

## NINDS CDE Notice of Copyright

### Family Strain Questionnaire Assessment of Preschooled Children's Participation

<b>Availability:</b>	The measure is copyrighted and there is a fee for use. The cost is \$50 for an individual or \$90 for an organization. This is a one-time fee that gets you a pdf of the measure and score sheet. To obtain a copy of this instrument please email Mary Law at <a href="mailto:lawm@mcmaster.ca">lawm@mcmaster.ca</a>
<b>Classification:</b>	Exploratory for Mitochondrial Disease (Mito)
<b>Short Description of Instrument:</b>	Semi-structured interview, plus 44 dichotomous items administer in about 20 minutes, aimed at investigating the subjective perception of emotional burden, problems in social involvement, the need for more information about the disease, satisfaction with family relationships and thoughts about death. Data were analyzed using the Rasch model for the reduction of items
<b>Comments/ Special Instructions</b>	All items are pictures and instructions are easy to translate into multiple languages. As this scale is easy to complete and uses no language, it usable for people of all educational levels.
<b>Scoring:</b>	The scale consists of 45 drawings of everyday activities in the areas of play (PA), skill development (SD), active physical recreation (AP), and social activities. For diversity scores, parents/caregivers respond with a yes or no indicating whether their child participates in the activity pictured. For participation intensity scores, parents/caregivers record how often their child participated in the activity over the last 4 months using a 7 point ordinal scale ranging from once over the last 4 months to daily or more frequently. Two scores (diversity and intensity scores) are generated for each item and in the 4 activity areas. Participation diversity is a count of the total number of reported activities the child participated in over the previous 4 months. Participation intensity reflects the average amount of time that the child spent participating in all activities compared to the total number of possible activities. Intensity is derived by dividing the sum of the frequencies for all items by the number of possible items in each activity area.
<b>References:</b>	Law M, King G, Petrenchik T, Kertoy M, Anaby D. The assessment of preschool children's participation: internal consistency and construct validity. <i>Phys Occup Ther Pediatr.</i> 2012;32(3):272-87.