that assesses psychological empowerment across four factors: attitudes of control and competence, formal participation, informal participation and skills and knowledge, rated on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree).

2.3.2 | Well-being

Psychological well-being was assessed using the PERMA (positive emotion, engagement, relationships, meaning, accomplishment)-Profiler (PP) (Butler & Margaret, 2016). The 23-item scale assesses five dimensions of psychological well-being (positive and negative emotions, engagement, relationships, meaning and accomplishment), along with items assessing overall well-being, loneliness and physical health using an 11-point Likert scale (0 = not at all, 10 = completely).

2.3.3 | Hope

Hope was assessed using The Adult Hope Scale (AHS) (Snyder et al., 1991). Participants' scores were rated on an 8-point scale on 12-items assessing goal-directed determination (agency) and planning ability (pathway).

2.3.4 | Agency

Participants indicated the extent to which they had achieved the goals set when they completed the N & N programme and whether they have continued to set goals for themselves, their child and their family.

2.3.5 | Other information

Other information collected included demographic data (child's age, diagnosis and ethnic background), whether additional services were received from the host organisation (Plumtree Children Services) and the level of support required by the child to enable participation in daily activities. At follow-up, participants were also asked about any of the ways in which they are still involved with N & N and/or Plumtree Children Services.

2.4 | Data analyses

Chi square and *t*-tests were used to compare the characteristics of the responders and nonresponders with the follow-up survey. Descriptive statistics were used to describe the proportion of participants still setting and achieving goals at T3. The mean total scores of AHS, PP and PES were compared across the three timepoints using repeated analysis of variance (ANOVA) analyses with pairwise post hoc comparisons using the Friedman test (Pallant, 2020) for nonparametric data. *p*-values were Bonferroni-adjusted (Pallant, 2020), and data were tested for normality of distribution using the Shapiro–Wilk test (Shapiro & Wilk, 1965).

Two analyses were performed to explore factors that may be associated with better outcomes. First, a linear regression model was used to explore the factors that may be associated with higher outcome scores at T3. Second, a group-based trajectory analysis was performed to determine whether there were characteristics that could explain different trajectories of participants over the three timepoints. Text comments provided by participants about their experience were coded and organised into themes. R studio version 1.2.5033 with R-4.1.1 was used to perform the statistical analysis (R core team, 2013).

3 | RESULTS

Thirty participants responded to the T3 survey. There were no significant differences between the responders and the nonresponders in relation to key characteristics, suggesting that while the study sample is small ($n = 30$), it appears to be representative of the larger sample (see Table 2).

3.1 | Differences in clinical outcomes

Differences in the three clinical outcome measures assessing empowerment, well-being and hope were assessed using repeated ANOVA, with changes in participants' scores illustrated in Figure 2.

3.2 | Empowerment

For empowerment, there was a significant difference between the PES scores across three timepoints (F (2,52) = 10.106, $p < 0.01$, eta2 [g] = 0.096). Post hoc pairwise comparison showed a significant difference in total mean score between T1 and T2 ($p < 0.01$) and a significant difference between the means of T1 and T3 ($p < 0.01$). The mean difference between T2 and T3 was not significant ($p = 1$) (Table 3).

Figure 3 illustrates changes in PES, PP and hope across the three time points. Changes in the individual factors for the PES scale (Factor 1 = attitudes of control, Factor 2 = formal participation, Factor 3 = informal participation, and Factor 4 = cognitive appraisal of skills) appeared to be similar to the overall picture for the total PES score (Figure 3a). For well-being, differences in the mean total scores on the PP were found between different timepoints (F (2, 58) = 6.766, $p < 0.01$, eta2[g] = 0.058). Post hoc pairwise comparisons showed a significant difference in the means between T1 and T3 ($p < 0.01$) and between T2 and T3 ($p = 0.047$). The mean difference between T1 and T2 was not significant ($p = 0.846$) (see Figure 3b). The mean scores of the AHS were abnormally distributed and thus were analysed using the Friedman test. There were no significant differences in the AHS outcome measure at the different timepoints [$\chi^2(2) = 2.0566$, $p = 0.3576$] (Figure 3c).

3.3 | Exploration of factors influencing outcomes

Given that the PES and PP improved over time, we used a linear mixed model to explore associations between improvement in these scores and participant characteristics. The model included timepoint, parent education level, cultural/language diversity (yes or no), child's age, ongoing involvement in Plumtree and level of support required by the child. Of these, only time had a significant impact on the outcomes score for PES. A group-based trajectory analysis performed for each of the three outcomes measures (PES, PP and AHS) indicated no

TABLE 2 Baseline characteristics of survey responders and nonresponders.

	All now and next participants *n* = 212 (nonresponders)	Study sample *n* = 30 (responders)	*P*-value
Gender			0.251
Male	44 (20.8%)	3 (10.0%)	
Female	168 (79.2%)	27 (90.0%)	
Parent/carer age			0.356
Mean	41.6	42.8	
Median	41.0	42	
Missing	23 (10.8%)	1 (3.3%)	
Child's age			0.814
0–7 years	69 (32.5%)	13 (43.3%)	
8 + years	38 (17.9%)	9 (30.0%)	
Missing	105 (49.5%)	8 (26.7%)	
Education of parent			0.653
Secondary education	30 (14.2%)	3 (10.0%)	
Postsecondary education	170 (80.2%)	27 (90.0%)	
Missing	12 (5.7%)	0 (0%)	
Culturally and linguistically diverse (CALD)			0.614
Yes	48 (22.6%)	5 (16.7%)	
No	164 (77.4%)	25 (83.3%)	
PES total score at baseline			
Mean	3.34	3.32	0.972
Missing	47 (22.2%)	0 (0%)	
AHS total score at baseline			
Mean	45.4	46.7	0.545
Missing	47 (22.2%)	0 (0%)	
PP score at baseline			
Mean	6.30	6.42	0.595
Missing	47 (22.2%)	0 (0%)	

distinct patterns of participant group trajectory scores in any outcome measure across the three timepoints.

3.4 | Goal setting

Most participants in the study sample reported that they had either partially achieved or fully achieved goals that they had set for themselves, their child and their family since completing the N&N programme (see Figure 4).

4 | DISCUSSION

This study examined the longer-term outcomes in empowerment, hope and well-being 6 to 30 months after completing a peer support programme for parents of children with disability. Empowerment and well-being improved from T1 to T2, with gains maintained at 6–30 months later. Hope scores did not significantly change over time. The programme was well received by participants, and survey responses suggested that participants continued to set and achieve goals over time using resources from the programme.

This study provides preliminary insights into medium- and long-term outcomes of peer support. Recent systematic reviews conducted by Shilling et al., (2013), Sartore et al. (2021) and Lancaster et al. (2022) conclude that none of the included studies incorporated a medium- or longer-term follow-up time point. Some positive outcomes occurred, which deserve replication in other studies. Firstly, longer-term results indicated that participants continue to make or maintain gains in empowerment that they made during the programme. Well-being outcomes continued to increase from T2 to T3, possibly because of the sleeper effect, where the information from the programme requires time and opportunity for the parents to practise and implement the strategies learnt (Sofronoff et al., 2011). Secondly, none of the outcomes for well-being, empowerment and hope declined significantly over the long-term. Positive psychological

