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Enacting Power at the Decision-Making Table: Foregrounding the Voices of People with Intellectual and Developmental Disabilities in the Policy Process through Engagement with Families in Relational Self-Advocacy

Renforcer le pouvoir dans la prise de décision : Mettre de l'avant les voix des personnes ayant une déficience intellectuelle et un trouble du développement dans le processus politique par l'engagement des familles dans l'auto-détermination relationnelle

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Abstract

Self-advocacy by people with intellectual and/or developmental disabilities (IDD) has long been an important driver of collective empowerment and social recognition for the IDD movement.

In recent years, new avenues to mobilization (including the increased involvement of self-advocates within formal advocacy groups and the growth of self-advocacy networks through social media and online communities) have led to more direct engagement by self-advocates in processes of policy consultation at the governmental level.

Still, despite advancements in inclusion practices, there remain significant questions as to whose voices are foregrounded (i.e., are the most prominent), and to what extent policymakers meaningfully engage with self-advocates.

By contrast, family advocates have historically had more opportunities than self-advocates to engage directly with political institutions. Family advocates have been instrumental both in advocacy group formation and pursuit of the legal enshrinement of IDD rights, paving the way for significant policy advances.

The present paper assesses the commonalities and cleavages between self-advocacy and family advocacy, with specific attention to the historical evolution of IDD advocacy in Canada.

The comparison is framed by addressing two primary objectives of IDD advocacy: i) promoting authentic individual and collective counter-narratives (i.e. the lived experiences of people with IDD that challenge dominant ableist assumptions) and ii) effecting policy change.

We conclude by examining the interconnectivity of the two forms of advocacy and the potential of relational approaches based on interdependence and social connection of people with IDD and their close supports to overcome pervasive social and political institutional barriers.

Résumé

La défense des intérêts des personnes présentant une déficience intellectuelle et/ou développementale (DI-TD) est depuis longtemps un moteur important de revendication collective et de reconnaissance sociale dans les mouvements politiques œuvrant pour la défense de droits des personnes ayant une déficience intellectuelle et/ou un trouble du développement.

Récemment, de nouvelles voies de mobilisation (notamment la participation accrue des personnes œuvrant au sein des groupes de défense de droit officiels, et la croissance de ces réseaux par le biais des médias sociaux et des communautés en ligne) ont conduit à un engagement plus direct des personnes concernées dans les processus de consultation politique à l'échelle gouvernementale.

Pourtant, malgré les progrès réalisés en matière d'auto-détermination auprès de cette population, des questions importantes demeurent à savoir : quelles voix sont mises en avant (c'est-à-dire, lesquelles sont les plus importantes ou les plus amplifiées) et dans quelle mesure les décideurs politiques s'engagent de manière significative auprès des personnes ayant un DI-TD.

En contrepartie, les défenseurs des familles ont historiquement eu plus d'occasions que les individus eux-mêmes pour de mettre de l'avant ces enjeux et interpeller directement les diverses institutions politiques impliquées. Les organismes se portant à la défense des familles ont joué un rôle déterminant dans la formation de groupes de défense de droits et dans la quête de l'entérinement juridique des droits des personnes handicapées, pavant ainsi la voie à des avancées politiques significatives.

Le présent article évalue les points communs et les clivages dans l'entérinement juridique et la défense des droits des familles, en portant une attention particulière à l'évolution historique de la défense des droits des personnes handicapées au Canada. Ladite comparaison est encadrée par deux objectifs principaux de la défense des intérêts des personnes atteintes de DI-TD, soit : i) la promotion de contre-récits individuels et collectifs authentiques (c.-à-d. les expériences vécues des personnes avec de diagnostics de DI-TD qui remettent en question les hypothèses dominantes sur la capacité physique) et ii) la réalisation de changements de politiques.

Nous concluons en examinant l'interconnexion des deux formes de défense de droits et le potentiel des approches relationnelles basées sur l'interdépendance et la connexion sociale des personnes vivant avec les diagnostics de DI-TD et de leurs proches-aidants pour surmonter à la fois les barrières institutionnelles, sociales et politiques.)

Mots clés : auto-défense, défense familial, défense pour les personnes vivant avec de TDI, auto-défense canadien, auto-défense relationnel, mouvement social, neurodiversité.

