Cambridge Disability Law and Policy

Family Policy and Disability

Arie Rimmerman

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University of Haifa

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PREFACE

In the postscript of my recent book, *Social inclusion of people with disabilities: national and international perspectives*,[1] I highlighted the central role that the family plays in providing socialization, support, stability and opportunities for social inclusion. This is a particular challenge for a family of a child with severe disability, which requires coping with extra demands in order to provide the care needed. There is no doubt that this responsibility takes its toll on personal and marital life, is a financial burden and curtails employment opportunities. In my earlier book, I noted that government policies are primarily aimed toward individuals with disability, with those targeting family protection or support being the exception.

I have been interested in studying families of children with disability throughout my academic career in social work research and social policy. I have written about the intentions of families to seek out-of-home placement in the late 1980s and early 1990s.[2] The overwhelming belief then was that the main reason was personal, and that the inability of families, primarily parents, to cope with ongoing stress induced them to apply for placement. Critical resources include financial and professional assistance for associated medical problems and family social support.[3] I do believe today that one of the main reasons that

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[1] Arie Rimmerman, *Social inclusion of people with disabilities: National and international perspectives*. (Cambridge: Cambridge University Press, 2012).

[2] See Arie Rimmerman, "Alternatives to institutions and family support." In *The human rights of persons with intellectual disabilities: Different but equal.* Edited by Stanley S. Herr, Lawrence O. Gostin and Harold Hongju Koh (Oxford: Oxford University Press, 2003), 415–28.

[3] Gwynnyth Llewellyn et al., "Out-of-home placement of school-age children with disabilities and high support needs," *Journal of Applied Research in Intellectual Disabilities* 18 (2005),

parents apply for out-of-home placement is the lack of family-support policies that would help parents to balance the demands of caring for the child with disability and the needs of other family members, sharing workload and responsibility, and integrating the child into the everyday world.

The introduction of disability rights legislation in the early 1990s, and particularly the social model, shifts the attention of social scientists to the range of inequalities that families with children with disability experience as compared to those without disability.[4] One of the outcomes of my involvement in family policy research was a joint study with Susan L. Parish, Michal Grinstein-Weiss and others, analyzing participants of the 2001 *Survey of Income and Program Participation* (SIPP) to determine the extent of disability-based net worth and income gap among US households.[5] The findings demonstrated that households with a member with disability had substantially reduced net worth and income compared to households without adults with disability, regardless of family structure. This involvement did not end there; I have been asked by Israeli Central Statistical Bureau to lead the first Israeli household study on disability, as well as by Ministry of Welfare and Social Affairs, to survey support needs of families of children with intellectual disability.

Two recent events inspired me while writing this book – the first was a conference held by advocacy organization KESHER to promote new legislation of behalf of Israeli families of children and adults with disability, and the second was a conference on the implementation of the UN Convention of the Rights of Persons with Disabilities (CRPD) in Israel, held at the University of Haifa.[6] The KESHER conference

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1–6. In this particular study, the researchers explored the relationship between family life variables and out-of-home placement tendency for families of school-age children with disabilities and high support needs. Out-of-home placement tendency was associated with three interrelated family life variables: (i) difficulty balancing the demands of caring and the needs of other family members; (ii) sharing workload and responsibility; and (iii) integrating the child into the everyday world.

[4] Monica Dowling and Linda Dolan, "Families with children with disability – inequalities and the social model," *Disability and Society* 16 (2001), 21–35.

[5] Susan L. Parish et al., "Assets and income: Disability-based disparities in the US," *Social Work Research* 34 (2010), 71–82.

[6] KESHER is an advocacy organization that aims to strengthen the status of parents and families with a disabled child, promoting their rights and the utilization of these rights, and developing further services that will benefit and empower them. This NGO provides a range

debated the need to enact new legislation for families, to supplement unmet needs in the current social protection legislation and to modify tax regulations. My lecture, which discussed current European comparative support policies aimed at families of children with disability, was based on this book's Chapter 7, "Comparative family policies of the United States and European countries," while Chapter 8, "The UN Convention of the Rights of Persons with Disabilities (CRPD) and family policies," is based on my presentation at the University of Haifa on the CRPD. The thoughtful discussion afterwards convinced me to add a closing section on the future of family policy and disability in times of economic crisis.

