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PERSPECTIVES
ON SOCIAL
INCLUSION

Social Inclusion as Solidarity:

Rethinking the Child Rights Agenda

Michael Bach



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ON SOCIAL
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Rethinking the Child Rights Agenda

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About the Laidlaw Foundation

The Laidlaw Foundation is a private, public-interest foundation that uses its human and financial resources in innovative ways to strengthen civic engagement and social cohesion. The Foundation uses its capital to better the environments and fulfill the capacities of children and youth, to enhance the opportunities for human development and creativity and to sustain healthy communities and ecosystems.

The Foundation supports a diverse portfolio of innovative and often unconventional projects in three program areas: in the arts, in the environment and improving the life prospects for children, youth and families.

Working for social inclusion is a theme that underlies much of the Foundation's activities. The key words in the Foundation's mission — human development, sustainable communities and ecosystems — imply that achievement will rely on the enhancement of capacity and capability. Not only is social inclusion being developed as an emerging funding stream, it is an embedded Laidlaw Foundation value, both structurally and programmatically.

Nathan Gilbert
Executive Director

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Foreword:

The Laidlaw Foundation's Perspective on Social Inclusion

The context for social inclusion

Children have risen to the top of government agendas at various times over the past decade, only to fall again whenever there is an economic downturn, a budget deficit, a federal-provincial relations crisis or, most recently, a concern over terrorism and national security. While there have been important achievements in public policy in the past 5 to 10 years, there has not been a sustained government commitment to children nor a significant improvement in the well-being of children and families. In fact, in many areas, children and families have lost ground and social exclusion is emerging as a major issue in Canada. Examples abound and include these facts.

- the over-representation of racial minority families and children among those living in poverty in large cities, and the denial of access to many services by immigrant and refugee families;
- the 43% increase in the number of children in poverty in Canada since 1989, the 130% increase in the number of children in homeless shelters in Toronto, as well as the persistence of one of the highest youth incarceration rates among Commonwealth countries;
- the exclusion of children with disabilities from public policy frameworks (e.g. the National Children's Agenda), from definitions of 'healthy' child development and, all too often, from community life.

These situations provide the context for the Laidlaw Foundation's interest in social inclusion. The Foundation's Children's Agenda program first began exploring social inclusion in 2000 as a way to re-focus child and family policy by:

- re-framing the debate about poverty, vulnerability and the well-being of children in order to highlight the social dimensions of poverty (i.e. the inability to participate fully in the community)
- linking poverty and economic vulnerability with other sources of exclusion such as racism, disability, rejection of difference and historic oppression
- finding common ground among those concerned about the well-being of families with children to help generate greater public and political will to act.

The Foundation commissioned a series of working papers to examine social inclusion from a number of perspectives. Although the authors approach the topic from different starting points and emphasize different aspects of exclusion and inclusion, there are important common threads and conclusions. The working papers draw attention to the new realities and new understandings that must be brought to bear on the development of social policy and the creation of a just and healthy society.

These are:

- Whether the source of exclusion is poverty, racism, fear of differences or lack of political clout, the consequences are the same: a lack of recognition and acceptance; powerlessness and 'voicelessness'; economic vulnerability; and, diminished life experiences and limited life prospects. For society as a whole, the social exclusion of individuals and groups can become a major threat to social cohesion and economic prosperity.
 - A rights-based approach is inadequate to address the personal and systemic exclusions experienced by children and adults. People with disabilities are leading the way in calling for approaches based on social inclusion and valued recognition to deliver what human rights claims alone cannot.
 - Diversity and difference, whether on the basis of race, disability, religion, culture or gender, must be recognized and valued.
- The 'one size fits all approach' is no longer acceptable and has never been effective in advancing the well-being of children and families.
- Public policy must be more closely linked to the lived experiences of children and families, both in terms of the actual programs and in terms of the process for arriving at those policies and programs. This is one of the reasons for the growing focus on cities and communities, as places where inclusion and exclusion happen.
 - Universal programs and policies that serve all children and families generally provide a stronger foundation for improving well-being than residual, targeted or segregated approaches. The research and anecdotal evidence for this claim is mounting from the education, child development and population health sectors.

Understanding social inclusion

Social exclusion emerged as an important policy concept in Europe in the 1980s in response to the growing social divides that resulted from new labour market conditions and the inadequacy of existing social welfare provisions to meet the changing needs of more diverse populations. Social inclusion is not, however, just a response to exclusion.

Although many of the working papers use social exclusion as the starting point for their discussions, they share with us the view that social inclusion has value on its own as both a process and a goal. Social inclusion is about making sure that all children and adults are able to participate as valued, respected and

contributing members of society. It is, therefore, a normative (value based) concept - a way of raising the bar and understanding where we want to be and how to get there.

Social inclusion reflects a proactive, human development approach to social well-being that calls for more than the removal of barriers or risks. It requires investments and action to bring about the conditions for inclusion, as the population health and international human development movements have taught us.

Recognizing the importance of difference and diversity has become central to new under-

standings of identity at both a national and community level. Social inclusion goes one step further: it calls for a validation and recognition of diversity as well as a recognition of the commonality of lived experiences and the shared aspirations among people, particularly evident among families with children.

This strongly suggests that social inclusion extends beyond bringing the ‘outsiders’ in, or notions of the periphery versus the centre. It is about closing physical, social and economic distances separating people, rather than only about eliminating boundaries or barriers between *us* and *them*.

The cornerstones of social inclusion

The working papers process revealed that social inclusion is a complex and challenging concept that cannot be reduced to only one dimension or meaning. The working papers, together with several other initiatives the Foundation sponsored as part of its exploration of social inclusion, have helped us to identify five critical dimensions, or cornerstones, of social inclusion:

Valued recognition – Conferring recognition and respect on individuals and groups. This includes recognizing the differences in children’s development and, therefore, not equating disability with pathology; supporting community schools that are sensitive to cultural and gender differences; and extending the notion to recognizing common worth through universal programs such as health care.

Human development – Nurturing the talents, skills, capacities and choices of children and adults to live a life they value and to make a contribution both they and others find worthwhile. Examples include: learning and developmental opportunities for all children and adults; community child care and recreation programs for children that are growth-promoting and challenging rather than merely custodial.

Involvement and engagement – Having the right and the necessary support to make/be involved in decisions affecting oneself, family and community, and to be engaged in community life. Examples include: youth engagement and control of services for youth; parental input into school curriculum or placement decisions affecting their child; citizen engagement in municipal policy decisions; and political participation.

Proximity – Sharing physical and social spaces to provide opportunities for interactions, if desired, and to reduce social distances between people. This includes shared public spaces such as parks and libraries; mixed income neighbourhoods and housing; and integrated schools and classrooms.

Material well being – Having the material resources to allow children and their parents to participate fully in community life. This includes being safely and securely housed and having an adequate income.

Next steps: Building inclusive cities and communities

Over the next three years, the Children's Agenda program of the Laidlaw Foundation will focus on *Building inclusive cities and communities*. The importance of cities and communities is becoming increasingly recognized because the well-being of children and families is closely tied to where they live, the quality of their neighbourhoods and cities, and the 'social commons' where people interact and share experiences.

Christa Freiler
Children's Agenda Program Coordinator
Laidlaw Foundation

The Laidlaw Foundation's vision of a socially inclusive society is grounded in an international movement that aims to advance the well-being of people by improving the health of cities and communities. Realizing this vision is a long-term project to ensure that all members of society participate as equally valued and respected citizens. It is an agenda based on the premise that for our society to be just, healthy and secure, it requires the inclusion of all.

Paul Zarnke
Chair, Children's Agenda Advisory Committee
Laidlaw Foundation

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*This series is dedicated to the memory of
Dr. Jennifer Keck who died on June 12, 2002
after a long battle with cancer.*

*Jennifer was a key member of the editorial committee,
an insightful and passionate reviewer of the working papers,
and an unwavering advocate for
social justice and the social inclusion of all people.*

Social Inclusion as Solidarity:

Rethinking the Child Rights Agenda

Social Inclusion as Solidarity

Rethinking the Child Rights Agenda

Introduction

A few months back a story came to me across cyberspace attached to an e-mail message. The story goes like this:

In Brooklyn, New York, CHUSH is a school that caters to learning disabled children. Some children remain in CHUSH for their entire school career, while others can be mainstreamed into conventional schools. At a CHUSH dinner, the father of a CHUSH child delivered a speech that would never be forgotten by all who attended. After extolling the school and its dedicated staff, he cried out, "Where is the perfection in my son Shaya? Everything God does is done with perfection. But my child cannot understand things as other children do. My child cannot remember facts and figures as other children do. Where is God's perfection?" The audience was shocked by the question, pained by the father's anguish and stilled by the piercing query. "I believe," the father answered, "that when God brings a child like this into the world, the perfection that he seeks is in the way people react to this child." He then told the following story about his son Shaya:

One afternoon Shaya and his father walked past a park where some boys Shaya knew were playing baseball. Shaya asked, "Do you think they will let me play?"