Introduction

Advocacy efforts to promote the inclusion of people with intellectual and/or developmental disabilities (IDD) are confronted by a persistent paradox. On one hand, advocating for policy change is more effective when advocates have access to the policy process, where attitudinal barriers (e.g., ableist stigma and discrimination) that create and sustain exclusion at both social and political levels can be confronted. However, access to the policy process is also impeded by these same barriers, so that people with IDD and their family members are rarely afforded opportunities to contribute meaningfully to the design and implementation of the policies that directly affect them. This has necessitated an alternative vision of IDD advocacy, where rather than formally engaging with political institutions that generate exclusion (i.e., through consulting on policy design or launching legal challenges), the focus is instead on creating and promoting positive representations of IDD as a social/political identity, with the aim of empowerment at the individual level. In important ways, this latter vision of IDD advocacy is oppositional to the former because it flourishes outside of existing political institutions by taking aim at the oppressive ideas that are *baked into the cake* (i.e., embedded within political institutions since their formation). As such, there exists a tension between these two visions of IDD advocacy, which are not mutually exclusive, but not altogether compatible either.

This concept paper addresses this tension in IDD advocacy in Canada by examining the shifting composition and goals of the social movement within the political opportunity structure, which is defined as the specific institutional context that shapes the available avenues to achieve desirable policy outcomes (Tarrow, 1994). Specifically in contentious political contexts, where multiple groups compete to shape the policy agenda, political opportunity structures are understood as the avenues to effect change within a fundamentally static institutional environment. For example, in some advocacy contexts change may be more effectively targeted by engaging with formal institutions through judicial challenges or presentations to parliamentary committees, while other contexts may favour more informal avenues to change such as public demonstrations or awareness campaigns. While the concept of political opportunity structure allows broader application to such topics as social movement formation and collective identity construction, it is specifically useful in mapping how conflicts between political groups and actors are mediated and constrained by the opportunities for action afforded them by political institutions (Vanhala, 2014; Smith, 2008). To this end, we use it to elucidate an important historical shift in Canadian IDD advocacy, from the first appearance of advocacy groups following the collective action of family advocates, to the present day wherein self-advocate voices are increasingly prominent (Park, 2003; Vanhala, 2014). Rather than explain this shift, we simply acknowledge it as a heuristic tool that is useful to compare the evolution of family advocacy and self-advocacy. That is, by examining the evolution of these two forms of IDD advocacy within the political opportunity structure, we gain insights into how to overcome the tension between IDD advocacy aimed at: i) society (through identity formation/individual empowerment), and ii) the state (through the Canadian government and public institutions).

Society-focused advocacy is broad in scope and includes community-building efforts through the sharing of resources, information and experiences among people with IDD and their close supports. By contrast, state-focused advocacy is less accessible, often involving formal engagement with political institutional arenas such as the judicial arena (i.e., through legal challenges), the policy arena (i.e., through legislative consultation in policy design processes or contribution to the implementation of relevant policies), and the political arena (i.e., through organized advocacy efforts to get IDD issues on the political agenda before provincial and federal elections). We address these two aims of IDD advocacy in turn, before concluding with a discussion of tensions, overlaps and potential avenues for future collaboration between family advocates and self-advocates in Canada. In this way, we position family advocates and self-advocates not as competitors, but rather as key partners in addressing social and political institutional barriers that continue to marginalize Canadians with IDD.

We invoke the concept of relational autonomy to argue that the basis of this partnership between family advocates and self-advocates is their shared engagement with disabling barriers. Relational autonomy is defined as a model of self-determination that extends the notion of the *self* beyond an individual, to include the vital relationships with others that support and influence one's engagement with the world (Downie and Llewellyn, 2011; Ho, 2008). Disabling barriers may be both attitudinal (e.g., discriminatory hiring practices or stigmatization of IDD in group settings) and environmental (e.g., public spaces that are physically inaccessible or otherwise unaccommodating to people with IDD). Although uniquely positioned in relation to these barriers, both family and self-advocates face struggles of access and equity on a daily basis, and their experiences of such are often lived interdependently and relationally. These shared experiences (between family advocates and their relatives with IDD, or self-advocates and their support network including family, friends and support workers) of confronting disabling barriers constitute a shared positionality – a relational selfhood – that extends beyond the isolated positions of the individuals therein (Downie and Llewellyn, 2011). A project of relational self-advocacy therefore has the potential to resolve some of the inherent tensions between advocacy *for* versus *by* people with IDD, while also transforming the nature of engagement with political institutions that treat rights (e.g., freedom from discrimination) as individual entitlements (Mackenzie & Stoljar, 2000). In this way, relational autonomy has the potential to guide a vision of IDD advocacy that permeates the individualized biases of biomedical or liberal notions of personhood and capitalizes on the transformative potential of empowering people with IDD to effectively participate in policymaking.

