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FAMILY LIFE CYCLES OF FAMILIES WITH A CHILD WITH A DISABILITY

Abstract:

Family life cycles represent developmental stages marked by changes in family structure, roles, and responsibilities. Families with a child with a disability face unique challenges that may prolong, shorten, or entirely exclude certain stages. This paper examines the experiences of these families, from the newborn stage to the elderly family stage.

In the newborn phase, parents experience intense emotions such as shock, sadness, and uncertainty due to the disability diagnosis, facing additional responsibilities like medical visits and early interventions. This often leads to social isolation and strain on the marital relationship. In the preschool phase, children with disabilities exhibit slower development and greater dependency, prolonging parental responsibilities and complicating the transition to school education due to limited inclusivity. In the school phase, families face challenges in selecting an appropriate school, administrative barriers, and the need for individualized education plans, while social barriers further hinder inclusion. In the adolescent phase, the need for autonomy is impeded, causing emotional difficulties. In the launching and empty nest phases, parents remain in an intensive caregiving role, experiencing anxiety about their child's future and a lack of support. Systemic support, including inclusive education and support networks, is crucial for improving the quality of life for these families.

Keywords: *family life cycles, child with a disability, social isolation, parental support*

Introduction

Family life cycles refer to the various stages a typical family goes through as it evolves and experiences different life events and transitions. These stages may be characterized by changes in family structure, roles, and responsibilities. Although each family is unique and may not precisely follow these stages, the family life cycle theory provides a general framework for understanding the typical trajectory of family development (Radulović et al., 2024).

Families with a child with a disability navigate these cycles, but some stages may be prolonged, shortened, or never experienced. As families progress through the cycles, they develop skills and knowledge about their child and their disability. In the initial stages of coping with the disability, family members often react to the disability itself, sometimes overlooking the child's broader needs. During these moments, professionals should assist families in seeing the child as a whole, not just their disability.

A child's disability may cause a family to become stuck in a particular life cycle stage. Families may also experience disrupted expectations for typical life cycle changes, such as when informed that their child may never learn to read, reach puberty, or be capable of forming their own family (Brotherson et al., 1995).

Additionally, as families move through the life cycle continuum, additional stresses may arise as they face increasing challenges in raising and managing the child (Dyson, 1993).

Although family life cycle theory begins with the premarital stage and a childless married couple, given the context of this study, we start with a family with a newborn or child up to 30 months, which is essentially the third family life cycle in standard theory.

Methodology

This study employs a qualitative and descriptive-analytical methodology, grounded in theoretical synthesis and supported by empirical evidence. The analysis is based on an extensive review of international and domestic literature, empirical studies, and statistical data relevant to families of children with disabilities. The family systems theory serves as the primary framework, enabling the exploration of how the presence of a child with a disability affects structural, relational, and functional dynamics across successive stages of the family life cycle.

In addition to theoretical perspectives, the study incorporates secondary data sources, including reports from the State Statistical Office of the Republic of North Macedonia (2024), the Concept for Inclusive Education (2020), and recent empirical findings (e.g., Keskinova & Ajdinski, 2023; Namkung et al., 2018). This combination of theoretical and empirical inputs allows for a systemic and context-sensitive analysis of how disability alters family trajectories,

prolongs or disrupts life cycle stages, and generates unique psychosocial challenges across the life span.

Family Life Cycles

Family With a Child Aged Newborn to 30 Months

In this phase, the presence of a child with a disability further complicates parents' adaptation to new roles. Beyond the usual challenges of caring for a newborn, parents often face intense emotions such as shock, sadness, fear, and uncertainty about the future. The diagnosis or initial suspicions of a disability can trigger a strong emotional response, including a grieving process for the expected but unrealized vision of their child.

Caring for a child with a disability often requires additional time, energy, and resources, leading to greater fatigue and sleep deprivation for parents. Medical appointments, early interventions, and rehabilitation therapies may become part of the daily routine, demanding greater organization and coordination. This can impact work schedules and financial stability, as one parent may need to reduce work hours or fully dedicate themselves to caregiving.

Social isolation is expected for new parents, even with typically developing children (Laszloffy, 2004), but the risk and intensity of isolation are significantly higher in families with a child with a disability. These families often feel misunderstood by their surroundings or struggle to find adequate support. Friends and extended family may lack understanding of the challenges, leading to emotional distancing. In this context, support networks (parent groups for children with disabilities, professional counselors, and specialized services) become critical in reducing stress and strengthening parental capacities.

