

A Family Systems Perspective on Supporting Self-Determination in Adults with Intellectual
Disabilities During Transitions

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A dissertation submitted to the
Faculty of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Clinical Psychology

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Summary

This dissertation concerns the family context of self-determination in adults with intellectual disabilities (ID) during life transitions. Although self-determination is interpreted in different ways in different disciplines, the construct is frequently used to describe the attitudes and behaviours that allow people to feel autonomous and causal in their lives. Research on self-determination in adolescents and adults with ID has commonly occurred in community and special education sectors, with an emphasis on arranging supports for people with ID to develop component self-determination skills, like choice making, problem solving, and goal setting. From the perspective of organismic-dialectical theories, people develop and express self-determination through relationships and person-environment interactions at multiple system levels. Further research on the way family interactions and supports influence the self-determination of adults with ID is important. To address this need, this dissertation includes a qualitative study presented in two manuscripts and a quantitative study presented in one manuscript.

The qualitative study explored processes and challenges in the family system during significant life transitions with an adult family member with ID. Families participated in semi-structured interviews and ethnographic observations of daily activities every three to four months for one year. Manuscript 1 concerns the influence of family processes on the self-determination of two young adults with ID as they attained adult roles in the community. Parents were observed to model goal setting, encourage choice making, and scaffold new skills, which helped the young adults with ID to experience autonomous motivation in their transitions. Parents reported feeling unsure of the best way to promote their adult child's independence while ensuring his or her safety. They tried to resolve this dilemma with open and honest

communication. Most interestingly, families collaborated in choice making to the extent that every family member perceived autonomy in transition planning and implementation.

Manuscript 2 concerns the influence of transition processes and challenges on the quality of life and resilience of four families with an adult family member with ID. Although families reported different transition types, they progressed through similar transition stages. They invested in quality of life and self-determination as a foundation, considered future support needs, pre-planned and actively planned transitions, implemented transitions, adjusted to new roles and routines, and reflected upon their growth. Although all families experienced challenges during their transitions, two families entered a state of crisis when they did not receive mental health and residential supports. Findings highlight that transitions are lifelong processes in the family system, and risk and protective factors at multiple system levels affect resilience and self-determination.

The quantitative study, presented in Manuscript 3, considers that the family system functions within broader socioecological environments that include formal services for adults with ID. Community participation supports provide opportunities to develop self-determination in recreational, educational, and vocational activities. In a cohort of families requesting community participation supports, the vast majority of parents endorsed the expectation that this service would improve choice-making outcomes for their adult child with ID. Preliminary results suggest that the gender and prior choice-making experience of the adult with ID may be associated with the odds of parents endorsing this expectation.

The General Discussion integrates the primary findings from each manuscript within a conceptual framework informed by self-determination theory, family systems theory, and family resilience models. This dissertation has theoretical implications for the way the self-

determination construct is understood and applied in research with families with a family member with ID. Further, this dissertation reveals practical implications for supporting families with a family member with ID during important life transitions.

Keywords: intellectual and developmental disabilities, family systems theory, self-determination theory, family resilience, choice making, transition to adulthood, transition to supported independent living, access to services

Acknowledgements

I am immensely grateful to the people who supported me in completing my dissertation and graduate training in clinical psychology. First and foremost, I am deeply indebted to my dissertation advisor, Dr. Virginie Cobigo. She welcomed me into her research team and patiently guided me through every step of the dissertation process, offering steadfast support. I sincerely appreciate the time and energy she invested to help me reach my professional and personal goals. I also extend my gratitude to the Informed Decisions and Actions (IDeA) for Inclusion research team for creating a supportive and stimulating working environment.

I am grateful to my committee member and collaborator, Dr. H  l  ne Ouellette-Kuntz, for welcoming me as a trainee with the Multidimensional Assessment of Providers and Systems (MAPS) research program and entrusting me with data from two MAPS projects, which she co-
led with Dr. Yona Lunsky. Over the years, Dr. Ouellette-Kuntz generously shared her time and expertise, in a helpful and encouraging manner. Several academic partners, community partners,
research assistants, and trainees also contributed to the development and execution of the MAPS
projects. In particular, I would like to thank Mary Blinkhorn for conducting the interviews and
Ashleigh Blinkhorn for preparing the dataset and answering my many logistical questions.

I would like to express my gratitude to my committee members, Drs. Stuart Hammond and John Sylvestre, for providing insightful comments that stretched my thinking and prompted me to strengthen my dissertation. I especially appreciated their advice and flexibility when I was in the final stages of preparing my dissertation. I would also like to thank Dr. Dwayne Schindler for providing statistical consultations and Dr. Alyssa Counsell for answering my endless statistical questions and caring enough about my progress to plan our academic writing retreats.

Amidst the challenges of graduate training, I found myself surrounded by the right people at the right time. I am eternally grateful to Dr. Pierre Ritchie for offering much-needed advice and to Dr. Julie Desjardins for nurturing my development and confidence as a clinical psychologist. I owe a heartfelt thank you to the friends I made in this program for providing informational and emotional support and, mostly, for listening. I am so honoured to join them in this profession.

Finally, I would like to acknowledge the families who participated in this research. They openly shared their stories so that we might understand the challenges and triumphs of supporting self-determination and navigating transitions with an adult family member with an intellectual disability.

contributed to the development of the literature review and methodology. In addition, anonymous reviewers from the *Journal of Applied Research in Intellectual Disabilities* provided comments that contributed to the current structure of the first manuscript. Compared to the version accepted for publication, the version of the first manuscript in this dissertation includes more substantive details on the data analysis, in response to feedback from Dr. Sylvestre.

The studies in this dissertation were undertaken as part of the Multidimensional Assessment of Providers and Systems (MAPS; www.mapsresearch.ca) research program. MAPS was supported by research grants from the Government of Ontario's Ministry of Community and Social Services. My graduate research was financially supported by the Joseph-Armand Bombardier Canada Graduate Scholarship (2011, 2013–2016) from the Social Sciences and Humanities Research Council (SSHRC) and the Ontario Graduate Scholarship (2012) from the Government of Ontario Ministry of Training, Colleges and Universities. The views expressed in this dissertation are not necessarily the views of all MAPS partners, researchers, collaborators, or those of the Ministry.

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General Introduction

General Introduction

An intellectual disability (ID) is a condition that originates before the age of 18 characterized by limitations in both intellectual functioning (e.g., reasoning, academic learning, problem solving) and adaptive behaviour (e.g., communication, social participation, academic and occupational functioning; American Association on Intellectual and Developmental Disabilities, 2010; American Psychiatric Association, 2013). Formerly termed mental retardation, an ID may alternatively be referred to as a developmental disability in Ontario, Canada or an intellectual and developmental disability in the literature. Diagnostic manuals use the terms intellectual disability (Diagnostic and Statistical Manual of Mental Disorders, DSM-5, American Psychiatric Association, 2013) and intellectual developmental disorder (International Classification of Diseases and Related Health Problems, ICD-11, World Health Organization, 2018). Diagnosis requires clinical assessment and standardized testing of both intellectual and adaptive functioning (American Psychiatric Association, 2013). Classifying the severity of ID (i.e., mild, moderate, severe, profound) depends on the level of support needed in conceptual, social, and practical domains of adaptive functioning. ID is a heterogeneous diagnostic category. Associated conditions may include Down syndrome, fetal alcohol syndrome, fragile X syndrome, Rett syndrome, autism spectrum disorder (ASD), and cerebral palsy if deficits in intellectual functioning in the developmental period affect the ability to independently fulfill social responsibilities and respond to environmental demands. Compared to those without ID, children and adults with ID are more likely to experience co-occurring physical health and mental health conditions (Cooper et al., 2015; Einfeld, Ellis, & Emerson, 2011; Lunskey et al., 2018). The prevalence of ID in the general population is 1 in 100 (American Psychiatric Association, 2013).

Historically, institutionalization and exclusion practices did not offer opportunities for people with ID to govern their own lives. In recent decades, awareness has shifted to person-centred and person-directed practices that empower people with ID to build and enact their own visions for their lives (Lotan & Ells, 2010; Martin, Grandia, Ouellette-Kuntz, & Cobigo, 2016). Ratified in Canada in 2010, the United Nations' (2006) *Convention on the Rights of Persons with Disabilities* (CRPD) upholds the rights to equality and non-discrimination; outlines specific actions for inclusion in education, employment, and health and community services; and mandates reviews of the way these policies are implemented (Government of Canada, 2018). More specifically, the CRPD recognizes "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" and "the opportunity to be actively involved in decision-making processes about policies and programmes" (United Nations, 2006, p. 2). The guiding values of inclusion, choice, and independence are also reflected in Ontario legislation in the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (Government of Ontario, 2008).

Central to policy and service provision, and to this dissertation, is the self-determination of people with ID. Admittedly a nebulous construct, self-determination is associated to varying degrees with feeling autonomous, psychologically empowered, and capable of making choices to realize personal preferences and goals. Shogren, Wehmeyer, Buchanan, and Lopez (2006) conducted a content analysis of 30 years of ID literature and noted an increasing focus on inclusion, strengths and capabilities, and self-determination over time. In particular, the proportion of articles with a focus on strengths and capabilities that covered an essential characteristic of self-determination increased from 28.8% in the years 1975 to 1984 to 48.1% in

the years 1995 to 2004. Self-determination is associated with increased quality of life (Lachapelle et al., 2005), including enhanced academic achievement (Erickson, Noonan, Zheng, & Brussow, 2015), post-school outcomes (Shogren, Villarreal, Lang, & Seo, 2017), and task engagement and interest, as well as decreased challenging behaviours (Cannella, O'Reilly, & Lancioni, 2005). Efforts to equip caregivers to promote self-determination in people with ID are considered central to best practice (Brown & Brown, 2009; Lotan & Ells, 2010). Because people with ID receive care from family members for a variety of daily living tasks and may continue living in their parental home in adulthood (Braddock, Emerson, Felce, & Stancliffe, 2001; Larson, Lakin, Anderson, & Kwak, 2001), self-determination is best understood as a function of the family environment.

The way family interactions and supports influence the development and expression of self-determination in people with ID has received insufficient focus in the literature (Curryer, Stancliffe, & Dew, 2015; Wehmeyer, 2014). This dissertation employs a socioecological systems lens to examine the family context of self-determination for adults with ID and the implications for service delivery. Self-determination theory (Deci & Ryan, 1985, 2000, 2002; Ryan & Deci, 2017), family systems theory (Begun, 1996; Bowen, 1978), and family resilience models (Henry, Morris, & Harrist, 2015; Patterson, 2002) provide an overarching framework. Specifically, this dissertation includes a general introduction, two studies presented in three manuscripts, and an integrated discussion. To provide a foundation for the manuscripts in this dissertation, this general introduction reviews the existing literature and research rationale. First, meanings and interpretations of the self-determination construct are presented, especially as they vary by discipline. Second, factors that affect the way people with ID develop and express self-determination are discussed at multiple system levels. Third, family efforts to support self-

determination in people with ID, and the ethical and practical challenges in doing so, are reviewed. Finally, the research context and objectives for each study and manuscript are introduced.

Meanings and Interpretations of Self-Determination

Adults with ID understand self-determination to mean being in charge, voicing preferences and interests, setting and working toward goals, and making choices for living arrangements, vocational pursuits, and leisure activities (Nonnemacher & Bambara, 2011; Shogren & Broussard, 2011). Parents who have a son or daughter with ID tend to describe self-determination as acting autonomously, directing one's own life, and recognizing one's own skills and limitations (Arellano & Peralta, 2013). These are important perspectives, yet an operationalized definition of self-determination is necessary to guide research and practice. Wehmeyer (2004) contends that self-determination is "laden with multiple meanings and intents that have resulted in confusion and misunderstanding ... a buzzword, implying different things to different people" (p. 338). An understanding of self-determination requires an understanding of its evolution and varied applications by discipline (Wehmeyer, 2004, 2005; Wehmeyer, Shogren, Little, & Lopez, 2017a). For the purpose of this dissertation, an examination of the way the fields of philosophy, intellectual disability, special education, and psychology have contributed to this construct is relevant.

Contributions from Philosophy

Self-determination emerged from the philosophical doctrine of determinism (Wehmeyer, 2004, 2005; Wehmeyer et al., 2017a). Determinism concerns explanations for human behaviour. Hard determinism holds that behaviour is entirely the product of causal laws, such as genetic predispositions, preceding experiences, reinforcement histories, and unconscious processes

(Sappington, 1990). Free choice and moral responsibility are said to be illusory because even wishes and desires are themselves the product of causal laws. For example, in his treatise *On the Improvement of the Understanding*, Jewish-Dutch philosopher Benedict de Spinoza (1632–1677) reasoned that humans exist in fully deterministic systems:

In the mind, there is no absolute or free will; but the mind is determined to wish this or that by a cause, which has been determined by another cause, and this last by another cause, and so on to infinity. (1662/1883, Prop. XLVIII)

Soft determinism holds that causal laws and free will are not mutually exclusive, and people can experience volition in their behaviour (Sappington, 1990). People consciously make choices that will affect their lives, although these choices are determined by preceding causes. For example, in his treatise *An Essay Concerning Human Understanding*, English philosopher John Locke (1632–1704) reflected on free will:

Though I have endeavoured to express the act of volition, by CHOOSING, PREFERRING, and the like terms ... volition is nothing but that particular determinism of the mind, whereby, barely by a thought, the mind endeavours to give rise, continuation, or stop, to any action which it takes to be in its power. (1690/1975, XXI.30)

Libertarianism and indeterminism hold that human behaviour is not influenced by external factors at all (Sappington, 1990). Rather, people freely and actively make choices that shape their destiny, and their choices emanate entirely from their free will. From philosophical roots, self-determination evolved along two distinct paths, referring first to an individual characteristic for volitional action and second to a group right for political sovereignty (Wehmeyer, 2004). The second, more recent meaning has been attributed to President Woodrow Wilson's 1918 speech to

the United States Congress, outlining a peaceful post-war society in which defeated countries should have the opportunity for self-governance (Heater, 1994, as cited in Wehmeyer, 2004).

Contributions from the Field of Intellectual Disability

Swedish philosopher Bengt Nirje (1972) applied the second politicized meaning of self-determination in the disability field as a call to action for dignity and equality (Wehmeyer et al., 2017a; Wehmeyer & Shogren, 2017). In this way, self-determination as a group right referred not to citizens of a defeated country but to people collectively known by a disability status that had historically limited their right to self-governance. The construct developed through the 1970s and 1980s in parallel to the disability rights movement, becoming synonymous with power and independent control over one's life. The disability field, then, "[applied] the national, political, or collective meaning of the self-determination construct to the level of the person" (Wehmeyer, 2005, p. 119). Researchers have concerns that self-determination as independent control is too far removed from its philosophical antecedent, inaccurate and limiting for people who have severe disabilities, overly simplistic in focusing on 'allowing' choice making, and inflexible to individually versus collectively oriented cultures and the amount of control each person desires over each area of his or her life (Abery & Stancliffe, 2003a, 2003b; Wehmeyer, 2004, 2005; Wehmeyer & Abery, 2013; Wehmeyer et al., 2011). Young (2001) suggests that conflating self-determination with non-interference and non-influence from others does not properly account for our embeddedness in social relationships. Wehmeyer (2005) contends:

Control may be a useful heuristic when rallying others to the cause, but it is not an accurate way to define self-determination and, I believe, its use represents the most consistent misuse of the self-determination construct and contributes significantly to the

limited degree to which the field has focused on promoting the self-determination of people with severe disabilities. (p. 116)

Best practices for ensuring people with ID are empowered in directing their lives include supported decision making (Devi, 2013) and person-directed planning (Martin et al., 2016). These are important efforts that are related to, but not synonymous with, self-determination as volitional action.

In contrast to viewing self-determination as independent control, another model in the field of ID considers person-environment interactions at multiple system levels, consistent with Bronfenbrenner's (1979) ecological systems theory (Abery & Stancliffe, 1996, 2003a). The tripartite ecological model of self-determination (Abery & Stancliffe, 2003b) emphasizes congruence between the level of control the individual *desires* and *exercises* in the areas of life he or she considers important. The individual may seek independence as a way of expressing his or her self-determination; however, independence and self-determination are not synonymous. At the same time, the individual may voluntarily relinquish or share control with trusted others as a way of expressing his or her self-determination. In this way, the individual who values social interdependence and aligns his or her choices with others' wishes is not necessarily limiting his or her self-determination: "Such an analysis misses the point of self-determined behaviour; it is not if one is acting independently, making one's own decisions, solving one's own problems, but rather whether one is the causal agent in one's life" (Wehmeyer et al., 2011, p. 25).

Contributions from Special Education

Wehmeyer and colleagues applied the self-determination construct to evaluate and improve classroom settings and curricula for students with disabilities. They incorporated philosophical underpinnings with rights-based language and, more recently, aligned with

organismic and motivational paradigms in the psychological literature (Shogren et al., 2015; Wehmeyer et al., 2017a). In the field of special education, a widely accepted definition of self-determination is that of “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). Consistent with its application in education, self-determination is associated with skills that can be explicitly taught. Component skills include problem solving, goal setting, self-advocating, and choice making (Wehmeyer et al., 2007). Specific models and theories include the functional model of self-determination (Wehmeyer, Kelchner, & Richards, 1996; Wehmeyer, 1999) and causal agency theory (Shogren et al., 2015).

Functional model of self-determination. According to the empirically validated functional model of self-determination (Wehmeyer et al., 1996; Wehmeyer, 1999), self-determination is neither understood nor measured by the behaviour itself but rather by the *function* of the behaviour for the individual. That is, an individual acting in a self-determined manner is acting to become the causal agent of his or her life, to have some effect over his or her environment. Using discriminant function analyses, Wehmeyer et al. (1996) identified four primary characteristics of self-determined behaviour: *autonomy* is acting in accordance with personal interests, free from coercion; *self-regulation* is evaluating the environment and selecting a course of action for the situation; *psychological empowerment* is feeling effective in influencing outcomes; and *self-realization* is using knowledge of personal strengths and limitations to inform actions. These characteristics were operationalized into the *Arc’s Self-Determination Scale* (Wehmeyer & Kelchner, 1995). Researchers have built upon the functional model of self-determination to develop and evaluate interventions to improve self-determination in students with disabilities. For example, the self-determined learning model of instruction

organizes resources so educators can support students with disabilities in setting and attaining individualized goals, directing their own learning, and preparing for transitions to employment (Lee, Wehmeyer, & Shogren, 2015; Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012).

Causal agency theory. More recently, self-determination researchers in the field of special education expanded upon the functional model of self-determination by incorporating theoretical underpinnings from organismic theories in positive and motivational psychology. Causal agency theory (Shogren et al., 2015) describes the process of becoming self-determined in the context of person-environment interactions that fulfill psychological and biological needs and create conditions for self-determined actions. Self-determined actions have three essential characteristics: *volitional actions* are intentional, autonomous, and consciously chosen; *agentic actions* are self-regulated and self-directed; and *action-control beliefs* reflect perceived utility of a behaviour and personal empowerment for meeting a goal. Self-determined actions, in turn, lead to feelings of causal agency and ultimately to an agentic self. Conditions in the socioecological environment either support or hinder this process. Causal agency theory summarizes self-determination in this way:

A dispositional characteristic manifested as acting as the causal agent in one's life. Self-determined *people* (i.e., causal agents) act in service to freely chosen goals. Self-determined *actions* function to enable a person to be the causal agent in his or her life. (Shogren et al., 2015, p. 258)

One of the reasons for developing causal agency theory was the “need to align with research and practice in positive psychology” (Shogren et al., 2015, p. 255), which is discussed next.

Contributions from Psychology

In the late 1800s, psychology emerged as a discipline unique from philosophy. Early theorists were hard determinists (Sappington, 1990). For example, psychoanalysts like Sigmund Freud (1856-1939) viewed behaviour as entirely caused by unconscious forces, whereas behaviourists like John B. Watson (1878–1958) and B. F. Skinner (1904–1990) viewed behaviour as entirely caused by learned or conditioned responses to stimuli. In contrast, humanists like Carl Rogers (1902–1987) and Abraham Maslow (1908–1970) were libertarians who posited that human behaviour is motivated by a self-actualizing tendency and a desire to fulfill psychological needs. Moving toward soft determinism and advancing theories of personality within person-environment interactions, Andras Angyal (1902–1960) distinguished between autonomy and homonomy (Angyal, 1941, as cited in Marsh, 1960; Trist, 1992). He posited that autonomy or self-determination represents the tendency to master the environment as a separate being, whereas homonomy or self-surrender represents the tendency to willingly accede to the environment as a cause larger than the self. Angyal (1965) asserted that autonomy is essential to living organisms, and independence is naturally balanced with interdependence:

The human being is both a unifier, an organizer of his immediate personal world, and a participant in what he conceives to be the superordinate whole to which he belongs. His striving for mastery is embedded in his longing for participation. (p. 29)

De Charms (1968) expanded upon internal versus external motivators of human behaviour with his theory of perceived locus of causality. A person with an internal perceived locus of causality is the “origin” of autonomous behaviour, whereas a person with an external perceived locus of causality is the “pawn” to heteronomous forces.

Building upon these foundations, and central to this dissertation, Edward L. Deci and Richard M. Ryan formalized self-determination theory to describe types and qualities of motivation and their effects on behaviour and well-being (Deci & Ryan, 1985, 2000, 2002; Ryan & Deci, 2000, 2017). Deci and Ryan emphasize person-environment interactions and constraints that determine human behaviour, while also asserting that autonomy and volition have a role in modern psychology when terms are applied precisely (Ryan & Deci, 2006). Self-determination theory, therefore, reflects a position of soft determinism. Since its inception in the 1980s, self-determination theory has been empirically evaluated, expanded, and refined by numerous international scholars with applications in health care, education, and parenting, to name a few.

Self-determination theory. Self-determination theory is a meta-theory of motivation, development, and well-being at the intersection of social, developmental, personality, and clinical psychologies (Ryan & Deci, 2017). Self-determination theory is situated within an organismic-dialectical paradigm, which assumes people are naturally oriented to explore, learn, and actively shape the environment to become causal agents of behaviour, integrate a sense of self, and achieve optimal well-being. To actualize their inherent growth tendency, people interact with the environment in service to three universal psychological needs: *competence*, or “feeling effective in one’s ongoing interactions with the social environment and experiencing opportunities to exercise and express one’s capacities”; *relatedness*, or “feeling connected to others” and “having a sense of belongingness both with other individuals and with one’s community”; and *autonomy*, or “[experiencing] behaviour as an expression of the self, such that, even when actions are influenced by outside sources, the actors concur with those influences, feeling both initiative and value with regard to them” (Deci & Ryan, 2002, pp. 7–8; Ryan, 1995). Note that Deci and Ryan define autonomy as self-regulating and self-endorsing actions, not as an

ability to act separately from the environment. Although terms are often used interchangeably, autonomy is quite distinct from independence, in that the latter refers to acting self-sufficiently, without the influence of outside forces. This distinction is especially important for people with ID who can be supported in acting autonomously, according to their interests and values, regardless of the extent to which they depend on others for support.

Factors in the environment either support or thwart basic psychological needs and, in turn, growth, integrity, and well-being (see Figure 1; Deci & Ryan, 2000; Ryan & Deci, 2017). Essentially, conditions that support competence, relatedness, and autonomy facilitate self-determination. *Effectance supportive* environments set structures and organize resources, provide informational and process-oriented feedback, and communicate clear expectations (Grolnick, Deci, & Ryan, 1997; Ryan & Deci, 2017; Soenens, Deci, & Vansteenkiste, 2017). *Relationally supportive* environments afford the involvement of others through respectful, warm, and empathic interactions. *Autonomy supportive* environments provide choices and meaningful rationales for rules, pace learning by developmental needs, encourage self-regulation, and prioritize the intrinsic value of activities. Conditions that thwart competence, relatedness, and autonomy diminish self-determination. Such environments are overly challenging and discouraging, rejecting and impersonal, and coercive and demanding, respectively. Although not the focus of this dissertation, developmental psychologists also consider the way these person-environment interactions co-act with perceptual, linguistic, self-regulating, and moral developmental processes (Sokol, Hammond, Kuebli, & Sweetman, 2015).

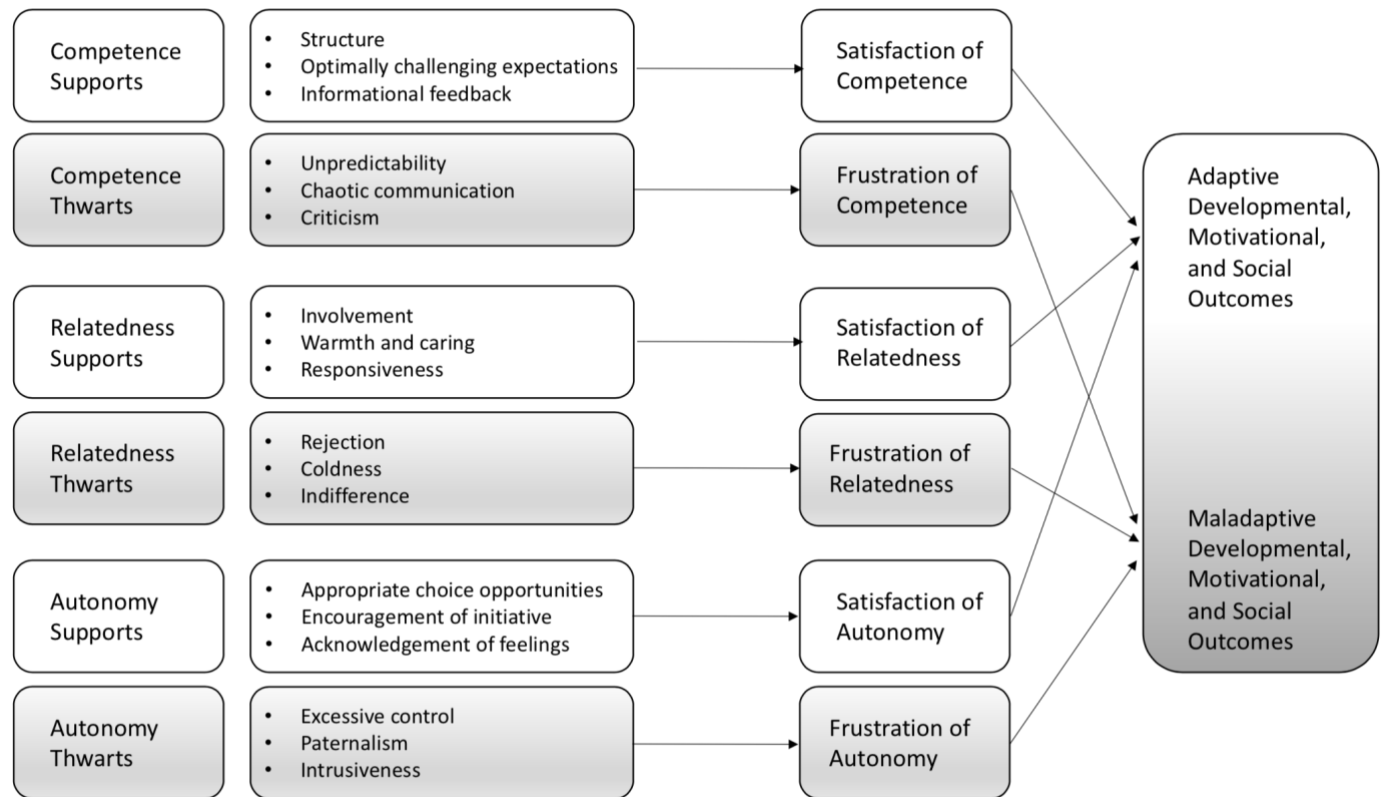


Figure 1. Conceptual model of environmental supports and thwarts for basic psychological needs and resulting need satisfactions and frustrations. Adapted from Soenens et al. (2017, p. 174). Used with copyright permission.

Self-determination continuum. In the context of psychological need satisfaction versus frustration, self-determination theory presents a framework for distinguishing controlled motivation and autonomous motivation (Ryan & Deci, 2017). *Controlled motivation* involves feeling pressure, obligation, or coercion to engage in the behaviour. Controlled motivation may produce short-term compliance if the external contingencies are desired, or defiance if the environment is too controlling. Controlled motivation is associated with negative outcomes in well-being, learning, and relationships. In contrast, *autonomous motivation* involves experiencing the behaviour as originating from the self, acting intentionally and volitionally. The behaviour is thus self-endorsed: The actor “assents to, concurs with, and is wholly willing to engage in the behaviour” (Ryan & Deci, 2017, p. 14). Autonomous motivation is associated with

positive outcomes in mental and physical health, flexibility and creativity, and task engagement, interest, and persistence. Different types of motivation occur on a continuum, with the following regulatory styles reflecting the least to the most self-determination (see Figure 2; Deci & Ryan, 2000; Ryan & Deci, 2017).

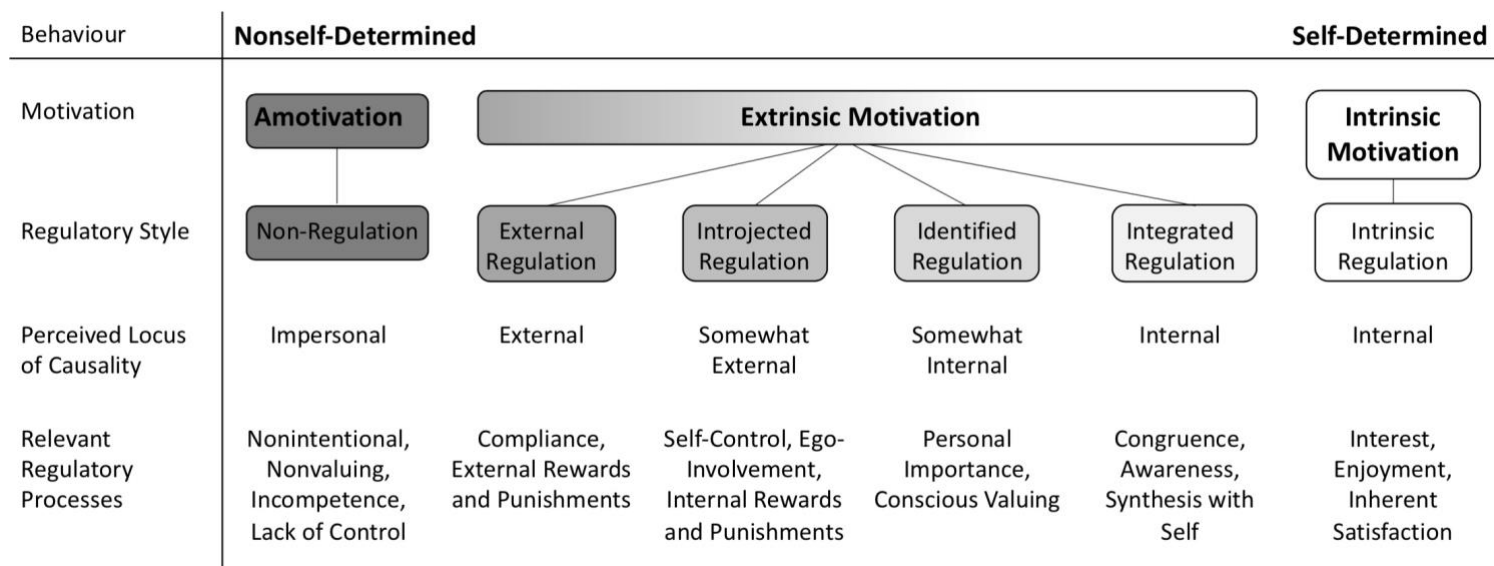


Figure 2. The self-determination continuum showing types of motivation, regulatory styles, loci of causality, and regulatory processes. Adapted from Ryan and Deci (2000, p. 72). Used with copyright permission.

Amotivation. Motivation is characterized by an energy and an intention to act (Ryan & Deci, 2017). In contrast, amotivation is passive. There is no intention to act because of either perceived incompetence or indifference. Amotivation that is characterized by perceived incompetence is conceptually similar to learned helplessness in overly controlling environments (Abramson, Seligman, & Teasdale, 1978; Seligman, 1975). Amotivation is the absolute lack of self-determination toward the target behaviour.

