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"If I Died Tomorrow, I'd Die Knowing That My Son Is Safe, Loved by the People in Here, Well Cared for, and Happy": Exploring Maternal Perspectives on Community Living for Their Adult Children with Intellectual and Developmental Disabilities

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Abstract: There is abundant evidence that, following community transition or deinstitutionalization, persons with intellectual and developmental disabilities experience improvements in quality of life and well-being. However, very little research in this area has been conducted in the Canadian context. In this qualitative study, individual in-depth interviewing was used to explore the perspectives of eight Canadian mothers of adults with intellectual and developmental disabilities regarding their children's residences and access to services after community transition. Within an interpretive description framework, narrative data collected during semi-structured interviews with participating mothers were analyzed using thematic analysis. Three main themes portraying a combination of positive and negative maternal perspectives emerged from the data: (1) quality of care, (2) quality of life, and (3) health status and behavior. The study findings bring attention to the importance of offering individualized community living options that are person- and family-centered to all persons with intellectual and developmental disabilities.

Keywords: intellectual disabilities; developmental disabilities; community living; family members; quality of life

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Academic Editor: Janet Finlayson

Received: 24 October 2024
Revised: 1 April 2025
Accepted: 15 April 2025
Published: 17 April 2025

Citation: Cameranesi, M.; Baranowski, M.; McCombe, L.; Kostal, K.; Mignone, J.; Shooshtari, S. "If I Died Tomorrow, I'd Die Knowing That My Son Is Safe, Loved by the People in Here, Well Cared for, and Happy": Exploring Maternal Perspectives on Community Living for Their Adult Children with Intellectual and Developmental Disabilities. *Disabilities* **2025**, *5*, 39. https://doi.org/10.3390/disabilities5020039

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1. Introduction

Intellectual developmental disorders, also known as intellectual and developmental disabilities, are a group of conditions that emerge during early childhood and affect cognitive, adaptive, and social functioning across the lifespan [1]. Individuals with these conditions may require varying levels of support in areas such as communication, daily living skills, social engagement, and employment. The level of support needed varies widely depending on the individual's abilities and environmental factors.

Historically, persons with intellectual and developmental disabilities were placed in large institutions that provided all-inclusive care and supports in a restricted environment [2]. However, an increased awareness of the rights of persons with disabilities catalyzed the community transition movement. This movement advocates for a shift away from institutional care toward community-based living arrangements that promote independence, choice, and social participation. In this context, community transition refers to

the process by which individuals with intellectual and developmental disabilities move from large institutional-based living arrangements to small community-based settings, such as group homes, supported living programs, or independent housing [3,4]. This transition involves adjusting to new living environments, accessing community-based services, and navigating changes in social, emotional, and daily life routines. Community transition can occur at the individual level, as a person adapts to a new living arrangement, or at the systemic level, as organizations and policies shift toward inclusive, community-based models of care.

This shift has been driven by legal frameworks, such as the United Nations Convention on the Rights of Persons with Disabilities [5], which emphasize the right to live in the community and receive support services that enhance self-determination, autonomy, independence, and full inclusion in society. However, the rights and resources available to adults with intellectual and developmental disabilities vary significantly across countries and regions due to differences in healthcare systems, legal protections, and societal attitudes towards disability [2,3]. For instance, countries in the Global North, like the United Kingdom, Canada, and Australia, have relatively well-established systems for community-based services, although access to these services may differ significantly within regions. In contrast, countries in the Global South, such as Brazil, India, and South Africa, often face challenges in providing adequate community support due to financial constraints, underdeveloped infrastructure, and less comprehensive disability laws.

These changes have placed new demands on families, who must adapt to their loved ones' transitions while maintaining positive relationships with them and service providers [2]. This study explores the experiences of eight Canadian mothers of adults with intellectual and developmental disabilities, focusing on their perspectives on community-based living arrangements and services following their loved ones' transition. The importance of family perspectives in understanding these transitions is critical, as families often serve as primary advocates and support systems for their loved ones, facing both emotional and financial burdens during the process [2].

1.1. Study Setting

In Canada, the country in which this research was conducted, healthcare services are publicly funded and administered by provincial governments. Across the country, there is substantial variation in the availability and quality of healthcare and social services between provinces, with some regions having more robust community-based care systems, while others struggle with limited resources and long waiting lists [2]. As a result, the experience of families navigating this transition varies widely depending on their location, the availability of services, and the policy environment. Although some studies reported the experiences of families with regards to the community transition of their loved ones in the Canadian province of Ontario [6], it is unclear how family members experience the changes in living arrangements and access to services that their loved ones go through following community transition in the Canadian Province of Manitoba. In this province, the Ministry of Health is responsible for overseeing healthcare services, while the Ministry of Families oversees social services, with the two sets of services delivered separately to Manitobans. Additionally, while the province is supporting community living for persons with intellectual and developmental disabilities, no specialized health services are available in the province for these adults. In the province, adults with intellectual and developmental disabilities living in the community access mainstream health services, including primary care, specialized medical care, mental health services, dental and vision care, rehabilitation services, and pharmaceutical services. Conversely, specialized social services, such as residential support services, employment and vocational support, income

and disability benefits, community day programs, personal support services, advocacy, and case management, are available to these adults and their families.

