Examining Health Conditions, Body Functions, Activity and Participation, and Quality of Life among Adults with Learning Disabilities – Towards a Theoretical Model

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A THESIS SUBMITTED FOR THE DEGREE
"DOCTOR OF PHILOSOPHY"

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November 2015

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Recommended by _____ Date _____
(Supervisor)

Approved by _____ Date _____
(Chairperson of PhD Committee)

Methods

2.1. The Sample

A convenience sample of 110 adults from the Southern and Central regions of Israel participated in the study. The final sample size (55 adults with LD and 55 matched controls) was determined using the statistical power analysis program G*Power3, version 3.1.9.2 (Faul, Erdfelder, Land, & Buchner, 2007), which calculated a sample power of 0.999 with an effect size of minimum 0.66 and α error probability of 0.05.

Participants were invited to participate in the study via e-mails and Facebook. Those who wanted to participate in the study contacted the researcher and were asked initial questions to confirm inclusion criteria. The inclusion criteria were: 20-50 years of age with Hebrew reading and writing skills at the level of mother tongue, intact vision and hearing or corrected with an aid, no observed motor or neurological disabilities, and generally healthy with no chronic diseases or significant injuries that may influence daily activity and participation and QoL. To assure the inclusion criteria participants reported if Hebrew was their first and main language and filled in a health questionnaire (the ICF checklist). Participants of the study group presented an observation of LD signed by a certified professional: a qualified LD diagnostician or a psychologist that was a LD specialist. Participants were included in the study if they were diagnosed as having LD as children or as adults and if they had past interventions for their LD. Controls had to answer "no" to two questions: "Has anyone ever told you that you may have a LD?" and "Did you ever think you may have a LD?". Co-morbid health conditions as ADHD and DCD were examined in both groups through measures used in this study (ASRS, and ADC, respectively) (see The Instruments).

2.2. The Instruments

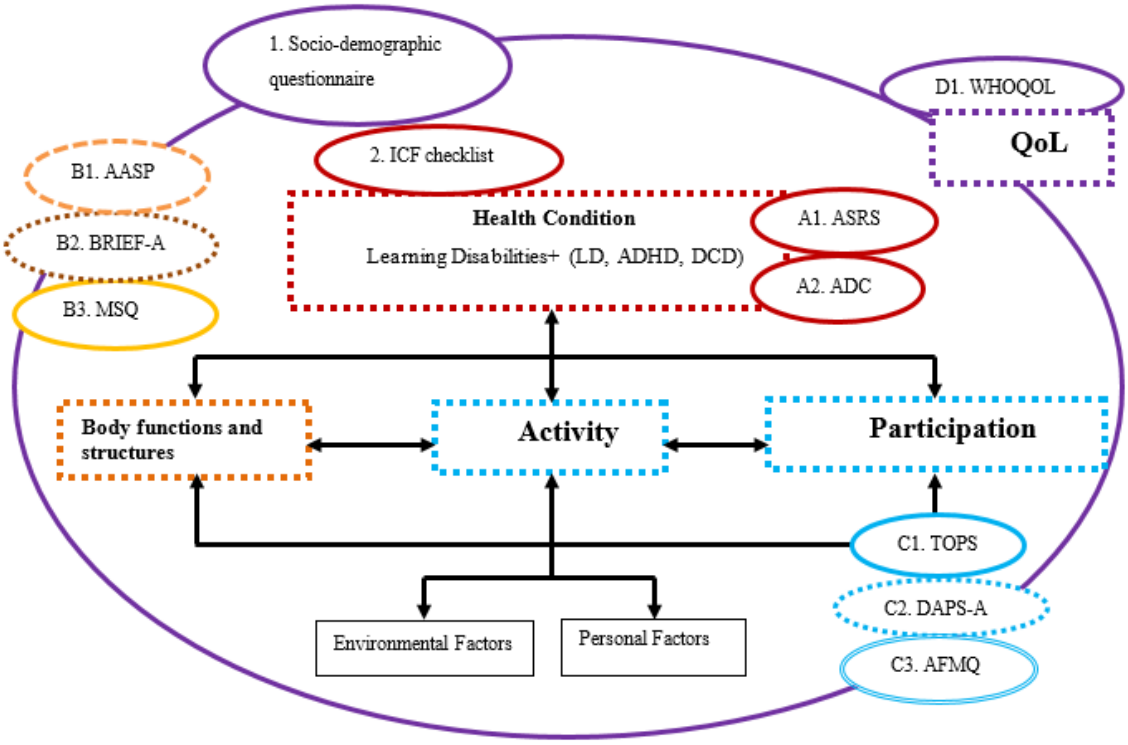
The instruments used for gathering data regarding descriptive characteristics of the sample, including socio-demographic and health-related characteristics, associated health conditions, body functions, daily activity and participation and QoL are listed in Table 1 and in Figure 2. The first column on the left hand side gives the construct to be examined. The second column presents the instruments used to examine the construct and the third column lists the authors of the instruments.

