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UNDERSTANDING AND ADDRESSING VOICES OF ADULTS WITH DISABILITIES WITHIN THEIR FAMILY CAREGIVING CONTEXTS: IMPLICATIONS FOR CAPACITY, DECISION-MAKING AND GUARDIANSHIP

Legal Capacity, Decision-Making and Guardianship

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The LCO commissioned this paper to provide background research for its Legal Capacity, Decision-Making and Guardianship project. The views expressed in this paper do not necessarily reflect the views of the LCO.

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I. INTRODUCTION

Despite decades of human rights enlightenments, adults with developmental disabilities continue to experience among the most poorly understood support needs and preferences of any population.[1] Adults with disabilities have relatively less access to social inclusion and as part of an overall aging population, these adults are increasingly outliving the support capacity of aging parents and do not often have spouses and children to turn to for support. In addition, voices of adults with disabilities, because they are often expressed in less conventional forms, are under-represented in professional interactions and research related to support.[2] In sum, adults with disabilities live with a paradox of having amongst the most pressing of support needs yet the greatest difficulties in having their needs understood and addressed.

Caregiving parents are instrumental in communicating and supporting needs and preferences of adults with disabilities. Caregiving advocates and scholars have diligently built understandings of the contributions of caregiving parents by upholding family care and support as a precious resource without which, formal social programs would be overwhelmed to the point of collapse. Countries compile estimates of the monetary value of the work of informal caregivers and a robust body of research is dedicated to understanding stress associated with the work of caregiving. While we have achieved more respectful understandings of caregiving, including in terms of its often immeasurable value, these understandings come partly at the expense of adults with disabilities as they are derived mainly by studying the perspectives of caregivers rather than care receivers. This paper commissioned by the Law Commission of Ontario is rooted in concern that focusing on caregivers, while important, shifts attention away from the perspectives of adults with disabilities. The purpose of this paper is to illuminate whether, how and to what extent voices of adults with disabilities are "heard" within their family caregiving contexts and to discuss the implications of this for legal principles of capacity, decision-making and guardianship in relation to adults with disabilities.

A. Theoretical Framework

This paper is theoretically anchored in frameworks of disability studies and social capital. Deriving from disability studies, our focus is on developing more sophisticated approaches to hearing and responding to voices of adults with disabilities rather than on remediating communication impairments of adults with disabilities. Further guiding our work is Alejandro Portes' discussion of social capital.[3] Referencing Bourdieu's idea of social capital as encompassing the support and opportunities that accrue as result of being part of networks of relationships, Portes cautions against viewing such networks as "unmixed blessings". We believe adults with disabilities derive tremendous support and opportunities from their caregiving networks. But membership in these networks can also obscure the expression of needs and preferences by adults with disabilities given comparatively strong voices of caregivers. Disability studies and social capital concepts are used to focus this paper on building capacity to understand and address needs and preferences of adults with disabilities amidst the supporting and obscuring that can occur in caregiving.

II. BACKGROUND

A. In Family We Trust

Anchored in early twentieth century efforts by parents advocating for their children's "educability" and rights to attend school[4] families are viewed as critical to supporting and communicating needs of people with disabilities. Current day focus on parents as advocates is manifest in the ever expanding "Warrior-Hero Mothers" phenomenon; warrior-hero is a frame of reference for profiling the efforts of mothers fighting for understanding and support for their sons and daughters with Autism. The term warrior-hero stands in stark contrast to Post World War II era understandings of Autism in children as related to parenting deficiencies, particularly parents' failure to show adequate affection to their children.[5]

Evolving views of parents as advocates and experts in the needs of their children are part of a broader neo-liberal ideology upholding family "as a symbol of warmth and emotional bonds"[6], as "naturally given and socially and morally desirable"[7] and thus, the natural and best provider of care. Accordingly, acts governing mental capacity, and corresponding resources to support families in planning for their members who have disabilities, are predicated on assumptions that adults who lack capacity would want their family caregivers making decisions on their behalf. [8]

1. Elevating the Work and Voices of Family Caregivers

The extensive and constant demands of caregiving are reflected in discussions of caregivers as "unsung heroes"[9] and caregiving as synonymous with "being responsible for".[10] Researchers who study stress and coping in families who have members with disabilities have found an array of forms of stress including financial, temporal, and occupational stress[11], and the stress of ‘courtesy stigma’, that is, disability by association, experienced by families.[12] The demands of caregiving have been associated with family ‘dysfunction’ in the form of ‘negative’ coping strategies [13] and unhealthy caregiver lifestyles.[14] Studying caregiving parents in particular, some researchers note that keeping pace with care needs once a child with disabilities becomes an adult is distinctly difficult[15] while other researchers point out that parents of adult children with disabilities experience a unique form of stress in the “against the grain” quality of an adult child not attaining independence in ways that are typically expected.[16] In building understandings of stresses inherent to the extensiveness of care provided by parents, we learn little about the perspectives of care receiving adult children.

