

RADICAL Inclusion

August 2021

JOHN HUMPHREY CENTRE
for PEACE and HUMAN RIGHTS

EXECUTIVE SUMMARY

From September - December 2020, a team of thirteen people worked collaboratively to engage in a review of human rights in Alberta as it relates to the Convention on the Rights of Persons with Disabilities. The majority of this team was made up of folks who experience disability personally. We also had representation from others who had disability within their family.

The following report is an outcome of the critical human rights issues identified that are impacting people living with disability in Alberta. Recognizing the Government of Canada is working to operationalize the rights of people living with disability, the reality is that rights are being contravened right now and **there is an urgency for change; we are in crisis.**

Our goal with this report is to make submissions to the UN Treaty Body responsible for the rights of persons with disabilities as well as other relevant government bodies in Alberta and Canada who have responsibilities to bear in advancing and promoting these rights.

The struggle for the rights of people living with disabilities in Canada is wrought within a historical system of eugenics and dehumanization. The systems in Alberta, which this report speaks from, are set up to further disable and disenfranchise. If the rights of people with disabilities are advanced and upheld in our communities however, we can make fundamental shifts to strengthen our economy and society. **The challenge ahead is to deepen the understanding of ableism and to break down the barriers to accessing rights in a dignified manner.**

ABOUT US

RADICAL INCLUSION

Radical Inclusion was developed as an effort to create a strong network of people with lived experience in disability to strengthen voices, provide their perspective, and be a force for change. The goal of the effort was to deepen discussions and knowledge on disability and human rights while building strategies for action and education. Ultimately, Radical Inclusion's primary goal was to develop and submit a report to the United Nations' Committee on the Rights of Persons with Disabilities and to give the perspective of people who live it every day.

This group was facilitated by the John Humphrey Centre for Peace and Human Rights with funding support from the Edmonton Community Foundation.

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TABLE OF CONTENTS

Financial Barriers	1 - 5
Issue Background	1- 3
Contraventions	4
Calls to Action	5
 Employment and Careers	 6 - 9
Issue Background	6 - 7
Contraventions	8
Calls to Action	9
 Housing	 10 - 14
Issue Background	10 - 11
Contraventions	12
Calls to Action	13 - 14
 Healthcare	 15 - 19
Issue Background	15 - 16
Contraventions	17
Calls to Action	18 - 19
 Justice and Law Enforcement	 20 - 24
Issue Background	20 - 21
Contraventions	22
Calls to Action	23 - 24
 Conclusion	 25
 Anecdotal Appendices	 ~ iv ~

FINANCIAL BARRIERS

Issue Background

Many people living with disabilities in Alberta experience poverty.

In Alberta, the income support program is called Assured Income for Severely Handicapped (AISH). Their mandate is to provide financial and health benefits for eligible Albertans with permanent medical conditions that prevent them from earning a living. The Radical Inclusion team's lived experiences provided numerous examples which justify this program is in need of drastic improvements that focus on dignity and rights.

Current income support systems lack clarity in how they can be accessed and approved. Furthermore, reporting requirements and income thresholds deter and/or prevent people with disabilities from pursuing work or careers because additional income and subsidies are clawed back when thresholds are reached.

Radical Inclusion participants expressed that people are kept in a state of poverty. They maintain AISH and comparable programs do not enable independence and/or autonomy in earning money, nor do they facilitate building a more secure and stable life for themselves and/or their families. Furthermore, participants reported that in order to qualify for any assistance, they must present themselves as a victim or as incapable, using language that only describes their worst case scenarios which is not a true representation of their day to day lives.

While Alberta has one of the most generous income support programs in Canada, the monthly amount allocated to individuals

with disabilities does not account for the actual costs of living. The maximum amount of AISH is \$1,685 per month which, considering true economic costs and realities, is not enough to be able to live in a dignified manner and to meet one's basic costs of living.

If AISH was a regular full time job, the hourly rate would be \$9.72/hour while minimum wage in Alberta is \$15/hour. If one does gain employment, there is an income exemption which only allows for an additional net income of \$1,072/month to be earned before clawbacks. The maximum one can take home with AISH and employment income is \$3,226 monthly. The average cost for a one bedroom apartment in Edmonton is \$1,500-\$1,600/month which varies throughout the province. According to the Assured Income for the Severely Handicapped (AISH) Caseload report from the Government of Alberta, of 69,977 AISH recipients in Alberta, only 6.4 percent, or 10,982 are employed.

There are costs to disability which are not factored into the income supports such as the costs of equipment or supplies that are needed. While funding is provided through the Alberta Aids for Daily Living program (AADL), it often doesn't cover the full costs and frequently has limitations around what or how much one can access in a year. A \$500 extra cost for someone needing medical supplies can place them in financial jeopardy. Additionally, if a person with a disability on income supports can't afford upgrades on equipment, or medical supplies, authorized by AADL, their independence in their home and community may be marginalized.

An additional element to income support is that if an individual living with disability becomes involved in a relationship, the benefits provided will be reduced and the individual becomes financially dependent on their partner. Many people living on income supports are left with the decision not to get married because they are afraid of losing their benefits. Marriage to someone on income supports creates an unequal partnership and has the potential to cause stress and strain on the relationship. This also impacts choices made around having children.

Income support for people with disabilities living in Alberta limits our ability to achieve “Living Independently and Being Included in the Community” (Article 19). These supports do not cultivate a spirit of innovation, growth, motivation and empowerment.

The costs of disability are more than financial, they include costs on our relationships with partners, family and friends. There are serious, unacknowledged, emotional and physical costs. Families often will carry the burden of those costs, including care. Families can face barriers in being able to work full time and the individual living with disability is unable to gain independence from them. For those that do not have this familial support, there is an additional burden of isolation.