In 2013, the long-term residential care facility housed at St.Amant, located in the city of Winnipeg in the Canadian Province of Manitoba, stopped accepting long-term admissions and began a transformation of services involving, among other changes, offering long-term residents community living options. The present study investigated the perspectives of mothers of adults with intellectual and developmental disabilities who moved to the community during this first wave of transitions. Following this shift, in 2023, the government of Manitoba also announced the closure of the only long-term care facility still operating in the province, the Manitoba Developmental Centre. The results of this study will be useful in informing this second wave of community transitions in Manitoba.

St.Amant is the largest not-for-profit organization in Manitoba supporting persons with intellectual and developmental disabilities and their families via a wide range of programs and services (http://stamant.ca, accessed on 14 March 2025) [7]. In 2013, the organization started offering community living options to its long-term residents; between 2014 and 2019, a total of 64 individuals transitioned to community living. In 2016, a longitudinal research study was implemented, which aimed at evaluating the process and outcomes of St.Amant's community transitions (see, for example, [8]). The research presented in this paper is one component of this larger ongoing longitudinal mixed methods evaluation study.

1.2. Background

Previous research has examined family members' perspectives on the community transition of their loved ones with intellectual and developmental disabilities. This research suggests that during and following the community transition process, family members may experience anxiety regarding their loved ones' health and well-being and worries about maintaining contact with their loved ones after community transition [3–5]. However, research also shows that over time, most family members shift from opposition to satisfaction regarding community living [9,10]. Family members seem to especially appreciate the quality of care their loved ones receive in the community. For instance, Jones and Gallus (2016) found that regardless of family members' original attitudes toward community transition, following their loved ones' move, they desired and valued respect for their relatives' history, collaboration with community staff, high-quality consistent care, and community inclusion for their relatives [9].

There is also evidence that transitioning to community living has a compounding positive impact on persons with intellectual and developmental disabilities and their families [11]. In a study evaluating the community transitions of young adults with intellectual and developmental disabilities, family members indicated that their loved ones became more independent and self-determined in the community, while family members learned to give their children more autonomy in their decision-making.

Some family members do not favor the possibility of their loved ones moving into more independent community-based settings [12]. In this regard, the main concerns expressed by family members involve their fear that their loved ones may experience barriers to exercising their choices and accessing relevant health and social services, while also risking to experience loneliness and an unsafe environment [11–13]. Family members appear also to be concerned about the location of the new home, and the readiness of the community, including community-based services and direct professional staff.

1.3. The Present Study

The objective of our investigation was to explore the perspectives of mothers of adults with intellectual and developmental disabilities regarding their children's accommodations and access to services following community transition in the city of Winnipeg, Manitoba, Canada. This study is based on an analysis of narrative data generated using in-depth semi-structured in-person individual interviews with eight primary informants. The study aimed to answer the following two interrelated research questions:

1. What can we learn from mothers of adults with intellectual and developmental disabilities who experienced community transition in the city of Winnipeg regarding their children's new lives in the community?
2. According to mothers, what characterizes the lives of adults with intellectual and developmental disabilities who experienced community transition in this context?

Answers to these questions will provide valuable information to other family members and healthcare professionals about what makes community transitions successful (or not) in similar contexts [10]. This information has the potential to inform the planning and implementation of future community transitions for similar populations in comparable contexts (including in other settings in Manitoba) that are successful and well received by families [9,12].

2. Methods

2.1. The Interpretive Description Methodology

The interpretive description methodology [14] was used as a methodological framework in the development and implementation of the study described here. Interpretive description is a qualitative research approach that is customarily used in the applied health field [14,15]. This flexible yet rigorous qualitative research approach is best suited for investigations that aim to generate knowledge relevant for clinical practice. By listening to the voices of persons with lived experiences, interpretive description aims to provide empirical evidence that is valuable in informing future decisions in health-related settings. We used interpretive description principles as a methodological framework to investigate the unique lived experiences of mothers of adults with intellectual and developmental disabilities living in community-based settings to generate knowledge useful in informing future community transitions and community-based service delivery in the Canadian Province of Manitoba and beyond.