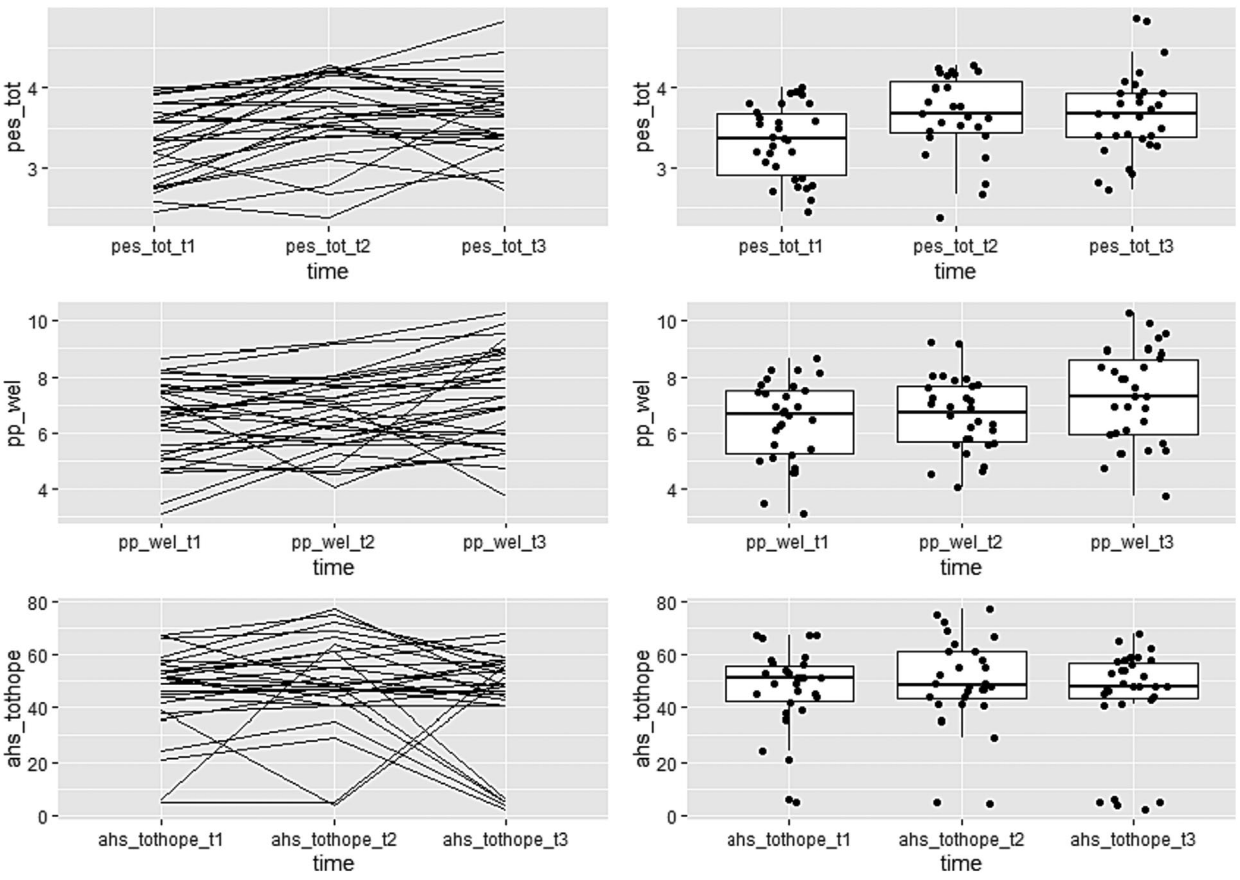


FIGURE 2 Participant outcome score change patterns and distributions across three timepoints.

TABLE 3 Repeated ANOVA analysis for PERMA profiler and psychological empowerment scale pairwise comparison.

	PERMA profiler			Psychological empowerment scale		
Group comparison	Total score T1–T2	Total score T1–T3	Total score T2–T3	Total score T1–T2	Total score T1–T3	Total score T2–T3
Statistic	−1.0952	−3.1874	−2.5633	−4.3468	−3.8045	−0.1039
df	29	29	29	26	29	26
p adjusted	$p = 0.846$	$p = 0.010$	$p = 0.047$	$p = 0.0005$	$p = 0.002$	$p = 1$

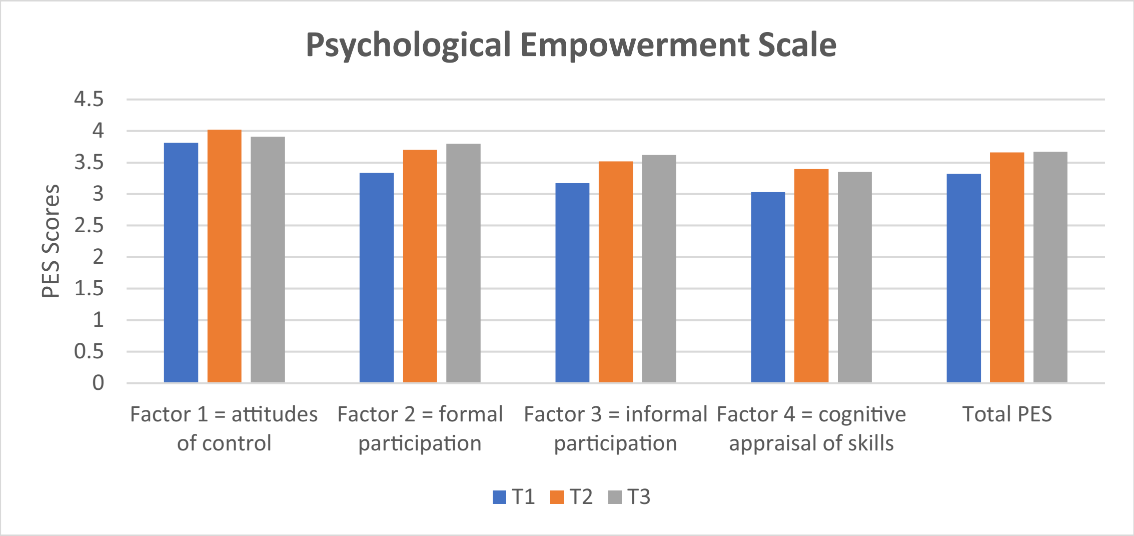
interventions have been reported to have lasting effects (Cohn & Fredrickson, 2010), and it is possible that the effects of peer to per support between parents builds capacity and empowerment, contributing to lasting effects.

Goal setting and goal attainment are key components of the N&N programme. Most participants reported significant gains in their goal setting and goal achievement. Akey et al. (2000) state that the individual's sense of control, competence and motivation contributes to goal-setting abilities, and goal setting, in turn, leads to increased feelings of empowerment. More than half of the respondents appreciated that they learnt goal-setting skills from the programme, and most achieved their goals. Qualitative comments supported the quantitative findings, with comments suggesting that the focus on goals is a key element of the programme. Notably, factors such as education level, CALD background, child's age, disability diagnosis or level of support required by the child did not relate with well-being outcomes, though this might be due to the small sample size.

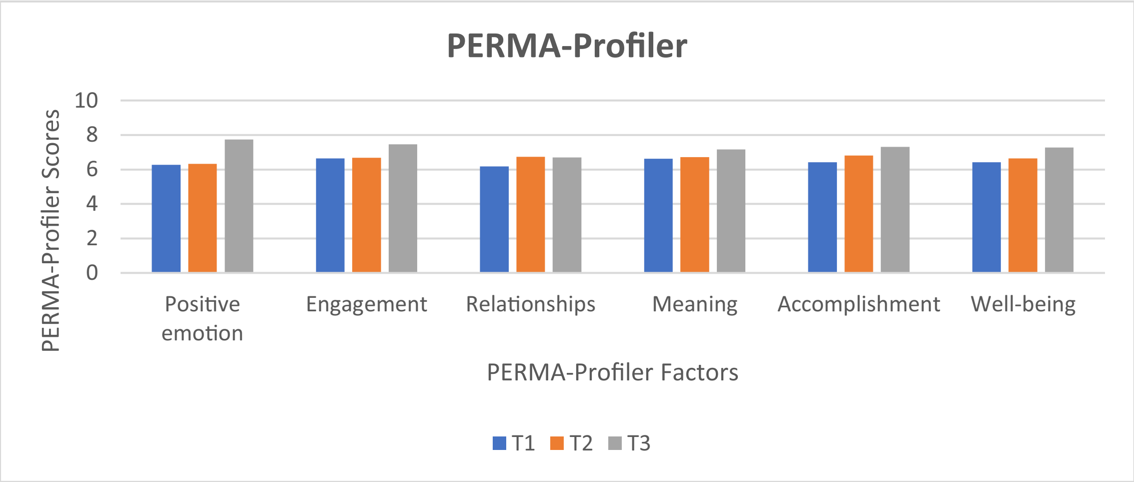
A key benefit of peer support is the relationships that are built amongst participants. N&N gave participants the opportunity to remain involved in a variety of ways, such as connecting through social media, becoming a peer leader or staying connected as alumni. These factors might have helped to sustain the gains made during the programme. Notably, 46.7% of participants continue to be involved in the organisation's activities in some way. Further research using large samples and more rigorous designs may help improve understanding of how peer support programmes affect participant outcomes and to what extent the formation of long-term relationships play a part (Chakraborti et al., 2021).