Extrinsic motivation. Extrinsic motivation refers to the desire to engage in an activity for instrumental reasons, with the goal of obtaining specific outcomes (Deci & Ryan, 2000; Ryan & Deci, 2017). Extrinsic motivation can be experienced as either controlled or autonomous,

depending on the form of behaviour regulation and the extent of its internalization in the self-concept. External regulation and introjected regulation are controlled. Identified regulation and integrated regulation are autonomous, preserving a sense of choice and volition.

External regulation. External regulation is acting in response to environmental contingencies to obtain rewards and avoid punishments (Deci & Ryan, 2000; Ryan & Deci, 2017). The resulting behaviours are controlled and not self-determined. Behaviours performed only in response to environmental contingencies are poorly maintained over time. An example is handing in a school assignment because parents otherwise threaten to remove privileges.

Introjected regulation. Introjected regulation is acting in response to internal pressures to reduce feelings of guilt and shame or increase feelings of pride and self-worth (Deci & Ryan, 2000; Ryan & Deci, 2017). The behaviour regulation occurs within the person; however, it remains separate from the feelings and motivations that form the self-concept. Behaviours that are regulated through introjection are not considered to be self-determined. An example is handing in a school assignment because failing the course would cause the actor to feel anxious and ashamed.

Identified regulation. With identified regulation, the actor pursues the behaviour to achieve an outcome that is consistent with his or her goals (Deci & Ryan, 2000; Ryan & Deci, 2017). The motivation is derived from accepting the behaviour as personally beneficial. An example is handing in a school assignment because the actor believes an understanding of the subject matter will further his or her career goals.

Integrated regulation. Integrated regulation is the most self-determined form of extrinsic motivation (Deci & Ryan, 2000; Ryan & Deci, 2017). The motivation is internalized within the self-concept. The behaviour itself is not inherently satisfying; however, the actor intentionally

and volitionally pursues the behaviour in congruence with his or her interests and values. An example is handing in a school assignment because the actor values learning and academic success.

Intrinsic motivation. Intrinsic motivation refers to the desire to self-initiate and self-regulate an activity that inspires interest and enjoyment (Deci, 1975; Deci & Ryan, 1980; Ryan & Deci, 2017). The actor does not depend on environmental reinforcements to engage in the behaviour. Rather, the actor perceives the behaviour itself as rewarding and pursues its inherent value. In this way, intrinsic motivation is intentional and volitional. As the most self-determined form of behaviour regulation, intrinsic motivation is, by definition, autonomous. To maintain intrinsic motivation, the actor requires sustenance in the form of basic psychological need satisfaction (Deci & Ryan, 2000). The conditions that enhance or diminish intrinsic motivation have been studied extensively. A well-established finding is that expected or tangible rewards diminish intrinsic motivation, whereas verbal or relational rewards enhance intrinsic motivation (for a meta-analysis, see Deci, Koestner, & Ryan, 1999).

Internalization. Consistent with the organismic-dialectical perspective of self-determination theory, people are naturally inclined to move along this continuum toward more autonomous forms of motivation in a process called *internalization* (Deci & Ryan, 2000, 2002; Ryan, 1995; Ryan & Deci, 2017). Internalization refers to incorporating the behaviour regulation into the self-concept so that it becomes self-regulated. Internalization of extrinsically motivated behaviours (i.e., integrated regulation and identified regulation) results in feeling autonomous. Partial internalization (i.e., introjected regulation) or a lack of internalization (i.e., external regulation) result in feeling controlled. Fundamentally, internalization is a natural socialization process (Deci & Ryan, 2000; Grolnick et al., 1997; Ryan & Deci, 2017). It enables people to take

on developmentally appropriate responsibilities, assimilate familial and cultural norms and values, and participate effectively in social environments. This process is most likely to occur if people believe they can achieve what is required of them; if they respect, admire, and feel close to the person providing the regulation; and if they believe the behaviour is personally relevant and in line with their interests and values. Internalization is further facilitated when individuals perceive a sense of choice (Deci & Ryan, 2002). Critically, internalization reflects the level of psychological need satisfaction in the given activity and environment (Deci & Ryan, 2000; Ryan, 1995; Ryan & Deci, 2017).

Choice Making in Self-Determination

Choice making is integral to self-determination; however, its application varies by discipline. In the ID field, choice making has a rights emphasis. It is a core indicator and value in service delivery and a means for people with ID to exercise independent control over their lives. Choice making is thus interpreted as synonymous with self-determination. Wehmeyer (2003) has criticized this view: “There is a modern tendency to equate self-determination with only one aspect of its expression, making choices. There are numerous problems with elevating choice as the ultimate value in promoting self-determination” (p. 19). In the field of special education, choice making has a skills emphasis. Choice making is considered a component skill of self-determination and an important way of expressing self-determination (Palmer et al., 2012); however, these terms are not synonymous (Wehmeyer, 2005):

It is important to reiterate that self-determination is not just choice making. Acting volitionally implies action based on one’s preferences, which in turn suggests the importance of making choices. The problem, however, is that people have interpreted

promoting self-determination to mean only “allowing” a person to make choices ... there is more to being self-determined than simply making a choice. (p. 115)

In the field of psychology, choice making has a motivational emphasis. Self-determination theory (Deci & Ryan, 2002) conceptualizes choice making as a vehicle for fulfilling psychological needs in order to transform controlled motivation into autonomous motivation. Regardless of its application, choice making is the most prominent theme in the self-determination intervention literature (Algozzine, Browder, Karvonen, Test, & Wood, 2001). Choice making is associated with increased quality of life, health, and independence for people with ID (Neely-Barnes, Marcenko, & Weber, 2008; Rabiee & Glendinning, 2010).

Choice making is often described as simply selecting an option and communicating it to others; however, true choice making is an expression of preference in which the actor perceives two or more reasonable options and realizes that he or she can influence the outcome of events (Brown & Brown, 2009; Harris, 2003; Webber & Cobigo, 2014). In a scoping review of the literature, Webber and Cobigo (2014) identified four components of successful choice making. First, the actor must be provided with frequent, developmentally appropriate opportunities to make both routine choices (e.g., meals, clothing) and life choices (e.g., service providers, vocational activities). Second, the actor must perceive a range of suitable options from which to choose. One desirable option amidst several undesirable options does not represent a fair choice-making opportunity. Third, the actor must have all relevant information about the available options and enough time to evaluate this information, so he or she can make an informed choice. True choice making is free from coercion and reflects the goals of the individual more than the goals of others. Finally, effective choice making hinges on a supportive environment in which caregivers encourage, accept, and reward choice making. Caregivers must respect and follow

through with the actor's choice but welcome a change of opinion at any time. Further, caregivers must allow the actor to fully experience the consequences of his or her choice, if safe to do so, while providing honest feedback. Choice making may entail an element of risk. Collaborative problem solving and explanations that are accessible and appropriate to the actor's support needs enable the actor to learn from poor choices and make better choices in the future (Nonnemacher & Bambara, 2011).

Self-Determination for People with Disabilities

Self-determination emerges across the lifespan as people experience opportunities for causal agency in their lives and develop the associated attitudes and skills (Heller et al., 2011; Shogren et al., 2015); however, this process may be qualitatively different for people with ID. People with ID tend to report lower levels of self-determination than their peers without disabilities (Mumbardó-Adam, Shogren, Guàrdia-Olmos, & Giné, 2017; Wehmeyer & Metzler, 1995) and their peers with learning disabilities (Chou, Wehmeyer, Palmer, & Lee, 2017; Seong, Wehmeyer, Palmer, & Little, 2015a). To elaborate, Wehmeyer and Metzler (1995) analyzed the responses of over 4,000 adults on the United States' National Consumer Survey, which included questions about choice, independence, community participation, and needed services and supports. Respondents with ID perceived fewer choices and less control over their lives compared to respondents without disabilities. Mumbardó-Adam, Shogren, et al. (2017) compared the self-determination scores of 114 students aged 13 to 22 with and without ID in Spain. Compared to their typically developing peers, students with ID reported lower volitional action, agentic action, and action-control beliefs, as well as fewer opportunities to exercise self-determination in their home.

Self-determination may also vary according to disability type. Seong et al. (2015a) surveyed 954 students aged 11 to 22 with a diagnosis of either ID or learning disability (LD). Autonomy, self-regulation, and psychological empowerment were significantly lower in students with ID compared to students with LD. Having established factorial invariance, the authors interpreted the results as true disability differences rather than construct measurement differences. Using the same measure, Chou et al. (2017) compared the self-determination scores of 222 students aged 13 to 22 with a primary diagnosis of either ID, LD, or ASD. This time, self-regulation, self-realization, and psychological empowerment were significantly lower in students with ID compared to students with LD, whereas students with ASD were significantly lower in autonomy. Cavendish (2017) surveyed 190 high school students with low incidence disabilities¹ (i.e., ID, visual or hearing impairment) and high incidence disabilities (i.e., LD, other health impairments, emotional or behavioural disorder). Disability type predicted self-determination scores when controlling for other variables, with students with low incidence disabilities scoring significantly lower than those with high incidence disabilities. Socioecological factors are essential for understanding differences in self-determination by disability type. Individual, relational, and environmental factors contribute to the self-determination of people with disabilities (Shogren, 2013; Wehmeyer & Abery, 2013).

Individual Factors

Cognitive ability. Cognitive ability refers to mental activities for attending to information, processing information, learning, remembering, and problem solving. Compared to their typically developing peers, adults with mild to moderate ID have been found to have more difficulty evaluating multiple sources of information (Willner, Bailey, Parry, & Dymond, 2010).

¹ Low and high incidence disabilities are based on national prevalence rates from the U.S. Department of Education

On a task that involved weighing small, immediate rewards versus large, delayed rewards, adults with ID produced more random patterns. They also achieved lower scores on a financial decision-making task. Cognitive ability may impact the level of support needed to develop and express self-determination (Wehmeyer et al., 2011).

Verbal ability. Verbal ability refers to receptive vocabulary, expressive vocabulary, and mental activities for attending to and processing orally presented information. The communication support needs of people with disabilities when understanding and expressing choices are a practical challenge for caregivers (Finlay, Walton, & Antaki, 2008). Caregivers may need to interpret their sounds, facial expressions, gestures, and affective and behavioural responses to understand their needs and preferences. In the absence of suitable communication tools, caregivers may incorrectly assume people with limited verbal ability also lack the capacity to make choices. Pilnick, Clegg, Murphy, and Almack (2010) examined moment-to-moment interactions in transition planning and review meetings with eight young adults with moderate to profound ID transitioning from child to adult services. Support workers' efforts to engage adults with ID in these meetings were not always successful. Misunderstandings occurred when support workers asked more than one question at a time, repeated the same question, used different settings (e.g., work, school, home) or tenses (e.g., past, present, future) in the same part of the conversation, and conditionally reinforced answers. Support workers seemed to assume that incoherent responses from adults with ID were a function of communication difficulties rather than a mutual misunderstanding. Finlay, Antaki, and Walton (2008) studied communication patterns in residential settings between adults with ID with limited verbal abilities and their support workers. Residents' nonverbal communication (e.g., sound of dissent, turning away) was not always acknowledged by support workers as an absolute refusal of an activity. At times,

support workers interpreted nonverbal communication as a dispositional characteristic and tried to re-initiate the activity with encouragement, problem solving, and insistence. When support workers did attend to nonverbal communication, they were more attuned to residents' preferences. Further knowledge is needed to mobilize caregivers to facilitate choice-making opportunities and understand preferences in people with communication support needs (Finlay, Antaki, & Walton, 2008; Finlay, Walton, & Antaki, 2008). Assessment by proxy is not always accurate (Cobigo, Morin, & Lachapelle, 2009; Golubović & Škrbić, 2013); thus, nonverbal means of communication are required.

Gender. Gender has been examined less frequently as a covariate in levels of self-determination, and findings are inconclusive (Shogren, 2013; Shogren & Shaw, 2017; Wehmeyer et al., 2011). Rodriguez and Cavendish (2012) examined moderators of the relationship between family environments and self-determination in 157 Latino and Anglo high school students with disabilities (i.e., ID, LD, ASD, other health impairments, emotional or behavioural disorder, hearing impairment). Controlling for other variables, gender significantly predicted self-determination scores. Females scored significantly higher than males in both Latino and Anglo groups. Perceived family environment was also more predictive of self-determination scores for females (accounting for 41% of the variance) compared to males (accounting for 9% of the variance). The authors hypothesized that females with disabilities build their self-determination through relationships, whereas males with disabilities rely to a greater extent on building competency through tasks. In a sample of 190 high school students with disabilities (i.e., ID, LD, attention-deficit hyperactivity disorder, other health impairments, emotional or behavioural disorder, visual or hearing impairment), Cavendish (2017) found that gender significantly predicted self-determination scores when controlling for other variables. Again, females scored

higher than males. In contrast, an examination of self-determination scores in over 4,000 high school students aged 13 to 22 with varying levels of disability yielded no differences between females and males (Shogren, Shaw, Raley, & Wehmeyer, 2018). When examining gender concurrently with disability type and ethnicity, however, females without disabilities and with learning disabilities scored lower than their male counterparts. In a recent meta-analysis of 16 studies that measured self-determination with valid and reliable psychometric tools, Mumbardó-Adam, Guàrdia-Olmos, et al. (2017) found that the relationship between intellectual functioning and self-determination may be stronger in females versus males.

Race and ethnicity. The influence of race and ethnicity on levels of self-determination is inconclusive. Rodriguez and Cavendish (2012) found that ethnicity predicted self-determination scores in high school students with disabilities at a statistically significant level when controlling for other variables. Latino students scored higher than Anglo students. Further, perceived family environment was nearly three times more predictive of self-determination scores in Anglo students compared to Latino students. In contrast, Cavendish (2017) found that neither race nor ethnicity significantly predicted self-determination scores as reported by high school students with disabilities. Mumbardó-Adam, Guàrdia-Olmos, et al. (2017) conducted a meta-analysis to examine personal factors that may moderate the relationship between intellectual functioning and self-determination scores. They found this relationship may be stronger in White/Caucasian people with ID compared to non-White people with ID.

Relational and Environmental Factors

Culture. Self-determination has universal value; however, the way people conceptualize and express self-determination varies by culture (Shogren, 2011, 2012). Research suggests European American parents of children with disabilities are more likely to emphasize

independent living as an aspect of self-determination, compared to parents from diverse cultures (Zhang, 2005; Zhang, Landmark, Grenwelge, & Montoya, 2010). They may prioritize applications for supported independent living facilities and group homes, for example. Shogren (2011) reviewed the existing literature on cultural perspectives of self-determination in the special education field and identified key themes. Collectivist cultures tended to conceptualize self-determined behaviour as embodying group values and fulfilling roles to meet group needs. Shogren (2011) asserted the need for culturally sensitive efforts, namely “a flexible self-determination perspective that works to understand each student and family’s unique value system” (p. 122). Similarly, Hispanic mothers of children with severe disabilities have reported holding views on self-determination that conflict with practices in their children’s schools (Shogren, 2012). They stressed the importance of professionals seeking to understand and respect each family’s culture and values when setting goals for the future.

Caregivers and living arrangements. Adults with ID have reported that support workers can promote their self-determination by listening attentively, assisting them with problem solving to meet their goals, and providing them with information and honest explanations to make choices (Nonnemacher & Bambara, 2011). Conversely, support workers can interfere with their self-determination by making decisions for them, controlling their spending money, using manipulation or persuasion, and neglecting to follow through on agreements. Jingree, Finlay, and Antaki (2006) analyzed moment-by-moment interactions between adults with ID living in residential settings and their support workers. Although support workers stated their intention to uphold policies to protect residents’ choice and independence, they were observed to use leading questions, ignore or dismiss residents’ concerns, and differentially reinforce residents’ statements.

It is essential to equip support workers with the training and resources to promote self-determination in people with all levels of support needs; however, support workers experience a number of obstacles, especially in residential settings (Finlay, Antaki, & Walton, 2008; Finlay, Walton, & Antaki, 2008). On the one hand, support workers must promote residents' self-determination in order to support their quality of life. On the other hand, support workers must adhere to legal and ethical standards in order to ensure residents' health and safety. These demands occasionally conflict, especially when time and resources are limited. For example, residents' meal preferences may be contrary to the nutritional requirements and monthly weigh-ins mandated by the care facility as duty of care. Moreover, support workers may have to manage competing perspectives from supervisors, residents, and residents' family members or guardians. Van der Meulen, Hermesen, and Embregts (2018) interviewed 15 support workers on the way they recognize and justify restraints on freedom in residential and community living facilities with adults with mild to moderate ID. Support workers limited residents' freedom in several aspects of daily life (e.g., meals, hygiene, recreational activities, relationships, bedtime) by appealing to organizational limitations and residents' needs for structure, safety, and optimal health. For example, support workers chose meals for a resident who was overweight and diabetic, limited nightly screen time for a resident who was having trouble sleeping, and enforced a 9:30 pm bedtime for all residents because they had to finish their shifts by 10:00 pm. Support workers reported managing these interactions by communicating with residents, offering suitable choice-making opportunities, showing respect for residents' feelings, and occasionally disguising their efforts to limit residents' freedoms. They experienced doubt, guilt, and moral ambivalence about their actions.

The extent to which support workers balance competing priorities and provide choice-making opportunities is related to the type of residence (Heller et al., 2011; Neely-Barnes et al., 2008; Stancliffe et al., 2011). Neely-Barnes et al. (2008) observed that adults with ID living in smaller residences experienced greater respect for their rights, which was associated with greater choice making and quality of life. Likewise, Stancliffe et al. (2011) observed that adults with ID who lived in more independent settings, such as their own apartment or a group home, exercised more choice than did those in institutions, such as nursing homes. These findings may also reflect that those living in more independent settings tend to have lower levels of support needs; however, the influence of living arrangement on the development of self-determination is important to consider.

Opportunities to develop and express self-determination. People can learn and develop self-determination when they have the right environmental supports (Algozzine et al., 2001; Cannella et al., 2005; Ryan & Deci, 2017; Wehmeyer, Shogren, Little, & Lopez, 2017b). For example, in a study of 114 youth aged 13 to 22 with and without ID in Spain, opportunities to exercise self-determination at home and at school significantly predicted students' reported self-determination scores (Mumbardó-Adam, Shogren, et al., 2017). Moreover, Wehmeyer and Garner (2003) found that choice-making opportunities significantly predicted self-determination scores in 301 adults with ID and other developmental disabilities, whereas intellectual capacity did not. The presentation of these opportunities is inversely related to the severity of disability (Arellano & Peralta, 2013). Essentially, people with ID experience more asymmetrical power relationships than those without ID, tending to require support from others to complete their daily living activities (Lotan & Ells, 2010). This power differential may result in decisions being made for them rather than with them, such that any sense of autonomy remains illusory (Foley,

2013; Knox & Bigby, 2007). For example, research demonstrates that parents are more persistent and directive during problem-solving discussions with children with ID than with typically developing children (Floyd, Harter, & Costigan, 2004; Wieland, Green, Ellingsen, & Baker, 2014). Fundamentally, the reason that people with ID are less self-determined than their typically developing peers may have more to do with a lack of opportunity to develop these skills than with actual cognitive or verbal limitations (Heller et al., 2011; Wehmeyer & Abery, 2013; Wehmeyer et al., 2011). Cognitive ability—rather than determining capacity for self-determination—influences the environmental supports needed to actualize self-determination (Wehmeyer et al., 2011).

Interventions to promote self-determination. Research has reliably demonstrated that people with mild to profound ID have the capacity to become more self-determined through interventions that target component skills (Algozzine et al., 2001; Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013). To begin, Algozzine et al. (2001) conducted a review of 51 studies and a meta-analysis of 22 studies on interventions to promote self-determination in people with disabilities by targeting component skills, such as goal setting, problem solving, self-advocating, and choice making. Group interventions had a moderate effect, and single subject interventions had a strong effect. Cobb et al. (2009) conducted a narrative synthesis of seven meta-analyses and confirmed that interventions to promote self-determination in people with disabilities resulted in enhanced component skills. Such interventions continue to garner empirical support (Seong, Wehmeyer, Palmer, & Little, 2015b; Shogren et al., 2012; Wehmeyer et al., 2013). For example, Wehmeyer et al. (2013) randomly assigned 371 high school students with ID or LD to a placebo control group or a self-determination intervention group. Over three years, the intervention group

showed significantly greater improvement in self-determination skills compared to the control group.

Research on self-determination typically focuses on individual-level factors (Shogren, 2013), and self-determination interventions typically occur in community and special education settings with researchers, service providers, and teachers (Algozzine et al., 2001). Comparatively little is known about the way family attitudes, interactions, and environments impact self-determination in people with ID. Curryer et al. (2015) illustrated this point in observing that, of the 51 studies reviewed by Algozzine et al. (2001), “only five included parents in any way, and none involved parents of adults who had left school” (p. 396).

The Family Context of Self-Determination for People with Intellectual Disabilities

Since the deinstitutionalization movement of the late 1960s, Canadians with ID have had more options for living arrangements. The United Nations’ (2006) CRPD states that people with ID must have the “opportunity to choose their place of residence and where and with whom they live” (Article 19). Because of changes to legislation, as well as medical advancements leading to longer lifespans, a significant proportion of people with ID continue to live in their parental home throughout adulthood and receive support from their family members to complete their daily living tasks (Braddock et al., 2001; Larson et al., 2001). Accordingly, the ID literature has shifted its focus from the experiences of people with ID to a broader examination of the experiences of their family system (Gardiner & Iarocci, 2012; Turnbull, Summers, & Brotherson, 1984; Turnbull, Turnbull, Erwin, Soodak, & Shrogen, 2015).

Socioecological models examine development in the context of broader familial and social factors (Bronfenbrenner, 1979). In particular, *family systems theory* (Bowen, 1978) conceptualizes the family as a dynamic system in which each individual plays an integral part.

The individual cannot be understood in isolation. Each member of the family influences and is influenced by every other member, as well as by wider social, economic, and political systems. *Family quality of life* refers to the health and functionality of the family system, the extent to which “the family’s needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them” (Park et al., 2003, p. 368). *Family resilience* refers to the family’s “positive adjustment in the context of challenging life conditions” (Gardner, Huber, Steiner, Vazquez, & Savage, 2008, p. 107), which may involve maintaining hopeful attitudes, balancing the needs of all family members, and adapting to new roles and environmental demands (Gardner & Harmon, 2002).

Research on family resilience has evolved through the ABCX model of family stress (Hill, 1958), the double ABCX model (McCubbin & Patterson, 1983), the resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993), and the family adjustment and adaptation response model (Patterson, 1988, 2002), for example. Most recently, Henry et al. (2015) proposed the family resilience model: Risk, protection, vulnerability, and adaptation interact and are influenced by families’ worldviews and interpretations of situations, mechanisms for regulating family life and fulfilling family functions, and wider socioecological environments. Reflecting a “synergy” of family systems and subsystems, *family adaptive systems* affect positive to negative responses to stressors (Henry et al., 2015, p. 31). The emotion system regulates communication and well-being in relationships (e.g., support, encouragement, cooperation); the control system regulates authority and behaviours (e.g., boundaries, structure, respect); the meaning system concerns family identity and cohesiveness over time (e.g., cultural identity, values, outlook); and the maintenance system includes all processes in family life that fulfill basic needs (e.g., responsibilities, resources, duty of care to vulnerable members).

The entire family system is affected when a family member has a disability (Dowling & Dolan, 2001; Gardiner & Iarocci, 2012). Families caring for a member with ID may experience positive outcomes, such as enhanced spirituality, tolerance, compassion, cooperation, and ability to cope with difficult circumstances (Mandleco, Olsen, Dyches, & Marshall, 2003; Myers, Mackintosh, & Goin-Kochel, 2009). Siblings who have a brother or sister with ID have been observed to have higher levels of cooperation and self-control compared to siblings in typically developing dyads (Mandleco et al., 2003). Parents of children with ID have described a sense of patience and an appreciation for the small blessings in life (Myers et al., 2009).

Families caring for a member with ID may also experience challenges and social inequalities (Dowling & Dolan, 2001). Siblings who have a brother or sister with ID have reported anxiety, loneliness, resentment, decreased social opportunities outside the home, and role tension within the family to a greater extent than siblings in typically developing dyads (Mandleco et al., 2003). Parents of children with ID have described experiencing additional time demands, stress, fatigue, and worry compared to parents of typically developing children (Al-Krenawi, Graham, & Al Gharaibeh, 2011; Dowling & Dolan, 2001; Myers et al., 2009). Indeed, caregivers invest a significant amount of time and energy into applying for services, driving to appointments, and assisting with daily living tasks, which may limit their own employment and leisure opportunities (Dowling & Dolan, 2001). If appropriate supports are not in place to foster resilience, families are at risk for financial strain, social isolation, and crisis. Essentially, the quality of life and self-determination of people with ID are embedded within the quality of life and resilience of their family system.

Challenges in Supporting Self-Determination

Although families tend to report positive attitudes toward self-determination, they also face challenges in understanding and promoting self-determination in a member with ID (Arellano & Peralta, 2013; Carter et al., 2013). To begin, research by Arellano and Peralta (2013) suggests that parents provide limited choice-making and goal-setting opportunities for their children with mild to profound ID aged 5 to 20. In a survey of 201 parents, only 19% reported consistently providing opportunities for their children to choose clothing and meals, and 40% reported presenting easy goals for their children to protect them from failure. Nearly half of parents reported making choices for their children because of knowing them very well (44%) and knowing their best interests (46%); however, research on assessment by proxy has demonstrated only moderate agreement with a person's true preferences (Golubović & Škrbić, 2013). Although this study included parents of young children in the sample, early socialization and autonomy supportive parenting affect the development and expression of self-determination over time (Grolnick et al., 1997; Palmer, 2010; Palmer et al., 2012; Palmer, Wehmeyer, & Shogren, 2017).

Families continue to shape the choices and activities of adult members with ID (Bigby, Whiteside, & Douglas, 2017; Foley, 2013; Knox & Bigby, 2007). Bigby et al. (2017) interviewed 23 parents and support workers on the way they support decision making in adults with ID. Carers tended to orient adults with ID to realistic and practical options, generally for the purpose of risk management. Bigby et al. (2017) interpreted carers' actions as "based on paternalism, best interests, or values and self-interest of the supporter" (p. 10) and acknowledged difficulty in "finding ways to enable risk that minimize harm without changing a person's preferred choice" (p. 11). Foley (2013) captured 10 parents' perspectives on the social lives of their adult children with Down syndrome. Worried for their adult children's decision-making

capacity and vulnerability to abuse and exploitation, parents positioned themselves as “gatekeepers” of their adult children’s social life, especially for romantic and sexual relationships. Moreover, research by Carter et al. (2013) suggests that parents experience a disconnect between feeling that self-determination is important and observing such skills in their young adults with ID aged 19 to 21. In a survey of 68 parents, less than 5% perceived their young adults as performing well in decision making, problem solving, goal setting, self-advocacy, and self-regulation. Critically, nearly 80% of parents rated choice making as a “very important” skill, but only 13.3% felt that their young adults performed this skill “very well.” Overall, parents may have difficulty translating their belief in the importance of self-determination into practice to promote these skills. One interpretation for this difficulty is that parents are attempting to balance competing priorities in the family system.

Individual quality of life versus family quality of life. The construct of quality of life includes emotional, material, and physical well-being, interpersonal relationships, personal growth, social inclusion, rights and freedoms, and self-determination (Special Interest Research Group on Quality of Life, 2000). In the family system, quality of life is important not only for each individual but also for the family as a functioning whole. When family members share the same needs and preferences, individual and family quality of life may be realized simultaneously. The issue arises, however, when one member’s perspective is either overlooked or perceived to be at odds with another member’s perspective. For example, the member with ID may have difficulty asserting his or her needs and preferences, perhaps because of cognitive or verbal limitations or underdeveloped self-determination skills. Alternatively, families may knowingly or unknowingly override the wishes of the member with ID. Families may assume that they know the best interests of the member with ID and act without consulting him or her

(Arellano & Peralta, 2013). In the case of disagreements, parents may have to prioritize one member's needs and preferences over those of another (Pilnick, Clegg, Murphy, & Almack, 2011). For example, facilitating the vocational pursuits of the member with ID would benefit his or her self-determination and quality of life, but the investment of time, energy, and finances could detract from the needs and extracurricular activities of other members in the family system (Pilnick et al., 2011; Turnbull & Turnbull, 2001).

Writing as academics with 50 years of combined experience in the field of developmental disability and as parents of an adult son with ID, Turnbull and Turnbull (2001) detailed their efforts to help their son achieve his goal of living in his own home. They had to navigate funding eligibility and applications, attend hearings with local and state representatives, explore housing options with realtors, secure a favourable mortgage rate, coordinate supports with their son's roommates to maximize quality of life, address challenging behaviours and implement a positive behavioural support system, and meet with a variety of consultants to achieve the right medication regimen for their son's mental and physical health. They estimated that they each spent 15 hours per week on efforts to support their son's self-determination, while also balancing full-time employment and other family members' needs. Turnbull and Turnbull (2001) reflected that, despite their professional training, these tasks were a "daunting responsibility":

It is ironic that in order to envision and strive for individual and family quality of life, one's own quality of life can be negatively impacted in the process! However, few people admit the serious impact on quality of life for some family members in the pursuit of self-determination and long-term gain in quality of life for individuals with significant cognitive disabilities. (p. 60)

Unfortunately, not every family has the Turnbolls' knowledge and resources to help a member with ID fully realize his or her choice. Pilnick et al. (2011) analyzed moment-by-moment interactions in eight transition planning meetings to examine what happens when the views of young adults, aged 18 and 19, with moderate to severe ID conflict with those of their family carers. When enacting the choices of the young adults with ID would require limiting the choices of other family members, parents tended to acknowledge self-determination as important while also providing moral justifications for its impracticality. Service providers ultimately honoured parents' views for pragmatic reasons. Pilnick et al. (2011) considered that definitions of self-determination must evolve to account for this embeddedness in interpersonal relationships.

Independence versus protection. In trying to optimize the quality of life of the person with ID, parents face an important dilemma: They must strike a balance between promoting independence and protecting someone whom they perceive to be vulnerable to harm (Almack, Clegg, & Murphy, 2009; Mill, Mayes, & McConnell, 2009; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012). On the one hand, parents must allow their son or daughter to take risks and have new experiences because self-determination is integral to quality of life. On the other hand, they must ensure the safety and emotional, material, and physical well-being of their son or daughter. These competing discourses may be especially apparent during the transition to adulthood, with parents fearing others will take advantage of their child in environments beyond the safety of home and the structure of school (Almack et al., 2009; Isaacson, Cocks, & Netto, 2014). In addition to navigating an ambiguous moral position, parents are navigating a plethora of professional opinions, policies, and societal constructions regarding their competency or 'goodness' as caregivers. Parents may anticipate facing the scrutiny of others, and thus scrutinize

their own decisions and their identity as responsible caregivers (Almack et al., 2009). Further, parents may struggle to articulate their own needs in difficult circumstances, feeling that they must project an image of positivity and self-sacrifice (Knight, 2013).

Parents may feel emotionally challenged if they believe that their son or daughter is making choices that are not in his or her best interests. In some cases, parents may decide to overrule the choices of their son or daughter with the justification that they “know best” (Almack et al., 2009; Saaltink et al., 2012). For example, a mother interviewed in Almack et al.’s (2009) study expressed that if she allowed her adult son to choose his daily activities, he would live a sedentary lifestyle, play videogames, and eat. She felt that this would socially isolate him and detract from his quality of life, so she overruled his preference and arranged for him to attend a residential college. Parents interviewed in Saaltink et al.’s (2012) study also expressed difficulty managing the risks of too much freedom versus too much protection. Independence was most often granted to the person with ID for matters that would only affect him or her, such as clothing and food preferences. Independence was permitted to the extent that choices were normative, safe, and consistent with family values. Parents reported occasionally taking measures to protect their son or daughter from harm and the undue influence of others, such as providing suggestions or guiding him or her toward the “right” decision.