Finally, the marital relationship faces particular strain in this phase, with marital breakdowns occurring more frequently (Peti, 2006), even among couples without the added challenge of a child's developmental difficulties. The intense focus on the child can reduce mutual connection between partners, increasing the likelihood of conflicts and emotional distance. Effective communication, mutual support, and shared acceptance of the situation are essential for maintaining family stability and emotional well-being.

Family With a Preschool Child With a Disability

While typically developing children in this phase develop independence and autonomy, children with disabilities may progress more slowly or require greater support. Some children may have limited ability to explore their environment or need additional assistance with daily activities, leading to prolonged dependence on parents, which affects parental roles and expectations.

Enrolling in preschool can be complex, as not all preschool institutions and programs are adequately adapted for children with disabilities. Parents often must advocate for inclusive education, adapted conditions, or specialized support, which can cause additional stress. This transition, instead of being a relief, may become a source of anxiety for parents uncertain about their child's acceptance by educators and peers. In the Republic of North Macedonia, according to 2023 data, only 392 children with disabilities attend preschool (State Statistical Office, 2024).

In families with multiple children, sibling rivalry can be more complex. Siblings may show love and protective behavior but may also feel neglected due to the increased attention given to the child with a disability. This requires additional effort from parents to balance support for all children.

Socialization for a child with a disability may be limited, impacting parents as well. Instead of naturally connecting with other parents through playgrounds or school activities, they may face isolation or need to seek specialized support groups, reducing their social contacts and creating feelings of loneliness.

Additionally, work-family balance is a greater challenge. Hiring caregivers or accessing specialized care institutions is complex and sometimes financially inaccessible. Parents may need to make career sacrifices or seek flexible work arrangements to meet their child's needs.

Emotionally, parents may face guilt, exhaustion, and worry about the future. They often need guidance and support to manage stress and maintain their partnership, as daily challenges can lead to distancing between partners.

Family with a School-Aged Child with a Disability

This is a dynamic period of family life, emphasizing education, socialization, and the development of the child's interests and talents. Parents continue to play a key role in their child's life and education, laying the foundation for future academic and social success (McGoldrick et al., 2015).

Starting formal education brings additional challenges for families with a child with a disability. They face administrative, pedagogical, emotional, and social barriers that affect the child's educational experience and overall family dynamics.

Choosing an appropriate school is a major challenge, with parents facing the dilemma of enrolling their child in a regular school with inclusive education, a specialized school with adapted teaching methods, or considering homeschooling. Although inclusion is legally guaranteed in many countries, many schools lack adequate infrastructure, trained staff, or resources to meet these children's needs. Individual Education Plans (IEPs) or modified programs are critical for quality education, enabling tailored teaching processes through specialized methods, adapted materials, flexible learning and testing schedules,

and support from special educatorsand rehabilitators, speech therapists, psychologists, and other professionals. However, the challenge remains that few schools can effectively implement such programs, potentially leading to a lack of quality education.

Social barriers in schools are significant, with children with disabilities often facing a lack of acceptance, discrimination, or bullying, as well as limited participation in activities like sports, excursions, or projects. Overcoming these requires efforts from parents and teachers to raise peer awareness, organize inclusive activities, and create supportive environments. Parents of the child with disability must also be more involved in the educational process, collaborating with teachers and professionals, attending meetings, monitoring progress, and advocating for their child's rights, which can be exhausting without adequate school support.

Additionally, many children with disabilities need services such as speech therapy to improve communication, physical therapy for motor challenges, and occupational therapy to develop independence in daily skills, with the organization and coordination of these services posing an additional burden for parents, who need to align the school schedule with the therapy schedule.

In the Republic of North Macedonia, the Ministry of Education introduced the "Concept for Inclusive Education" in 2020, aiming to enhance inclusive education processes. Key measures include total inclusion for all children with disabilities, teaching assistance (educational and personal assistants), and transforming special schools into resource centers (Concept for Inclusive Education, 2020).

Family With an Adolescent with a Disability

The presence of an adolescent with a disability complicates the already challenging dynamics of this family life cycle stage, as the need for independence and autonomy may be limited by physical, cognitive, or social challenges. While peers progress toward greater independence, adolescents with disabilities may experience a slower pace, leading to frustration and emotional difficulties. Two-thirds of adolescents with disabilities (67.1%) face anxiety, depression, problematic behavior, physical bullyingor peer arguments, as well as difficulties in forming and maintaining friendships, compared to 32% of typically developing adolescents (Characteristics of Adolescents with Disabilities). Peer influence may be reduced due to limited opportunities for full inclusion in social activities, increasing the role of parents in creating alternative support and socialization opportunities.