While participants experienced significant gains in empowerment and well-being over time, there was variability in the participants'

(a) Psychological Empowerment Scale



(b) PERMA Profiler



(c) Adult Hope Scale

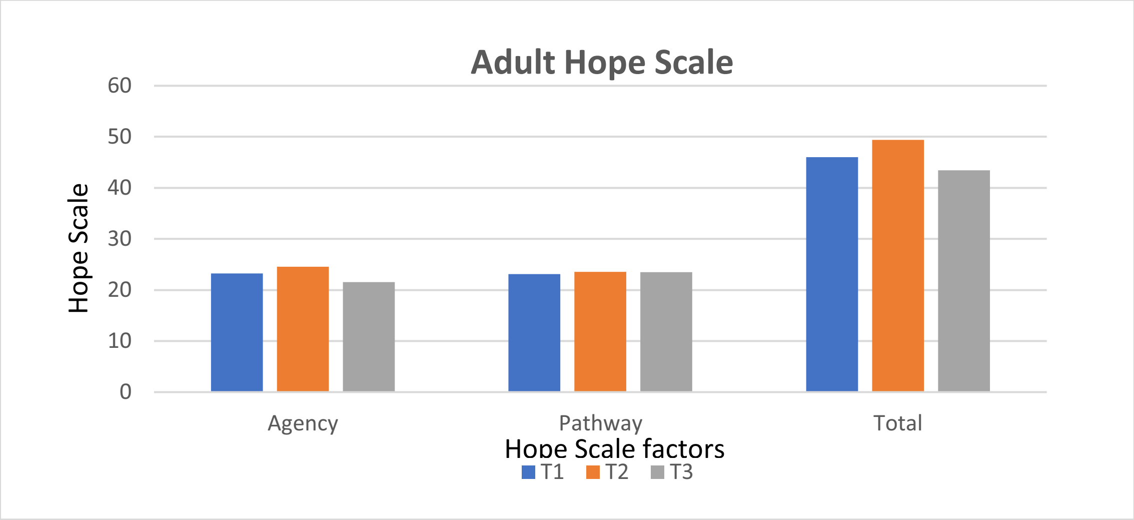


FIGURE 3 (a–c) Changes in psychological empowerment, PERMA and hope across the three time points.

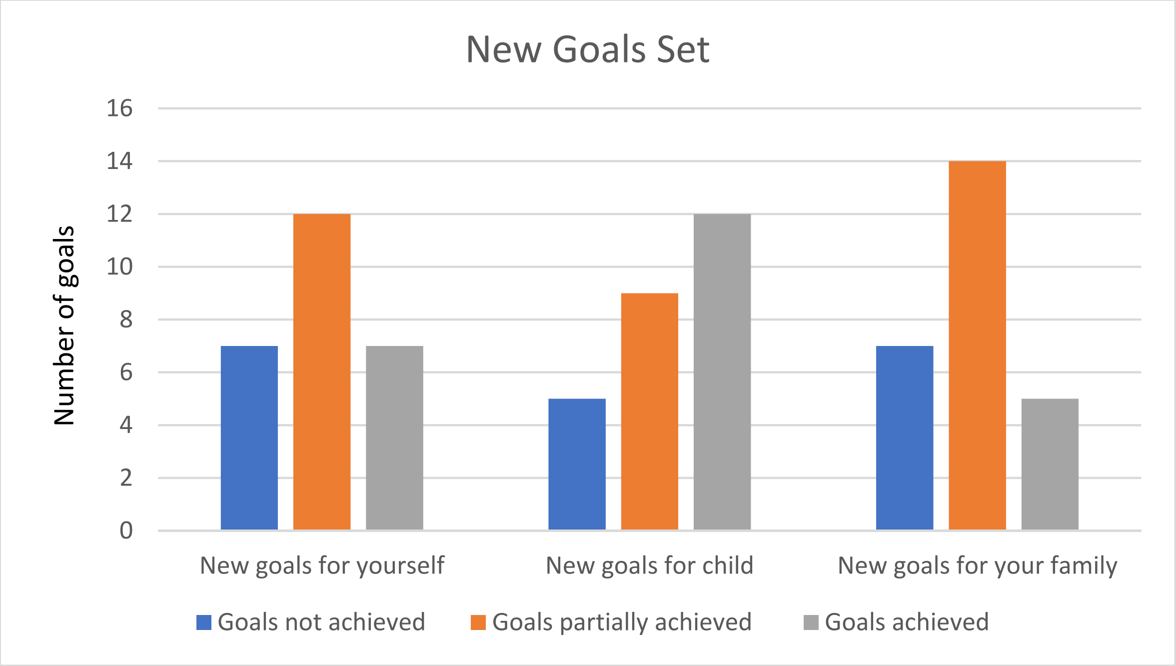


FIGURE 4 Setting new goals.

response pattern. Due to the sample size, it was not possible to identify distinct trajectories occurring within groups. Future studies should consider factors that distinguish participants' experiences with peer support programmes.

Hope scores for participants did not follow the same upward trajectory as well-being and empowerment. Snyder's Snyder (2000) model of hope is based on having goals, having pathway and feeling agency. Hope is related to participants' feelings and attitudes towards the future, and it is possible that at T3, participants were not feeling as hopeful regarding their futures due to the COVID-19 pandemic, economic instability or other local and global events. Still it is interesting that the goal component of hope increased, even as agency and efficacy did not increase. Future studies should consider both levels of hope as well as conditions that make hope more or less possible.

5 | LIMITATIONS

The sample size for this study was small, and results need to be replicated in larger samples. The length of the questionnaire may have been an issue, as 32% of the sample completed only part of the questionnaire. A larger data set of long-term outcomes ranging from 24 to 30 months would be preferrable, to extend understanding of long-term programme outcomes. In addition, incomplete responses and low numbers impacted our ability to draw on data for studying relationships between the severity of disability of the child and the outcome variables. The impact of the COVID-19 pandemic on the results needs to be considered as the participants in this study had completed the programme prior to the COVID-19 pandemic (and therefore completed the outcome measures for T1 and T2) and then completed the T3 outcomes measures during disruptions related to COVID-19. It is noteworthy that participants still demonstrated positive effects despite the COVID-19 challenges, but the direct impact of COVID on participants in this study is unknown.

6 | IMPLICATIONS

Our study suggests that professionals designing and considering the implementation of peer support programmes for families would benefit in designing programmes that facilitate ongoing involvement opportunities for the parents, leading to lasting and ongoing benefits for empowerment, well-being, hope and capacity-building. Further studies using rigorous designs and larger samples are needed to identify and examine the factors that contribute to effective peer support and sustainable improvements. Larger sample sizes would allow for subgroup analysis of associated factors and greater power. Future studies also should include repeated time points and higher quality study designs including randomised controlled trials, with the organisation blinded to participant condition.

7 | CONCLUSION

Our study found that improvements in parents' well-being and empowerment were maintained over a 6- to 30-month period after completing the N&N programme. While there is agreement that peer support programmes are worthwhile for parents, this study demonstrated that the gains in empowerment and well-being made during the peer support programme were sustained over the medium- and longer-term time frame. While parents of children with disability face many challenges, past studies on family quality of life show that many parents find their positive adaptations, attitudes and beliefs that help them establish a better sense of their family quality of life (Bhopti et al., 2020). Our study contributes to evidence of the lasting effects of positive psychology interventions (Cohn & Fredrickson, 2010) via peer support programmes and demonstrates that building parent capacity, empowerment, well-being and hope has a lasting effect for the parents and their children.

AUTHOR CONTRIBUTIONS

Katharine Lancaster: Conceptualization; investigation; writing—original draft; methodology; formal analysis; project administration; writing—review and editing; validation; data curation; resources. **Margaret L. Kern:** Conceptualization; writing—review and editing; methodology; formal analysis; validation; supervision. **Katherine Harding:** Writing—review and editing; methodology; supervision. **Mogi Bayasgalan:** Resources; data curation. **Annick Janson:** Writing—review and editing; resources; data curation; conceptualization. **Sylvana Mahmic:** Conceptualization; writing—review and editing; data curation; resources. **Anoo Bhopti:** Conceptualization; writing—review and editing; validation; formal analysis; supervision; methodology.

