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Challenges of Providing Transitional Care and Empowerment for Individuals with Intellectual Disabilities (ID): A Qualitative Study of Families' Experiences Through Guardian Interviews

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Abstract

This study aimed to explore the challenges and strategies associated with transitional care for individuals with intellectual disabilities (ID) through interviews with 12 guardians. The research identified key issues including system fragmentation, the inadequacy of tailored services, and the critical role of informal support networks. Findings reveal that guardians experience significant difficulties navigating a fragmented care system and face challenges in accessing services that meet their loved ones' specific needs. Despite these obstacles, guardians employ proactive strategies, such as developing personalized care plans and fostering independence and self-advocacy, to manage the transition effectively. The study emphasizes the need for integrated care models and tailored support services, as well as support for guardians in care planning. It also highlights the importance of strengthening informal support networks. Limitations include the small sample size and reliance on self-reported data, which may impact the generalizability of the findings. Future research should explore broader populations and conduct longitudinal studies to assess the long-term effectiveness of transitional care interventions. Overall, this study has provided valuable insights for improving transitional care programs and supports the development of more coordinated, responsive, and personalized care strategies for individuals with ID.

Keywords: *Transitional Care, Intellectual Disabilities, Care Coordination, Personalized Support, Informal Support Networks.*

Introduction

The transition to adulthood is a critical period for individuals with ID, presenting unique challenges and opportunities for their families. This phase involves navigating complex systems of care, education, and employment while striving to foster independence and empowerment (Malapela et al., 2020; Roberts et al., 2018). Despite the increasing recognition of the importance of transitional care, many families continue to face significant barriers that hinder the effective support and empowerment of their loved ones with ID. These barriers include limited access to resources, inadequate support services, and a lack of coordinated care, all of which exacerbate the difficulties associated with this transitional period (Osako et al., 2023).

Existing literature extensively documents the challenges faced by individuals with ID and their families during transitions. However, there remains a gap in understanding the nuanced experiences and needs of these families, particularly from the perspective of the guardians who are directly involved in their care. By exploring the lived experiences of guardians, the researcher gained deeper insights into the specific obstacles they encounter, as well as the strategies they employ to overcome these challenges. This understanding is crucial for developing more effective and responsive transitional care programs that truly address the needs of individuals with ID and their families (Roos & Søndenaa, 2020).

This study has filled this gap by conducting in-depth interviews with guardians of individuals with ID, focusing on their experiences with transitional care and empowerment. By employing a qualitative research approach, this study captures the rich, detailed narratives of these guardians, shedding light on the complexities of providing care during transitions. Through this exploration, the researcher identified key themes and patterns that inform the development of more tailored and supportive interventions.

The findings from this study contribute to the growing body of knowledge on transitional care for individuals with ID. By highlighting the voices of guardians, this research emphasizes the importance of

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considering family perspectives in the design and implementation of care programs. Ultimately, this study supports the development of more holistic and effective strategies that promote the well-being and empowerment of individuals with ID during their transition to adulthood.

Literature Review

Introduction to Transitional Care

Definition and Scope

Transitional care refers to the comprehensive process of managing and coordinating the transfer of individuals from one phase of care to another, particularly from adolescence to adulthood for those with chronic conditions or disabilities. This transition involves shifting from pediatric to adult healthcare systems, which can be challenging due to differences in service delivery models, provider expectations, and care coordination (Bouck et al., 2016). The scope of transitional care encompasses not only medical and therapeutic needs but also educational, social, and psychological aspects. Effective transitional care aims to ensure continuity, minimize disruptions, and enhance the overall well-being of individuals as they navigate this critical phase of life (Young-Southward et al., 2017).

Importance in the Context of ID

In the context of ID, transitional care is of paramount importance due to the unique challenges these individuals face. For individuals with ID, the transition from childhood to adulthood often involves navigating a complex array of services and supports, which can be further complicated by the fragmentation of care systems and limited availability of tailored services (Pallisera et al., 2016). The transition period is a crucial time for fostering independence, self-advocacy, and integration into the community, making it essential to provide specialized support to address their specific needs (Young-Southward et al., 2016). Ensuring a smooth transition can significantly impact their quality of life, including their ability to access appropriate educational and vocational opportunities, maintain health, and achieve personal goals (Bouck et al., 2016). Thus, understanding and addressing the intricacies of transitional care within this context is vital for promoting positive outcomes and enhancing the overall effectiveness of support systems for individuals with ID.

