

RETHINKING AND REDEFINING CARE AND WELL-BEING FOR YOUNG ADULTS ON THE AUTISM SPECTRUM

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Abstract

The stress of primary caregivers, most often parents, for young adults with autism spectrum disorders is often multi-dimensional. The autistic adults with high support needs often need lifelong care that adds to the burden of caring for the family. The challenges that come with caring for a child with autism can be extremely stressful for parents and caregivers who may lack their own support systems. Wellness is important for both the autistic individuals as well as for the primary care givers themselves. Teaching autistic children and adolescents' self-care skills early in life can help ease some of these worries and increase their independence at home, school and in their community. There are lots of tools available to support autistic youth's independence with self-care. This includes both low- and high-tech solutions, such as visual schedules, picture checklists, or the use of task completion and habit-building apps. Also, it has been seen that parents who create a strong support system and take care of themselves are better able to handle the everyday challenges of raising a child with autism. The time has come for reimagining caregiving and wellness of young adults with autism. This paper is an overview of the need to rethinking and redefining about caregiving and wellness for adults with autism and is based on the lived experiences of parents caring as well as training their adult autistic sons or daughters' self-care skills.

Keywords: Redefining, Rethinking, Care, Well-being, self-care skills, autism

Introduction

Rethinking care and well-being for young adults on the autism spectrum requires a shift from

deficit-driven frameworks toward a strengths-based, neurodiversity-affirming understanding of autism. Contemporary scholarship emphasises that adulthood is a period when autistic individuals seek autonomy, identity development, and meaningful participation in society[1, 2]. Thus, care must not be conceptualised merely as intervention but as the creation of supportive environments that respect individual agency and promote flourishing. This aligns with emerging neurodiversity perspectives, which advocate valuing neurological differences rather than pathologizing them [3].

Redefining care also requires recognising the heterogeneity of the autism spectrum. Young adults often navigate transitions related to higher education, employment, independent living, and complex social networks, necessitating personalised, collaborative, and rights-based approaches to support [4]. Person-centred planning and supported decision-making enhance self-advocacy and reinforce autonomy, showing positive effects on long-term well-being and community inclusion [5]. The emphasis shifts from “correcting” behaviour to enabling meaningful engagement, developing life skills, and nurturing interests that contribute to identity and emotional resilience.

A holistic understanding of well-being must extend beyond clinical outcomes to include social belonging, accessible learning environments, inclusive employment, mental health supports, and community participation [6]. Socio-ecological models emphasise that well-being is shaped by the interplay of individual abilities and supportive environmental contexts [7]. When educational institutions, workplaces, and community systems adopt universal design, sensory-friendly practices, and inclusive policies, the result is greater independence, reduced anxiety, and stronger social connectedness among autistic young adults [8].

This rethinking and redefining approach to care and wellbeing seeks to address the unique needs of individuals with autism by creating supportive environments, building resilience, and enhancing the well-being of both the individual and their caregivers. This holistic framework acknowledges the interconnectedness of physical, emotional, social, and mental health for persons with autism and aims to foster inclusive, empowering and meaningful lives for them.

Autism Spectrum Disorder (ASD) is a complex developmental condition that affects how individuals communicate, interact socially, and process sensory information. Due to the diverse nature of autism, caregiving and wellness approaches often need to be highly individualized and adapted across a person’s lifetime. Traditionally, caregiving for individuals with autism has focused heavily on symptom management and basic life skills development, yet as the understanding of autism grows, there is a shift toward a more holistic and compassionate approach that recognizes the importance of emotional well-being, autonomy, and quality of life. A study underscores the need for autism-specific, family-centered care in planning and service delivery to meet unique family and caregiver needs [9]. A report by Ramcharan in 2001 emphasizes a strengths-based, inclusive approach in caregiving, advocating for goals focused on quality of life, autonomy, and well-being [10].

Key Principles for Reimagining Caregiving and Wellness

1. Person-Centered Care

Individualized Support: Care plans are tailored to each individual's preferences, strengths, sensory needs, and challenges, rather than following a one-size-fits-all approach.

Active Inclusion: Involve individuals with autism in the decision-making process regarding their care whenever possible, respecting their autonomy and preferences.