Table 1: An overview of the instruments used in this study

No.	Examined Construct	Instrument	Authors
	Descriptive Characteristics		
1	Socio-demographic characteristics	*A Socio-demographic questionnaire*	Rosenblum & Sharfi, In process
2	Health-related characteristics	*Brief health information, ICF checklist*	WHO, 2003
A	**Health conditions**		
1	ADHD	*The Adult ADHD Rating Scale (ASRS-V1.1)* (Heb.)	Adler, Kessler, & Spencer, 2003
2	DCD	*Adult Developmental Coordination Disorders / Dyspraxia Checklist (ADC)* (Heb.)	Kirby et al., 2010
B	**Body functions**		
1	Sensory functions	*The Sensory Profile - Adolescents/Adult version (AASP)* (Heb.)	Brown & Dunn, 2002
2	Higher-level cognitive functions (EF)	*The Behavioral Rating Inventory of Executive Functions – Adolescents/adults version (BRIEF-A)* (Heb.)	Roth et al., 2005
3	Sleep functions	*The Mini Sleep Questionnaire (MSQ)* (Heb.)	Zomer, Peled, Rubin, & Lavie, 1985
C	**Activity and Participation**		
1	Organization in time	*Time Organization and Participation (TOPS)* (Heb.)	Rosenblum, 2012
2	Managing one's own activity level	*Daily Activities Participation Scale – for Adults (DAPS-A)* (Heb.)	Sharfi & Rosenblum, in process
3	Economic self-sufficiency	*The Adult Finance Management Questionnaire (AFMQ)*(Heb.)	Sharfi, Rosenblum, & Barkley, in process
D	**Quality of Life**		
1	Quality of life (physical, psychological, social, environmental)	*World Health Organization Quality Of Life questionnaire (WHOQOL-BREF)* (Heb.)	WHO, 2004

Figure 2. below presents a graphic description of the instruments used in the study as related to the modified ICF Model and the QoL concepts that were examined. Each construct and the instruments selected for its measurement appear in colors as follows: Health conditions in red, Body functions in yellow-brown, Activity and participation in blue, and QoL in purple. Detailed descriptions of the instruments follow the figure.

Figure 2: A Graphic Presentation of the Instruments Used in this Study as Related to the modified ICF Model and QoL and the Concepts Which Were Examined



Descriptive Characteristics

1. *A Socio-demographic questionnaire* - a 36-item self-report questionnaire was constructed for this study. Twenty-five questions related to socio-demographic information of the participant. Eleven additional questions related to his/her past experiences in high school, employment and developmental background.
2. *The Brief Health Information, ICF Checklist* (WHO, 2003) - a 17-item self-report questionnaire designed to gather basic data on the subject's health, based on the ICF concepts. It is a short version of the *ICF checklist* and was translated into Hebrew for the study. Back and forth translation ensured the translation's validation process. Participants evaluated their physical, mental and emotional health on a 5-point scale and

reported on present diseases, past injuries and hospitalizations (health conditions). They reported on their body functions such as, their height, weight, hand dominance. They answered questions relating to contextual factors such as, use of medications, substance consumption, use of aids and health services. Lastly, concerning activity and participation, they reported whether they needed any assistance in performing daily activity and gave an evaluation of the level of their performance of activity in the past month. The ICF checklist served to identify health-related issues and develop ICF core sets among populations with various health-conditions (e.g., Ustun, Chatterji, & Konstansjek, 2004; Cieza, Ewert, Ustun, chatterji, Konstansjek, & Stucki, 2004). It has been suggested that within a given disorder, both brief and comprehensive core sets can be established to serve specific purposes (Vieta et al., 2007).