Society-Focused Advocacy for Promoting Authentic Counter-Narratives

The history of self-advocacy in western liberal democracies has been a subject of inquiry and reflection by scholars, practitioners and activists for several decades, with documentation emerging from the United Kingdom, Australia, the United States and Canada, wherein self-advocacy among people with IDD has gained momentum since the early 1970s[1]. The literature has pointed to several categories or *sites* of self-advocacy, largely situating comparisons between individual and collective forms. Buchanan and Walmsley (2006) have referred to self-advocacy in the United Kingdom and Australia as both a means for "individuals to gain voice and affirm

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[1] People First of Canada began in 1973 and developed a national office in the early 80s.

identity and as a collective movement representing the interests of a particular group" (p. 133). Self-advocacy as an individual practice is identified in the literature as having a personal emancipatory goal; that is, to enhance identity and positive self-concept, resist stigma, and provide opportunities for the development of skills and social relationships among people living with IDD. Social recognition, by far the most common identified goal of individual self-advocacy, is operationalized as a process and an outcome through the foregrounding of voice, lived experience (life story) and perspective. Self-advocacy as a collective practice has been identified as both reducing labelling and the stigma it engenders and contributing to the fight for rights and entitlements within society. In a comparative article on empowerment, rights and self-advocacy in Canada and the United Kingdom, Stainton (2005) identified four key elements necessary to create conditions for empowerment to occur: "support for people to articulate their claims; support for people to identify, obtain and manage supports necessary to actualize their claims; providing control over resources; and governance" (pp. 291-292). Each of these key elements emphasizes the importance of self-advocates actively shaping the policy agenda, which requires not only access to political institutions, but a degree of consensus over the guiding aspirations of IDD social movements.

Tensions between individual and collective forms of self-advocacy do exist, with the former focused predominantly on individualized strategies for enhancing positive identity and social recognition, and the latter seeking to move beyond recognition to transform the political landscape. Such tension is clearly not dichotomous. Positive identity, skills development for personal gain (such as employment and friendship) and social recognition (largely at the local level) can invariably lead to the creation of collective voice (Petri et al., 2020). Accordingly, several questions arise as to the inherent possibilities of moving from identity and well-being at the individual and relational level to the eradication of oppression through policy advocacy at the socio-political level. In a recent study on People First movements in Ontario and Nova Scotia, Butler (2020) calls attention to the mutually constitutive and relational nature of individual and collective self-advocacy, suggesting that consciousness-raising about rights and entitlements can serve to shift focus from individual resilience in the face of stigma and exclusion to collective resistance against oppressive circumstances. Her work calls attention to the inter-relationship between identity and rights awareness as central features of self-advocacy, a process she defines as situating "voice and storytelling through a power relations lens" (pp. 217-218). In line with this perspective, Anderson and Bigby (2017) have invoked the concept of *self-authored spaces* (Milner and Kelly, 2009) as sites where people with IDD "can find community, celebrate their individuality and work together to produce social change" (p. 110).

One important key factor in the shift from individual to collective self-advocacy as a means of shaping political change is related to the question of who *controls* processes and agendas. By definition, self-advocacy calls up the notion of *the self*, that is, self-advocacy is or should be about people with IDD as creators and drivers. However, much of the movement to organize under the umbrella of self-advocacy has been directed by others, most notably family members, service providers and/or other allies within community-based organizations. In the case of service provider or community-supported forms of self-advocacy, these have mainly focused on self-advocacy as an individualized process of self-affirmation, skills development and social inclusion at the local level. Within wider disability-rights organizations where collective resistance and rights-based forms of engagement more commonly take centre stage, people with IDD have been largely underrepresented to date. In each of these cases (family, service delivery or community-based), models in which people with and without IDD act collectively under the leadership and guidance of self-advocates are less common.