Flexible Caregiving: Recognize that needs and capacities change over time. Caregiving strategies should be adaptable, responsive, and developmentally appropriate, considering shifts in sensory preferences, cognitive abilities, and communication skills.

The paper by Pellicano and co-workers in 2014 highlights the importance of individualized and person-centered approaches, emphasizing the need for tailored support and family involvement in service delivery for autistic individuals [11].

2. Family and Caregiver Wellness.

A review paper in 2012 by Karst & Van Hecke examined the broad impact of autism on families and caregivers and suggested models for intervention that include wellness and support mechanisms for caregivers [12]. Another paper by Bengt Sivberg of Lund University, Sweden in 2002 explored the stress experienced by caregivers of children with autism and advocated for interventions that address caregiver wellness as a vital part of autism support [13].

Supporting Caregivers: The well-being of caregivers directly impacts the quality of care they can provide. Offering emotional, financial, and practical support through counseling, respite care, and financial assistance programs is crucial.

Empowering Families: By providing knowledge and resources, families can become more confident and effective caregivers. Training on communication strategies, stress management, and adaptive skills development empowers families to create a more supportive environment.

3. Integrative Therapies and Wellness

The foundational text by Ayres on sensory integration offers insights into sensory processing challenges faced by autistic individuals [14 – 17]. There are suggestions of various strategies for creating sensory-friendly environments [18]. A pilot study supported the use of sensory integration therapy in autism care, showing positive outcomes in behavior and attention through sensory-based interventions [19].

Sensory-Friendly Environments: Modify home and community spaces to reduce sensory stressors and make daily life more comfortable. This can include quiet rooms, access to noise-cancelling headphones, low lighting, and calming sensory tools.

Holistic Therapies: Introduce evidence-based therapies such as music therapy, art therapy, yoga, and animal-assisted therapy, which can provide sensory regulation, improve focus, and promote relaxation.

Mindfulness and Relaxation Techniques: Simple mindfulness practices, deep breathing, and relaxation techniques can be effective for managing stress and increasing emotional regulation in individuals with autism.

4. Focus on Strengths and Positive Outcomes

The study by Dunn and co-workers in 2012 at the Department of Occupational Therapy Education, School of Health Professions, University of Kansas Medical Center, USA; supported a strengths-focused intervention approach, emphasizing the importance of engaging autistic children in activities that build their competencies and sense of accomplishment [20]. A meta-analysis study highlighted the effectiveness of social skills interventions in promoting social engagement and inclusivity for individuals with autism [21].

Strength-Based Approaches: Emphasize the individual's abilities and interests rather than focusing solely on challenges. Recognize and celebrate achievements, however small, to build self-esteem and foster motivation.

Goal-Oriented Support: Set realistic, meaningful goals based on personal interests and values, allowing individuals with autism to pursue activities and routines that give them joy and purpose.

5. Community Integration and Social Connectedness

An article discussed community integration for individuals with disabilities and the positive impacts of moving from institutional to community-based settings, which foster social connectedness and inclusivity [22].

Creating Inclusive Spaces: Develop community centers, schools, and workplaces that are autism-friendly, allowing individuals to engage in society without sensory or social barriers.

Peer Support and Social Circles: Encourage peer relationships through structured activities, such as social clubs, hobby groups, and local community programs, where autistic individuals can build friendships and social confidence in a safe setting.

Educational and Vocational Training: Provide resources for skills development that can enhance independence and facilitate meaningful employment opportunities, allowing individuals with autism to participate fully in society.

Strategies for Implementing Rethinking and Redefining Care and Wellbeing among individuals with Autism Spectrum Disorder (ASD)

1. Enhanced Training for Caregivers and Professionals

Autism-Specific Education: Train caregivers, therapists, and educators on autism-specific caregiving techniques, including sensory integration, effective communication strategies, and behavioral support.

Emotional Intelligence and Sensitivity: Encourage caregivers to develop empathy and a deep understanding of the emotional and sensory worlds of individuals with autism, leading to more compassionate and effective care.

2. Building a Network of Support Systems

A study addressed caregiver burnout and highlights factors that can help mitigate stress, such as family cohesion and satisfaction with leisure time, which contribute to improved well-being in caregivers.

3. Creating Support within the Community

Community Support Services: Establish a network of support services, including day-care centers, respite care facilities, and residential support, where families can seek help when needed.