Independence versus protection has been a longstanding conversation in the ID field. In 1972, Robert Perske called for people with ID to experience the *dignity of risk*:

We can say ‘We will protect you and comfort you and watch you like a hawk!’ Or we can say ‘You are a human being and so you have the right to live as other humans live, even to the point where we will not take all dangers of human life from you.’ ... The world in which we live is not always safe, secure, and predictable ... [People with ID] may, can,

will, and should respond to risk with full human dignity and courage ... Where many of us have worked overtime in past years to find clever ways of building the avoidance of risk into the lives of [people with ID], now we should work equally hard to help find the proper amount of normal risk ... There can be such a thing as human dignity in risk, and there can be a dehumanizing indignity in safety! (p. 26)

Fundamentally, negotiating “the proper amount of normal risk” for people with ID remains a delicate balancing act.

Dissertation Overview

Much of the research on self-determination in people with ID has focused on individual-level factors (Shogren, 2013) and school-based interventions (Wehmeyer & Abery, 2013). The ID literature has called for a socioecological perspective on self-determination with a stronger emphasis on the family context (Curryer et al., 2015; Curryer, Stancliffe, Dew, & Wiese, 2018; Palmer, 2010; Shogren, 2013; Wehmeyer, 2014). Further research is needed to investigate the development of self-determination in the context of parents’ efforts to support these skills (Carter et al., 2013; Curryer et al., 2015; Wehmeyer & Abery, 2013), family well-being and communication (Carter et al., 2013), family involvement in choice making (Palmer, 2010), and family resolution of disagreement (Wieland et al., 2014). Research that has practical implications for improving choice making for people with ID is warranted (Brown & Brown, 2009; Harris, 2003). Critically, one of the global research priorities in the field of ID is to examine the most efficient ways to support and empower families caring for a member with ID (Tomlinson et al., 2014).

This dissertation examines processes and challenges in the family system that impact the self-determination of adults with ID and the implications for service delivery. Self-determination

is positioned as a psychological construct within organismic-dialectical paradigms of human behaviour. According to self-determination theory (Deci & Ryan, 2002; Ryan & Deci, 2017), autonomous motivation and, ideally, intrinsic motivation are the epitome of self-determined behaviour. In what may be the first empirical evaluation of a self-determination theory model in adults with ID, Frielink, Schuengel, and Embregts (2018) found via structural equation modelling that participants' perspectives of autonomy supportive environments, psychological need satisfaction, and autonomous motivation affected their psychological well-being. Results support the universal application of self-determination theory in people with special needs as in the general population. Although self-determination theory in the field of psychology (Deci & Ryan, 2002; Ryan & Deci, 2017) provides an organizing framework in this dissertation, self-determination models in the field of special education are conceptually similar in their focus on person-environment interactions that enable volitional, agentic actions (Shogren et al., 2015; Wehmeyer et al., 1996) and allow for interconnectedness with carers (Abery & Stancliffe, 2003b; Wehmeyer et al., 2011).

This dissertation is embedded in the Multidimensional Assessment of Providers and Systems (MAPS), a research program that investigates services and outcomes for adults with ID and their families in Ontario, Canada. The MAPS team is an interdisciplinary collaboration of researchers and community partners seeking to generate evidence to inform actions to promote inclusion and quality of life. The MAPS team is directed by Dr. Hélène Ouellette-Kuntz, an epidemiologist and Professor in the Departments of Public Health Sciences and Psychiatry (Division of Developmental Disabilities) at Queen's University. Dr. Virginie Cobigo, the advisor of this dissertation, is a core MAPS member. She is a clinical psychologist and Associate Professor in the School of Psychology at the University of Ottawa, with a Research Chair in the

Children's Hospital of Eastern Ontario Research Institute. The MAPS research program was supported by research grants from the Government of Ontario's Ministry of Community and Social Services (2010–2015). This dissertation includes two studies that used MAPS data.

Study 1 Overview

Study 1 considers that life transitions are especially important for conceptualizing self-determination in the family system. The way families adapt to transitions affects family quality of life (Gardiner & Iarocci, 2012), and self-determination is best understood within family processes and supports (Wehmeyer, 2014). Although promoting self-determination is best practice in transition planning (Wehman, 2011), the way families plan and implement transitions and the extent to which the family member with ID feels autonomous in this process are not well understood. The purpose of Study 1 is to examine the lived experiences of families with an adult family member with ID as they navigate life transitions with effects on individual and family quality of life, resilience, and self-determination. Study 1 aims to answer the following research questions: (1) How do families plan and implement a transition with a family member with ID? (2) What is the role of each family member in the transition process? (3) What feelings and challenges are experienced by each family member in the transition process? (4) How are these feelings and challenges managed in the family system, especially when family members disagree or have different needs? and (5) What services or supports might facilitate effective choice making and transition planning in the family system?

Data for Study 1 were collected by the MAPS team in a longitudinal, ethnographic case study and film documentation called *Working Together to Support Transitions*. This project was co-led by Dr. Ouellette-Kuntz and Dr. Yona Lunsky, a Clinician-Scientist at the Centre for Addiction and Mental Health (CAMH). Several academic partners collaborated to develop the

data collection protocol. Dr. Cobigo and I also contributed to the data collection protocol by developing semi-structured interview questions on family choice-making processes and challenges during transitions, with feedback from my committee member Dr. John Sylvestre. Working Together to Support Transitions was supported by a Developmental Services Research Grant from the Government of Ontario's Ministry of Community and Social Services. The Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board approved Working Together to Support Transitions for ethical compliance on October 10, 2013 (see Appendix A) and approved collaboration with team members from the University of Ottawa on February 7, 2014 (see Appendix B). The University of Ottawa Health Sciences and Science Research Ethics Board approved this collaboration on May 20, 2014 (Appendix C) and approved the secondary use of MAPS data for this doctoral dissertation on July 10, 2015 (see Appendix D), and each year thereafter. A member checking procedure was also approved as a modification on June 27, 2017 (see Appendix E).

Four families who reported experiencing a significant life transition with their family member with ID participated in semi-structured interviews and ethnographic observations of their daily activities every three to four months for one year. The MAPS team transcribed the data verbatim and provided the transcripts to the University of Ottawa in their entirety. I conducted qualitative case study analyses to explore each family's transition processes and experiences over time, to understand their story as it evolved (Miles, Huberman, & Saldaña, 2014; Yin, 2009). The meaning that each family attributes to their story is bound to a particular time, place, and set of personal characteristics and framed within a wider sociopolitical context (Creswell, 2007; Yin, 2009). Qualitative case study analyses were inductive in that I stayed grounded in the data and allowed the meaning to emerge from the data. I present the findings

from Study 1 in two manuscripts in this dissertation. Manuscript 1 focuses on efforts to promote self-determination in two families as the young adult with ID transitions to more autonomous roles. Manuscript 2 explores all four families' challenges and coping strategies during transition planning, implementation, and adjustment processes.

Study 2 Overview

Study 2 concerns the system of services and supports in which the family system operates while trying to promote self-determination in an adult family member with ID. Community participation supports empower adults with ID in their daily lives and encourage them to be more actively involved in their community. These supports can help adults with ID engage in social activities (e.g., sports, hobbies), develop self-help skills (e.g., learning to ride the bus or go shopping), continue their education after high school (e.g., using the library, registering in college courses), and prepare for a job or volunteer opportunity (e.g., practicing work-related skills). These extracurricular and vocational activities may provide opportunities to develop skills and express self-determined behaviours; however, it is unclear whether parents hold this expectation when they make a service request on behalf of their adult child with ID.

Understanding service expectations may enhance working relationships with service providers, enabling greater communication and service satisfaction (Russell, 2003). The purpose of Study 2 is to examine parents' expectation that their son or daughter's receipt of community participation supports would enhance his or her choice-making skills. Choice making is associated with developing and expressing self-determination (Ryan & Deci, 2017; Wehmeyer, 2005).

Specifically, Study 2 aims to answer the following research question: What individual, parent, and family characteristics are associated with parents' expectations that community participation supports would facilitate their adult child's ability to make choices?

Data for Study 2 were collected by the MAPS research program in a multi-phase longitudinal study on parents' experiences of requesting and waiting for formal developmental services for their adult child with ID (Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013). The MAPS Parents Seeking Adult Developmental Services for their Children project was co-led by Dr. Ouellette-Kuntz and Dr. Lunsky, with the involvement of several academic and community partners. Funding was provided by the Government of Ontario's Ministry of Community and Social Services. The Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board approved Parents Seeking Adult Developmental Services for their Children for ethical compliance on July 28, 2011 (see Appendix F). The University of Ottawa Health Sciences and Science Research Ethics Board approved the secondary use of MAPS data for this doctoral dissertation on July 10, 2015 (see Appendix D), and each year thereafter.

Parents Seeking Adult Developmental Services for their Children had three phases. Phase I involved a cross-sectional survey of 211 parents at the time they requested formal developmental services for their adult child with ID. Phases II and III were follow-up studies, which took place 12- and 24-months after Phase I, respectively. For the purposes of this dissertation, only data from Phase I were requested. Data included characteristics of the individual for whom developmental services were requested (i.e., age, gender, medical and behavioural support needs, safety concerns, choice-making experience), the parent (i.e., age, relationship status, education, coping style), and the family (i.e., income, dependents in home, resilience, distress). I conducted a series of exploratory logistic regressions to examine predictors of parents' expectation that community participation supports would improve their son or

daughter's ability to make daily choices and participate in life decisions. I present the findings from Study 2 in Manuscript 3 of this dissertation.

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A Family Systems Perspective on Supporting Self-Determination in Young Adults with
Intellectual Disabilities

Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*. Advance online publication. doi:10.1111/jar.12601

Abstract

Efforts to promote self-determination in people with intellectual disabilities (ID) are considered best practice. Further research is needed to understand these efforts in the family system. This study explored the way families understand and promote self-determination in young adults with ID during transitions to more autonomous adult roles. Qualitative case studies were conducted with two Canadian families who participated in semi-structured interviews and ethnographic observations every quarter for one year. Analyses were informed by family systems theory and self-determination theory. Families considered the needs and preferences of the young adults with ID, suggesting individualized approaches for balancing independence and protection. Families set short-term and long-term goals for increased independence, scaffolded the learning of new skills, and collaborated on important choices. Interestingly, collaboration occurred to the extent that all family members perceived agency in planning and implementing transitions. Findings suggest families supported the young adults with ID in their psychological needs for competence, relatedness, and autonomy, which allowed them to experience autonomously motivated transitions. Findings have implications for supporting choice making and transition planning in the family system.

Keywords: intellectual and developmental disabilities, family systems theory, self-determination theory, choice making, transition to adulthood, post-school outcomes, qualitative case studies

A Family Systems Perspective on Supporting Self-Determination in Young Adults with Intellectual Disabilities

Situated within human agentic theories, self-determination is a personal characteristic comprised of “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). Component skills include goal setting and attaining, problem solving, and choice making (Palmer et al., 2012; Palmer, Wehmeyer, & Shogren, 2017); however, empirically validated models of self-determination emphasize the function of these behaviours, not the behaviours themselves (Wehmeyer, 1999). That is, causal agents act intentionally, in accordance with their goals and values, to have an effect and create change (Shogren et al., 2015; Wehmeyer, 2004). An essential feature of self-determination is autonomy: Causal agents perceive their behaviours as self-endorsed and self-regulated, as “an expression of the self, such that, even when actions are influenced by outside sources, the actors concur with those influences, feeling both initiative and value with regard to them” (Deci & Ryan, 2002, p. 8; Wehmeyer, 2005; Wehmeyer, Kelchner, & Richards, 1996). Fundamentally, self-determination is associated with increased quality of life (Lachapelle et al., 2005), including enhanced academic achievement (Erickson, Noonan, Zheng, & Brussow, 2015), post-school outcomes (Shogren, Villarreal, Lang, & Seo, 2017), and task engagement and interest, as well as decreased challenging behaviours (Cannella, O’Reilly, & Lancioni, 2005). Self-determination is a human right, and efforts to protect and promote self-determination are best practice.

Self-determination develops over the lifespan through person-environment interactions that satisfy psychological needs (Deci & Ryan, 2000; Grolnick, Deci, & Ryan, 1997) and support component behaviours and attitudes of causal agency (Wehmeyer, Shogren, Little, & Lopez,

2017). People with intellectual disabilities (ID) tend to report lower levels of self-determination than do their peers without disabilities (Mumbardó-Adam, Shogren, Guàrdia-Olmos, & Giné, 2017; Wehmeyer & Metzler, 1995) and with learning disabilities (Chou, Wehmeyer, Palmer, & Lee, 2017; Seong, Wehmeyer, Palmer, & Little, 2015). Although cognitive ability may impact the support needed to develop and express self-determination, socioecological factors are essential for understanding this difference (Shogren, 2013; Wehmeyer et al., 2011). People with ID experience more directive relationships and restrictive environments than do those without ID (Foley, 2013; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012; Stancliffe et al., 2011); thus, they have fewer opportunities to develop skills that significantly predict self-determination, including choice making (Wehmeyer & Garner, 2003) and goal setting (Shogren, Wehmeyer, Palmer, & Paek, 2013). Research has reliably demonstrated that people with ID have the capacity to become more self-determined through interventions that target component skills (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009). These interventions typically focus on individual-level factors and occur in community and special education settings (Algozzine et al., 2001). Comparatively little is known about the way people with ID develop and express self-determination in the family.

The ID literature has called for a stronger emphasis on the way self-determination emerges in the family system (Curryer, Stancliffe, & Dew, 2015; Wehmeyer, 2014), with the perspective that all members influence and are influenced by every other member (Bowen, 1978). Children with ID rely on their caregivers as their earliest teachers for developing component self-determination skills (Palmer et al., 2012), and adults with ID often continue to live in their parental home and receive support from their family members (Braddock, Emerson, Felce, & Stancliffe, 2001). Families may face numerous challenges in promoting self-

determination in members with ID (Curryer et al., 2015). They may struggle to balance the needs and preferences of members with ID with those of other members (Pilnick, Clegg, Murphy, & Almack, 2011). When the needs and preferences of all members cannot be simultaneously realized, families may knowingly or unknowingly override the wishes of members with ID by appealing to practical considerations, citing moral justifications, or expressing that they “know best” (Arellano & Peralta, 2013; Pilnick et al., 2011). Another challenge arises as families try to find a balance between promoting independence and protecting members whom they perceive to be vulnerable to harm (Almack, Clegg, & Murphy, 2009; Saaltink et al., 2012). In navigating these competing discourses, caregivers may feel emotionally challenged by time and financial constraints, professional opinions, and societal constructions regarding their competency (Almack et al., 2009). Adults with ID may perceive family involvement as overprotective (Shogren & Broussard, 2011), or as collaborative and reasonable (Curryer, Stancliffe, Dew, & Wiese, 2018), yet family interactions that affect these interpretations remain to be understood.

Conceptualizing self-determination in the family system is especially important during life transitions, which provide opportunities to respond to challenges, adjust to changing circumstances and familial roles, and experience growth and resilience (Gardiner & Iarocci, 2012; Mill, Mayes, & McConnell, 2009). A significant transition for people with ID is entering adulthood and attaining adult roles in the community, which may involve leaving the formal education system to pursue vocational opportunities (Davies & Beamish, 2009) and moving out of the parental home to explore another residential option (Isaacson, Cocks, & Netto, 2014). Research suggests that people with ID transitioning to adulthood experience more frequent and more distressing worries than do their typically developing peers (Forte, Jahoda, & Dagnan, 2011). Young adults with ID have described feeling anxious, socially isolated, unprepared for

adult responsibilities, and uncertain for their future (Young-Southward, Cooper, & Philo, 2017). As families navigate this transition, adult siblings may assume greater caregiving and supervising responsibilities of their brother or sister with ID (Hall & Rossetti, 2017). Amidst changing caregiver roles, families may also feel challenged by discontinuity in services and barriers to education, employment, and community living and participation (Gillan & Coughlan, 2010; Leonard et al., 2016). The balance between independence and protection may be especially difficult to achieve as emerging adults with ID explore environments beyond the structure of school and the safety of home (Almack et al., 2009). Families have described this transition as one of considerable adjustment, with effects on all family members' daily activities and emotional well-being (Davies & Beamish, 2009; Leonard et al., 2016).

Although promoting self-determination is an important step in transition planning, people with ID are not always directly involved in the choices that will affect their lives (Davies & Beamish, 2009; Knox & Bigby, 2007; Leonard et al., 2016). The way families navigate transitions and the extent to which people with ID feel included and perceive their agency in this process are not well understood. To support self-determination in people with ID, research is required to explore family efforts to promote self-determination, family involvement in choice making, and family resolution of disagreement (Curryer et al., 2015; Curryer et al., 2018; Wehmeyer, 2014). Research that has practical implications for improving choice making and transition planning for people with ID is warranted. This study aimed to investigate how the self-determination of young adults with ID is understood and supported within their family system during transitions to more autonomous adult roles.

Method

Context

This study is embedded in research from the Multidimensional Assessment of Providers and Systems (MAPS), a provincial research program directed by the third author that investigates services in Ontario, Canada for adults with ID and their caregivers. The MAPS team conducted a longitudinal quantitative study with a cohort of English- and French-speaking families requesting services through regionalized centralized intake between July 2011 and March 2012 for adult family members with ID living in the parental home. In this initial study, 211 parents completed telephone interviews and/or self-administered questionnaires at intake and at 6, 9, 12, 18, and 24 months to capture changes in services and supports needed and received, parental stress and well-being, family distress and coping, and independence, choice, and social inclusion for family members with ID.

From this initial study, MAPS purposefully selected participants for a longitudinal ethnographic study on the needs and experiences of families navigating significant transitions with adult family members with ID. Research assistants created a participant pool with special consideration for representing different levels of support needs, ages and life stages, regions of Ontario, and structures of formal and informal supports. Selection of diverse transition experiences included young to older adults with ID leaving the formal education system for vocational pursuits, leaving the parental home for supported independent living or long-term care, or leaving day activities for retirement. From this participant pool, MAPS invited seven families to participate, and five agreed. One family was subsequently deemed ineligible, resulting in a sample of four families.

Informed consent was obtained from anyone whose voice, image, or likeness would be recorded. An interviewer and videographer visited the four families every three to four months for one year between 2013 and 2014. These full-day visits involved posing open-ended questions to different configurations of family members and support persons, shadowing daily activities, and journaling observations. Examples of open-ended questions included, “What change is taking the most effort?” and “Where do you see yourself in five years?” Family members were also asked to elaborate on the way they made choices for their transition, responding to questions such as, “Who was involved in making this choice?” and “How do you feel about this choice?” Interviews and observations were video recorded and transcribed verbatim. Families were later invited to review and comment on the video recordings to highlight what they perceived to be most important in their story.

The first author collaborated with MAPS to access the data. Ethics approval was obtained from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the University of Ottawa Health Sciences and Science Research Ethics Board. Analyses for the current study were completed independently of any analyses by MAPS.

Participants

Adults with ID and their families were selected for the current study if they reported navigating the transition to adulthood. Two of the four families were included because adults with ID between 18 and 30 years of age were completing a life transition that involved gaining more independence and community participation. Two families were excluded because adults with ID over 30 years of age were moving to community living and long-term care facilities, and environmental constraints beyond the family system significantly influenced transition processes. Participant names have been changed to protect anonymity.

The Barlow family. Kimberley Barlow is a female in her early twenties who has Down syndrome, hearing and speech difficulties, and behavioural support needs. Kimberley lives with her married mother and father and her younger sibling. She has older siblings who have left the parental home. She grew up and finished high school in a rural community. Kimberley's life transition involves leaving the formal education system and pursuing vocational and cooperative education programs in urban centres. The household income is greater than CAN\$95,000.¹

Data collection with the Barlow family occurred every three months between 2013 and 2014, for a total of four full-day visits. Participants in semi-structured interviews included Kimberley, her parents, and her service provider. Participants in ethnographic observations included all interviewees as well as Kimberley's cousin and peers in social activities. Although Kimberley's siblings did not participate directly, Kimberley and her parents discussed sibling relationships and sibling involvement in transition planning and implementation.

The Daly family. Peter Daly is a male in his late-twenties who has been diagnosed with autism spectrum disorder and ID. He has mental health and behavioural support needs. Peter lives with his married mother and father in an urban centre, and he has an older sibling who has left the parental home. Peter is acquiring independent living skills by transitioning to his own apartment in the basement of the parental home. The household income is greater than CAN\$95,000¹.

Data collection with the Daly family occurred every three months between 2013 and 2014, for a total of four full-day visits. Participants in semi-structured interviews included Peter, his parents, his bowling coach, his volunteer coordinator, and his community support workers. Participants in ethnographic observations included all interviewees as well as Peter's colleagues

¹ The median income for Canadian households in 2015 was CAN\$70,336 (Statistics Canada, 2017).

in his place of volunteering and his peers in social activities. Peter's sibling did not participate directly; however, Peter's parents discussed sibling relationships and sibling involvement.

Research Team and Reflexivity

The first author, a doctoral candidate in clinical psychology, conducted qualitative case study analyses in collaboration with two senior ID researchers. Clinical training in social determinants of health, systemic psychotherapies, and motivation influenced interactions with the data and provided a theoretical framework. Family systems theory (Begun, 1996; Bowen, 1978) conceptualizes individuals as interconnected and interdependent members of a dynamic system. Self-determination theory (Deci & Ryan, 2000, 2002; Ryan & Deci, 2017) is a psychological meta-theory of motivation, development, and well-being. Since its inception in the 1980s, self-determination theory has been empirically evaluated and refined with applications in health care, education, and parenting, to name a few. Situated within an organismic-dialectical paradigm, self-determination theory posits that human beings are naturally oriented to grow and become causal agents in their lives, and their growth tendency is dependent on the fulfillment of three universal psychological needs: *competence* is feeling effective, exercising capabilities, and building mastery in navigating the environment; *relatedness* is sensing connection and belonging with others; and *autonomy* is experiencing behaviours as originating from the self, such that actions are self-endorsed and self-regulated. Although terms are often used interchangeably, autonomy is distinct from independence in that the latter refers to acting without the influence of outside forces. This distinction is especially important for people with ID who can be supported in volitional, agentic actions regardless of the extent to which they depend on others for assistance.

Factors in the socioecological environment either support or thwart the fulfillment of these needs and, in turn, motivation and unified sense of self (Ryan, 1995; Ryan & Deci, 2017). *Effectance supportive* environments set structures and organize resources, provide informational and process-oriented feedback, and communicate clear expectations (Grolnick et al., 1997; Ryan & Deci, 2017; Soenens, Deci, & Vansteenkiste, 2017). *Relationally supportive* environments afford the involvement of others through respectful, warm, and empathic interactions. *Autonomy supportive* environments provide choices and meaningful rationales for rules, pace learning by developmental needs, encourage self-regulation, and prioritize the intrinsic value of activities. When person-environment interactions satisfy psychological needs, the agent experiences *autonomous motivation* and expresses self-determination through intentional and volitional actions (Ryan & Deci, 2017). Autonomous motivation is associated with positive outcomes in mental and physical health, flexibility and creativity, and task engagement, interest, and persistence. Its epitome is intrinsic motivation. In contrast, *controlled motivation* involves feeling undue pressure, obligation, or coercion to act, which negatively affects well-being, learning, and relationships.

Analysis

The current study uses a multiple case embedded design to examine processes and outcomes at the level of the individual, dyad, family, and socioecological system (Yin, 2009). Procedures for analyzing qualitative case studies were informed by Miles, Huberman, and Saldaña (2014) and Yin (2009). First, interview transcripts were reviewed several times in their entirety, while journaling initial impressions and emerging insights. Informed by the theoretical framework and the reading of the transcripts, a provisional coding structure was developed to reflect participants' choices and challenges over the course of their transitions. The first author

conducted a first cycle of line-by-line coding in NVivo Version 11 using simultaneous codes for descriptive concepts, interpersonal processes, and emotional tones (Miles et al., 2014). The second author audited the coding, and the first and second authors revised the coding structure and created operational definitions and decision rules. Although initial codes reflected the conceptual framework, the authors remained grounded in the data, following inductive and iterative explanation building processes (Srivastava & Hopwood, 2009; Yin, 2009).

The first author then conducted a second cycle of coding to condense codes, identify meaningful patterns, and move toward higher-order explanations (Miles et al., 2014). To aid in this process, the first author generated within-case matrices to visually organize each family's story and cross-case matrices to identify common themes. Case analysis meetings between the first and second authors served to discuss impressions, rule-out alternative interpretations, and clarify patterns. Ongoing feedback was provided by the third author, who was familiar with participants' stories, having directed the data collection. Next, narrative summaries were generated to describe the way families influenced self-determination in young adults with ID while navigating transitions (Miles et al., 2014; Yin, 2009).

To enhance the trustworthiness of the data, case descriptions were mailed to participants with an invitation to comment on the researchers' interpretations (Miles et al., 2014; Yin, 2009). In addition to including member checking procedures, methodological rigour was achieved by maintaining process journals, examining the data for disconfirming evidence, discussing alternative explanations with colleagues, and triangulating data from multiple informants (e.g., adult with ID, parent, service provider) and collection methods (e.g., prolonged case interviews, direct observations, member checking feedback).

Findings

Within-case and cross-case analyses revealed strategies and interactions that influenced the self-determination of the young adults with ID during their transitions to more autonomous adult roles (see Table 1). Strategies were commonly implemented by parents; however, adults with ID and their parents described interactions in the family system in response to these strategies. Henceforth, the use of “family” or a family name encompasses the adult with ID and his or her parents, together. Parents and siblings are identified when their actions do not include the adult with ID. First, a narrative summary of each family’s transition experience is presented. Next, cross-case themes are described with illustrative quotes. Similarities and comparisons between families are noted.

The Barlow Family’s Transition Story

Kimberley Barlow is cheerful, friendly, and energetic. She enthusiastically pursues new activities, such as horseback riding, dancing, music, and art lessons. She has a “strong independent streak” and asserts “big dreams” for her future. Kimberley grew up and finished high school in a rural community.

Mr. and Mrs. Barlow had many discussions with Kimberley about the adult roles they would help her to attain. Kimberley shared many different ideas, such as going to college, working in the community, becoming a movie star in New York or Los Angeles, and attending university in Paris. Mr. and Mrs. Barlow considered Kimberley’s need for fun and independence, their responsibility for ensuring her safety, and their family resources for facilitating her goals.

Table 1

Family System Influences on the Self-Determination of Young Adults with Intellectual Disabilities

Theme	Barlow Family	Daly Family
Considering individual and family needs	Kimberley is enthusiastic and eager to explore. Mr. and Mrs. Barlow helped Kimberley turn her “big dreams” into optimally challenging goals that would be feasible within family resources and capabilities.	Peter prefers the predictable and familiar. Although he expressed a desire to move out of the parental home, he lacked the skills and confidence. Mr. and Mrs. Daly initiated the steps for Peter’s transition so he could realize his capabilities.
Balancing priorities	Mr. and Mrs. Barlow questioned the best way to promote Kimberley’s independence and maintain her safety.	Mr. and Mrs. Daly questioned when to push Peter to realize his capabilities and when to give him space.
Setting short-term and long-term goals	The Barlows set the short-term goal for Kimberley to attend a vocational program in a city two hours away and the long-term goal for Kimberley to attend a cooperative education program in a city four hours away.	The Dalys set the short-term goal for Peter to live in a basement apartment in the parental home and the long-term goal for Peter to live in his own apartment in the community.
Scaffolding	Mr. and Mrs. Barlow helped Kimberley stay on her own for increasing amounts of time. They gradually reduced their supervision as Kimberley appeared comfortable.	Mr. and Mrs. Daly helped Peter learn to cook, clean, and navigate the community on his own. They gradually reduced their involvement as Peter demonstrated competence.
Making choices	Mr. and Mrs. Barlow reported involving Kimberley in most choices, and Kimberley agreed. Considerations for family resources and capabilities, healthy behaviours, risk management, and skills acquisition influenced choice-making options.	Mr. and Mrs. Daly encouraged Peter to make choices and observed his increasing confidence. They were more directive when teaching Peter new skills and initiating steps for his transition. They reported worrying for his safety.
Collaborating	The Barlows described choice making for Kimberley’s transition as “unanimous.” Everyone perceived involvement in planning and executing Kimberley’s transition. Kimberley expressed agency.	Each member of the Daly family perceived agency in making choices for Peter’s transition. They could not reliably identify any one member as having the final say. Peter expressed agency.

Mr. and Mrs. Barlow also recognized that educational and leisure opportunities to meet Kimberley's goals would be more plentiful in urban centres:

In the long-term, [rural community] just doesn't fit our vision ... [Kimberley] wants to be independent. She wants to live on her own. She wants to do lots of fun things, be very involved in her community, have a job. And there just aren't as many opportunities in [rural community].

Mr. and Mrs. Barlow wanted to help Kimberley select experiences she could realistically handle that also aligned with long-term goals for her quality of life, social inclusion, and independence. Mr. and Mrs. Barlow investigated a vocational program in a city two hours from their rural community. They presented the option to Kimberley and observed her enthusiasm: "Kimberley said she wanted to do it, so then it was, the choice was pretty instantaneous." The Barlows, with input from Kimberley's sister, chose to rent a home in a town halfway between their rural community and the city to facilitate the commute. During data collection, the Barlows lived and commuted between these three communities while Kimberley proudly earned her college diploma.

As data collection finished, Mr. and Mrs. Barlow were helping Kimberley plan the next step for her independence. Kimberley wanted to move to a city four hours from her rural community to live in a student residence or a host-family home and attend a cooperative education program: "I like go [city] and I say yes. I say yes!" To better envision this goal, the Barlows visited the program and learned about skills for independent living that Kimberley would need to develop to successfully attend the program. Mr. and Mrs. Barlow expressed their commitment to help Kimberley attain these skills. Kimberley expressed excitement for her future: "I like to be adult. It's very good. And my heart tells me I have to go to college."

The Daly Family's Transition Story

Peter Daly is quiet, reserved, and family-oriented. Although he enjoys socializing, he needs encouragement to form friendships and try new activities. He needs time to feel comfortable in new environments. Peter's parents have typically initiated new activities on his behalf, nudging him to succeed in his educational and social pursuits. In this way, Peter discovered his interests in bowling, kayaking, skiing, and traveling.

Peter noticed that his peers were leaving their parental home and acquiring adult roles. He asserted his own desire for independence; however, his anxiety intensified and affected his quality of life whenever the time to move out approached. Mrs. Daly explained, "First it was, 'When I'm 18, I'll move out.' And then he got 18 and, 'When I'm 21, I'll move out.' And then he says, 'For sure, when you retire, I'll move out.'"

Peter had difficulty stepping outside of his comfort zone. Weighing these considerations, Mr. and Mrs. Daly proposed that Peter gradually build his confidence by transitioning to an apartment in their basement: "The decision was, 'How do we do this without having his anxiety being worse?' ... That's when we said, 'Okay, let's slow down ... You're going to move out, but still with us.'"

Mr. and Mrs. Daly invested time and energy to teach Peter independent living skills: "He could stay with us, and we could more or less train him on how to look after certain things, cooking, cleaning, all of those things for, I guess, life skills." They perceived that they initiated the choices for Peter to learn to shop for groceries and cook, explore the community, and search for employment. Importantly, Peter also perceived his agency in these choices. During data collection, Mr. and Mrs. Daly gradually decreased their supervision of Peter while increasing his contacts with a community agency that supported his social inclusion and independence. Mr. and Mrs. Daly renegotiated their caregiver roles as Peter demonstrated more confidence.

As data collection finished, Mr. and Mrs. Daly perceived that Peter would be ready in one or two years to move from his basement apartment in the parental home to his own apartment in the community. Mr. Daly reflected, “He has to feel comfortable by himself, and when he makes that decision, that’s great for us. We are not going to make that decision for him. We are only going to get him ready to make that decision.” Peter recognized his progress and shared his goal to continue to develop his independence, with his family’s support: “I don’t want to be here when I’m 40 ... I want to be completely independent when I’m 40 ... [This transition] is a step in the right direction.” One year after data collection finished, Mrs. Daly reached out to the MAPS team to share that Peter was happily living in his own apartment in the community.