B. Understanding Adults with Disabilities within their Family Care Contexts

1. Familiarity and Compliance

Voices of adults with disabilities may be relatively difficult to discern within interactions among family members given that familiar interactions tend to be characterized by habitual and compliant behaviors. A line of critical examination of evidence of self-determining behavior by adults with disabilities was undertaken in the 1980’s when the community living movement was in its early stages. Rooted in concern for whether people with disabilities truly exercised self-determination, Mayer Shevin and

Nancy Klein [17] along with Gloria Kishi and colleagues [18] provided early cautions against confusing habitual behavior and passive compliance for enacting choice and/or giving consent. In this era, concern was focused on self-determination for adults with disabilities in formal care and service settings such as vocational programs and group homes. Similarly themed critical examinations have more recently been extended to informal, unpaid care environments of home and family. A number of researchers call attention to the intertwined nature of caregiver/care receiver relationships between parents and their adult children with disabilities and discuss how these ties are characterized by adult child compliance.[19] Indeed, expectations for compliance by adults with disabilities are implicit in the very resources created to guide families in planning for the future of adults with disabilities. For example, the “Safe and Secure” handbook, developed by Al Etmanski and colleagues, and widely used in Western Canada, emphasizes the centrality of “family” vision and control. [20] In the “Safe and Secure” resource, formal care systems are characterized as replete with potential for adults with disabilities to “fall through the cracks” and contrasted with hopes and needs of concerned, caring families.[21] Families are urged to take control and create care plans. In adopting a take charge stance recommended in this handbook, strong, articulate voices of families take precedence, both subtle and obvious, over less conventional voices of adults with disabilities.[22]

2. Differing Views

We are concerned about structured processes, such as those recommended by planning resources, which are built upon, and reinforce, families taking charge/adults with disabilities complying and our concern is shored up by research accounts of ways in which views of adults with disabilities differ from the views of their caregiving parents. Differences in views may be evident in accounts provided by caregiving parents. For examples, Catherine Thornberry and Karin Olson[23] found tendencies by caregiving parents to infantilize their adult children with disabilities while Williams and Robinson[24] present reports by parents that include parents disputing their son or daughter's beliefs in their own capabilities. Indeed, compared with care receiving adults with disabilities, their caregiving parents place greater emphasis on care receiver dependence.[25] Some researchers design their studies to draw out and compare caregiver versus care receiver views by interviewing care receivers separate from caregivers or by examining information from professionals working with adults with disabilities.[26] In their study of decision-making over housing options for adults with developmental disabilities, Laura Bowey and Alex McGlaughlin highlight problems inherent to habits of compliance with their findings that adults with developmental disabilities were reluctant to verbalize their own wishes in the interest of avoiding conflict with their caregiving parents.

Differences in family member viewpoints are evident in studies where caregiver/care receiver voices are collected separately yet this work is in its emerging stages. We elaborate on this line of inquiry by contributing an analysis of family level data where multiple perspectives have been obtained from within each family, most often as part of group interview processes. In our group interview data, families not only describe, but also enact, caregiving and care receiving roles. We augment these family perspectives with focus group data from representatives of agencies supporting adults with disabilities and their families thus incorporating paid support sector perspectives on family level interactions, needs and decision-making.

III. RESEARCH METHODS

We employ a narrative approach to focus on collecting and understanding stories of successes and struggles in care receiving, caregiving and decision-making for adults with disabilities as told by adults with disabilities, their caregiving parents and siblings and their paid caregivers. For the current paper, we elaborate our narrative approach by incorporating a complexity inspired approach[27] to emphasize the interactive, co-created nature of messages. We study the voices of adults with disabilities in interactions that include their family caregivers to better understand how views and experiences expressed by adults with disabilities compare with, and are influenced by, those expressed by their caregiving parents and siblings.

A. Sample Recruitment and Data Collection

Our sample is a subset (N = 50) of participants from a broader qualitative study (N = 112) about successes and struggles in caregiving, care receiving and decision making experiences of families of adults with disabilities and/or mental health issues described by adults with disabilities and/or mental health issues, their caregiving parents and siblings and representatives from agencies supporting adults with disabilities and/or mental health issues and their families. Participants took part in in-depth interviews which were semi-structured to support rapport and allow flexibility of the interview structure around predetermined topics of living with and/or supporting someone living with disability and/or mental health issues.

We define disability broadly as including Autism Spectrum Disorder, Developmental disability, Down syndrome, Fetal alcohol spectrum disorder and Prader-

Willi syndrome. Mental health issues were also defined broadly in the larger study as including mood and anxiety disorders, bipolar disorder and schizophrenia. This study was funded by the Canadian Institute for Health Research and was conducted between 2010 and 2012 in two major urban centres and one smaller community in Alberta. Participants were recruited through newsletters and electronic distributions of a number of agencies providing support for adults with disabilities and their families. Participants were pre-screened by telephone or email to ensure they met inclusion criteria. To be included, family members had to be 18 years of age or older and report that they, their sibling or their adult child have a disability and/or mental health issue. Agency representatives were eligible to be included if they were employed in the provision of support and services to adults with disabilities and/or mental health issues and their families.

Family member participants had the choice of interview format in which to participate: 1) One-on-one interview with the researcher; 2) Interview with the researcher along with one or more of their family members; and/or 3) Focus group – with or without one or more family members – which included the researcher and participants from other families. In our endeavor to collect multi-dimensional data illustrative of family dynamics, effort was taken to collect as many perspectives from within each family as possible.