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CONFLICT OF INTEREST STATEMENT

The authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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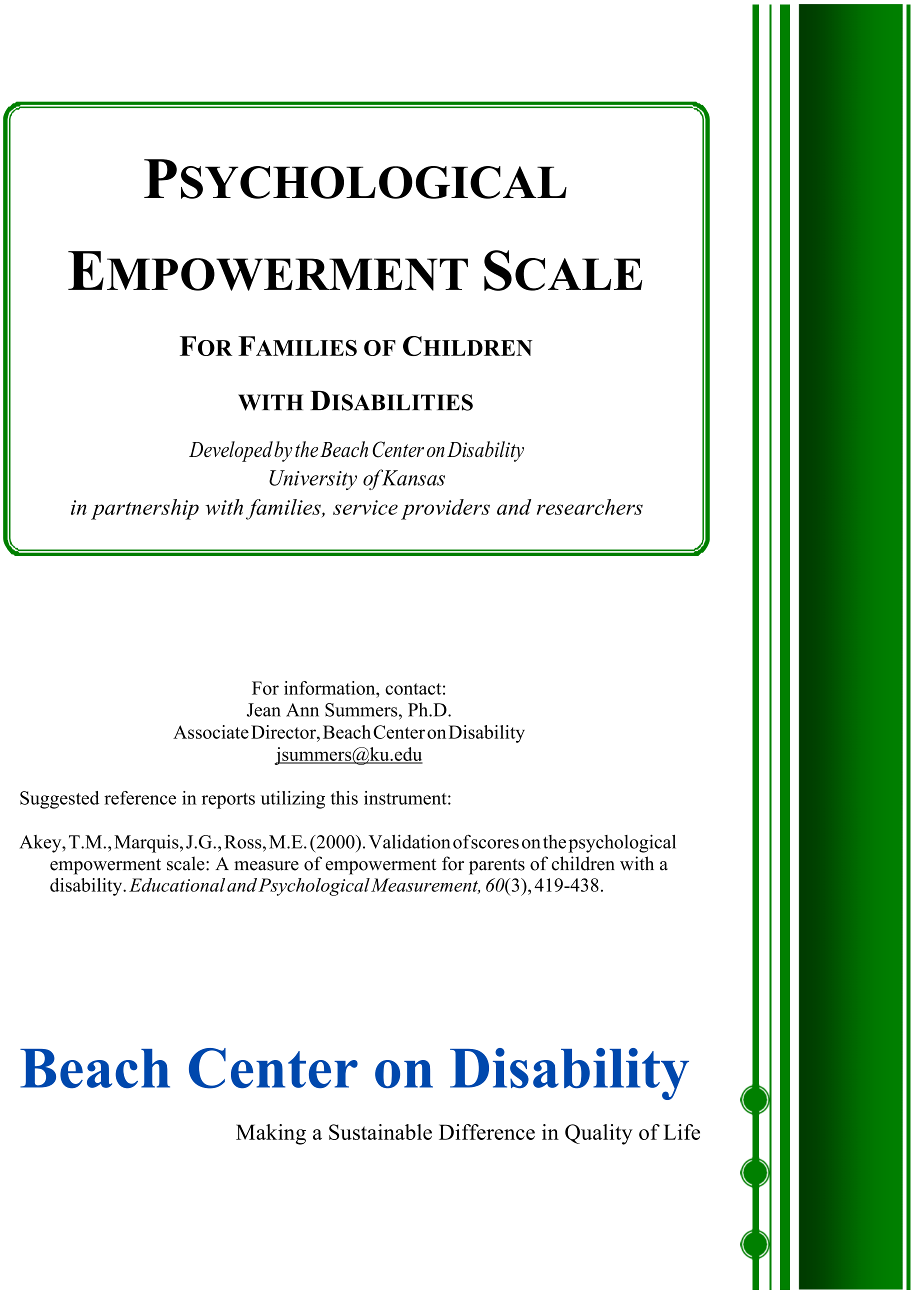
How to cite this article: Lancaster, K., Kern, M. L., Harding, K., Bayasgalan, M., Janson, A., Mahmic, S., & Bhopti, A. (2024). Exploring long-term outcomes of a peer support programme for parents* of children with disability in Australia. *Child: Care, Health and Development*, *50*(2), e13236. https://doi.org/10.1111/cch.13236

APPENDIX A: Measures

A.1 | Psychological empowerment scale



PSYCHOLOGICAL

EMPOWERMENT SCALE

FOR FAMILIES OF CHILDREN

WITH DISABILITIES

Developed by the Beach Center on Disability
University of Kansas
in partnership with families, service providers and researchers

For information, contact:
Jean Ann Summers, Ph.D.
Associate Director, Beach Center on Disability
jsummers@ku.edu

Suggested reference in reports utilizing this instrument:

Akey, T.M., Marquis, J.G., Ross, M.E. (2000). Validation of scores on the psychological empowerment scale: A measure of empowerment for parents of children with a disability. *Educational and Psychological Measurement, 60*(3), 419-438.

Beach Center on Disability

Making a Sustainable Difference in Quality of Life

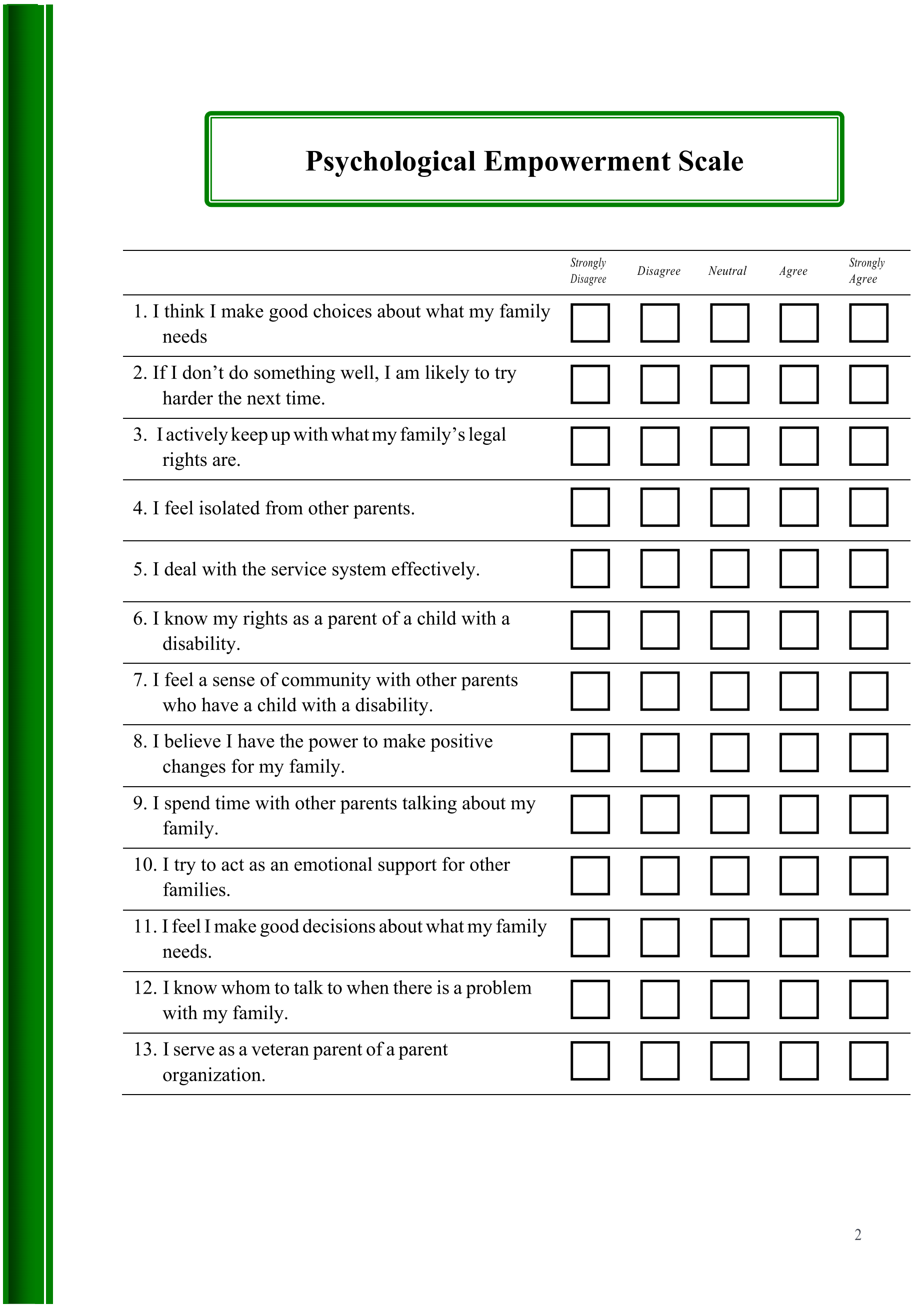
Psychological Empowerment Scale

SURVEY INFORMATION AND INSTRUCTIONS

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable.