One site of potential democratization related to intersectional diversity (across identity categories and social locations including disability, age, race, class, cognition, Indigenous identity, sexual and gender identity, etc.) is the recent proliferation of social media as a forum for sharing life stories, experiences, and perspectives in order to combat stigma and enhance recognition (Hulko et al., 2020). However, the random, localized nature of these self-advocacy accounts may limit the potential of individuals and groups to build consensus on a national policy agenda or platform. Moreover, formal avenues to policy change, which typically require practical involvement in stages of the policy process such as agenda setting, defining policy problems, and contributing to the design and implementation of IDD policy, are more effectively targeted through engaging directly with political institutions: namely, the relevant departments/ministries and the courts.

State-Focused Advocacy for Policy Change

Political institutional avenues to effect policy change have historically been inaccessible to self-advocates, despite recent trends toward inclusion in processes of policy consultation and deliberation. By contrast, family advocates have had more success influencing public policy, as evidenced by their integral role in establishing the advocacy groups that have been at the foreground of crucial disability policy victories. For example, during the drafting of the Canadian Charter of Rights and Freedoms 1982, family advocates played an integral role in gaining the explicit recognition of *mental and physical disability* among the identity categories protected from discrimination in section 15 (1). The catalyst for this hard-fought victory was the lobbying efforts of several disability advocacy groups before the Hays-Joyal Committee, whose recommendation to include disability categories caused a dramatic about-face from Justice Minister Jean Chrétien, who had previously recommended excluding disability (Boyce et al., 2001). One aspect that makes this victory so significant, particularly for people with IDD, is the discretion it gave the courts to interpret what constitutes equal treatment and freedom from discrimination under the law. For example, several Supreme Court of Canada rulings extend the Charter equality provision into the preservation of self-determination and autonomy, which must come to bear on any decision to declare legal incapacity (see Kerzner, 2006, pp. 348-350). This is one of several ways that the Charter has been used to advance legal personhood for people with IDD.

While the significance of these policy advances should not be understated, it is puzzling that such victories of disability personhood occurred largely without the direct involvement of *disabled persons*, specifically self-advocates themselves. Indeed, the IDD advocacy group at the center of Charter negotiations was the Canadian Association of the Mentally Retarded (CAMR, now Inclusion Canada), whose formal submission was provided by David Vickers, parent to a child with an intellectual disability (Boyce et al., 2001, p. 52). While family advocates also have a vested interest in the advancement of legal protections and are insulated from some of the social/attitudinal barriers that limit engagement with political institutions among people with disabilities, their positionality also precludes them from *identifying* as disabled. This is an important caveat when we consider IDD advocacy as a social movement that engages with identity politics by targeting ableist structures, and thus employs a *dual strategy* that aims to effect change in both society and the state (Smith, 2005, p. 36). The effectiveness of this dual strategy involves reflecting upon the shared goals and collective interests of the members of an identity group. This requires more than the mere involvement of self-advocates, but their leadership in creating/shaping the agenda: nothing about *them* without *them*.

This is not meant to suggest that self-advocates have been wholly unsuccessful at shaping the agenda. An important example is the role that self-advocates played in advocating for the involvement of CAMR as legal intervenors in the *E. (Mrs.) v. Eve* case, where a mother sought a non-therapeutic forced sterilization of her daughter with an IDD. In addition to pushing for the organization's involvement, self-advocates active in the CAMR Consumer Advisory Committee also significantly shaped the framing of the legal arguments before the Supreme Court of Canada which led to a victorious decision that the mother did not have legal authority to consent to the non-therapeutic sterilization (Vanhala, 2014). This had the important effect of elevating the stature of self-advocates within CAMR[2]; and some of these self-advocates also went on to create a national organization for IDD self-advocates: People First of Canada (Park et al., 2003). The formation of People First of Canada as an independently funded and governed organization represents a pivotal point in the history of Canadian IDD self-advocacy. Moreover, the fact that they historically emerged out of – and currently work in partnership with – Inclusion Canada, demonstrates a strong foundation for building consensus and collaboration in future advocacy efforts. This relationship also demonstrates that neurotypical allies can be involved in collective advocacy, but that they must do so alongside social identity movements, rather than by leading, subsuming or infiltrating them.