A. Health Conditions

A1. *The Adult ADHD Rating Scale (ASRS-V1.1)* (Kessler et al., 2005) - an 18-item self-report questionnaire translated to Hebrew, available at the official web site of the authors. The purpose of which is to examine attention abilities of the subject. Participants indicate how often, over the past 6 months, they felt as described in each item on a 5-point scale. The first six items constitute a screener scale and are considered a standardized and well-validated tool for assessment of current ADHD symptoms in individuals aged 18 years and older (Kessler et al., 2005; 2006; 2007). These items have medium sensitivity (68.7%), high specificity (99.5%) and high classification ability (97.9%) (Kessler et al., 2005). According to the scoring instructions, each participant was classified in this study as having or not having ADHD symptoms, based on his marks in the first six items.

A2. *The Adult Developmental Coordination Disorders / Dyspraxia Checklist (ADC)* (Kirby et al., 2010) - a 40-item Hebrew self-report questionnaire aimed at examining the motor coordination abilities of the subject. The questionnaire includes three subscales which evaluate: (A) Difficulties that the individual experienced as a child (10 items); and (B and C) Current difficulties that the individual considers as affecting his performance (10 and 20 items, respectively). Each item received 1-4 points. Higher scores indicate a higher risk for DCD. Levels of internal reliability for the whole scale ($\alpha = 0.953$) as well as for the three subscales ($0.873 < \alpha < 0.914$) have been established (Kirby et al., 2010). These researchers accomplished construct validity based upon differences between adults with DCD and a control group, and a significant moderate concurrent validity was established. The present study calculated a mean and a standard deviation of 59.55 (11.40) for controls

(N=110), based on 55 controls from the study and 55 from data previously gathered in the CHAP laboratory. A cut-off score of 76.65 (mean score + 1.5 SD) was then calculated to discriminate between adults with and without DCD symptoms.

B. Body Functions

B1. *The Sensory Profile – Adolescents/Adult Version (AASP)* (Brown & Dunn, 2002) - a 60-item self-report questionnaire aimed at examining sensory modulation and processing of the subject. A validated translation into Hebrew was implemented in the current study. In this questionnaire, using a five-point Likert scale, participants indicate how often they respond to a sensory event in the manner described in each item. For scoring, the 60 items are sorted into four subscales reflecting different sensory processing patterns based on factor analysis: low registration, sensation seeking, sensory sensitivity and sensory avoiding (Engel-Yeger & Dunn, 2011). Each subscale includes 15 items, while higher scores indicate decreased sensory functions. The questionnaire is standardized, was reported to have good psychometric properties (Engel-Yeger & Dunn, 2011) and has norms for the general population aged 18-64 (Brown & Dunn, 2002).

B2. *The Behavioral Rating Inventory of Executive Functions – Adolescents/adults Version (BRIEF-A)* (Roth et al., 2005) - a 75-item self-report questionnaire designed to examine behavioral manifestations of the EF (higher-level cognitive functions). A validated translation to Hebrew was implemented in the current study. Initial results supported the internal consistency, structure validity and discriminant validity of the Hebrew version among adults with ADHD (Rotenberg-Shpigelman, Rapaport, Stern, & Hartman-Maeir, 2008). Each item is scored from 1-3 points. Nine subscale scores are calculated, and serve to calculate two index scores: 1) a behavioral regulation index (BRI), including inhibition, set-shifting, emotional control and self-monitoring subscales scores, and 2) a meta-cognition index (MI) including task initiation, working memory, planning/organization, task monitoring and organization of materials subscales scores. The subscales and indexes are standardized to produce T-scores according to age and gender norms. Finally, a global score named Global Executive Composite (GEC) is calculated by adding the two index scores (Roth et al., 2005). Higher scores indicate greater difficulties, with T scores ≥65 considered clinically significant (Grane, Endestad, Pinto, & Solbakk, 2014). The *BRIEF-A* is known for its ecological validity (Vriezen, & Pigott, 2002) and verisimilitude between test items and daily, real-life pressures (Koven, & Thomas, 2010; Taylor, 2004).

B3. *The Mini Sleep Questionnaire (MSQ)* (Zomer et al., 1985) - a short, 10-item self-report questionnaire developed in Hebrew is aimed at examining the subject's sleep quality and risk for insomnia. Participants indicated how often they face different sleep difficulties on a seven-point scale. Two scores were calculated: a mean of the 10 items for a final score of sleep quality, and an insomnia score, calculated by adding items 1, 2 and 7. Higher scores indicate decreased sleep quality. The authorized Hebrew version distinguishes between adults with and without post-traumatic-stress-disorder (Koren, Arnon, Lavie, & Klein, 2002), and is sensitive to change in quality of sleep following medical intervention among women who suffered from headaches (Hering-Hanit, Yavetz, & Dagan, 2000).

