

Israeli Households Caring for Children and Adults with Intellectual and Developmental Disabilities: An Explorative Study

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Abstract—Background: In recent years we are witnessing a welcome trend in which more children/persons with disabilities are living at home with their families and within their communities. This trend is related to various policy innovations as the UN Convention on the Rights of People with Disabilities that reflect a shift from the medical-institutional model to a human rights approach. We also witness the emergence of family centered approaches that perceive the family and not just the individual with the disability as a worthy target of policy planning, implementation and evaluation efforts. The current investigation aims to explore economic, psychological and social factors among households of families of children or adults with intellectual disabilities in Israel and to present policy recommendation. Methods: A national sample of 301 households was recruited through the education and employment settings of persons with intellectual disability. The main caregiver of the person with the disability (a parent) was interviewed. Measurements included the income and expense surveys; assets and debts questionnaire; the questionnaire on resources and stress; the social involvement questionnaire and Personal Wellbeing Index. Results: Findings indicate significant gaps in financial circumstances between households of families of children with intellectual disabilities and households of the general Israeli society. Households of children with intellectual disabilities report lower income and higher expenditures and loans than the general society. They experience difficulties in saving and coping with unexpected expenses. Caregivers (the parents) experience high stress, low social participation, low financial support from family, friend and non-governmental organizations and decreased well-being. They are highly dependent on social security allowances which constituted 40% of the household's income. Conclusions: Households' dependency on social security allowances may seem contradictory to the encouragement of persons with intellectual disabilities to favor independent living in light of the human rights approach to disability. New policy should aim at reducing caregivers' stress and enhance their social participation and support, with special emphasis on families of lower socio-economic status. Finally, there is a need to continue monitoring the economic and psycho-social needs of households of families of children with intellectual disabilities and other developmental disabilities.

Keywords—Disability policy, family policy, intellectual and developmental disabilities, Israel, households study, parents of children with disabilities.

I. INTRODUCTION

IN recent years we are witnessing a welcome trend in innovations regarding disability policies: From protection to inclusion. This involves a change in orientation from

institutionalization to community living as expressed in article 19 of the Convention on the Rights of Persons with Disabilities (CRPD). Article 19 in the CRPD defines the right of persons with disabilities for independent living in the community [1].

As a result of deinstitutionalization policy, international treaties and domestic legislations on disability rights, as well as improvements in assistive technology, more and more children with disabilities and chronic conditions are living at home with their families and within their communities. In other words, nowadays more households than ever before include children with disabilities [2].

Having a child diagnosed with a disability may have profound effects on the course of a family's life in general and on parents in particular [3]. The adverse effect on family members is usually connected to the high resources invested in caring for the disabled child, e.g., time, money, and energy. Interestingly, family functioning, in turn, can affect health status, disability aspects and the well-being of the disabled child [2].

Extensive research addressed the vast impact of raising a child with disability on family life in various domains such as employment and personal development, financial, psychological and social aspects. Cummins [4], who reviewed the quality of life of people caring for a relative with a severe disability, concluded that families, especially mothers, are paying a very high price for providing care, which usually results in a subjective quality of life that is well below normal.

Research has shown that parents of children with serious health problems and disabilities demonstrate lower rates of work-force participation [3], [5], [6] that limits their ability to provide for their families. The financial costs of raising a child with a disability are significant; excluding the cost of food, parents spent on average twice as much as parents spent on non-disabled children, with increased financial costs for day-to-day items. Furthermore, despite this increased spending, parents felt that they were able to provide their disabled children with less than half of the goods and services essential for them to achieve a reasonable quality of life [7]. It has been documented that families of children with disabilities, who tend to have significantly lower incomes and greater dependency, are affected by poverty more severely than either poor families without childhood disability or affluent families of children with a disability [8], [9].

Having a child with a disability poses diverse and complex demands, which may result in higher level of parental stress

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[10]-[12]. It seems that the stress of mothers of children with disabilities do not necessarily derive solely from their caregiving tasks; it may also be connected to barriers for personal growth [6].