Our family member sub-sample for this analysis includes 20 members from seven families all of which include and adult with a developmental disability. Data from these seven families were collected through seven one on one interviews, 3 interviews that included one or more of their family members, and three focus group interviews, with or without other members from their family, that included participants from other families. Our 20 family member participants are all from families from whom we obtained multiple and sometimes simultaneous family member perspectives enabling us to hear different within family views about support dynamics as well as observe these support dynamics first-hand. Our 20 family members include seven adults with disabilities, seven of their caregiving parents and six of their caregiving siblings. Five adults with disabilities took part in an interview or focus group interview with one or more of their caregiving parents or siblings. Two adults with disabilities took part in a one on one interview while their caregiving parent or sibling took part in a different one on one or focus group interview. Family participants are from a range of family structures (intact, reconstituted and adopted; two parent, lone parent and no parent) and include adults who have a variety of disabilities and who range in age from 19 to 71 years. Three families are from a small community and four are from a large urban centre. Family member participants are summarized by family position and interview type in Table 1.

Table 1: Number of Participants by Family Position and Interview Type

NUMBER OF FAMILIES FROM WHICH PARTICIPANTS WERE INTERVIEWED	**n= 7**
TOTAL FAMILY MEMBERS INTERVIEWED	**n= 20**
Total Adults with a developmental disability	n= 7
Total Caregiving parents of adults with a developmental disability	n= 7
Total Caregiving siblings of adults with disabilities	n= 6
ADULTS WITH A DEVELOPMENTAL DISABILTY BY INTERVIEW TYPE	
One on one interview with a researcher	n= 2
Interview with a researcher that included one or more other family members	n= 3
Focus group interview with one or more caregiving parent or sibling along with participants from other families	n= 2
CAREGIVING PARENT BY INTERVIEW TYPE	
One on one interview with a researcher and focus group interview with one or more other family members along with participants from other families	n= 1
Interview with a researcher that included one or more other family members	n= 3
Focus group interview with one or more other family members along with participants from other families	n= 2
Focus group interview without other family members but with participants from other families	n= 0
CAREGIVING SIBLING BY INTERVIEW TYPE	
One on one interview with a researcher	n= 3
Interviews with a researcher that included one or more other family members	n= 1
Focus group interview with one or more other family members along with participants from other families	n= 2
Focus group interview without other family members but with participants from other families	n= 1

Our agency representative sample includes 30 participants employed providing support and services to adults with disabilities and/or mental health issues and their families who took part in one of five focus groups. 19 agency representatives are employed in service and support provision targeting adults with disabilities, three are employed in agencies providing support and services to adults with mental health issues and 8 are employed by agencies serving adults with disabilities and/or mental health issues. Two agency representative focus group interviews were conducted in a small community and three were conducted in one of two large urban centres. Agency representative participants are summarized in Table 2.

Table 2: Number and Type of Agency Representation at Agency Focus Groups

AGENCY REPRESENTATIVE FOCUS GROUPS	**n= 30**
Representatives from agencies supporting adults with disabilities and their families	n= 19
Representatives from agencies supporting adults with mental health issues and their families	n= 3
Representatives from agencies supporting adults with disabilities and mental health issues	n= 8

Ethics approval for this study was provided by the Conjoint Health Research Ethics Board of the University of Calgary and all participants signed an informed consent form; adults with disabilities signed an informed consent form and also had a family caregiver sign a surrogate consent form. All interviews were audio recorded and transcribed verbatim. Pseudonyms are assigned to participants who are quoted.

B. Data Analysis

This qualitative analysis of our data began with a broad organization of the data achieved through repeatedly listening to interview and focus group recordings and reading the transcripts.[28] Once we achieved a familiarity with the data, we began a thematic analysis by examining what is in the text and giving it a name or code. As per Bruce Berg[29] codes or themes are chosen to "reflect all relevant aspects of the messages and retain, as much as possible, the exact wording used in the statements." As well as being guided by sensitizing concepts from the research literature pertaining to successes and struggles in care receiving, caregiving and decision-making for adults with disabilities, we examined our data for evidence of "voice" of adults with disabilities and ways in which voice is verbally and non-verbally supported versus obscured or obstructed by caregiving parents. We examined what is in the "text" and what interactions surround particular text.

C. Trustworthiness

1. Triangulation of Sources and Data Collection Methods.

The trustworthiness of our data is augmented by the triangulation of data sources embedded in our design of including multiple views and processes from within caregiving family contexts. We triangulate further by using one on one, group and focus group interview methods with distinct as well as overlapping groups of participants.

Thus in our analysis, we compare perspectives within and between families and we compare family perspectives with those of agency representatives.

2. *Peer Debriefing*

Identification and refinement of themes is shared by the four authors/data analysts working on this project. Themes were regularly discussed via email and face to face meetings, to generate additional or alternate themes, check identified themes against the experiences of analysts and obtain consultation in the case of confusing or ambiguous themes.

IV. FINDINGS

A. Family Profiles

1. Mike and Janice

Janice is mother and primary caregiver to Mike, 24, born with Down syndrome. Mike is third of four children having two elder sisters and a younger brother. Mike and his younger brother reside with Janice and Mike attends a day program full-time. Janice is no stranger to difficult times as over the years she has lost five of her seven siblings as well as her husband. Janice and Mike have support from friends and family, notably Janice's older sister who lives nearby. Janice and Mike were interviewed together for 65 minutes. Mike speaks in one or two word utterances and has a pronounced memory for names.

2. Maria, Gary, Crystal, Carrie and Andrew

Maria and Gary, who have been married for 35 years, head their family of five. Support for daughter Crystal, aged 33, diagnosed with a developmental disability, OCD and schizophrenia, defines much of family life for Maria and Gary. Crystal has two siblings, Carrie, age 31 who lives with her husband Matthew and is expecting their first child, and Andrew, age 27 who lives on his own.