Considering Individual and Family Needs

Kimberley tends to be enthusiastic, “open to new ideas,” and eager to explore and attain adult roles: “She wants to do everything that [her siblings] are doing, and more.” Mr. and Mrs. Barlow perceived that moving to Paris would be neither safe nor feasible within their resources and capabilities at the time. They worked to find a compromise that would still allow Kimberley to explore beyond her rural community, meet new friends, and study in her areas of interest. They discussed with Kimberley whether vocational college in Ontario would satisfy her desire for adventure while also promoting her quality of life, social inclusion, and independence. Mr. Barlow added, “I said [to Kimberley], ‘Save your money. We’ll go to Paris for a vacation.’ She thought that was a great idea, too.” These conversations involved “setting limits” and “trying to redirect into some things that work.” Conceptualizing Kimberley’s transition as a family transition, the Barlows promoted Kimberley’s self-determination by helping her to identify goals that would be challenging yet attainable: “She has, you know, big dreams, big goals, and hopefully over time we can help her to reach some of those goals as a family, together.”

Peter tends to be quiet and reserved: “Peter doesn’t like anything until you make him do it a couple of times ... It’s just a matter of trying to get him going ... He’ll eventually feel comfortable.” Mr. and Mrs. Daly recognized that Peter gravitated toward the predictable and familiar, and if they allowed him to pace his transition, he would miss opportunities for social inclusion and independence that would otherwise benefit his quality of life. The Dalys promoted Peter’s self-determination by nudging him toward adult roles so he could realize his capabilities. The Barlow and Daly families approached transitions with consideration for family resources and Kimberley and Peter’s daily living skills, preferences, readiness for change, motivational tendencies, and long-term best interests.

Balancing Priorities

Parents described extensive efforts to encourage independence in their young adults with ID while simultaneously protecting their health, safety, and best interests. Mr. Barlow commented, “With every choice to do with Kimberley, we’re doing this kind of teeter-totter, how much can we leave her on her own?” He noticed that this question is more pronounced in raising a child with ID:

It’s always that worry of danger and safety and knowing that Kimberley’s judgement isn’t the best at times, her safety judgements of things. Who’s going to be there watching out for her, making sure that she does the right things? I mean, we have that [worry] with all of our kids, but a little more with Kimberley.

Mrs. Daly captured the same dilemma:

I would just love it if [Peter] became independent. However, what is safe independency and what is not safe independency? I would like him to become independent. However, I want for him to be safe and for him to be healthy.

Parents commented on their worry and uncertainty in navigating these competing discourses. Mrs. Daly wondered, “Am I doing the right thing? Am I doing the wrong thing? That is the question the whole time. Am I pushing too hard? Am I not pushing enough?” She reported having honest conversations with Peter about the way this dilemma affects their relationship: “I try to tell him, you know, ‘If I’m just too much, just tell me.’” She also reported welcoming feedback from Peter’s sister, suggesting that an adult sibling may provide a new perspective and temper parental influence when it becomes overprotective:

My daughter is the one that said, ‘You know, mom, he doesn’t have to clean that apartment like you would. You have to let go.’ So, I take my cues from my daughter, but I would like for somebody to be able to say, ‘Don’t push’ or ‘Push more.’ But I guess I can’t have it all. I have to use my instinct and then for him sometimes to get mad at me to realize you know, okay, I’ve got to take it easy.

The way parents balanced independence and protection was unique to Kimberley and Peter’s needs. At times, Mr. and Mrs. Barlow appeared to err on the side of protection to balance Kimberley’s natural motivation for independence and exploration, whereas Mr. and Mrs. Daly tried to encourage Peter’s independence to balance his preference for safety and routine. In both cases, parents routinely monitored the effects on Kimberley and Peter’s quality of life.

Setting Short-Term and Long-Term Goals

Setting specific goals provided direction and motivation for the Barlow and Daly families to work toward a self-determined future for Kimberley and Peter. Parents articulated their vision for their young adults with ID to live independently, feel happy, pursue interests, participate in the community, and contribute to society. Mr. Barlow expressed, “We want Kimberley to have lots of good relationships with lots of different people and hopefully be able to live at least semi-

independently most of her life, independently making choices that she wants.” He emphasized, “We believe that Kimberley should be out there in the community, as part of the community. She has a lot to offer the community.” Mrs. Daly echoed these sentiments: “I always wanted [Peter] to be just like anybody else: independent ... working, making his own way in life.” The vision for a self-determined future appeared to be the motivating force for the Barlow and Daly families to facilitate Kimberley’s transition to a vocational program and Peter’s transition to his own apartment, respectively. “That is what motivates us to keep doing what we’re doing,” Mr. Barlow stated.

The Barlow family set the short-term goal for Kimberley to attend a vocational program in a city two hours from their rural community and the long-term goal for her to attend a cooperative education program in a city four hours from their rural community: “We’re trying to come up with a plan that would look long term but also short term. What are some reasonable goals for Kimberley over the next year or two, and how could we help her to achieve those goals?” Similarly, the Daly family planned the short-term goal for Peter to learn to live independently in a basement apartment in the parental home and the long-term goal for him to live independently in the community: “We looked for a year for a house to be able to put an apartment in for Peter because we didn’t want to have him live independently right from day one where he would be totally scared.” Stepwise goals served as indicators for pacing the transition and gauging progress. Mrs. Daly reflected, “The choices [for this transition] were made by looking at what everybody needs to do to become independent and then putting the plan together as to what steps need to be taken.”

Scaffolding

In working toward collaborative goals, parents helped Kimberley and Peter to increase their independence in a stepwise manner, tailoring the level of support to their needs and gradually reducing the level of support as they demonstrated competence. To illustrate, the Barlow family planned for Kimberley to stay home alone for increasing amounts of time with periodic check-ins. After Kimberley had practiced spending afternoons alone, Mr. and Mrs. Barlow suggested, “One night, we’re going to let Kimberley come home and make her supper, get herself ready for bed, and we’ll go over around 11 or 12 and just show up. In truth, I think she’s ready for that.” In a follow-up interview, Mr. Barlow observed that the family was feeling “more comfortable” and seeing “growth” in Kimberley’s independence: “She’s taking on that role as an independent adult, making choices on her own, with the ultimate goal of living on her own.”

In the Daly family, Peter connected with a community agency to expand his support network. As Peter grew more comfortable with the community agency and improved in his daily living skills, Mr. and Mrs. Daly renegotiated their caregiver roles and gradually decreased their supervision of Peter. Mrs. Daly demonstrated scaffolding in the way she taught Peter to plan and cook his meals. At first, she cooked alongside Peter in the upstairs kitchen, giving him step-by-step instructions. She commented in an early interview, “Another year—not even a year—and he’ll be able to do this by himself. This is my goal—to progress for him to cook meat. Now, he’s cooked salmon and he’s seen how easy it was.” Then she encouraged him to cook in the basement kitchen, with the community agency overseeing his meal planning and grocery shopping. Then she noticed Peter’s ability to prepare his meals on his own, with occasional feedback on the contents in his fridge. “I very seldom go downstairs now,” Mrs. Daly observed

in a follow-up interview, “Only once a week do I try to go down there ... I think he’s feeling more comfortable and we’re feeling more comfortable about just leaving him be.” Scaffolding allowed Kimberley and Peter to develop their confidence and experience success.

Making Choices

Parents shared their belief that choices are important, and Kimberley and Peter have the right to make choices. Mr. Barlow asserted, “We’ve always been big believers in letting our kids make their own decisions and not trying to live their lives for them.” Parents provided ample choice-making opportunities to support self-determination. Mr. Barlow explained, “We do try to involve her in most choices of what she’s doing, what activities she wants to do, what work she wants to do, what her long-term goals are.” Kimberley agreed, “So my dad and my mom let me know I [have] some choices.” Parents tailored their support to Kimberley and Peter’s level of readiness and confidence in choice making. For example, Mrs. Daly initially provided Peter with encouragement, information, and supervision in choice making. Over the course of data collection, she noticed Peter appeared more confident:

[Peter] doesn't even tell me when he chooses now. That's a big change because, in the beginning, I was involved in choosing with him. Now, he doesn't even tell me when he chooses his choices. So, he is becoming more independent. When you look at it, it is a big step.

Circumstances in the family system inevitably influenced choice-making opportunities. First, parents were observed to be more directive in interactions with their adult children with ID when teaching a new skill, encouraging a healthy behaviour, or enforcing a household rule. Second, it was important to parents to provide choice-making opportunities that would be feasible within family resources, so they could honour their adult children’s response and

balance all family members' needs. Mr. Barlow explained, "Kimberley's definitely involved in a lot of choices ... but we don't offer that we're ready to move to Los Angeles so she can try out for movie auditions." Indeed, family members had to compromise to balance needs, preferences, and quality of life in the family system. Third, parents' efforts to promote independence while also managing risk for their adult children with ID affected choice making. Parents anticipated intervening if they observed abusive or exploitative situations, for example. These factors considered, Table 2 presents a continuum of family system influence on Kimberley and Peter's choices and behaviours.

Collaborating

Families described working together in planning and implementing their transitions. Parents shared a genuine desire to understand their young adults' likes and dislikes, listen intently, ask for opinions, and welcome feedback. Mr. Barlow expressed, "Kimberley is often the impetus. She often throws out the idea initially, and we will work really hard to try and find a way." He continued, "We really listen to her ideas and hear them ... A lot of [our choices] were dependent on the feedback that Kimberley gave us." Mr. Daly indicated that although he and Mrs. Daly were initiating Peter's transition, they involved him in the process: "[Peter] knew what we were trying to accomplish right from day one, so we had his buy-in."

Interestingly, family members collaborated to the extent that they could not reliably identify any one person as having the final say on important choices for the transition. In some instances, shared agency was expressed: "It had to be unanimous, that we could all do it ... It was definitely a consensus," said Mrs. Barlow, regarding the choice for Kimberley to attend a vocational program in another city. Even so, Kimberley perceived her own autonomy in choices for her transition to college:

Table 2

Family System Influences on the Choice Making of Young Adults with Intellectual Disabilities

Level of Influence	Supportive Interview Quotes and Observations
Adult with ID chooses independently	Interviewer: What choices do you make at the grocery store? Peter: Well, buying vegetables. Buying stuff like Nutella, or sugary stuff. Mr. Barlow: [Kimberley] wants to do karate at the karate club, so she even identified things within [city] that would be good for her.
Parent presents choice-making opportunity, and adult with ID responds	Mr. Barlow: There's two [hiking] trails. Which one do you want to go on? Kimberley: That one. Mr. Barlow: You want to go down that way. Okay, we can do that.
Parent provides suggestion, and adult with ID responds	Peter: How many potatoes do we need? Mrs. Daly: Well, you usually eat one and a half per meal, and you're doing three meals. [Peter counts potatoes.]
Parent provides instruction, and adult with ID responds	Mrs. Daly: Okay, drain your carrots ... What should you have? Peter: Oven mitts. Mrs. Barlow: What did [health care professional] say? You should wear it all the time. You can hear people better. [Kimberley puts in her hearing aid.]
Parent chooses, and adult with ID participates in discussions	Mrs. Barlow: We'd drive back to [rural community] and then to horseback riding, which is not quite as far as [city] ... when December was minus 30, it's too cold! And so, I pointed out to [Kimberley] how tired I was, so I didn't think, starting in March, we were going to do floor hockey this year. It'll have to wait probably until next year. Mr. Barlow: We talked about it. 'It's really hard for mom and dad living in [rural community] to travel all the way to play floor hockey.'
Parent provides safety limit or anticipates intervening for safety reason	Mr. Barlow: There's definitely some safety [choices] ... we definitely want to be involved in and wouldn't let her make completely independently. Example, she wants to drive a car; she'd love to drive the car ... [We say] 'You have to pass a driver's test' and point out to her, it's not really to say, 'Absolutely no, you can never do that,' but it's like, 'Here are the things you need to do if that's a real goal for you' ... A boyfriend we thought was maybe taking advantage of her, I could see that might be a case where we'd step in ...

Note. Level of influence depended on (a) parents teaching new skills, (b) parents balancing individual quality of life with family quality of life, and (c) parents balancing independence with risk management.

Interviewer: Kimberley, who decided you were going to go to [community centre]. You or your parents?

Kimberley: Me!

Interviewer: So, you wanted to do it, and you told them you wanted to do it?

Kimberley: Yeah, I did that, so my mom knows that, so she knew all about it.

In other instances, agency was perceived by more than one family member, as demonstrated by Mrs. Daly and Peter's responses in separate interviews:

Interviewer: Who was involved in deciding that [Peter] needed to cook on his own?

Mrs. Daly: I think I made that choice, that he needed to cook on his own.

(...)

Interviewer: Who was involved in deciding he needs to look for a job?

Mrs. Daly: I [decided]; however, again, communicating with him. Is it something that he wanted? Is he leery?

Interviewer: Where did the idea come from to develop independence?

Peter: I think I thought of it myself.

(...)

Interviewer: To learn to cook, where did that idea come from?

Peter: I figured, to be independent, you have to learn to cook.

(...)

Interviewer: Where did the idea come from to get a paying job?

Peter: Everybody else has a paying job, so why can't I?

The analytic plan was to elucidate each family member's role and agency in making choices for the transition. In actuality, the extent of collaboration, interdependence, and reciprocity in the data limited the utility of role-by-time matrices. The entire family as a dynamic system appeared to become the choice-making agent, with Kimberley and Peter perceiving their own autonomy in the process.

Discussion

Much of the research on self-determination in people with ID focuses on individual-level factors, with interventions in special education and community settings targeting component self-determination skills, such as goal setting, problem solving, and choice making (Algozzine et al., 2001). The role of families in supporting self-determination in people with ID has received insufficient focus in research (Curryer et al., 2015; Wehmeyer, 2014). This study informs our understanding of the way family systems influence self-determination in young adults with ID during transitions, and the way young adults with ID perceive and exercise this self-determination.

The Barlow and Daly families envisioned a self-determined future in which Kimberley and Peter would be able to pursue hobbies and vocations, contribute meaningfully to society, and live semi-independently, echoing participants' definitions of self-determination in the literature (Arellano & Peralta, 2013; Nonnemacher & Bambara, 2011; Shogren & Broussard, 2011). Families identified the necessary steps to achieve these life goals, modelling effective short-term and long-term goal setting. Throughout this process, the Barlows and Dalys exhibited parenting strategies within family environments that supported Kimberley and Peter's psychological needs (Deci & Ryan, 2000, 2002; Grolnick et al., 1997). They promoted competence by modeling goal setting and problem solving, teaching and scaffolding daily living skills, evaluating and praising

progress, and providing choice-making opportunities. They promoted relatedness by facilitating social inclusion and community participation, gathering formal and informal supports, and exhibiting warm and reciprocal familial interactions. They promoted autonomy by providing information and structure, eliciting opinions and feedback, considering preferences and best interests, and ensuring goals and choice-making opportunities aligned with interests and values. When autonomy is supported, goals are more intrinsically motivating and satisfying (Sheldon, 2002). Frequent opportunities to make both routine and life choices are associated with feeling effective and developing self-determination (Deci & Ryan, 2002; Wehmeyer & Garner, 2003). The Barlow and Daly families were perhaps more conscious of the importance of choice making and more deliberate in eliciting Kimberley and Peter's participation compared to other families in the literature (Arellano & Peralta, 2013; Knox & Bigby, 2007). In these ways, Kimberley and Peter were supported in feeling confident and effective in their actions.

Families individualized the aforementioned strategies according to family resources, daily living skills, readiness for change, motivational tendencies, and long-term best interests. Mr. and Mrs. Barlow chose to compromise with Kimberley, redirecting her focus from universities overseas to vocational programs within province. In contrast, Mr. and Mrs. Daly chose to nudge Peter forward, encouraging him to realize his ability to leave the comfort of the parental home. These seemingly opposing strategies served the common purpose of helping Kimberley and Peter to experience success in meeting realistic goals. Goals that are ambitious yet attainable provide an *optimal challenge*, facilitating feelings of effectiveness in the environment, task engagement and interest, and intrinsic motivation (Deci, 1975; Grolnick et al., 1997). Moreover, these stories highlight the importance of individualized transition plans, with ongoing efforts to achieve the right balance between encouraging choice and independence and

protecting safety and best interests. Consistent with previous findings (Almack et al., 2009; Foley, 2013; Isaacson et al., 2014; Saaltink et al., 2012), parents expressed difficulty in determining when, and to what extent, to become involved in their young adults' lives. Interestingly, the balance between independence and protection shifted slightly over the course of the study, as parents gradually recognized their young adults' developing independence and redefined their caregiver roles. This shift is not without growing pains. As participants in Isaacson et al. (2014) observed, parents may need one to two years to feel comfortable when their young adults with ID leave the perceived safety of home and school environments.

In implementing individualized transition plans, families demonstrated varying levels of influence over the choices and behaviours of the young adults with ID. This influence occurred on a continuum from allowing Kimberley and Peter to choose independently according to their preferences, inviting them to respond to reasonable choice-making opportunities, providing suggestions and instructions with varying expectations for compliance, and making choices on their behalf with their involvement in discussions to balance family needs. Mitchell (2012a) observed a similar continuum in parental involvement from encouraging adolescents and young adults with ID to participate fully in making choices about their lives to making choices without their awareness. Mitchell reported that parental involvement depended on contextual factors, including people with ID's understanding of the choice, parents' perceptions of the complexity and risk of the choice, parents' attitudes on autonomous adult roles, and parents' desire to protect their children. Similarly, Saaltink et al. (2012) reported that parents allowed adolescents with ID to make choices only to the extent that their choices would fall within parents' perceptions of safety and family values and conventions. In this study, parental involvement in choice making reflected considerations for skill acquisition, family resources, family needs, and risk

management. Kimberley and Peter demonstrated the most independence in choosing daily activities and leisure pursuits, whereas they collaborated with their parents in choosing vocational pursuits and living arrangements and executing their transitions.

Although the level of influence over Kimberley and Peter's choices and behaviours did vary, overall, families demonstrated high levels of collaboration in planning and executing their transitions. Families described consensual choice making processes, with consideration for the needs and preferences of every family member. Most importantly, young adults with ID perceived their own agency in choices for their transition, even if their parents believed they had initiated those choices. Families did not allocate specific transition planning tasks to any family member, nor did they identify any member as having more power or responsibility in choice making. Rather, families appeared to develop shared meaning and purpose, and although they encountered many challenges, they worked together to meet their goals. This study observed more collaboration than has been reported elsewhere in the literature during transition planning (Davies & Beamish, 2009; Knox & Bigby, 2007; Leonard et al., 2016). The interconnectedness and reciprocity in the data illustrate family systems theory (Bowen, 1978), such that every family member influences and is influenced by every other member in a dynamic system. The family system emerged as the choice-making agent. Complementary findings are noted in Mitchell (2012b), in which young people with disabilities aged 13 to 22 reported minimal conflict and emphasized "being of a like mind" to their parents regarding choices for medical procedures (p. 262). Similarly, Curryer et al. (2018) observed that adults with ID aged 20 to 49 regarded family involvement in choice making as reasonable and collaborative: "They did not view such mutual decision making with family as a reduction in their level of control. In cases when choices were

limited by family, such limits were generally readily accepted and viewed as a sign of love and care” (p. 197).

Findings raise important questions about the influence of the family system on the self-determination of the individual. The United Nations’ (2006) *Convention on the Rights of Persons with Disabilities* recognizes “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices” (p. 2). Best practices for ensuring people with ID are empowered in directing their lives include supported decision making (Devi, 2013) and person-directed planning (Martin, Grandia, Ouellette-Kuntz, & Cobigo, 2016). At the same time, family systems theory holds that individuals are interconnected and interdependent (Bowen, 1978); family stress and resilience theories hold that families co-construct identities and worldviews (Patterson & Garwick, 1994); and self-determination theory holds that individuals develop and express self-determination in the context of their relationships and socioecological environments (Ryan & Deci, 2017). Self-determination may involve interdependence with others so long as interests and opinions are respected (Young, 2001) and voluntarily relinquishing or sharing control with others so long as congruence remains between the level of control desired and exercised (Abery & Stancliffe, 2003). Exchanging ideas, providing information, and communicating expectations and limits in an empathic manner are normative socialization processes in families (Grolnick et al., 1997). Researchers and disability advocates also raise valid concerns that family influence could become coercive and paternalistic (Bigby, Whiteside, & Douglas, 2017). So, what does it mean to be a self-determined individual in a family system, especially when the choice of one family member will affect every other family member and the system as a functioning whole? When is family influence normative, and when is it infringing upon individual self-determination? The perspective of the individual with

ID is important to consider: In this study, Kimberley and Peter perceived their agency in choice making, expressed agreement with transition processes, and demonstrated increased enthusiasm, readiness, and autonomous motivation in attaining adult roles.

Implications

A theoretical understanding of family systems theory (Bowen, 1978) and self-determination theory (Ryan & Deci, 2017) leads to implications for supporting people with ID. Efforts to promote self-determination must evolve to include familial support and consistency across home, school, and community environments (Shogren, 2013). Service providers are encouraged to work collaboratively with families when seeking to support people with ID in developing self-determination and in planning life transitions. The health, functioning, and quality of life of the family system, and the way this system either promotes or thwarts the self-determination of family members with ID, must be carefully considered. Service providers may assist families in identifying and implementing strategies that promote self-determination, such as setting optimally challenging goals, scaffolding new skills, and providing frequent choice-making opportunities. Parents in this study worried they might be overstepping, struggled to reconcile independence and protection, and requested feedback to achieve the right balance. Service providers may support families in mindfully monitoring the balance between independence and protection and the outcomes on quality of life and self-determination for family members with ID. To ensure that people with ID maintain their sense of agency within their family system, efforts to fulfill their psychological needs, invite their opinions, and collaborate on goals that are important to their lives are paramount. Service providers are encouraged to monitor whether people with ID perceive their own contributions in choice-making processes and recognize their own values and goals in desired outcomes.

Limitations

This study provides an in-depth understanding of two families with distinct transitions (i.e., school to post-school, parental home to another residential option) and geographical regions (i.e., rural, urban); however, they are homogeneous in several protective factors. They belong to racial and linguistic majorities, benefit from formal and informal support networks, and have high socioeconomic statuses. Their resources to rent and build new housing proved essential to successful transitions. The parents in these families had already supported their eldest typically developing children in leaving the home and assuming adult roles, which may have afforded some familiarity with this transition. The young adults with ID in these families are high functioning, verbal, and physically healthy. Research suggests that a lower frequency of challenging behaviours and lower support needs in family members with ID living in the home are protective factors for family quality of life (Boehm, Carter, & Taylor, 2015). These factors considered, the goal-setting and scaffolding strategies used in this study to facilitate transitions to autonomous adult roles are less transferable to families with compounded psychosocial vulnerabilities, families in a state of crisis, and families caring for members with high support needs.

Another limitation of this study is the lack of siblings' perspectives. In one family, a sibling suggested living arrangements to facilitate the transition and appeared to be admired and emulated by the adult with ID. In another family, a sibling appeared to provide a moderating role when parents exerted too much influence over the adult with ID. The influence of these actions on self-determination during transitions remains to be understood. One study found that children without ID who perceived their mothers as supporting their autonomy were more likely to also perceive their sibling as supporting their autonomy, perhaps because of psychological need

satisfaction and observational learning within the family (van der Kaap-Deeder et al., 2015).

Directly involving siblings is an important avenue for research on self-determination and transitions. Longitudinal research that incorporates the perspectives of multiple family members, including siblings, and measures self-determination with psychometric tools is warranted.

Research with larger samples and more diverse families will substantively add to the literature.

Conclusions

Awareness of the need to support people with ID in the context of their socioecological environments is growing (Shogren, 2013). Accordingly, the ID literature is shifting its focus from the experiences of people with ID to a broader examination of the experiences of their family system (Gardiner & Iarocci, 2012). This longitudinal multiple-case study captured interconnectedness and collaboration in the family system, efforts to promote self-determined transitions, and challenges and adjustments over time as adults with ID attained autonomous adult roles. Situated in family systems theory (Bowen, 1978) and self-determination theory (Ryan & Deci, 2017), this study informs our understanding of the role of the family system in fulfilling the psychological needs for competence, relatedness, and autonomy that allow self-determination to develop. From this perspective, self-determination is a sense of agency that naturally emerges when individuals interact with their environment in a way that fulfills their psychological needs and promotes autonomous motivation.

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A Family Systems Perspective on Navigating Transitions with Adults with Intellectual
Disabilities

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Manuscript submitted for publication.

Abstract

Significant transitions for adults with intellectual disabilities (ID) include leaving the formal education system to pursue a vocational opportunity, moving from the parental home to another residential option, and entering a long-term care facility. These transitions may involve stress and worry, changes in service access and continuity, and barriers to education, employment, and community inclusion. This study explored the way families caring for family members with ID plan and implement transitions and cope with associated challenges. Qualitative case studies were conducted with four Canadian families who participated in semi-structured interviews and ethnographic observations every three to four months for one year. Family systems and family resilience provided a theoretical lens. Families identified philosophies and practices that served as foundations for transitions. Families proactively considered future support needs; however, barriers to accessing housing and mental health services affected transition implementation. Securing formal and informal supports and focusing on long-term gains helped families persevere during difficult times. Following transitions, families experienced stages of adjustment and reflection. Transitions were conveyed as meaningful lifelong processes rather than isolated events. As families encountered and overcame challenges, they experienced periods of instability and stability in the family system. Findings highlight the need for early provision of transition planning supports and flexible and responsive services.

Keywords: intellectual and developmental disabilities, family systems theory, family resilience, transition planning, access to services, crisis, coping strategies, qualitative case studies

A Family Systems Perspective on Navigating Transitions with Adults with Intellectual Disabilities

Life transitions involve adapting to changing roles and responsibilities, reevaluating goals and values, and overcoming challenges in order to experience growth and resilience. Research on life transitions for people with intellectual disabilities (ID) tends to focus on three significant events: (a) leaving the formal education system and pursuing vocational opportunities (Davies & Beamish, 2009), (b) moving from the parental home to another residential option (Isaacson, Cocks, & Netto, 2014), and (c) entering long-term care (Bigby, Bowers, & Webber, 2011). Awareness is growing of the need to understand and support people with ID within their socioecological environments (Gardiner & Iarocci, 2012). Family systems theory (Begun, 1996; Bowen, 1978) conceptualizes the family as a dynamic system in which every member affects and is affected by every other member, as well as by wider social, economic, and political systems. The entire family system is affected when one member has a disability (Al-Krenawi, Graham, & Al Gharaibeh, 2011; Dowling & Dolan, 2001) and, more specifically, when he or she experiences a life transition (Gillan & Coughlan, 2010; Leonard et al., 2016).

Life transitions require that families adapt to changing interpersonal roles and responsibilities. As their child with ID ventures into new environments, parents may feel concerned for his or her quality of life, vulnerability to harm, and ability to cope with disruptions in routines, relationships, and formal and informal services (Almack, Clegg, & Murphy, 2009; Leonard et al., 2016). Parents report difficulty balancing the desire to promote their child's independence with the instinct to ensure his or her safety (Almack et al., 2009; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012). Parents may expect to have extended caregiving responsibilities (Dyke, Bourke, Llewellyn, & Leonard, 2013) and struggle to renegotiate

parenting roles (Isaacson et al., 2014). At the same time, adult siblings often assume greater supervising and caregiving responsibilities of their brother or sister with ID (Hall & Rossetti, 2017). Approximately one-third (Heller & Kramer, 2009) to half (Bigby, 1997) of families plan for a sibling to transition to the role of primary caregiver. In ideal circumstances, siblings are well-positioned to ease the transition because they have grown up learning their brother or sister's needs and preferences.

As caregiving dynamics shift, families also experience challenges in navigating and accessing formal services. Discontinuity exists between school and post-school services and between child and adult services for people with ID (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2017; Pallisera, Vilà, & Fullana, 2014). Research has consistently documented that parents feel they receive insufficient or untimely information about transition plans, procedures, and service options (Bhaumik et al., 2011; Dyke et al., 2013; Martinez, Conroy, & Cerreto, 2012). Although transition planning is best practice, families perceive barriers to participating in transition planning (Hirano, Rowe, Lindstrom, & Chan, 2018), disparity between mandated programs and actual experiences (Hetherington et al., 2010), insufficient support for parents (Bhaumik et al., 2011), and a lack of person-centered practices (Gillan & Coughlan, 2010). Moreover, families experience difficulty accessing services and securing suitable living arrangements and vocational and employment opportunities for their family members with ID (Bhaumik et al., 2011; Dyke et al., 2013; Gillan & Coughlan, 2010).

Families may experience high levels of stress as they navigate life transitions. For example, young adults with ID may worry more frequently and rate their worry as more distressing compared to their typically developing peers (Forte, Jahoda, & Dagnan, 2011). Parents may feel anxious, disempowered, and distressed (Gillan & Coughlan, 2010; McKenzie et

al., 2017). Leonard et al. (2016) found that over half of parents helping their child with ID transition to adulthood described a level of worry that affected daily activities and well-being. Similarly, Davies and Beamish (2009) noted that nearly half of parents navigating post-school options with their child with ID reported significant adjustments to their family life, with some reducing or terminating employment outside the home to meet increased caregiving duties. Despite significant stressors, families are capable of resourcefulness and resilience: They establish new coping strategies, utilize resources, adapt to changes, balance needs, and cultivate positive attitudes despite adversities (Gardner & Harmon, 2002).

One of the global research priorities in the field of ID is to examine the most efficient ways to support and empower families (Tomlinson et al., 2014). Studies on life transitions for people with ID tend to focus on specific time-bound events, transition planning interventions, and parents' retrospective reports of needs and preferences during this process. One exception is Isaacson et al.'s (2014) longitudinal qualitative case study of two young adults with ID and their families as they "launch" from the parental home. Further research is required to explore the way people with ID and their families experience transitions across the lifespan, overcome challenges, and adapt to new interpersonal roles and routines (Gardiner & Iarocci, 2012). This study endeavoured to describe the way adults with ID and their families in Ontario, Canada plan and implement a life transition, navigate the effects of the transition on every family member as well as the family system as a functioning whole, and cope with associated challenges.

Method

Context

Health care and community services. Canada has a universal publicly funded health care system by which each of 13 provincial and territorial health insurers regulates reasonable access to medically necessary physician and hospital services (Esmail & Barua, 2018). Supplementary services (e.g., vision and dental care, pharmaceuticals, mental health care, elective procedures, home care and long-term care) are typically financed by private insurers and sometimes partially financed by public insurers. Canadians may pay for supplementary health insurance, pay directly for services, or endure long wait times in the public system. Health care professionals do not routinely receive specialized medical and psychiatric training for meeting the needs of people with ID.

Community and developmental services and social assistance programs are subject to eligibility criteria, service availability, and system priority. In the province of Ontario, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* passed in 2008 to streamline the process of requesting supports and ensure equity of access to supports for adults with ID in their own community. Since 2011, each region of Ontario has been served by one of nine Developmental Services Ontario agencies, which processes applications in a standardized way, determines eligibility and support needs, and provides information on available resources. Unfortunately, service demand far outweighs supply, and adults with ID and their families report fragmented and uncoordinated services that do not sufficiently address their needs (Dubé, 2016).

Research program. The Multidimensional Assessment of Providers and Systems (MAPS) is a research program comprised of a team of researchers and community partners

promoting evidence-informed actions to support people with ID and their families in Ontario, Canada. The current study uses ethnographic, longitudinal data from a MAPS project on the needs and experiences of families navigating a significant transition in the care of their adult family member with ID. English- and French-speaking families received invitation letters if they requested services through their regional intake between July 2011 and March 2012 for their adult family member with ID living in their home and reported a current or upcoming transition. Four families were purposefully sampled to represent different age cohorts, transition types, and geographical regions in Ontario.

Participants whose voice or likeness would be recorded provided informed consent. An interviewer and videographer visited the four families every three to four months over a 12-month period from 2013 to 2014. Ethnographic data collection involved conducting semi-structured interviews with different configurations of family members and support persons, journaling impressions, and observing activities during day-long visits (e.g., hiking, shopping, cooking, attending church services). Open-ended questions included, “What change has been the best for you?” and “What change is taking the most effort?” Families described their feelings, challenges, coping strategies, and successes throughout their transitions. Interviews and observations were video recorded and transcribed verbatim. Families periodically reviewed the video recordings and responded to open-ended reflection questions to highlight what they perceived to be most significant in their evolving story.

For the current study, the first author accessed all transcripts of interviews and observations, as well as selected video clips, to conduct qualitative case study analyses. Approval was obtained from the Queen’s University Health Sciences and Affiliated Teaching Hospitals

Research Ethics Board and the University of Ottawa Health Sciences and Science Research Ethics Board.