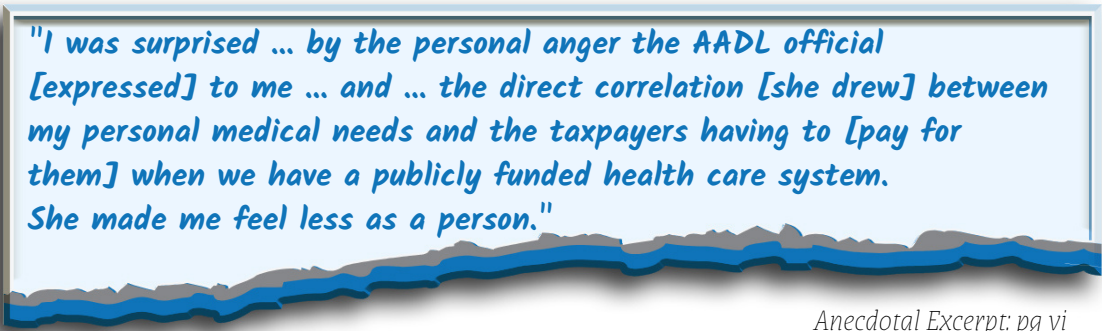
Many Radical Inclusion participants report feeling overly monitored and policed by income support mechanisms, specifically but not exclusively AISH; many express privacy concerns. Those who receive AISH, are subject to heightened surveillance of their finances and daily decisions. There is a requirement to provide a high level of information to government officials (e.g monthly pay statements, yearly audit of bank statements, and personal and financial information from spouses) that impacts the dignity of the recipients. A better balance between people’s needs and income support programs must be found.

Radical Inclusion participants expressed concern whether government officials, who make determinations about who is eligible to access income supports, are qualified to make those decisions. Overwhelmingly, Radical Inclusion participants felt that they are repeatedly required to prove they are “disabled enough” to justify receiving the bare minimum of income assistance, despite repeatedly providing comprehensive personal, medical and financial information. They also question the medical capacity of government officials who make determinations and their knowledge to translate and understand this information.

FINANCIAL BARRIERS

Rights that are currently being contravened under the Convention on the Rights of Persons with Disabilities (CRPD) and other Human Rights Treaties

- CRPD Article 17: Protecting the Integrity of the Person
- CRPD Article 19: Living Independently and Being Included in the Community
- CRPD Article 20: Personal Mobility
- CRPD Article 28: Adequate Standard of Living and Social Protection
- International Covenant on Civil and Political Rights Article 17
- Universal Declaration of Human Rights Article 12.



"I was surprised ... by the personal anger the AADL official [expressed] to me ... and ... the direct correlation [she drew] between my personal medical needs and the taxpayers having to [pay for them] when we have a publicly funded health care system. She made me feel less as a person."

Anecdotal Excerpt: pg vi

CALLS TO ACTION: FINANCIAL BARRIERS

- We suggest the AISH program undergo a name change to reflect appropriate language; for example Alberta Disability Income Supports program.
- We call upon the provincial government in Alberta to meaningfully include people with disabilities in re-writing policies and programs regarding income support. Independent decision making and self-regulation must be essential to the framework of the program.
- Global assumptions and categorizations must not be made. An income support program for people with disabilities must accommodate an individual's spectrum of needs rather than label all of us as incapable, fully dependent or fully independent.
- Clear, transparent standards and protocols for determining who is eligible for income supports need to be established and those who make those decisions need training. We recommend that standards be set and developed that allow medical professionals in collaboration with their patients to determine their eligibility. Government officials without medical knowledge (or direct lived experience) must not be responsible for making eligibility decisions for people with disabilities. Leaving decisions of who is "disabled enough" cannot be left to government officials who are often short term and who may not be grounded effectively in the realities of disability.
- Medical professionals need standardized awareness and competency training to ensure they have clear guidelines and understanding to make decisions regarding income supports for people with disabilities.
- We recommend education around ableism, discrimination and human rights for all government employees who work for disability support programs.
- Federal, provincial and municipal income supports must be coordinated to the benefit of the recipients. For example, eligibility and income thresholds are not standardized between all programs and/or branches of government.

EMPLOYMENT AND CAREERS

Issue Background

Individuals living with disability need opportunities to be independent, both financially and personally. While higher education may be available to them, opportunities to develop careers are limited because they are often overlooked in the workplace. They may not be considered for greater responsibilities or higher paying jobs due to discrimination. The Radical Inclusion team believes assumptions are often made, including:

- they may not be able to do the job;
- they may need too many accommodations if hired;
- they cannot be relied upon to complete the job if hired;
- they will require too many sick days; and,
- they will constantly need to be supervised.

If people with disability do make it through the job application process and are invited to interview, accessibility often becomes an issue. They may not want to self-identify on their resume, for fear of elimination at the outset, and once they are given an opportunity to interview they often encounter barriers to the building, office, location of employment or equitable and accessible methods of communication. Some participants expressed a lack of clarity around who bears responsibility for providing accessibility aids; the employer or the employee?

People living with disability need the chance to develop their career or pursue meaningful employment and are often placed in positions where there are little or no opportunities to grow (underemployed).

Employment agencies specifically for people with disabilities often do not recognize the desire and ability to excel and be challenged. They will often place clients with disability in minimal wage/skill positions where little or no accountability is necessary or expected and there is no opportunity for advancement in the company. People with disabilities are often a commodity for funding for agencies, often have boundaries of participation such as age or IQ, and are not centered around the person and their development.

Participants described situations where both employers and disability employment agencies underestimated and underemployed people with disabilities. Participants felt there were expectations that they should be thankful for any job they are hired for regardless of how they feel about it. These factors lead to financial limitations, self-respect issues, and the person's ability to grow and contribute in society.

People living with disability have reported having to undertake capacity tests (eg. IQ tests) that often challenge their dignity, or are told they do not qualify for specific disability employment supports, based on the type of disability. Participants reported feeling that they were hired as a token or as a way for a company to satisfy diverse hiring quotas. Employers sometimes expect to receive grants or subsidies, in order to pay the wages of people with disabilities, unlike their able bodied counterparts who are hired and paid based on their merit and skill sets alone. More than one participant described being asked by their employer to search for job grants/subsidies based on disability to keep or maintain their employment.

EMPLOYMENT AND CAREERS

Rights that are currently being contravened under the Convention on the Rights of Persons with Disabilities (CRPD) and other Human Rights Treaties

- Article 5: Equality and Non-Discrimination
- Article 8: Awareness-raising
- Article 16: Freedom from exploitation, violence and abuse
- Article 27: Work and Employment

Rather than hiring people with disabilities, we are frequently expected to volunteer - not allowing us the same level of respect and remuneration our "able-bodied" counterparts earn.

