JoDD Journal on Developmental Disabilities Volume 27 Number 2, 2022

Editorial: Special Issue on Families

Changing Social Welfare Provisions and Shifting Family Dynamics

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Introduction

This special of the Journal on Developmental Disabilities (JoDD) brings together articles centering on the experiences of families supporting children, youth, and adults with intellectual and developmental disabilities. Fifteen years had passed since JoDD published its first full issue focusing on the experiences of families (Condillac, 2004). As social work scholars with practice experience in Ontario and Quebec, we had concerns about the persistence of long-standing issues affecting families, as well as the emergence of new issues. It was the right time to revisit the theme of families in a contemporary context.

Special Issue Highlights and Editorial Process

We are pleased to present 11 unique and rich contributions from self-advocates, frontline practitioners and emerging and senior scholars that are underpinned by a life course lens to examine family experiences. The JoDD editorial team recommended we split this bounty into two special issues. The first special issue (Volume 27, Issue 2) includes six contributions, and the second special issue (Volume 28, Issue 2) includes five contributions. All contributions went through a double-blind peer review process. The articles were published on a first-come, first-serve basis, with our special issue introductions bridging articles contained in both issues.

Evident in many of the contributions is how the socio-political and economic decisions of the past continue to have cascading impacts and implications on present-day familial experiences. For example, Madeline Burghardt's contribution highlights how the institutionalization of family members with intellectual and developmental disabilities created intragenerational trauma that still resonates in the present day for families who often had complicated family narratives about having an "absent" child or sibling.

We also see in other contributions in this issue how changing – and often constraining - social welfare provisions have led to families requiring new skills and practices to support their family members, including relational advocacy (Shari Brotman and Daniel Dickson), service navigation

(Jeffrey McCrossin, Angela Marques Filipe, David Nicholas, and Lucyna Lach), and helpseeking (Gina Glidden). We also note that the wealth of experiences and knowledges acquired by families and parents are beginning to be valued and translated into direct support interventions, such as the emergence of innovative – but not uncontested – peer support models (Jeffrey McCrossin, Wendy Mitchell, Franceska Grantzidis, Angela Clancy, and Lucyna Lach).

When we set out to put together our special issue, little did we know that our editorial process would take place amidst a global pandemic - a new force of change that had very profound implications for families, especially for those supporting loved ones with intellectual and developmental disabilities. Three articles in the second issue highlighted how the COVID-19 pandemic reorganized the landscape that families must navigate, including access to publicly funded services and education. Maude Champagne, Rachel Willis, and James Reynolds highlighted how the COVID-19 pandemic resulted in challenges for families supporting children and youth impacted by Fetal Alcohol Spectrum Disorder. Mélina Rivard, Céline Chatenoud, Charlotte Magnan, Manuelle Beuchat, Catherine Mello, Heather M. Aldersey, and Chun-Yu Chiu discussed the impact of the interruptions of early intervention services for families with children with autism in Quebec. Further, Nicole Luymes, Brianne Redquest, Lauren Rollo, and Paula Fletcher interviewed mothers on their autistic children's school experiences before the pandemic and thoughtfully connected their analysis to the present-day context.

We also received several arts-based contributions including a moving co-constructed poem exploring the meaning of family written by a mother-scholar Shari Brotman, her son David Kinloch, and his formal caregiver Stephen Thomas. In another arts-based piece that includes a link to a digital story, Patty Douglas, Katherine Runswick-Cole, Penny Fogg and Sara Ryan explored how (m)others are made to feel *mad* in professional encounters, making innovations in narrative research and digital re-storying. Through arts-based research, Jeffrey McCrossin, Angela Marques Filipe, David Nicholas and Lucyna Lach offered a textually and visually rich allegory of navigation to illustrate the concept of care, while Christina Yarmol's arts-based contribution centred the voices of self-advocate artists and their visually stunning art contributions.

The contributions contained in these special issues use identity first language or people first language depending on authors' orientations. In this way, our interdisciplinary issues highlight the diversity of the language used to recognize the positionality of disabled people and people with intellectual and developmental disabilities. We appreciate the tension that language use brings with it (Titchkosky, 2001), and we are pleased to include the work of scholars and artists reaching for new ways of describing complex tensions and relationships.

We hope the articles in this double special issue provide fodder for further examination, analysis and critique of the ways social welfare provisions are shaping and influencing the lives of families, just as families are reshaping and influencing dominant meanings, practices and possibilities.

Extending Gratitude

This collaborative work was also spurred by the ethos, mandate and legacy of the *Journal on Developmental Disabilities*. JoDD has been publishing open access scholarly work targeting support professionals and students in the field of developmental disabilities for over 20 years,

largely centering on the local Canadian context in these publications. As social work academics, we understand the importance of having accessible and local research to inform the work that we do and are pleased to contribute our special issues to these ongoing conversations.

As emerging scholars, we were deeply grateful for support and mentorship from Dr. Maire Percy, Chief Editorial Board, and the administrative support from Jennifer Shaw. We are also grateful to peer reviewers who contributed reviews of the rich and diverse manuscripts contained in these two special issues.

References

Condillac, R. (2004). Editorial. Special Issue on Families of Individuals with Developmental Disabilities. *Journal on Developmental Disabilities*, 11 (1), p.vii.

Titchkosky, T. (2001). Disability: A rose by any other name? "People-First" language in Canadian society. *Canadian Review of Sociology/Revue canadienne de sociologie*, *38*(2), 125-140. <u>https://doi.org/10.1111/j.1755-618X.2001.tb00967.x</u>