

## Life Participation for Parents (LPP) ® (2005)

<b>Background Literature</b>	Family-centered practice goes beyond child related goals to incorporate changing the quality of life for the whole family (Rosenbaum, King, Law, King, & Evans., 1998). Families are interdependent and intervention with the child can have a significant impact on life participation for the entire family, especially the parents. Raising a child with special needs can influence a parent's time usage, health, and choice of activities (Crowe, 1993; Jones & Passey, 2005; Kuhaneck, Burroughs, Wright, Lemanczyk & Darragh, 2010; & Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). In order to provide best- practice family-centered intervention therapists need to understand individual barriers to life participation for the child, parents, and other family members (Hinojosa, Sproat, Mankhetwit & Anderson, 2002; Roberts & Lawton, 2001; Rosenbaum et. al. 1998).
<b>Source</b>	Patricia E. Fingerhut, OTR, PhD. 301 University Boulevard Galveston, Texas, 77555-1142 <a href="mailto:pefinger@utmb.edu">pefinger@utmb.edu</a>
<b>References</b>	Fingerhut, P.E. (in press) Life Participation for Parents: A tool for family-centered occupational therapy, <i>American Journal of Occupational Therapy</i> .  Fingerhut, P.E. (2009). Measuring Outcomes of Family-Centered Intervention: Development of the Life Participation for Parents (LPP). <i>Physical &amp; Occupational Therapy in Pediatrics</i> , 29(2), 113-128.
<b>Purpose</b>	The LPP was developed to enhance family-centered practice by providing a self-report questionnaire to measure satisfaction with the efficiency and effectiveness of parental life participation while raising a child with special needs.
<b>Type of Client</b>	The LPP is appropriate for any primary caregiver of a child with special needs.
<b>Clinical Utility</b> Format  Procedures  Completion time	The LPP consists of 23 items related to activities / occupations engaged in by primary caregivers that may be influenced by the role of raising a child with special needs. Questions relate to the parent/caregiver's satisfaction with the effectiveness (quality of performance) and efficiency (time spent) of participation in activities / occupations.  Parents/caregivers complete the questionnaire using a 5-point Likert scale. There is also space for qualitative comments to provide more information to the therapist for focused follow-up.  It takes approximately 10 minutes for the client to complete the LPP and less than 10 minutes for the therapist to score.
<b>Reliability</b> Internal Consistency Test-retest	n = 162, $\alpha = .90$ (Fingerhut, in press) n = 17, r = .89 (Fingerhut, in press)

<p><b>Validity</b> Goodwin &amp; Leech, 2003 test content</p> <p>response processes</p> <p>internal structure</p> <p>relations to other variables</p> <p>consequences of testing</p>	<p>Content of the questionnaire items was established through literature review and review by therapist and parent stakeholders (Fingerhut, 2009)</p> <p>Interviews with parents and therapists established that the items/questions were understood, were relevant to the construct being measured, and captured a range of responses providing evidence of response processes (Fingerhut, 2009)</p> <p>A principal component analysis resulted in a 2- factor model accounting for 43.81% of the variance. These factors represented the satisfaction with efficiency and satisfaction with effectiveness consistent with the occupational adaptation frame of reference used in constructing the questionnaire.(Fingerhut, in press)</p> <p>The LPP correlated moderately with the Parenting Stress Index – Short Form (Abidin, 1986) (n = 37, r = .54). Variables of child’s diagnoses, age, or time in therapy did not predict parental responses.(Fingerhut, in press)</p> <p>More research using the LPP in practice is needed to establish consequences.</p>
<p><b>Sensitivity to Change</b></p>	<p>Test-retest reliability has demonstrated that responses are stable over the short term. Further research in a pretest – intervention – posttest format is needed to establish if the LPP is sufficiently sensitive to measure outcomes.</p>
<p><b>Administration Procedure</b></p>	<p>The LPP can be given to a parent/caregiver to be completed during a treatment session, in the waiting room, or to be returned at a future time. It should be explained to the parent/caregiver that the questions relate to the parent/caregiver’s life participation and not the child’s, and that the information is to assist in developing family-centered intervention.</p>
<p><b>Scoring Procedure</b></p>	<p>A lower score indicates more participation issues. Questions are worded both positively and negatively. For this reason questions 2,4,6,8,10,11, &amp; 12 need to be reverse scored. (ie. The chosen Likert score is subtracted from 6 (6-x) in these questions to give the score that will be added into the total.) Therapists can use the scores to assess relative concerns for the parents and the qualitative comments to develop further dialogue for designing family-centered intervention.</p>
<p><b>Background References</b></p>	<p>Abidin, R.R. (1986). <i>Parenting Stress Index</i>. Charlottesville, VA: Pediatric Psychology Press.</p> <p>Crowe, T.K. (1993). Time use of mothers with young children: The impact of a child’s disability. <i>Developmental Medicine and Child Neurology</i>, 35, 621-630.</p> <p>Goodwin, L.D. &amp; Leech, N.L. (2003). The meaning of validity in the <i>New Standards for Educational and Psychological Testing</i>: Implications for measurement courses. <i>Measurement and Evaluation in counseling and Development</i>, 36, 181-191.</p> <p>Hinojosa, J., Sproat, C., Mankhetwit, S., &amp; Anderson, J. (2002). Shifts in parent–therapist partnerships: Twelve years of change. <i>American Journal of Occupational Therapy</i>,56(5), 556–563.</p> <p>Jones, J. &amp; Passey, J. (2005). Family adaptation, coping and resources: parents of children with developmental disabilities and behavior problems. <i>Journal of Developmental Disabilities</i>, 11(1), 31-46.</p> <p>Kuhaneck, H.M., Burroughs, T., Wright, J., Lemaczyk, T., &amp; Darragh, A. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. <i>Physical &amp; Occupational Therapy in Pediatrics</i>, 30(4), 340-350.</p> <p>Roberts, K. &amp; Lawton, D. (2001). Acknowledging the extra care parents give their disabled children. <i>Child, Care, Health &amp; Development</i>, 27(4), 307-319.</p> <p>Rosenbaum P., King S., Law M., King, G., &amp; Evans, J. (1998). Family-centered service: A conceptual framework and research review. <i>Physical and Occupational Therapy in Pediatrics</i>, 18(1), 1-20.</p> <p>Schaaf, R., Toth-Cohen, S., Johnson, S, Outten, G. &amp; Benevides, T. (2011). The everyday routines of families of children with autism. <i>Autism</i>, 15(3), 373-389.</p>