We have equal skill sets, levels of education and work ethic and we expect the same opportunities to advance our careers.

CALLS TO ACTION: EMPLOYMENT AND CAREERS

- Call for a provincial review of employment standards and practices for both employers and disability employment agencies, both private and non-profit, led by a committee of people with disabilities, with the intent to develop ways to educate employers and agencies in more inclusive hiring practices and their legal obligations. This committee will examine different models of employment practices that are truly and meaningfully accessible and include all people in the workplace. This committee will develop recommendations for policies and practices that will be followed and mandatory in Alberta.
- Promote increased and sustainable funding for mentorship and self-advocacy programs, giving people with a disability a better chance to voice their needs and concerns without prejudice.
- Shift away from short term project based funding for employment and mentorship programs and move to long term sustainable program funding with measurable accountability.
- Challenge disability employment agencies to stop under employing their clients and promote people with disabilities (with qualifications) into leadership roles.
- Call for granting programs to allow people with disability to develop and grow their own businesses.
- Provide grants and subsidies to employers for accommodations of people with disability.

HOUSING

Issue Background

Access to available, accessible, adequate and affordable housing for people living with disability is extremely limited in Alberta. Currently, there is no ongoing commitment from the government to ensure accessible housing exists within the housing market. Most efforts are made within the context of social housing, which assumes that people with disabilities all have the same needs (for example, all segregated into one housing development or cannot afford market rent). Wait lists to get an accessible place can take years and there is no choice in what housing you have access to. This creates a situation where once one finds housing, it can become a prison. There are few alternatives out there and even if one finds housing, it does not mean it meets their accessibility needs. People become isolated and hidden in their homes.

It is commonplace for people to be denied rentals when the landlord discovers a person applying is living with disability and/or receiving disability income support (e.g., AISH). People often do not know or understand their rights and what avenues exist to address discrimination; which is difficult to prove. The process of seeking remedy through human rights complaints is a draining and long process which does not address these barriers.

Pets are often something that people need to support mental health and prevent isolation. Having a pet is again not a common option available to people living with disability as it places increasing barriers to accessing housing. Some disabilities require service animals which are not well understood or accommodated.

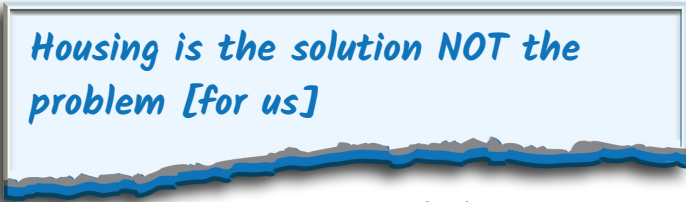
When one's housing is inaccessible, it not only affects one's ability to have stability, security and dignity; it affects relationships with family and friends who also don't have accessible homes.

The lack of accessible and adequate housing further creates a dependency relationship on caregivers and family and further disables.

While there are some income-tested subsidy programs to allow for modifying homes, the income thresholds are normally low. The amount of \$7500 - \$15000 over 10 years does not reflect the true cost of accessibility modifications. For example, kitchens and bathrooms are extremely expensive adaptations. If one does not have their own money, there are limitations to their ability to adapt and carry the costs of disability.

Inaccessible housing significantly impacts a person with disability's ability to reach their full potential. The energy consumed navigating an inaccessible home directly limits one's ability to also engage in employment, taking care of the home, or studying, for example.

The Radical Inclusion team expressed frustration when looking for accessible, affordable housing. Accessible and affordable housing does not appear to be advertised in areas average people look. A few participants mentioned that they assumed they would look for housing like everyone else does (eg. rental guides, internet). They did not think to look to charities or nonprofits in order to find housing. There does not appear to be a registry of available, accessible and affordable housing. (Note: not every person who requires accessible housing requires affordable housing.)



Housing is the solution NOT the problem [for us]

Anecdotal Excerpts: pg xvii

HOUSING

Rights that are currently being contravened under the Convention on the Rights of Persons with Disabilities (CRPD) and other Human Rights Treaties

- Article 5: Equality and Non-Discrimination
- Article 19: Living Independently and Being Included in the Community
- Article 28: Adequate Standard of Living and Social Protection

I competed in the 1988 Paralympics in Korea, in my young mind, if I could play wheelchair basketball internationally in the big city, I should be able to find somewhere to live [and] I was excited to start my life ...

Anecdotal Excerpts: pg xvi

... the next 15 years were a struggle and at the root of [that] was housing. I looked for housing [but] might find 2 or 3 choices; always inadequate [to suit my needs] and in random [at times even unsafe] locations.

... wheelchair accessible units rarely come available for rent ... [IF we actually find something] no one moves out because there is literally nowhere else to go.

Anecdotal Excerpts: pg xvii

CALLS TO ACTION: HOUSING

- We call for the provincial and municipal governments to consult with people living with disabilities to build more efficient, accessible, affordable housing and/or require builders and developers to widely advertise their units in public spaces as well as specialized organizations and programs.
- Provide subsidy programs for the private sector builders and/or developers for additions and/or improvements for older buildings.
- Flexible and accessible subsidy programs which allow people living with disability to be able to modify their homes without carrying a major financial burden. Although some programs exist, they do not reflect true costs and/or timelines (basically the current reality).
- The current Rapid Housing Initiative from the federal government is a commitment to address homelessness. A disability lens must be applied to this at the front end. All shelters or new builds in this response must be accessible. Currently in Edmonton, the shelters available do not accommodate effectively for people living with disabilities. If funding is being provided for this and new builds are being created, 100% of these new builds need to be barrier-free.
- In all housing efforts for people living with disability, an approach must be taken that ensures wrap-around supports for people. Creating housing in a manner that has in-house supports and services enables dignity but also efficiency and access.
- Just like the walkability index, new builds and builders must integrate an accessibility index that must be publishable for the community to see and assess. This could include access to stores, doctors and other key necessities that people living with disabilities need access to. Additionally, consider the development of visitability Index for housing to support family and community connection.
- Prioritize and fund programs for education and development of tenant's rights with a focus on disability. Plain Language is needed to understand their rights and responsibilities in housing.