Siblings may take on protective roles or feel burdened by additional family responsibilities, impacting their adolescent development. Parents face a dual challenge: supporting the adolescent with disability in his academic, social, and emotional maturation while maintaining effective communication, balancing authority with independence, and ensuring emotional stability for the whole

family. This period requires increased flexibility, patience, and availability, as parents adapt to the child's individual needs while managing personal and family resources.

Launching Family with a Person with a Disability

Parents of a person with a disability in the launching family phase face additional challenges, as fostering independence may be significantly more complex or even impossible. Instead of redefining their roles and focusing on personal interests, they often remain in an intensive caregiving role, leading to chronic fatigue and exhaustion. This can cause heightened anxiety about the future, particularly regarding long-term care and stability for their child if they can no longer provide care. While other parents use this phase to deepen their relationships or pursue new interests (Radulović et al., 2024), parents of a person with a disability often feel constrained in personal and professional aspects, leading to further social isolation as peers move on with life changes that remain out of reach. Health challenges in this phase may be exacerbated by the stress of caregiving.

Parents of Persons with Disability in the "Empty Nest" Phase

In the "empty nest" phase, parents of a person with a disability often face a starkly different reality from those whose children become independent. Instead of experiencing relief and newfound freedom, they may remain primary caregivers, unable to step back from intensive responsibilities. This can deepen feelings of fatigue, isolation, and regret for missed opportunities for personal growth. Up to 81% of parents/caregivers report having no time for their personal needs (Still in the Shadows with Their Future Uncertain, 2011).

Emotionally, like other parents in this phase, they may face aging and the loss of their own parents (Wawrzyniak, 2015), but without the ability to take time for grieving or self-care. Their focus remains on the person with a disability, increasing vulnerability to depression and chronic stress.

Elderly Family with a Person with Disability

In the elderly family phase, parents of a person with a disability face increased health problems, financial concerns, and emotional challenges. They must ensure long-term care for their child while coping with their own aging.

Financial planning is more complex, as parents must secure not only their own stability in retirement but also long-term support for their child, particularly if the child cannot be independent. Issues of inheritance, guardianship, and legal protection become critical, with many families seeking solutions like trust funds or appointing guardians.

Family relationships also change. If there are other adult children, questions may arise about taking responsibility for their sibling with a disability, potentially leading to conflicts or strengthened family bonds, depending on the extended family's willingness to assume care.

A 2011 study confirms the challenges parents face in this life cycle (Still in the Shadows with Their Future Uncertain, 2011):

- 61% of parents or caregivers worry that the person with a disability will be placed in an unapproved institution after they can no longer provide care.
- 62% lack a clear plan for where the person with a disability will live when they age.
- 59% report insufficient information to decide who will care for the person with a disability after their death or incapacity.
- 65% feel they do not receive enough assistance in planning for the person's future.

Discussion

Families with a child with a disability experience significant deviations from the typical stages of the family life cycle. In the newborn stage (0-30 months), parents face intense emotions, including shock, sadness, and uncertainty due to the disability diagnosis. These emotions are often accompanied by a grieving process for the "expected" child, which complicates their adjustment to new parental roles. Additional responsibilities, such as medical appointments and early interventions, lead to fatigue and social isolation, as parents often feel misunderstood by their surroundings. Marital relationships may come under strain, with an increased risk of conflict due to the focus on the child's needs. A study conducted in the Republic of North Macedonia in 2023, involving a sample of 220 parents of children with disabilities, revealed that only 35% of children with disabilities begin treatment immediately after receiving a diagnosis. In contrast, for 43.1%, treatment starts more than five months after the initial diagnosis, and for 6.9%, treatment is delayed by two or more years. These findings point to multiple issues: the absence of rehabilitation centers, limited availability of specialized teams dedicated to working with these children, restricted financial support, and lack of family assistance. Additionally, challenges in the initial moment of opening the diagnosis may trigger undesirable emotional responses in parents, leading to a focus solely on the child's disability and neglect of their broader needs (Keskinova & Ajdinski, 2023).

In the preschool phase, the slower development of independence in children with disabilities prolongs parental responsibilities. The transition to preschool education is hindered by limited inclusivity in many institutions, requiring parents to advocate for adapted conditions. This can cause additional stress (Guralnick, 2000), particularly if institutions lack trained staff or resources. In families with multiple children, siblings may feel neglected or develop a pro-

tective attitude, necessitating careful balancing of attention from parents (Ross & Cuskelly, 2006).