# Life Participation for Parents (LPP) ® (2005)

Parent's Name \_\_\_\_\_ Child's Name \_\_\_\_\_

Quality therapy needs to be family-centered. Raising children with special needs affects all family members. This questionnaire addresses many activities of a parent/caregiver that may be affected by raising a child with special needs.

**Instructions:** Read the questions and think how this aspect of your life is affected by raising a child with special needs. Circle the response that most closely describes how you feel about the statement. Explain how these activities are difficult on the lines labeled comments below. If the question does not apply to you circle not applicable.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
1	2	3	4	5	6

**1. I spend more of my time caring for my child's physical and personal hygiene needs than I would like. (e.g. feeding, bathing, toileting, dressing, safety, moving them around, etc.)**

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
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Comments: \_\_\_\_\_

**2. I am able to manage my child's physical and personal hygiene needs.**

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
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Comments: \_\_\_\_\_

**3. I spend more of my parenting time doing things a teacher/therapist would do with my child than I would like. (e.g. homework, therapy home programs etc.)**

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
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Comments: \_\_\_\_\_

**4. I feel I do a good job when I do the things a teacher/therapist might do for my child.**

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
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Comments: \_\_\_\_\_

**5. My child's need for emotional support is wearing me out. (e.g. not able to entertain themselves, upset easily, cannot manage change in routine etc.)**

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	Not Applicable
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Comments: \_\_\_\_\_

**6. I am able to meet my child's emotional needs.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**7. I spend more time arranging services for my child than I would like. (e.g. appointments with health professionals, school services etc.)**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**8. I am good at getting services for my child.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**9. I spend more of my time arranging and providing social activities for my child, than I would like. (e.g. things to do, people to play with etc.)**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**10. I am good at providing for my child's social activities.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**11. I am able to manage household chores while caring for my child. (e.g. paying bills, cleaning, making meals, doing laundry etc.)**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**12. I am able to effectively do errands with my child. (e.g. shopping, banking, deliveries)**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**13. Having a child with special needs has interfered with my ability to hold a job or pursue education.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**14. Financial issues related to my child's special needs are a source of stress for our family.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**15. Having a child with special needs has restricted my ability to spend time with my friends and family as often as I would like to.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**16. Spending time with my friends and family with my child present is stressful.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**17. Having a child with special needs restricts the time I would like to spend with my spouse / significant other.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**18. Having a child with special needs restricts the time I would like to spend with my other children.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**19. Having a child with special needs affects my ability to be involved in community activities as often as I would like. (e.g. religious services, charitable organizations, political or community organizations)**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**20. Having a child with special needs has affected my health.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**21. Having a child with special needs has affected my sleep.**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**22. Having a child with special needs affects my opportunities to engage in personal activities. (e.g. hobbies, sports, leisure activities)**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Both Agree and Disagree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<i>Not Applicable</i>
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Comments: \_\_\_\_\_

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**23. Thinking back on a typical day, are there other activities that you would like to participate in? How are these affected by having a child with special needs?**

Comments: \_\_\_\_\_

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