CALLS TO ACTION: HOUSING

- Mandate that all housing subsidies, whether federal, provincial or municipal, are tied to the individual and NOT to a specific location or rental.
- Embed protections for people living with disability within landlord and tenancy acts to ensure there is thought and attention paid to the specific needs of people living with disability and that consider emergency measures such as fires as well as maintenance and safety procedures. This information from each landlord should be provided to tenants as policy.
- Each person who lives with disability should have the choice to have a personal advocate with them in meetings related to housing matters. This assures respect and that all voices are heard, without any level of control etc, and ensures that there is common understanding.
- It is important for the provincial government to make it easier for Albertans to access the affordable housing and housing stability supports they need by creating clear and consistent parameters for funding and available programs. Transparency is a key for making Albertans in the disability community, who require clear and in Plain Language rules to plan and invest in the efficient operation and development of affordable housing.
- Call on the province of Alberta, and other provincial and territorial governments, to ratify and implement the Convention on the Rights of Persons with Disabilities and create their own accessibility act to support people living with disabilities.
- More effort to transition between stages of life (e.g. from home to university, from university onwards) and creating connection points to know where to access housing. Strengthen knowledge of who to contact, what to do and create community connections.
- Regular inspections on homes to ensure landlords are following AHS protocols. Too many landlords are negligent and unsupportive, and there should be an accountability process in place.

HEALTHCARE

Issue Background

Although healthcare is free in Canada, the provision of healthcare is overall not fully accessible, both in terms of accessible spaces and in terms of medical practitioners who are educated in disability rights. Some medical professionals (in all areas) lack knowledge and the ability to assist and accommodate, and they can be demeaning and dismissive. A lack of consistency exists between practitioners and the way they provide service is also a barrier to seeking support.

As children, people with disabilities often have specialists to follow up with them through the many medical issues they experience. When the time comes to transition out of pediatric services, adults with lifelong disabilities are faced with trying to find doctors with the same level of expertise to treat them. Some pediatric specialists have volunteered to carry adults on as patients; however, this is a choice for them and often adds to their workloads.

While medical supplies and equipment can be accessed by people with disabilities through the Alberta Aids to Daily Living program (AADL), this comes with many issues. One of the major issues is that AADL was first created for Seniors and not to accommodate people with disabilities who have very specific and unique needs for ongoing and upgraded supplies and equipment. These mobility equipment and medical supplies come with conditions, such as the need to be continually re-assessed by specialists who are difficult to get appointments with. Additionally, equipment provided through government programs is often in bad shape, old and inadequate; so it does not serve the person's needs. In turn, because some medical practitioners are not trained to understand disability, the equipment provided makes people even more dependent on others; for example, not providing equipment that people are able to use independently.

People with permanent disabilities have a lifelong journey with habilitation; medical practitioners work from the approach of rehabilitating people rather than working with people with disability and listening to their lived experiences to support them in maintaining their independence.

People experiencing sensory disabilities often encounter inaccessible spaces and practitioners who do not understand or know how to provide appropriate accommodations. This means important information cannot be received and/or understood properly. It is also very difficult to find information provided in Braille, and there are usually little to no accommodations provided for people with loss of hearing. This can have serious consequences for people in the healthcare system. The COVID-19 pandemic has brought these challenges to light and made them clear; the lack of accommodations in hospitals, clinics and pharmacies creates barriers to people living with disability to being informed and treating themselves. These lack of accommodations can be fatal.

HEALTHCARE

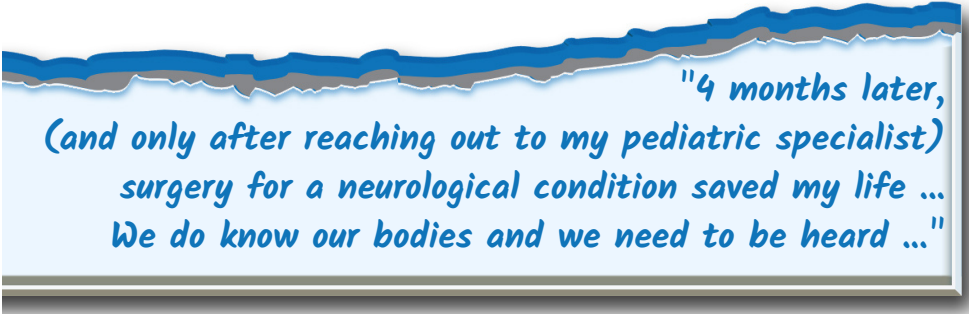
Rights that are currently being contravened under the Convention on the Rights of Persons with Disabilities (CRPD) and other Human Rights Treaties

- Article 5: Equality and Non-Discrimination
- Article 9: Accessibility
- Article 19: Living Independently and Being Included in the Community
- Article 21: Freedom of Expression and Opinion, and Access to Information
- Article 25: Health
- Article 26: Habilitation and Rehabilitation



"My family doctor said I was out of shape, when I began falling during transfers ... in 30+ years I had not fallen - I said something isn't right"

Anecdotal Excerpts: pg xiii



"4 months later, (and only after reaching out to my pediatric specialist) surgery for a neurological condition saved my life ... We do know our bodies and we need to be heard ..."

CALLS TO ACTION: HEALTHCARE

- We call on provincial governments, medical associations, and universities/colleges to make education and training mandatory for doctors and other medical professionals on disability rights, accommodations, equity, empathy and dignity.
- We call on provincial governments to consult the disability community to improve accessibility for doctors' offices, hospitals and other medical spaces.
- We call on provincial governments to assume responsibility for providing services, information in Plain Language and access to equipment and supplies so that we can move away from overly restrictive regulations and funding models to a system which promotes independent and healthier living. We call on all levels of government to uphold the accommodations as laid out in the Eldridge case.
- We call on provincial governments to prioritize the establishment of disability health centres that can act as hubs to access all services and supports in one place and promote habilitation as opposed to rehabilitation.
- We call on the federal/provincial government to provide subsidies to businesses to be able to afford the costs of creating an accessible medical space/office (for example an exam table can generally cost around \$3,000, whereas a table that can move up and down can cost \$10,000).
- We call on the provincial governments to develop and mandate communication protocols between doctors and other medical professionals so they work holistically with their patients. This communication protocol needs to include an option to sign a FOIP/Consent form upon their first appointment with a medical practitioner (it should not be something people have to ask for). For those who have pre-existing relationships with doctors and other medical professionals, a reasonable timeline should be established for ensuring that all patients have been presented with this option.