Crystal lives with her parents, and Maria has been full time caregiver for Crystal's entire life. Gary is newly retired from a 40-year career in financial services and now more involved in Crystal's daily support and routines. Carrie and Andrew were each interviewed one-on-one for 90 minutes while Maria, Gary and Crystal were interviewed together for two and one half hours. After the first hour of the group interview, Crystal had her lunch then left with Gary to be dropped at her day program. The interview continued one-on-one with Maria for 40 minutes until Gary returned and rejoined the interview for the final 30 minutes.

3. Donna, Martin, Susan and Joelle

Donna and Martin lead their reconstituted and adoptive family in support for Susan, age 20, who has a developmental disability. In addition, Susan's sister Lisa, age 24, was labeled "gifted" when Lisa was in grade 7 and presented some distinct learning and social needs. Further, Lisa had sustained a brain injury four years earlier but had since resumed much of her former education and work pursuits. Donna and Martin have been married 29 years and adopted both Susan and Lisa as newborns. Three step sisters to Susan and Lisa, Joelle, age 37, Rhonda age 38 and Jamie age 43, from Martin's first marriage, round out this family. Data from this family were collected in an interview lasting 130 minutes that included Donna, Martin, Susan, and Joelle.

4. Sandy and Dave

Dave, a middle-aged man with a cognitive disability, lives in a small town in a rental property owned by his mother Sandy. Dave and his older brother Robert are Sandy's children from a previous marriage. Sandy married Chris when Dave was five and Robert was seven and Chris is the father figure with whom Dave and Robert identify. Sandy and Chris live on a farm a few kilometers from the town where Dave lives and Robert, his wife and two grown sons live on a neighboring farm. Sandy describes Dave as central in the life of her family. Dave lives with a roommate and has a full schedule of paid and volunteer work and is well known in town. Dave and Sandy each took part in one on one interviews; Sandy's interview lasted fifty-three minutes while Dave's total interview time was twenty-nine minutes. Sandy also took part in the second half of a ninety minute focus group interview that included caregivers from other families.

5. *Allison, Jean and Barbara*

Allison, a 31 year old woman diagnosed with Prader Willi Syndrome, lives on a farm with her parents Jean and Arthur. Allison has part time employment in a small town a few kilometers from her home. Allison's siblings, Barbara, 26 and Mark, 22, live in a large urban centre an hour away from their parents' farm and are central to Allison's support. Jean, Barbara and Allison took part in a family member focus group lasting two hours. Barbara also took part in a 30 minute one-on-one interview.

6. *Lindsay and Ruth*

Ruth is a middle aged woman and the eldest of five siblings. Ruth and two of her sisters, Andrea and Gillian, have developmental disabilities. Ruth and Andrea live independently and are involved in supporting Gillian who has severe disabilities and lives in a group home. Ruth, Andrea and Gillian all receive considerable support from their sister Lindsay. Rounding out the sibling group is brother Kyle who has removed himself from support provision for his sisters with disabilities. Ruth and Lindsay took part in a family focus group lasting two and one half hours.

7. Geraldine and Henry

Geraldine, aged 80, along with caregivers from other families, took part in a ninety minute focus group interview where she discussed support she provides for her brother Henry, aged 71, who has a developmental disability. Henry moved to reside in a seniors home once his mother was no longer able to care for him. Henry, a man of few words, attends a day program and enjoys being part of social interactions. Henry took part in a one-on-one interview with a researcher which lasted 15 minutes.

B. Family Care Context Facilitation of Voice

Our samples provide evidence of parents and siblings representing and facilitating the voices of their sons/daughters/sisters/brothers with disabilities in ways that reflect intimate knowledge and skill at avoiding stress and conflict. For example, Janice, interviewed with her son Mike who has Down syndrome and limited verbal abilities, strikes a balance between facilitating, and yet not pushing, Mike to express himself. Janice uses gentle probes yet retreats when Mike says ‘no’ or withdraws. Janice specifically prompts Mike to share utterances resembling the names of people in Mike’s close family and social network. Janice pauses her prompts when Mike is stumped to come up with a particular name then gently rejoins Mike several minutes later when he remembers and is ready to share further names.

Intimate knowledge and skill at avoiding stress and conflict was evident in an interview that included Susan, who is 19 years old and has a developmental disability, along with her older half-sister Joelle and their parents Donna and Martin. Donna sets the stage for the family’s appreciation of Susan’s personality and style as she describes raising Susan relative to another daughter Lisa, who was identified in junior high school as gifted. Donna points out how a sense of crisis ensued for Lisa when anything was less than perfect. Comparatively, Donna notes that for Susan, the ups and downs of life are like “water off a duck’s back.” Playing out her straight forward, unruffled style, Susan shares some experiences including having established an important friendship: “We met in element, we met in middle school, grade 6 band class. She was being bullied a lot and I just, I didn’t see any, I didn’t see any problems with her as we, we became friends really quick.” Susan goes on to share her interests including her love of animals. Donna and Martin elaborate about Susan’s skills and interests with Donna pointing out: “Susan is exteam, extremely artistic” This prompts a series of questions from the researcher inviting Susan to describe the materials and colors she uses in her art work and perhaps show a sample or photograph of her work. Susan declines to do any of this in a direct and matter of fact way. Donna and Martin then provide brief details about the types of materials Susan uses in her art then wrap up the topic with Donna noting “She was, she’s always been, ah, very reluctant to show anything, even to us” and Martin echoing “Extremely reluctant to share”. In similar fashion, Susan is supported by her parents and half-sister as she leaves and rejoins the interview several times, asking occasional questions about what is being discussed.