I hope that the book will provide a comprehensive and insightful understanding of governments' response to families of children with disability and, in particular, present the family policies provided in Western countries to respond to their needs and concerns.

Arie Rimmerman
Haifa, Israel

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of services for special families, including a center for information, guidance and advocacy, groups offering support and parental guidance, as well as groups for additional family members (siblings), and demographics. Their conference, held on January 30, 2014, in Kiryat Ono, discussed the need for supplemental legislation for families. The one-day International Conference on Implementation of the UN Convention of the Rights of Persons with Disabilities (CRPD) was held at the University of Haifa on February 4, 2014.

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This book was made possible by the generous and consistent support of my research staff at the Richard Crossman Chair of Social Welfare and Social Planning at the University of Haifa. I am grateful to colleagues and graduate students who share with me my thoughts about the book and have offered their comments and suggestions. I have been fortunate to learn a great deal from my recent contacts with KESHER regarding their efforts to advocate for new family-support legislation.

Special thanks to Susan Parish and Michal Grinstein-Weiss, then at the University of North Carolina at Chapel Hill, for involving me in their secondary analysis of the 2001 Survey of Income and Program Participation (SIPP) to determine the extent of disability-based net worth and income gap among US households.[1] The end result was not only a joint article but a recognition of the importance of assets and income status among families with members with disability. I am thankful to Gerard Quinn for his insightful thoughts about the CRPD, and particularly Articles 12 and 19, which were helpful in the writing of Chapter 8. I would like to thank my colleagues with whom I informally discussed some of the ideas examined in the book. Finally, I am grateful to my family for facilitating this important project, and in particular my wife Shula for her tremendous support.

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[1] Susan L. Parish et al., "Assets and income: Disability-based disparities in the US," *Social Work Research* 34 (2010), 71–82.

CONTENTS

1 INTRODUCTION

Over the past three decades, there have been a number of attempts to encourage a family perspective in policymaking.[1] Despite these endeavors, there has been no sustained effort to analyze policy from such a perspective, and few groups consistently represent family interests. There is no doubt that the social status of people with disabilities has changed since the early nineties, as traditional medical and social welfare approaches have been replaced by social-functional and human rights perspectives. One of the core questions is whether this transition has incorporated responses to concerns raised by families of children and adolescents with disability. Family policy addresses families of children younger than eighteen years or those whose offspring are enrolled in full-time education, not having left the parental household or not being married or in a relationship.[2] Kamerman and Kahn defined it broadly – "everything that government does to and for the family."[3] These policies encompass four explicit functions: family formation, economic support, child-rearing and caregiving.[4] Despite the pivotal

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[1] See, for example, Thomas Bahle, "Family policy patterns in the enlarged EU," Jens Alber, Tony Fahey and Chiara Saraceno (eds.), *Handbook of quality of life in the enlarged European Union* (London: Routledge, 2007), 47–73; Linda Hantrais, *Family policy matters: responding to family change in Europe* (Bristol: Policy, 2004).

[2] Theodora Ooms, "Families and government: implementing a family perspective in public policy," *Social Thought* 16 (1990), 61–78.

[3] Sheila B. Kamerman and Alfred J. Kahn, "Families and the idea of family policy," Sheila B. Kamerman and Alfred J. Kahn (eds.), *Family policy: government and families in fourteen countries* (New York: Columbia University Press, 1978) 3.

[4] David Blankenhorn, "American family dilemmas," David Blankenhorn, Steven Bayme and Jean Bethke Elshtain (eds.), *Rebuilding the nest: A new commitment to the American family* (Milwaukee, WI: Family Service America, 1990) 3–25.

role of families in our society, policymakers tend to make decisions through individual lenses rather than from the perspective of families in which most individuals reside.[5] A similar reality is seen in the disability area, with most of the policies aimed toward children or adults with a specific impairment, responding primarily to their medical and social welfare needs. Although families efficiently perform several important functions within society in ways that no other institution can either do or do as well, governments tend to view them as secondary to their policy decisions and allocation of resources.