Social support has been found to be a significant predictor of parental stress [12]. However, families of children with disabilities have disadvantages in many aspects of their social life. For instance, parents of children with disabilities report fewer social contacts with friends. The lower levels of social participation can be explained by the child's functional limitations which place restrictions on the family's social engagement [3].

II. THE ISRAELI SCENE

There is scarce research on households of families caring for children with intellectual disabilities in Israel. According to the 2016 Israel social services review, most persons with intellectual disabilities (68%) live at home within their families. However, most of the government's budget for residents with disabilities (78%) is spent on out-of-home placement options and only a small portion (22%) on community-based services [13].

Families of children with developmental disabilities (under 18) are entitled to a caregiver's allowance to assist them with the extra cost for caring for their children and to compensate for their loss of income. These benefits are paid by the Israeli National Insurance Institute based on child's level of dependency. Adults with Intellectual Disabilities (defined as those above 18 years and four months) are entitled to a 'general disability allowance' for those that demonstrate an incapability to earn minimum wage [14].

It is important to note that the caregiver's allowance is not means tested benefit; caregivers do not need to demonstrate that their income and capital are below specified limits in order to receive it. However, the 'general disability allowance' paid to adults with disabilities is means tested and linked to the person's inability to work. It is not clear how households with a child or adult with intellectual disabilities use both allowances, particularly poor families. There is a concern that poor families may use these allowances for food and consumption of the households' basic needs.

III. RATIONALE AND AIMS OF THE STUDY

Many of the consequences of having a disabled child are not inevitable and can be counteracted by adequate policy measures that provide better services and more support to families with disabled children [15]. However, although families have an important role in our society, policymakers tend to design policies and programs aimed at the individual rather than with families in mind [16]. This is also the case when it comes to policies concerning persons with disabilities: most of the policies directed toward children or adults with disabilities target their medical and social welfare needs. The family of the disabled individual is perceived as secondary in policy decisions and in the allocation of resources [17].

Although extensive theoretical literature around family-

centered approaches does exist, the evidence base is more limited, and further research focused on the processes and outcomes of families is needed [18], [19]. Monitoring and evaluation are necessary to achieve evidence-based policy suggestions, evidence-based management, and evidence-based accountability [20].

Household studies are a useful tool to assess family resources and needs. A good example for this is the Family and Individual Needs for Disability Supports (FINDS) survey that was launched to assess the state of the caregivers of individuals with intellectual and developmental disabilities in the United States [21]. Without getting into detailed findings, Anderson et al. [21] concluded that caregivers of individuals with intellectual and developmental disabilities needing support identify numerous unmet needs for the individual they care for as well as for themselves. The FINDS survey reflects the ever-increasing reliance on families to be the primary support system to individuals with intellectual and developmental disabilities.

To promote better services for families, the disabilities administration at Israel's Ministry of Social Affairs and Social Services initiated the Israeli households' study of families who support persons with intellectual disabilities. The study that was conducted by Rimmerman, Gur and Grinstein-Weiss [22] aims to examine economic, psychological and social factors among households of families of children or adults with intellectual disabilities in Israel.

IV. METHOD

Sample

Our sample included 301 households of families of children or adults with an intellectual disability. Participants are parents who are the main caregivers of the person with the disability. Potential interviewees were identified through employment centers (for adults with intellectual disabilities) or child-care centers (for children). Employment and child-care centers were randomly and geographically proportionally selected from a list of all Israeli employment and child-care centers for persons with intellectual disabilities. The list was provided by the disabilities administration at the Israel's Ministry of Social Affairs and Social Services. Table I presents the sample characteristics.

The vast majority of the interviewees were women. The mean age was 52 years old. 82% of the participants are Jews and 18% are Arabs.

The families in the sample have a mean of 3.67 children ($SD = 1.99$); over 40% have four or more children. One-third of the caregivers have vocational or academic education, while two-thirds have high school education or less. Almost half of the caregivers are employed, but a large proportion (47.5%) is excluded from the work force, meaning that they do not currently have, and are not looking for, a job. Among those who are not working, one-fifth are retired, while almost half (44.1%) pointed to their roles as primary caregivers as their main reason for not working. 41.2% of the caregivers reported that they spend more than 15 hours caring for their son or

daughter with the disability in a typical day. 20% of the caregivers reported 6-10 hours of care.