Accessible Mental Health Resources: Ensure that individuals with ASD have access to a mental health professional.

Accessible Mental Health Resources: This approach allows persons with autism and their families have access to mental health services, including specialized counseling, to address stress, anxiety, and other challenges associated with caregiving and autism

4. Emphasis on Technology and Assistive Tools

Assistive Communication Devices: For non-verbal individuals or those with limited verbal skills, technology such as augmentative and alternative communication (AAC) devices can improve self-expression and foster greater independence.

Digital Wellness Tools: Apps and online platforms can provide sensory tools, relaxation exercises, and organizational support for both individuals with autism and their caregivers, promoting independence and ease of management.

5. Legal and Advocacy Support

Access to Rights and Services: Advocacy for policies that ensure the rights of persons with autism, including access to healthcare, education, and employment, is vital for sustained wellness.

Empowerment Through Legal Literacy: Caregivers and individuals with autism should be made aware of their rights and resources, providing them the confidence to seek fair treatment and accommodations.

6. Research and Evidence-Based Interventions

Ongoing Research: Invest in research to better understand autism, including studies on sensory processing, brain development, and effective therapeutic approaches.

Studies addressed caregiver burnout and highlights factors that could help mitigate stress, such as family cohesion and satisfaction with leisure time, which contribute to improved well-being in caregivers [23].

Application of Findings: Encourage the adoption of evidence-based practices and therapies that promote wellness and effective caregiving, constantly refining methods based on new insights.

Expected Benefits of Rethought and Redefined Care and Wellbeing for persons with autism and their families.

1. Enhanced Quality of Life

This holistic approach helps individuals with autism and their families experience a higher quality of life, characterized by improved emotional well-being, social engagement, and personal growth.

2. Greater Independence

By focusing on skill-building, autonomy, and personalized care, individuals with autism can achieve higher levels of independence, allowing them to navigate daily life with more confidence and less reliance on caregivers.

3. Reduced Caregiver Burnout

By offering support systems and resources, caregivers can experience reduced stress, greater emotional resilience, and enhanced satisfaction, ultimately enabling them to provide better care.

4. Positive Social Integration

Inclusive, community-based opportunities for persons with autism foster social connectedness, acceptance, and mutual understanding, benefiting both individuals with autism and society as a whole.

Discussion

Research on caregiver burnout in families of individuals on the autism spectrum indicates that chronic stress often arises from the cumulative demands of behavioural challenges, limited social support, and restricted personal time [24]. However, studies also show that certain protective factors can mitigate this stress and enhance caregiver well-being. For instance, family cohesion has been identified as a significant buffer, promoting emotional resilience and reducing the psychological burden experienced by parents and caregivers [25]. Similarly, satisfaction with leisure time, especially opportunities for restorative activities and respite has been linked to lower levels of burnout and improved mental health outcomes [26, 27]. These findings underscore the importance of strengthening family systems, providing structured respite services, and enabling meaningful leisure engagement to support caregiver well-being in the long term. There have been studies which addresses caregiver burnout and highlights factors that can help mitigate stress, such as family cohesion and satisfaction with leisure time, which contribute to improved well-being in caregivers [28, 29].

Ultimately, rethinking and redefining care for young autistic adults demands a shift in societal attitudes from viewing autism as a burden to understanding it as a form of diversity

that enriches communities. This reorientation supports an ethic of interdependence, where families, professionals, and communities collaborate to create enabling ecosystems that uphold dignity and potential [30]. There has been a paradigm shift in understanding neurological Differences in the context of the UN Sustainable Development Goals (SDGs) and resulted in rethinking and redefining neurodiversity approaches in all aspects of care and wellbeing of autistic individuals [31]. Such an approach not only promotes well-being for autistic individuals but also advances broader goals of social justice and inclusive development.

Conclusion

Rethinking and redefining on care and wellbeing for individuals with autism moves beyond basic care to embrace a person-centered, strength-based, and supportive framework. This approach promotes meaningful, inclusive, and dignified lives for individuals with autism and seeks to empower caregivers and families, creating an ecosystem of compassionate support. The goal is a world where each individual with autism can reach their fullest potential in an environment that respects their uniqueness, enhances their wellness, and integrates them fully into the fabric of society.

Conflict of Interest

The authors declare that there are no conflicts of interest regarding the publication of this work.

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