C. Activity and Participation

C1. *Time Organization and Participation (TOPS)* (Rosenblum, 2012)– a 35-item self-report questionnaire in Hebrew aimed at examining organization in time while performing daily tasks. The questionnaire includes 5-point scales in three parts that evaluate the individual's abilities: -to perform each daily activity at an appropriate *pace*, as expected by the environment (*TOPS-A*);*–performance* of organization in time over the course of the day or within a certain period of time (*TOPS-B*); *and* emotional responses following unsuccessful organization of time (*TOPS-C*). Two additional items in part D relate to the influence of change in routines and various stimuli on the individual's organization in time abilities and are used for clinical purposes (Rosenblum, 2012). Thus, these items were not examined. Lower scores indicate higher risk for difficulties (more limitations) in organization in time and participation in daily tasks. High internal consistency was reported for the *TOPS'* general score ($\alpha = 0.92$), and for factors A, B and C ($0.87 < \alpha < 0.92$). Construct validity was reported by differences in age groups (Rosenblum, 2012).

C2. *The Daily Activities Participation Scale – for Adults (DAPS-A)* (Sharfi & Rosenblum, in process). The *DAPS-A* was developed for the needs of the current study based on the Activity Card Sort (ACS) (Baum & Edwards, 2001). The ACS is a valid and reliable assessment (Baum, 1995; Packer, Boshoff, & DeJonge, 2008; Katz, Karpin, Lak, Furman, & Hartman-Maeir, 2003) aimed at evaluating the involvement of the individual in leisure activities and general functioning, while relating to his personal preferences (Baum & Edwards, 2001). However, an adaptation was required for adults with LD because the ACS was designed for elderly people. Following a procedure of content validation conducted in cooperation with Professor Baum, developer of the ACS, 50

items were included in the *DAPS-A*, aimed at examining subjects' ability to manage their own activity level (WHO, 2001). The activities were divided into four domains based on the ACS division: (a) "IADL/maintenance activities" (items 1-16), for example, washing dishes, house cleaning, shopping for groceries; (b) "social activities" (items 17-27), for example, meeting a good friend, phone/computer chat, participating in family events; (c) "demanding leisure activities" (items 28-36), for example, ball games, swimming/diving, dancing; and (d) "low energy/quiet activities" (items 37-50), for example, reading, computer games, drawing, and logic games. Subjects were requested to mark the most appropriate options relating to each activity that they perform or want to perform. Scoring was as follows: first, scores reflecting the level of activity of the subject, based on the number of activities performed: (a) general activity level, and (b) activity level in each of the four above-mentioned domains. Second, scores reflecting the level of the subject's *independence* in performance of activities. Percentages were calculated based on the number of activities performed without any reminders or help, out of the total number of activities performed by the subject in each of these domains. A good internal reliability for all 50 items ($\alpha = .81$) and acceptable moderate internal reliability for the four domains ($.66 \leq \alpha \leq .83$) were reported (Grinblat & Rosenblum, 2012). In the present study, a Cronbach α measure revealed good internal reliability for all 50 items ($\alpha = .85$). The mean score for all 50 items was 127.77±19.29. A moderate internal reliability was obtained for the IADL/maintenance activities domain ($\alpha = .59$) and an acceptable moderate internal reliability for the other three domains: social activities ($\alpha = .75$), demanding leisure activities ($\alpha = .81$), and low energy/quiet activities ($\alpha = .76$). The validation of the *DAPS-A* is still in its first stages. Therefore, the present study used the scores of the IADL/maintenance activities domain, which related to day-to-day procedures or duties, for examining the participation and independence of adults with LD in managing their own activity level and compared them with controls.

C3. *The Adult Finance Management Questionnaire (AFMQ)* (Sharfi, Rosenblum, & Barkley, in process) - a short 10-item self-report questionnaire developed to meet the needs of the current study, based on the *Structured Interview of Impairment,* which consists of specific questions about money management (Barkley et al., 2008). An expert consultation was conducted with Dr. Barkley who approved the content of the items of this questionnaire, aimed at examining economic self-sufficiency of the subjects as reflected in their daily finance management performance (WHO, 2001). The participants indicated the level of appropriateness of each item regarding their performance on a 5-

point scale. A final score was calculated by computing the scores of the 10 items with higher scores indicating increased economic self-sufficiency. Mean scores were then calculated and acceptable Cronbach α values were obtained: For the entire group (N=97) 42.36 (SD=5.85) and a Cronbach α value of 0.784; For the LD group (n=43) 40.49 (SD=6.94) and a Cronbach α value of 0.787; for controls (n=54) 43.85 (SD=4.31) and a Cronbach α value of 0.743.