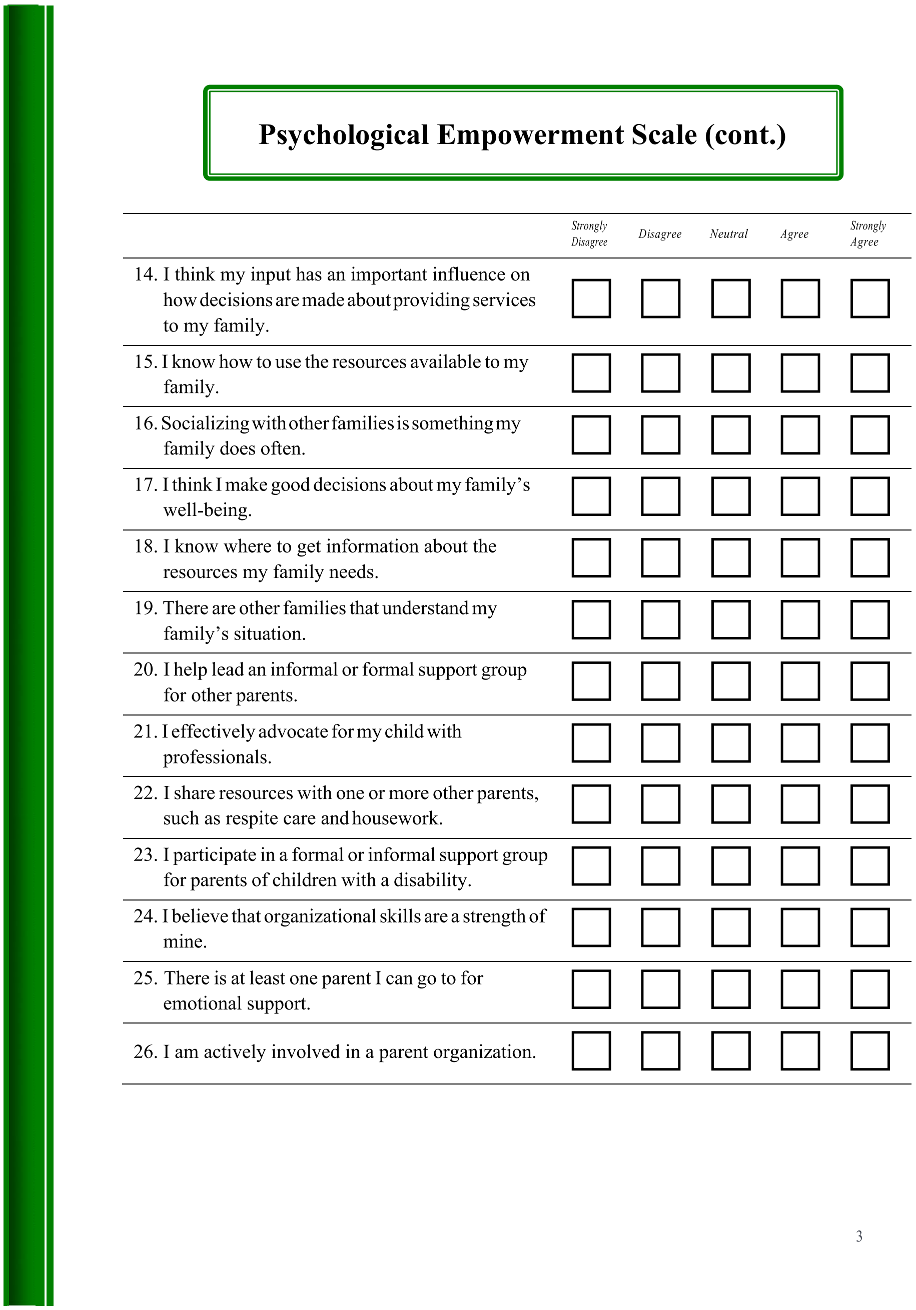
Thank you so much for sharing your opinion with us!

By completing this survey, you indicate that you have been informed of the important aspects of this study.



Psychological Empowerment Scale

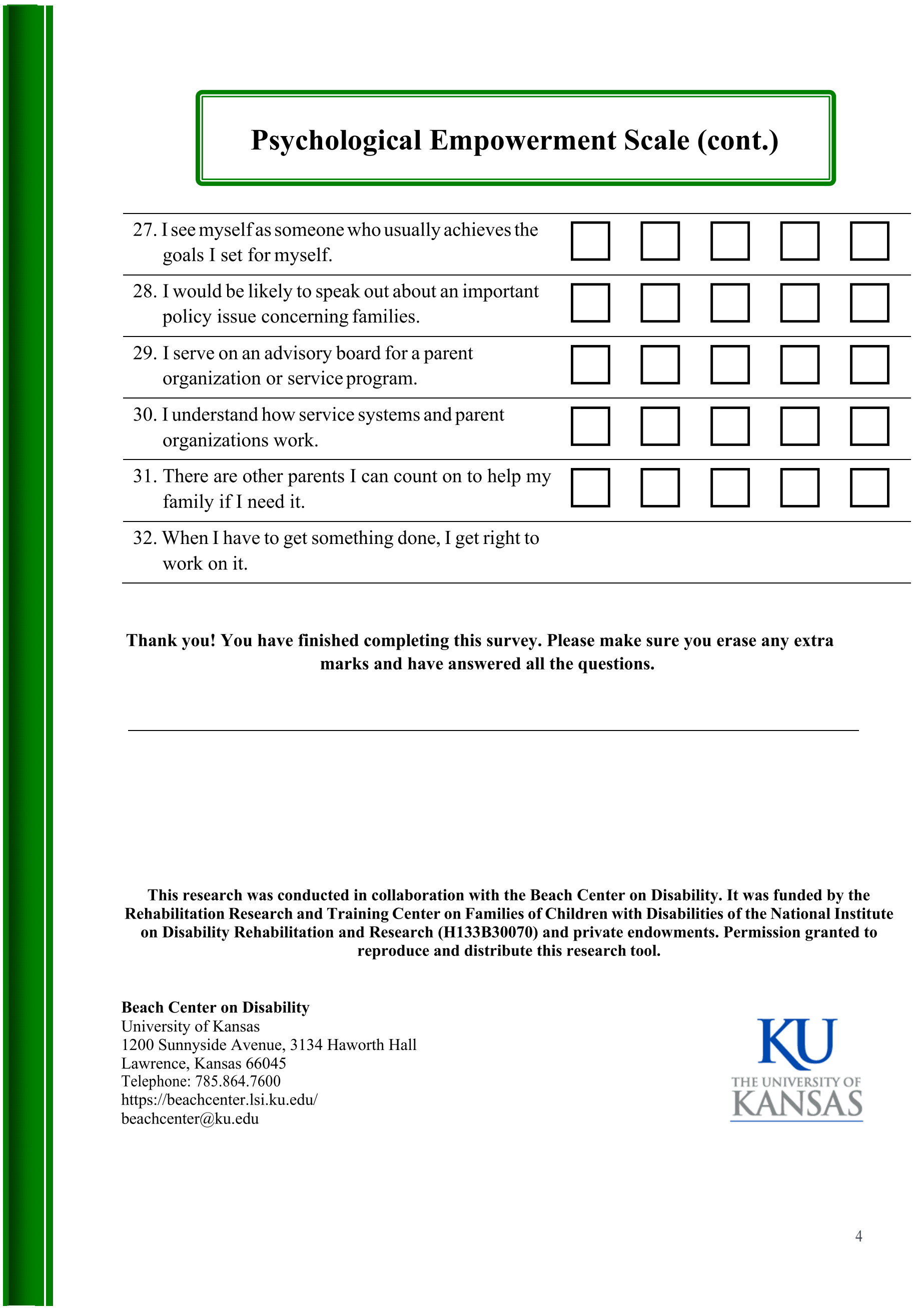
	Strongly Disagree	*Disagree*	*Neutral*	*Agree*	*Strongly Agree*
1. I think I make good choices about what my family needs	☐	☐	☐	☐	☐
2. If I don't do something well, I am likely to try harder the next time.	☐	☐	☐	☐	☐
3. I actively keep up with what my family's legal rights are.	☐	☐	☐	☐	☐
4. I feel isolated from other parents.	☐	☐	☐	☐	☐
5. I deal with the service system effectively.	☐	☐	☐	☐	☐
6. I know my rights as a parent of a child with a disability.	☐	☐	☐	☐	☐
7. I feel a sense of community with other parents who have a child with a disability.	☐	☐	☐	☐	☐
8. I believe I have the power to make positive changes for my family.	☐	☐	☐	☐	☐
9. I spend time with other parents talking about my family.	☐	☐	☐	☐	☐
10. I try to act as an emotional support for other families.	☐	☐	☐	☐	☐
11. I feel I make good decisions about what my family needs.	☐	☐	☐	☐	☐
12. I know whom to talk to when there is a problem with my family.	☐	☐	☐	☐	☐
13. I serve as a veteran parent of a parent organization.	☐	☐	☐	☐	☐