In family member focus group settings, parents and siblings facilitate the voices of their family member with a disability by reinforcing ideas that are expressed and asking for ideas that are not expressed. For instance, Allison, who has Prader-Willi syndrome, expresses that she would like to live in a group home as well as with her family. Allison’s mother and sister endorse her view adding: “we always include her and I couldn't' imagine planning something without her." In another family member focus group, Lindsay intentionally stops the flow of conversation to make space for her sister Ruth, who has a developmental disability, to share her ideas. With some prompts from Lindsay, Ruth expresses pride in maintaining her own apartment along with feelings of worry over financial matters.

C. Family Context Constraints on Voice

1. Voices Obscured by Established Care Identities

Voices of adults with disabilities can be obscured amidst discussions that include their caregiving family members. For example, family members in focus groups describe challenges of navigating educational, social, medical and financial needs for adults with disabilities and point out "You have to have people around them to know what's good for them". Lindsay, discusses being alternate guardian for Ruth, who is also a participant at the focus group, as well as for two other sisters with disabilities noting: "they can't take care of themselves." Illustrating how adults with disabilities may need others to be involved in setting priorities and making decisions, Sandy, in a focus group interview, and her son Dave who has a developmental disability in a private interview, each describe Dave's abilities to live with a room-mate and manage many aspects of day to day life, including holding a job and preparing meals; yet Dave and Sandy are both clear that Dave relies on Sandy to do his food shopping in order to ensure he has a well-balanced diet. Not unlike Sandy, Carrie, whose sister Crystal is diagnosed with PDD, OCD and schizophrenia, describes her worry for Crystal's safety saying "I'm very protective of her…I don't trust the public. I don't want her to take public transit …I worry that she'd get taken advantage of."

Accepting that adults with disabilities need support in ways described by Lindsay and Sandy, two representatives from an agency supporting adults with disabilities add their caution about families failing to evolve their ideas of what their family member with a disability may be capable of doing and deciding. Instead, family members may attach a young "chronological age": "It doesn't matter that they're legally eighteen. It's very, very, shocking and hard for them (families) to understand and cope with that whole mentality that they're legally an adult and can make their own decisions". Indeed, many adults with disabilities have lived their entire lives in their parents' homes and "under" their parents' care resulting in entrenched roles for both care receiver and caregiver. Dave, a middle-aged man with a developmental disability, has a job and lives with a room-mate with whom he shares household responsibilities. Yet his mother Sandy conveys the workings of caregiver/care receiver identities as she notes that despite Dave's competence and independence, Dave "will phone the minute that he has any kind of a problem."

Bernard, employed by a mental health support agency, speaks of caregiving as an ingrained identity noting that caregiver care-receiver relationships are mutually reinforcing: "They have adopted this as their lifestyle. It's almost symbiotic." Ingrained, symbiotic care identities play out in multiple ways in Crystal's family related to care for Crystal, 33, diagnosed with pervasive developmental disorder (PDD), obsessive compulsive disorder (OCD) and schizophrenia, who was interviewed together with her parents, Maria and Gary, with whom she lives. Crystal's sister Carrie and brother

Andrew, with each of whom Crystal spends one weekend every 4-6 weeks, were each interviewed separately. Although Crystal begins her interview, that included her parents, with insightful questions for the researcher about distinctions between streams of graduate education at the researcher's University, when the researcher poses questions to Crystal, Crystal looks first to Maria. Crystal offers Maria opportunity to lead the response to the question that had been posed or, if Crystal does begin an answer, she does so cautiously while looking to Maria to ensure her answer is "on the right track". Accordingly, Maria and Gary correct a number of Crystal's responses including Maria disputing claims Crystal makes about how much time was required for Crystal to get accustomed to her medication. Maria corrects Crystal's table manners during the interview and when Crystal describes progress she had made, both Maria and Gary remind Crystal of how much effort it takes them as parents to keep her focused on completing required tasks. On a number of occasions, the focus shifts from Crystal's accomplishments to the work required of Maria and to a lesser extent, Gary, in supporting Crystal. As Gary talks about having to remind Crystal many times about what needs to be done, Maria comments: "My whole life is spent waiting for Crystal." In her own defense, Crystal claims: "I, I, sometimes I'm in a zone and I don't remember. I, I..." Although at one point, Maria notes that "Crystal makes her bed, she washes, gets herself cleaned and looks after her own self", at another point, Maria summarizes that "Crystal doesn't do anything for herself". Later Maria concludes that Crystal is "a lot of work" while Crystal timidly chimes in "I just need some training and education".

In her private interview, Crystal's sister Carrie expresses delight in having contact with the "real" Crystal following a series of trials with different medications. Carrie expresses feeling protective and worried that Crystal can be “taken advantage of”. At the same time, Carrie emphasizes “pushing Crystal to do what I know she can do” and points out that Crystal engages in more self-help and independent living skills when she stays at Carrie’s house compared with when she is home with Maria and Gary.