Participants

The current study included four families in Ontario, Canada navigating a significant transition. Adults with ID and their parents were the primary interview respondents. Other interview respondents included community support workers, health care professionals, coaches, and volunteer coordinators who were identified by the families as significant to their lives and transitions. Although siblings did not participate directly, adults with ID and their parents described the effects of the transition on their family system. Pseudonyms are used to protect participants' anonymity. Demographic information and transition synopses are presented in Table 1.

Analysis

Qualitative case study analysis was conducted to examine the meaning of families' transition processes in the context of their personal characteristics and socioecological environments (Yin, 2009). Family systems (Begun, 1996; Bowen, 1978) and family resilience (Patterson, 1988, 2002; Henry, Morris, & Harrist, 2015) provided a conceptual framework. Family systems methodology considers the subjective experiences of multiple family members, the way their experiences change and interact over time, and the effects on family quality of life (Gardiner & Iarocci, 2012). Family resilience models consider risk, protection, vulnerability, and adaptation in the context of families' systems of meaning, adaptive functioning, and socioecological environments (Henry et al., 2015).

Table 1

Demographic Information and Transition Synopses

Adult with Intellectual Disability	Family	Transition
Kevin - Male in his 50s - An “extremely willing worker” who likes to be busy and helpful - Enjoys bowling, bocce ball, church, and jigsaw puzzles - Autism Spectrum Disorder and significant behavioural, medical, and mental health support needs	Anderson - Married mother and father in their 80s - Siblings out-of-home - Household income between \$45,000 and \$55,000 - Urban residence	Context - When Kevin reached adulthood, 10-year period of “ill-fated” attempts to live on his own, with arrangements lasting only weeks or months - Family relinquished efforts, and Kevin lived with parents for 20 more years - With increasing age and compounding health issues, family reached state of crisis and needed residential placement for Kevin Transition Event - Kevin is moving from his parental home to a supported independent living apartment
Sasha - Female in her 30s - Prior to illness, enjoyed skiing and appeared “quiet,” “eager to please,” and “very independent” - Cerebral Palsy, impaired mobility, and significant behavioural and mental health support needs	Baker - Married mother and father in their 60s - No siblings - Household income between \$55,000 and \$65,000 - Urban residence	Context - Family initially planned for Sasha to move to a group home - Sasha’s support needs changed drastically with onset of seizures and mental illness - Family reached state of crisis and needed emergency placement for Sasha Transition Events - Sasha moved from her parental home to an emergency placement in a long-term care facility - Sasha moved buildings in long-term care facility - Following a crisis, Sasha was transferred to psychiatric care in a hospital - Sasha is staying in a hospital until a placement becomes available to meet her complex needs

Kimberley • Female in her early 20s • A “pleasant, warm, welcoming individual who is very social” and has an “upbeat attitude towards life” • Enjoys singing, dancing, and cooking • Down syndrome, hearing loss, and behavioural support needs	Barlow • Married mother and father in their 50s • Siblings out-of-home and sibling in-home • Household income greater than \$95,000 • Rural residence	Context • Family recognized vocational opportunities for Kimberley would be limited in a rural area • Family pre-planned for Kimberley to participate in urban centre • Family arranged housing to facilitate commute to urban centre Transition Event • Kimberley is leaving the formal education system and pursuing a vocational program
Peter • Male in his late 20s • A “joker” who is “quiet,” “passionate,” “persistent,” and “family oriented” • Enjoys bowling, comics, traveling, and volunteering • Autism Spectrum Disorder and behavioural and mental health support needs	Daly • Married mother and father in their 50s • Sibling out-of-home • Household income greater than \$95,000 • Urban residence	Context • Family initially planned for Peter to transition to supported independent living • Peter experienced heightened anxiety, and parents viewed community housing options as insufficient • Family planned for Peter to move out gradually Transition Event • Peter is moving to a basement apartment in the parental home and pursuing paid work

Note. Household income is in Canadian dollars. Canadian median income was \$70,336 in 2015 (Statistics Canada, 2017).

Case study analysis was informed by Miles, Huberman, and Saldaña (2014) and Yin (2009). Specifically, the first author reviewed transcripts of prolonged case interviews and direct observations several times in their entirety and documented initial impressions. Guided by the conceptual framework and the reading of the transcripts, the first author proposed a coding structure and completed line-by-line coding in NVivo Version 11, while continuing to journal impressions and decision-making steps (Miles et al., 2014). Simultaneous codes captured descriptive concepts, interpersonal processes, and emotional tones. The second author audited and revised the coding structure according to operational definitions and decision rules. Although initial codes reflected the conceptual framework, the authors used an inductive approach to data analysis by establishing a chain of evidence, searching for patterns in the data, having the flexibility to generate codes that diverged from the provisional coding structure, and remaining open to alternative explanations (Yin, 2009).

The first author condensed codes to identify higher-order patterns and explanations (Miles et al., 2014). To aid in this process, themes and descriptive phrases for each of the four cases were entered into separate but commonly formatted role-by-time matrices to reveal the perspectives and experiences of multiple informants as they change over time, which is conducive to family systems methodology. It was then possible for the first author to create narrative summaries to present a coherent story for each family, with input from the second author. The third author, who was familiar with participants' stories in her capacity as MAPS director, provided ongoing feedback on these interpretations. The data were further condensed into cross-case role-by-time matrices to facilitate the identification of common themes.

Methodological rigour was achieved by maintaining process journals, triangulating data from multiple informants and sources, and peer auditing (Miles et al., 2014; Yin, 2009).

Moreover, the first and second author participated in case analysis meetings to clarify patterns, examine the data for disconfirming evidence, and rule out alternative interpretations (Miles et al., 2014). To validate the data, member checks were conducted by mailing each family a letter describing themes in their transition experience and inviting their feedback (Miles et al., 2014; Yin, 2009).

Findings

In one family, the adult with ID was leaving the formal education system and entering a vocational program. In three families, the adult with ID was adjusting to a new residential option, including a basement apartment in the parental home, an assisted living apartment in the community, and a long-term care facility. Interestingly, families' responses to open-ended questions about transition experiences extended far beyond these specific time-bound events. Transitions unfolded in stages, in the context of warm and autonomy supportive family relationships. Progression between stages was fluid, with many processes co-occurring. Time intervals between stages varied depending on the support needs of the family member with ID, the complexity of the transition goals, the services available for meeting those goals, and the challenges encountered along the way. Taken together, participants' voices converged to tell the story of transitions as meaningful, lifelong processes in the family life cycle.

Building Transition Foundations

Families incorporated having a family member with special needs into their identities and values. Parents shared impassioned efforts to promote the quality of life, social inclusion, and self-determination of their child with ID. These values and practices formed a nurturing environment in which transition events would unfold.

“He was a special person that came into our lives”: Forming identities and values.

Parents viewed their caregiving role as qualitatively different to that of parents with typically developing children. Mrs. Anderson reflected on the family system forming a new equilibrium when welcoming a child with special needs: “I loved [Kevin] just like I did the other children and tried to treat him accordingly. It was a bit hard. He got too much attention, whereas the other kids didn’t get enough. They had to adapt.” Parents anticipated extended caregiving roles over the family life cycle. Mrs. Daly recalled, “From the beginning, I always thought, ‘What happens when we’re not here?’ And that’s been my thought all along. And I think it’s the thought of any parent that has a person with a disability.”

In developing their identities, families envisioned the quality of life they hoped to foster for their family member with ID. Parents described integrating their child into their family system and recognizing his or her unique gifts and personality. Happiness, social inclusion, and self-determination appeared to be guiding priorities. “I want [Kevin] to be happy. I want him to be treated well. To be treated like a human being ... with respect and dignity,” Mr. Anderson expressed, with Mrs. Anderson adding, “Just to fit in, to feel accepted ... and work at something in the community.” Families’ identities and values influenced their actions.

“I have no problem at all standing up and saying what I believe”: Living in pursuit of values. Consistent with their stated values, all families engaged in specific actions to promote the social inclusion of their family member with ID. For example, parents listened to their child’s interests and supported his or her involvement in community activities, including bowling, kayaking, and gymnastics. In the Barlow and Daly families, social inclusion meant enrolling Kimberley and Peter in integrated classrooms in the formal education system. Mr. Anderson explained that social inclusion also meant searching for a church congregation that would

“accept Kevin for who he was and [make] him feel welcome.” Kevin shared that he feels appreciated in his church congregation: “[Pastor] is really nice ... And the kids are starting to like me, too. And everybody else, when I come, they like me a lot!”

Families also recognized the importance of facilitating self-determination by providing opportunities for their family member with ID to learn new skills, make choices, and solve problems. As an example, Mr. Anderson honoured Kevin’s desire to contribute to the family by shoveling snow, chopping wood, and mowing lawns. Mr. Anderson helped Kevin to develop competence and autonomy in these tasks by providing structure, reasonable expectations, and concrete instructions in the context of ample praise and patience: “He could feel useful because he knew he was helping me, doing things that were necessary. He knew that it was greatly appreciated ... I wouldn’t hesitate to praise him for what he had done, which he thrives on.”

When encountering barriers to their child’s happiness, social inclusion, and self-determination, parents tended to assume an advocacy role. At times, this role involved sharing values and experiences with others to raise awareness of the rights of people with disabilities. At other times, this role involved challenging others’ biases and fighting for their child to be treated with respect and dignity. “It’s not hard to make those arguments if you truly believe in them. We believe in Kimberley being included in the community,” Mr. Barlow asserted. Mrs. Daly provided an example of advocating for Peter’s education:

‘Peter could probably get a job packing groceries.’ This is what I was told ... the Guidance Counselor at the time said, ‘Well, you don’t think Peter is going to go to college, do you?’ And I said, ‘I don’t know. It’s not up to me to say if he’s going to go to college or not. Peter can do whatever he chooses to do.’

Peter acknowledged his mother's support: "She practically fought every step of the way for my education." Nurturing environments were protective as families approached transition events.

"We wanted to be proactive": Considering future support needs. Long before their child with ID was ready to pursue vocational opportunities or community living, parents considered future support needs and transitions. They gathered ideas for vocational trainings, day programs, group homes, community living facilities, and community agencies that support the social inclusion of people with disabilities. Kimberley's parents attended Down syndrome conferences to learn about educational opportunities. Peter's parents put his name on a wait list for an assisted living apartment, and Sasha's parents did the same for a group home. "We were thinking ahead," Mrs. Baker explained, "Where will Sasha go when she needs to get her own home? So, we looked around a bit, but there was no panic. We just wanted to do some pre-planning." Parents anticipated they would encounter barriers. Indeed, the availability and accessibility of formal supports affected transition planning and implementation.

Implementing Expected versus Unexpected Transitions

While all four families shared similar values, their stories diverged according to their access to resources and residential supports. The Barlow and Daly families were able to progress as expected through transition planning and implementation. In contrast, the Anderson and Baker families reached a state of crisis that necessitated unexpected transitions. Whether expected or unexpected, transitions inevitably destabilized the family system.

"We worked out the logistics": Planning and implementing expected transitions. The Barlow and Daly families engaged in planning and problem-solving discussions, set short-term and long-term goals, and collaborated on important choices. Kimberley's family helped her plan the transition to a vocational program in a city two hours from their rural community. After

much deliberation, they rented a house in a nearby town to facilitate their commute. All family members participated. “Our other kids all hear about these [plans] and provide their input,” Mr. Barlow explained, “We try out ideas and think about things and say, ‘How would that work?’” Instead of waiting for an assisted living apartment, Peter’s family searched for a new house in which to build a basement apartment. This way, Peter could learn independent living skills and gradually feel comfortable away from his parents: “For Peter’s future, if we’re not here, we have to do something, and we don’t want to leave everything on his sister.”

When families achieved a plan that would meet every family member’s needs and level of readiness, they implemented transitions and changed their daily lives in significant ways. The Barlows moved into their rental house and proceeded to live in and commute between three communities while Kimberley attended classes. The Dalys moved into a new house in a new neighbourhood, built an apartment, and moved Peter into his apartment. Mrs. Daly also retired to devote more time to this transition:

There’s nothing in the system that lets you say, ‘Okay, now you take my son and you help him become independent.’ And I knew that’s important, where we’re at in our life.

We know we’re not going to be here all the time. So, did I have to retire? No. Did I think that retirement would benefit Peter? Yes. Because then I was able to work with him.

Although the Barlow and Daly families encountered hardships, they were able to implement their transitions as planned, with a sense of choice and control.

“We didn’t make the choice”: Experiencing unexpected transitions. The Anderson family had planned for Kevin to transition to independent living when he reached adulthood. After several “ill-fated attempts” in the 1980s and 1990s, with moves lasting only weeks or months, it was decided that Kevin would continue to live in the parental home until suitable

residential supports became available. The Baker family had placed Sasha's name on a wait list for a group home. Before placements became available to enact planned transitions, the Andersons and Bakers reached a state of crisis. Kevin and Sasha's mental health and support needs changed drastically, caregiver demands intensified, and essential resources remained out of reach. Kevin moved to the first available apartment in a community living facility, and Sasha moved to an emergency placement in a long-term care facility. "We didn't make the choice," Mr. and Mrs. Anderson said together, "We were desperate." Mr. Baker expressed a similar sentiment, "We were basically told, 'This is where she goes, and if you don't take it, she goes to the bottom of the list.'" These abrupt transitions were dictated by crisis rather than by choice.

Encountering Challenges that Disrupt Transitions

Families experienced hardships that disrupted transitions. Some challenges occurred throughout the family life cycle, such that compounding stress interfered with transitions. Other challenges occurred or intensified during transitions. Challenges caused families to either expend significant energy to stay on course or veer unexpectedly off course, for varying lengths of time, from months to decades. Whereas the Barlow and Daly families were able to resume their planned transitions, the Anderson and Baker families were forced to forge new paths.

"Some people don't share our vision": Societal attitudes and abuses. All families described stigma, exclusion, and mistreatment. For example, Mrs. Daly noted others' low expectations for Peter: "We always had people telling us, 'Well, you don't expect he'll do this.'" When Sasha became the first young adult with a developmental disability to move into her long-term care facility, Mr. Baker reflected, "The nursing director there, as soon as we got there, said this wasn't her choice ... We were being judged. No doubt about it." This theme was especially prominent in the Anderson family. Kevin was raised in an era when the institutionalization of

people with disabilities was still common, the rights of people with disabilities were not legally protected in the way they are today, and specialized services for Autism Spectrum Disorder were not yet developed. “The amount of abuse he has suffered has been absolutely incredible,” Mr. Anderson lamented, “[Kevin] didn't have a job where he wasn't being abused. He wasn't in a school where he wasn't being abused.” Kevin recalled physical violence: “I didn't like the way they would bang, bang. They hit me so much.” Mr. Anderson observed people to take advantage of Kevin's strong work ethic, manipulating him to do more of his share without remuneration:

There were about five or six workers sitting there laughing and joking and making fun of Kevin, mostly because he was doing all of the work ... [They said] ‘If you come in on your day off, we can't pay you, but we'll give you a free meal, free lunch.’ They got him to clean all the bathrooms and scrub the kitchen floor and do all the dirty work that nobody else wanted to do, and then as a reward, they gave him one free pancake.

Kevin agreed, “When I'm having a job, people misuse me.” In light of these experiences, families described frustration, helplessness, powerlessness, and mistrust in society.

“We couldn't just think that the system was going to be there to take care of things”:

Service availability and accessibility. “You can't just seek services and get them. You've got to push,” Mrs. Daly expressed. All families reported that services to meet their needs were either unavailable or inaccessible, requiring extensive effort and advocacy to navigate eligibility criteria, funding applications, and wait lists. Three families described a lack of suitable, affordable housing for people with disabilities as a significant barrier to planned transitions. The Dalys had the resources to build an apartment for Peter when they became disillusioned with wait times in the public system, whereas the Andersons and Bakers reached a state of crisis before Kevin and Sasha received residential placements. Mr. Anderson reported a futile search for a home for Kevin:

I said to [Mrs. Anderson], ‘Sure, Kevin should be on his own, and I agree that he shouldn’t at this late stage still be living with us, but having said that, where is he going to go? What are we going to do with him?’ I wanted to make sure that it was going to be a proper setting for him where he would be happy and would be supervised properly ... such a place never became available for some reason.

Three families wished for services to facilitate social inclusion. The Dalys “fought” for a funded spot in an agency that helps people with disabilities connect with the community. The Bakers searched for an organization to provide a “companionship model” for Sasha while in long-term care “just to be a friend.” Mrs. Baker realized, “There’s nobody in all the organizations I talked to, and I’ve talked to many, and they’ve talked to each other ... That saddens me because there’s nothing available.” Services in rural areas were especially limited, such that the Barlows relocated for Kimberley’s social and vocational opportunities. Integrating into a new community proved difficult, as Mr. Barlow explained:

It seems like there hasn't been a lot of support. Maybe it would've been nice if [Agency] said, ‘Let's help you out. Let's talk to Kimberley about what things she likes to do. Here’s a program we know of’ ... [Agency] should be trying to assist us in terms of breaking into the community. And maybe they will, but so far, I haven’t seen a lot of it. Most of it seems to fall back on us, and our friends, and whatever contacts we can make.

Two families reported disappointment with educational and employment opportunities for people with disabilities. Mr. Barlow considered rural living to add to these challenges: “In our community itself ... there’s really nothing in terms of a program to help Kimberley develop her skills.” In searching for employment opportunities with Peter, Mrs. Daly commented, “I’m hoping that the federal government will soon realize that they should be the ones that show the industries

how to go about opening their doors to people with disabilities and start hiring more people with disabilities.”

All families experienced confusion and uncertainty in planning and navigating their transitions. They wanted information and support with coordination. “I needed an agency that would help me understand—or, I don’t want them to tell me what to do—but guide me through this, what to do,” Mrs. Daly said.

“She just falls in between the cracks”: Complex mental health needs. In three families, the adult with ID experienced mental health concerns that impacted transitions. The Dalys accessed psychological and psychiatric support for Peter’s anxiety and slowed down the pace of his transition. In the Anderson and Baker families, Kevin and Sasha’s mental health support needs were harder to meet. Still living in the parental home in his 50s, Kevin had a serious injury that required surgery and intensive care. Amidst post-operative complications, he became extremely anxious and dysregulated, contacting emergency responders on a daily basis for reasons unbeknownst to his parents. Mr. Anderson intensified efforts to find a suitable residential placement for Kevin, to no avail:

We got the impression that if Kevin had no mental or emotional or physical disabilities whatsoever, and was able to work full-time unsupervised, then maybe they would find a place for him. Well, that was begging the question. The reason that we were so desperate to find a place for Kevin was precisely because of his mental and physical and emotional problems. So, we felt very frustrated with that experience. And we thought, you know, which way are we going to turn?

Sasha’s support needs also changed in her mid-20s with the onset of seizures and mental illnesses. Mrs. Baker stated, “Sasha fell in the entrance, and she went all spastic, and she went all

tight ... To me, that's when I lost Sasha. She has *never* been the same since. *Never.*" Thereafter, Sasha engaged in self-harm behaviours, like scalding herself in the shower. She pulled out her hair. She engaged in both binging and restricting behaviours, eating frozen food at night and hearing voices telling her to refuse to eat. In her "manic stage," she became "very very aggressive" and "punched through walls." Mrs. Baker shared that Sasha attempted suicide and had four psychiatric hospitalizations in one year: "Her reason for that is, 'I don't want to live anymore because I don't want to be handicapped anymore.'" Mr. Baker expressed difficulty finding residential supports for Sasha's increasingly complex needs:

She just falls in between the cracks. 'Cause she's physically disabled as well as mentally ... most of these homes are either set up for the mentally disabled or for the physically disabled. There's very few that deal with them both.

The Andersons and Bakers found themselves navigating a system that is not designed for managing multiple diagnoses. As a result, they could no longer continue with their planned transitions.

"I'm seeing the toll this has taken on us, our marriage, our family": Caregiver demands and sacrifices. In all families, the time, energy, and finances required to support the transition of the adult with ID sometimes detracted from the needs of other family members. For example, Mr. and Mrs. Barlow discussed whether they would need to disrupt their careers and move to another part of the province to support Kimberley's vocational pursuits. "If I felt that there was a community somewhere that offered amazing opportunities for Kimberley, I mean, I would do my best to make that work," Mr. Barlow said. At the same time, the family system can become imbalanced when needs and preferences do not align for all family members:

It's trying to balance all these things. What are our best wishes versus what's best for Kimberley, and they don't always meet ... We are trying to fit Kimberley's goals with our personal goals. That's probably the biggest struggle we're having right now is to mesh the two together.

Mrs. Daly and Mr. and Mrs. Baker indicated that they retired prematurely to devote more time to caregiving. Mrs. Baker described high levels of stress and fatigue when Sasha's support needs changed:

And in that period of the severe mental illness, she was up all night. So, when we went to bed, we took shifts, actually, as much as possible. She would go through a frenzy where she would eat frozen foods, so she was in that binging mode at all times. And of course, with that, comes all the spillage of foods. Every morning, without fail, my husband washed the floor—the kitchen floor—on his hands and knees.

Mr. and Mrs. Baker struggled to provide 24-hour care to Sasha. "That's when the demands on our family really really got very high," Mrs. Baker indicated.

"I really didn't know which way to turn": Crisis. For the Anderson and Baker families, the aforementioned challenges culminated in a state of crisis. In his 50s, Kevin suffered a serious injury and an onset of mental illness. In their 80s, Mr. and Mrs. Anderson were managing their own health conditions, and they could no longer care for Kevin and maintain their property without his help. Mr. Anderson referred to this period as "indescribably hard" and "the most frustrating years of [his] entire life." Mr. Anderson reported spending up to 15 hours a day trying to find a placement to meet Kevin's needs, with no assistance in the process: "It was pretty grim. I went through some pretty difficult emotional experiences because of that. And then I made, like literally, not hundreds but thousands of phone calls saying like, 'Something's got to

work out. Something has to give.” Finally, the Andersons learned of an opening in a community living facility, and Kevin moved in to his new apartment.

Mrs. Baker described the way Sasha’s complex needs took a toll on their family quality of life:

My husband got ill last August ... He had a heart attack. They said at the hospital it was because of stress ... We are not blaming Sasha or anybody else. The hardship was very much a contribution to his heart attack. With that, she became immediately put on an emergency list for placement because we couldn’t handle each other and take care of her at the same time.

Two months later, Sasha received a temporary placement in a long-term care facility. A year and a half later, Sasha moved to a new building in the long-term care facility, which was extremely disruptive to her care plan. She regressed in functioning and “had a rage, an outburst.” She was taken to the hospital emergency room. Mr. and Mrs. Baker learned that Sasha would not be welcomed back to the long-term care facility because of their mandate to provide a safe environment for residents. Mrs. Baker commented, “It was very difficult for me—and for my husband—to accept knowing that she has no home to go to.” Sasha would remain in the hospital, receiving psychiatric care, awaiting a home to meet her complex needs. Mr. Baker commented, “It’s all setbacks now.”

Coping with Challenges and Resuming Transitions

Families demonstrated resilience in overcoming challenges and resuming their transitions. Coping strategies included adopting a positive attitude, focusing on long-term gains, and gathering resources. Strong familial relationships and social supports were protective factors in difficult times.

“I don’t listen to any negativity”: Finding a new perspective. Families reported adopting positive attitudes to cope with challenges. They referred to having a sense of humor, keeping an open-mind, practicing patience and gratitude, focusing on family members’ strengths, and celebrating every step toward their goals. Mr. Barlow expressed, “Kimberley brings a lot of joy to our life. And, for the most part, it’s rewarding. There are definitely stressful times, and I think it’s more challenging, but then sometimes the rewards seem greater even though sometimes they’re smaller.” Mrs. Barlow shared the importance of pausing and appreciating the present moment:

Sometimes you just have to step back. There’s a lot of anxiety out there. There’s a lot of pressure on what we are doing, what the government is doing. You know, you’ve got to really enjoy the world through her eyes too because, yeah, there are some really cool people that we’ve met.

Kevin said that he practices gratitude: “You should be glad and grateful that you have what you want, you know? Like, other people don’t. Be content.”

“There’s going to be some long-term benefit”: Persevering. Families focused on long-term goals to maintain their motivation when they felt unsettled, frustrated, and tired. For example, Mr. Barlow acknowledged that short-term sacrifices in time, energy, and resources would lead to long-term gains in Kimberley’s quality of life and the family system: “As our kids get older, when they’re more independent, you start to see more rewards, ‘Okay, it was worth doing that. It was worth it. And even though it was painful at the time, it was definitely worth it.’” Families referred to persisting and persevering. Peter said he will be able to reach his goals because he has “a stubborn family who won’t let [him] give up.” Mrs. Anderson reflected on maintaining hope for Kevin:

Oh, I prayed about it every day of my life. I thought, ‘There *must* be something else for this different kid.’ Oh yeah. As a mother, I think every mother who has a child [with special needs], has this dream—or not a dream, but a growing concern every day—that there *must* be something around the corner for a kid like this. I never gave up on him, no.

Mr. Barlow echoed the importance of persistence: “Hang in there and listen to your adult child ... Don't give up if something doesn't work. Keep trying. And, you know, eventually things do work out.”

“Use whatever resources you have available”: Accessing formal and informal supports. Whereas service barriers disrupted transitions, securing formal and informal supports facilitated transitions. Formal supports included medical care (e.g., emergency hospitalizations, pharmacotherapy), mental health care (e.g., psychological and psychiatric assessments, psychotherapy, counseling), vocational training (e.g., college and career guidance, on-the-job coaching), supported independent living (e.g., community living and long-term care facilities, life skills training, organizations that support social inclusion), and information and education (e.g., courses and conferences on disability, mental illness, and long-term care).

It was important that services supported the family system, not just the adult with ID. For example, Mrs. Baker reflected on receiving her own counselling to effectively manage transitions in Sasha’s care:

[My counselor] has made me stronger. He’s made me look at the big picture. He’s definitely made me look at my medical needs ... He’s been a valuable counselor. To make me strong. To make me open to decisions ... Otherwise I would have been, yeah, a servant for the rest of my days, in my 90s, taking care of her. But the letting go part? That was his prime concern. Letting her go and getting her ready for her own home.

Service providers who welcomed family input and prioritized rapport were perceived as most helpful. For example, Mrs. Baker said she appreciated coordination with Sasha's care team: "The process allows us to be participants, and that's very important ... there is a lot of family involvement and support if we need. Absolutely. So that's been a blessing." She continued, "They are all welcoming of suggestions or concerns." Mr. Anderson appreciated Kevin's psychiatrist: "She treats him and us and—well, anybody else—with the utmost respect ... She's been awesome. That's a real godsend." Kevin described a service provider at his community living facility as reassuring: "He told me not to worry, 'I got you in my care, so don't you worry.'"

The Barlow and Daly families described strong informal support networks in their immediate and extended family members, friends, neighbours, and communities. "Kimberley is very well known," Mr. Barlow said, regarding the benefits of rural living, "I walked down the street with Kimberley and every person, or every other person, would be saying, 'Hello Kimberley! How's it going?' Everybody knows her, watches out for her." Mr. Barlow explained that Kimberley's siblings share their opinions and take an interest in her life. Mrs. Daly also reported friendly relationships with neighbours and comfort in having Peter's sister living nearby: "If all of a sudden, I need to go to the doctor's and he has an appointment somewhere, then she is there to relieve me ... If I need her, she will be there." In the Anderson and Baker families, informal support was limited to the co-parenting relationship. "We support each other," Mr. Baker said, with Mrs. Baker adding, "Thank God for our long-term marriage."

Adapting to a New Stage of Life

Following the implementation of their transitions, families described efforts to adjust and return to equilibrium. New routines, interpersonal roles and responsibilities, and surroundings

affected the health and well-being of every family member as well as the family as a functioning whole.

“It’s not the same here, yet”: Feeling unsettled and adjusting. Families described feeling unsettled and tired in response to new demands from their environment. For instance, Kevin felt scared living away from his parents, and he tried to run away from his community living facility: “I climbed the fence.” The Barlow family described feeling tired maintaining two properties and waking very early to commute with Kimberley to college. Peter reported feeling “apprehensive” and “antsy” in the early stages of his transition: “Well, when they first started talking about it, it was all talk, like yeah, yeah [shrugs] ... But when they actually found the house and bought the house, I was kind of [demonstrates hyperventilating].” Mrs. Daly shared fond memories of her family’s former neighbourhood and the significance of adjusting to a new one:

It will take a long time. We, of course, had been there for 28 years. The neighbours knew Peter, and he felt safer there with the neighbours. And everybody would, if they saw Peter somewhere, ‘Do you want a ride, Peter?’ Peter knew them. But it's not the same here, yet. He doesn’t know the neighbors as much.

Navigating changes in interpersonal roles and responsibilities proved challenging for families. Mr. and Mrs. Baker had conversations with Sasha’s service providers about “empty nest syndrome” and learning to “be the visitor.” Mrs. Daly found herself re-appraising her caregiving role and learning to let go as Peter became more involved with a community support worker:

I find my role is changing now that we have an organization like [Agency] ... They’ve allowed me—not only allowed me, but have preferred that I step back ... If he chooses to tell me something, he’ll tell. And if not, that’s fine. It’s his life ... They’re really helping

him with living a more independent life without me, which is what we've been striving to do, but it's very difficult ... as a parent, to be able to step back and not protect.

Changing caregiving roles involved re-evaluating support needs and efforts to promote independence while maintaining protection. Mr. Barlow described this delicate balancing act:

We wrestle with how involved we should get ... You know, being parents and trying not to be—what's the word—helicopter parents. I guess just trying not to be overly involved, but at the same time recognizing we have a really important role.

“We’ve come a long way”: Feeling settled and reflecting. Gradually, the family system returned to equilibrium. Parents referred to a newfound sense of stability, contentment, and restfulness. Mr. Anderson commented on finally finding a “respectable place” for Kevin:

“Everything came together and answered our prayers, and Kevin’s where he is, and he’s happy, and we’re happy.” Although Sasha’s hospitalization was trying, Mrs. Baker also stated, “I know she’s in professional care, and that’s a *big relief*. I’m not alone to take care of her, so I feel very comfortable knowing it’s not a 24-hour day for me.” In this stage, parents were able to return to personal needs they might have neglected while prioritizing transitions. Mrs. Baker smiled, “Whereas I used to feel she was number one, I’m almost equally number one, ’cause she’s taken care of, so I’m slowly getting back into my own care.”

In this stage of adjustment, adults with ID described feeling safe, comfortable, and happy. “I was apprehensive at first, but I like it now,” Peter said of his basement apartment, “I’ll do what I want, when I want.” Initially scared and confused, and perhaps remembering instances of mistreatment, Kevin learned to feel safe in his new home, too:

They care about me. Then they said, ‘You are safe, Kevin, with us. So, don't worry, you know? You're not unsafe. You're safe.’ So, I have to get that in my mind. That I'm safe.

That nobody is going to abuse me, stuff like that.

Kevin concluded, “I’m just so happy that I’m over there. It’s better than any other place. I’ve tried living on my own [shakes head] didn’t work out.”

Feeling settled once more, families reflected on their transition processes, challenges, and accomplishments. They recognized personal growth in each family member and in the family system, expressing satisfaction and pride. For example, Kimberley excitedly shared that she earned her college diploma: “And now I graduate! Today is my last day.” Mr. Daly proudly reflected on Peter’s newfound confidence in buying groceries, cooking, cleaning, doing laundry, and taking public transportation:

He has no problem saying, ‘when you’re gone’ or ‘when mom’s gone,’ or whatever, you know, ‘I have so and so’ and ‘I can do this’ and ‘I can do that.’ So that’s quite promising.

By buying this house and having his apartment in the basement and working with various agencies, it’s coming to a point now where I think he will want to move out by himself.

Peter acknowledged living in his basement apartment as a “step in the right direction” toward his supported independent living goals.

“I’d like to do something with my life”: Setting future goals. After a period of stability, families recouped enough energy to set future goals. In this way, families resumed the transition cycle. For instance, Kimberley wanted to attend a cooperative education program: “I go to college in five years ... and I’m going to travel and live in [city].” Mr. and Mrs. Barlow discussed a permanent move to an urban centre: “It’s about helping her towards those goals in [city] ... What do we need to do to prepare?” Mr. and Mrs. Baker anticipated helping Sasha

transition to a new home when an appropriate placement became available: “There’s all kinds of professionals involved with that. If they’re going to find a placement, they’re going to find the right one.” Kevin said that his five-year plan involves “visiting other people, visiting parents, visiting family.” Although Peter was initially nervous to move into his basement apartment, he grew to desire more independence from his parents:

I just live in the basement. I tell them, a few weeks ago, ‘I’m not living on my *own*, I’m just living in the basement’... It’s not far away enough from my parents, I guess. If anything, it’s independent, but it’s not independent enough.