This leads to an important question: has the success of family advocacy itself served as a barrier for self-advocates to access relevant political institutions? While a definitive answer to this question is elusive, and well beyond the scope of the current contribution, we can identify a starting point for this focus of inquiry. To begin with, Canada's political institutions are inherently ableist, reflecting broader dominant social discourses which exclude people with IDD by positioning them as incompetent, incapable and/or dependent (Bach, 2017; Prince, 2009). The persistence of social and attitudinal barriers is what necessitates the dual strategy enacted by IDD social movements. Political institutions are by their nature far more resistant to change than social attitudes, exhibiting characteristics of stability and incrementalism (Lindblom, 1979); however, the inflow of new ideas into the political discourse is a major catalyst for the change of institutional norms (Schmidt, 2008). It follows that the ableism embedded in political institutions is far more resilient than ableism in society at large. Because political institutions act to continuously reinforce their ideational foundations, effecting significant change requires disrupting these ideas – in this case, ableist barriers to participation – because these are the engine of an institution's reproductive mechanisms (Thelen, 1999, p. 397). Therefore, assessing the role of family advocates in supporting self-advocates' access to political institutions requires taking stock of the former's success in challenging ableist ideational foundations embedded within these institutions.

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[2] This group of self-advocates also led a campaign to change the organization's name to the Canadian Association of Community Living. A much more detailed account of both the E. (Mrs.) v. Eve case, and the *change the name* campaign is provided in Vanhala (2014) and Park et al. (2003).

While family advocates have been comparatively more successful than self-advocates in gaining access to political institutions, they have successfully advanced the dual strategy by using their influence to target social barriers that exclude self-advocates. Notably, this has involved challenging legal barriers to personhood, which act to formalize and legitimize the exclusion of people with IDD. The history of Charter advocacy is an important example because it extended and protected legal definitions of personhood for people with IDD. Similarly, advocacy related to the design and adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006 was propelled by the efforts of the Canadian Association for Community Living (now Inclusion Canada) and focused on advancing personhood through explicit protections in Article 12 on the preservation of legal capacity and the formal recognition of supported decision-making (Vanhala, 2014; Bach, 2017). By promoting the personhood and decision-making capacity of people with IDD, these family-led advocacy efforts have delegitimized dominant narratives justifying the procedural exclusion of self-advocates, thus taking aim at the ideational foundations of Canada's ableist political institutions.

Self-advocates remain under-represented in policy advocacy, design and implementation, despite their increased inclusion in policy consultation and advisory boards in recent years. For example, in advance of the Accessible Canada Act 2019, self-advocates with IDD joined community consultation processes; however, the final language of the act is vague when it comes to identifying and accommodating social/attitudinal barriers that disproportionately affect people with IDD. Similarly, self-advocates were included in joint-committee testimony in the debate to extend Canada's medical assistance in dying legislation Bill C-7. Here self-advocates participated in an overwhelming show of unity, as reflected in a joint statement from disability advocacy groups[3] denouncing the bill's provision to classify "people with disabilities and disabling conditions as the *only* Canadians to be offered assistance in dying when they are not actually nearing death"[4]. Significantly, the advocacy around Bill C-7 makes frequent reference to how the enactment of the bill violates the rights protections enshrined in both the Charter and the CRPD. Once again, the voices of self-advocates were unable to overwhelmingly shift the debate around Bill C-7, and the Senate passed the bill in March 2021.

As is evident in these recent examples, while self-advocates are increasingly involved in policy consultation, their voices and unique positionality are not being respected in agenda setting, design or implementation. In effect, this follows a historical pattern of self-advocate inclusion as *tokenism* where – in the words of prominent self-advocate Peter Park – "(w)e are here as real tokens, not as individuals who are respected. They don't want to respect us. That's too much like work" (quoted in Hutton et al., 2010, pp. 112). Pressuring policymakers to do this work by respecting self-advocates as key stakeholders in policymaking processes is a necessary pre-condition for significantly addressing the marginalization of Canadians with IDD.