In his private interview, Crystal’s brother Andrew also expresses delight for who Crystal is noting “she has built in forgiveness, ah…teaches you about a better way to be around people. I, I find it very hard to forgive people…just her, her forgiveness is unbelievable and her compassion is unbelievable.” Andrew believes Crystal is a cohesive force in his family noting: “by having Crystal it’s brought us all together. You know, to support her, we all support each other.” Andrew believes that Crystal’s potential to be adaptable and independent is constrained by Maria’s long established caregiver identity. Andrew claims: “the concept that someone else could do it successfully I think threatens her [Maria’s] identity as a caregiver.” Andrew describes his mother as not having “had a chance to develop her life outside of that” and as focusing on “the short term and avoids the longer term arrangements.” Accordingly, Andrew notes having discussed future living arrangements for Crystal with Carrie and her husband but this is being treated as “a mysterious plan” about which Carrie and her husband “didn’t want mom [Maria] and dad [Gary] to know.” Andrew reasons that there would be “resistance there” and postulates that resistance would be more from Marian than Gary. Andrew believes “that a kind of a weaning needs to take place” for Crystal to recognize him or others as authority and not defer to Maria.

Maria, as primary caregiver to Crystal, rather than questioning her caregiver role, presents herself as an authority on her daughter’s needs to the extent that Crystal is often spoken about as if she was not present. When Crystal attempts to make her voice heard, she is often spoken over or interrupted by Maria. Indeed, Maria's other children are discussing future changes for Crystal without their mother's knowledge.

2. Voices Obscured Amidst Families as Fierce Defenders Against Systems

Authoritative family caregiver identity, such as that exemplified by Maria, may grow as families define themselves as "up against" a formal care system that cannot be counted on for appropriate support. Ideas of families versus systems continue to play out against a backdrop of the post war institutional era during which family member views were disregarded. Older family members in particular, have vivid recollection of trauma from life in large institutions. During a family member focus group, a mother of a middle-aged daughter describes reading stories written by residents of institutions as "terrible" and "unreal."

Donna discusses securing appropriate formal support for 19 year old Susan in terms of her own willingness to 'fight' and be vigilant. Reflecting on Susan's admission to school, Donna says:

> Well they weren't going to let us get in to any school where we weren't in the district. And, ah, I'm sorry we've met with the Minister of Health, we've met with the Minister of Education…When you have a child that needs support, if you don't stand up for them, they're just pushed aside and they fall through the cracks…you have to push so that they get the best that they can.

Even when hard won formal supports are in place, families defend against a sense of intrusion into their lives which these supports represent. At a family member focus group, a mother of two children with disabilities recalls fighting for needed support yet feeling "overwhelmed with somebody always knowing [their] frickin' business." This mother resents “well meaning” professionals telling her how her children are “supposed to interact”. She notes further that in light of professional involvement in family life, families live with the stress of the idea that they must follow every directive from professionals and if families “don’t do everything perfectly, then something’s going to go wrong with your child”.

At an agency representative focus group, one professional from a family support and advocacy agency discusses ways in which formal supports intrude into families’ lives as she notes that to be eligible for formal support such as respite families must “show all their needs and deficits…” She remarks further on the paradoxical nature of supporting people with disabilities and their families wherein: “We’re supposed to be pumping them up, talking to them about how they can be all they want to be and they can have authenticity …. and they can have citizenship and they should have these things and they should have all this stuff but first you gotta make them all pathetic”.
To this line of thinking, a focus group participant from a community agency providing support to adults with extreme behaviors adds dryly: “you gotta bleed first. You gotta suffer first”.

Crystal’s father Gary makes a point for why families go through the struggles associated with demonstrating “eligibility” for professional support as he speaks in terms of Crystal’s daughter’s diagnosis in terms of legitimacy: “The nice thing too about Crystal being diagnosed and making it medically official and having it written down is that now when we went for support… we could provide medical records that confirmed that she has these legitimate problems”.

The flip side of the "legitimacy" issue is illustrated by Jan, a family focus group participant whose sister Tanya was diagnosed with "schizophrenia like symptoms…in her late forties," and who comes from a "guarded family" who "coped within the family" despite knowing "from the time Tanya was small…there was something a little different about her." As Tanya's more complex needs manifested in adulthood, it "finally…came to a point where no one could deal with her". Jan states "when we went for help, they say no because it's not recognized that it was caused from birth, or a childhood disease or childhood symptoms…she doesn't qualify... there's no documentation of her ever having any mental health issues".

Families' quest to sufficiently demonstrate need in order to obtain services continues across the life course with their children's transition to adulthood often being distinctly stressful. In a family focus group, Jean, mother to Allison who has Prader- Willi syndrome, reflects: "when they're in the school system, the parents almost get kind of fooled 'cause there's usually quite a bit of support and then when they become an adult, oh that's quite different." Parents discuss abrupt changes in expectations or consequences for their adult child and one mother voices: "It's like the system give up on adults in a way… cause when they're children, they're learning things and they're moving forward and they're graduating from something."

Obtaining formal supports is one part of the journey; ensuring an adequate quality of formal supports is often an added struggle. Deficiencies in quality are many and varied and can stem from an undervalued workforce as per Carrie's description of the state of formal supports surrounding her sister Crystal: "they're short on workers because it's not an industry that pays a lot right so … they have to want to work with people and it ranges from anywhere with like Down syndrome to like my sister so or people in wheelchairs". Barbara adds that staff that are inadequately skilled/poorly trained can have the effect of contributing to, rather than solving, problems. Barbara illustrates with an example of her frustration with staff who "project their own drama" into the workplace and contribute to her sister Allison having behaviour outbursts: "It's like they're setting it off and then they'll go write up all this paperwork and say well she had this incident. Well you triggered it, like you're doing this."