Challenges in Transitional Care

System Fragmentation and Coordination Issues

System fragmentation and coordination issues represent significant challenges in transitional care. Many individuals with ID experience difficulties due to the lack of integration between pediatric and adult care systems. Jacobs et al. (2018) highlighted that fragmented care often results in inefficient service delivery and communication breakdowns among providers, which can disrupt the continuity of care and exacerbate stress for both individuals and their families. The transition period is marked by the need for coordination between various healthcare providers, educational institutions, and social services, yet the current systems frequently fall short in providing a cohesive approach (McDonagh & Kelly, 2010). This fragmentation can lead to gaps in care, inconsistent treatment plans, and a lack of clear guidance for families navigating the transition.

Availability and Accessibility of Services

The availability and accessibility of services are critical issues in transitional care. Egan et al. (2021) underscored that the limited availability of specialized services for individuals with ID can hinder effective transitions. Many regions face shortages of resources and specialized programs designed to meet the unique needs of these individuals, which can lead to insufficient support and inadequate preparation for adulthood. Furthermore, Levy et al. (2020) pointed out that even when services are available, they may not be easily accessible due to geographical, financial, or logistical barriers. These challenges highlight the need for increased investment in and expansion of services that are both accessible and tailored to the needs of individuals with ID.

Barriers to Effective Transition

Several barriers impede the effectiveness of the transitional care process. Malapela et al. (2020) identified that individuals with ID often face systemic and procedural obstacles, such as rigid eligibility criteria and lack of continuity in care providers, which can complicate the transition. These barriers can result in delays, reduced quality of care, and increased anxiety for individuals and their families. Additionally, the transition process is often characterized by a lack of comprehensive planning and coordination, as noted by Jacobs et al. (2018), which further exacerbates the difficulties faced by individuals moving from pediatric to adult care systems. Addressing these barriers is essential for improving the transitional care experience and ensuring that individuals with ID receive the support they need throughout this critical period.

Empowerment and Self-Advocacy

Theoretical Frameworks on Empowerment

Empowerment is a central concept in transitional care, particularly for individuals with ID. Theoretical frameworks on empowerment emphasize the importance of increasing individuals' control over their own lives and decision-making processes. According to Dunkley and Sales (2014), empowerment involves providing individuals with the skills, confidence, and resources needed to advocate for themselves and actively participate in their care and life planning. Roos and Søndenaa (2020) further defined empowerment as a process that enhances an individual's sense of autonomy and self-efficacy, crucial for navigating complex systems and achieving personal goals. These frameworks highlight the need for transitional care programs to integrate empowerment strategies that foster independence and self-advocacy.

Strategies for Promoting Self-Advocacy

Promoting self-advocacy is essential for supporting individuals with ID during the transition to adulthood. Winn and Hay (2009) identified several effective strategies, including providing individualized training on self-advocacy skills, creating opportunities for self-expression, and involving individuals in decision-making processes related to their care. Malapela and Thupayagale-Tshweneagae (2019) emphasized the importance of involving individuals in setting their own goals and making informed choices about their future, which can enhance their confidence and ability to navigate transitional challenges. Additionally, Young-Southward et al. (2017) highlighted the role of support networks and advocacy organizations in providing resources and guidance that empower individuals to advocate for their own needs and preferences.

Impact on Individuals with ID

The impact of empowerment and self-advocacy on individuals with ID is significant. Osako et al. (2023) demonstrated that when individuals are empowered and encouraged to self-advocate, they experience improved self-esteem, greater satisfaction with their care, and better overall outcomes. Empowerment not only supports individuals in managing their own care but also contributes to their personal growth and development. Furthermore, Roos and Søndenaa (2020) argued that self-advocacy skills are crucial for accessing appropriate services, achieving greater independence, and integrating more effectively into the community. By incorporating empowerment and self-advocacy strategies into transitional care programs, service providers can enhance the quality of life and overall well-being of individuals with ID.