CALLS TO ACTION: HEALTHCARE

- We call on all governments in Canada to acknowledge people with permanent disabilities and thereby reduce their administration costs by not forcing people to apply and re-apply to programs they've already been approved for. For a positive example, recently in Alberta, to receive a disability parking placard, people with permanent disabilities now only have to provide medical proof once, then re-register every five years which is similar to licensing requirements for everyone. Medical proof should not have to be provided to every government department separately. Considering the funds spent on disability, there is a need for a disability focused department to act as one central intake and information point. This way the medical proof provided is able to be considered across all government Ministries and Departments. This would be a cost savings to administration.
- We call for the implementation of a system to ensure all health care professionals have easy access to an updated full and historical medical history of each individual with a disability. This would remove the requirement of the individual or another person who was with them from having to provide history repeatedly, thus removing a huge weight off of whoever was asked to give the history. The client must have access to their medical file and this needs to be readily and easily available.

JUSTICE AND LAW ENFORCEMENT

Issue Background

Access to justice and engagement with the justice system and law enforcement poses significant challenges to people living with disability. Lawyers, judges, emergency response, law enforcement and non-profits all lack an informed understanding and knowledge about ableism and the needs of people living with disability. This extends to the public sector as well. For example, the Office of the Public Guardian and Trustee, whose mandate is to provide services, tools and support for personal and financial matters to vulnerable Albertans, have also been known to be demeaning and disrespectful and often fails to provide proper accommodations. We must understand and acknowledge that the realities for people living with disabilities is a result of our history which is embedded in eugenics, ableism and exclusion.

Some of us have reported that lawyers can often be dismissive and do not centre on the goals and needs of the clients. They do not seek to provide accommodations to allow engagement in the justice processes.

Radical Inclusion questions the training and education of law enforcement. Participants revealed experiences that indicate that law enforcement lacks proper training and education. Individuals may avoid reaching out for help due to fear. It was expressed that law enforcement does not seek to understand and does not fully hear the voice of people with disability and diminishes their experience of violence.


The current program of Legal Aid in Alberta is inaccessible to those living on AISH. AISH recipients receive \$1,685 per month and the qualifying income threshold for Legal Aid is \$1,668. Mere dollars blocks people living with disability, who are already struggling with poverty and the costs of disability, to access legal support. This places access to justice outside of the reach and capacity of people with disability relying on AISH income. Legal Aid Alberta does not consider the realities of the costs of living and disability.

People with disabilities living under guardianship have reported limited access to legal advice and representation. It is at the discretion of the guardian if legal representation is to be involved. Radical Inclusion questions whether people with disabilities living under guardianship are truly considered and represented as full citizens.

JUSTICE AND LAW ENFORCEMENT


Rights that are currently being contravened under the Convention on the Rights of Persons with Disabilities (CRPD) and other Human Rights Treaties

- Article 5: Equality and non-discrimination
- Article 8: Awareness-raising
- Article 13: Access to Justice
- Article 19: Living Independently and Being Included in the Community



"As an independent adult with disabilities ... I had the courage to fly overseas alone. [At the airport I was] forced to wear a derogatory sign identifying my disability to all"

Anecdotal Excerpts: pg xii



"After multiple runarounds and failed attempts to address this discrimination, I was told 'the only way to stop justice from being obstructed for persons with disabilities is for ME to change parliament???'"

CALLS TO ACTION: JUSTICE AND LAW ENFORCEMENT

- We call for an immediate change to the Legal Aid eligibility in Alberta. Those living on AISH should be automatically considered as eligible for legal support. However the income threshold amount must better reflect current economic realities for all people.
- We recommend that Edmonton Police Service, and other law enforcement agencies, work towards building a team based response model to engage with individuals in community; one that integrates trauma informed approaches and which couples social workers, mental health support and law enforcement working together to understand the unique needs of each person and responding to the person with kindness, dignity and respect.
- An individual with a disability should have the assurance of being able to have an advocate with them in meetings, court proceedings or other related legal matters. This assures respect and that all voices are heard, without any level of control etc, and ensures that there is common understanding.
- We call for sensitivity and disability awareness training for frontline - emergency response professionals and workers, particularly police.
- We call for education and training led by people with disabilities for lawyers and other legal professionals on ableism, accommodations and equity.
- The federal government, under the obligations of the Convention on the Rights of Persons with Disabilities, must set clear standards and guidelines for provinces and municipalities to meet in order to advance the rights of people with disability. There should be reporting and accountability mechanisms for provinces and municipalities to the federal government on their responsibilities related to the Convention. This will ensure a consistency in application across the country and a method to overcome jurisdictional gaps.

CALLS TO ACTION: JUSTICE AND LAW ENFORCEMENT

- Safe and independent spaces for remedy must be built to allow people with disability to file concerns and complaints independent of government agencies and influence. The current human rights remedy spaces also must become equitable allowing for all matters under government jurisdiction to be heard. For example, matters related to the transportation federally can not be heard by the Canadian Human Rights Commission.
- People with disabilities must be recognized as persons with human rights within all legislation and programs despite their disabilities.

CONCLUSION

In response to Canada's initial report (2012) to the Committee on the Rights of Persons with Disabilities, which includes information about Canada's implementation of the Convention on the Rights of Persons with Disabilities, the Committee developed a report (2015) with concerns and recommendations. In this report, the Committee applauds Canada for writing the protection of rights of persons with disabilities into law through the Canadian Human Rights Act and the Charter of Rights and Freedom which protect rights through the prohibition of discrimination on the grounds of "physical or mental disability".

Undoubtedly our experiences and our analysis highlights that institutions and systems (i.e., legal and beyond) continue to fail people with disabilities. We note that Articles 5 and 19 emerge in each of the five areas of concern described above in the subsection 'Rights that are currently being contravened under the Convention on the Rights of Persons with Disabilities'. Though these Articles commit governments (federal, band, provincial, municipal) to ensuring protection from discrimination (Article 5) and equal rights to participating in and benefitting from community life. We have demonstrated that discrimination persists and that people with disabilities are presented with barriers rather than possibilities for living independently in and with their communities.

