



Family Matters: Exploring the Impact of Employment Loss for People with an Intellectual Disability during the COVID-19 Pandemic

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Background

Families play a critical and ongoing role in the lives of their family members, including assisting, encouraging, and supporting them to secure and maintain employment. While there has been much research and inquiry into the impact of the pandemic on the employment status of job seekers / employees with an intellectual disability, much less focus has been directed to identifying the impact of the pandemic on families with the associated loss of employment by their family members with an intellectual disability.

Concerns about the Coronavirus and health have left many persons with an intellectual disability conflicted between the need to self-isolate at home and the need to be economically secure. These concerns are shared by families, particularly in situations where the family member with an intellectual disability is with their family. In situations where the individual is residing outside the family home, concerns and stressors also persist. For example, the nature and frequency of family visits is impacted, some individuals may return to living at home due to economic reasons, while others may have to move to remotework.

Family Matters: Exploring the Impact of Employment Loss for People with an Intellectual Disability during Covid-19 aimed to better understand the current and future support needs of families whose adult family members with an intellectual disability experienced employment disruption as a result of COVID-19 (either securing and/or maintaining employment).

The 2020 Statistics Canada survey, "*Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities*," (1) reveals that over one-third of participants with disabilities or chronic health conditions indicated that they have experienced temporary or permanent job loss or reduced hours due to the pandemic. An internal survey conducted by Ready Willing and Able (RWA, 2020) of its community employment partners revealed that 80% reported a substantial number of the individuals with disabilities they support (25%+) were laid off/furloughed.

Other research findings from the Ready Willing and Able survey indicated:

- Businesses were uncertain as to how to best support employees with an intellectual disability who were working from home.
- Parents were also concerned about the implications of employment during COVID-19 due to their family members' health and safety and potential transmission to others if their family member still lived at home.
- Families were also concerned about access to needed on-the-job supports, stability of employment opportunities during COVID-19 and potential impact on health benefits.

This report contains an overview of the methodology, findings, and reflections and nextsteps.

Methodology

Using qualitative research methods, this project aimed to:

1. identify the specific impacts of the pandemic on job seeking and employment loss on families
2. better understand how these impacts affected families and their relationship to their family members' with disabilities
3. identify ways in which families coped with the impact of employment loss due to COVID-19
4. identify supports and services that were helpful (or not available) to assist in mitigating the impact of the pandemic

Participant recruitment and demographics

Participants were recruited through Inclusion Canada's federation members by sending out recruitment material and project information, as well as posting on Inclusion Canada's social media. Participants were drawn from across Canada; including Alberta, Ontario, New Brunswick, Quebec, Manitoba, and Saskatchewan. All participants identified as family members of people with an intellectual disability whose employment was disrupted due to COVID-19, or as a person with an intellectual disability whose employment was disrupted due to COVID-19.

Data Collection

To better understand the experiences of families, twenty-nine participants, both family members and persons with intellectual disabilities, from across Canada participated in two focus groups to share their experiences. Nine people were selected from the focus groups to participate in a one-on-one interview and were compensated with an honorarium for their time.

Two focus groups were held in February 2021; 26 participants took part in the first focus group, representing 21 families, while 5 adults with intellectual disabilities participated in the second focus group. Nine participants from both focus groups participated in an additional one on one interview to provide greater detail on their experience and the impact of employment disruption on their lives.

Findings

Covid-19 has profoundly impacted individuals with intellectual disabilities and their families as many people with an intellectual disability have experienced employment loss or disruption. As many supports, activities, and services were interrupted or simply unavailable due to the pandemic, families were required to find alternatives for their family members with intellectual disabilities. For some families, this had a major impact on their lives and strained their relationship with their family member.

"These days, we (parents) work at spelling each other off to get our work done to make sure our son isn't just parked in front of the TV. Time that used to be available to us for creative work has certainly been curtailed. Keeping his mind active, keeping him in front of interesting things to do and experience falls entirely to us."

In some families, parents shared that the responsibilities fell to one parent over the other due to their own employment, family dynamic, and other factors. As a result of their family member's employment disruption, families described feeling:

- hopeless

- scared
- worried
- overwhelmed
- frustrated
- stressed

During this time, families also described feeling an increased sense of responsibility as their son or daughter looked to them to provide routine, structure, and new opportunities.