TABLE I
 SAMPLE CHARACTERISTICS

Variable	Parents of a child or adult with intellectual disability (N= 301)	
Gender	Men	41 (13.6%)
	Women	256 (85%)
Age (years)	<i>M</i>	52.63
	<i>SD</i>	12.38
Health status	Very good	107 (35.5%)
	Good	116 (38.5%)
	Not so good	51 (16.9%)
Marital status	Not good	27 (9%)
	Married	226 (75.1%)
	Single	14 (4.7%)
	Separated	1 (0.3%)
	Divorced	23 (7.6%)
	Widowed	26 (8.6%)
Number of children	In a relationship	6 (2%)
	1	23 (7.9%)
	2	68 (23.4%)
	3	76 (26.2%)
	4+	123 (42.4%)
Education	Less than 12 years of study	74 (25%)
	12 years of study	122 (41.2%)
	Vocational/academic education	100 (33.8%)
Employment	Employed	143 (47.5%)
	Unemployed	15 (5%)
	Not in labor force	132 (43.9%)

Half of the children and adults with ID are men (50.3%). 35.6% are under the age of 21. The mean age was 24.5 years old ($SD= 12.72$). One-fifth has mild ID, half has moderate ID, 15.3% has severe ID and 10.6% has profound ID.

Measurements

The research questionnaire included the following measurements: (1) Personal data questionnaire about the main caregivers; (2) Personal data questionnaire about the person with intellectual disability; (3) Income and expenditures survey [23], [24]; (4) Assets and liabilities index [25]; (5) Financial and other types of assistance from friends and family [26]; (6) Questionnaire of Resources and Stress [27]; (7) Social participation [28]; (8) Personal Wellbeing Index [PWI] [29].

Personal data questionnaire of the main caregivers: This questionnaire includes personal characteristics such as gender, age, religion, religiosity, marital status, number of children, health status, employment, education and housing factors.

Personal data questionnaire of the person with intellectual disability: This questionnaire includes personal details such as gender, age, level of intellectual disability according to the formal diagnosis of the Israeli disabilities administration at the ministry of social affairs and social services, additional diagnosis, and employment.

Income and expenditures survey [23], [24]: This questionnaire consists of two parts: household's income and expenditures. Household's income refers to the monthly

household's net income from different sources: paid work, assets, pension and provident fund, allowances and financial support from other households.

Household's expenditures questionnaire consists of 11 items which examine the monthly household's expenditure on food, housing, housing maintenance, furniture and equipment, clothing and footwear, health care, education, entertainment and cultural expenditures, transport and other different products and services.

Assets and liabilities index [25]: Assets and liabilities index collects household-level data on households' finances and consumption. The main aim of the survey is to gather micro-level structural information on European area households' assets and liabilities. The index consists of two parts: assets and debts. In the first part, participants were asked if they own the following assets: house or mobile home, business or farm, and other real estate or land (rental property, investment property, second residence) and asked to evaluate its value. In the second part, participants were asked whether they have different types of debts: mortgage, personal loans from a bank or credit union Credit or charge cards and asked to assess the amount of each debt.

Financial and other types of assistance from friends and family [26]: This questionnaire includes 12 items representing financial and other instrumental supports from friends and family (e.g., paying towards bills? buying or bringing you food or meals? helping with home repairs or decoration whether by paying for it or doing it for you?). Participants were asked to report whether they received each kind of support over the last 12 months.

Questionnaire of Resources and Stress [27] measures stress in families who are caring for ill or disabled relatives. The original measurement consists of 52 items examining four distinct factors: parent and family problems, pessimism, child characteristics, and physical incapacitation. The Hebrew version showed excellent internal consistency ($\alpha= .93$) [22]. In the current study, a shorter version of 20 items was used, with internal consistency of .85.