With emotion, Mrs. Daly said she will support Peter’s independence: “I don’t know what to expect, but, you know, I’m going to help him reach the goal that he wants. And he’s getting there!”

Discussion

Much of the literature on transitions for people with ID focuses on specific events bound by time and place, such as leaving the formal education system for vocational opportunities (Davies & Beamish, 2009; Dyke et al., 2013; Hetherington et al., 2010; Pallisera et al., 2014) or leaving the parental home for supported independent living (Isaacson et al., 2014). Transitions across the lifespan, as informed by family systems methodology, have received insufficient focus in research (Gardiner & Iarocci, 2012). This longitudinal, multiple-case study informs an understanding of the way families plan and implement transition events, navigate the effects on every family member as well as the family system, cope with associated challenges, and adapt to new interpersonal roles and ways of living.

Transitions as Lifelong Processes in the Family System

Families embedded their transition stories within their life stories, informing our understanding of motivations and preparations before the transition event, as well as adaptations and reflections after the transition event. Parents anticipated extended caregiving roles and anticipated future transitions as soon as they became aware their child had special needs. Parents described lifelong efforts to promote their child's happiness, social inclusion, and self-determination, preparing him or her for adult roles from the day of his or her birth. Family members worked together to establish family quality of life, a state of health and functionality in the family system in which "the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" (Park et al., 2003, p. 368; Gardiner & Iarocci, 2012). Essentially, family members balanced each other's needs, accessed strengths and resources to cope with challenges, and pursued valued actions to maintain a state of equilibrium.

States of stability and instability in the family system affected family quality of life. As families pre-planned and actively planned transition events, they anticipated a disruption to their equilibrium and experienced apprehension and uncertainty. Families implemented expected or unexpected transitions, depending on their support needs and access to services. In either case, transition events inevitably de-stabilized the family system. Families confronted unfamiliar challenges and described stress, anxiety, and fatigue. Stages of adjustment and reflection followed transition events. Developing coping strategies and renegotiating interpersonal roles, responsibilities, and priorities gradually re-stabilized the family system. Upon returning to equilibrium, families described relief, satisfaction, and pride in their accomplishments. Families

then considered future transitions and returned to goal-setting and pre-planning stages. In this way, the transition process is lifelong and cyclical in nature.

Challenges and Crises: Experiencing Instability in the Family System

Significant challenges disrupted transitions. Notably, all families reported stigma, exclusion, or abuse that compounded stress levels, indirectly interfering with transition events. Discrimination may diminish trust in society and intensify carers' efforts to protect those who may be vulnerable to harm (Almack et al., 2009; Mill, Mayes, & McConnell, 2009). Further, discrimination may diminish the perceived ability to transform situations and influence desired outcomes (Wehmeyer et al., 2011). In a scoping review of service use in family carers of adults with ID, Lunskey, Tint, Robinson, Gordeyko, and Ouellette-Kuntz (2014) reported that rates of service utilization are lower in older carers than in younger carers, with the hypothesis that "many children of adult carers were born at a time when few services, outside of institutionalization, were available" (p. 11). Negative service experiences were found to affect service engagement, regardless of level of need.

All families described service availability and accessibility issues, which are well documented in the ID literature (Bhaumik et al., 2011; Gillan & Coughlan, 2010; Saaltink & Ouellette-Kuntz, 2014). Three of four families identified a lack of suitable housing for adults with ID as a transition barrier, with two of these families reaching a state of crisis before residential placements became available. Families also reported limited options for employment, friendship support, and transition information and coordination. Services to support community participation are especially limited in rural areas (Anaby et al., 2013), prompting one family to relocate to commute to an urban centre. Carers described intensive efforts to obtain services to support transitions, such as advocating to managerial staff and spending hours per day on the

phone. Saaltink and Ouellette-Kuntz (2014) conducted in-depth interviews with eight families in Ontario and identified the following efforts to seek adult developmental services: administrative (e.g., completing applications and needs assessments), information gathering (e.g., determining service options and eligibility criteria), relationship building (e.g., finding an “insider” to advocate on their behalf), advocacy (e.g., making a case to agency or ministerial staff to move through the system), and effortful waiting (e.g., coordinating access to programs and professionals to enhance service users’ eligibility).

In three of four families, the adult with ID had mental health concerns that impacted transitions. In two families, the adult with ID’s support needs changed suddenly, necessitating emergency hospital visits and emergency residential placements. In Ontario, individuals with ID are more likely to visit the emergency department for psychiatric crises compared to individuals without ID (Durbin, Balogh, Lin, Wilton, & Lunskey, 2018), especially if they are living in the parental home rather than in a group home (Lunskey, Balogh, & Cairney, 2012). It is not uncommon for individuals with co-occurring ID and mental illness and their carers to perceive emergency services as stigmatizing and insufficiently adapted to their complex needs (Nicholas et al., 2017; Spassiani, Abou Chacra, & Lunskey, 2017). Concerns include dismissive interactions with service providers, diagnostic overshadowing, and overly simplistic care plans. For two families in this study, securing housing to meet complex needs seemed an insurmountable challenge, presenting a barrier to transitions. Adults with ID in Ontario are significantly more likely to be admitted to long-term care facilities than are adults without ID (Ouellette-Kuntz, Martin, & McKenzie, 2017). Long-term care facilities are designed to meet the medical needs of older residents, not the varied needs of younger residents with ID and mental illness. Ultimately,

an adult with ID in this study was transferred to a hospital to remain in psychiatric care because a long-term care facility could not meet her behavioural needs.

All families experienced disruptions in their transitions; however, two families reached a state of crisis, and two families did not. Patterson (2002) defines crisis as a period when “family demands significantly exceed their capabilities” leading to “disequilibrium and disorganization” (p. 351). In this study, families in crisis had a number of risk factors: The adults with ID had complex mental health presentations; suitable housing and in-home supports were unavailable; parents had health conditions that affected daily functioning; family income was below the national median; and informal social support was lacking. Conversely, families not in crisis had several protective factors: The adults with ID had high adaptive functioning; family income was above the national median, enabling creative solutions to mitigate gaps in publicly funded services; and friends, siblings, neighbours, and extended family provided informal social support. Complementary findings are reported in Ouellette-Kuntz et al.’s (2014) study of parents seeking services for their adult children with ID in Ontario, Canada. Family characteristics associated with a lower score on a measure of resilience included parental health conditions, child mental health and behavioural problems, additional family members requiring care, and annual income below CAN\$45,000. Families with lower resilience scores were more likely to be approaching or experiencing a state of crisis six months later. As in this study, Nicholas et al. (2017) found that parents caring for adult children with co-occurring ID and mental illness experienced detriments to their mental and physical health, social relationships, and community engagement. A final observation is that parents in one family continued to be primary caregivers into their 80s. Namkung, Greenberg, Mailick, and Floyd (2018) examined the cumulative effects of caregiving in a study spanning 20 years. By age 71, parents providing in-home care to adult

children with ID had poorer psychological well-being, physical health, and contact with friends compared to parents of adult children with ID living out-of-home and parents of adult children without ID.

The finding that families implemented expected versus unexpected transitions closely parallels Jokinen, Janicki, Hogan, and Force's (2012) distinction between planful (i.e., proactive) and demand (i.e., reactive) transitions. Planful transitions develop naturally and lead to more positive outcomes. Family members have the necessary resources, feel prepared, and remain in control of the process. In contrast, demand transitions occur suddenly and involve families relinquishing control of the process, leading to more adverse outcomes. Demand transitions may occur when a family member's injury, disease, or death leads to crisis and emergency relocation, for example. It is important to note that even the most proactive and resourceful families may experience demand transitions because of factors outside their control. In this study, families who reached a state of crisis had carefully considered support needs and housing options decades before they anticipated needing to transition. Unfortunately, they found that publicly funded services were unable to adapt quickly and flexibly to their changing circumstances.

Coping and Adapting: Searching for Stability in the Family System

Inherent to transitions, all families identified changes in roles, responsibilities, routines, and environments. Consistent with the literature, these changes involved caregiver stress and strain (Gillan & Coughlan, 2010; Leonard et al., 2016), efforts to rebalance independence and protection (Almack et al., 2009; Mill et al., 2009), and feelings of uncertainty, unpreparedness, and anxiety (Dyke et al., 2013; Forte et al., 2011). Families described a prolonged phase of adaptation. They re-established equilibrium by adopting positive attitudes, focusing on long-term goals, and gathering formal and informal supports to meet all family members' needs. Similar

coping strategies are reported in the literature, namely positive attitudes and positive reappraisals in difficult situations, with a focus on acceptance and personal growth (Gardner & Harmon, 2002; Paster, Brandwein, & Walsh, 2009), informal and formal social supports (Anaby et al., 2013; Gardner & Harmon, 2002; Paster et al., 2009), and consideration of the needs of all members in the family system (Gardner & Harmon, 2002).

Research on families caring for family members with ID has evolved from a deficit model to a strengths-based model (Gardner & Harmon, 2002). Amidst significant challenges in the transition process, families also demonstrated resilience or “positive adjustment in the context of challenging life conditions” (Gardner, Huber, Steiner, Vazquez, & Savage, 2008, p. 107). Research on family resilience seeks to explain the way families positively adapt when confronted with adversity, accounting for risk and protective factors at multiple system levels. For example, Patterson (1988, 2002) reasoned that families’ demands (i.e., stressors) and capabilities (i.e., resources) become imbalanced in periods of high risk and crisis, and resilient families are capable of restoring this balance. Meaning making—the way families co-construct their identity and worldview—is essential to this adaptation process. More recently, Henry et al. (2015) proposed that risk, protection, vulnerability, and adaptation interact and are influenced by families’ interpretations of situations, mechanisms for regulating family life and fulfilling family functions, and wider socioecological environments. According to an integrative review of 40 articles by Benzie and Mychasiuk (2009), family resilience rests upon individual-level factors (e.g., internal locus of control, emotional regulation, self-efficacy, health), family-level factors (e.g., stable intimate partner relationship, family cohesion, social support, adequate income and housing), and community-level factors (e.g., community involvement, peer acceptance, safe neighbourhoods, quality education and health care).

Limitations

This study used a longitudinal design to allow adults with ID and their parents to share their transition stories as they were unfolding. Participating family members represented diverse ages (i.e., 20s to 80s), geographical regions (i.e., urban, rural), support needs (i.e., mental health concerns, medical conditions, physical disabilities), and transition events (i.e., vocational program, supported independent living apartments, long-term care facility). It is a limitation, however, that participating families represented the cultural and linguistic majority and lower-middle to upper-middle socioeconomic backgrounds. Findings may be less transferrable to families who experience additional social inequalities and families who live in jurisdictions with differently structured health care and community services.

Another limitation is the absence of siblings' perspectives. That typically developing adult siblings build their own lives and leave their parental home poses a challenge for conducting research with all members of a family system. Three of the four adults with ID in this study have siblings; however, only one had a sibling staying in the parental home for any length of time. In one family, siblings were reportedly involved in planning the transition. In another family, parents were at least partially motivated for the transition because they wanted to spare their typically developing child from becoming a primary caregiver. Research suggests siblings have an important role in transitions, tending to assume greater supervising and caregiving responsibilities of their brother or sister with ID (Hall & Rossetti, 2017; Heller & Kramer, 2009). Future research is needed to expand upon siblings' role in transitions, especially in regard to family coping and resilience.

Conclusions

This longitudinal, multiple-case study explored transitions in the lives of adults with ID and their families in Ontario, Canada. Findings provide a more nuanced understanding of transitions as lifelong processes of change and adaptation, instability and stability, in the family system. Although families experienced hardships, they were able to restore balance and demonstrate resilience (Patterson, 1988, 2002). Findings have important implications. First, service providers working with adults with ID should seek family involvement and identify risk and protective factors at multiple system levels. Second, service providers and policymakers should continue to work toward creative solutions to deliver timely transition planning information and support. Third, Ontarian health care, housing, and social service systems are currently unable to flexibly respond to sudden changes in support needs, which can leave even the most planful families in a state of crisis. Ongoing efforts by service providers, researchers, and policy makers to address these systemic issues are worthwhile.

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Parents' Expectations of Choice-Making Outcomes from Community Participation Supports

Abstract

Research on parents' expectations of formal services for their adult children with intellectual disabilities (ID) is sparse. This study examined the relationship between service user, parent, and family characteristics and parents' expectations that community participation supports would improve their adult children's ability to make daily and life choices. Participants were English- or French-speaking parents ($N = 138$) in Ontario, Canada who requested formal services to help their adult children with ID ($N = 142$) participate in the community. Most parents endorsed expectations of choice-making outcomes from community participation supports for their adult children with ID. Exploratory logistic regressions were performed. Service user gender and prior choice-making experience, as rated by parents, predicted parents' service expectations. The odds of parents expecting community participation supports to improve their adult children's ability to make choices about everyday activities were higher when service users were males with prior choice-making experience. The odds of parents expecting supports to improve their adult children's participation in life decisions were higher when service users had prior choice-making experience. Results are exploratory, and further research is needed to understand the expectations of parents, adults with ID, and other family members when they seek formal services.

Keywords: intellectual and developmental disabilities, community participation supports, service expectations, choice making

Parents' Expectations of Choice-Making Outcomes from Community Participation Supports

Choice making as a human right is a central value in service delivery for people with intellectual disabilities (ID). Programs and policies aim to create environments in which people with ID are supported in making choices and exercising control in their lives (Brown & Brown, 2009; Devi, 2013). For example, the United Nations' (2006) *Convention on the Rights of Persons with Disabilities* upholds "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" and "the opportunity to be actively involved in decision-making processes about policies and programmes" (p. 2). Choice making is associated with increased quality of life (Brown & Brown, 2009; Cannella, O'Reilly, & Lancioni, 2005).

Choice making is often described as simply selecting an option and communicating it to others; however, true choice making is an expression of preference in which the actor perceives two or more reasonable options and realizes that he or she can influence the outcome of events (Brown & Brown, 2009; Webber & Cobigo, 2014). In a scoping review of the literature, Webber and Cobigo (2014) identified four components of successful choice making: (a) frequent, developmentally appropriate opportunities to make both routine choices and life choices; (b) a range of suitable, desirable options from which to choose; (c) relevant information and ample processing time; and (d) a supportive environment in which caregivers encourage, accept, and follow through on choice making, to the point of allowing the actor to fully experience the consequences of his or her choice. Accessible explanations and collaborative problem solving help the actor to learn from his or her choices (Nonnemacher & Bambara, 2011).

Adults with ID often continue to live in the parental home and receive support from their family members to complete their daily living tasks (Braddock, Emerson, Felce, & Stancliffe,

2001; Larson, Lakin, Anderson, & Kwak, 2001). The way the family system supports or thwarts the choice-making environment of people with ID is an important avenue for research (Curryer, Stancliffe, Dew, & Wiese, 2018; Wehmeyer, 2014). From an ecological systems perspective, the family system also functions within social, cultural, economic, and political environments (Bowen, 1978; Bronfenbrenner, 1979), which encompass formal services for meeting the needs of people with disabilities. Service delivery within a family systems framework is considered best practice (Begun, 1996; Turnbull, Summers, & Brotherson, 1984; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). The entire family—not only the adult with ID—is considered the consumer of services.

Families caring for a family member with ID are not always asked to describe their reasons for requesting formal services or the outcomes they anticipate as a result of receiving services (Russell, 2003). Expectations are “subjective predictions about the future” that affect and are affected by attitudes and actions (Russell, 2003, p. 145). Parents of adult children with ID may automatically generate unconscious expectations of services and service providers; however, they may only become aware of these expectations if they are not realized. Exploring parents' expectations is a process that may enhance their working relationship with service providers, enabling greater communication and service satisfaction (Russell, 2003, 2005).

Research on parents' expectations of developmental services is sparse (Russell, 2003). Related research suggests service user, parent, and family characteristics are associated with parents' expectations of post-school and employment outcomes for their children with disabilities (Blustein, Carter, & McMillan, 2016; Doren, Gau, & Lindstrom, 2012; Kang, 2015). In turn, parents' expectations are associated with their children's autonomy and likelihood of attaining high school diplomas, postsecondary enrollment, and paid employment (Doren et al.,

2012). In addition to facilitating collaborations with service providers, an understanding of parents' expectations may reveal ways to improve outcomes for their children with disabilities.

To the authors' knowledge, no study has examined parents' expectations of choice-making outcomes as a result of their adult children participating in formal services. Researchers have examined variables at multiple system levels that affect self-determination and choice-making skills for people with ID (Shogren, 2013; Wehmeyer & Abery, 2013; Wehmeyer et al., 2011); however, characteristics associated with parents' expectations of choice-making outcomes remain to be understood. The current study aims to answer the following research question: What service user, parent, and family characteristics are associated with parents' expectations that community participation supports will facilitate their adult children's ability to make daily choices and life choices?

Method

Context

The Government of Ontario passed the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* in 2008 to provide adults with ID and their caregivers with a streamlined process for requesting services and equitable access to services in their own community. Since 2011, each region of Ontario has been served by one of nine Developmental Services Ontario (DSO) agencies, which provides information on available resources, determines eligibility and support needs, and processes applications in a standardized way. By connecting to the DSO agency in their region, adults with ID and their caregivers are able to request a number of services through a central point of access. Whether their request is approved depends on eligibility criteria, service availability, and system priority.

DSO agencies arrange referrals to community organizations that provide different services. Residential services assist adults with ID in securing appropriate living arrangements, including group homes, host family homes, and specialized accommodations for living independently. Respite services provide primary caregivers with a break from their caregiving duties. Activities of daily living in-home supports help adults with ID to manage their daily routines as independently as possible. Person-directed planning services assist adults with ID in envisioning their own life goals and arranging the formal and informal supports necessary to reach those goals. Finally, community participation supports help people with ID enjoy social activities (e.g., sports, hobbies), develop self-help skills (e.g., learn to ride the bus or go shopping), continue their education after high school (e.g., use the library, register in college courses), and volunteer or prepare for a job (e.g., practice work-related skills).

Study Design

The Multidimensional Assessment of Providers and Systems (MAPS) is a collaboration of researchers and community partners in Ontario, Canada seeking to provide evidence to inform actions to improve services and supports for adults with ID and their caregivers. The MAPS team conducted a cross-sectional study of families' needs and experiences while seeking adult developmental services (Ouellette-Kuntz, Lunskey, Blinkhorn, Robinson, & Tint, 2013). All nine DSO agencies in Ontario assisted in recruitment by providing Request for Information forms in stamped envelopes to English- and French-speaking parents who requested services between July 4, 2011 and March 31, 2012 for a child with ID aged 16 or older living in their home. Parents were instructed to mail their Request for Information form to the MAPS team to learn more about the study. In response, the MAPS team mailed detailed study information, a consent form, and a paper and pencil survey in a self-addressed stamped envelope. Two weeks after

mailing the package, a member of the MAPS team called parents to follow-up, answer any questions, and ask additional questions by telephone interview.

The cross-sectional sample reflected the formal service needs and requests of 216 adults with ID, also referred to as service users. Respondents were 211 carers: 209 parents and two non-parent carers, hereafter collectively referred to as parents. Five of these parents requested adult developmental services for two adults with ID. Although recruitment efforts focused on families in which the adults with ID lived in the parental home, in actuality, 207 adults with ID lived in the parental home, and nine had left the parental home to live in the community by the date of their parents' telephone interview. Finally, in one family, the parent provided responses two months outside of the data collection period, in May 2012.

The current study uses secondary data from the MAPS research program to explore parents' service expectations regarding choice-making outcomes. This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the University of Ottawa Health Sciences and Science Research Ethics Board.

Measures

Mail survey. The MAPS mail survey contained 58 items designed to be completed by parents within 20 minutes. Secondary data requested from the mail survey concerned the adults with ID and their experience with choice making, as well as family demographics. Secondary data from two published tools embedded in the mail survey were also requested: (a) the Compensating Experiences subscale of the Inventory of Family Protective Factors (Gardner, Huber, Steiner, Vazquez, & Savage, 2008; see Appendix G) and (b) the Brief Family Distress Scale (Weiss & Lunsky, 2011; see Appendix H).

Inventory of Family Protective Factors. The Inventory of Family Protective Factors (Gardner et al., 2008) is a 16-item measure of family resilience. The respondent answers on a 5-point Likert scale from 1 (*Not at all like my family*) to 5 (*Almost always like my family*). The Inventory of Family Protective Factors has yielded good estimates of internal consistency in different samples (Cronbach's $\alpha = .87, .77$, and $.81$; Gardner et al., 2008). The measure has four subscales with four items each: Fewer Stressors (e.g., socioeconomic status, health problems, violence), Adaptive Appraisal (e.g., self-efficacy, acceptance of situation, sense of calm), Social Support (e.g., extended family, community involvement, service providers), and Compensating Experiences (e.g., mastery over adversity, sense of control, sense of meaning). Only the latter subscale was included in MAPS data collection. The Compensating Experiences subscale has yielded acceptable to good estimates of internal consistency (Cronbach's $\alpha = .87, .80$, and $.68$; Gardner et al., 2008).

Brief Family Distress Scale. The Brief Family Distress Scale (Weiss & Lunsky, 2011) is a single item designed to quickly gauge perceived family distress. The respondent is asked to choose a statement on a continuum that most accurately describes his or her family's current state of crisis. There are 10 response options from 1 (*Everything is fine, my family and I are not in crisis at all*) to 10 (*We are currently in crisis, and it could not get any worse*). Responses on the single-item scale have been found to positively correlate with ratings of caregiver distress, child externalizing problems, and adverse life events and negatively correlate with ratings of family empowerment and quality of life (Weiss & Lunsky, 2011).

Telephone interview. The telephone interview contained 63 items administered by a MAPS team member in approximately 30 minutes. Secondary data requested from the telephone interview concerned the support needs of the adults with ID, the type of services requested, and

parents' motivations and expectations in seeking services. Secondary data from a published tool called the Brief COPE (Carver, 1997; see Appendix I) administered over the telephone were also requested.

Brief COPE. The Brief COPE (Carver, 1997) is designed to capture different styles of responding to stressful circumstances. The 28-item measure consists of 14 subscales with two items per subscale. Each item is rated on a 4-point scale, ranging from 0 (*I haven't been doing this at all*) to 3 (*I have been doing this a lot*), such that a higher score reflects greater use of a particular coping strategy. No total score is calculated. Rather, subscales are selected according to the research goal, and scores for each coping strategy are examined independently. The MAPS team adopted five subscales from the Brief COPE: Active Coping (e.g., taking action to transform the situation), Using Emotional Support (e.g., seeking comfort and understanding), Using Instrumental Support (e.g., seeking help and advice), Planning (e.g., thinking and strategizing), and Acceptance (e.g., acknowledging reality). Internal consistency for the five subscales ranges from .57 to .73 (Carver, 1997).

Participants

Among the adults with ID in the MAPS cross-sectional study for whom adult developmental services were requested ($N = 216$), nine cases had missing information on the type of services requested. Among the adults with ID for whom this information was provided ($n = 207$), the most commonly requested service was community participation supports (68.6%), followed by residential services (44.4%), caregiver respite (32.4%), activities of daily living in-home support (6.8%), and person-directed planning (2.9%). The current study includes only those adults with ID for whom community participation supports were requested ($N = 142$) because this type of service may enhance self-determination and choice-making skills through

involvement in extracurricular and vocational activities. Person-directed planning also fosters choice making; however, this service was requested by too few participants to conduct meaningful analyses. DSO agencies accommodate as many service requests as needed; thus, those who requested community participation supports could also have requested additional services.

Cases with ($N = 142$) and without ($n = 65$) a request for community participation supports were compared using Chi-square tests for independence (with Yates' continuity corrections) and Independent samples t -tests (see Supplementary Table 1). Community participation supports were more often requested by parents with at least some postsecondary education (74.6%) compared to parents with no postsecondary education (52.5%), $\chi^2(1, n = 201) = 8.39, p = .004$, $\phi = .22$, and by parents in two-parent homes (73.5%) compared to parents in single-parent homes (57.4%), $\chi^2(1, n = 200) = 4.65, p = .03$, $\phi = .16$. Community participation supports were more often requested for male service users (73.9%) compared to female service users (58.9%), $\chi^2(1, n = 207) = 4.25, p = .04$, $\phi = -.15$. These are small effects, however. Those for whom community participation supports were requested tended to be younger ($M_{years} = 22.12, SD = 5.20$) compared to those for whom community participation supports were not requested ($M_{years} = 26.60, SD = 9.78$), $t(81.04) = 3.47, p < .001$ (two-tailed). The magnitude of the difference in the means was moderate (Cohen's $d = .57$). Parents' indications of their adult children's medical support needs, behavioural support needs, and risks to personal safety were not significantly associated with the request for community participation supports. Likewise, parent gender, household income, and family distress were not significantly associated with this service request.

Characteristics of the sample are presented in Table 1. The 142 adults with ID for whom community participation supports were requested tended to be males (69.7%) in early adulthood

Table 1

Sample Characteristics as Reported by Parents

Variables	%
Service User Characteristics (<i>N</i> = 142)	
Age in years (<i>n</i> = 142)	
16.0 – 20.9	52.1
21.0 – 24.9	30.3
25.0 – 29.9	8.4
30.0 +	9.2
Gender (<i>n</i> = 142)	
Male	69.7
Female	30.3
Medical support needs (<i>n</i> = 142)	
No	50.7
Yes	49.3
Behavioural support needs (<i>n</i> = 142)	
No	64.8
Yes	35.2
Safety concerns (<i>n</i> = 139)	
No	48.9
Yes	51.1
Parent Characteristics (<i>N</i> = 138)	
Age in years (<i>n</i> = 131)	
35.0 – 44.9	13.7
45.0 – 54.9	59.6
55.0 +	26.7
Gender (<i>n</i> = 138)	
Male	11.6
Female	88.4
Relationship status (<i>n</i> = 132)	
Single-parent home	29.5
Two-parent home	70.5
Education (<i>n</i> = 133)	
No postsecondary	23.3
At least some postsecondary	76.7
Family Characteristics (<i>N</i> = 138)	
Household income (<i>n</i> = 130)	
\$55,000 and below	48.5
\$55,001 and above	51.5
Other dependents in home (<i>n</i> = 136)	
No	50.0
Yes	50.0

Family distress ($n = 135$)	
Low	33.3
Medium	38.5
High	28.1

Note. Respondents were 138 parents who provided information on 142 adults with intellectual disabilities. Four families had two adults with intellectual disabilities.

($M_{years} = 22.12$, $SD = 5.20$) who lived in the parental home (97.9%)¹. They tended to have a modest amount of prior choice-making experience, as rated by their parents ($M = 2.1$, $SD = 1.7$ on a 7-point scale). Nearly half of the adults with ID had medical support needs (49.3%), and over one-third had behavioural support needs (35.2%). For over half of the adults with ID (51.1%), their medical or behavioural support needs resulted in their parents endorsing concerns for their safety. In addition to community participation supports, residential supports (37.3%), caregiver respite (35.2%), activities of daily living in-home supports (4.9%), and person-directed planning (3.5%) were additional services requested for this cohort of adults with ID.

Respondents were 138 carers: 137 parents and one non-parent carer, hereafter collectively referred to as parents because of their shared role experience. This means that four parents each requested community participation supports for two adults with ID. Parents were typically mothers (88.4%) in middle adulthood ($M_{years} = 52.02$, $SD = 6.42$) who were married or common-law (70.5%) and had at least some postsecondary education (76.7%). Exactly half of parents identified themselves as the primary caregiver to someone in the home in addition to the person for whom services were requested. Parents reported a moderate level of distress in their family ($M = 4.76$, $SD = 2.04$ on a 10-point scale).

Missing Data

Less than 5% of data were missing, and Little's MCAR test revealed no patterns in missingness, $\chi^2(5) = 8.65$, $p = .12$. Schafer (1999) regards missingness of 5% or less as inconsequential. Case deletion methods are not recommended for handling large amounts of missing data in small samples; however, data simulations suggest they perform as well as imputation methods and better than mean substitution methods with small amounts of

¹ Three adults with ID were living in the community at the time their parents completed the telephone interview.

missingness in sample sizes that allow for adequate power (Cheema, 2014). They also yield regression parameter estimates and model statistics that are comparable to analyses conducted with complete non-imputed datasets.

Analyses were conducted using pairwise deletion, with data meeting the assumption of missing completely at random (Baraldi & Enders, 2010). Pairwise deletion, or available case analysis, excludes only those cases that have missingness on the variables included in any given analysis. Because cases may be included in some analyses but not in others, an important consideration of pairwise deletion is that sample inconsistencies may lead to problems comparing analyses (Schlomer, Bauman, & Card, 2010). Given this concern, a sensitivity analysis was conducted with listwise deletion, or complete case analysis, which restricts analyses to cases with complete data and maintains a consistent sample size.

Cases with ($n = 24$) and without ($n = 118$) missing data were first compared on demographic variables using Chi-square tests for independence (with Yates' continuity correction) and Independent samples *t*-tests (see Supplementary Table 2). There were no statistically significant differences between cases with and without missing data. Cases with complete data were therefore considered to be a random subsample among those who requested community participation supports. The logistic regression procedures detailed in the following section were performed with both pairwise deletion and listwise deletion. Results were comparable, with the same final predictors reaching significance. Results were not sensitive to case deletion method. Results are therefore presented using pairwise deletion to ensure the highest possible power.

Analysis

Secondary data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 24.0. Data were screened and cleaned according to the procedures recommended by Tabachnick and Fidell (2007). For logistic regression, these procedures include ensuring appropriate ratios of cases to variables, adequacy of expected cell frequencies, independence of errors, linearity in the logit, and absence of multicollinearity. Linearity in the logit assumes a linear relationship between a continuous independent variable and the log odds of a dichotomous dependent variable. One variable—the Instrumental Coping subscale of the Brief COPE—violated this assumption, requiring a squared transformation with one dependent variable and an inverse transformation with another dependent variable. To address issues in cell frequencies, parent gender was removed as a predictor variable. Categories were also collapsed in parent education (i.e., no postsecondary vs. postsecondary), parent relationship status (i.e., single-parent vs. two-parent home), and household income (i.e., \$55,000 and below vs. \$55,001 and above). A continuous variable to reflect prior choice-making experience was created by tallying responses from seven ‘yes’ or ‘no’ choice-making questions (e.g., “Does your son or daughter have a personal life plan?” and “Does your son or daughter want to have control and input over hiring and management of support workers?”).

Analyses were exploratory because little is known about parents’ expectations of adult developmental services. There were no a priori hypotheses. Identified by theoretical plausibility, potential predictor variables included characteristics of the individual for whom developmental services were requested (i.e., age, gender, medical and behavioural support needs, safety concerns, choice-making experience), the parent (i.e., age, relationship status, education, coping style), and the family (i.e., income, dependents in home, resilience, distress). The two outcome

variables of interest were whether parents reported the expectation that community participation supports would improve their adult child's ability to make daily choices ('yes' or 'no') and participate in life decisions ('yes' or 'no').

Separate hierarchical logistic regressions were conducted to explore the incremental impact of service user, parent, and family characteristics on each of the outcome variables. To first select predictors for inclusion in the hierarchical logistic regressions, a series of direct logistic regressions was computed with conceptual groupings of potential predictor variables (D. Schindler, personal communication, August 3, 2017). Variables that reached significance in the series of direct logistic regressions with alpha set at $p < .10$ were included in the hierarchical logistic regressions. A more liberal alpha was used only for the purpose of selecting predictors, whereas a conventional alpha of $p < .05$ was used to gauge the contributions of predictors in the hierarchical logistic regressions (Ranganathan, Pramesh, & Aggarwal, 2017).

Results

Most parents reported anticipating that community participation supports would improve choice-making outcomes (see Table 2). Each service expectation is examined in turn.