2.2. Positionality

Our research team includes researchers, healthcare professionals, other practitioners, and advocates whose work is dedicated to improving the lives of all, including persons with disabilities. The research we perform is grounded in our strong commitment to promoting equity, diversity, inclusion, and accessibility (EDIA) for persons experiencing marginalization, discrimination, and barriers to accessing the services they need to live fulfilling lives and thrive in our society. We hold the fundamental belief that health and well-being are universal human rights, and this belief guides our approach to understanding and supporting equity-seeking populations, particularly individuals with intellectual and developmental disabilities. Our professional and personal backgrounds have shaped our view that social justice is integral to the research process, emphasizing the importance of amplifying voices that are often underrepresented in academic and clinical discourse. We are aware that our identities and professional roles may influence the research process, from the framing of research questions to the interpretation of findings. As such, we engage in ongoing reflexivity [16], both individually and as a team, to ensure that our values and assumptions do not unduly shape the data or outcomes of our research but

rather contribute to a more nuanced and empathetic understanding of participants' lived experiences. We strive to approach each phase of the research process with an awareness of both our positionality and the potential impact it may have on the research outcomes. This commitment to reflexivity is an essential part of our methodological approach.

2.3. Study Participants

Primary informants were eight mothers of adults with multiple intellectual and developmental disabilities who transitioned to community living from an institutional model of care at St.Amant's Health and Transition Services between 2015 and 2019. All interviewees were Caucasian females, and their ages ranged between 56 and 78 years (M = 63; SD = 5.3). At the time of the interviews, their children (five females and three males) were aged 27–52 years (M = 47; SD = 3.7) and had been living in the community for a minimum of 6 months and a maximum of 5 years (M = 38.5 months; SD = 9.2 months). Before transitioning to the community, they had lived in an institutional setting for 4–35 years (M = 21.3; SD = 8.1).

2.4. Data Collection Procedures

A total of 12 family members, including mothers and fathers, were available to participate in this investigation because they were involved in the lives of their loved ones. No siblings, extended family members, or formal caregivers were available for this investigation. Family members were recruited in collaboration with St.Amant. We used non-probability, purposeful sampling to recruit study participants in collaboration with the staff members who were planning and implementing community transitions at St.Amant. We used a maximum variation sampling technique [14] to engage a group of mothers that could provide a range of perspectives on the community transition processes their loved ones experienced. Family members of individuals with intellectual and developmental disabilities who were former residents of St.Amant's long-term care facility and had experience with the transition to a community living home were eligible to participate in this study. Potential participants were excluded if they did not have experience with the transition process or were unable to provide informed consent. Family members were invited to participate in the study based on their sex, age, ethnocultural background, socioeconomic circumstances, and length of involvement with St.Amant. Eleven mothers and one father were invited to participate in the study and eight mothers accepted this invitation (participation rate = 66.7%).

Mothers participated in an in-person, in-depth, semi-structured individual interview involving 15 questions investigating their perspectives of their loved ones' lives in the community. Interviews took place either in participants' homes or in the homes where their loved ones were residing at that time. These locations were chosen by study participants for their convenience and privacy.

A very flexible interview guide was used during data collection to allow the unique perspectives of each mother to emerge [14]. The interview protocol was developed based on a review of existing literature on community transition for individuals with intellectual and developmental disabilities. Input was sought from researchers and healthcare professionals working in the disability field (including professionals involved in the community transitions of former St.Amant residents), ensuring that the questions captured both lived experiences and service-related concerns. Questions were intentionally broad in scope, designed to elicit open-ended responses, allowing participants to share experiences and perspectives on their loved one's life in the community. The interview protocol was pilot-tested with the first participant to help refine wording and flow. No major revisions to the protocol were made following the pilot test. To enhance transparency, the full interview

protocol has been included as Supplementary Materials, providing a clear framework for how themes were derived from participants' accounts. Sample interview questions include the following:

- How do you feel about community living for your loved one?
- What characterizes your child's new life in the community?
- Did your feelings and thoughts remain the same throughout the community transition process or did they change?

The research protocol was approved by the University of Manitoba Health Research Ethics Board and St.Amant Research Access Review Committee prior to recruitment. During recruitment, family members were informed that their disinterest in participating in the study would not affect the services their children were still receiving from St.Amant (if any). Prior to starting the interviews, written informed consent was obtained from all participating mothers. Mothers were offered 20 CAD for participating in the interviews as compensation for their time and effort.