Role of Guardians and Family Support

Guardians' Experiences and Responsibilities

Guardians play a pivotal role in the transitional care of individuals with ID, encompassing a range of experiences and responsibilities. Barron et al. (2008) illustrated that guardians often bear significant emotional and logistical burdens as they navigate complex care systems and advocate for their loved ones. This responsibility includes coordinating with multiple service providers, managing day-to-day care needs, and making critical decisions regarding their loved one's transition to adulthood. Strnadová (2018) highlighted that guardians frequently experience stress and fatigue due to the demands of their caregiving role, emphasizing the need for supportive resources and interventions to assist them in managing these responsibilities effectively.

Family-Centered Care Models

Family-centered care models are crucial in supporting the needs of both individuals with ID and their guardians. Floyd et al. (2009) described family-centered care as an approach that prioritizes the involvement of families in the care process, recognizing their central role in supporting the individual's well-being and development. This model emphasizes collaboration between families and service providers, ensuring that care plans reflect the family's values, preferences, and needs. Man et al. (2014) further argued that family-centered care can improve outcomes by enhancing communication, building trust, and fostering a supportive environment for both individuals and their guardians. Such models are integral to creating a more holistic and responsive transitional care system.

Support Mechanisms for Families

Effective support mechanisms are essential for assisting families in their caregiving roles. Medforth and Boyle (2023) identified several key mechanisms, including access to respite care, peer support groups, and informational resources. Respite care provides temporary relief for guardians, allowing them to take breaks and reduce caregiver burnout. Peer support groups offer emotional support and practical advice from others in similar situations, fostering a sense of community and shared experience. Additionally, providing families with comprehensive information about available services and resources can help them make informed decisions and navigate the complexities of transitional care more effectively (Strnadová, 2018). Implementing these support mechanisms is vital for enhancing the overall caregiving experience and ensuring that guardians can effectively support their loved ones through the transition to adulthood.

Informal Support Networks

Types and Importance of Informal Support

Informal support networks play a crucial role in the lives of individuals with ID and their families. Pickler et al. (2011) identified several types of informal support, including family members, friends, neighbors, and community members who provide emotional, practical, and financial assistance. These support networks are essential for supplementing formal care services, offering personalized and contextually relevant support that is often not available through institutional care systems. The importance of informal support lies in its ability to provide a sense of belonging, reduce isolation, and enhance the overall quality of life for individuals with ID (Bhaumik et al., 2011).

Interaction with Formal Care Systems

The interaction between informal support networks and formal care systems is a key aspect of transitional care. Malasi and Juma (2024) discussed how informal support can complement and enhance formal care by bridging gaps in services, facilitating communication, and providing additional resources. However, Clark et al. (2015) highlighted that challenges can arise when informal and formal systems do not effectively coordinate, leading to potential conflicts or duplications in care. Successful integration of informal support with formal care systems involves recognizing the value of informal contributions, promoting collaboration, and ensuring that informal caregivers are included in care planning and decision-making processes (Tilley et al., 2022).

Enhancing Community and Family Support

Enhancing community and family support is essential for improving transitional care outcomes. Tilley et al. (2022) emphasized that strengthening community networks and support systems can provide additional resources and opportunities for individuals with ID, facilitating their integration and participation in community life. Initiatives that promote community engagement, such as support groups, advocacy organizations, and volunteer programs, can play a significant role in building robust informal support networks. Malasi and Juma (2024) also highlighted the importance of family support programs that offer training, resources, and respite care to help families manage the demands of caregiving. By fostering stronger community connections and supporting family caregivers, it is possible to enhance the overall effectiveness of transitional care and improve the well-being of individuals with ID.

Previous Research and Findings

Summary of Key Studies

Previous research on transitional care for individuals with ID has highlighted several critical themes and findings. Alnahdi et al. (2013) conducted a study that underscored the challenges of navigating fragmented care systems and emphasized the need for improved coordination between service providers. Their work highlights the complexities involved in transitioning from pediatric to adult care and the impact of these challenges on individuals and their families. Young-Southward et al. (2016) provided insights into the effectiveness of self-advocacy training programs, demonstrating that such interventions can significantly enhance individuals' ability to manage their care and advocate for their needs. Additionally, research by Pickler et al. (2011) explored the role of informal support networks, finding that these networks are essential for complementing formal care systems and providing additional support.