The Kessler and National Organization on Disability survey [28], that measures social participation, was designed to gather data about longitudinal trends on a variety of issues faced by people with disabilities, and to examine the gaps between Americans with disabilities and the general population. In the current study, we used a shorted version assessing five social scenarios: visits with close friends, relatives or neighbors; attendance at a place of worship, participation in social events, engagement in civil or voluntary activities and visits to public places in the community. Frequency of each social participation domain was rated on seven-point Likert scales that range from 'never' to 'more than twice a week.'

The PWI [29] consists of seven items assessing satisfaction, each one corresponding to an area of quality of life: standard of living, health, achievement in life, relationships, safety, community connectedness, and future security. Scores in these areas are used to determine the answer to the first question: 'How satisfied are you with your life as a whole?' and provide insights into the various factors that shape subjective well-

being. Answers are reported on an 11-point Likert-type scale with anchor points of 'completely satisfied' (10), 'neutral' (5), and 'completely dissatisfied' (0). Raw scores were converted into a standard 0–100 scale. In the current study, the scale yielded internal consistency of .85.

Procedure

The study was approved by the institutional review board of the University of Haifa in Israel. A pilot study was conducted on 28 households to validate the research questionnaire. Subsequently, a total of 301 households agreed to participate in the study following an initial request from a representative from the employment or child-care center of the person with the intellectual disabilities. Most interviews took place at the participant's residence. Only a few were conducted in a different place at the participant's special request (e.g. a café). Each interview took approximately one hour to complete.

Statistical Analysis

Descriptive statistics are presented with respect to financial, psychological and social measurements. Descriptive comparisons are presented between the results and existing data sources about the general society in Israel.

V. RESULTS

Financial Aspects

The majority of the participants (79%) reported that they own their house; a higher rate than in the general society in Israel (67%) [30]. The mean net monthly income of households of a child or adult with intellectual disability was 13558 NIS ($SD= 9157$) as compared to 15427 NIS in the general society in Israel [23]. Net income per capita was 4260 NIS ($SD= 3075$) as compared to 4707 NIS in the general society in Israel [23]. Table II presents households' income

from different sources as compared to the general society in Israel.

Table II indicates that parents of children and adults with intellectual disabilities demonstrated approximately half of the income from paid work as compared to the general society in Israel. Income from other sources, such as assets and pension, are also lower in comparison to the general society. Net income from allowances is higher among participants than the general society. 40.4% of the net household's income is based on allowances.

TABLE II
 HOUSEHOLDS' INCOME (NET): A COMPARISON BETWEEN HOUSEHOLDS OF A CHILD OR ADULT WITH INTELLECTUAL DISABILITY AND THE GENERAL SOCIETY IN ISRAEL (IN NIS) [23]

Source of income	households of a child or adult with intellectual disability (N=301)		General society in Israel
	M	SD	M
Paid work	6283	6784	14470
Assets	253	1405	882
Pension	794	2374	1281
Allowances	5468	4793	1559
Financial assistance from other sources	484	1697	479

Mean household total expenditure was 12691 NIS ($SD = 8990$); slightly higher than the mean total expenditure in the general society in Israel ($M = 12323$) [24]. Expenditure per capita in our sample ($M = 3896$, $SD = 2653$) was also slightly higher than the mean total expenditure in the general society in Israel ($M = 3760$) [24].

29% of the participants reported having mortgage loans; a similar rate as in the general society in Israel [31]. 41% reported having other kinds of loans, as compared to 33% of the general households in Israel [31].