Geraldine, whose brother Henry is aged 71 and has a disability, elaborates with a concern that the quality of formal support environments is related not only to staff but also to other participants in the environment. Geraldine's example is about how adults with lifelong disabilities can be stigmatized by older adults without lifelong disabilities as she reflects on time Henry spent in a long term care facility: "He was ostracized. Other senior citizens ostracized him."

At an agency representative focus group, a social worker raises a relatively universal issue of the constraining nature of government sponsored income support for adults with disabilities stating simply that "If they're on AISH (Assured Income for the Severely Handicapped), we enforce poverty". Robert, from a small community agency that supports adults with disabilities and/or mental health issues, highlights the distinct ways in which financial constraints of disability support incomes can play out for people in small communities, particularly in times of economic prosperity and rising rents: "they end up in a town with 50 people in it cause they can get a house for 300 (dollars) you know but they have no driver's license, now they're geographically isolated and there's no way they can afford to get out of that town."

Crystal’s father Gary conveys a sense for his family coming to terms with inadequacies of the formal support and services system as he reflects: “we come to the basic conclusion - how bad is it to have Crystal with us? It’s very tolerable. Ah, we don’t mind having her with us. Yes, it, it restricts our life somewhat but overall we can deal with it and in our view, it’s a hell of a lot better than the alternatives”.

3. Agency Empathy for Families with a Dash of Caution

Aligning with parents and siblings of adults with disabilities who express frustrations with systems that are not supportive, most agency representative focus group participants express empathy and characterize families as understandably frustrated and weary of the journey of finding appropriate supports.

Agency support and empathy for families is offset slightly as some agency representatives share experiences with family members who are people from whom adults with disabilities require protection. Describing families who are extended beyond their limits, a supportive employment coordinator notes that under conditions of extreme family stress adults with disabilities are susceptible to being “...over medicated, maybe shut away, not included in the community any longer, um, you know rights taken away, opportunities that vanish, um, independence taken away.”

A developmental disability resource center supervisor elaborates on the idea of individuals being compromised and indeed, endangered by families as he describes experience with a parents or siblings using their family member’s disability support income to pay their own living expenses. In an extreme example, he recalls a woman who had received a cash settlement for having been involuntarily sterilized while living in an institution in the early 1970’s. This woman had purchased a home with her sister and her sister’s boyfriend, both of whom had mental health issues and addictions. Eventually: “the police were called because of the smell. That’s how bad it was. She spent six months in the hospital recovering when... police pulled her out of the house. It was worse than any hoarding show apparently known to mankind.”

V. DISCUSSION

More than a decade ago, Harriet Lefley and Agnes Hatfield spoke of the need for planning in relation to “the greying of the deinstitutionalized population.”[30] Indeed, the aging of our population will continue to intersect in new ways with needs arising from cognitive impairment. Adults with disabilities are almost guaranteed to experience changes in care arrangements in their final decades of life and our persistent climate of fiscal restraint surrounding these changes makes it increasingly important that endeavors continue towards hearing and responding to efforts by adults with disabilities to direct their own lives. Jonathan Potter and Alexa Hepburn use the concept of “footing” to invoke critical examination of interactions that occur during research interviews.[31] These authors are calling upon qualitative researchers to take more careful account of interviewer/interviewee position relative to each other. We suggest that “footing” is a useful concept for thinking about voice within families in relation to decision making.

Our findings leave us cautiously optimistic about potential for adults to be on sound footing to have their views understood and responded to within their family caregiving contexts. Our optimism stems from detailed evidence of family caregivers facilitating equal footing by acting as respectful, supportive voices for their child or sibling with the use of prompting and clarifying questions that are effective yet not overbearing. Pauses and silences are used to allow processing time for footing to be gained and ideas expressed. Amidst a lively focus group discussion, Lindsay creates space for her sister Ruth to “represent herself”. Interactions between Janice and her son Mike with Down Syndrome and limited verbal abilities, demonstrate Janice’s ability to strike a balance between facilitating and respecting Mike’s voice with gentle probes yet retreating when Mike holds his footing by saying no or projecting a closed silence.

At the same time, we have evidence of care identities from which it is difficult to disentangle the views of adults with disabilities as their voices can be diminished or negated in conversation. Such is the pronounced experience of Crystal, an articulate woman diagnosed with PDD, OCD and Schizophrenia, who speaks about her symptoms and adjustment to medication only to be contradicted by her mother, Maria. Crystal established solid footing relative to the researcher by opening the interview with questions and conversation about graduate education. Yet after an early contradiction by Maria, Crystal does not regain momentum to continue to share her perspectives about the impact of her medication on her schizophrenic voices. Further, Maria’s dedicated and authoritative style of support leaves Crystal’s siblings reluctant to “hold their own” by freely sharing their insights and vision for their sister in Maria’s presence. In Crystal’s family, a key caregiver has longstanding and pervasive control over Crystal’s care, including the ways in which other family members are involved. Accordingly, formal agencies are obligated to follow the lead of the main family caregiver(s) to the exclusion of ideas from other family members including the adult with a disability.

Uneven footing for adults with disabilities is also evident amidst family caregivers who act as “fierce defenders” against the system. Parents and siblings defend their family’s dignity and rights to live a normal life as they resist intrusion and exposure to professionals. They specifically defend the humanity of, and growth opportunities for, their family member with disability amidst systems full of cracks and insufficient resources. While these efforts by families, and the results produced (such as access to inclusive education, respite, effective residential support) may be admirable, we caution that a fierce defender stance can dominate a family's identity such that views of the adult with a disability are only assumed to be represented.