This book aims to explore the status and scope of family policies related to households with disabled children and to provide an in-depth review of legal and programmatic aspects of these policies at the national level. In addition, the book presents and discusses conceptual, legal and evidence-based differences in family-centered policies between the United States and European countries, particularly the United Kingdom, France and Sweden. Europe has two different models, France and Sweden with generous policies, and the United Kingdom with a piecemeal approach. Finally, the book continues the discussion regarding the critical role of family-centered policies as expressed in the Convention on the Rights of Persons with Disabilities (CRPD). This important international treaty challenges current domestic policies and requires countries to apply practices and entitlements related to families of disabled children.

Chapter 1 provides the reader with the guidelines and structure of the book. Chapter 2 introduces the conceptual base of family policy and demonstrates and discusses US and European core family policies. If the first part of the chapter intends to provide conceptual base, the second introduces US and selected European family policies and discusses major differences between the two. The chapter also presents the diversity of family policies within Europe, as with France and Sweden, which have probably the most progressive explicit family policies, and the United Kingdom with more conservative and regulated implicit policies in the middle. The chapter ends with reference to family

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[5] Linda L. Hass and Steven K. Wisensale (eds.), *Families and social policy: National and international perspectives* (Binghamton, NY: Haworth, 2006).

disability policy and raises two core questions: does family policy intend to cover all families, including those with children with disability, and is there a need for a specific family disability policy or can it be added as a supplement? These questions will be responded to in the next chapters in discussing US and European family policies toward families of children with disability.

Chapter 3 introduces the needs of families of children with disability and their personal, marital and financial challenges. The focus here is on the financial burden; because childhood disabilities have direct and indirect economic costs on the family and society, the burden is strongly linked to type and severity of disability. Chapter 3 demonstrates ways of measuring direct monetary costs as well as indirect or out-of-pocket costs. The chapter also discusses both the difficulties in estimating reductions in parents' ability to sustain paid employment and the cost of the unavailability of adequate childcare. These estimates vary from one country to another and greatly depend on explicit and implicit policies. Aside from the financial burden on families, the chapter reviews core surveys on families' met and unmet needs. Finally, there is an extensive review of the demonstrated needs of parents of children with autistic spectrum disorder (ASD), medical complexities (CMC) and mental illness and their vulnerability to considering out-of-home placement.

Chapter 4 characterizes US family policy and describes the in-kind benefits with modest and inconsistent cash benefits to some low-income families and the tax benefits to the middle and upper classes. There is an extensive review of these services, primarily Supplemental Security Income (SSI) and Medicaid, as well as the Individuals with Disabilities Education Act (IDEA), formerly called P.L. 94–142 or the Education for All Handicapped Children Act of 1975.

The chapter discusses three themes that reflect family policies in this area. The first introduces the division between families with middle-high to high income regarding provisions for their children with disability. The second theme addresses the Americans with Disability Act (ADA) and the rights of children with disability and their parents' to accessibility and inclusion in society. Finally, the chapter discusses the progressive legislation of IDEA and the right of parents to be informed and participate in the educational decision-making process.

Chapter 5 reviews and discusses family disability policy in three European countries – the United Kingdom, France and Sweden – based on the Esping-Andersen's Comparative Macro-Sociology of Welfare States. The United Kingdom represents the liberal and social democratic approaches of welfare state; French policy is a mixture of liberal and conservative corporatist principles, while Sweden is a typical social democratic welfare state.[6] The chapter discusses the United Kingdom's mixed family policy and its ambitious plans such as its Aiming High for Disabled Children policy, with particular focus on cash benefit policies and special provisions for children with disability and their families.[7] French social insurance policy and comprehensive childcare system is discussed with respect to the gradual transition from universal to tailor-made family policy. The chapter ends with Sweden's comprehensive social insurance coverage for families of young children including means-tested supplements for those with disabled children (maintenance support and housing allowance, and care allowance for disabled children).[8] Sweden still looks like a family policy leader with an impressive array of benefits to children with disability and families, though less so than in the past.