Shaya's father approached one of the boys in the field and asked if Shaya could play. The boy looked around for guidance from

his teammates. Getting none, he took matters into his own hands and said, "We are losing by six runs and the game is in the eighth inning. I guess he can be on our team and we'll try to put him up to bat in the ninth inning."

Shaya's father was ecstatic as Shaya smiled broadly. Shaya was told to put on a glove and go out to play short center field. In the bottom of the eighth inning, Shaya's team scored a few runs but was still behind by three.

In the bottom of the ninth inning, Shaya's team scored again and now with two outs and the bases loaded with the potential winning run on base, Shaya was scheduled to be up. Would the team actually let Shaya bat at this juncture and give away their chance to win the game?

Surprisingly, Shaya was given the bat. Everyone knew that it was all but impossible because Shaya didn't even know how to hold the bat properly, let alone hit with it. However as Shaya stepped up to the plate, the pitcher moved a few steps to lob the ball in softly so Shaya would at least be able to make contact.

The first pitch came in and Shaya swung clumsily and missed. One of Shaya's teammates came up to Shaya and together they held the bat and faced the pitcher waiting for the next pitch. The pitcher again took a few steps forward to toss the ball softly

towards Shaya. As the pitch came in, Shaya and his teammate swung at the bat and together they hit a slow ground ball to the pitcher. The pitcher picked up the soft grounder and could easily have thrown the ball to the first baseman. Shaya would have been out and that would have ended the game. Instead, the pitcher took the ball and threw it on a high to right field, far beyond the reach of the first baseman.

Everyone started yelling, "Shaya, run to first. Run to first."

Never in his life had Shaya run to first. He scampered down the baseline wide-eyed and startled.

By the time he reached first base, the right fielder had the ball. He could have thrown the ball to the second baseman who would tag out Shaya who was still running. But the right fielder understood what the pitcher's intentions were, so he threw the ball high and far over the third baseman's head. Everyone yelled, "Run to second, run to second." Shaya ran towards second base as the runners ahead of him deliriously circled the bases towards home. As Shaya reached second base, the opposing short stop ran to him, turned him in the direction of third base and shouted, "Run to third." As Shaya rounded third, the boys from both teams ran behind him screaming, "Shaya run home."

Shaya ran home, stepped on home plate and all 18 boys lifted him on their shoulders and made him the hero, as he had just hit a "grand slam" and won the game for his team.

"That day," said the father softly with tears now rolling down his face, "those 18 boys reached their level of God's perfection."

I was very moved by this story. One of the lines that struck me most was the father's

belief that "perfection" lies not in his son, or in any child, but in the ways people react to his child. This insight shifts our view about what matters. We turn from a child's disability to the ways in which he is recognized by others, to the way others "react" and know him. The shift in view the story records is central, I believe, to understanding what social inclusion is all about. My aim in this paper is to formulate a notion of social inclusion that could help to advance a political and public policy agenda for the well-being of children in Canada, with a particular focus here on children with disabilities and their families.

The paper is organized around the following contentions. Social inclusion is more a normative than descriptive term. I suggest that one of its core notions is that societal institutions should be organized to provide *valued recognition* to diverse groups, to the 'others' often marginalized by a dominant political culture. Calls for inclusion as valued recognition are growing as the dilemma of the 'rights revolution' becomes clear – a context where rights are expanded and exclusion is entrenched. A social inclusion agenda could address this dilemma by promoting social solidarity across expanding social, ethnic and cultural differences that increasingly characterize and divide so many societies, often in destructive ways. I argue that policy analysis should reveal ways that social, economic and political arrangements systematically undermine social solidarity by devaluing certain people and groups, even though their rights are assured. Fostering solidarity across differences in our society is an important step in creating a culture where the citizenship rights people hold can be more fully realized in their daily lives.

In the final section of the paper, I show how a social inclusion analysis could be applied to the exclusions facing children with disabilities to generate a public agenda for change. It

would bring to light a number of the rules and practices by which the devaluation of children with disabilities is constructed. Stereotyping of children, practices to 'cleanse' the human genome of genetic disability, and indicators for

measuring and monitoring child development at a population level that equates disability with ill-health and abnormal development, are the priorities that I suggest for analysis.

1. Calling for inclusion, and facing the dilemma with the rights revolution

Defining social inclusion

A large body of literature on social exclusion details various ways in which particular population groups are denied participation in, and access to, benefits and advantages of political, social and economic institutions. Social inclusion names a goal that brings exclusion into view and into question. It expresses an aspiration that the arrangements between us be inclusive – whether in our personal relationships, a neighbourhood baseball game like the one Shaya joined, or in our social, political and economic institutions in the public and private sector. 'Social inclusion' names an ideal that arrangements not disadvantage certain 'others' because they are different from the dominant norm; that arrangements not allocate benefits, status and advantages in ways that misrecognize, devalue or stereotype certain groups in relation to others. It means that arrangements should not foster or fund forms of recognition that deepen and entrench the social distance between certain groups (e.g. residential and education segregation of disabled persons would not survive such a test). Socially inclusive arrangements would help to nurture paths of mutual recognition that close the distance in ways that bring respect and value for the differences that define us.

When social inclusion is viewed in this way, we can understand how the term might

sometimes be used as a political claim for full citizenship, or as an ideal to which societal organizations and institutions should aspire, or as a way to name the process of reform of such arrangements. There are many institutional arrangements to which the claims, ideal, and process of social inclusion could apply – for example, early childhood development services, recreation services, education, family support services, labour market training, arrangements that provide benefits through the tax system and by other means, and even those institutions that regulate, fund and undertake social and health research on human populations (e.g. the Human Genome Project), etc. Simply stated, such institutional arrangements should be inclusive, we should be able to examine the extent of their social inclusivity, and we should be able to launch a process of reform that we might call social inclusion.

Calls for inclusion from the disability rights movement

Disability rights movements have helped to formulate this understanding of social inclusion. Over the past few years there have been many calls from disability movements nationally and internationally to advance a new agenda of inclusion with its variants of education inclusion (Bunch and Valeo, 2000), labour market and workplace inclusion (The Roehrer Institute, 1993), or community inclusion (The

Roeher Institute, 2000a; 2000b; 2001a). A call for inclusion is particularly resonant in the disability movement because it speaks directly to the problem of recognition and misrecognition of others. Many are seeking not only the 'integration' of children with disabilities in the education system (usually a mix of regular and 'special' or segregated classes and schools), but their 'inclusion'. This means an understanding of the child as a child first; full education in regular classrooms; valued recognition that we expect all children to obtain from teachers and peers; inclusion in the activities and personal relationships in which children come to be known personally and the needed physical, curricular and other accommodations to make this happen. It also means that difference and diversity will be taken seriously – systems will be developed that enable communication among children, even when some children do not communicate through spoken or written language. In this sense, social inclusion is not an agenda for homogenization, it is one that seeks to bring to the forefront the challenges of articulation and alliance and communicative capacities across the social, physical and communicational differences that define us.

Similarly, with labour market and workplace inclusion the issue is not simply provision of paid work opportunities to working-age adults with disabilities. Sheltered workshops have provided that for a number of years, but at the cost of many adults, particularly those with intellectual disabilities, not being recognized as capable of participating with co-workers in regular workplaces and the labour market, nor as deserving of basic labour rights. In this context, inclusion is the process of adapting workplaces, accommodating individuals, and ensuring that labour market information is provided to individuals with disabilities in ways that enable their access to training and paid work opportunities in the mainstream.

'Community inclusion' has been conceptualized as a multi-faceted process with personal, institutional and societal dimensions. It is the process of fostering 'valuing' personal relationships for people marginalized by a disability status, securing rights protections, ensuring economic and educational inclusion and reconstructing community institutions (education, recreation, social services, etc.) to enable full participation by people with disabilities (The Roeher Institute, 2000b).

The vision of citizenship that a call for inclusion appeals to goes beyond the exercise of political rights, and social and economic claims on the state. It demands social, cultural, political and economic participation in all institutions of society. The calls expand the arena for realizing citizenship from state provision to include civil society (that sphere of association, free press, public forums and community institutions), "emancipatory inasmuch as it liberates the individual from entrenched social hierarchies and allows interaction across formerly separated spaces" (Chandoke, 1995 p. 198). Calls for educational, workplace and community inclusion are consistent with the shifts in theories of citizenship that Kymlicka and Norman (1994), Young (1990, 2000), Chandoke (1995, 1999), and others point to – citizenship is fundamentally about full and democratic participation and inclusion in the institutions of society. Such calls speak to a desire to go beyond the juridically defined individual of liberal theory whose rights are realized but may still encounter exclusion. The calls from the disability movement for inclusion envision forms of social identity, reciprocity and solidarity that provide a foundation for rights to be realized in relation to others, for a life well-lived in community.