D. Quality of Life

D1. *The World Health Organization Quality Of Life Questionnaire (WHOQOL-BREF)* (WHO, 2004) - a formal Hebrew version of a 26-item self-report questionnaire to evaluate the subject's self-perception regarding his QoL. Participants indicated their levels of satisfaction or agreement with the items on a 5-point scale, referring to their lives during the fortnight preceding the completion of the questionnaire. Scores for four domains are calculated as follows: (a) Physical QoL - seven items relating to daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity; (b) Psychological QoL - six items relating to body image and appearance, negative feelings, positive feelings, self-esteem, spirituality/ religion/personal beliefs, thinking, learning, memory and concentration; (c) Social QoL - three items relating to personal relationships, social support and sexual activity; and (d) Environmental QoL - eight items relating to financial resources, freedom, physical safety and security, health and social care, home environment, opportunities for acquiring new information and skills, participation in leisure activities, physical environment and transport. Higher scores indicate increased QoL perceptions. As far as it is known, cut off scores for the general adult population, have not yet been established. However, psychometric measures of this questionnaire are based on data from 23 different countries (N=11,830), and include good to excellent internal reliability, inter-items correlations, discriminant validity and construct validity (based on factor analysis) (Skevington, Lotfy, & O'Connell, 2004). Good internal reliability was reported for the Hebrew version as well (Goldman, 2010).

2.3. Procedure

After receiving approval from the Ethics Committee for Human Subject Research in the Faculty of Social Welfare and Health Sciences at Haifa University Israel, this study was conducted in several stages.

Preliminary qualitative interviews

The researcher interviewed eight adults with LD aged 25-40, with various personal, occupational, educational, and socio-economic statuses. The interview related to their LD experiences, daily activity and participation in various life domains, hobbies, social roles, routines, social and physical environments, cognitive and communication abilities, QoL, and life satisfaction. Data was recorded and transcribed after each interview. Repeated issues were compared with previous qualitative data that was gathered by the CHAP Laboratory (Rosenblum & Weintraub, 2007). A short description of the main repeated issues can be found in the Results section p. 34. In addition, examples for this qualitative data can be found in Sharfi and Rosenblum (2014b) (Appendix 1).

A systematic review of the literature on the daily activity and participation of adults with LD

This procedure was conducted to establish the existing body of knowledge concerning the activity and participation of adults with LD and to validate the repeated issues that were to be examined in this study. See the full systematic review in Sharfi and Rosenblum (2014a) (Appendix 2).

Planning the study and preparation of the evaluation set according to the qualitative data and the review of the literature

Each construct was measured using the most appropriate instrument that was available at the time. Instruments for the measurement of activity and participation were scarce. Therefore, in order to measure the construct of managing one's own activity level, the *DAPS-A* was developed, and the *AFMQ* was built for measuring the construct of economic self-sufficiency. A detailed description of the instruments included in this study appears above in the instruments section (p. 24-31).

Data gathering

Data was collected between March 2011 and August 2012. The researcher met each participant individually in a quiet location and he/she signed a written informed consent, completed a *socio-demographic questionnaire*, and proceeded with the set of questionnaires described

above. Adults with LD were offered the option of having the questions read aloud, and were given a free professional consultancy advisory hour for participating in the study.

2.4. Statistical Analysis

In the present study all statistical analyses were conducted using the IBM SPSS statistics program, version 19. Descriptive statistics were calculated to demonstrate socio-demographic characteristics. A Cronbach α measure used for factor analysis was calculated to examine the internal reliability and describe scale statistics of the *DAPS-A*, and the *AFMQ*. Independent t-tests and MANOVA were carried out, to examine differences between-groups for every instrument in each of the calculated subscales scores and grades when the data met assumptions for a parametric test. Non-parametric tests such as Chi-tests, Mann-Whitney and Kolmogorov-Smirnov tests were implemented when the data did not meet the required assumptions for a parametric test. Pearson correlations examined the relationships between the variables in the group with LD, and regression analyses using a stepwise method were then conducted to examine predictive relationships between the variables. In all the following tables p-value is reported as not significant (NS) if p-value > 0.05.