2.5. Thematic Analysis

Interviews lasted between 40 and 60 min, and they were audio-recorded and transcribed verbatim. Upon transcription, all potentially identifiable information were redacted to protect the anonymity and confidentiality of study participants; all names reported in this paper are pseudonyms. Two authors (M.C. and M.B.) independently conducted inductive thematic analysis based on interpretive description [14]. The two authors have been conducting research in the disability field for several years; one of them has a young child with a developmental disability. The analysis of narrative data began with coding individual data segments and grouping these fragments into recurring patterns. We then examined the relationships between these patterns and organized them into cohesive findings.

The thematic analysis process unfolded in three sequential stages [14]. First, the two authors achieved familiarity with the data with the intention of opening their minds to the text and its meanings. At this stage, the two authors read the interview transcripts carefully several times in their entirety to become familiar with the data and start to explore the maternal perspectives that emerged from the data. The authors also searched for unique and novel points of view rather than what is already known, while keeping the study aim in mind. In stage two of this process, the search for patterns of maternal perspectives deepened. During this stage, while reading the transcripts, the authors marked meanings corresponding to maternal perspectives of their children's lives in the community and gave these meanings preliminary names using short descriptive words in the margins. As the analysis progressed, these preliminary codes were related to each other to obtain a sense of patterns of codes, and they were compared to identify differences and similarities among perspectives. At this stage, patterns of codes were also further examined, and the first themes emerged. In the last stage of this thematic analysis process, the authors organized categories into meaningful themes by organizing codes into categories and then themes. Themes were generated following the process outlined by Braun and Clarke, involving searching for themes, reviewing the generated themes, and defining and naming the themes [17]. During this stage, the tentative themes emerging from the data were discussed with a third author (S.S.) with extensive experience in conducting research with families impacted by intellectual and developmental disabilities.

To ensure the credibility and rigor of our analysis, themes were identified through an iterative coding process, with multiple rounds of coding and refinement. We validated the themes through intercoder reliability checks, peer debriefing, and member checking. Only when all three coders involved in the thematic analysis agreed on the themes generated did we end this iterative process. Additionally, we ensured analytical rigor by maintaining

an audit trail of coding decisions and refining themes based on patterns emerging from the data [18]. We systematically recorded how coding and theme development evolved during the data analysis process to promote transparency and credibility. Throughout the data analysis process, the main coder also engaged in reflexive journaling. Scientific rigor and phenomenological validity were established by maintaining reflexivity and striving for credibility and the transferability of study findings. Themes were validated by performing member checking with two study participants.

3. Findings

Although each study participant's account was unique as it was organized around specific themes and distinct emotional tones, three overarching themes that reflect the most meaningful perspectives of mothers emerged from the data. Maternal accounts focused on the quality of the care and services their children were receiving in the community (Theme #1), their quality of life in the community (Theme #2), and their children's changes in health status and behavior following their transition to the community (Theme #3). These three themes are presented below, with the most predominant theme, both within and across the mothers, presented first (Theme #1) and the least prevalent theme presented last (Theme #3).

3.1. Theme 1: "Our Children Are Well-Cared-For"

During the interviews, most mothers discussed the high quality of the care their children were receiving in the community and expressed a general sense of satisfaction and contentment regarding the care and services their children were receiving in their new residences and throughout the community. According to the mothers, their children were receiving high-quality care in the community due to a variety of factors, including individualized care and services reflecting each person's unique needs.

> Ellen: "*The level of care she is getting now compared to St.Amant I hate to say it, is way more! Way more. It's one on one. . . .They [staff] worked with Melissa's needs. . . when she moved in [the new community home] and proposed an in-house day program. . . .Something was going on all the time, and it was finally approved much to our relief. So, the nice thing about that was if one of the ladies was having a bad night, with seizures or whatever, and they were supposed to, say go to the zoo the next morning, it was like okay we're not going to the zoo now, we will do our baking today and we'll go to the zoo tomorrow. Which was really nice because the schedule then was very fluid to the needs of the girls. Uhm, and it made everybody much happier. And it still is that way with Melissa, and they really take into account her needs. . .*"

Most mothers discussed how competent and caring staff members thoughtfully attended to their children's needs and respected their unique identities. Some mothers spoke about the low turnover of the staff and the presence of daily routines in the homes as key factors in their perception of high-quality care for their children in the community.

> Faith: "*. . .And I think she [Emily] found the perfect lady to take care of her. . . I couldn't have picked a better person to be a second mother to Emily. She dresses her like a doll. They take her out. . . .And she is starting to know her character, her personality, quite a bit. . . .Emily's a very huggable person, so. . . She cuddles with her on the sofa many times. And she's always so well dressed. I'm very happy. Very satisfied with the care she's received.*"

> Carol: "*It's been wonderful. . . .He's progressed, and the people here are just marvelous. The staffing is more stable, and Samuel is. . . I mean this is his home, he's comfortable here. . . They get to spend more time with Samuel, and they've brought out all these*

wonderful things that were hidden. If I died tomorrow, I'd die knowing that my son is safe, loved by the people in here, well cared for, and happy."