Why call for inclusion now? Dilemma of the 'rights revolution'

Why these calls now? In their historical context, calls for inclusion appear at the cusp of the disability rights movement, mobilized most strongly in Canada over the past two decades. Part of the answer, it seems to me, lies in the assumed relationship between rights granted and valued recognition realized. In his recent tracing of "the rights revolution", its history and current achievements, Ignatieff (2000) suggests that the "political and social history of Western society is the story of the struggle of all human groups to gain inclusion" in a political community where everyone has an equality of rights (p. 140). It is true that an impressive framework of constitutional and statutory rights has been established in Canada at the federal, provincial and territorial levels.

Canadians now have protections to equal benefit and advantage of the law without discrimination on the basis of disability written into our constitution. We have rights to freedom from discrimination on the basis of age, disability, gender, race, etc. – in access to employment, housing and services available to the public – written into our provincial/territorial and federal human rights codes. International human rights instruments have also expanded. *The Universal Declaration on Human Rights*, and various subsequent conventions, hold the promise that the state's granting and protection of human rights will redress economic and social inequality and denial of freedoms. For children, the 1989 *UN Convention on the Rights of the Child* signifies the recognition of children as full citizens – deserving of comprehensive human rights protection.

This array of rights, Ignatieff suggests, requires of us all the "recognition, empathy, and if possible, reconciliation" with others who we understand bear equal rights to our own. Yet Ignatieff seems a little more sanguine than I

am in assuming that the institutionalization of rights will bring recognition and empathy across the boundaries of gender, race, ethnicity, religion and ability that continue to divide us. We have secured inclusion for many under the banner of human rights, but have we gained full inclusion for those who, nonetheless, through various policies and practices seem to be less recognized and valued than others? That the extension of human rights is a condition of valued recognition, does not mean that valued recognition necessarily follows. This dilemma – of rights *without* recognition – is what we might call the dilemma of the 'rights revolution'.

Evidence abounds that exclusions persist for many groups despite an expansion of rights. For example, there exists a litany of exclusions of children and youth with disabilities and their families, including: endemic discrimination faced in access to life-saving treatments, to health care, to childcare services, to education (The Roeher Institute, 2000a); the sexual abuse of children and youth with disabilities – 50 percent of children and youth who are deaf; 60 percent of young women with an intellectual disability (The Roeher Institute, 1988; Sullivan, Vernon and Scanlon, 1987); access to the justice system denied because they are often not considered credible witnesses to their own victimization (The Roeher Institute, 1995); inadequate integration into national child development schemes in many countries – children miss out on key developmental opportunities, and are often not seen as worthy of the investment (Alur, 2000); continual downgrading of parents' labour force participation – for many to unemployment because they cannot obtain the workplace flexibility or outside supports they need (Irwin and Lero, 1997; The Roeher Institute, 2000c); the overrepresentation of children with disabilities among those neglected and maltreated and who are in the child welfare system (Trocme, et al., 2001), etc.

For children and adults with disabilities, and their families, a rights-based approach to citizenship finally gives people a claim to press on the state, finally gives a promise of equality to challenge the violence, the poverty, the education exclusion so many face. But like so many others the members of this group face the harsh realities of the rights revolution of the latter part of the 20th century. We have largely been getting what we asked for in terms of human rights instruments – but people are still excluded. The advances in social and economic rights and human rights law for children, for people with disabilities and others, have come with three main problems.

First, exit systems are in place where the law imposes obligations on the state and others to secure human rights for people with disabilities, granting to governments, employers and providers of services ways of exiting from their responsibilities and obligations when the costs seem too high – for instance, when inclusive education imposes an ‘undue hardship’ on the school board, or when the rights of children with disabilities under Article 23 of the *UN Convention on the Rights of the Child* are limited to the extent that states have resources to deliver on them.

Second, in the Canadian legal context at least, the application of human rights law tends to provide individual compensation rather than systemic and proactive policy change. As human rights are more and more institutionalized, fewer cases based on disability are coming forward. A small subset of disability cases are proceeding, usually not those related to developmental or intellectual disability.¹ Remedies in the cases are individualized – compensation for discrimination, rather than the systemic change that this movement has been calling for. For those who do persist with a complaint, the process is long, and the outcome often provides little in return – certainly not

“inclusion” as the disability movement expresses that ideal. Often the discrimination is based on stereotypes and devaluing attitudes which the individual compensation does little to address.²

Third, human rights laws are still fragile structures when it comes to addressing discrimination and disadvantage faced by people with disabilities. These laws still need embedding in our legal and political cultures, and in our policy frameworks if they are to be instruments of change. In Canada, children with disabilities have no entitlement to the disability-related supports they require to live at home with their families, though a medical diagnosis might give them an entitlement to long-term institutional care. Moreover, attempts to institutionalize greater entitlements meet resistance and those won remain fragile. For example, the Government of Ontario repealed the provincial *Employment Equity Law* when the Conservative Party came into power in the 1990s. This law required that large employers simply identify and plan to address the workplace barriers to employment of people with disabilities, women, racial minorities and Aboriginal or First Nations peoples, that they provide reports on the progress of removal of barriers, and report on the numbers of people among these four groups who were employed in their organizations. This fragility is as true in the western industrialized countries as it is in the south. Writing in the Indian context, Sheth (1991) suggests that political, social and economic rights provisions, as advanced as they might be on paper, prove of “limited utility for those without entitlements and outside of the organized sectors” (p. 34).

For many in the disability movement these exit systems can only be resolved if we make integral to securing citizenship and human rights the process of recognizing and supporting others in ways that make their

inclusion possible and valued. But how do we get there from here? How do we confront the dilemma of the rights revolution where rights granted do not mean recognition secured? If universal human rights provisions on their own do not secure inclusion for all among those who are recognized with value and status, and

if our inclusion and value depends to a significant extent on recognition from others (e.g. school teachers, employers, community service providers, other citizens), the first step is to better understand this process of denial and the granting of the recognition we seek.

2. Jurisprudence and theories of equal recognition

How is it that children with disabilities come to be recognized as something less than fully human, less deserving of the same moral and legal status as others? How are we to understand what is at the root of the various forms of exclusion, the various ways in which children with disabilities are misrecognized? Where do we turn if a human rights strategy cannot on its own address these exclusions? In *Making All the Difference: Inclusion, Exclusion, and American Law*, Minow (1990) suggests that the social and economic boundaries that define status according to class, race, age, ability, sexual orientation, etc. – are rooted in some way in law. While statutory and case law define and grant rights, they also define conditions for exercising those rights, and for being known and recognized as a person or group able to exercise those rights. This is where the formula that equates the granting of rights, with securing equal and valued recognition, breaks down. Along with the rights granted, the exit systems the law also establishes can, in fact, mobilize the kind of recognition that devalues certain groups. We cannot fully understand the nature of exclusion of children, and of children with disabilities in particular, or how we might secure their inclusion among those fully valued, unless we bring into view this relationship between human rights, law and state policy, and the forms of knowledge and recognition they command.

Social inclusion as valued recognition – what the jurisprudence suggests

Issues of recognition by others, and who is included among those obtaining valued recognition and who is not, are central issues in recent jurisprudence in Canada concerned with interpreting constitutionally-protected equality rights. In the 1989 *Andrews v. Law Society of British Columbia* case, for example, a non-Canadian citizen argued that a provincial statute regulating the legal profession infringed on his equality rights because it restricted him from practicing law in Canada, simply on the grounds that he had not received his legal education in Canada. His nationality, he claimed, was used by a Canadian institution to recognize him and his capacities in devaluing ways. Writing the majority opinion for the Court and striking down the provision, MacIntyre J. wrote that equality rights under the Canadian *Charter of Rights and Freedoms* require:

*the promotion of a society in which all are secure in the knowledge that they are recognized at law as human beings equally deserving of concern, respect, and consideration.*³

In the 1998 *Vriend v. Alberta* case, a man brought a human rights complaint on the basis that he had been fired from a teaching position because he was gay. The Supreme Court of

Canada eventually ruled on the case, where the Court quoted a minority judgement in the *Egan* case:

A discriminatory distinction is one “capable of either promoting or perpetuating the view that the individual adversely affected by this distinction is less capable or less worthy of recognition or value as a human being or as a member of Canadian society, equally deserving of concern, respect, and consideration.”

In the *Law v. Minister of Human Resources Development* (1999) case a 35-year-old woman, denied a surviving spouse pension under the Canada Pension Plan because she was not 65, claimed she had been discriminated against on the basis of her age. In a judgement rejecting her claim, the Supreme Court of Canada reviewed cases under the equality rights section of the *Charter*, and wrote:

It may be said that the purpose of s. 15(1) [the equality rights provision in the Charter] is to prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, or political or social prejudice, and to promote a society in which all persons enjoy recognition at law as human beings or as members of Canadian society, equally capable and equally deserving of concern, respect, and consideration.

