

# 1 INTRODUCTION

Over the past three decades, there have been a number of attempts to encourage a family perspective in policymaking.<sup>1</sup> 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with disabilities has changed since the early nineties, as traditional medical and social welfare approaches have been replaced by social-functional and human rights perspectives.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.<sup>2</sup> Kamerman and Kahn defined it broadly – “everything that government does to and for the family.”<sup>3</sup> These policies encompass four explicit functions: family formation, economic support, child-rearing and caregiving.<sup>4</sup> Despite the pivotal

<sup>1</sup> 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).

<sup>2</sup> Theodora Ooms, “Families and government: implementing a family perspective in public policy,” *Social Thought* 16 (1990), 61–78.

<sup>3</sup> 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.

<sup>4</sup> 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.<sup>5</sup> 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

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

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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.<sup>6</sup> 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.<sup>7</sup> 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).<sup>8</sup> 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

<sup>6</sup> Esping-Andersen’s “typology of welfare state” is presented in Gösta Esping-Andersen, *Three worlds of welfare capitalism* (Princeton, NJ: Princeton University Press, 1990).

<sup>7</sup> 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.

<sup>8</sup> 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.

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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

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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 child-care. 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.<sup>1</sup> 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.<sup>2</sup>

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

<sup>1</sup> 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.

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



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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.<sup>3</sup> A close look at the US Constitution shows the family is not mentioned or recognized as a legal institution, just the individual.<sup>4</sup>

The most desirable approach is to define families according to the particular issue involved.<sup>5</sup> Aside from the difficulty in defining family, Theodora Ooms claims that “Families are everyone’s concern, but nobody’s responsibility.”<sup>6</sup> 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.<sup>7</sup> 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.

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

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

<sup>5</sup> 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.

<sup>6</sup> See Theodora Ooms, “Families and government: implementing a family perspective in public policy,” *Social Thought* 15 (1990), 77.

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

The twentieth century saw significant changes in the demography of Europe and the United States associated with the need to redefine roles and the structure of families. Among the notable changes were increased longevity, deferred age of marriage, lower fertility, increased divorce and declining existence of extended families. The early twenty-first century is characterized by even greater family diversity; the “traditional” breadwinner/homemaker family no longer constitutes the main family form or the only normative environment in which children are born and raised.<sup>8</sup> Instead, single parenthood, one-person households, unmarried and same-sex cohabitation and remarried families have become more prevalent and are increasingly recognized as suitable living arrangements.

Family-related regulations and provisions existed in civil law and in many social policies long before explicit family policies were formulated. Nevertheless, there is an impression that policies toward families, in particular in Europe, have been changed over time in response to changing concerns about family life.<sup>9</sup> Early family policies focused on the provision of children’s allowances and benefits to increase fertility rates and reduce the costs of child-rearing. The increasing rates of divorce, cohabitation and single parenthood have weakened the traditional bonds of family life, requiring different government responses. The role of the state has expanded in helping to address these issues by offering a wide range of public measures, which are reflected in the growth of social welfare provisions for cash and in-kind benefits, including family allowances, household help, parental leave, lone-parent cash benefits and payments for childcare.

There is disagreement among scholars as to whether family policies are restricted to families and children or also include adults and aging populations. However, it appears that most of those policies aimed toward adults and aging populations are family-support policies. Children may be distinguished from other groups of the population

<sup>8</sup> See Bahira Sherif Trask, *Globalization and families: accelerated systemic social change* (New York: Springer, 2010). The book argues that globalization has had profound implications for understanding social life and in particular gender ideologies, work-family relationships and conceptualizations of children and youth. Therefore, there is a need to make the interplay between globalization and families a primary focus.

<sup>9</sup> See Neil Gilbert, “Motherhood, work, and family policy,” Jill Berrick and Neil Gilbert (eds.), *Raising children: emerging need, modern risks and social responses* (New York: Oxford University Press, 2008), 98–115.