Mandy: "*. . .But they're very good at [community agency]. They're extremely good. . . Since he [Mark] moved to [community agency], from two days after he moved, he's up at 6:30 every morning. . . And I was very happy about [staff]. . . We were absolutely floored when he said she likes me! She's good to me!"*

Some mothers discussed their satisfaction and contentment with the frequent contacts they were able to maintain with their children while they were living in the community. According to the mothers, these contacts were facilitated by flexible and accommodating staff members with whom study participants had established a pleasant collaborative relationship.

Ellen: "*There's a lot of things that we'll discuss [with the community home staff] about Melissa, like if there's anything going on with her medically or whatever. . . I don't just make a decision and say you have to follow it. I will go and talk to the staff that work with her and okay what's your opinions? . . .It's not only good for Melissa and the staff who's looking after her, but it's also good for me because I'm making a more informed choice with other people who are with her every day, uhm, so it just works to her benefit."*

Mandy: "*We discuss everything with [name of community agency]. . . Like, they phone when they want to do this, can we try this? . . .We also told [name of community agency] our expectations, and [community agency] were very good. . . .And then [community agency] were so good, they got in touch with me to see what I expected, what I wanted, and they went out and had meetings with Mark [son]."*

Although most maternal experiences were organized around positive themes and emotional tones, during the interviews, one mother expressed dissatisfaction regarding the services her child was experiencing in the community due to high turnover.

Carol: "*. . .Turnover in staff. . . .So, when there was a, y'know a staff change or turnover, well naturally, it affected him, I mean he's in a brand new place, a brand new environment, and then he's just getting used to certain people and then all of a sudden, they're gone."*

3.2. Theme 2: "Our Children Enjoy a Superior Quality of Life"

The second theme that emerged from study participants' accounts pertain to mothers' perception that their children were enjoying a superior quality of life in the community, likely due to the high-quality care they were receiving. For example, Ellen described the services her daughter Melissa was receiving in the community as organized into an approach to care that promoted Melissa's emotional well-being, self-determination, personal development, and interpersonal relations (i.e., quality of life domains) [19].

Ellen: "*The staff very quickly picked up on Melissa's nonverbal communications. They involve her in choices. They involve her in things, like when they take her shopping, they let her choose what she wants. Because they do know her answers, how to tell if it's yes or no. I couldn't be happier. She's, uhm, grown that much more. She doesn't mind the outings anymore. And that's one thing that the staff does there, they include her in conversations, uhm, and they started doing a lot more day programs in the house with other homes, which is really cool. And uhm, Melissa absolutely loves it and her friends have increased. And it's really nice, because uhm, she's laughing more, she's participating more. . . During meetings and conversations that involve her, she is part of it. And they'll take her opinion, uhm, they'll ask her questions, so they know what she wants. And it's just, that much better."*

All mothers described the very rich and active social life their children were enjoying in the community as an indicator of improved quality of life. During the interviews, mothers discussed how happy and satisfied they were that their children had the opportunity to perform a personalized and diversified portfolio of recreational activities both in their new home and in the community. Enjoyment, fulfillment, and personal development were often mentioned by mothers as byproducts of these experiences that their children were enjoying.

> Ellen: "*Her [daughter's] social life on the weekends, forget it. . . She has more of a social life than I do. Uh, I'm very happy with it. . . .The first thing that they [staff] did was a potluck. They did a potluck lunch with other homes. . . .The first time, one other person showed up, and now there's like twenty something people coming to these things. . . .The kids from the houses really enjoy getting together. And Melissa has made a really good friend in one of the other kids. . . They get along very well. And it's now expanded to an in-house music program where the other people come. Melissa will join them at breakfast club. . . I know they've met her friend from the other house on shopping trips and outings and stuff. It's really great. I can't say enough about it. So, she started going outside a whole lot more at the house. . . They go to the park, they go to the mall, they go to. . . out wherever. I'm very satisfied.*"

> Carol: "*He [son] is doing things and going places that I never, ever, ever in a million years thought he was capable of! And now, I go home and I cry tears of joy because I mean, he lives a much busier social life than I will ever live! He's going to restaurants. . . He goes swimming once a week. . . .They go to the arcade. He goes to the bank. They take him shopping. . . .He went to a hockey game. I think, he's been to a baseball game. It's opened a whole new world for him!*"

Other mothers spoke of their children's improved quality of life in the community by discussing how their loved ones were enjoying more opportunities to spend time outdoors and participate in activities in their neighborhood, compared to when they were residing in a congregated institutional setting.