These cases suggest that what we come to know of one another, how we come to know it, and the institutionalized distinctions on which our views of one another rest, matter fundamentally. We might call the process of securing the equal value recognition characterized in these judgements as the process of social inclusion – inclusion among those recognized and valued “as a human being or as a member of Canadian society, equally deserving of concern, respect, and consideration.”

Guided by the language of the *Law v. Minister of Human Resources Development* case, this process of social inclusion is one of constructing forms of knowledge, and institutional rules and boundaries that confer recognition and respect on individuals and groups as valued members of society, and that do not systematically undermine that respect.

We cannot take for granted that rights instituted means that valued recognition follows. Despite the legal requirements to ensure equal recognition under human rights law there are instructive cases where exclusions seem enforced because of whose knowledge is given status, whose act of recognition matters. For example, in the *Eaton v. Brant County Board of Education* case⁴, the Supreme Court of Canada ruled that a school board was not required to accommodate Emily Eaton in a regular classroom because of the extent of her communication and other needs, and that a segregated environment did not impose a burden on Emily. In the Court’s view, what came to be defined as Emily’s physical, intellectual and communication competencies marked her as so different than other children that the instruction she was deemed to require was considered impossible in a regular classroom. Segregation was thereby justified.⁵ The Court ruled that knowledge about Emily’s “actual characteristics” resides only with those who know by the means of a bio-medical account of disability – where a ‘characteristic’ comes to light only by its deviation from what is presumed to be ‘normal’.⁶ Moreover, this particular form of knowledge was validated as the only foundation for defining best interests of the child in this case, and for making the educational placement. The knowledge of Emily Eaton’s parents was consigned to the category of parental preference and choice. The struggle over whose knowledge, whose form of recognition of Emily was to count, and questions about the extent to which different forms

of recognition bring dignity, were not addressed, were not adjudicated. Nonetheless, the court did decide whose knowledge of Emily was to be valued, what attitudes about Emily mattered, and what forms of recognition were to count in determining where she would go to school.

Resolving the dilemma of the rights revolution – at least in theory

If there is no simple equation between rights granted and forms of recognition that secure value and inclusion, then what other variables matter? In his analysis of the rights revolution, Ignatieff suggests that recognition of others

is something more than a process of concession and negotiation alone. Properly considered, recognition is an act of enlargement that enables both sides to envisage new possibilities of living together. We don't simply recognize each other for what we are; we recognize what we could become together (p. 136).

Honneth (1995) seeks to articulate a theory of recognition to make explicit how this 'enlargement' happens. He does so by making problematic the ways in which, and the practices with which, we come to know one another. He does not assume that rights possessed lead simply to valued recognition. Rather, he understands an extension of human rights as one strategy in weaving bonds of recognition in society. In developing a multi-layered theory of recognition, he begins with the assertion that the value of "human dignity" emerges as a mobilizing force throughout history in response to forms of personal degradation. In asking what then must constitute human dignity, Honneth suggests that it depends upon intersubjective, mutual recognition. Hegel's and Mead's theories of intersubjectivity provide

the starting point for Honneth – the self develops in "a process in which the individual can unfold a practical identity to the extent that he is capable of reassuring himself of recognition by a growing circle of communicative partners" (1995, p. 249). He proceeds to identify three distinct forms of degradation and disrespect, and corresponding forms of recognition.

Physical maltreatment of another person's body – sexual exploitation, trafficking in children, torture, other forms of physical abuse – is the first and most basic. Such actions by others bring many harms. For Honneth, one of the most profound is denying the person a recognition that personal control over and care for his or her body is, to others, worth preserving. Its converse is a form of mutual recognition that gives one self-confidence from an early age. It comes in the attachment to one's intimate circle and brings an understanding that one's physical and emotional needs can be heard and responded to by others; that others will take care with respect to one's body and grant respect to the boundaries it establishes. Such forms of recognition are granted by one's "concrete others" (Benhabib, 1987), those in a relationship of personal knowing and attachment. Honneth calls this form of recognition simply – love. But, as we have seen, love is not enough to make sure that a child can get into school, or that an adult will have a job, friends in the community, or exercise the right to vote.

So Honneth turns to the history of a second kind of disrespect – a disrespect that denies a person possession and enjoyment of legally established rights within a society. Refusing to recognize a person as a full member of society, as "a full-fledged partner in interaction who possesses equal moral rights" (p. 251), can bring a loss of self-respect. It denies the opportunity to view oneself, according to Honneth, from the standpoint of the "generalized other" in Mead's terms who is

institutionalized in established rights. The corresponding form of mutual recognition is a condition in which a person “learns to see herself from the perspective of her partners in interaction as bearers of equal rights” (p. 254). As we have seen, even as people obtain their rights as citizens, they face exclusion. Such forms of recognition are not enough.

A third form of disrespect comes from others devaluing the ways in which persons or groups realize themselves, the form of life they establish or participate in, “within the horizon of the cultural traditions of a given society” (p. 251). Such a denial of recognition for the social contributions and forms of life of others undermines the value that a person or group can attach to their own abilities, their own ways of life. Honneth sees the counterpart form of mutual recognition as “solidarity” – an approval for “unconventional lifestyles” and valuing of people’s uniqueness and difference. Such approval across cultural, racial, linguistic and genetic differences, for example, provides individuals and groups with a cultural vantage point from which to affirm and value their own differences, and those of others.

These three types or “patterns” of mutual recognition – love, right and solidarity – each correspond to different levels of society: those concrete others in intimate relation to a person; the institutional framework of a society and, the broader set of cultural values and social forces. I find in Honneth’s framework a key source for conceptualizing social inclusion as a multi-faceted and dynamic process for constructing at interpersonal, institutional, and societal levels the valuing forms of knowledge and recognition the Supreme Court of Canada suggests are central to realizing human dignity and equal recognition of worth.

Towards a social inclusion as solidarity agenda

I would argue for a social inclusion agenda that focuses more clearly than it has on Honneth’s third level of recognition – of building a social solidarity that can bring value and recognition across differences of gender, language, communication, culture, age, ability, etc. This is not to leave aside a concern for fostering capacities and conditions for nurturing and attachment (level 1 in Honneth’s framework), or for strengthening protection, participation and provision rights for children (level 2). Rather, it is to acknowledge that the solidarity that brings recognition across deeply divided social spaces is weak in certain respects in Canadian and other societies. Formulated in this way, ‘solidarity’ is not simply about coalition building, or forging alliances for a particular political struggle. Following Honneth, it is much more about bringing to critical light the extent of recognition granted to different forms of life, the breadth of diversity that a particular set of cultural and institutional arrangements allow, and the forms of knowledge that fortify exclusionary divides.

Advancing solidarity – in the way that Honneth defines the term – as valuing forms of life characterized by many social differences including race, ethnicity, language and disability, can be read as a guiding purpose in recent political philosophy. In *Inclusion and Democracy* (2000), for instance, Young suggests that solidarity is now a goal we need to pursue in order to secure inclusion for disadvantaged groups defined by culture, race, gender and disability in the benefits and resources allocated by state and society (housing, for example). She also advances solidarity as a goal to guide strategies and designs for political inclusion in processes of decision-making in local, regional, national and international governance. She frames the ideal as “differentiated solidarity” to account for the fact that valued recognition of

others can mean supporting groups to form and support one another on the basis of particular affinities of race, ethnicity, etc. For Young, solidarity creates an obligation to “constitute and support institutions of collective actions organized to bring about relations of justice among persons” – where she defines justice as obtaining the conditions for self-development and self-determination (p. 224). By bringing focus to solidarity as the test for the inclusiveness of social, economic and political institutions, Honneth and Young provide a vantage point for thinking about the possibilities and limitations of granting rights protections. Human rights can also serve as a test of inclusiveness – i.e., do all individuals and groups have adequate rights protections to enable them to access social, economic and political institutions? The test of solidarity shifts the obligation for securing inclusion exclusively from those who must press their rights claims in order to get access to the education system, or to paid employment, or to the political process. A focus on solidarity puts the obligation on others to enable those claims to be made and realized. It establishes the obligation, for example, to create education systems where all children can be included and fully recognized by others in ways that value them, and thereby thrive.