Our findings illustrate some of the many ways in which footing for adults with disabilities can be fragile amidst their caregiving contexts. To the relatively obvious and well established concerns with potential for families to be dishonest and abusive, we provide evidence of ways in which even the most dedicated of families can obstruct voices of adults with disabilities. Our recommendations to legal practitioners committed to supporting adults with disabilities in directing their own lives centre on the idea of involvement of an external, decision facilitator towards counteracting fragile footing.

A. Incorporation Of External Decision Facilitation

In light of ways in which lives of caregivers and care receivers can be intertwined, incorporating an external decision facilitator increases potential that interests and needs of adults with disabilities that may go un-noticed amidst familiar interactions, will be identified. A well-equipped external decision facilitator would possess understanding of the history of devaluation of people with disabilities including the role of families in fighting for the rights of their family members. Although rights are relatively well established in Canada, families continue to face stigma and tests of endurance in securing access to appropriate supports and services. Indeed, as our agency representatives and families attest, service providers require documentation of deficits and problems to justify service provision[32] and families can be left feeling exposed and intruded upon. As such, decision facilitators would hold high regard for the invaluable contributions made by families and a commitment to advancing the interests and needs of family caregivers. To honour families' sense of boundaries and privacy, we recommend decision facilitator relationships be framed in "guest-host" terms in accordance with family nursing approaches wherein nurse practitioners are ever mindful of their status as guests when providing nursing care in the intimate home environments of patients.[33] At the same time, it is important for decision facilitators to be keenly aware of potential for collective and individual family journeys to impact the ways in which caregiving family members present needs and interests of adults with disabilities. Well-equipped decision facilitators can play an important role in supporting families to critique their own established patterns in terms of potential obstructions to expression of interests and needs by adults with disabilities. Decision facilitators are advised to review a series of short videos, produced by the Social Care Institute for Excellence in the United Kingdom, which illustrate navigation of decisions about topics such as safety, money and treatment amidst the dynamics of needs for care. [34]

B. Accessing Multiple Caregiver Perspectives

We recommend that decision facilitators engage with as many members of the caregiving family of the adult with disabilities as possible. We supply evidence of caregiving family members as offering extensive insights into the interests and needs of adults with disabilities. At the same time, we find different and sometimes competing facets of interest and need provided by different caregiving family members and we are confident that obtaining multiple perspectives from within families will enrich decision-making. Further, agency providers of formal care have distinct perspectives on interests and needs of adults with disabilities and their views ought to be included wherever possible.

C. Hearing Individuals with Disabilities

At the most foundational level, an external decision facilitator will ensure provisions are made to accommodate adults with disabilities in having their less conventional voices hear.

1. Technology-based Supports

A burgeoning array of technology-based augmentative and alternative communication options exist. Decision facilitators would be advised to consult resources such as the newly revised text by David Beukelman and Pat Mirenda on Augmentative and Alternative Communication for a consideration of options[35] Further, given the growing prevalence of brain injuries resulting from stroke, journals dedicated to aphasiology (which target understanding and responding to “aphasia”, a scientific term for communication comprehension and articulation difficulties) are particularly sound resources for keeping abreast of augmentative and alternative communication developments.

2. Non Technology-based Supports

Non-technology supports, many of which are common-sense yet get overlooked in the interest of expediency, are also abundant. At the simplest level, decision facilitators are advised to be attentive to stress that can be caused by time pressure.

Accordingly, creating a context for decision-making interactions that entails speaking at an unrushed pace and providing extra time for responses is recommended. Using short, simple, high frequency words can help generate fuller responses. Building from here, rewording questions that do not seem well understood, posing closed ended questions and offering suggestions can be useful strategies as can taking time out when understanding of a topic is not clear.[36] Booth and Booth remind that communication with inarticulate subjects can entail considerable creative guess work.[37] Blake Poland and Ann Pederson add points about insights that may accrue by attending to meanings of silence in conversation with adults with disabilities and note that silence tends to be overlooked as it appears to be opposite to, rather than part of, speech.[38] Relatedly, speech language specialists have developed orthographical transcription practices to support fuller understandings of people with speech disorders. Orthographical transcription entails meticulous recording and examination of speech/vocalizations including dis-fluencies, such as hesitations and stutters, as well as changes in inflection, in audio and video recorded conversations and subsequent transcriptions of these conversations.[39]

Policies and practices related to aging populations have been focused on meeting care needs for elders with little attention given to how caregiving roles, such as lifelong care for a child with disabilities, being vacated by elders, will be filled. In this paper we address this “beyond parent care” gap by examining and making recommendations for ways that adults with disabilities can be more fully supported to direct their own lives.

D. Limitations

Our findings are limited because our samples are biased by self-selection that favors family caregivers who are highly involved in the lives of their sons/daughters/brothers/sisters as well as prepared to discuss and demonstrate their involvement. The ways in which dedicated caregivers can obstruct voices of adults with disabilities heightens a sense of urgency that we, and our colleagues, should study effects of less involved family members on voices of adults with disabilities, perhaps from perspectives of agency representatives given the relative inaccessibility of less involved family members.

Our findings are further limited by the small size of our samples. In particular, and consistent with our recommendations for communication accommodation, we continue to grapple with methodological steps necessary to engage first hand perspectives of adults with disabilities in research studies. Aligning with the spirit of this commissioned paper, we will continue our endeavors to capture these under-represented voices and we will encourage our colleagues in this pursuit.

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