> Faith: "*I would say even just going for walks on the sidewalk with the kids [is a benefit of moving to the community]. . . .She [daughter] enjoys the nature. Not that here she couldn't enjoy nature, but y'know it's just. . . It's just a different . . .Feeling. Yes, that you're part of the neighbourhood.*"

Most mothers described their children's residences in the community as their homes because of the comfortable homey feeling they experienced when visiting them. Additionally, many mothers described their children's residences in the community as beautiful and functional homes situated in safe neighborhoods. The residences' location was often mentioned by the mothers as one key aspect of their positive lived experiences as all the mothers wished to be physically close to their children to maintain regular contact with them.

> Ellen: "*That's the one big thing about the house right now, it's Melissa's home. And she is at home there. . . .[Melissa lives] in a group home. . . About five minutes away from my house, which I absolutely love. I was looking forward to her being closer to me. . . I was absolutely thrilled that it was going to be that close. And it's within five minutes of my son. . . So, I was very happy with the location.*"

> Brenda: "*What a beautiful home they built for her [daughter], it's lovely, no complaints there, it's lovely. I really like it. It's a safe neighbourhood. It's quiet. The house is new, it's modern, and they have it really nicely furnished. . . She [staff member] made the home beautiful, that's what I really loved.*"

Ina: "*Yeah, it [home] is nice. It's big, it's wheelchair accessible. And the area is a good area.*"

Faith: "*. . .The house, when we go there, it's very clean and tidy, and decorated. It's always decorated too, for themes. I could not say anything negative. They have a beautiful back yard. . . It's a nice neighbourhood. The house is very neat and very well taken care of. And she has a fish aquarium. Emily [daughter] and Kim [roommate] love to look at the fish.*"

3.3. Theme 3: "Our Children Are Doing Better"

During the interviews, study participants also discussed their children's health status and behavior in their new community homes. According to most mothers, since their community transitions, their children had experienced some improvements in physical health and behavior, as revealed by a decrease in health issues, medications, and behaviors of concern, compared to when they were living in a congregated institutional setting.

Carol: "*His [son's] behaviour was more erratic. I mean his behaviour was quite erratic when he was at [institution].*"

Mandy: "*. . .They [staff] have got him totally off them [medications] in the daytime. . .*"

Faith: "*. . .Now she's off her insulin. . . So. . . As far as her diet, it's well taken care of. . . .She's well taken, y'know medically. . . And medically, there's doctors, or dentists, whatever. It's all there for her to access.*"

Goldie: "*At [institution]. . . They were giving him two or three. . . Three types of medications. And now he's only getting one at the home.*"

Some mothers mentioned that because of receiving high-quality care, their children had experienced some improvements in their functioning and adjustment.

Ellen: "*. . .Melissa has really come out of her shell. She's making new friends; she's trying new things. . . .Just the involvement with. . . Non-special need people, like her workers and stuff, they'll talk to her. I mean, some of her workers are about the same age. And they'll talk to her as an equal.*"

One mother, on the other hand, discussed her experience of her daughter's deteriorating health and behavior in the community. As shown below, during her interview, Ina discussed how her daughter Nancy experienced a worsening in behaviors of concern as well as some sleep problems following a "very smooth" transition to the community.

Ina: "*I'm happy. It's just that [daughter]'s behaviour is coming back again. The aggressive behaviour. . . Now it's back. . . The psychotic meds, they had to increase it. . . She was good. This recently, it's escalating. It started last year. . . The challenge, like now, the challenge is her behaviour. [The move was] very smooth until just now, that she's showing this escalation of aggressiveness, sometimes head banging. . . That stuff she wasn't doing before, it's like it's coming back. We don't know why. Ripping off her clothes. . . But so far, she's okay. It's just that. . . Like I said, her behaviour is the only thing right now. And she's not sleeping. That's one thing. She's not sleeping now.*"

4. Discussion

The most prevalent theme that emerged from the data, both within and across study participants, speaks of mothers who perceived their children's lives in the community very positively due to the high-quality care they were receiving from competent, attentive, and sensitive staff members. From the mothers' perspectives, a general sense of satisfaction and contentment transpired about the lives that their adult children were living in the community. This was due to the high-quality care they were receiving in their new community

homes, the overall high quality of life they were enjoying, and some improvements in health behavior they experienced. Even though not openly specified by the mothers, a clear connection among these three themes emerged from study participants' accounts. In fact, it can be speculated that receiving high-quality individualized care, involving professional, caring, and respectful relationships between direct support professionals and residents promotes positive quality of life and may also lead to improvements in health and behavior.