A conception of solidarity can also be rooted in the intellectual contributions to understanding societal recognition of different groups made by Canadian philosophers. For instance, Taylor (1994) called the politics of our times a ‘politics of recognition’; Tully (1995) refers to the ‘politics of cultural recognition’ in his study of the constitutional misrecognition of First Nations peoples in Canada; Kymlicka’s (1995) study advances proposals for securing recognition of diverse and disadvantaged cultural communities through constitutional and legal protection of minority rights and O’Neill’s (1994) study of children

demonstrates their absence from the visions of liberal political theory. Honneth’s work, and that of Canadian political philosophers are informing theories and proposals for recognition of diverse and marginalized religious, ethnic, and cultural communities in the U.S. (Gutmann 1994), in India (Chandoke 1999), and in the European Community (Habermas 1998) to name a few of the applications. Much of this work seeks to account for the ‘struggle for recognition’ of diverse groups in a political age so defined by individual rights.⁷

Solidarity is O’Neill’s answer to the question about what can ground a full citizenship for children in an age defined by liberal individual rights. As he writes in *The Missing Child in Liberal Theory*, “any form of sustainable society is grounded in a vast lore/law that requires us to extend ourselves in a community of civic obligation towards others whose recognition simultaneously affords us our own moral worth” (1994, p. 86). And, he confirms, solidarity is a means by which this kind of recognition is mobilized in a society, it is the basis of “any adequate concept of citizenship” (p. 111).

Solidarity is also one way of answering Tully’s question about the “spirit” appropriate to an age of cultural diversity. After his detailed analysis of the conventions for a constitutionalism that could account for that diversity in the Canadian context, and after his argument that “mutual recognition” among cultures must be a guiding convention for such a constitutionalism, he quotes Vaclav Havel to answer his question: “if the world today is not to become hopelessly enmeshed in ever more terrifying conflicts, it has only one possibility: it must deliberately breathe the spirit of multicultural co-existence into the civilization that envelops it.” Still quoting, Tully writes “the ‘basis’ of this ‘new spirit’ is for different peoples, religions, cultures’ to learn to ‘respect each other’, to ‘respect and honour each others’

differences” (p. 212).

Taylor suggests that in the midst of our contemporary diversity, what makes us equally worthy of respect is a “universal human potential, a capacity all humans share. This potential, rather than anything a person may have made of it, is what ensures that each person deserves respect.” Moreover, “our sense of the importance of potentiality reaches so far that we extend this protection even to people who through some circumstance that has befallen them are incapable of realizing their potential in the normal way” (1994, pp. 41-42). Taylor argues that this “presumption” of equal worth should guide our “approach” to others different from us, and help guide us through the contemporary struggles and “politics of recognition”. With Habermas, I would say that solidarity names the acts of approaching, recognizing, and honouring others in ways that bring an equal worth and respect, even to the strangers in our midst:

Equal respect for everyone is not limited to those who are like us; it extends to the person of the other in his or her otherness. And solidarity with the other as one of us refers to the flexible “we” of a community that resists all substantive determinations and extends its permeable boundaries ever further. This moral community constitutes itself solely by way of the negative idea of abolishing discrimination and harm and of extending relations of mutual recognition to include marginalized men and women... The “inclusion of the other” means... that the boundaries of the community are open for all... and most especially for those who are strangers to one another and want to remain strangers (Habermas, 1998, pp. xxxv-xxxvi).

There is yet an adequate study to be done in political philosophy that would consider how people with disabilities might be viewed as

a cultural community whose status is deserving of the recognition, collective rights and constitutional protections that Kymlicka, Taylor, Tully, Chandoke and others consider necessary for other cultural communities more conventionally defined. In studies extending the analysis beyond ethno-racial-cultural-linguistic communities, there should be no simple equation with differences defined by gender as Wolf (1994) has argued, and I suspect the same is true for disability. But there are useful links and equivalencies to be drawn. Certainly, the negative stereotyping and construction of people with disabilities as diseased, as deficits, as abnormal, to be rehabilitated, or genetically cleansed, suggests disadvantages and cultural harm similar in scale to other groups for whom claims to cultural and political recognition have become so urgent. And certainly within the disability movement claims for recognition of rights to self-determination, to escape institutional confinement, etc. echo the calls of other groups in many ways. Moreover, without more collectively defined rights to needed disability-related supports and accommodations in education, the labour market, etc. there is little doubt that the citizenship of this group remains diminished and neglected.

There is no uniform answer to the constitutional and human rights guarantees necessary to recognize cultural diversity, and indeed the solution is undoubtedly place and nation specific. While they disagree to some extent on what the rights regime might look like, and some focus on actual proposals more than others, Taylor, Tully, Chandoke, Honneth, Habermas, Young, and others look beyond particular frameworks of rights for solutions to the misrecognitions and failures of recognition in our age of diversity. They theorize and seek to establish principles for the acts of solidarity, the modes of dialogue, the cultural means of recognition which might ground and help to negotiate an adequate framework of rights in differ-

ent settings. Either implicitly or explicitly they distinguish the recognition that comes with rights granted, from the social solidarity and political culture that makes those rights manifest and that hold a promise for cultural recognition. It is an atrophied or absent “spirit” and political culture of recognition, or solidarity, that helps to explain the negotiation of an unjust framework of rights and a daily disrespect in so many lives.

I believe that useful implications for a social inclusion agenda for children with disabilities can be drawn from Honneth’s analysis of how institutionalized rights are inadequate

on their own to ensure valued recognition. Understandings of other theorists in social and political philosophy about the need for solidarity and mutual recognition to ground a just framework of rights can also contribute to such an agenda. Collectively, their work brings me to an assessment and to a question: The current frameworks of constitutional and statutory rights do not yet secure inclusion for Emily Eaton among classmates in a regular school where possibilities for her valued recognition might have a fighting chance. So what other strategies might a broader solidarity agenda point toward?

3. A ‘social inclusion as solidarity’ agenda for children with disabilities

Given the dilemma of rights and recognition I have outlined above, I would argue that we need a focused public agenda to advance solidarity with children with disabilities and their families. Undoubtedly, there are numerous issues to confront. But the analysis I have laid out in this paper suggests the challenge is to build a broadly-based valued recognition in society of children with disabilities on which the numerous issues can then be better addressed; and on which the full citizenship of children with disabilities will rest. Otherwise, the citizenship of all of us – who withhold that solidarity – will be diminished. In Ignatieff’s terms, our sense of self and community will not be ‘enlarged’ to the extent it might have been if we had more widely woven the bonds of recognition and reciprocity.

I suggest three priorities for a public agenda to build ‘solidarity for social inclusion’ of children who are marginalized and devalued because they do not measure up to physical and intellectual norms. These priorities are distilled from three aspects of exclusion that

the current rights discourse has not fully addressed: i) institutionalized forms of knowledge that stereotype and objectify on the basis of disability; ii) misrecognition and devaluing of different forms of physical and intellectual life (i.e. genetic differences read as genetic deficiencies and abnormalities) and iii) a ‘naturalizing’ of certain kinds of capacities and developmental paths over others (i.e. particular, dominant forms of communication and mobility that devalue other forms of communication or mobility, and thereby undermine justifications for investment in developing alternative capacities). Formulated in this way, these issues go beyond education, or the need for disability supports, or child poverty per se. When the question is about the forms of recognition that result in various exclusions of children with disabilities then new, and I believe deeper, issues rise to the surface.

Stereotyping and objectification in public policy

It is clear that Emily Eaton was excluded from

a regular classroom because of the way in which the conflict over different forms of knowledge was adjudicated. Forms and technologies for producing knowledge based on a typology of disorders and capacities which constructs disability as a fixed and absolute quantity ruled the day. The social and economic relations by which those technologies were deployed were occluded in the adjudication (the professional interests, the institutionalized requirements for an either/or educational placement process, the history of the constructs that informed the categorical assessments of Emily). Thus disability came to be seen as an ontological feature of an individual life rather than a social relation, a status ascribed by others. In another case put before the Supreme Court of Canada, which dealt with a right to interpreter services in order to effect the right to access health care services, this social construction of disability was a central element of the ruling and led to a very different conclusion by the Court:

It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions. The historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the “equal concern, respect and consideration” that s.15(1) of the Charter demands. Instead they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms.⁸

The conflict over whose knowledge should matter and how is at the core of what moral philosopher Lorraine Code (1987) refers to as “epistemic responsibility” – the moral responsibility for knowing others well. She suggests this requires that we do not objectify others beyond recognition as humans. We have a responsibility not to use stereotypes in knowing others – because that is the source of hate, of devaluation of others (Code, 1989). She suggests, along with other philosophers MacIntyre (1981), Taylor (1989), Benhabib (1986), Kearney (1998) that we can only know another well if we know them narratively – or through their personal story. We become valued in the eyes of others, and our ‘self’ is born – only in stories written and rewritten by ourselves and those who know us – stories of the past, of hopes for a future. Research has shown, in fact, that people’s attitudes about those with disabilities change most clearly when they come to know them personally, and coming to know someone personally is to know them through their personal stories of struggle, of hope, of pain, of misfortune, of likes and dislikes, of family and friends (The Roehrer Institute, 2000a).

