

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 families 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

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