These findings can be used to inform future community transitions in Manitoba that are well received by both family members and persons with disabilities. For instance, there is some evidence that individuals with intellectual and developmental disabilities use behaviors of concern as a form of expressive communication and that residing in an environment that is attentive to and supportive of alternative forms of communication in these persons may have positive cascade effects by reducing these behaviors [20]. Therefore, it is possible that the improvements in health and behavior observed by mothers in their adult children following community transition were due to a change in environment involving transitioning to a smaller residence in which direct support professionals are better able to learn the communication patterns used by residents and support alternative, healthier ways of communicating emotional states, needs, and wants. Given this positive cascade effect on well-being, attention to supporting and promoting alternative means of communication should be given by direct support professionals working with adults with intellectual and developmental disabilities during and after the community transition process.

Beautiful, functional, and dignified homes, as well as an approach to care that promotes peoples' emotional well-being, self-determination, personal development, and interpersonal relations, and that offers residents ample opportunities to spend time outdoors and cultivate activities in the community (i.e., social inclusion) were also common lived experiences discussed by mothers during the interviews. Most mothers indicated that their children were receiving a high quality of individualized care from community staff, which likely promoted their children's quality of life and well-being. This is a finding that highlights the importance of adopting a person-centered approach to deinstitutionalization and community living in all future community transitions. Mothers valued the thoughtful care provided when staff attended to their children's unique needs, further emphasizing the need for staff training to develop fundamental skills such as person- and family-centered care.

Most mothers communicated a general sense of relief in knowing that their children were well taken care of in their community homes. It is common for family members of adults with intellectual and developmental disabilities, particularly aging parents, to be concerned about their adult children's living arrangements and supports as they know that they will not be able to care for their children forever [9,20]. During her interview, Carol stated that if she died tomorrow, she would die knowing that her son is safe, loved by the community staff who support him, well cared for, and happy; most mothers who participated in our study shared Carol's perspective. This key finding reinforces the criticality of enabling persons with intellectual and developmental disabilities to live independent lives in the community not only to ensure their access to resources that promote their well-being (e.g., personal care services) but also to lessen the caregiving burden from their family members [10].

Mothers also expressed appreciation for staff that facilitated connections with the family and supported their children's participation in a range of social activities; this is another area where qualified staff can impact community living experiences. As McCausland et al. pointed out [21], following community transition, persons with intellectual and developmental disabilities enjoy better social connections; however, older groups tend to have smaller social networks that include mostly staff members and peer residents. This

reality highlights the central role that community staff play in promoting social connections, friendships, and close relationships among these people [22]. Thus, the social connections of persons with intellectual and developmental disabilities living in the community could be enhanced by leveraging staff members' role as a liaison between the person and the community [13,23].

Upholding the right of persons with intellectual and developmental disabilities to live independently in the community and be included in their community means enabling them to live where and with whom they choose; to participate in meaningful community activities based on personal interests; to have relationships with friends, family, and significant others; to be physically and emotionally healthy; and to have opportunities to learn, grow, and make informed choices [2,4,5,24]. Overall, the study findings suggest that community living that is person- and family-centered improves the well-being of persons with intellectual and developmental disabilities by providing them with the environment and resources they need to live a high quality of life. This finding, which aligns with existing evidence about community transition in other jurisdictions [25], pinpoints the need to offer individualized community living options to all persons with intellectual and developmental disabilities, including those who will experience community transition in Manitoba in the future. Additionally, policies that support agencies in retaining direct support professionals should be implemented at the local and larger national level to avoid disruption in service provision that may have a negative impact on residents' health and well-being.

Notwithstanding the overarching positive perspectives that emerged from the accounts of study participants, some exceptions must be noted here. One mother expressed dissatisfaction and worry regarding the living conditions and support care her daughter, Nancy, was receiving in the community. At the time of data collection, Nancy had been living in the community for over 5 years and, therefore, the regression to pre-transition status in health and behavior her mother noticed in Nancy may be due to an "adjustment effect" commonly described in this population following community transition [25]. Future research conducted using quantitative longitudinal designs, including, for instance, mixed effect models, may help explain these findings [26].

In future research, mothers could be re-interviewed to learn about changes in their experiences as their loved ones continue to live and age in the community. The knowledge generated can be used for planning future successful community transition plans in Manitoba (e.g., those implemented at the Manitoba Developmental Centre), and beyond. Future research could also expand recruitment to other Canadian regions and internationally to learn about the experiences of families who live in different contexts.