Kearney (1998) writes of the ‘moral-transformative’ nature of witnessing the personal narratives of others in public spaces and forums. In their witnessing, such narratives are the source of empathy and the stuff of new social bonds. In the stories heard lies a critique of structures of domination that exclude. In the moral visions they point to are utopias for the future. The recent report of the Law Commission of Canada (2000) on abuse of children in institutions considers whether such an approach – through a Truth Commission, for example – might be needed to bring about valued recognition of and restitution for victims of abuse. Truth and reconciliation commissions in South Africa, the Nuremberg trials and the work of the War Crimes Tribunal in

gathering testimony from refugees fleeing Kosovo, are all examples of the work of building solidarity on which a new foundation for affirming and asserting rights was established, even if in the midst of horrific abuses of those rights.

Knowledge is not a neutral affair, and state and other interests in regulating the status of different accounts about a child with a disability are determinative in a child's life and possibilities. A social inclusion as solidarity agenda for children must confront the question of whose knowledge counts in public policies regulating educational placement, and other allocation decisions (such as triaging of health services for children whose projected quality of life might be considered inadequate to justify heart surgery; long-term institutionalization of children). It must also consider how to nurture new forms of social knowledge that bring to life the narratives of those systematically excluded by disability, by poverty, by institutionalization. I suggest three possible directions to explore in such an agenda.

First, clear principles are needed to guide public policy to ensure that personal, narrative knowledge of a child's capacities, hopes, forms of communication, needs – often the knowledge with which parents and family members have the most expertise – is granted priority status in educational placement decisions for children with disabilities.

Second, there is a need to critically examine and revise eligibility criteria for access to needed health and social supports at home, in the community, and at school in order to question the forms of knowledge-making that require parents to have their children labelled with 'severe' deficits and syndromes as a condition of gaining access to any supports at all. In the education system, the examination might look at the 'catch 22' many parents encounter: have a child labelled as severely as possible in

order to gain access to supports, but then face the prospect that the child may not be placed in a regular classroom because those responsible for gathering knowledge to determine educational placements will likely find the child too severely disabled to benefit from, or to be accommodated into, a regular classroom. Efforts to restructure relationships and status between different forms of knowledge would be driven by the insight that children with disabilities will come to be known by others as children first, only if they are borne through personal narratives about their possibilities, and not confined by labels and stereotypes.

Third, consideration might be given to the creation of a public sphere where children, youth and adults with disabilities (including the disproportionately high proportion who live in poverty), and their families, can document and widely share their own personal stories (their hopes, their accomplishments, the barriers they face in accessing services, jobs, food, adequate income). The forums and public media that might help constitute such a public space could help shape a political culture strong enough to advance a full citizenship agenda for people with disabilities and their families (through reforms in social assistance, income tax, labour market policy - e.g. paid leave for caregiving - and disability supports policy, for example). Without such a public sphere, Canadians are unable to witness and come face-to-face with the realities of a growing proportion of the population. The creation of an inclusive public sphere does not replace the need for a human rights agenda. A social inclusion as solidarity strategy would supplement the agenda. It would focus on the apparent lack of political will to advance anti-poverty and social support policies; on the need to foster a more supportive political culture; and on the need to form bonds of solidarity to nurture such a culture. That solidarity is only possible if Canadians come to hear and witness the

faces and stories of disability and poverty in Canada. One might argue that Canadians have heard, and they won't listen, but such an argument should not be accepted uncritically. It may be that our strategies for solidarity-building – for giving testimony and witnessing – have not been compelling enough, and that they need rethinking.

Public policy and genetic value

There are growing concerns in the disability movement about the eugenic potential of the genetic technology revolution, and the implications for public policy are just now being articulated. As standards of good prenatal care in some jurisdictions now require publicly funded genetic testing (Weir, 1996) and as the (in part) publicly financed Human Genome Project draws the boundary around what it means to be genetically 'human', the status of those with genotypes outside of the norm comes into question, and human value tends to be reduced to genetic makeup (Wolf, 1995). Recent legal judgments confirm such outcomes. Damages for 'wrongful birth' are being awarded to parents of children born with disabilities, because the mother's physician did not make available the genetic testing that would have identified Down's syndrome, for example, or give the woman information on which to base a decision about selective abortion. Genetic screens and tests are technologies for knowing others as genetically deficient and therefore as something less than human. As technologies for knowing and judging the possibilities and shape of human life, they should be a central concern in an agenda for the valued recognition and status of all children. The information they generate can present a divide in social solidarity that is difficult to overcome without a conscious rethinking of how the knowledge is produced and used. Otherwise,

the technologies will sustain and supplement forces of exclusion. Their very existence, for example, has been used by insurance companies to suggest that parents who knowingly bear a child with so-called 'genetic deficiencies' should not be eligible for the extended benefits for that child (Wolf, 1995). The possibilities of genetic knowing makes the bearing of a child with a disability a private affair, and therefore makes the financial responsibility for care a private matter as well.

Who benefits from the genetic technology revolution? The biotechnology research and development industry clearly benefits with the equation of genetic normalcy and good maternal health care. The value of 'gentech' stocks skyrocket, and health care systems in Canada and elsewhere absorb the burgeoning costs of purchasing genetic screens, and physician charges for applying the tests. The insurance industry benefits as it divests itself of responsibility for the costs of care where women make decisions to bear children who might have a disability. The industry also benefits as the costs of medical insurance balloon in the wake of recent decisions like that of the highest appeal court in France to award damages against a physician that did not genetically test a fetus for Down's syndrome prior to the child's birth.

But at what cost? The cost, the disability rights movement and some ethicists are arguing, is the perpetuation of the stereotype of disability as abnormal, as a burden, as a genetic failure that should be cleansed (Asch and Geller, 1996; Wolf, 1995; Cole 2001). Just as decisions to selectively abort on the basis of sex are understood to do harm beyond the fetus involved, to do harm to women as a whole, so too selective abortion on the basis of disability has been argued to bring harm to people with disabilities as a whole. The availability of the technology and its systematic use threaten a

eugenics that makes mutual recognition across the differences between us that much more difficult to nurture.

What might a social inclusion as solidarity agenda entail were it to address the divides being established among humans on the basis of their genotypes and screened genetic conditions? Caulfield, et al. (2001) suggest the need for an analytic framework of “tests” to determine whether public funding or access to a genetic test is justified. The first analytic test determines whether a particular genetic service is “morally acceptable”. Such a framework provides a useful place to begin, depending of course on how the criteria for ‘moral acceptability’ are determined. To deal with the concern that ‘disability’ might be left as morally ‘irrelevant’, a framework to regulate both research and applications in the health care system might also require that groups who may be adversely affected by genetic research or applications (e.g. through the stereotypes it might perpetrate, or through the inattention in research to the ethical and legal questions genetic technologies raise) be part of the ethics approvals process. This could be fairly simply addressed by requiring that representatives of national or regional disability rights organizations be part of ethics review committees at major research institutions (universities, Canadian Institutes for Health Research), and be part of any technology assessment process that guides development of purchasing and practice guidelines in the health care system. Their participation would ensure that the perspectives of people with disabilities are part of the ongoing dialogue about the potential for a new eugenics that genetic research and testing/screening raises, and about the guidelines to be developed for minimizing such risks.

Ensuring an inclusive design for the national monitoring mechanisms on genetic research and applications in Canada, called for under the recent UNESCO *Declaration on*

Human Rights and the Human Genome to which Canada is a signatory, could also help to advance solidarity across the genetic divides now being etched. The monitoring mechanisms should engage disability, First Nations, and other groups who stand to be substantially disadvantaged through basic and applied genetic research (e.g. by ‘patenting’ of genetic sequences, or by the hierarchy of human value that comes with the enterprise to establish normal and abnormal genotypes). The national monitoring mechanisms could be structured to ensure that groups are resourced to participate in the monitoring of impacts of genetic technologies, and in the consideration of regulatory frameworks to ensure that the research accords with the commitments in the UNESCO Declaration to ensure a recognition of and respect for human diversity, dignity, and human rights. Solidarity emerges through understanding that often comes with face-to-face dialogue. Ongoing dialogues between geneticists and people with disabilities could be organized to resist the genetic reductionism that has come with much of the new wave of genetic research under the Human Genome Project.

These specific strategies would not address all of the citizenship and inclusion issues raised by the spectre of the genetic revolution. A human rights agenda is also clearly needed to ensure that adequate protections are in place to prevent discrimination on the basis of genetic differences – in access to insurance coverage, health care, education, training and the paid labour market, etc. But, on their own, such human rights provisions will likely be as inadequate in securing full citizenship as are existing human rights provisions in ensuring equality and prevention of discrimination on other grounds. A social inclusion as solidarity agenda would help to bridge the gulf of understanding between the scientific community and the truths it bears (which often seem

invulnerable to human rights provisions), and the disability community whose members bear the narrative knowledge of human life well-lived in the midst of genetic diversity. At its core, the solidarity agenda must confront the forms and technologies of knowledge-making used to establish hierarchies of human value, and give greater status to forms of knowledge borne by those near the bottom of the hierarchy.