In conclusion, the Radical Inclusion team believes that support for people with disabilities in Alberta and Canada is fragmented, difficult to navigate and often exclusive rather than inclusive. The current framework used to create disability programs relies primarily on economics versus quality of life. Although this report describes five areas of concern, there are many other areas that need to be addressed. Among them, the rights of children with disabilities and the role of nonprofits and charities around disability.

Most of the team had never participated in a group that was comprised solely of people with disabilities, where their voices and experiences were heard and validated. Radical Inclusion strongly believes that groups like ours should be the norm rather than the exception. A concerted effort is critical to put us in the positions where decisions are being made with us rather than for us.



Anecdotal First Person Stories

The following stories are real life experiences
and are included to highlight the systemic barriers
faced by people living with a disability.

ANECDOTE ONE: ALBERTA AIDS TO DAILY LIVING

Alberta Aids to Daily Living (AADL) is a cost share program meant to provide financial coverage for basic and essential medical equipment and supplies for people with disabilities, chronic illness and seniors. These supplies and equipment are vital for maintaining a healthy and possibly more independent life. While in theory AADL is a great program, unfortunately **many inner issues have come about within this program.**

One major problem is in order to stay covered clients must provide proof every few years that they still have their disability or illness even if it is clear it is lifelong or that that person has had it since birth. This means providing the same redundant paperwork, documentation, and letters from specialists every time. This is a **waste of paper, resources and doctors' time.** In some cases clients who may require incontinence supplies must go through embarrassing and degrading situations such as recording a bladder and bowel diary for 5-7 days. If that person is having a good week bathroom wise, their supplies could be cut to a smaller amount. If it is a worse week, then you could end up with inappropriate supplies even after you try to explain your regular supplies are what works best for you. My solution to this is to simply **have official documentation from all specialist doctors stating that the client's situation is permanent and have those documents kept on file** and to have it between the doctors and the client to decide which equipment or supplies are needed and fitting to that person.

My last issue is that of treatment from AADL personnel. More often than not **we are treated as second class citizens or even just numbers** to them. In the summer of 2017 I called my supplier to re order my medical supplies as I do every other month. I was told to call AADL because I had to get my coverage reinstated. I didn't receive a notice from AADL ahead of time for this, which to me is unethical.

I called an official at AADL and told them my supplies had been cut off. I was quickly told not to word it that way.

To bring some clarity of my situation, I need catheters to live. If I don't have those catheters I will get very sick.

I very politely and in a nice, normal conversational tone said that it was frustrating that I essentially have to pay or receive permission to get vital supplies I need to go to the bathroom and that it was a human rights issue. This woman from AADL then changes her tone almost threateningly and "warns me" to "be careful when bringing up human rights because taxpayers pay for my supplies and they have rights too".

This remark really shocked me as these are supplies that I cannot live without. **I was surprised with the personal anger that the official directed towards me. I was surprised at her direct correlation between my personal medical needs and taxpayers when we have a publicly funded health care system. She made me feel less as a person.**

This was a woman with the power to take or give my supplies with the push of a button abusing her power with intimidation (and it worked). We are constantly told to sit down and be grateful for the bare minimum of essential medical supplies we are given (example I am only allotted 60 catheters every two months thus forcing me to reuse them) because money is seen as more important than our own basic health requirements.

There have been several times when I've been told by peers that they have been told they were cut off from supplies without warning and have no choice but to use credit or savings to get them. Some of my peers just accept this as "this is just the way it is" without realizing their rights are being violated. My solution to this problem is simple. Sensitivity training and the hiring of more people with disabilities within AADL. This is not a job I believe that should be solely based on educational credentials. They need to make sure they are hiring people with the ability to be empathetic and to see their clients as people who deserve to be treated with dignity and respect just like anyone else. We also need to be teaching people with disabilities that they have the right to fight for their basic human rights especially when it comes to their overall health.

ANECDOTE TWO: BARRIERS TO WORK

Income supports are far below poverty income levels and when you try to change your income and do some work

*** C's story

A friend on AISH in Alberta was struggling to survive on income below the poverty line she received. She started doing shift work to help pay bills and survive.

AISH has income limits and her shift work had on demand hours:

- if she worked too many hours, AISH clawed back 75 cents on every dollar over the limited amount she earned; therefore, she will work for pocket change per hour (25 cents).
- If she refuses shift work offered she risks never being called back again and losing her job.
- There is no balance
- -----

ANECDOTE THREE: GOVERNMENT

Discrimination by Politicians and those who run Canada. If they refuse to adhere to the Convention on the Rights of Persons with Disabilities (CRPD) and other Human Rights obligations, why would the rest of Canada?

****Example 1**

I have had multiple Federal and Provincial incidents and can vouch what is written below is 100% true. Politicians - including the head of the country do not support, nor uphold Human Rights in Canada.

The Head of Country had a Cross Canada Tour - I wished to attend the event in my city but I needed the accommodation of captioning to be included as a person with disabilities. I submitted my accommodation request well in advance to the political party's organizers and received no response.

I resent my accommodation request and multiple advocates sent accommodation requests as well in emails and telephone calls to ensure myself and others attending with the need for captioning had the accommodations they needed. There was no response. I went to the event expecting to be included as a person with disabilities but was horrifically shocked to find that our multiple written requests for inclusive accommodation were totally ignored. I was not included nor accommodated at all. It is also important to note that sign language is not accessible nor the accommodation that works for all hard of hearing individuals.

Many other persons with disabilities experienced similar issues with their accommodation needs not being met during the head of Canada's country wide tour. The cross-Canada tour events were held in inaccessible buildings. For wheelchair users, persons with disabilities were expected to stand in line for hours with nowhere to sit and rest. There were persons with disabilities fainting and falling etc.

We were left feeling that politicians do not accommodate people with disabilities needs at all.