TABLE III
 THE QUESTIONNAIRE ON RESOURCES AND STRESS: PERCENTAGE OF PARTICIPANTS BY ITEM

Items of the questionnaire on resources and stress	%
A member of my family has had to give up education (or a job) because of _____	82
Our family agrees on important matters	91
The constant demands for care for _____ limit growth and development of someone else in our family	76
I have given up things I have really wanted to do in order to care for _____	84
_____ is able to fit into the family social group	55
In the future our family's social life will suffer because of increased responsibilities and financial pressure	64
I can go visit with friends whenever I want	28
Taking _____ on a vacation spoils pleasure for the whole family	55
The family does as many things together now as we ever did	57
I get upset with the way my life is going	37
There are many places where we can enjoy ourselves as a family when _____ comes along	48
It is easy for me to relax	47
I get almost too tired to enjoy myself	52
There is a lot of anger and resentment in our family	24
The constant demands to care for _____ limit my growth and development	65
I feel sad when I think of _____	66
Caring for _____ puts a strain on me	58
Members of our family get to do the same kinds of things other families do	47
I rarely feel blue	57
I am worried much of the time	59

The monthly savings of the sampled households was 2177 NIS ($SD = 2009$). 37% of the participants stated that they are able to save money each month, while 43% reported that they are not able to save. One-fifth of the participants said that their debt increases every month. 52% of the participants stated that they can easily handle an unexpected expenditure of 5000 NIS. One-fifth was not sure whether they would be able to handle it. 10% said that they would not be able to come up with this amount. Furthermore, 62% of the participants stated they do not receive financial and instrumental support from family, friend and non-governmental organizations.

Psychosocial Aspects

Stress

Table III presents items analysis of the questionnaire on resources and stress [27].

Table III shows that participants' stress is especially apparent with respect to sacrifices that they have had to make in their own life in order to care for a child or adult with disability and in negative feelings that they have experienced. As specified in Table III, the majority of the participants (82%) reported that one of the family members had to give up education or a job and that they (84%) had to give up things they had really wanted to do in order to care for the child or adult with the disability. Two-thirds of the participants stated that the constant demands to care for the person with disability limit their own growth and development. Furthermore, many participants reported experiencing negative feelings such as sadness and worry. 58% said that caring for the disabled person puts a strain on them.

Wellbeing

Fig. 1 presents mean scores of subjective wellbeing in different life domains.

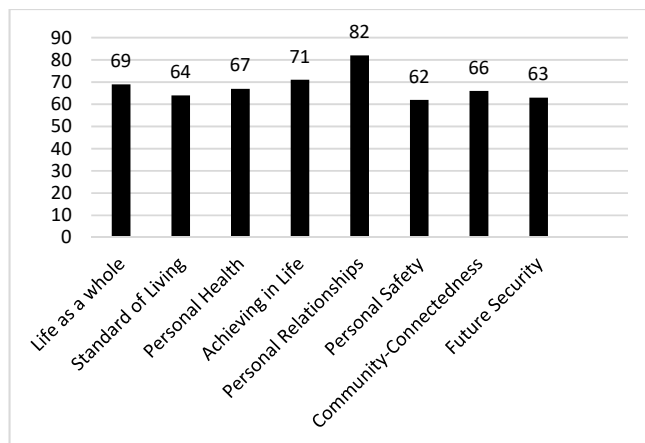


Fig. 1 Mean score of PWI by life domains

According to Cummins and Lau [29], the normative range in the western society is 70-80. Fig. 1 shows that participants' wellbeing is lower than the norm in most life domains, except for in personal relationships. Participants reported low subjective wellbeing with respect to standard of living, personal safety and future security.

Social Participation

Participants were asked how many hours they spent outside their house on the previous day. Findings show that 30% of the participants stated that they did not leave their houses at all, as compared to 8.7% in the general society in Israel [32]. Participants spent on average 5.34 hours outside their houses on the previous day ($SD=3.9$). Table IV presents frequencies of different kinds of social participation.

TABLE IV
SOCIAL PARTICIPATION FREQUENCIES

	Never	Less than once a month	1-3 times a month	more than once a week
Visit close friends, relatives or neighbors	12.2	18.9	36.8	32.1
Go to a place of worship	67.1	11.9	2.0	19.0
Go to social events and cultural institutions	40.8	30.6	24.1	4.4
Participate in voluntary or civil activities	65.4	10.8	10.8	12.9
Go to public spaces in my community	21.7	12.2	20.3	45.8

Table IV indicates that three-quarters of the participants attended social events, visited, cultural institutions and partake in social participation within their communities less than once a month. One-third of them visited public spaces in their community less than once a month.