Measuring healthy child development

Psychoanalytic theory, theories of cognitive development and social psychology all emphasize that healthy, “normal” development occurs as infants, toddlers, young children and adolescents reach and pass through certain developmental stages or benchmarks. Failure to reach certain stages (in terms of language and communication abilities, cognitive, and motor skills and ego and identity formation) is usually regarded as a sign of “abnormal development”. When failure is first noticed, assessments are often called for to determine nature of disability, and to assign a particular bio-medical status.

The systematic exclusion of children with disabilities from a conceptual and monitoring framework of healthy child development is evident in a growing body of literature on the importance of ensuring that adequate investments are made in the 0-6 age group so that they are “ready to learn” at school age (McCain and Mustard, 1999). Indicators of readiness to learn usually include:

- physical well-being and appropriate motor development
- emotional health and a positive approach to new experiences
- age-appropriate social knowledge and competence

- age-appropriate language skills
- age-appropriate general knowledge and cognitive skills.⁹

Many children with disabilities are simply unable to meet some of these developmental outcomes. They may communicate in different ways than the majority of children raised in a hearing and English- or French-speaking culture. They may not be able to move in the same ways or have the same kinds of agility as those who fall within the statistically “normal” range. When viewed from the perspective of children with disabilities, the cultural bias of these outcomes is clear. They mark a group of children that education systems, in their current design, are most able to include and educate. They are based on a narrow theory of development in which verbal language skills are associated with cognitive development, readiness to learn and healthy development.

Establishing a framework of developmental outcomes is not simply an exercise of academic value. With the recent adoption by the federal and provincial/territorial governments of the ‘Early Childhood Development Agreement’, the federal government has committed a transfer to provinces and territories of \$2.2 billion a year for five years for early childhood services. Both levels of government have committed to monitoring their investments in early child development and the outcomes for children. How outcomes are conceptualized, and the benchmarks selected for developmental progress, will help to determine which children are seen to most benefit from investments. Concerns have been expressed that some children with developmental and other disabilities are losing access to early childhood services such as speech and language therapy because these children are considered unable to adequately benefit from this investment. It is believed that the scarce dollars and services would be better invested in other children.¹⁰

Mackelprang and Salsgiver (1999) review some of the intellectual foundations for a broader view of developmental theory that would begin to address the cultural biases of predominant approaches, and make possible the development of a more inclusive set of outcomes and indicators. This work suggests we need to shift from measuring the gap between age and expected developmental achievements, to focus on the conditions that enable people with disabilities to carry out “developmental tasks”, that are culturally shared and defined. To be able to communicate with others, for instance, is a developmental task whose achievement need not be measured by verbal language skills in the dominant language. Moving into adulthood need not be defined by the capacity for independence, which would exclude from successful adult achievement those who require ongoing personal supports. It can also be defined by the control one is given over one’s supports, and the opportunity to develop and pursue a wider range of goals.

A more inclusive developmental framework for children would pay more attention to conditions which enable access to needed resources and which structure opportunities for development, for social interaction and for exercising control over one’s environment. Novick, drawing on the work of the Laidlaw Foundation’s *Children at Risk Programme* and a wide body of research in the field, suggests that an adequate theory of child development must incorporate an understanding of the various domains which structure opportunities, social interaction, control and access to resources. He includes the structural domain (broad societal cultural forces), institutional, personal, familial and communal domains.¹¹ This approach shifts the focus from one of strict age-related developmental stages to be achieved, to an understanding that every child has a unique “developmental path” (or unique ways of realizing different developmental tasks whether they

be managing communication and interaction with others, developing personal identity, moving from adolescence into adulthood). The task of public policy, social investment and community development is to ensure that children have access to the life chances they need to pursue and realize their unique path across all domains of development. How different domains structure and distribute life chances, in ways that account for differences of sex, race, economic class and disability becomes a subject for research and a matter of public monitoring.¹² Taylor’s formulation, of each person’s unique potential as the basis of worth and equal respect, provides the ethical foundation for a public policy that values diverse developmental paths. It provides an ethical foundation for choosing self-anchored indicators in measuring a child’s development.¹³

How could a social inclusion as solidarity agenda be struck to confront the divides structured in a developmental investment strategy that values children with certain physical, intellectual and developmental characteristics over others? First, it is essential that an inclusive framework of developmental outcomes be established as the basis of public investments and monitoring. Second, population survey instruments are needed to gather data on indicators consistent with outcomes and domains of development incorporated into the framework, with a particular emphasis on the extent to which children obtain the needed supports and opportunities to develop and exercise communicative and other capacities. Third, disability organizations could be supported to engage in the public monitoring of child outcomes so that perspectives of children and youth with disabilities are adequately represented. Population survey instruments could then be designed to incorporate evolving understandings of needed supports and the various ways children develop and exercise learning, communicative and other capacities. Finally,

given the importance of communicative capacities to a child's intellectual and social development, it is essential to critically review the breadth of communication systems funded and used in early childhood services and the education system (e.g. written and spoken language, sign language interpretation, augmentative communication technologies and use of a child's unique gestural and behavioural sign systems where spoken language is not used).

A social inclusion as solidarity agenda asks *what* knowledge, *whose* knowledge, and which communicative competencies are left outside of public sphere and public discourse. Bridging social, economic and cultural differences that bring valued recognition to those who are devalued and excluded, requires that we promote dialogue and understanding across public spaces previously silent to their voices and their realities. The agenda *would not* be

about ensuring everyone's access to every benefit and advantage Canadian institutions have to offer. Rather, it would ask that distinctions made in the rules and practices of institutions, services and organizations not systematically undermine the recognition and status of any group based on their age, capacity, sexual orientation, gender, etc. Moreover, it would be about fostering forms of knowledge and recognition that value others, and about questioning forms of recognition that distance, that devalue, that cast aside. At an institutional level it would add to the rights protections associated with citizenship, a prescription to identify and transform policies and practices that violate human dignity through stereotyping and discrimination. At a personal level it would call for a 'virtue' of citizenship practised through knowing and recognizing others in ways that bring human dignity.

Conclusion: Policy Implications

Women's movements, disability rights activists, poverty action groups¹⁴, First Nations' members and various groups based on distinct ethno-racial-linguistic differences increasingly claim exclusion of one form or another. These are important voices. They speak from outside institutions and organizations of power, privilege and advantage in Canadian society. They tell us something about ourselves, about how we are 'reacting' to the differences in our midst, about our collective state of imperfection. At their roots, these claims of exclusion are about the denial of valued recognition in Canadian society, and speak back to the ways that some come to be known by others. The denial of valued recognition is organized in concrete ways through our political culture, legal systems, public policies and practices.

In this paper I have suggested that we can usefully understand social inclusion as a political claim, as an ideal for social institutions and as a process for building solidarity and valued recognition across diverse persons and groups in the spaces structured by the state and civil society – schools, labour markets, health care institutions, community associations, public governance, etc. Social inclusion is about rewriting the rules, recasting our cultural images and resources and instituting practices to bring equally valued status to those who have been assigned a place of lesser value and status in Canadian society. Social inclusion does not demand that we assimilate and homogenize social and cultural differences in our education, health care, political and other systems. Valued recognition of others entails respecting their differences and identities in

ways that enable them to speak their voices, exercise their rights, and secure their own path to well-being. Social inclusion also demands reciprocity. Groups who seek status and public space, but whose mission and practice involves stereotyping and devaluing others, are not deserving of equally valued recognition and status by their broader society.

What are the policy implications of this understanding of social inclusion for advancing the well-being of children in Canada? First, it brings focus to the ways in which knowledge about children, and about certain groups of children is made. It asks about the status that different kinds of knowledge are given in gaining access to these different settings and institutions. Forms of knowledge that stereotype children as so different than other children that they are refused access to education, for instance, are challenged in such an agenda.

Secondly, an agenda for social inclusion raises a challenge to create new public spaces where the lives and realities of children and their families can be witnessed, where testimony can be given, where a new commitment to invest can take root. It is in these acts of recognition that the other, Kearney argues, comes to make an ethical difference, where new social bonds can be woven across the differences that divide. Surely this is the promise of a citizenship that values belonging, dignity, reciprocity and respect - where rights claims and aspirations obtain not only legal but broad social recognition and commitment. Only then are needed policy investments likely to follow. I believe the analysis outlined above applies not only to issues facing children with disabilities and their families; they have provided a case study with which to explore the notion of social inclusion as solidarity. The analysis, it seems to me, applies also to other issues affecting children. Persistent, deepening child poverty in Canada, for example, is not a consequence of a lack of resources, or labour

markets and policies that cannot be restructured. It results from a lack of will and commitment, where the fact of poverty does not seem to matter enough. A social inclusion as solidarity agenda focuses, for example, on building a much wider recognition of the realities of children and families who are poor, of making their realities matter to all Canadians in a way that commitment to address the structural roots of poverty will follow. A solidarity agenda does not on its own put bread on the table. It creates the public consciousness and commitment for public policies and practices to make sure it gets there.