ANECDOTE FOUR: GOVERNMENT

****Example 2**

A provincial politician planned to host an event online regarding people with disabilities. I wished to attend this public event and requested accommodation of captioning to accommodate my hearing disability and even included information on how to implement them providing where to get a professional captioner for accuracy and, if that was not an option, how to implement free automatic captions online for the event.

I sent an email accommodation request well in advance of the event. I received a response from an assistant that they were looking into things

At the last minute, the politician canceled this event and then stated the issue was accessibility concerns. This felt like blaming the disabled for their needs :(Imagine persons with disabilities needing accommodations!

If politicians, and head of country, cannot and refuse to uphold Human Rights and the CRPD, how can ANYWHERE in Canada be expected to uphold Human Rights. Or the United Nations' CRPD?

Human Rights is written on paper only. One must exert one's disabled self repeatedly to have even the simplest accommodation request implemented. If denied you are then up to the great challenge to file a human rights complaint which will take at least 2 years or, usually longer, to address.

ANECDOTE FIVE: JUSTICE

**** Obstruction of Justice**

Federal Human Rights & Canadian Transportation Association (CTA)

I am an independent adult with disabilities. When I was 22 years old I had enough courage and independence to fly overseas and back alone. In the Canadian airport, I said goodbye to my family and was left alone with airline staff from a Major Canadian Airline.

When my family left, the airline staff took out a large Derogatory sign with a rope around it and ordered me to put it on! I, an independent adult living with disability, refused to wear this derogatory sign. I then was bullied by multiple staff and informed if I did not put the sign on I would be refused to fly. After protesting further, I eventually submitted and put the derogatory sign around my neck.

I wore the degrading sign during my hours-long wait before boarding my flight. And during my 9+ hour flight both ways, as this was what I was ordered to do. I was mortified, oppressed and discriminated against due to being a person with disabilities.

I filed a Federal Human Rights complaint. Not an easy task at all when you can not afford a lawyer to help. The Federal Human Rights Commission's response was to redirect me to a separate federal Agency that deals with discrimination related to federal transportation, the Canadian Transportation Association (CTA). I followed directions and contacted CTA. Their online forms had no info on how to file discrimination complaints. We phoned and they stated they did not have jurisdiction to handle discrimination and sent me back to Federal Canadian Human Rights Commission.

The Federal Human Rights Commission insisted CTA had jurisdiction so we went back to CTA. CTA again refused to take my discrimination case and sent us back to Federal Human Rights.

CONT.

This happened over and over again until I obtained an advocate willing to speak on my behalf during mediation with CTA and the offending airline. The offending airline (and CTA) refused to permit my advocate to help me therefore disabling me further.

I appealed my case numerous times with the Federal Human Rights Commission to look at and take my discrimination case (which they refused repeatedly). Until I was no longer permitted to appeal any further.

I received Zero Justice. In the year following, I tried to address this Discrimination. When I brought up the issues during a Canadian Association of Statutory Human Rights Agencies (CASHRA) Human Rights Conference, I was told by one of the top individuals of Canadian Federal Human Rights that they were aware of the issues and again stated that the CTA has been given the power to deal with persons with disabilities discrimination complaints when it applies to travel. Clearly CTA does not handle discrimination the same way the Canadian Human Rights Commission handles discrimination. In my case they flat out refused to handle my case. **Another human rights person at CASHRA also stated "the only way to change the situation and stop persons with disabilities having their justice obstructed is for ME to change Parliament."**

A person with disabilities is expected to change Parliament in order to get equality for all people with disabilities. Not an easy task at all when the injustice is not even being acknowledged :(

I know of other people who had the same experience with the CTA and federal human rights and received no justice. Mine is not an isolated case.

Canada is supposed to be a wonderful country to live in. This does not apply if you have a disability :(

ANECDOTE SIX: MEDICAL

I was born 54 years ago with Spina Bifida - with no feeling from below my chest down, my mobility is restricted to a wheelchair. I've lived half a century longer than doctors expected me to. My parents chose to raise me alongside of my three older siblings despite the advice provided to them at that time by doctors. They couldn't have possibly known what myelomeningocele meant or all that raising a child with this disability might entail.

It is important to note that I grew up with the same expectations placed on me as were placed on my siblings. My parents had the benefit of life experience and raised me knowing my life would have a lot of challenges "normal" children's lives would not. I did not have that life experience. "Normal" to me meant following my siblings' example - grow up, graduate high school, pursue a post-secondary education, get a job and a career - oh and possibly find someone to spend my life with and start a family of my own.

In hindsight, being able to now draw upon my own life experiences, I've come to see things more realistically and clearly. I am completely independent, live on my own and pursued a career in teaching and graphics - all with direct and overwhelming impacts on both my overall health and my work/life balance.

I've had numerous instances where medical issues have left me precariously close to death. Each of these situations have taught me a great deal about myelomeningocele; hydrocephalus; meningitis; MRIs; blood cultures; ileoconduits; colostomies; kidney issues (a direct result of the ileoconduit); intravenous going interstitial; biopsies; BP; reactions to medications, adhesives, latex and any other medical supplies I've repeatedly been exposed to; red flags to watch for when I'm on my way to becoming septic; cellulitis; wound care; pressure wounds ... a great number of medical conditions and hospitalizations "normal" individuals may never have been faced with. I would never presume to know better than a physician; however, I have learned a great deal about medical conditions as they relate to me and I am very aware when my body is on its way to becoming medically compromised.

CONT.

Radical Inclusion strongly believes education and awareness is critical in supporting individuals with disabilities. In my own personal experience medical professionals require increased education and awareness in dealing with individuals living with a disability. On one occasion, I was told by my family doctor that I was merely out of shape, when I began falling during transfers. Other symptoms I was experiencing included tingling in my hands and sleep apnea type issues. **In 30+ years of independently transferring, they were as stable as anyone healthy walking on two feet,** and suddenly I was informed that I was too weak and that I should exercise more, the other symptoms virtually ignored.

Shortly after seeking help from my pediatric neurosurgeon (at 30+ years old), I was diagnosed with Arnold Chiari Malformation – a condition that if left unchecked would become life threatening with the potential to cost me the use of my arms, jeopardize my ability to breathe and cost me my hard earned independence. This condition required neurological surgery. **If the family doctor I first saw had been more aware that we as individuals with disabilities actually do KNOW our bodies** and had he been more open to listening to what we say is not “normal” for us, **I might have been diagnosed much sooner than I was.** If I had accepted his initial diagnosis and not pushed to get to the bottom of my health issues, and had it not been for that pediatric neurosurgeon being willing to listen and explore further, I very well could not have made it to 54 years.