Chapter 6 introduces assessment instruments used to examine family policies provisions and family disability policy in particular. It presents four types of assessment including recipients' profiles, government entitlements and their costs, access and utilization, and impact of certain entitlements or social rights on recipients. Unfortunately, there are few studies on families of children with disability or entitlements and issues of access, utilization and impact. Most of the studies try to establish common and standard disability measures for children's disability and characterize socioeconomic needs of their parents. The

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[6] Esping-Andersen's "typology of welfare state" is presented in Gøsta Esping-Andersen, *Three worlds of welfare capitalism* (Princeton, NJ: Princeton University Press, 1990).

[7] Patricia Sloper, Bryony Beresford and Parvaneh Rabiee, "Every Child Matters outcomes: what do they mean for disabled children and young people?" *Children in Society* 23 (2009), 265–78.

[8] There are two general allowances: *Barnbidrag or* child allowance and *Tillfällig föräldrapenning id vård av barn*, which provides parental benefit, temporary parental benefit, pregnancy benefit, child pension and pension rights for childcare years. In addition, there are three universal pieces of legislation, the Social Services Act (1982), the Health and Medical Services Act (1983) and Sweden's Education Act 1985.

chapter reviews efforts made by the Organisation for Economic Co-operation and Development (OECD), as well as other international bodies, to compare countries and states with respect to selected entitlements or social rights, particularly regarding their cost. The same applies to studies that assess the impact of certain policies on families of children with disability or assess accessibility and utilization issues.

The most common comparison presented is cross-country family policies by entitlements or social rights. It provides insightful information demonstrating differences between the United States and European countries and within those countries. Secondary are accessibility and utilization studies examining implementation of certain entitlements or UK and US provisions. Finally, the chapter discusses the quantitative and qualitative impacts of certain social entitlements on children with disability and their families. Most of these studies used secondary data and tended to track changes in household measures such as household income and employment, rather than children's progress or well-being.

Chapter 7 analyzes US and European policies toward families of children with disability as reflected by comparative analyses of their cash benefits, tax credits and deductions and the in-kind provisions of the United States, the United Kingdom, France and Sweden. The chapter introduces an interesting comparison between two central cash benefits schemes, the US Supplemental Security Income (SSI) and the UK Disability Living Allowance (DLA), which provides insights on the substantial differences between the two countries. Both programs are intended to assist with the extra cost of caring for their children with disability. However, the SSI is means tested and geared toward low-income families, whereas the DLA is non–means tested and is provided based on severity and mobility elements. There are additional comparisons related to tax credits and deduction and in-kind provisions, demonstrating that Sweden and France provide marginal tax credits and deductions, the United Kingdom moderate tax credits or deductions, while the United States provides more tax deduction opportunities than the rest of the countries. Finally, the chapter demonstrates the differences in services infrastructure among these countries and explains the linkage between cash benefits and tax credit and deduction with in-kind provisions.

Chapter 8 presents and discusses the place of the family in the CRPD, examining whether this treaty supports family rights or regards them just as a supplement to members with disability in the family. This debate parallels the discussion about the centrality of family policy in most of the developed countries and those between conservatives and liberals regarding the role of the state in providing rights and services. The first section provides an overview of five explicit articles concerning the family (8, 16, 22, 23, 28) and eleven articles (5, 6, 7, 9, 12, 18, 19, 24, 25, 30, 33) implicitly requiring a mainstreaming of the family dimension in order to ensure effective implementation. The second part is basically an analysis of gaps and conflicts between the CRPD's explicit and implicit articles related to family policy and US, UK and European countries' domestic legislation. Obviously, the most fascinating debate has been around ratification of the Convention in the United States, where conservative advocacy groups raised concerns that US ratification may give governments, and not US parents, the right to make educational and treatment-related decisions for their disabled children. On the other hand, the Obama administration defused these concerns, stating that current US legislation supports parents' rights and that there will not be any major change. At the center of the debate is Article 7(2) concerning the debate about protecting the best interests of the child with disability and the fear of homeschooling advocates that the Convention would undermine their parental right to educate their children.

The chapter also discusses the approach of European countries to the Convention, which is basically favorable, with the European Union (EU) ratifying the CRPD just weeks after the European Commission (EC) published the European Disability Strategy 2010–2020.