Consistencies and Gaps in the Literature

Consistencies across the literature reveal a shared recognition of the challenges faced by individuals with ID during transitional periods. Studies consistently highlight issues related to system fragmentation, the need for tailored support services, and the importance of informal support networks (Jacobs et al., 2018; Egan et al., 2021). However, gaps in the literature remain, particularly concerning the integration of informal and formal care systems and the specific strategies for enhancing self-advocacy and empowerment (Malasi & Juma, 2024). While existing research provides valuable insights, there is a need for further investigation into the effectiveness of various transitional care models and the development of evidence-based practices to address identified gaps.

Contribution of Existing Research to Current Understanding

Existing research contributes significantly to the current understanding of transitional care by identifying key challenges and effective strategies for supporting individuals with ID. Studies have demonstrated the impact of empowerment and self-advocacy on improving transitional outcomes and highlighted the importance of family-centered care models (Dunkley & Sales, 2014; Floyd et al., 2009). The literature also emphasizes the role of informal support networks in complementing formal care systems and enhancing overall care quality (Pickler et al., 2011). These contributions provide a foundation for developing more comprehensive and integrated transitional care programs that address the identified needs and challenges.

Implications for Transitional Care Programs

Recommendations from Previous Research

Based on previous research, several recommendations for improving transitional care programs emerge. Jacobs et al. (2018) suggested enhancing care coordination and developing integrated service models to address system fragmentation. Alnahdi et al. (2013) recommended expanding the availability of specialized services and resources tailored to the needs of individuals with ID. Additionally, the literature highlights the need for implementing self-advocacy training programs and strengthening informal support networks (Young-Southward et al., 2016; Malasi & Juma, 2024).

Integration of Findings into Program Development

Integrating these findings into transitional care program development involves adopting a holistic approach that incorporates the recommendations from existing research. Developing comprehensive care models that integrate formal and informal support systems, enhancing service coordination, and providing targeted empowerment strategies are essential steps. By incorporating these elements, transitional care programs can better address the needs of individuals with ID and their families, leading to more effective and supportive care transitions.

Conclusion

Summary of Key Insights

The literature review reveals that transitional care for individuals with ID involves complex challenges, including system fragmentation, limited service availability, and the need for effective self-advocacy and empowerment strategies. Key insights from previous research emphasize the importance of integrating formal and informal support systems, enhancing care coordination, and providing tailored support services. The role of guardians and family support is critical, and informal support networks play a significant role in complementing formal care systems.

Relevance to the Current Study

The insights gained from the literature review are highly relevant to the current study, which aims to explore the experiences of guardians and identify strategies for improving transitional care. By addressing the identified challenges and incorporating recommendations from previous research, the study contributes valuable knowledge to the field and provides actionable recommendations for enhancing transitional care programs. This understanding will help inform the development of more effective and responsive care models that better support individuals with ID and their families during critical transitional periods.

Methodology

Research Design

This study employed a qualitative research approach to explore the experiences of guardians of individuals with ID during transitional care. Qualitative research was particularly suited for this study as it allows for a deep, contextualized understanding of the lived experiences and perceptions of participants. Through this approach, the researcher captured the rich, detailed narratives that quantitative methods might overlook, providing a comprehensive view of the challenges and strategies associated with transitional care and empowerment.

Interviews were chosen as the primary research tool due to their ability to facilitate in-depth discussions and uncover nuanced insights. The interview format allowed participants to share their personal experiences in their own words, offering a level of detail and depth that other data collection methods, such as surveys, might not achieve. This method was particularly effective in exploring complex, sensitive topics, as it provided a safe space for participants to express their thoughts and feelings openly.

Participants

Participants in this study consisted of 12 guardians of individuals with ID in Saudi Arabia. The selection criteria for participants include: being a primary caregiver or guardian of an individual with ID, having recent or ongoing experience with transitional care, and willingness to participate in an in-depth interview. These criteria ensured that participants have relevant and current experiences that contribute to the study's objectives.

The demographic information of the 12 guardians included a diverse mix of age, gender, and socio-economic backgrounds to capture a wide range of perspectives. The participants included both male and female guardians, ranging in age from mid-30s to late 60s, with varying levels of education and socio-economic status. This diversity helped to ensure that the findings are representative of different family contexts and experiences.

The recruitment process involved a combination of purposive and snowball sampling techniques. Initial participants were identified through local support groups and organizations that assist families of individuals with ID in Saudi Arabia. These participants were then asked to refer other guardians who meet the selection criteria. This approach ensured that a broad range of experiences and perspectives were included in the study, while also leveraging the trust and networks within the community to facilitate participation.