Education and awareness in caring for individuals with disabilities is also critical for medical professionals overall. At 52, I was brought into the hospital with a ureter blockage leaving me septic. My body had begun to shut down to the point where I ended up with pneumonia and became extremely weak and ill. During my hospital stay, relatively newly graduated registered nurses were assigned to me and because I was so weak, I required assistance changing the ileoconduit appliance (for urination). Rather than accept that I had at least 45 years of experience dealing with this appliance and how it might work best to attach a night drainage system to a valve, **the nurses in question completely shut me down.** I was not allowed to explain myself, I was not allowed to demonstrate what I knew would work and I was left with nothing attached, forcing me to call on nurses more often to drain my bag and put more of a strain on their workload.

CONT.

During the same hospitalization, after sepsis, pneumonia and several surgical procedures, when I felt I was in no condition to return home yet and do my own transfers and self-care, **I was asked why I didn't want to be discharged. My transfers were far from safe, it was -35 outside, I lived alone and I was desperately trying to reteach myself how to breathe without gasping the moment I laid down and to rebuild my strength enough to transfer safely again.** All of this transpired over a weekend, so there was no access to Physio or Occupational therapists to consult with. All I needed was a few more days in hospital, to feel a bit more confident and stronger and I would be fine.

Had unit nurses, residents, doctors and care-givers been more aware that once we are discharged we are often on our own, I would have been made to feel more comfortable staying in this safe environment. We are often transferring independently and if we should fall, we could land ourselves back in the hospital and put ourselves in potentially dangerous positions – thus occupying a hospital bed for even longer than if they had given us a few more days to get used to how our weakened bodies move independently again.

ANECDOTE SEVEN: AFFORDABLE & ACCESSIBLE HOUSING

I've been telling this same story for 20 years. Maybe this time I will get it right and things will finally change. I am an independent woman who uses a manual wheelchair full time. I grew up on a farm in northern Alberta but moved to Edmonton to get a post-secondary education and play competitive basketball in 1986.

Housing was an issue from day one.

In my young mind, if I could play wheelchair basketball internationally in the big city, I should be able to find somewhere to live. I was excited to start my life. I competed in the 1988 Paralympics in Seoul, South Korea.

The next 15 years were a struggle which you don't need to hear. But always **at the root of it was housing**. I negotiated with landlords and roommates to help overcome the barriers. **When I looked for housing, I might find 2 or 3 choices; always inadequate** and in random locations. I started suffering with chronic depression in 1995.

I had worked so hard as a kid! Not only was I managing a complicated body (it was complicated!!), but I did everything everyone else did. I went to school, got good grades. I wasn't shy and radically included myself everywhere I could. I got my driver's license, owned my own vehicle. **I paid market rent for inaccessible apartments for over 20 years.**

Finally, in 2004 I did find wheelchair accessible housing. I found Artspace Housing Cooperative. Artspace is a housing development on the east side of downtown Edmonton. It consists of an eight-story high rise and a row of townhouses. Twenty nine out of eighty-eight units are adapted for people who use wheelchairs.

Artspace also owns a homecare company which provides services authorized and funded by Alberta Health Services. These services make it possible for many people with disabilities to live independently as opposed to living in long term care or in unhealthy, co-dependent relationships.

CONT.

Our members with disabilities are able to participate more in the community whether it be working or volunteering. Simply, we use less healthcare dollars by sharing these resources amongst our members. This housing development opened for tenants in 1990. **The wheelchair accessible units rarely come available for rent.** Those of us who live here joke about only leaving here in a coffin. **No one moves out because there is literally nowhere else to go.**

A majority of members have very sad stories about where they lived before finding Artspace. One of our most recent members had been living in a hospital for 5 months because there was nowhere that could accommodate him.

Housing is essential to living a good life here in Canada. Everyone should have access to housing that enables them to live independently and pursue work and/or careers. **I retired at the age of 36 for medical reasons and I believe lack of accessible housing was a major barrier to success.** I have done most of my advocacy work since I have found accessible housing myself. People who are marginalized by housing cannot be expected to advocate for themselves when they are experiencing a lack of freedom and mobility.

Even today, conversations around accessible housing unnerve me because I think the conversation will be reduced to how we can do “more” with less money and reducing my life to a dollar sign.

Housing in a northern climate is an absolute necessity.

If we want our economy to thrive, people need to live in housing that enables them to work and participate in society. It’s pretty hard to live a meaningful life if you have minimal access to the community around you. People with disabilities need to be meaningfully included in society because it is a violation of our human rights and just irresponsible to not include us.

Housing is the solution not the problem. Appropriate housing would save our healthcare system a lot of money and maybe reduce taxes for everyone.

ANECDOTE EIGHT: HOUSING

I am a consumer of housing. I've been looking for wheelchair accessible housing since 1986.

There is no market for wheelchair accessible housing in Edmonton. There is also not a market for "visitable" housing. I know this because I have been looking for it for 35 years.

I have written countless letters, met city councilors and MLA's. I even served on the board of a non-profit housing society until I was removed for checking into the CEO's credentials. (He bought his MBA online for \$750).

I have been told many times, by builders in particular, that I have no right to tell people how to build or develop housing. They laugh when I describe a barrier-free neighbourhood. Most landlords have denied me accommodations.

I've been told by government that this is a capitalist society and the "free" market will provide and adjust to what consumers need. I, too, am a consumer, yet I've been needing housing since 1986. Finally, in 2004 I did find wheelchair accessible housing. I found Artspace Housing Cooperative.

The waitlist for accessible units in this cooperative is extremely long. The twenty nine modified units are currently occupied, therefore other people with disabilities seeking housing from Artspace are left to wait until something becomes available. Our disabled tenants are unlikely to vacate, as they have nowhere else to go. There simply is not enough accessible housing to accommodate the number of people needing it. In my opinion what is innovative when it comes to affordable housing?

**Barrier free / Visitable design for
all housing from today forward.**





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