Table 2

Parents' Service Expectations for their Adult Children with Intellectual Disabilities

Service Expectation	Yes (%)	No (%)
Are you expecting community participation supports to improve your son or daughter's ability to make choices about everyday activities? ($n = 139$)	82.0	18.0
Are you expecting community participation supports to improve your son or daughter's involvement in discussions about future life decisions? ($n = 140$)	75.0	25.0

Expectation that Community Participation Supports Would Improve Daily Choice Making

From a direct logistic regression series (see Table 3), independent variables that reached $p < .10$ were included in a hierarchical logistic regression model: service user gender and choice-making experience; parent age, education, and instrumental coping style; and household income. A test of the full model containing all six predictors against the constant-only model was statistically significant, $\chi^2(6) = 27.87, p < .001$. The full model explained between 20% (Cox and Snell R square) and 32% (Nagelkerke R square) of the variance in parents' service expectation. Table 4 shows the full model with regression coefficients, odds ratios, and 95% confidence intervals for odds ratios for each of the six predictors. Service user characteristics in Step 1 explained the most variance in the model, from 13% (Cox and Snell R square) to 20% (Nagelkerke R square). According to the Wald criterion, parents' service expectation was most reliably predicted by service user choice-making experience, $\chi^2(1) = 6.99, p < .01$, and service user gender, $\chi^2(1) = 5.32, p = .02$. Holding constant other predictors in the model, for every point increase on service user choice-making experience, the odds of parents endorsing the expectation that community participation supports would improve daily choice making increased by 70%. Compared to parents of adult sons, the odds of parents of adult daughters endorsing this service expectation decreased by 73%. Parent age, education, and instrumental coping style and household income did not reliably predict the outcome.

Table 3

Exploratory Logistic Regressions for Variables Predicting Parents' Expectations that Community Participation Supports Would Improve Service Users' Ability to Make Daily Choices and Life Choices

Variables	Model	Expectation to Improve Daily Choices					Model	Expectation to Improve Life Choices				
		<i>B</i>	Std. Error	Odds Ratio	90% CI			<i>B</i>	Std. Error	Odds Ratio	90% CI	
Service User Characteristics	1a						2a					
Age		0.06	0.06	1.06	0.96	1.16		0.02	0.05	1.02	0.94	1.12
Gender		-1.43**	0.53	0.24	0.10	0.57		-0.82+	0.48	0.44	0.20	0.96
Medical support needs		0.30	0.58	1.35	0.52	3.52		0.30	0.52	1.35	0.58	3.18
Behavioural support needs		-0.35	0.68	0.71	0.23	2.14		-0.26	0.59	0.77	0.29	2.01
Safety concerns		-0.03	0.71	0.97	0.30	3.12		-0.42	0.63	0.65	0.23	1.83
Choice-making experience		0.60***	0.18	1.83	1.35	2.47		0.59***	0.16	1.80	1.39	2.34
Parent Characteristics	1b						2b					
Age		0.09+	0.05	1.09	1.01	1.18		0.05	0.04	1.05	0.99	1.11
Relationship status		-1.10	0.70	0.33	0.11	1.04		-0.43	0.50	0.65	0.29	1.49
Education		-1.57+	0.83	0.21	0.05	0.82		-0.88	0.59	0.42	0.16	1.09
Active coping		-0.04	0.23	0.97	0.66	1.42		-0.22	0.20	0.80	0.58	1.12
Emotional coping		-0.11	0.14	0.89	0.71	1.12		-0.18	0.12	0.84	0.69	1.03
Instrumental coping ^a		-2.59*	1.08	0.08	0.01	0.44		0.38	0.36	1.46	0.80	2.64
Planning coping		-0.12	0.23	0.88	0.61	1.28		0.14	0.19	1.15	0.85	1.57
Acceptance coping		0.02	0.14	1.02	0.81	1.28		0.03	0.12	1.03	0.84	1.27
Family Characteristics	1c						2c					
Household income		-1.26*	0.52	0.29	0.12	0.67		-0.47	0.42	0.63	0.31	1.24
Other dependents in home		0.23	0.49	1.26	0.57	2.79		0.24	0.42	1.27	0.64	2.54
Compensating experiences		0.02	0.08	1.02	0.89	1.17		0.05	0.07	1.05	0.94	1.18
Family distress		-0.05	0.12	0.95	0.78	1.16		-.12	0.10	0.89	0.75	1.05

Note. + $p < .10$. * $p < .05$. ** $p < .01$. *** $p < .001$.

^a Inverse of Instrumental coping in Model 1b and square root of Instrumental coping in Model 2b

Model 1a: $\chi^2(6, n = 133) = 22.14, p = .001. R^2 = .15$ (Cox & Snell), .25 (Nagelkerke).

Model 1b: $\chi^2(8, n = 126) = 17.40, p = .03. R^2 = .13$ (Cox & Snell), .20 (Nagelkerke).

Model 1c: $\chi^2(4, n = 130) = 6.85, p = .14. R^2 = .05$ (Cox & Snell), .08 (Nagelkerke).

Model 2a: $\chi^2(6, n = 134) = 22.64, p = .001. R^2 = .16$ (Cox & Snell), .23 (Nagelkerke).

Model 2b: $\chi^2(8, n = 127) = 8.08, p = .43. R^2 = .06$ (Cox & Snell), .09 (Nagelkerke).

Model 2c: $\chi^2(4, n = 131) = 3.71, p = .45. R^2 = .03$ (Cox & Snell), .04 (Nagelkerke).

Table 4

Hierarchical Logistic Regression for Variables Predicting Parents' Expectation that Community Participation Supports Would Improve Service Users' Ability to Make Daily Choices

Step	Variables	Expectation to Improve Daily Choices			
		B	Std. Error	Odds Ratio	95% CI
1	Service User Characteristics				
	Gender	-1.30*	0.56	0.27	0.09 0.82
	Choice-making experience	0.53**	0.20	1.70	1.15 2.53
2	Parent Characteristics				
	mAge	0.08	0.05	1.09	0.99 1.20
	Education	-1.27	0.86	0.28	0.05 1.50
	Instrumental coping ^a	-1.35	1.01	0.26	0.04 1.88
3	Family Characteristics				
	Household income	-0.95	0.57	0.39	0.13 1.19
	(Constant)	2.05	1.08	7.78	

Note. * $p < .05$. ** $p < .01$.

Step 1: $\chi^2(2) = 16.72$, $p < .001$, $R^2 = .13$ (Cox & Snell), .20 (Nagelkerke).

Step 2: $\chi^2(3) = 8.20$, $p = .04$, $\Delta R^2 = .05$ (Cox & Snell), .09 (Nagelkerke).

Step 3: $\chi^2(1) = 2.95$, $p = .09$, $\Delta R^2 = .02$ (Cox & Snell), .03 (Nagelkerke).

Full model: $\chi^2(6, n = 125) = 27.87$, $p < .001$, $R^2 = .20$ (Cox & Snell), .32 (Nagelkerke).

^a Inverse of Instrumental coping

Gender coded as 0 for male and 1 for female. Choice-making experience scored from 0 to 7. mAge re-scaled to minimum value of 38.4 years. Education coded as 0 for no postsecondary education and 1 for at least some postsecondary education. Brief COPE Using Instrumental Support subscale scored from 0 to 6. Household income coded as 0 for \$55,000 and below and 1 for \$55,001 and above.

Expectation that Community Participation Supports Would Improve Ability to Participate in Life Decisions

From a direct logistic regression series (see Table 3), independent variables that reached $p < .10$ were included in a full model: service user gender and choice-making experience. Neither parent nor family characteristics reached the significance required to be included as predictors. Service user characteristics were entered in a single step. A test of the full model containing two predictors against the constant-only model was statistically significant, $\chi^2(2) = 21.13, p < .001$. The full model explained between 14% (Cox and Snell R square) and 21% (Nagelkerke R square) of the variance in parents' service expectation. Table 5 presents the regression coefficients, odds ratios, and 95% confidence intervals for odds ratios for both predictors. According to the Wald criterion, only service user choice-making experience reliably predicted parents' service expectation, $\chi^2(1) = 14.67, p < .001$. For every point increase on service user choice-making experience, the odds of parents endorsing the expectation that community participation supports would facilitate participation in life decisions increased by 86%. Service user gender did not reliably predict the outcome.

Table 5

Logistic Regression for Variables Predicting Parents' Expectation that Community Participation Supports Would Improve Service Users' Ability to Make Life Choices

Variables	Expectation to Improve Life Choices				
	<i>B</i>	Std. Error	Odds Ratio	95% CI	
Service User Characteristics					
Gender	-0.69	0.46	0.50	0.20	1.23
Choice-making experience	0.62***	0.16	1.86	1.36	2.56
(Constant)	0.21	0.33	1.24		

Note. *** $p < .001$.

Full model: $\chi^2(2, n = 137) = 21.13, p < .001, R^2 = .14$ (Cox & Snell), .21 (Nagelkerke).

Gender coded as 0 for male and 1 for female. Choice-making experience scored from 0 to 7.

Discussion

The current study explored the relationship between service user, parent, and family characteristics and parents' expectations that community participation supports would improve choice-making outcomes for their adult children with ID. The large majority of parents indicated that they did expect community participation supports to enhance their adult children's ability to make choices about everyday activities (82%) and participate in discussions about life decisions (75%). Among the predictor variables explored, two appear to be important for future research: service user gender and prior choice-making experience.

There was a significant association between service user gender and the request for community participation supports, with parents of adult sons requesting this service more often than parents of adult daughters. Service user gender also significantly predicted whether or not parents who requested community participation supports endorsed the expectation of improved daily choice making. The odds of reporting this expectation were higher for parents of adult sons compared to parents of adult daughters. To the authors' knowledge, no other study on parents' expectations of choice making for their adult children with ID is available to contextualize this gender difference. More generally, research on the influence of gender on self-determination—a construct that encompasses choice making—has yielded contradictory findings (Cavendish, 2017; Rodriguez & Cavendish, 2012; Shogren, 2013; Shogren & Shaw, 2017; Shogren, Shaw, Raley, & Wehmeyer, 2018; Wehmeyer et al., 2011). Research on parents' expectations has concerned outcomes other than choice making. In a sample of over 1,000 parents of adolescents and young adults with ID or autism spectrum disorder (ASD), Blustein et al. (2016) found that male service user gender was negatively correlated with parents' expectation for employment in the community. Similarly, in a sample of over 2,000 parents of adolescents with disabilities

receiving special education services, Doren et al. (2012) found that parents of daughters had significantly higher expectations for enrollment in postsecondary education compared to parents of sons. Further research in ID is required to examine the role of gender in self-determination, service expectations, service expectations of self-determination, and choice-making outcomes. Understanding the experiences of men and women with ID in terms of community opportunities and societal attitudes toward protection and risk management may be of particular importance.

Service user choice-making experience significantly predicted parents' expectations that community participation supports would improve both daily and life choice making. The odds of parents endorsing these service expectations increased as their reports of their adult children's prior choice-making experience also increased. Results are consistent with theoretical frameworks in developmental psychology and self-determination: In environments that support choice making, experience with choice making builds competence for future choice making (Palmer, 2010; Palmer et al., 2012). Choice-making opportunities have been found to significantly predict self-determination scores in adults with ID and other developmental disabilities (Wehmeyer & Garner, 2003), and opportunities to exercise self-determination at home and at school have been found to significantly predict adolescents' and young adults' self-determination scores (Mumbardó-Adam, Shogren, Guàrdia-Olmos, & Giné, 2017). Parent and family characteristics, as measured in the original MAPS study, did not significantly predict parents' service expectations. At the same time, conceptualizing choice-making experience as a service user characteristic is simplistic. Choice making occurs in a supportive environment in which trusted persons create choice-making opportunities and honour responses. At least theoretically, choice making reflects service user, parent, and family characteristics simultaneously.

Similar results are reported in Blustein et al.'s (2016) study on parents' expectations for post-school and employment outcomes for their children aged 22 and younger with ID or ASD. Parents' expectations for their children to be employed in the community were significantly predicted by their children's work-related experiences at home (e.g., helping with chores), at school (e.g., participating in vocational training), and in the community (e.g., having a summer job or internship). Parent and family characteristics (e.g., education, ethnicity, income) did not affect parents' employment expectations. Results in this study and in Blustein et al.'s (2016) study suggest that the life experiences of people with disabilities—whether related to choice making or working—are associated with their parents' expectations for them. The direction of this relationship remains to be understood. Parents who have high expectations for their children may deliberately create environments in which their children are more likely to accrue life experiences and achieve desired outcomes. Seeing their children excel may, in turn, reinforce their expectations.

Limitations and Future Directions

The exploratory nature of this study has a number of methodological limitations. First, analyses would have been underpowered had all theoretically plausible predictors been included in the same logistic regression; therefore, potential predictors were narrowed down according to their statistical significance in conceptually grouped direct logistic regressions (D. Schindler, personal communication, August 3, 2017). In a slightly different sample, different potential predictors may have reached significance in this initial step, affecting variable entry and fit in the final logistic regression models. Results in the final logistic regression models are tentative and must be confirmed in additional samples. Results are intended to identify avenues for future research.

Another limitation concerns the structure of the sample. It should be reiterated that 138 parents responded on behalf of 142 adults with ID. The duplication of parent and family demographic characteristics in four cases introduced a small amount of dependency in the data structure, which may have slightly inflated the standard error and increased the chance of a Type I error. Importantly, the service user characteristics and the outcome variables of interest—service expectations—were unique to each adult with ID.

Additional limitations concern the study design. Any use of secondary data is limited to the variables in the original study. It was not possible to include a validated assessment of adaptive skills and support needs within service user characteristics. In the initial study, the MAPS team requested data on the Supports Intensity Scale (SIS; Thompson et al., 2004) from all DSO agencies processing participants' service requests. Unfortunately, the SIS was not completed for enough participants within the data collection period to conduct meaningful analyses. Although SIS scores were not included in the current study, reports on three SIS variables were available, namely parents' ratings of whether their adult children had medical support needs, behavioural support needs, and any resulting risks to personal safety.

Although service user gender and service user choice-making experience uniquely contributed to one or both of parents' service expectations, most predictors in the regression models did not reach statistical significance. Different predictors of parents' service expectations need to be examined, and parents' expectations need to be understood in a more nuanced way. Examining expectations as they relate to values, attitudes, and previous service experiences may be worthwhile. More importantly, future research needs to hear from adults with ID themselves on what they need and expect from the services they use and why. Given the limited research on expectations of services for people with ID, qualitative and mixed-methods approaches are

perhaps better suited for advancing this knowledge. Inviting service users and their family members to express their individual and collective needs, values, and goals as they relate to service expectations may be worthwhile.

Conclusions

Understanding families' service expectations—in this study, parents' service expectations—may allow service providers to collaborate more effectively with families and tailor services to meet their needs (Russell, 2003). Parents in this study overwhelmingly endorsed the expectations that community participation supports would facilitate their adult children's ability to make daily choices and participate in life decisions. With this knowledge, providers of adult developmental services in Ontario may wish to enhance their working relationship with families by communicating about choice-making expectations and identifying ways to enhance choice-making outcomes. Results suggest that service user gender and prior choice-making experience may contribute to parents' expectations; however, further research is needed to understand families' expectations of adult developmental services.

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Supplementary Table 1

Comparing Cases with (N = 142) and without (n = 65) a Request for Community Participation Supports

Variables	Chi-square tests for independence with Yates' continuity correction				
	<i>n</i>	<i>df</i>	χ^2	<i>p</i>	phi
Service User Characteristics					
Gender	207	1	4.25	.04	-.15
Medical support needs	207	1	0.47	.50	.06
Behavioural support needs	207	1	0.22	.64	.04
Safety concerns	204	1	1.26	.26	.09
Parent Characteristics					
Gender	207	1	1.07	.30	.09
Relationship status	200	1	4.65	.03	.16
Education	201	1	8.39	<.01	.22
Family Characteristics					
Household income	195	1	1.19	.28	.09
Variables	Independent samples <i>t</i> -tests (two-tailed)				
	<i>n</i>	<i>df</i>	<i>t</i>	<i>p</i>	Cohen's <i>d</i>
Service User Characteristics					
Age	207	81.04	3.47	<.01	.57
Parent Characteristics					
Age	200	89.66	4.01	<.01	.65
Family Characteristics					
Family distress	204	103.19	0.99	.32	.16

Supplementary Table 2

Comparing Cases with (n = 24) and without (n = 118) Missing Data

Variables	Chi-square tests for independence with Yates' continuity correction				
	<i>n</i>	<i>df</i>	χ^2	<i>p</i>	phi
Service User Characteristics					
Gender	142	1	0.14	.71	.05
Medical support needs	142	1	0.00	1.00	-.01
Behavioural support needs	142	1	0.00	.98	-.02
Safety concerns	139	1	1.73	.19	-.13
Parent Characteristics					
Gender	142	1	1.26	.26	.12
Relationship status	136	1	0.56	.45	.09
Education	137	1	1.13	.29	-.12
Family Characteristics					
Household income	134	1	0.21	.65	.06
Variables	Independent samples <i>t</i> -tests (two-tailed)				
	<i>n</i>	<i>df</i>	<i>t</i>	<i>p</i>	Cohen's <i>d</i>
Service User Characteristics					
Age	142	140	-0.29	.77	.07
Parent Characteristics					
Age	135	133	-0.01	1.00	.00
Family Characteristics					
Family distress	139	137	0.04	.97	.01

General Discussion

General Discussion

This dissertation aimed to extend the literature on the way families understand and influence the self-determination of an adult family member with an intellectual disability (ID), particularly during life transitions. This is a timely research direction. In recent decades, constructs related to self-determination, including autonomy and choice making, have increased in the ID literature (Shogren, Wehmeyer, Buchanan, & Lopez, 2006). In countries that have ratified the United Nations' (2006) *Convention on the Rights of Persons with Disabilities*, people with ID often continue to live with and receive support from family members throughout adulthood (Braddock, Emerson, Felce, & Stancliffe, 2001; Larson, Lakin, Anderson, & Kwak, 2001). Moreover, efforts to support people with ID by also coordinating with and supporting their family system have been promoted as best practice (Gardiner & Iarocci, 2012; Turnbull, Turnbull, Erwin, Soodak, & Shrogen, 2015). Research on the self-determination of people with ID has commonly occurred in the special education sector, especially in supporting transitions to post-school opportunities (Lee, Wehmeyer, & Shogren, 2015; Wehmeyer & Abery, 2013). Researchers have recently called for a stronger emphasis on the way people with ID develop and express self-determination in their family system (Curryer, Stancliffe, & Dew, 2015; Curryer, Stancliffe, Dew, & Wiese, 2018; Wehmeyer, 2014) and experience life transitions in their family system (Gardiner & Iarocci, 2012).

This dissertation contains a qualitative study presented in two manuscripts and a quantitative study presented in one manuscript. The qualitative study concerned processes and challenges in the family system during significant life transitions with an adult family member with ID. Manuscript 1 considered the influence of these processes and challenges on the self-determination of two young adults with ID as they developed greater independence and

responsibility. Manuscript 2 considered the influence of these processes and challenges on the quality of life and resilience of four adults with ID and their family system. Families may also expect formal services to help them in promoting self-determination in their adult family member with ID. The quantitative study, presented in Manuscript 3, examined service user, parent, and family characteristics associated with parents' expectations that community participation supports would enhance choice-making outcomes for their adult children with ID. Consistent with a shift in the ID literature from focusing on the experience of individuals with ID to focusing on their experience as shaped by broader familial and social factors, this dissertation is informed by self-determination theory (Deci & Ryan, 1985, 2000, 2002; Ryan & Deci, 2017), family systems theory (Begun, 1996; Bowen, 1978), and family resilience models (Henry, Morris, & Harrist, 2015; Patterson, 1988, 2002).

This general discussion serves to review the primary findings in this dissertation and integrate them with the broader psychological, developmental, and disability literatures. First, a brief overview of each manuscript is provided. Second, primary findings are highlighted. Third, theoretical and practical implications are discussed. Finally, strengths and limitations of this dissertation and directions for future research are considered.

Manuscript Overview

Manuscript 1

In the Barlow and Daly families, Kimberley and Peter were navigating young adulthood and transitioning to adult roles in their communities. Interpreted in the context of self-determination theory (Deci & Ryan, 2000, 2002; Grolnick, Deci, & Ryan, 1997; Ryan & Deci, 2017), familial processes and strategies influenced Kimberley and Peter's self-determination in this critical stage. Parents promoted Kimberley and Peter's competence by modeling goal setting

and problem solving, teaching and scaffolding daily living skills, evaluating and praising progress, and providing choice-making opportunities. They promoted relatedness by facilitating social inclusion and community participation, gathering formal and informal supports, and exhibiting warm and reciprocal familial interactions. They promoted autonomy by providing information and structure, eliciting opinions and feedback, considering preferences and best interests, and ensuring goals and choice-making opportunities aligned with Kimberley and Peter's interests and values. At times, parents were directive with Kimberley and Peter, especially when teaching new skills, managing safety risks, and allocating family resources. Understanding Kimberley and Peter's perspectives in response to their parents' involvement is most important (see also Curryer et al., 2018). Kimberley and Peter recognized their agency in transition choices, expressed satisfaction with transition outcomes, and demonstrated increased confidence and autonomous motivation in attaining adult responsibilities. Overall, the Barlow and Daly families demonstrated high levels of collaboration in choice making, consistent with family systems theory (Bowen, 1978).

Manuscript 2

The Anderson, Baker, Barlow, and Daly families presented their transition stories as meaningful lifelong processes, not time-bound events. Transitions unfolded in stages and reflected periods of stability and instability in the family system (Bowen, 1978; Patterson, 1988, 2002). First, families created foundations for transitions by promoting self-determination and individual and family quality of life (Gardiner & Iarocci, 2012). Second, families engaged in pre-planning and active planning stages, which involved assessing the availability and accessibility of formal services to meet transition goals. Third, families implemented either planned or unplanned transitions. The Barlow and Daly families had the resources and supports to

implement planned transitions for Kimberley and Peter. In contrast, the Anderson and Baker families reached a state of crisis while waiting for residential and mental health services for Kevin and Sasha, and they had to implement unplanned transitions. Finally, families experienced stages of adjusting to their new lives and reflecting on their challenges and achievements. Upon re-stabilizing, families considered future transitions, resuming this cycle. Throughout these stages, challenges related to societal attitudes and abuses, service availability and accessibility, complex mental health needs, and caregiver stress threatened equilibrium in the family system. Families coped by adjusting their expectations, focusing on long-term goals, and accessing formal and informal supports (Gardner & Harmon, 2002; Paster, Brandwein, & Walsh, 2009). Interpreted in the context of family systems and resilience theories (Henry et al., 2015; Patterson, 1988, 2002), families restored the balance between stressors and capabilities and returned their family system to equilibrium.

Manuscript 3

Adults with ID and their families can request a variety of formal services by connecting with their Developmental Services Ontario (DSO) agency. Community participation supports aim to help adults with ID access meaningful activities in their community. This service is thought to enhance self-determination and choice-making skills through extracurricular, educational, and vocational pursuits. Among a cohort of families requesting community participation supports in Ontario, the vast majority of parents expected this service to improve their adult children's ability to make daily choices and participate in life decisions. Exploratory logistic regressions were conducted to see if service user, parent, and family characteristics were associated with parents' endorsement of these service expectations. Among the predictors included in this exploratory study, two appear important for future research: service user gender

and prior choice-making experience. The odds of parents endorsing the service expectation of improved daily choice making were higher when service users were male. The odds of parents endorsing the expectations for improved daily choice making and improved participation in life decisions were higher when service users had prior choice-making experience. Further research is needed to identify different predictors of parents' service expectations, examine the relationship between parents' service expectations and service users' experiences and outcomes, and understand service users' expectations.

Integration of Primary Findings

The Family Life Cycle Shifts When a Family Member has Special Needs

The family life cycle refers to normative transitions in the family system that necessitate changes in roles, responsibilities, and dynamics (Carter & McGoldrick, 2005). Transitions marked by social rituals and conventions include leaving the parental home as a young adult, marrying and forming a new household, welcoming and raising children, and, in turn, preparing those children to leave the parental home and form a new household. Unfolding within the social, economic, and political systems of a historical era, this cycle is shaped by “vertical” or transgenerational stressors (e.g., social prejudices, family legacies and emotional patterns, genetics) and “horizontal” or developmental stressors (e.g., individual physical and cognitive development, unexpected losses or accidents, world events). The family life cycle shifts when a family member has a disability (DeMarle & Le Roux, 2001; Hanline, 1991). Some stages are shortened or lengthened, some have a different meaning, and some are never realized. Family members' roles and responsibilities must accommodate these changes.

This dissertation illustrates changes in the family life cycle when a family member has ID. Four families shared their lives while navigating important transition events, which included

the individual with ID leaving the formal education system for vocational opportunities and leaving the parental home for supported independent living or long-term care. Interestingly, families' stories extended far beyond these specific, time-bound events. Parents shared that they considered transitions from the moment they realized their child had special needs. Parents anticipated extended caregiving roles, pre-planned transitions years and even decades prior to implementation, and slowed the pace of transitions to accommodate their adult child's support needs and readiness. Parents provided this information while also reflecting on their identity and values as a family with a family member with special needs. Findings suggest they adapted their vision for their family life cycle.

This dissertation also lends itself to a discussion on the transition to adulthood and what it means to attain adult status in society. Traditional markers of adulthood have included finishing high school, obtaining paid employment, forming an independent residence, and marrying and having children (Furstenberg, 2010; Janus, 2009; Leiter & Waugh, 2009). These markers were normative for the first two-thirds of the twentieth century. Since the 1960s, changes in social and economic structures in industrialized societies have resulted in a more protracted transition to adulthood (Furstenberg, 2010). Today, adults prolong their education, delay independent living and childbearing, and continue to rely on their families of origin for financial and emotional support well into their 20s and even 30s. Given these trends, developmental psychologists and theorists have critiqued the use of objective milestones to define adulthood. For example, Arnett (2000, 2004) argued that, following a distinct stage of exploration and identity formation, the subjective experience of attaining adulthood is more closely associated with perceived developments in character.

People with ID experience societal barriers in attaining conventional markers of adulthood (Janus, 2009). Compared to their typically developing peers, they are more likely to experience hiring discrimination, inaccessible work and living spaces, and social exclusion and isolation. In this dissertation, two young adults with ID expressed an awareness of their siblings and peers attaining more conventional markers of adulthood. Kimberley wanted to travel and go to university like her siblings, and Peter spoke about people his age moving out and finding paid work. Parents' descriptions of successful transitions to adulthood for their children with ID are more nuanced and varied than the conventional milestones (Floyd, Costigan, & Piazza, 2009; Henninger & Taylor, 2014). For example, parents tend to emphasize free choice over financial independence (Floyd et al., 2009), contributing meaningfully to society and learning new skills over obtaining full-time competitive employment, and living with support from non-parent carers over living independently (Henninger & Taylor, 2014). Overall, characterizations of adulthood for people with ID stress the importance of tailored environmental supports for realizing their full potential in well-being, vocational pursuits, and community participation. In this dissertation, Kimberley and Peter benefitted from family support to navigate societal barriers and realize opportunities for their adult lives.

Lifelong Efforts to Promote Self-Determination Provide a Foundation for Transitions

Much of the transition literature focuses on specific events bound by time and place, such as leaving the formal education system for vocational opportunities (Davies & Beamish, 2009; Dyke, Bourke, Llewellyn, & Leonard, 2013; Hetherington et al., 2010; Pallisera, Vilà, & Fullana, 2014) or leaving the parental home for other residential options (Isaacson, Cocks, & Netto, 2014). An interesting finding in this dissertation is the extent to which families shared their early preparations and motivations for their transitions. To begin, from the day their child with ID was

born, parents identified values that motivated them to advocate for their child and create opportunities for self-determination, social inclusion, and quality of life. Parents' values engendered autonomy supportive family environments in which their child could build his or her own life vision. Parents who supported their child in the transition to adulthood, specifically, also demonstrated goal setting and scaffolding in warm, structured environments. In addition, parents commonly requested formal services to promote community participation and choice making. These efforts, which started in early childhood and continued throughout adulthood, likely promoted the development of self-determination and facilitated the transition process.

According to socioecological models, individual, family, and community factors affect the way self-determination emerges across the lifespan (Deci & Ryan, 2002; Shogren, 2013). Family relationships are especially influential for healthy development (La Guardia & Ryan, 2002; Grusec, 2011). The early childhood foundations model for self-determination holds that the beliefs and skills that contribute to the development of self-determination have roots to be nurtured in early childhood (Palmer, 2010; Palmer et al., 2012; Palmer, Wehmeyer, & Shogren, 2017). In particular, caregivers and educators can collaborate to provide developmentally appropriate cues and environmental supports for choice making and problem solving, self-regulation, goal setting and attainment, and engagement with surroundings. Component beliefs and skills for self-determination are also supported by biophysical, psychosocial, and sociocultural processes (Sokol, Hammond, Kuebli, & Sweetman, 2015). These include perceptual and sensorimotor functions (e.g., ability to sustain attention, recognize goal-directed actions, imitate others), linguistic functions (e.g., ability to understand and express intent with volitional words or gestures, understand and express social roles with personal and possessive pronouns), executive and self-regulative functions (e.g., ability to plan and carry out goal-

directed actions, at first with support), and moral functions (e.g., ability to reflect upon actions, consider alternative actions, internalize social conventions).

Researchers and clinicians recommend a number of strategies for nurturing a foundation for self-determination in childhood. Many of these strategies are intuitive to caregivers who provide a balance of warmth and structure. To promote choice making, for instance, caregivers can create frequent choice-making opportunities tailored to support needs, provide reasonable options and sufficient information, and encourage efforts to communicate likes and dislikes (Dunn & Thrall, 2012; Palmer et al., 2012; Palmer et al., 2017; Webber & Cobigo, 2014).

Problem solving is facilitated when caregivers model and scaffold problem-solving steps, discuss successes and failures, and encourage children to try again when their first attempts do not work (Dunn & Thrall, 2012; Palmer et al., 2012). Caregivers encourage self-regulation by enforcing routines and limits on behaviours, teaching coping and self-soothing skills, encouraging children to recognize cues for unmet physical needs (Dunn & Thrall, 2012), monitoring sensory stimulation and calming overstimulation, and providing support for learning to control impulses (Palmer et al., 2012). To promote engagement with the environment, caregivers can provide accessible leisure spaces and activities and encourage age-appropriate exploration and responsibility (Dunn & Thrall, 2012; Palmer et al., 2012). Recommendations for caregivers to support self-determination in adolescents with disabilities also include modeling self-confidence, encouraging exploration while balancing risk management, setting expectations that are challenging yet attainable, emphasizing effort and process instead of outcome in goal-directed activities, and providing honest feedback (Wehmeyer, Davis, & Palmer, 2010; Wehmeyer & Shogren, 2017). Findings in this dissertation suggest that efforts to promote self-determination in adulthood include modeling goal setting, providing choice-making opportunities, scaffolding the

learning of new skills, and listening and compromising to ensure that family decisions protect the autonomy of the adult with ID.

From the perspective of self-determination theory, the aforementioned strategies are ways of fulfilling the psychological needs for competence, relatedness, and autonomy that engender autonomous motivation (Ryan & Deci, 2017; Soenens, Deci, & Vansteenkiste, 2017). Parenting environments that fulfill these needs are considered to have high levels of structure, involvement, and autonomy support (Grolnick et al., 1997). Taken together, self-determination develops and changes over the lifespan through social interactions and environmental influences. This dissertation emphasizes that self-determination is a developmental and relational process: Parents shared efforts to build a foundation for self-determination when their children with ID were young, and families continually invested in this foundation over the family life cycle. This foundation facilitated resourcefulness and resilience during transitions.