Data Collection

The data collection process involved conducting in-depth, semi-structured interviews with the 12 guardians. Each interview lasted between 60 to 90 minutes and took a place either in person or via video conferencing, depending on the participants' preferences and availability. The semi-structured format allowed for flexibility, enabling the interviewer to probe deeper into specific areas of interest while maintaining a consistent framework across all interviews.

The interview protocol was designed to elicit detailed information about the participants' experiences with transitional care and empowerment. Key questions included:

- Can you describe your experience with transitioning your loved one with an ID to adulthood?
- What specific challenges have you faced during this transitional period?
- How have you addressed these challenges?
- What resources or support systems have been most helpful to you?
- Can you provide examples of successful strategies or interventions that have empowered your loved one?
- What do you believe are the most critical needs for families during this transition?

Ethical considerations were paramount in this study. Participants were provided with detailed information about the study's purpose, procedures, and their rights, including the right to withdraw at any time. Informed consent was obtained prior to each interview, ensuring that participants understand and agree to the conditions of their involvement. Confidentiality was maintained by anonymizing all data and securely storing interview recordings and transcripts.

Data Analysis

The data analysis process began with the transcription of all interviews. Transcriptions were carefully reviewed for accuracy and completeness. The data was then coded using a combination of deductive and inductive coding techniques. Deductive codes were derived from existing literature and the research questions, while inductive codes emerge from the data itself during the coding process.Thematic analysis was employed to identify, analyze, and report patterns (themes) within the data. This process involved several steps: familiarization with the data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, producing the final report and then carefully translating each theme and quote into English language. This systematic approach ensured a thorough and nuanced understanding of the data.

To ensure reliability and validity, multiple strategies were employed. Triangulation was used by comparing findings across different participants and sources. Peer debriefing sessions with colleagues help to challenge and refine the analysis. Member checking was conducted by sharing preliminary findings with participants to verify the accuracy and resonance of the interpretations. These methods helped to enhance the credibility and trustworthiness of the study's findings.

Ethical Considerations

Ethical rigor was paramount in this study. To uphold confidentiality and anonymity, all participant identifiers were replaced with pseudonyms, and personal information was carefully removed from all transcripts and research outputs. Data was securely stored in encrypted files and was accessible only to the researcher. Throughout the publication process, care was taken to ensure that data presentation does not inadvertently reveal the identities of participants.

Handling of sensitive information was managed with strict protocols. Participants were thoroughly informed about their right to withdraw from the study or skip any questions without consequence. The interviews were conducted in a professional, respectful, and supportive manner to foster an environment where participants feel safe sharing their experiences. Each interviewer was trained to handle sensitive topics with care, ensuring that all participants were comfortable and supported throughout the process.

The study has obtained approval from the relevant institutional ethics committees, confirming adherence to ethical research standards. The review includes an assessment of the study’s design, informed consent procedures, and measures for safeguarding participant confidentiality and well-being. This approval underscores the study’s commitment to ethical integrity and the protection of participants' rights and privacy.

Results

The analysis of the interviews with 12 guardians provides a detailed understanding of the challenges and strategies related to transitional care for individuals with ID. The results are organized into key themes, supported by illustrative quotes and summarized in tables to enhance clarity and comprehensibility.

Challenges in Transitional Care

System Fragmentation and Coordination

A predominant challenge reported by guardians is the fragmentation and lack of coordination within the transitional care system. This issue is evident in both the management of services and the integration of support resources.

Table 1. Challenges in System Coordination

Challenge	**Number of Guardians Reporting**	**Example Quote**
Lack of Service Coordination	10	"It's like juggling multiple balls – no one talks to each other, and it's overwhelming."
Bureaucratic Hurdles	8	"The paperwork is endless and confusing; it feels like it's a full-time job just keeping up."
Delays in Accessing Resources	7	"Waiting for approvals and services takes months, and it's incredibly frustrating."

Limited Availability of Tailored Services

Guardians consistently express difficulty finding appropriate services tailored to their loved ones' specific needs.

Table 2. Availability of Support Services

Issue	**Number of Guardians Reporting**	**Example Quote**
Inadequate Service Options	9	"There are very few programs designed for my child's needs; it feels like we're always making do."
Insufficient Adaptation of Programs	6	"Programs exist, but they aren't adapted for the unique challenges my child faces."