VI. DISCUSSION

Families are considered the primary caregivers and critical source of support for their children with disabilities. Parents of children with disabilities are considered the main providers for their offspring with intellectual disabilities but receive a disproportionately small share of the public spending allocated for developmental disabilities services [33], [34]. They may experience significant personal and marital challenges,

financial burdens and curtailed employment opportunities [35].

The financial, psychological and social circumstances of these families need to be of interest to researchers, practitioners and policymakers in the field of disability services. It is crucial to understand how children with disabilities and their families change over time, and why some demonstrate better outcomes than others. This kind of information is necessary to the formulation of intervention strategies to promote more positive outcomes among these families [36].

This explorative study aimed to explore economic, psychological and social factors among households of families of children or adults with intellectual disabilities in Israel.

Findings showed that households demonstrated lower net income and income per capita as compared to the general society in Israel. Furthermore, participants earn approximately half of the income from paid work than the general society in Israel and their income from assets and pension are also lower than the general society. Total household's expenditures and the rate of loans are higher than the general society. 40.4% of the net household's income comes from allowances. A higher proportion of the participants reported not receiving financial and instrumental support from family, friends and non-governmental organizations. These findings confirm previous research that indicated that families of children with disability often experience financial hardship [7]; families supporting a child with intellectual disability were significantly economically disadvantaged when compared with families supporting a child who did not have intellectual disability [37]. The low income from work that was found reflects that parents of disabled children demonstrate lower rates of labor-force participation. Many parents of children with developmental disabilities worked only few hours, while many were fulltime homemakers [3], [5]. Shearn and Todd [6] added that working mothers of disabled children were more likely to work in part-time jobs, and in low wage and low status positions. In addition, their positions did not reflect their aspirations, skills, and abilities.

Our findings indicate that participants' stress is especially apparent with respect to sacrifices that they had to make in their own life in order to care for a child or adult with disability and in negative feelings that they experience. Shearn and Todd [6] also suggested that the stress that mothers of children with disabilities experience do not derive solely from their care-giving tasks, but also from barriers to personal growth in other important life domains, such as employment.

In consistent with previous study, our findings indicated low social participation and decreased well-being among parents of children with ID. Seltzer et al. [3] claimed that families of children with disabilities show disadvantages in many aspects of their social life and extensive research confirmed a decreased quality of life [4], [9], [38].

Many of the consequences of having a disabled child are not inevitable and can be counteracted by adequate policy measures that provide better services and more support to families with disabled children [15].

Although the CRPD focuses on individual rights of people with disability, it touches upon the social rights of the family as well. The preamble of the CRPD reflects this approach: "...persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute toward the full and equal enjoyment of the rights of persons with disabilities" [1]. In addition, the need to provide adequate standards of living and social protection to persons with disabilities and their families is the focus of Article 28 [1].

It is concluded that governmental services, benefits and allowances play an important role in keeping households of families of children and adults with intellectual disabilities out of poverty. However, the high financial dependency of the

family on disability allowances may stand in the way of the person with the disability achieving independent community living. In cases where the person with the disability is successfully placed in residential setting, his or her allowances can no longer support the family. Further research and policy discussions should address this complex issue.

The decreased social participation, low rate of social support and increased stress may indicate social barriers for social inclusion. Policy making should aim at reducing caregivers' stress and enhance their social participation and support, with special emphasis on families from lower socio-economic status. It is recommended that the Israeli disabilities administration will address this issue by developing an extensive program to increase families' social inclusion and family resilience.

This study's limitations include self-reported data that may contain several potential sources of bias and a long interview that deals with sensitive personal information. The study's sample included only families of a child or adult that has been diagnosed by the State of Israel as having intellectual disabilities. As such, these families are entitled to a wide range of services, allowances and benefits.

Future studies should track the financial and psychosocial needs of families of children and adults with intellectual disability with special emphasis on poor families and families of undiagnosed persons with disabilities. Furthermore, the Israeli disabilities administration should promote a households' study among other population such as families of children and adults with autism.

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