Psychological Need Fulfillment Informs Both Self-Determination and Resilience

This dissertation incorporates family resilience models (Henry et al., 2015; Patterson, 1988, 2002) and self-determination theory (Deci & Ryan, 1985, 2000, 2002; Ryan & Deci, 2017) to describe the way families with a family member with ID navigate life transitions. The Barlow and Daly families had formal and informal supports and socioeconomic advantages while planning and implementing their transitions. Protected from a state of crisis, the Barlow and Daly families had the time and energy to focus on promoting self-determination in their family member with ID. In contrast, the Anderson and Baker families reached a state of crisis and reported feeling hopeless, desperate, and helpless to transform their situations. The Anderson family rescinded their transition efforts for decades because the services they very much needed were unavailable. These feelings reflect the constructs of amotivation (Ryan & Deci, 2017),

learned helplessness (Abramson, Seligman, & Teasdale, 1978), and external locus of causality (de Charms, 1968). Research suggests that parents who feel no sense of control over the important outcomes in their lives are more likely to experience stress, anxiety, and depression (Lloyd & Hastings, 2009). Findings highlight that, even in the most planful families, inadequate formal and informal support is a risk factor for individual and family resilience and self-determination. Eventually, families were able to access needed supports and return to stability, demonstrating that resilience is a process in interactions with the environment (Masten, 2018; Patterson, 1988, 2002).

Self-determination and resilience are theoretically intertwined. For instance, feeling connected to others is a universal psychological need in self-determination theory (Ryan & Deci, 2017), and social support is strongly associated with physical and psychological health and resilience to stress (Ozbay et al., 2007). Feeling competent and volitional in the environment are foundational needs in self-determination theory (Ryan & Deci, 2017) that are also captured in validated measures of resilience (Connor & Davidson, 2003; Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003). Further, parental processes that promote resilience in children include balancing risk and protection, providing structure and age-appropriate support for emotional and behavioural regulation, creating opportunities to exercise competence and build mastery, and encouraging choice-making and problem-solving capacities, all in the context of warm and secure attachments (Masten, 2018; Young, 2016). Indeed, the nutriments for resilience are similar to the recommended strategies for building a foundation for self-determination (Dunn & Thrall, 2012; Grolnick et al., 1997; Palmer et al., 2012; Palmer et al., 2017).

Efforts to empirically describe the relationship between self-determination and resilience are in their infancy. In recent investigations by Perlman and colleagues, adults living with

debilitating mental illnesses in Australia completed valid and reliable measures of their self-determination and resilience. Perlman et al. (2017) found that the basic psychological need for relatedness significantly predicted resilience scores in 159 adults, whereas competence and autonomy did not. Perlman et al. (2018) found that the basic psychological needs for relatedness, competence, and autonomy significantly predicted self-determination scores in 106 adults, and self-determination scores significantly predicted resilience scores. Caldwell, Jones, Gallus, and Henry (2018) found that family empowerment significantly predicted family resilience as reported by a sample of 56 carers with relatives with ID. Empowerment is often defined as a sense of self-efficacy or a perceived ability to affect change. Empowerment is an essential characteristic in the functional model of self-determination (Wehmeyer, 1999) and a construct parallel to the psychological need for competence in self-determination theory (Ryan & Deci, 2017). Efforts to empower families caring for family members with ID are recommended to facilitate positive family adaptation, especially during transitions (Caldwell et al., 2018).

The Family System Is Collaborative and Interdependent

An important contribution of this dissertation is the interconnectedness observed in the family system. Families considered transitions in the lives of their family member with ID to be transitions in their family life cycle, with effects on all family members. Family members developed shared values and goals, worked together to plan and implement transitions, and experienced each other's challenges and successes as their own. Themes of disagreement were not apparent in the data, consistent with findings in Mitchell (2012) and Curryer et al. (2018) regarding shared family choice making. Findings illustrate the dynamic interdependence of family systems theory (Bowen, 1978).

High levels of agreement and collaboration were especially apparent in the way the Barlow and Daly families made choices for Kimberley and Peter's transitions to adulthood. Family members described sharing ideas, compromising, and reaching a consensus. In fact, collaboration occurred to the extent that all family members perceived agency in important choices for their transitions. It was particularly interesting that Mrs. Daly perceived that she made the choices for Peter to learn to cook and search for employment; however, Peter described these choices as his own. Even if his parents initiated these choices, Peter appeared to integrate them into his own values and sense of motivation. Kimberley also maintained a sense of agency when choices for her transition were influenced by her parents' considerations for family resources and risk management. The family system emerged as the choice-making agent, with every family member also maintaining a sense of autonomy.

These observations can be explained by organismic integration theory, an aspect of self-determination theory that describes the transformation of externally regulated behaviour into self-regulated behaviour (Deci & Ryan, 2002; Ryan & Deci, 2017). Individuals may initially engage in a behaviour because they perceive external contingencies and practicalities; however, they have a natural tendency to transform the 'have to' into a 'want to' in a process called internalization. Internalization is a normative socialization process in families that is associated with increased well-being (Grolnick et al., 1997; Ryan & Deci, 2017). Individuals internally adapt to cope with environmental demands and social conventions, while maintaining a coherent sense of self and exercising curiosity and willingness. Internalization is most likely to occur if individuals believe they can achieve what is required of them; if they respect, admire, and feel close to the person providing the regulation; and if they believe the behaviour is personally relevant and in line with their interests and values. Internalization is further facilitated when

individuals perceive a sense of choice. Taken together, when the psychological needs for competence, relatedness, and autonomy are fulfilled, individuals preserve their sense of agency and experience autonomous motivation in their actions.

The Family System Functions Within Broader Socioecological Systems

A systems lens is important to this dissertation (Bowen, 1978; Bronfenbrenner, 1979). Adults with ID navigate life transitions and develop and express their self-determination in their family system, and their family system is affected by broader socioecological environments. For instance, one family carried a legacy of societal stigma, having lived through an era of institutionalization devoid of specialized services for supporting their family member with ID in the community. One family was affected by their rural geography, choosing to relocate and commute long distances to urban centres to access the right opportunities for their family member with ID. Access to formal and informal supports beyond the family system was a distinguishing factor between families who entered a state of crisis and families who evaded a state of crisis. Moreover, parents frequently requested formal services to support their family system in supporting their adult child with ID. The majority of parents endorsed the expectation that community participation supports would promote choice-making skills in their adult child with ID, for example. Overall, findings point to the need to support the family system and consider the family system as the consumer of services in seeking to support adults with ID (Begun, 1996; Turnbull, Summers, & Brotherson, 1984). Efforts to understand families' needs and strengths at multiple system levels, mobilize resources and supports at multiple system levels, and build strong lines of communication across system levels are best practice (Henry et al., 2015; Turnbull et al., 2015).

Implications

Theoretical Implications

The self-determination construct has been interpreted and applied in multiple ways, some far removed from their philosophical antecedent (Wehmeyer, 2004, 2005; Wehmeyer, Shogren, Little, & Lopez, 2017). In the ID field, the self-determination construct evolved alongside the disability rights movement, referring to the right for people with ID to independently control their own lives. Policies and best practices seek to mobilize supports and redistribute power to people with ID so they can make their own choices, set their own goals, and ultimately direct their own lives (Devi, 2013; Martin, Grandia, Ouellette-Kuntz, & Cobigo, 2016). These values are espoused in influential policy documents. In England, for example, *Valuing People* (2001) states, “The government’s objective is to enable people with [ID] to have as much choice and control as possible over their lives and the services and supports they receive” (Department of Health, 2001, p. 4). An understanding of self-determination as independent control may ensure concerted efforts to advocate for people who have been historically oppressed and who have more observable interdependence with carers.

Other interpretations of self-determination focus on volitional autonomously motivated behaviours, the way these behaviours serve the actor’s quality of life, and the process by which these behaviours emerge in the context of environmental nutrients (Ryan & Deci, 2017; Shogren et al., 2015; Wehmeyer, 1999). From this perspective, choice is a vehicle for developing self-determination and an expression of self-determination; however, choice and self-determination are not synonymous (Wehmeyer, 2004, 2005; Wehmeyer et al., 2011). People exercise self-determination in ways that are important to them, which may involve gaining more independence; however, independence and self-determination are not synonymous. This

perspective is inclusive of people with diverse support needs who may desire choice-making supports, as well as people with interdependent social values who may prioritize collaborative choice making and shared control (Abery & Stancliffe, 2003; Wehmeyer et al., 2011). People may exercise self-determination in acceding to others' wishes, for example, so long as they do so volitionally in accordance with their needs and interests. Essentially, the intention behind the behaviour and the function of the behaviour matter more than the behaviour itself (Wehmeyer, 1999).

An understanding of self-determination as volitional action has, at its core, an important distinction between independence and autonomy. In self-determination theory (Ryan & Deci, 2017), independence refers to self-reliance, whereas autonomy is characterized by self-endorsing and willingly engaging in behaviours as congruent with personal interests and values. The opposite of autonomy is not dependence or interconnectedness but rather heteronomy, or perceiving behaviours as controlled by others. Importantly, autonomy is more predictive of quality of life and healthy development than is independence. For instance, Petegem, Beyers, Vansteenkiste, and Soenens (2012) surveyed over 700 adolescents on independent decision making, autonomous versus controlled motivation, and psychological and relational well-being. Independent decision making was related to more problem behaviour, whereas autonomously motivated decision making was related to psychological well-being. Chen, Vansteenkiste, Beyers, Soenens, and Petegem (2013) conducted a similar study with nearly 600 adolescents in China. They found that autonomously motivated decision making was related to subjective well-being, whereas independent decision making was not. In both studies, autonomy could be expressed as choosing independence or as choosing conformity to parents. The consensus in self-determination theory is that independence and separation are not required to develop autonomy

and may, in cases of emotional detachment, detract from it (La Guardia & Ryan, 2002; Ryan & Deci, 2017; Ryan & Lynch, 1989).

Clarity is needed in applying the self-determination construct in research and practice with children, adolescents, and adults with ID and their family system (Wehmeyer, 2004, 2005; Wehmeyer & Abery, 2013). Conflating self-determination with personal control and independence is incongruous with a system defined by its interdependence. A more nuanced understanding is needed. Human agentic theories of self-determination consider person-environment interactions, especially in social relationships, that give rise to volitional autonomously motivated behaviours (Ryan & Deci, 2017; Shogren, Little, & Wehmeyer, 2017). Considering Kimberley and Peter's self-determination from this perspective is worthwhile: Although their personal control was influenced and, at times, constrained by their family system, they expressed agreement with transition processes, perceived their agency in choice making, and exhibited increased enthusiasm and readiness for adult responsibilities. Our data do not provide any indication that Kimberley and Peter resented their families' collaboration in their transition experiences (see also Curryer et al., 2018; Mitchell, 2012). Rather, Kimberley expressed excitement about attending college, and Peter, who was initially hesitant to live away from his parents, expressed satisfaction with his burgeoning independence. This dissertation contributes theoretically to the literature by investigating the role of the family system in fulfilling the psychological needs for competence, relatedness, and autonomy to promote self-determination.

Practical Implications

This dissertation underscores the need to support people with ID by also supporting their family system (Gardiner & Iarocci, 2012; Turnbull et al., 1984). In fact, participating families

described service providers as most helpful when they prioritized rapport, considered family needs, and encouraged family involvement. Findings suggest a number of ways to support families, especially during life transitions. First, service providers and policymakers should continue to work toward creative solutions to deliver timely transition planning information and support (Bhaumik et al., 2011; Dyke et al., 2013; Martinez, Conroy, & Cerreto, 2012). Parents in this study reported contemplating transitions as soon as they learned of their child's special needs and pre-planning transitions years and even decades before implementing them. Over this period, parents reported needing specific guidance in navigating available services and recreational, educational, and vocational opportunities. Second, service providers should monitor risk and protective factors at multiple system levels, consistent with family resilience models (Henry et al., 2015; Ouellette-Kuntz et al., 2014). Findings suggest risk factors for entering a state of crisis include unmet mental health and residential support needs, health conditions that affect daily functioning, a household income below the national median, and an insufficient informal support system. Third, Canadian health care, housing, and social service systems are currently unable to flexibly respond to sudden changes in support needs, which can leave even the most planful families in a state of crisis (Dubé, 2016). Ongoing efforts by service agencies, researchers, and policy makers to address these systemic issues are necessary.

In addition to supporting the family system, concerted efforts are needed for supporting the quality of life and self-determination of the family member with ID within this system. Findings suggest that modeling goal setting, scaffolding new skills, and providing choice-making opportunities are ways of accomplishing these aims. Findings also suggest that parents face challenges in this process, namely balancing their adult child's quality of life with the entire family's quality of life and balancing their adult child's independence with his or her safety.

Parents negotiated these balancing acts by inviting feedback from all family members, reinforcing choices that were feasible within family resources and capabilities, and, ideally, reaching a compromise. Critically, parents expressed the need for help in balancing these priorities. They questioned the extent of their influence in their adult child's life and worried they might be overstepping. Service providers may be uniquely placed to normalize these challenges while also providing objective feedback to guard against coercive or paternalistic practices. Service providers in these positions would benefit from an understanding of self-determination that is more nuanced than personal control. Even when control is shared within the family system or constrained by the family system, self-determination can be promoted by fulfilling the psychological needs for competence, relatedness, and autonomy. The essential message is to monitor the influence of the family system on the quality of life and self-determination of the adult with ID.

Limitations and Future Directions

Limitations

Specific limitations are covered in each manuscript in this dissertation. Briefly, the limitations of the first study include the lack of ethnic and linguistic diversity in the participating families and the limited information on the role of siblings in the family system. Further, there may have been a self-selection bias. Among the families the MAPS team purposefully invited to participate, those who agreed may have had more confidence in their relationships and more openness in sharing their stories. Findings may not represent families who have contentious relationships and experiences of shame regarding their challenges. The most important limitation of the second study is its exploratory nature, such that the findings are interpreted only to guide future research opportunities.

The MAPS director, Dr. Hélène Ouellette-Kuntz, is a Professor in the Departments of Public Health Sciences and Psychiatry at Queen's University with over 25 years of experience in the field of ID in Ontario. The MAPS team includes senior researchers and trained research assistants who collaborated with Dr. Ouellette-Kuntz in developing the data collection protocol and conducting the semi-structured interviews and ethnographic observations. By the time I joined this project, the four families had already formed relationships with a warm and competent interviewer and videographer. My presence part-way through the data collection would have likely undermined these relationships. I was able to learn more about the data collection procedures by reviewing the ethics application and meeting with the primary research team.

The primary research purpose was to explore families' lived experiences in navigating transitions, particularly regarding the structure of formal and informal supports and the impact of those supports on the social inclusion of the adult with ID. For my dissertation, the secondary research purpose was to evaluate families' challenges, coping strategies, and efforts to promote self-determination. Data were already of sufficient depth and breadth for my research questions; however, I also developed an interview guide to include in one of the four interview protocols to

ensure sufficient data for understanding families' choice-making processes. In lieu of conducting the interviews, I met with the interviewer for an afternoon to share my interview guide and research questions and to learn about her experiences with the participating families. When the interviewer returned to the participating families, she informed them of my dissertation research. The families provided their informed consent for their data to be used for a secondary purpose.

Important contextual information may be missing in secondary qualitative data, a problem of “not having been there” (Heaton, 2008, p. 40). A recommendation for mitigating this limitation is to negotiate levels of access to the primary researchers and to the original data. The MAPS team provided me with all transcripts of semi-structured interviews and ethnographic observations, as well as some video clips. I was not in a position to verify the accuracy of the transcripts against the audiovisual footage and, in some cases, the transcripts were missing non-verbal cues that might have enhanced my interpretations. A strength is that Dr. Ouellette-Kuntz is a member of my dissertation committee and a co-author on the manuscripts. If I ever felt that I was missing important contextual information, her perspective was very helpful. To validate my interpretations, I also conducted my own member checks by mailing each family a letter summarizing themes in their transition story and inviting their feedback.

Future Directions

A number of avenues are available for researchers to advance our knowledge of transition experiences and efforts to support self-determination in families with a family member with ID. Consistent with family systems and family life cycle perspectives, future research should include multiple family members and support persons over time. In particular, more information on the role of siblings in the family system is needed. Preliminary findings suggest siblings may assist in planning and implementing transitions and moderating overprotective parental influences.

Siblings may also model conventional markers of adulthood that adults with ID may wish to emulate. Future research should seek to verify these themes, incorporate siblings' voices, and investigate siblings' actions in relation to the self-determination of their brother or sister with ID. Consistent with ecological systems perspectives, future research should also consider the structure of formal and informal supports and families' expectations for these supports to promote self-determination.

An overarching aim for future research is to identify the best ways to support families in supporting their family member with ID in developing and expressing his or her self-determination. Parents in this dissertation envisioned a self-determined future for their adult child with ID and made concerted efforts to support his or her choices; however, they still reported needing help in this process. Research also suggests that, when the needs of different family members conflict, the choice of the family member with ID is sometimes undermined (Bigby, Whiteside, & Douglas, 2017; Pilnick, Clegg, Murphy, & Almack, 2011). There are empirically validated programs to promote self-determination in the classroom (Lee et al., 2015; Wehmeyer et al., 2012; Wehman, 2012) and recommendations to support self-determination in the home (Wehmeyer et al., 2010); however, whether Canadian families have access to this information and support in tailoring this information to their needs is unclear. Further research is needed to examine the availability, accessibility, and utility of this information for Canadian families with a family member with ID. As part of this inquiry, approaches that incorporate families' perspectives over time with valid and reliable measures of self-determination may be worthwhile.

As the ID field moves toward a more sophisticated understanding of the family context of self-determination, important questions remain. How can families and service providers monitor

the influence of the family system on the quality of life and self-determination of the family member with ID? What level of direction might be considered normative in the relationship between parents and their adult child? What level of direction might be considered developmentally appropriate when the adult child has higher support needs? What level of direction borders on coercive and paternalistic? Self-determination as independence and personal control is an empowering philosophy in the delivery of formal services to adults with ID. In the family system, however, perspectives on self-determination must account for interconnectedness and interdependence (Wehmeyer & Abery, 2013). Further to this point, Carter and McGoldrick (2005) suggest that complete independence is “a fiction”:

Healthy development requires finding an optimal balance between connectedness and separateness, belonging and individuation ... In general, developmental theories have failed to describe the progression of individuals in relationships toward a maturity of interdependence. Yet human identity is inextricably bound up with one's relationship to others ... Human beings cannot exist in isolation, and the most important aspects of human experience are relational. (p. 9)

The distinction in self-determination theory (Ryan & Deci, 2017) between independence and autonomy may offer important directions in researching self-determination in the family system.

Conclusions

Despite its limitations, this dissertation contributes to the literature in several ways. First, studies on transitions in families with a family member with ID have tended to focus on specific events bound by time and place, such as leaving the formal education system (Davies & Beamish, 2009; Dyke et al., 2013; Hetherington et al., 2010; Pallisera et al., 2014) and leaving the parental home (Isaacson et al., 2014). This dissertation identified processes and challenges

that are consistent across multiple types of transitions. Second, studies on transitions have tended to focus on the experience of one type of stakeholder, either individuals with ID (Forte, Jahoda, & Dagnan, 2011), their parents (Bhaumik et al., 2011; Davies & Beamish, 2009; Dyke et al., 2013; Gillan & Coughlan, 2010), or their service providers (Pallisera et al., 2014). This dissertation focused on the way the family system negotiated transitions, with an emphasis on family quality of life and family resilience. Research by Isaacson et al. (2014) is another exception, wherein multiple family members were included. Third, studies on self-determination in the field of ID have typically concerned the development and evaluation of school and community interventions (Lee et al., 2015; Wehmeyer et al., 2012), with an expressed need for exploring the family context of self-determination (Curryer et al., 2015; Wehmeyer, 2014). This dissertation revealed ways that the family system appears to influence the self-determination of an adult family member with ID. Finally, using self-determination theory (Ryan & Deci, 2017) as a conceptual framework is a unique contribution in the field of ID. In contrast to emphasizing independence and personal control, this organismic-dialectical perspective emphasizes person-environment interactions that fulfill psychological needs and support autonomous motivation. An essential message in this dissertation is that families are of vital importance in fulfilling the psychological needs for competence, relatedness, and autonomy that allow an individual to feel volitional and autonomously motivated in areas of life deemed important.

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Appendices

Appendix A

Queen's University Ethics Approval for Working Together to Support Transitions

**QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD-DELEGATED REVIEW**

October 10, 2013

Mrs. Helene Ouellette-Kuntz
Department of Public Health Sciences
Queen's University

Dear Ms. Ouellette-Kuntz

Study Title: EPID-445-13 Working Together to Support Transitions - Documentary
File # 6010972

Co-Investigators: Dr. Y. Lunskey, Dr P. Minnes, Dr. J. Weiss, Ms. K. McKenzie, Ms. R. Saaltink, Mrs. M. Blinkhorn, Ms. A. Demore, Ms. A. Blinkhorn, Ms. N. Bedford

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol, interview script, potential participants numbers, recruitment/invitation letter, information/consent form for extras, revised information/consent form – son/daughter, revised information/consent form for parent, review and questions/script for participants with intellectual or developmental disabilities for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following listing of ethics requirements you must fulfill over the course of your study:

Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. Please use event form: HSREB Multi-Use Amendment/Full Board Renewal Form associated with your post review file # 6010972 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information. Serious Adverse Event forms are located with your post-review file 6010972 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

A rectangular grey box used to redact the signature of the Chair of the Health Sciences Research Ethics Board.

Chair, Health Sciences Research Ethics Board
October 10, 2013

Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete



QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards and operates in compliance with the Tri-Council Policy Statement; Part C Division 5 of the Food and Drug Regulations, OHRP, and U.S DHHS Code of Federal Regulations Title 45, Part 46 and carries out its functions in a manner consistent with Good Clinical Practices.

Federalwide Assurance Number: #FWA00004184, #IRB00001173

Current 2013 membership of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board:

Dr. A.F. Clark, Emeritus Professor, Department of Biomedical and Molecular Sciences, Queen's University (Chair)

Dr. H. Abdollah, Professor, Department of Medicine, Queen's University

Dr. R. Brison, Professor, Department of Emergency Medicine, Queen's University

Dr. C. Cline, Assistant Professor, Department of Medicine, Director, Office of Bioethics, Queen's University, Clinical Ethicist, Kingston General Hospital

Dr. M. Evans, Community Member

Ms. J. Hudacin, Community Member

Dr. B. Kisilevsky, Professor, School of Nursing, Departments of Psychology and Obstetrics and Gynaecology, Queen's University

Mr. D. McNaughton, Community Member

Ms. P. Newman, Pharmacist, Clinical Care Specialist and Clinical Lead, Quality and Safety, Pharmacy Services, Kingston General Hospital

Ms. S. Rohland, Privacy Officer, ICES-Queen's Health Services Research Facility, Research Associate, Division of Cancer Care and Epidemiology, Queen's Cancer Research Institute

Dr. A. Singh, Professor, Department of Psychiatry, Queen's University

Ms. K. Weisbaum, LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

Appendix B

Queen's University Ethics Approval for Collaborating with University of Ottawa Team Members on Working Together to Support Transitions



Amendment Acknowledgment/Approval Letter

February 07, 2014

Mrs. Helene Ouellette-Kuntz
Department of Public Health Sciences
Queen's University

**RE: File #6006507 EPID-371-11 Parents Seeking Adult Developmental Services for their
Children: A Provincial Study [Phase II]**

Dear Mrs. Ouellette-Kuntz:

I am writing to acknowledge receipt of the following:

- Adding two team members: Dr. Virginie Cobigo and Whitney Taylor
- Provision of a copy of the Ms. Taylor's CORE certificate

I have reviewed these amendments and hereby give my approval. Receipt of these amendments will be reported to the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Yours sincerely,



Albert Clark, Ph.D.
Chair
Health Sciences Research Ethics Board

Appendix C

University of Ottawa Ethics Approval for Collaborating with Queen's University Team Members on the Interview Protocol

File Number: h05-14-20

Date (mm/dd/yyyy): 05/20/2014



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Hélène	Ouellette-Kuntz	Health Sciences / Others	Principal Investigator
Yona	Lunsky	Others / Others	Co-Principal Investigator
Virginie	Cobigo	Social Sciences / Psychology	Co-investigator
Whitney	Taylor	Social Sciences / Psychology	Student Researcher

File Number: H05-14-20**Type of Project:** Professor's Research**Title:** Parents Seeking Adult Development Services for their Children

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
05/20/2014	05/19/2015	Ia
(Ia: Approval, Ib: Approval for initial stage only)		

Special Conditions / Comments:

Please note that while the researchers (Ms. Taylor and Dr. Cobigo) have been added to the research team for the overall project (including all of its phases), the REB did not review phases I, II, and III given that data has already been collected. Only the "Working Together to Support Transitions" ethnographic study and film documentation has been reviewed by the uOttawa REB.

File Number: h05-14-20

Date (mm/dd/yyyy): 05/20/2014



Université d'Ottawa **University of Ottawa**
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: <http://www.research.uottawa.ca/ethics/forms.html>.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: <http://www.research.uottawa.ca/ethics/forms.html>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uottawa.ca.

Signature:

Kim Thompson
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

Appendix D

University of Ottawa Ethics Approval for the Secondary Use of MAPS Data

File Number: H06-15-13

Date (mm/dd/yyyy): 07/13/2015



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Virginie	Cobigo	Social Sciences / Psychology	Supervisor
Whitney	Taylor	Social Sciences / Psychology	Student Researcher

File Number: H06-15-13

Type of Project: PhD Thesis

Title: Supporting Choice in Families Caring for Adults with Intellectual and Developmental Disabilities

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
07/10/2015	07/09/2016	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

N/A

File Number: H06-15-13

Date (mm/dd/yyyy): 07/13/2015



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: <http://research.uottawa.ca/ethics/submissions-and-reviews>.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: <http://research.uottawa.ca/ethics/submissions-and-reviews>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Catherine Paquet
Director
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

Appendix E

University of Ottawa Ethics Approval for Member Checking Procedure



Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Health Sciences and Science Research Ethics Board

APPROVAL OF MODIFICATIONS

June 27, 2017

Whitney D. Taylor

Virginie Cobigo
School of Psychology
Faculty of Social Sciences
University of Ottawa
136 Jean-Jacques Lussier
Ottawa, ON K1N 6N5

RE: Supporting Choice in Families Caring for Adults with Intellectual and Developmental Disabilities (H 06-15-13)

Dear Ms. Taylor and Professor Cobigo,

The Health Sciences and Science Research Ethics Board has examined your request for ethics approval of the following modifications to your research project:

- Dr. Hélène Ouellette-Kuntz from Queen's University joins the research team as co-investigator.
- Four families who participated in the interviews conducted for the original research project will be asked to review the interpretation of the data. Each family will be sent a letter outlining the way the researchers interpreted their interview data.

Your request has been accepted. The certificate of ethics approval renewed on July 10, 2016 and valid until July 09, 2017 covers these modifications.

During the course of the study, any further modifications to the protocol or forms may not be initiated without prior written approval from the REB. You must also promptly notify the REB of any adverse events that may occur.

If you have any questions, please do not hesitate to contact me at extension 5387.

Sincerely yours,

Germain Zongo
Protocol Officer for Research Ethics
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

Appendix F

Queen's Ethics Approval for Parents Seeking Adult Developmental Services for their Children



**QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD-DELEGATED REVIEW**
July 28, 2011

Ms. Helene Ouellette-Kuntz
Department of Community Health and Epidemiology
191 Portsmouth Avenue, Kingston, Ontario, K7M 8A6

Dear Dr. Ouellette-Kuntz

**Study Title: EPID-347-11 Parents Seeking Adult Developmental Services for their
Children: A Provincial Study**

File # 6006134

**Co-Investigators: Y. Lunskey, J. Weiss, P. Minnes, M. McDonald, J. Gordon, S. Robinson,
A. Tint, J. Rouette, A. Blinkhorn**

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol (Project_2011_07_12), telephone interview booklet, mail-out questionnaire, Parent Service Project Consent Form (Form_2011_07_12, Parents Seeking Adult Developmental Services for Their Children_Request for Information Form, Parent Service Project_Consent Form_Version 1.1 (2011_07_25) for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following listing of ethics requirements you must fulfill over the course of your study:

Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. Please use event form: HSREB Multi-Use Amendment/Full Board Renewal Form associated with your post review file # **6006134** in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information. Serious Adverse Event forms are located with your post-review file **6006134** in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Chair, Research Ethics Board
July 28, 2011

Investigators please note that if your trial is registered by the sponsor, you must tale

responsibility to ensure that the registration information is accurate and complete



QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

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Federalwide Assurance Number: #FWA00004184, #IRB00001173

Current 2011 membership of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board:

Dr. A.F. Clark, Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)

Dr. H. Abdollah, Professor, Department of Medicine, Queen's University

Dr. R. Brison, Professor, Department of Emergency Medicine, Queen's University

Dr. M. Evans, Community Member

Dr. S. Horgan, Manager, Program Evaluation & Health Services Development, Geriatric Psychiatry Service, Providence Care, Mental Health Services, Assistant Professor, Department of Psychiatry

Dr. B. S. Kisilevsky, Professor, School of Nursing, Department of Psychology and Obstetrics & Gynaecology, Queen's University

Ms. D. Morales, Community Member

Dr. W. Racz, Emeritus Professor, Department of Pharmacology & Toxicology, Queen's University

Dr. B. Simchison, Assistant Professor, Department of Anesthesiology, Queen's University

Dr. A.N. Singh, WHO Professor in Psychosomatic Medicine and Psychopharmacology
Professor of Psychiatry and Pharmacology, Chair and Head, Division of Psychopharmacology, Queen's University, Director & Chief of Psychiatry, Academic Unit, Quinte Health Care, Belleville General Hospital

Dr. E. Tsai, Associate Professor, Department of Paediatrics and Office of Bioethics, Queen's University

Rev. J. Warren, Community Member

Ms. K. Weisbaum, L.L.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

Appendix G

Compensating Experiences Subscale from the Inventory of Family Protective Factors in the MAPS Mail Survey

	Not At All True (Not At All Like My Family)	Mostly Not True (A Little Like My Family)	Somewhat True (Some of the Time Like My Family)	Mostly True (Generally Like My Family)	Very True (Almost Always Like My Family)
1. Our family has been able to resolve many (but not all) of our problems by ourselves.	1	2	3	4	5
2. Our family has control over many (but not all) events in our lives.	1	2	3	4	5
3. Our family has coped well with one or more major stressors in our lives.	1	2	3	4	5
4. Our family has been able to make “the best out of a bad situation” a number of times.	1	2	3	4	5

Appendix H

Brief Family Distress Scale in the MAPS Mail Survey

Circle the <u>ONE</u> statement below that is MOST TRUE for you and your family, in terms of your current request for adult developmental services for your child.	
1	Everything is fine, my family and I are NOT in crisis at all.
2	Everything is fine, but sometimes we have our difficulties.
3	Things are SOMETIMES stressful, but we can deal with problems if they arise.
4	Things are OFTEN stressful, but we are managing to deal with problems when they arise.
5	Things are OFTEN VERY stressful, but we are getting by with a lot of effort.
6	We have to work extremely hard every moment of every day to avoid having a crisis, but we are not in crisis at the moment.
7	We will not be able to handle things soon. If one more thing goes wrong – we will be in crisis.
8	We are currently in crisis, but we are dealing with it ourselves.
9	We are currently in crisis, and we have required help from crisis services (e.g. Emergency room, hospital, community crisis supports).
10	We are currently in crisis, and it could not get any worse.

Appendix I

Brief COPE in the MAPS Telephone Interview

The following statements deal with ways you've been coping with the stress in your life since you applied for adult developmental services for [child's name]. There are many ways to try to deal with things. These items ask what you've been doing to cope with this situation. Different people deal with things in different ways and I'm interested in how you've tried to deal while waiting for services. Each item says something about a particular way of coping.

I want to know to what extent you've been doing what the item says, including how much or how frequently. Don't answer on the basis of whether it seems to be working or not—**just whether or not you're doing it**. Try to rate each item separately from the others.

Make your answers as true FOR YOU as you can. The response choices are:

0 = I HAVEN'T BEEN DOING THIS AT ALL

1 = I'VE BEEN DOING THIS A LITTLE BIT

2 = I'VE BEEN DOING THIS A MEDIUM AMOUNT

3 = I'VE BEEN DOING THIS A LOT

_____ I've been concentrating my efforts on doing something about the situation I'm in.

_____ I've been getting emotional support from others.

_____ I've been taking action to try to make the situation better.

_____ I've been getting help and advice from other people.

_____ I've been trying to come up with a strategy about what to do.

_____ I've been getting comfort and understanding from someone.

_____ I've been trying to get advice or help from other people about what to do.

_____ I've been thinking hard about what steps to take.

_____ I've been accepting the reality of the situation.

_____ I've been learning to live with it.