With employment loss due to COVID-19, self-advocates experienced:

- lack of connection
- uncertainty
- loss of routine
- no independence
- loss of purpose
- difficulty maintaining relationships
- difficulty connecting with family
- lack of socialization

Employment disruption for people with an intellectual disability emphasized the critical role that meaningful and inclusive employment plays in the wellbeing of the entire family unit. Without a job to go to, many families described the heavy weight of responsibility as they looked for activities to fill their adult family members' days.

“We all know being gainfully employed is so important- to be productive, to contribute to society, to gain skills and to socialize with others while doing this. We have seen this in our family situation. Our daughter expresses so much joy and pride when she brings home that paycheck [...] and it is never a struggle to get her out of bed to go to work. She loves what she does and loves to be with others.”

Families described the multiple losses experienced by their family member as a result of unemployment, including loss of routine, skills, independence, social connection, and life purpose.

“Employment matters. Purpose matters. Our lives ALL matter. Some just need more help and support than others to achieve this, but it is a basic need that needs to be fulfilled, especially for this population.”

Connecting with families across Canada to better understand the impact of COVID-related employment disruption revealed a critical need for enhanced supports, services, and advocacy. Additionally, hearing directly from persons with intellectual disabilities who experienced employment disruption emphasized the importance and value of employment to one's life purpose.

Key Findings

1. Successful and meaningful employment has an immense impact on the entire family unit due to the value a job brings beyond financial gain. A job provides structure, routine, inclusion, independence, relationship building, contribution to community, and recognizing worth.

2. Many families were heavily involved in supporting their family member to obtain employment and succeed on the job. Families identified a need for greater access to employment supports, job coaches, and employment resources in their communities.
3. The personal wellbeing of parents (social life, mental health, finding time for hobbies, etc.) has been negatively affected as significant energy and resources have been spent on ensuring their family member has access to meaningful activities throughout the day that build and maintain employment skills.
4. Families expressed worry that their family member's job would not be offered back to them and instead be filled by someone without a disability.
5. Individuals with intellectual disabilities experienced significant uncertainty regarding job security, felt a lack of connection to others, and some expressed feeling as though their life no longer had purpose.

Additional Key Findings

While families indeed expressed stress, fear and worry as a result of their family member's employment disruption, they also identified several positive aspects including:

1. Spending good quality time together
2. Enjoying being together under one roof
3. New opportunities for their family member to improve skills
4. Parents learned new things about their family member that they had not known previously
5. Parents learned how important employment is to their family member's sense of identity, purpose, relationships, and their place in the broader world

Reflections and Next Steps

Considerations for future programs and policies

Through hearing the lived experiences of families and persons with intellectual disabilities who have experienced employment loss or disruptions in job searching, Inclusion Canada has gained additional insight on the supports that families need during COVID-19 and beyond.

Many parents expressed that their family members' employment had been completely dependent on their efforts and their personal connections to jobs and industries. In fact, a few families emphasized that they did not know where to look for resources and supports to help their child find and maintain inclusive and meaningful employment in their communities.

While provincially and federally funded employment supports exist across the country, there is clearly continued work to be done to ensure families and their family members know about available employment supports. Further, to continue to develop, refine and enhance employment supports that meet the unique needs of people with an intellectual disability and their families across the country, organizations must:

1. Work with families across Canada to educate them on the inclusion movement, supports offered, and the resources and other supports that currently exist in their communities.

2. Promote opportunities for *inclusive, competitive and meaningful* employment for persons with an intellectual disability through initiatives such as Ready, Willing and Able.
3. Collaborate with other local and provincial/territorial organizations to strengthen and coordinate employment efforts in their communities.
4. Understand the factors that families face which can hinder successful employment for their family member with an intellectual disability such as inconsistent work hours, lack of job coaching or personal support, limited access to transportation, etc.

Building local capacity within existing delivery systems is also critical. Families identified the following needed supports:

1. Career development information to help families support and encourage their family members' to find and maintain inclusive employment.
2. Job coaches to facilitate natural supports and help to find and sustain employment – from getting to know their family members' abilities and strengths, to assistance in applying and interviewing for jobs in a career they are interested in pursuing, to on-the-job supports when needed.

Families emphasized that witnessing their family members' experience employment disruption has intensified the meaning of employment in their lives; it means much more than having a job. Employment means being among colleagues, having others recognize their purpose and abilities, being able to contribute to the community, and building relationships with allies who advocate for people with disabilities.

“Our family members bring something to the workforce that cannot be monetary value. They bring a culture and a change to that workforce that really emphasizes compassion and empathy.”

Bibliography

Statistics Canada. (2020). *Impacts of Covid-19 on Canadians Living with Long-term Conditions and Disabilities*. Statistics Canada.