Strategies for Empowerment

Personalized Care Plans

Many guardians develop customized care plans to manage the diverse needs of their loved ones effectively.

Table 3. Strategies for Developing Care Plans

Strategy	**Number of Guardians Reporting**	**Example Quote**
Creating Comprehensive Care Plans	11	"We put together a detailed plan that includes every aspect of care, from daily routines to emergency contacts."
Coordinating Multiple Services	8	"I make sure to coordinate between therapists, doctors, and social workers to ensure everyone is on the same page."

Fostering Independence and Self-Advocacy

Guardians focus on empowering their loved ones by building independence and self-advocacy skills.

Table 4. Strategies for Empowerment

Strategy	**Number of Guardians Reporting**	**Example Quote**
Involving in Decision-Making	10	"We involve our child in every decision; it's important for their confidence and sense of control."
Encouraging Self-Advocacy	7	"We encourage our child to speak up for themselves and to advocate for their own needs."

Support Systems and Resources

Reliance on Informal Networks

Guardians rely heavily on informal support networks, including family and community resources.

Table 5. Sources of Support

Source of Support	**Number of Guardians Reporting**	**Example Quote**
Family and Friends	12	"Our family is our biggest support system – they help with everything from emotional support to practical tasks."
Support Groups	8	"Being part of a support group has been invaluable for sharing experiences and advice."

The findings underscore the complexity of transitional care and the necessity for more integrated and responsive support systems. Guardians' experiences highlight both the systemic issues and the effective strategies they employ, providing a foundation for future improvements in transitional care programs.

Discussion

Interpretation of Key Findings

System Fragmentation and Coordination

The findings underscore a significant challenge in the transitional care process: system fragmentation and a lack of coordination among various service providers. Guardians consistently report that navigating the disparate elements of care is cumbersome and inefficient. This fragmentation leads to delays, gaps in service provision, and added stress for families who must manage multiple points of contact. The lack of a unified approach exacerbates the difficulties of accessing and integrating the necessary resources, highlighting the need for a more cohesive system that facilitates seamless transitions and comprehensive support.

Availability of Tailored Services

The limited availability of tailored services emerges as a critical issue in supporting individuals with ID during their transition to adulthood. Guardians express frustration with the generic nature of many existing programs, which often fail to address the specific needs and challenges faced by their loved ones. This gap in service provision indicates a pressing need for programs that are not only available but also adaptable to the unique requirements of individuals with ID. Tailored services can significantly enhance the effectiveness of transitional care by providing targeted support that aligns with the individual's needs and goals.

Strategies for Personalized Care and Empowerment

Despite the systemic challenges, guardians demonstrate resilience and innovation in developing personalized care plans and fostering empowerment. By creating detailed care plans and actively coordinating between various services, guardians manage to provide a more integrated support system for their loved ones. Furthermore, efforts to build independence and self-advocacy in individuals with ID reflect a proactive approach to empowering them throughout the transition. These strategies not only address immediate needs but also contribute to long-term well-being and autonomy.

Role of Informal Support Networks

The reliance on informal support networks is a notable aspect of the guardians' experiences. Family, friends, and support groups play a crucial role in providing emotional, practical, and informational support. This reliance highlights the importance of these networks in supplementing formal services and filling gaps left by the system. The strong presence of informal support underscores the value of community and relational resources in managing the complexities of transitional care and suggests that enhancing these networks could further support guardians and individuals with ID.

Implications for Transitional Care Programs

Enhancing Service Coordination

The findings highlight a critical need for improved coordination among service providers to address the fragmentation experienced by guardians. Transitional care programs should prioritize creating integrated care models that streamline communication and collaboration between various services, including healthcare, education, and social support systems. Implementing centralized case management or coordination services could reduce bureaucratic hurdles and ensure that guardians receive cohesive support, thus alleviating some of the stress and inefficiencies associated with navigating the current system.

Developing Tailored Support Services

To better meet the needs of individuals with ID, transitional care programs must focus on developing services that are specifically tailored to their unique challenges. This includes designing and implementing programs that address the diverse needs of individuals with ID during their transition to adulthood. Tailored services should incorporate flexibility to adapt to individual requirements, providing personalized support that enhances effectiveness and promotes better outcomes. Engaging with guardians in the development and evaluation of these services can help ensure that they are both relevant and practical.