The school phase brings new challenges, including the selection of an appropriate school, administrative barriers, and the need for individualized education plans (Blackwell & Rossetti, 2014). Social barriers, such as bullying and discrimination (Ručman & Šulc, 2025), further complicate the child's inclusion in the school environment. Parents often must act as active advocates, which can be exhausting without adequate school support. Inclusive education is crucial for enabling children with disabilities to learn alongside their peers, but many schools still lack sufficient resources for effective implementation. During the transition process, parents often seek support from other parents with older children with disabilities to guide them through the educational process and prepare them for future challenges (Alberque & Matthews, 2024). However, in the Macedonian context, this parental need remains systemically unrecognized.

As children transition from childhood to adolescence, parents must navigate a range of stressors, both for their child and alongside them. These stressors occur at societal levels, within service provision, in family life, and on a personal level, with each stressor interconnected, creating a continuum of challenges (Kerr, Sharry & Wilson, 2022). In the adolescent phase, the need for autonomy in children with disabilities is often limited, leading to emotional difficulties, including frustration and anxiety. The absence of typical developmental milestones, such as obtaining a driver's license or completing high school, can leave families in a state of stagnation, without clear indicators of progress. Socialization is further restricted due to reduced peer influence, increasing the role of parents in creating opportunities for social interaction.

The launching phase, when children typically leave home, is particularly complex. Parents often remain in an intensive caregiving role, planning their child's future in terms of daily activities, employment, and support. This process can take years, even with significant resources, and frequently limits parents' personal and professional aspirations. In the empty nest and elderly family phases, parents continue to manage supports for their child, leading to chronic fatigue, financial pressure, and anxiety about the future, particularly regarding long-term care for their child (Namkung, Greenberg, Mailick & Floyd, 2018).

Families often receive contradictory messages from society: on one hand, normalization and inclusion are promoted, while on the other, practical support to achieve these goals is lacking. This discrepancy leaves families isolated and without sufficient support, underscoring the need for systemic solutions.

Conclusions and Recommendations

A central conclusion is that the family life cycles of families with a child with a disability often experience stagnation or prolongation of certain phases. During the preschool and school phases, the slower development of independ-

ence in the child, coupled with limited opportunities for inclusive education, forces parents to remain in an intensive caregiving role far longer than is typical. This not only depletes their physical and emotional capacity but also fosters a sense of isolation, as social networks typically formed through school activities or peer groups remain inaccessible. In adolescence, the child's need for autonomy is frequently restricted, leading to frustrations and emotional difficulties. In later phases, such as the launching and empty nest stages, parents remain trapped in the role of primary caregivers, with little room for personal growth or relief. This ongoing responsibility, combined with anxiety about the child's future, particularly regarding long-term care, underscores the critical need for robust and accessible systemic support.

To address these challenges, it is essential to establish a comprehensive support system that enables families to navigate these complex life cycles. A key step is enhancing inclusive education, which not only allows children with disabilities to learn alongside their peers but also eases transitions through educational stages, reducing parental stress. This requires investments in teacher training, specialized resources, and individualized education plans that genuinely meet children's needs. Simultaneously, creating support networks, such as parent groups and counseling services, can alleviate feelings of isolation and provide families with a space to share experiences and practical solutions.

Raising public awareness about the challenges these families face is equally vital. Through educational campaigns, society can move beyond stigma and foster a supportive environment, facilitating the social inclusion of children with disabilities and their families. Training for professionals, including healthcare workers, is another critical component, as they often serve as the first line of support. They must be equipped with the knowledge and skills to provide holistic care, focusing not only on the child but also on the well-being of the entire family.

Long-term planning for the future of a child with a disability is perhaps one of the most pressing issues. Families frequently face a lack of information and resources to ensure stability for their child after their passing or incapacity. Providing legal and financial support, such as trust funds or appointing guardians, can reduce parental anxiety. Additionally, developing respite care programs would offer parents brief breaks from their intensive responsibilities, lowering the risk of burnout.

Financial support, through subsidies for medical expenses and specialized equipment, would ease the economic burden, allowing families to focus on their child's well-being.

These solutions, integrated into a cohesive framework, can empower families to address their challenges and improve their quality of life. With support from society, educational institutions, and professionals, these families can find strength and hope to move forward, creating an environment where their children can reach their potential and parents can achieve a balance between caregiving and personal growth.

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