In "Closing remarks" (Chapter 9), the author shares with the reader five themes that reflect his insights and a future projection of family policy and disability. The first theme discusses the conceptual basis of family policy, particularly the differentiation between explicit and implicit policies and their relevance to families of children with disability. The second theme identifies the gaps between family needs as demonstrated in surveys of households and contemporary family policies. The third theme provides insights into the differences between the policies of the United States and three European countries toward families of children with disability and within European countries. The fourth theme discusses the CRPD, in particular articles that touch upon family issues and family policies. Finally, the author discusses the future of family policy toward families of children with disability in times of economic crisis.

2 FAMILY POLICY: A CONCEPTUAL BASE

In the past fifty years, the family has undergone significant transformation. In many Western countries, the extended family has almost disappeared, and the traditional two-parent family has become much less widespread. Families have seen more significant changes in the labor market, and as a consequence more mothers are employed. These changes, including in education, longevity and lifestyle, have had remarkable impacts on housing, pensions, health care and childcare. Regardless of these changes, families are central to our existence and play a valuable role in society by promoting socialization, economic productivity, social competence and, indirectly, additional merits.[1] Interestingly, they are considered to be an important political asset by local and national politicians and endorsed by all political parties regardless of their ideological platform.[2]

There are, primarily, different ways of looking at families, most of them relating to structural or functional features. The structural approach views the family according to the composition of its membership as related to blood, marriage or legal bond, such as adoption or sharing a household. Structural definitions of family also focus on the relationships that create social bonds between members. Important bonds are created by communication, power and affection, as well as

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[1] For comprehensive coverage of the role of families in society, see Karen Bogenschneider and Thomas J. Corbett, "Building enduring policies in the 21st century: the past as prologue," Marilyn Coleman and Lawrence H. Ganong (eds.), *Handbook of contemporary families: Considering the past, contemplating the future* (Thousand Oaks, CA: Sage, 2004), 451–68.

[2] Karen Bogenschneider, *Family policy matters: how policymaking affects families and what professionals can do* (New York: Taylor & Francis, 2002), 24.

the daily work and leisure of family members. Families may be structured by such characteristics as gender, age and generation, as well as by their connections to the outside world. These structures are also useful for distinguishing families from other kinds of social groups and organizations. A second way to look at families is on the basis of functional elements, centering on the importance of human reproduction and nurturing dependent children, including those with disabilities, for a relatively long period of time. The functional approach tends to understand the relationship within the family and to identify dysfunctional types.

It is evident that these types of definitions have their own limitations. For example, the structural definition excludes homosexual partners and cohabitating couples who are not related by birth, marriage or adoption but who nevertheless fulfill family-like functions. Therefore, there is no consensus on a single definition or whether both structural and functional definitions are needed.[3] A close look at the US Constitution shows the family is not mentioned or recognized as a legal institution, just the individual.[4]

The most desirable approach is to define families according to the particular issue involved.[5] Aside from the difficulty in defining family, Theodora Ooms claims that "Families are everyone's concern, but nobody's responsibility."[6] According to Patricia Strach, the family plays an important role in American politics, particularly in campaigns and slogans, but is often viewed as part of the private realm.[7] A similar view is commonly held in the United Kingdom and other European countries, where the family is seen as a private entity and separate from public life.

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[3] See Karen Bogenschneider, *Family policy matters: how policymaking affects families and what professionals can do*, 3rd ed. (New York: Routledge, 2014).

[4] Theodora Ooms, *Toward more perfect unions: putting marriage on the public agenda* (Washington, DC: Family Impact Seminar, 1998).

[5] Phyllis Moen and Alvin L. Schorr, "Families and social policy," Marvin B. Sussman and Suzanne K. Steinmetz (eds.), *Handbook of marriage and the family* (New York: Plenum, 1987), 795–813.

[6] See Theodora Ooms, "Families and government: implementing a family perspective in public policy," *Social Thought* 15 (1990), 77.

[7] Patricia Strach, *All in the family: the private roots of American public policy* (Stanford: Stanford University Press, 2007), 1–17.