Making the Invisible, Visible:
Brain Injury, Personal Supports, and Income Security

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My objectives

- Discuss some ‘invisible’ social and economic aspects of disability
- Suggest what making them visible will require in political action and policy changes
- Present some proposals for ‘making the invisible visible’ through public policy initiatives
Visible Disabilities

- Most Canadians think of *physical* disabilities when they consider disabilities
- Disability therefore associated with visibility
- First appearances of bodily signs, limitations or aids
- Examples: white cane, guide dog, wheelchair, Downe syndrome, ventilator
Invisible Disabilities

- Impairments usually not immediately apparent to other people
- Not known about in advance of meeting a person
- Not disclosed publicly by the person or others close to the person
- Examples: diabetes, chronic fatigue, epilepsy, head injuries, sleep disorders
Thinking of invisibility this way...

- Disabilities are understood as personal attributes and *internal* deficits
- Visibility and invisibility both *individualize* the condition, impairment and needs
- Reinforces a medical model of disability
- Downplays social relationships and the importance of community environments
Invisibility can be isolating

- “I am a survivor and I’m happy to be me. I feel that sometimes people look at me differently. I sometimes wonder if I’d had a scar people could see me – if that would make a difference in their stares. They say it’s the invisible injury; it may be but I am not. I am told I look like everyone else, they just say that. That’s all.”
Another view of invisibility

- Invisibility *is* something even if it is unseen, just like culture
- The invisibility of injuries and impairments are cultural creations from public assumptions and misunderstandings, professional beliefs, popular images, and political indifference
- Invisibility often interconnects with social exclusion, neglect, and poverty
Making the invisible, visible

- Personal aspects
- Organizational efforts
- Unintended consequences
- Political dimensions
Personal aspects

- Peer self-help groups
- Parent groups and family networks as resources
- Recognizing the assets, skills, and experiences of the person
- Redefining injuries as ‘hidden gifts’ that can teach others
- Being visible, open in everyday encounters
Organizational efforts

- Formation of local non-profit societies for direct care, advocacy, support groups
- Injury and falls prevention programs
- Community education and awareness activities
- Establishment of registries and records: coroners’ offices, hospitals, police, insurance companies, ICBC, workers’ compensation schemes
- Monitoring, research and actions
Unintended consequences

- Because of public misconceptions, poor choices, and policy gaps, the invisibility of brain injuries too often result in visible problems.
- Addictions issues, social isolation, financial concerns and poverty, homelessness, severe stress on families and caregivers.
- These are the dark signs of invisibility, secondary effects which can be worse than the original injury.
Political dimensions

- Recognizing community needs
- Engaging in public conversations
- Reaching judgments about social rights and responsibilities
- Identifying social policy goals
- Creating public services and supports
Political seeing

- These dimensions amount to what has been called *political seeing*:
  “the capacity to see anew, to see empathetically” that is, thoughtfully and with compassion
- This capacity “arises out of social interaction and out of imaginative efforts by individuals to see in common.”
- Inventing new expectations and newly imagined public goods.

Disability-related supports

- Technical aids and devices, medications
- Personal assistance with activities of daily living
- Supports within education systems
- Workplace supports and job accommodations
- Household adaptations/special features
- Supports related to transportation, leisure activities
- Community infrastructure that is accessible and inclusive in design and programming
Profile of need for supports

- About 2 million Canadian adults lack one or more of the disability supports they need
- Half of children with disabilities who need specialized aids do not have all the aids they require
- Families supporting a member with a disability have notably lower household incomes than other families
Demand for supports will grow

- Aging population of Canada
- Pressures on smaller families
- Public expectations for flexible, available, accountable services
- Further deinstitutionalization
- Labour market needs for skilled people
A five-point plan for reforming disability supports

1. Providing information – single access
2. Easing access to supports – review eligibility rules
3. Improving delivery of programs – consolidate programs, fill gaps
4. Developing citizen-centred – more individualized funding, peer support
5. Changing the broader context – legislation for accessibility
Canadiana with disabilities and their families are twice as likely to live in poverty as other Canadians.

Adults with traumatic brain injuries experience declines in employment and earned income two years and longer, after the time of the injury.

Many costs and expenses to families are not covered and reimbursed.

Our income support programs are failing people living with disabilities.
Income Insecurity

- Over-reliance on social assistance as primary source of income
- Benefit levels are inadequate
- Systems are stigmatizing
- Complicated, rule-heavy, personally intrusive administrative systems
- Inadequate supply of training and employment supports
Vision of eradicating poverty

- That all Canadians with disabilities – whether those disabilities are visible or invisible – have the income and resources they need to secure a good quality of life and to fully participate in all aspects of their communities.
Reform ideas on income support programs

- Modernize provincial social assistance systems
- Convert the Disability Tax Credit to a refundable cash benefit
- Review and simplify other tax credits
- Expand the Employment Insurance Sickness Benefit from 15 to 52 weeks
- Introduce partial benefits in the Canada Pension Plan Disability program
Longer-term reforms

- Cooperative federalism is required

- Federal Government take the lead on income security for Canadians with disabilities: a national basic income for people with severe disabilities, modeled after the Old Age Security program

- Provincial /Territorial Governments take lead for disability-related services and supports: re-investment of savings from people removed from welfare into personal supports
Moving to a visible community

- **From**: ‘I didn’t know you had a head injury.’

- **Through**: ‘I understand that you want help because of your injury.’

- **To**: ‘I believe adequate supports and income are necessary and would be good for everyone in the community to which I belong.’
The democratic noise of visibility

“In the end, human freedom will be found not in caverns of private solitude but in the noisy assemblies where women and men meet daily as citizens and discover in each others’ talk the consolation of a common humanity.”

B. Barber, Strong Democracy (1984: 311)