Psychological Empowerment Scale (cont.)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
14. I think my input has an important influence on how decisions are made about providing services to my family.	☐	☐	☐	☐	☐
15. I know how to use the resources available to my family.	☐	☐	☐	☐	☐
16. Socializing with other families is something my family does often.	☐	☐	☐	☐	☐
17. I think I make good decisions about my family's well-being.	☐	☐	☐	☐	☐
18. I know where to get information about the resources my family needs.	☐	☐	☐	☐	☐
19. There are other families that understand my family's situation.	☐	☐	☐	☐	☐
20. I help lead an informal or formal support group for other parents.	☐	☐	☐	☐	☐
21. I effectively advocate for my child with professionals.	☐	☐	☐	☐	☐
22. I share resources with one or more other parents, such as respite care and housework.	☐	☐	☐	☐	☐
23. I participate in a formal or informal support group for parents of children with a disability.	☐	☐	☐	☐	☐
24. I believe that organizational skills are a strength of mine.	☐	☐	☐	☐	☐
25. There is at least one parent I can go to for emotional support.	☐	☐	☐	☐	☐
26. I am actively involved in a parent organization.	☐	☐	☐	☐	☐

3



Psychological Empowerment Scale (cont.)

27. I see myself as someone who usually achieves the goals I set for myself.	☐	☐	☐	☐	☐
28. I would be likely to speak out about an important policy issue concerning families.	☐	☐	☐	☐	☐
29. I serve on an advisory board for a parent organization or service program.	☐	☐	☐	☐	☐
30. I understand how service systems and parent organizations work.	☐	☐	☐	☐	☐
31. There are other parents I can count on to help my family if I need it.	☐	☐	☐	☐	☐
32. When I have to get something done, I get right to work on it.					

Thank you! You have finished completing this survey. Please make sure you erase any extra marks and have answered all the questions.

This research was conducted in collaboration with the Beach Center on Disability. It was funded by the Rehabilitation Research and Training Center on Families of Children with Disabilities of the National Institute on Disability Rehabilitation and Research (H133B30070) and private endowments. Permission granted to reproduce and distribute this research tool.

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THE UNIVERSITY OF
KANSAS

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(Akey et al., 2000)

A.2 | The PERMA-Profiler

Updated October 14, 2016 - MLK

The PERMA Profiler

Julie Butler & Margaret L. Kern, University of Pennsylvania

Measure Overview

In his 2011 book *Flourish*, Dr. Martin Seligman, Distinguished Professor of Psychology at the University of Pennsylvania and one of the founders of the field of positive psychology, defined 5 pillars of wellbeing: PERMA (positive emotion, engagement, relationships, meaning, accomplishment). The PERMA-Profiler measures these five pillars, along with negative emotion and health.

P and N = Positive and Negative emotions
Emotions are an important part of our well-being. Emotions can range from very negative to very positive, and range from high arousal (e.g., excitement, explosive) to low arousal (e.g., calm, relaxed, sad). For **Positive emotion**, the PERMA-Profiler measures general tendencies toward feeling contentment and joy. For **Negative emotion**, the Profiler measures tendencies toward feeling, sad, anxious, and angry.

E = Engagement
Engagement refers to being absorbed, interested, and involved in an activity or the world itself. Very high levels of engagement are known as a state called "flow", in which you are so completely absorbed in an activity that you lose all sense of time.

R = Relationships
Relationships refer to feeling loved, supported, and valued by others. Having positive relationships with others is an important part of life feeling good and going well. Other people matter!

M = Meaning
Meaning refers to having a sense of purpose in life, a direction where life is going, feeling that life is valuable and worth living, or connecting to something greater than ourselves, such as religious faith, a charity or a personally meaningful goal. Meaning provides a sense that life matters.

A = Accomplishment
Accomplishment can be objective, marked by honors and awards received, but feelings of mastery and achievement is also important. The Profiler measures subjective feelings of accomplishment and staying on top of daily responsibilities. It involves working toward and reaching goals, and feeling able to complete tasks and daily responsibilities.

H = Health
Although not part of the PERMA model itself, physical health and vitality is another important part of well-being. The Profiler measures a subjective sense of health – feeling good and healthy each day.

Updated October 14, 2016 - MLK

Use of the Measure

The measure can be taken online at www.authentichappiness.org for free, after registering. (This will give you your scores and report, but not the data; if you want to collect data with the measure, you will need to set up your own survey with the questions, following the instructions below.)

You are welcome to use the measure **for noncommercial research or assessment purposes**, giving credit as noted below. There is no cost involved in using the measure for these purposes.

Before using the measure, please read through this document, and register by completing this form.

Please cite the measure as:

> Butler, J., & Kern, M. L. (2016). The PERMA-Profiler: A brief multidimensional measure of flourishing. *International Journal of Wellbeing*, 6(3), 1-48. doi:10.5502/ijw.v6i3.1

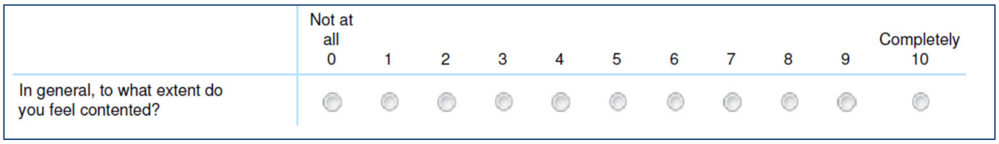
For commercial purposes, please contact the Penn Center for Innovation (pciinfo@pci.upenn.edu).

Questionnaire Administration

The PERMA-Profiler questions are provided on the next page. The measure consists of 23 items. The health, negative emotion, loneliness, and overall happiness questions act as filler questions and provide more information; for briefness, the 15 PERMA questions (3 per PERMA domain) could be used, but we recommend using the full measure.

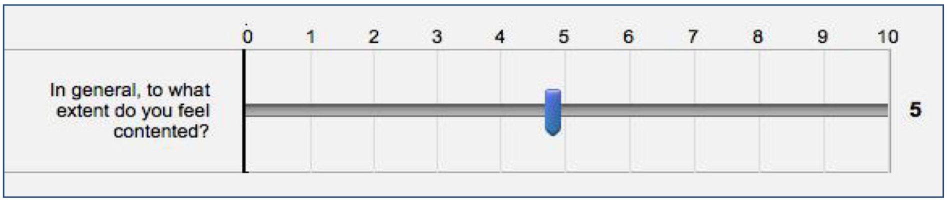
The questions should be presented in the order noted. We typically display each set on separate pages (see example below), but these could also be subsections on a single page. Questions are on an 11-point scale ranging from 0 to 10, with the end points labeled. We have often used radial buttons, but slider scales are an alternative, which seem to be easier for participants and more visually appealing.

Radial button presentation:



	Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
In general, to what extent do you feel contented?	○	○	○	○	○	○	○	○	○	○	○

Slider scale presentation:



In general, to what extent do you feel contented?