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[3] The 147 signatory organizations included groups representing various types of disability/impairment, as well as faith-based organizations and medical associations.

[4] Joint statement available at http://www.vps-npv.ca/stopc7

Discussion: Relational Self-Advocacy in Canada

The overlap between family and self-advocacy efforts targeting the procedural exclusion of people with IDD shows that there is potential for collaboration and interdependence between the two groups in a project of *relational self-advocacy*. The question remains, however, as to the extent to which both individual and collective self-advocacy has been able to redress social and political exclusion and enact power at the decision-making table. Can inclusion practices which aim to amplify voice and enhance social recognition adequately confront institutional barriers to political agency among self-advocates within governmental and institutional spaces? The current emphasis on the development of advisory functions through consultation and/or needs assessment undertaken by governments and public institutions demonstrates a small step forward, but still falls short of the long-term commitment made in section 5 (e) of the Accessible Canada Act 2019 to remove barriers to the involvement of people with disabilities in “the design and delivery of programs and services”. As such, it does not significantly transform unequal power relations or the inherent stereotypes on which these relations are justified by political actors in positions of authority.

It is impossible to wish away the incrementalism and inherent biases embedded within Canadian political institutions. For example, considering that both the family advocacy and self-advocacy movements have been devoted since their establishment decades ago to ending the horrors endured within residential institutions through community living alternatives, it is puzzling that residential institutions still operate in Canada. Indeed, even in provinces like Nova Scotia where formal policy commitments have been made to fully transition to community living, residential institutions persist as an emblem of the deeply ingrained biases that underlie the de-prioritization of IDD issues on the political agenda. Rather than limit their focus solely to state-focused advocacy, Canadian IDD advocates have employed a dual strategy that takes aim at the ideational foundations of these biases. On one hand, this requires a collaborative and inclusive approach to identity construction and consensus-building that effectively disrupts social barriers, such as the pervasive myths and stereotypes at the root of IDD stigma. On the other hand, this must involve increased engagement by self-advocates with political institutions grounded in respect and deference to their positionality, and the creation of new avenues for power sharing in decision-making to effect policy change, rather than mere tokenism.

Achieving this dual strategy requires a unified approach, building on important procedural and symbolic gains achieved by family advocates. The privileged positionality of self-advocates as expert witnesses to the full scope of disability policy in Canada necessitates their leadership in the policy process, rather than merely being subsumed within existing ableist institutions, as with tokenistic consultation processes. Self-advocacy, when too closely aligned to government, becomes burdened by prevailing understandings of policy expertise and the trappings that come along with it: “contracts, targets and imposed deadlines” (Buchanan and Walmsley, 2006, p. 137). These *deliverables* must also be informed and re-imagined with an IDD inclusive lens, and thus divorced from the paternalism of policy expertise produced within an ableist political institutional context.

Paternalism is also possible within large advocacy organizations, where paid, professional advocates may have more authority over shaping the agenda than self-advocates (Petri et al., 2020, pp. 216-217). *User-led* advocacy organizations where self-advocates actively shape organization objectives are more insulated from these power dynamics; however, these organizations (such as People First Canada) have been more successful targeting their efforts towards capacity building and agenda formation at the community level, rather than policy advocacy at the national level (Hutchison et al., 2007). Again, this may reflect the ableism of existing political institutions, but it may also signal the greater capacity that professionalized advocacy groups emerging out of family-led advocacy currently have for direct engagement with policymakers.

It is important to emphasize that the interests of family-led advocacy and self-advocacy often overlap, such that even when advocacy organizations are not user-led, their efforts may still reflect the consensus objectives of self-advocates. First, this is tenable because family members provide vital support to people with IDD in overcoming numerous barriers, forging relationality and interconnectivity based on their knowledge of the preferences and desires of their loved ones. This is the basis for the concept of relational autonomy in processes of medical decision-making, where family involvement can help preserve the autonomous agency of patients who are unable to independently express their wishes (Ho, 2008). In much broader terms, theorists in both feminist and disability studies have invoked the concept of the relational self to critique oppressive notions of performativity and reimagine humanity and subjectivity in more inclusive terms (see Goodley et al., 2014). In a detailed study of IDD self-advocacy in Canada, Butler (2020) finds that relational autonomy is also established and strengthened through membership in user-led advocacy groups, where new avenues of support and interdependence are forged by and among people with IDD. We cannot expect policymakers without this relational experience of IDD to act as allies, nor can we expect them to intuitively divorce themselves from their biases.