Study Limitations

Due to some methodological limitations, the findings of this study should be considered exploratory, with the potential for further investigation with larger, more diverse samples to build on and expand this investigation. First, the study included only families living in the Canadian city of Winnipeg, which limits the relevance of our findings to families living in other geographical areas, such as rural areas in Manitoba or jurisdictions outside Manitoba where health and social services are organized and delivered differently from the context discussed here. Sociodemographic factors, such as socioeconomic circumstances, level of education, language spoken, and social capital, may have shaped participants' access to resources and overall satisfaction with service delivery. However, due to the limited sociodemographic data collected, we were unable to analyze these factors. Only one data collection method—individual interviews—was used to investigate the study participants' perspectives, which prevented data triangulation. Additionally, the

size of our study sample was not determined by data saturation; instead, we interviewed everyone who expressed interest in participating in the study and, therefore, we were unable to confirm data saturation. We acknowledge that the exclusive focus on mothers living in urban settings limits the generalizability of our findings. Due to challenges in accessing other family members and families in rural or remote settings, our study was unable to include a broader range of participants, which may have influenced data saturation.

Access to other family members, such as siblings and extended family, was limited in our study as many of these family members were not actively involved in the lives of their adult children who transitioned to community living. This participation bias supports the existing literature on the key role mothers paly in caring for their children with intellectual and developmental disabilities. Mothers frequently serve as the main, and sometimes sole, caregiver for children with disabilities, a role that profoundly impacts their daily lives and personal identities [27]. Investigation of these topics, as well as caregivers' perspectives of individualized care and their satisfaction with care services, would be a meaningful extension of this research. Future research could focus specifically on the perspectives of both formal and informal caregivers to further enrich this area of inquiry.

We also acknowledge that the geographic scope of our study is a limitation, as experiences of community living may vary across urban, suburban, and rural settings. While our study offers valuable insights into the transition experience within an urban setting, future research should consider including participants from diverse geographic regions to examine how location-specific factors (e.g., availability of services, community support, transportation, and social networks) shape family members' experiences and the transition process.

Finally, the perspectives captured in this study primarily reflect those of mothers who remained actively involved in their adult children's lives. As such, the experiences of individuals with intellectual and developmental disabilities who do not have family involvement may differ significantly. The presence of an engaged family member may have mediated the transition experience, potentially leading to more positive outcomes, given their advocacy and support in navigating services. Future research should specifically try to capture the diverse perspectives of these families.

5. Conclusions

Most of the mothers who participated in this study expressed great satisfaction with the lives their children were enjoying in their new homes and the health and social services they were accessing in the community. Maternal satisfaction was based on their perception of the high-quality individualized care and high quality of life that their children were experiencing while living in the community, as well as their observations of the improved physical health and behavior of their loved ones as evidenced by a decrease in health issues, in the number of medications used, and in behaviors of concern. Our study findings bring attention to the importance of offering individualized community living options to all persons with intellectual and developmental disabilities, including those who will experience community transition in Manitoba in the future. Key elements of high-quality, individualized care include person-centered support, meaningful engagement opportunities, and responsiveness to the unique needs of individuals with intellectual and developmental disabilities [28]. However, challenges such as resource limitations and variability in service provision highlight areas for improvement. Our findings emphasize the need for continued efforts to enhance individualized care models, ensuring that services remain flexible, inclusive, and tailored to the evolving needs of individuals and their families. It is imperative that organizations and entities work in close collaboration with the family members of persons with intellectual and developmental disabilities to design

individualized, person-centered community transition and care plans to provide these families and their loved ones high quality services that will ultimately promote their health and well-being.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/disabilities5020039/s1, Supplementary File S1: Interview Guide.

Author Contributions: Conceptualization, M.C. and S.S.; methodology, M.C.; validation, S.S.; formal analysis, M.C. and M.B.; investigation, M.C.; data curation, M.C. and M.B.; writing—original draft preparation, M.C.; writing—review and editing, M.C., M.B., L.M., K.K., J.M. and S.S.; supervision, S.S.; project administration, L.M. and S.S.; funding acquisition, S.S. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by The Winnipeg Foundation (Community Grant # 2015-2262), and Mitacs.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of the University of Manitoba (protocol number HS20830 (H2017:175), approved on 27 September 2017.

Informed Consent Statement: Informed consent was obtained from all participants involved in the study prior to conducting any research activity.

Data Availability Statement: Given the qualitative nature of this investigation, the study data are not publicly available. Interested individuals are encouraged to contact the first author to request access to deidentified interview transcripts.

Acknowledgments: We sincerely thank all the mothers who participated in this study; without you, this work would have not been possible. We also thank all the members of our larger working group.

Conflicts of Interest: Lindsay McCombe is affiliated with the St.Amant. The other authors declare no conflicts of interest.

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