5

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The PERMA-Profiler Measure

#	Label	Question	Response Anchors
Block 1	**A1**	How much of the time do you feel you are making progress towards accomplishing your goals?	0 = never, 10 = always
	E1	How often do you become absorbed in what you are doing?	
	P1	In general, how often do you feel joyful?	
	N1	In general, how often do you feel anxious?	
	A2	How often do you achieve the important goals you have set for yourself?	
Block 2	**H1**	In general, how would you say your health is?	0 = terrible, 10 = excellent
Block 3	**M1**	In general, to what extent do you lead a purposeful and meaningful life?	0 = not at all, 10 = completely
	R1	To what extent do you receive help and support from others when you need it?	
	M2	In general, to what extent do you feel that what you do in your life is valuable and worthwhile?	
	E2	In general, to what extent do you feel excited and interested in things?	
	Lon	How lonely do you feel in your daily life?	
Block 4	**H2**	How satisfied are you with your current physical health?	0 = not at all, 10 = completely
Block 5	**P2**	In general, how often do you feel positive?	0 = never, 10 = always
	N2	In general, how often do you feel angry?	
	A3	How often are you able to handle your responsibilities?	
	N3	In general, how often do you feel sad?	
	E3	How often do you lose track of time while doing something you enjoy?	
Block 6	**H3**	Compared to others of your same age and sex, how is your health?	0 = terrible, 10 = excellent
Block 7	**R2**	To what extent do you feel loved?	0 = not at all, 10 = completely
	M3	To what extent do you generally feel you have a sense of direction in your life?	
	R3	How satisfied are you with your personal relationships?	
	P3	In general, to what extent do you feel contented?	
Block 8	**hap**	Taking all things together, how happy would you say you are?	0 = not at all, 10 = completely

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The PERMA-Profiler Measure

#	Label	Question	Response Anchors
Block 1	**A1**	How much of the time do you feel you are making progress towards accomplishing your goals?	0 = never, 10 = always
	E1	How often do you become absorbed in what you are doing?	
	P1	In general, how often do you feel joyful?	
	N1	In general, how often do you feel anxious?	
	A2	How often do you achieve the important goals you have set for yourself?	
Block 2	**H1**	In general, how would you say your health is?	0 = terrible, 10 = excellent
Block 3	**M1**	In general, to what extent do you lead a purposeful and meaningful life?	0 = not at all, 10 = completely
	R1	To what extent do you receive help and support from others when you need it?	
	M2	In general, to what extent do you feel that what you do in your life is valuable and worthwhile?	
	E2	In general, to what extent do you feel excited and interested in things?	
	Lon	How lonely do you feel in your daily life?	
Block 4	**H2**	How satisfied are you with your current physical health?	0 = not at all, 10 = completely
Block 5	**P2**	In general, how often do you feel positive?	0 = never, 10 = always
	N2	In general, how often do you feel angry?	
	A3	How often are you able to handle your responsibilities?	
	N3	In general, how often do you feel sad?	
	E3	How often do you lose track of time while doing something you enjoy?	
Block 6	**H3**	Compared to others of your same age and sex, how is your health?	0 = terrible, 10 = excellent
Block 7	**R2**	To what extent do you feel loved?	0 = not at all, 10 = completely
	M3	To what extent do you generally feel you have a sense of direction in your life?	
	R3	How satisfied are you with your personal relationships?	
	P3	In general, to what extent do you feel contented?	
Block 8	**hap**	Taking all things together, how happy would you say you are?	0 = not at all, 10 = completely

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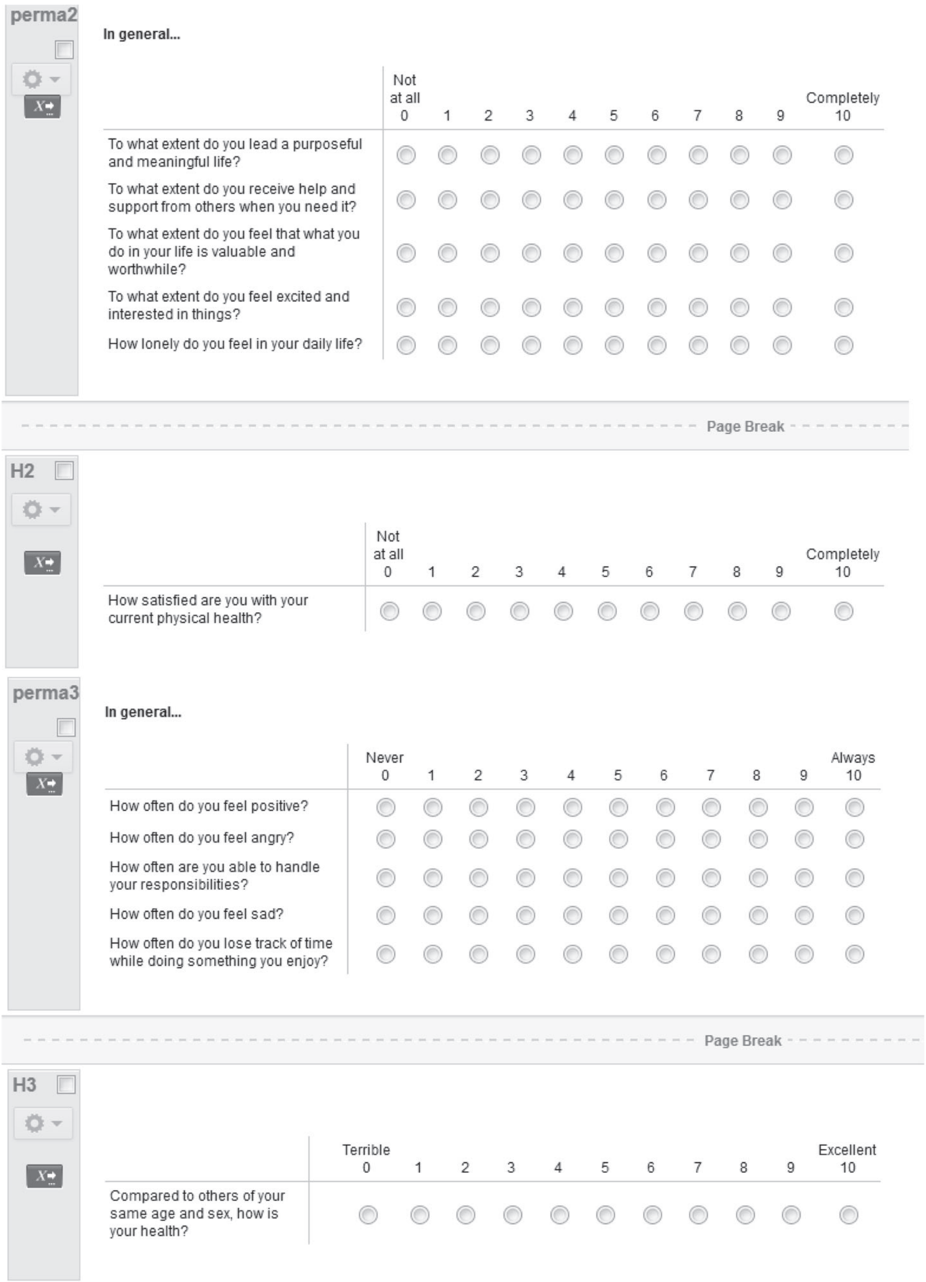

In general...

	Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
To what extent do you lead a purposeful and meaningful life?	○	○	○	○	○	○	○	○	○	○	○
To what extent do you receive help and support from others when you need it?	○	○	○	○	○	○	○	○	○	○	○
To what extent do you feel that what you do in your life is valuable and worthwhile?	○	○	○	○	○	○	○	○	○	○	○
To what extent do you feel excited and interested in things?	○	○	○	○	○	○	○	○	○	○	○
How lonely do you feel in your daily life?	○	○	○	○	○	○	○	○	○	○	○

	Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
How satisfied are you with your current physical health?	○	○	○	○	○	○	○	○	○	○	○

In general...

	Never 0	1	2	3	4	5	6	7	8	9	Always 10
How often do you feel positive?	○	○	○	○	○	○	○	○	○	○	○
How often do you feel angry?	○	○	○	○	○	○	○	○	○	○	○
How often are you able to handle your responsibilities?	○	○	○	○	○	○	○	○	○	○	○
How often do you feel sad?	○	○	○	○	○	○	○	○	○	○	○
How often do you lose track of time while doing something you enjoy?	○	○	○	○	○	○	○	○	○	○	○

	Terrible 0	1	2	3	4	5	6	7	8	9	Excellent 10
Compared to others of your same age and sex, how is your health?	○	○	○	○	○	○	○	○	○	○	○

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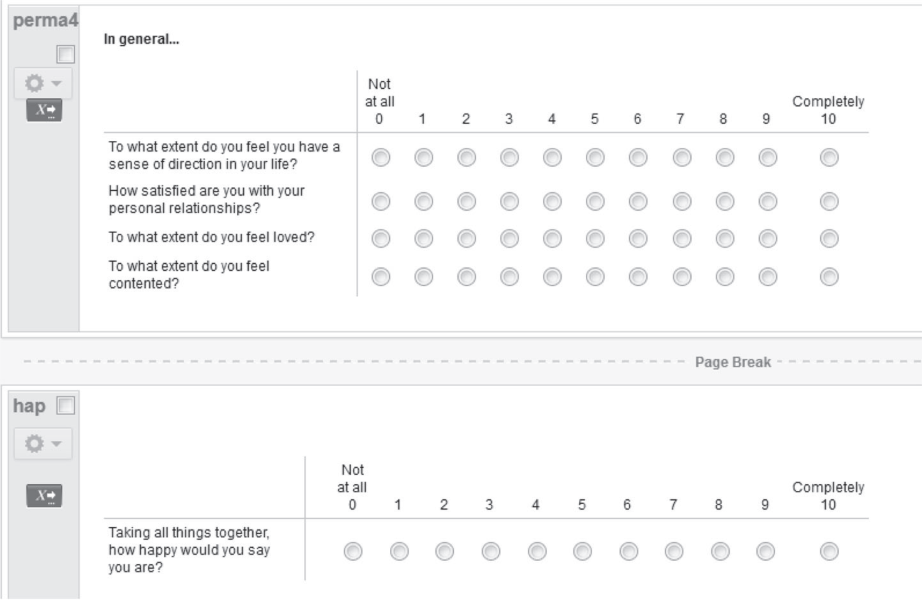

In general...

	Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
To what extent do you feel you have a sense of direction in your life?	○	○	○	○	○	○	○	○	○	○	○
How satisfied are you with your personal relationships?	○	○	○	○	○	○	○	○	○	○	○
To what extent do you feel loved?	○	○	○	○	○	○	○	○	○	○	○
To what extent do you feel contented?	○	○	○	○	○	○	○	○	○	○	○

	Not at all 0	1	2	3	4	5	6	7	8	9	Completely 10
Taking all things together, how happy would you say you are?	○	○	○	○	○	○	○	○	○	○	○

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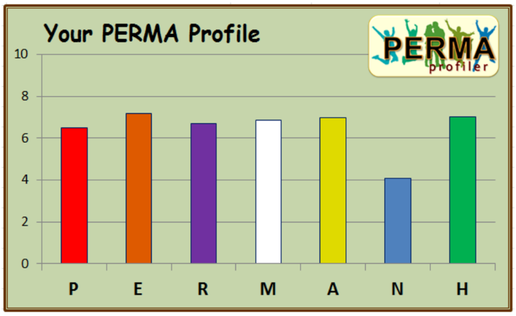
Scoring:

Scores are calculated as the average of the items comprising each factor:

Positive Emotion:	P = mean(P1,P2,P3)
Engagement:	E = mean(E1,E2,E3)
Relationships:	R = mean(R1,R2,R3)
Meaning	M = mean(M1,M2,M3)
Accomplishment	A = mean(A1,A2,A3)
Overall Well-being	PERMA= mean(P1,P2,P3,E1,E2,E3, R1,R2,R3, M1,M2,M3, A1,A2,A3,hap)
Negative Emotion:	N = mean(N1,N2,N3)
Health =	H = mean(H1,H2,H3)
Loneliness	Lon (single item)

Sample Scoring Presentation

In reporting information back to people, we have used a bar graph, providing a person's PERMA Profile:



Psychometric Information

See the paper (available from http://internationaljournalofwellbeing.org/index.php/ijow/article/view/526/579)

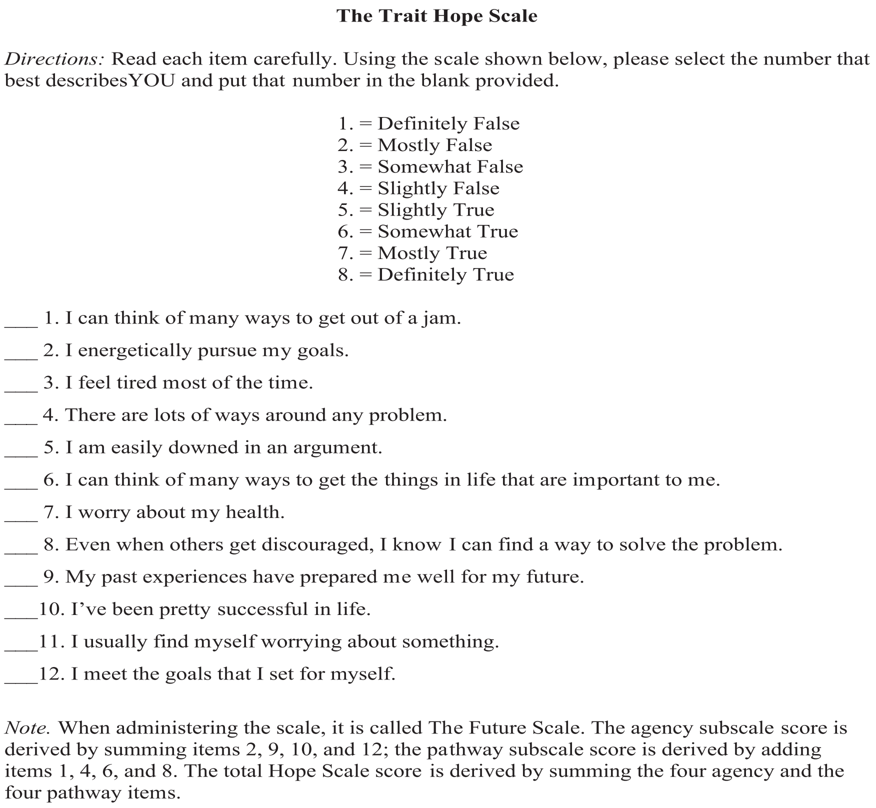
Contact Information

The measure is be available at www.peggykern.org/questionnaires.html

For questions, comments, or suggestions, please contact Dr. Kern at pkern001@gmail.com

(Butler & Margaret, 2016)

A.3 | Adult Hope Scale



The Trait Hope Scale

Directions: Read each item carefully. Using the scale shown below, please select the number that best describesYOU and put that number in the blank provided.

1. = Definitely False
2. = Mostly False
3. = Somewhat False
4. = Slightly False
5. = Slightly True
6. = Somewhat True
7. = Mostly True
8. = Definitely True

___ 1. I can think of many ways to get out of a jam.

___ 2. I energetically pursue my goals.

___ 3. I feel tired most of the time.

___ 4. There are lots of ways around any problem.

___ 5. I am easily downed in an argument.

___ 6. I can think of many ways to get the things in life that are important to me.

___ 7. I worry about my health.

___ 8. Even when others get discouraged, I know I can find a way to solve the problem.

___ 9. My past experiences have prepared me well for my future.

___10. I've been pretty successful in life.

___11. I usually find myself worrying about something.

___12. I meet the goals that I set for myself.

Note. When administering the scale, it is called The Future Scale. The agency subscale score is derived by summing items 2, 9, 10, and 12; the pathway subscale score is derived by adding items 1, 4, 6, and 8. The total Hope Scale score is derived by summing the four agency and the four pathway items.

(Snyder et al., 1991)

APPENDIX B: QUESTIONS FOR ONLINE SURVEY

1. Since completing the Now and Next programme, do you consider yourself to have **attained or achieved** any of the goals you have set during the programme?

a) for yourself.

Goals not achieved
Goals partially achieved
Goals achieved

b) for your child.

Goals not achieved
Goals partially achieved
Goals achieved

c) for your family.

Goals not achieved
Goals partially achieved
Goals achieved

2. Have you set any **new** goals since completing the Now and Next programme? a) for yourself.

0 goals
1–2 goals
3 or more goals

b) your child.

c) for your family.

0 goals
1–2 goals
3 or more goals

0 goals
1–2 goals
3 or more goals

No longer involved with Plumtree Children's services
Involved with Plumtree Children's services

3. We are interested to know if you are still involved with Plumtree.

If yes, in what ways are you still involved? Please tick all that apply.

Facilitator to lead/run groups
Engage with family leadership programme
Continue to do courses with Plumtree Children's services – e.g. student voice, child voice, parenting courses.
Joined with social media groups/global now and next alumni
Continue to meet with other parents/carers from Plumtree Children's services or stay connected with others in closed Facebook group
Attend Plumtree Children's services functions/events e.g. family conferences
Employed by Plumtree Children's services e.g. peer worker, writing grant applications, project management, admin, programme coordination
Volunteer at Plumtree Children's services
Child continues to use services provided by Plumtree Children's services e.g. kinder/allied health
Establish or set up their own organisation or ways to continue to support families as peer leaders – e.g reframing autism, reframing disability
Other – Please describe

4. Thinking now about the level of support your child needs (for families with more than one child please think about the child requiring the most level of support). What level of support does your child require to enable participation?

High level support needs
Medium level support needs
Low level support needs

5. What feedback or additional comments can you add?