Conclusion

Self-advocates and family advocates have unique and distinct roles to play in the political advocacy process. While family advocates are important, their positionality should not be conflated with that of self-advocates. However, they should also not be considered as barriers to effective self-advocacy. Instead, both family advocates and self-advocates can be conceptualized as necessary parts of a solidarity movement grounded in intersecting realities of IDD, which is based upon both the lived experience of IDD and the lived experience of care. Drawing from the concept of relational autonomy, a significant challenge for the IDD advocacy movement will be extending this interconnectivity and support to the most marginalized members of the community, including people with complex disabilities for whom family members may play a very direct role in advocating and communicating on their behalf, and also including people navigating the intersection of IDD with ageism, racism, sanism, and homophobia. For example, the current cohort of older adults with IDD is comprised of survivors of residential institutions, victims of forced sterilization and numerous other forms of trauma inflicted during an era when Canadian disability policy was more explicitly exclusionary (Hutton et al., 2017). Their lived experience with these most direct forms of ableism affords them a uniquely informed positionality in processes of collective identity construction and consensus building. The traumas that they have endured lends urgency to advocacy efforts to both inform and create policies to redress the forms of exclusion they have faced along their life course.

By amplifying the voices of those at the far margins, future IDD advocacy can signal the importance of positionality in informing policy solutions that effectively target barriers to inclusion. Given the multitude of voices and diverse positionalities within the IDD community, building consensus over practical strategies to advance the inclusion agenda will be challenging. Nonetheless, an important commonality between family advocacy and self-advocacy has been the high priority both place on building and defending the relational autonomy of people with IDD. Emphasizing this relationality remains a most promising avenue to confront the confounding paradox of mutually reinforcing able-isms in Canadian state and social structures. To this end, both self- and family advocates are necessary to ensure that change is operationalized in a way which both enhances leadership in agenda setting and serves to eradicate multiple forms of discrimination against people with IDD.

Key Messages from this Article

People with Disabilities. People with IDD must be included as decision-makers in the policies that concern them. Partnership between self-advocates, family-led and professional advocates must empower people with IDD as key decision-makers.

Professionals. Professionals can support relational self-advocacy by creating spaces for people with IDD and their families to speak out, share ideas and engage collectively to influence policy processes.

Policymakers. Canada's political institutions have inherently ableist biases. Designing and implementing policies to promote social inclusion requires engaging and empowering self-advocates in non-tokenistic ways (e.g., by ceding power in policymaking processes) to identify pressing issues and overcome ableist biases (e.g., valorization of independence, narrow definitions of personhood, treating IDD as a disease or personal tragedy) in policy processes.

Messages clés de cet article

Personnes en situation de handicap. Les personnes vivant avec les diagnostics de DI-TD doivent être incluses en tant que décideurs dans les politiques qui les concernent. Le partenariat entre les défenseurs de leurs propres intérêts, les défenseurs des familles et les professionnels doit permettre aux personnes vivant avec les diagnostics de DI-TD de devenir des décideurs clés.

Professionnels. Les professionnels peuvent soutenir l'auto-défense relationnel en créant des espaces où les personnes vivant avec les diagnostics de DI-TD et leurs familles peuvent s'exprimer, partager des idées et s'engager collectivement pour influencer les processus politiques.

Décideurs politiques. Les institutions politiques du Canada ont intrinsèquement des préjugés capacitistes. Pour concevoir et mettre en œuvre des politiques visant à promouvoir l'inclusion sociale, il est nécessaire d'impliquer et d'habiliter les auto-défendeurs de manière non-tokéniste (par exemple, en cédant le pouvoir dans les processus d'élaboration des politiques) afin d'identifier les problèmes urgents et de surmonter les préjugés capacitistes (par exemple, la

valorisation de l'indépendance, les définitions étroites de la personnalité, le traitement des DI-TD comme une maladie ou une tragédie personnelle) dans les processus d'élaboration des politiques.

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