Supporting Guardians in Care Planning

The proactive strategies employed by guardians in managing care highlight the importance of supporting them in developing comprehensive care plans. Transitional care programs should offer resources and training to assist guardians in creating detailed and effective care plans. This support could include providing access to care planning tools, guidance on navigating the service system, and professional advice to help guardians coordinate and integrate various aspects of care. By empowering guardians with the knowledge and resources they need, programs can enhance their ability to manage transitions more effectively.

Strengthening Informal Support Systems

The significant role of informal support networks in the transitional care process underscores the need to strengthen and expand these systems. Transitional care programs should recognize and leverage the contributions of family, friends, and support groups by fostering community connections and providing resources that enhance these informal networks. Initiatives could include support group facilitation, community engagement activities, and training for family members to better support their loved ones.

Strengthening informal support systems can complement formal services and provide a more holistic support structure for individuals with ID and their families.

Comparison with Existing Literature

Consistencies and Contrasts with Previous Research

The findings of this study resonate with several key studies in the literature. For instance, Clifton et al. (2021) also report significant challenges related to system fragmentation and the difficulties guardians face in navigating multiple service providers. Similar to our findings, Clifton et al. found that guardians experience substantial stress due to the lack of coordination and integration among various support services. This alignment underscores the persistent issue of fragmented care in transitional systems for individuals with ID.

Contrasting with earlier research, which identified general gaps in support services, our study provides a more nuanced view of the specific types of tailored services that are lacking. Levy et al. (2020) highlighted broad insufficiencies in transitional care programs but did not delve into the specifics of how these gaps affect guardians' experiences. Our study builds on this by detailing the particular needs for specialized programs and interventions that address the unique challenges faced during the transition to adulthood.

Additionally, while Nichols and Davis (2020) explored the role of informal support networks, their study did not capture the depth of reliance on these networks as found in our research. Nichols and Davis noted the importance of community support but did not fully examine how guardians leverage family and friends for practical and emotional assistance. Our findings offer a more comprehensive perspective on the critical role that informal networks play in managing transitional care.

Novel Insights and Contributions

This study introduced several novel insights that extend the existing body of knowledge. For example, the detailed examination of guardians' strategies for personalized care planning provides new understanding beyond the general recommendations made by Raymond et al. (2018). They emphasized the need for better care planning but did not explore the specific practices employed by guardians to develop and implement these plans. Our study highlights these practical approaches, such as the creation of comprehensive care plans and the active coordination between services, offering a richer perspective on how families navigate transitional care.

Furthermore, our focus on the proactive efforts of guardians to foster independence and self-advocacy provides a new contribution to the literature. While Chong et al. (2024) discussed the general benefits of promoting self-advocacy, our study provides specific examples of how guardians incorporate these strategies into their care plans, thus offering a more detailed view of the practices that support individuals with ID during their transition.

Finally, the study's emphasis on strengthening informal support networks adds to the understanding of community-based resources in transitional care. While prior research, such as the work by Tellman et al. (2022), acknowledged the value of informal support, our study provides a deeper exploration of how these networks are utilized and the impact they have on the transitional process. This insight underscores the importance of integrating and enhancing informal support systems within formal care frameworks.

Overall, the study's findings contribute valuable new perspectives to the field, providing both consistent and novel insights that can inform future research and the development of improved transitional care programs.

Practical Recommendations

Policy and Programmatic Changes

To address the identified challenges in transitional care, several policy and programmatic changes are recommended. First, there is a need for the development and implementation of integrated care models that enhance coordination among various service providers. Policies should mandate collaboration between healthcare, educational, and social support systems to streamline service delivery and reduce bureaucratic barriers. Additionally, funding should be allocated to create and expand tailored support services that address the specific needs of individuals with ID during their transition to adulthood.

Second, policymakers should focus on reducing the complexity of the care system by simplifying access to resources and support services. This could involve creating centralized case management systems or single points of contact that can assist guardians in navigating the various aspects of transitional care. Enhanced training for service providers on the specific needs of individuals with ID can also help ensure that services are both relevant and responsive.