A social inclusion as solidarity agenda should be paramount if we are to move forward on the kind of covenant for children that O'Neill (1994) calls for, and address the exclusions that persist. The covenant does not need to be written. It is already expressed in many national and international human rights instruments – most clearly for children in the *Convention on the Rights of the Child*. It could be articulated anew, but the sources for its expression and for legal and moral obligation are there. What is missing is the commitment to realize it. What is missing is the process of social inclusion that will bring all children within the ambit of moral consideration, worthy of securing the personal and collective obligations they are due. So many children and families are absent from the public sphere – children with disabilities and their families, aboriginal children, children growing up in poverty, victims of abuse and violence. Commitment for the covenant will grow only as their testimonies are more widely witnessed, their realities and possibilities more clearly documented in population surveys and by other means, and in ways that make their concerns and aspirations resonate in Canadian political culture. By these means we might shed better light on the absences in our collective social imaginations.

Social inclusion as solidarity does not deny the need for a strong framework of rights for children. It does require that we look at how children and youth come to be known, at the policies and practices of genetic differencing, of educational segregation, of communicational straightjacketing. A solidarity agenda would not seek to eradicate diversity. It would make problematic the organization of advantage and disadvantage across the differences that define us. With such an agenda we would not be satisfied with a simple extension of rights, safe in the knowledge that children and adults can then press claims to battle the walls that exclude them. It would demand that 'citizenship virtues' of reciprocity, or knowing others well, be actively fostered. It would sound a call to mobilize personal and collective forms of recognition that bring dignity and value to all children.

I have sought throughout this paper to draw the links between human rights, full citizenship, social inclusion and solidarity. The notion of citizenship and what it requires has evolved historically through many political and intellectual struggles. The calls for social inclusion have been made in its shadow – calls to be included as citizens from those not yet seen in the light it sheds. Hence, the strategies for social inclusion have evolved and changed as the concept of citizenship has been rewritten. In the past 50 years, a human rights agenda has been the most compelling strategy to advance inclusive citizenship. While that agenda has clearly not yet been fulfilled, it is becoming increasingly clear that, on its own, it still leaves some in the shadows. I have suggested that a solidarity agenda should now constitute a major agenda for socially inclusive citizenship – one that fully accounts for and recognizes all children in equally valuing ways. In the arguments I have laid out here a solidarity agenda need not depart from a human rights agenda. Rather, they represent different orders of analy-

sis and criticism in a common cause to secure valued recognition of devalued groups.

Institutionalizing human rights has been one means to fuel the social inclusion of devalued groups among those who obtain valued recognition and citizenship in society's institutions. Solidarity agendas must also be struck to complement establishment of human rights if we are to more fully confront the refusal by some to include others in ways that bring value, respect and dignity. Social inclusion is not the aim. Valued recognition, respect and dignity that make full social, economic and political participation possible, name the core elements of citizenship and the aspirations to which human rights instruments intend. Social inclusion names social and political struggles to realize these aspirations in the lives of people and groups so often misrecognized, devalued and denied. It offers an ideal for institutional arrangements. Criteria for inclusivity could also help guide institutional reform.

In these times we find ourselves in, a commitment to social inclusion must involve steps to bring understanding across the divides that establish race, language, gender, ability, creed, genotype, economic class and nationality as grounds of status and value. To bring inclusion where it has so often been denied, we must forge a solidarity that listens across these divides of status and then questions their roots in law and in domestic and foreign policy. We must question the institutionalized refusal to know and respect others well. Thereby, the daily realization of children's rights might become a much deeper concern and commitment for governments, communities and other citizens. The evidence makes clear that a solidarity and political culture valuing all children is certainly not a given in our society; it is yet to be woven.

Endnotes

- ¹ This may be because the link between reason and citizenship remains firmly entrenched in our political culture, statutory law and legal reasoning making human rights claims by people with intellectual disabilities that much harder to press.
- ² See Judith Mosoff, "Is the Human Rights Paradigm 'Able' to Include Disability? Who's In? Who Wins? What? Why?," *Queens Law Journal* 26 (2001).
- ³ *Andrews v. Law Society of British Columbia*, 1 S.C.R. 143 at 171 (1989).
- ⁴ *Eaton v. Brant County Board of Education*, 1 S.C.R. 241 (1997).
- ⁵ For a detailed analysis of this case see the Canadian Association for Community Living, *Intellectual Disability and the Supreme Court: The Implications of the Charter for People who have a Disability*, (Toronto, 1999).
- ⁶ In contrast, a "social model" of disability is being advanced by those who find in the bio-medical account a reductionist tendency – reducing the disability to individual characteristics defined as deficits (Barnes, 1991; Rioux, 1994; Oliver, 1996). In a social model, disability arises from the discrimination and disadvantage individuals experience in relation to others because of their particular differences and characteristics. This shift in thinking finds a primary source in feminist theories of difference where the challenge is to recognize differences of gender, race, sexual orientation, physical and intellectual characteristic, etc. without assigning social or economic value on the basis of these differences (Minow, 1990).
- ⁷ Kymlicka's (1989) analysis of liberal and communitarian theories of the self helped enormously in resolving the theoretical impasse between liberal accounts of the political and ethical primacy of the individual, and communitarian accounts of the person that emphasize the importance of community, tradition and culture (e.g. MacIntyre, 1981; Sandel, 1982). Kymlicka addressed the impasse by revealing the link between the self-development and self-determination that liberal political philosophy so values, and the availability of cultural resources that a community provides an individual – resources of language, modes of thought, horizons of meaning, etc. Recognizing the centrality of community and culture to individual self-development and freedom begs the question of how to provide recognition and protection for diverse communities, some of which may be threatened by cultural genocide, which face systematic discrimination by dominant cultures, or which come into being with the massive dislocations and migrations that are unlikely to subside in these times.
- ⁸ *Eldridge v. British Columbia (Attorney General)*, 141 D.L.R. (4th) 577 at 613 (1997). In confronting the issue of recognition of people with disabilities in Canadian society directly, the court moved to clearly articulate a "right to effective communication" in this case, establishing that in order for deaf citizens in Canada to access their right to health care, they were entitled to interpreter services in the health care system.
- ⁹ See G. Doherty, *Zero to Six: The Basis for School Readiness* (Ottawa: Human Resources Development Canada, 1997).

- ¹⁰ Examples of children who lost access to such services were reported in a series of consultations conducted by The Roeher Institute. See The Roeher Institute, *Moving In Unison into Action* (Toronto, 2001(b)).
- ¹¹ See Marvyn Novick, "Prospects for Children: Life Chances and Civic Society" (Toronto: Laidlaw Foundation, 1997).
- ¹² The Roeher Institute has drawn on this work and related literature, as well as a series of consultations with disability and family organizations, children's services providers and government policy analysts, to reconceptualize a framework of healthy child development for monitoring public investments and their impact on children. The framework includes a set of seven developmental outcomes, framed to be inclusive in their basic conceptualization (e.g. all children could meet the developmental targets with adequate supports). The outcomes include: physical well-being, emotional and mental well-being, social well-being (membership, participation, social relationships), spiritual well-being, communicative capacity, learning capacity and a positive future for a child envisioned by others. The 'domains of development' which should provide support and opportunity for children to pursue and reach these outcomes include family, school, community, paid labour market (for parents), public policy (for investment in needed developmental supports). This framework is presented and discussed in The Roeher Institute, *Toward An Inclusive Approach To Monitoring Investments And Outcomes In Child Development And Learning: Draft Discussion Document* (Toronto, 2001c).
- ¹³ Self-anchored indicators measure a child's progress in reaching their own potential. Rather than measuring a child against a fixed norm or criterion of capacity, self-anchored indicators measure a child's progress over time in meeting his or her unique communicational, motor, relational, learning and other goals. Self-anchored indicators are already in use in some population surveys. For example, the National Population Health Survey asks people to rate their own health status. Such a survey leaves the definition of health up to the respondent. For a discussion of self-anchored indicators and a critique of norm-referenced assessments as the sole basis for assessing child development, see The Roeher Institute, *Toward An Inclusive Approach To Monitoring Investments And Outcomes In Child Development And Learning: Draft Discussion Document* (Toronto, 2001c).
- ¹⁴ I am not suggesting here that 'poverty' represents a difference that should be valued, or that those living in poverty constitute a unique cultural identity of their own choosing. We need a sustained attack on poverty that addresses its systemic roots in inequitable access to education, labour markets, income support, health care, social supports, transportation and decent housing. I am arguing, however, that those living in poverty tend to be constituted by others in stereotyped and devaluing ways, where their poverty is seen as an individual rather than structural problem. Building a much broader solidarity with those living in poverty is required, I suggest, in order to foster a political culture where the will might be borne to address the systemic roots of poverty. Until people living in poverty matter more to Canadians in general, the political and cultural forces that demonize them and justify political inaction will win the day.

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