Best Practices for Service Providers

Service providers are encouraged to adopt best practices that align with the study's findings. These practices include developing and implementing personalized care plans that are tailored to the unique needs of individuals with ID. Providers should work collaboratively with guardians to create comprehensive plans that integrate various aspects of care and support.

Additionally, service providers should emphasize the importance of empowering individuals with ID through programs that foster self-advocacy and independence. Training programs should be designed to support guardians in these efforts, providing them with the tools and resources needed to promote their loved ones' autonomy.

Strengthening connections with informal support networks is also crucial. Service providers should facilitate access to community resources and support groups, recognizing the valuable role these networks play in the transitional care process. Encouraging community involvement and creating opportunities for guardians to connect with one another can enhance the overall support system.

Suggestions for Future Research

Exploring Broader Populations

Future research should explore transitional care experiences across a broader range of populations. Studies could investigate how different cultural, socioeconomic, and geographic factors impact the challenges and strategies related to transitional care. Expanding research to include diverse groups can provide a more comprehensive understanding of the universal and unique aspects of transitional care for individuals with ID.

Longitudinal Studies on Transitional Care Outcomes

Longitudinal studies are needed to assess the long-term outcomes of transitional care programs. Research should track the progress and effectiveness of various interventions over time to determine their impact on the well-being and autonomy of individuals with ID. Such studies can provide valuable insights into the sustainability of transitional care approaches and help refine strategies to improve long-term outcomes for individuals and their families.

Limitations and Considerations

Study-Specific Limitations

This study, while providing valuable insights, has several limitations that should be acknowledged. First, the sample size of 12 guardians, while providing in-depth qualitative data, is relatively small and may not fully capture the diversity of experiences and challenges faced by all families dealing with transitional care. The findings may be influenced by the specific experiences of the participants and may not reflect the broader population of guardians.

Second, the study relies on self-reported data from interviews, which can be subject to recall bias and subjective interpretation. Participants may have reported their experiences based on their immediate feelings or perspectives, which might not always align with objective measures or long-term experiences.

Additionally, the study's focus on guardians' perspectives may overlook the viewpoints of other stakeholders, such as service providers or individuals with ID themselves. Incorporating multiple perspectives could offer a more comprehensive understanding of the transitional care process.

Implications for Generalizability

The findings of this study, while insightful, may have limited generalizability due to the specific characteristics of the sample. The experiences reported by the 12 guardians may not represent the experiences of all families dealing with ID, particularly those from different cultural, socioeconomic, or geographic backgrounds.

To enhance the applicability of the findings, future research should aim to include larger and more diverse samples. Additionally, incorporating perspectives from various stakeholders involved in transitional care can provide a more holistic view and improve the generalizability of the results.

In summary, while the study offers important contributions to the understanding of transitional care for individuals with ID, it is essential to consider these limitations and the implications for generalizability when interpreting the findings and applying them to broader contexts.

Conclusion

This study has provided a comprehensive examination of the challenges and strategies associated with transitional care for individuals with ID, as experienced by guardians. The findings reveal significant issues related to system fragmentation, the limited availability of tailored services, and the critical role of informal support networks. Guardians face substantial difficulties in navigating a fragmented care system, highlighting the need for more coordinated and integrated approaches to transitional care.

The study also underscores the resilience and resourcefulness of guardians as they develop personalized care plans and employ strategies to foster independence and self-advocacy in their loved ones. These insights contribute valuable understanding to the field, revealing both the practical approaches used by families and the areas where existing support systems fall short.

Based on these findings, several practical recommendations emerge. Policy and programmatic changes are needed to enhance service coordination, develop tailored support services, and support guardians in care planning. Strengthening informal support systems is also crucial to providing a more holistic approach to transitional care. Service providers should adopt best practices that align with these recommendations, including personalized care planning and empowerment strategies.

The study's limitations, including the small sample size and reliance on self-reported data, must be considered when interpreting the results. Future research should explore broader populations and conduct longitudinal studies to assess the long-term impact of transitional care interventions. Such research will be essential in refining and improving transitional care programs to better meet the needs of individuals with ID and their families.

Overall, this study contributed to the growing body of knowledge on transitional care, offering insights that can inform both practice and policy. By addressing the identified challenges and implementing the recommended changes, it is possible to enhance the effectiveness of transitional care programs and improve the overall well-being of individuals with ID during this critical phase of their lives.

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