

# Creating Community Across Disability and Difference

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*Cet article nous parle d'un projet, Building Bridges, qui examine les interactions quotidiennes des personnes avec des différences physiques et des handicaps. Il n'y a pas beaucoup d'espace où les femmes peuvent discuter de ce qu'elles vivent dans leur travail, nous avons donc développé des ateliers pour participants afin qu'ils s'ouvrent à de nouvelles significations de la différence.*

*Physical difference is looked at from the point that you would never want to have it happen to you. As if it's not something that you could possibly gain from. People need to understand that there are things to be gained from our experiences....*

In our society, there are few positive images of women living with facial and physical differences and disabilities. While contending with discriminations faced by many women, women with physical differences and disabilities also are subjected to the stigma of a body which is perceived as not quite female, (Garland Thomson) "less than whole," (DiMarco) and "not quite human" (Goffman). Women's experiences are directly related to western society's homogenized, naturalized, and patriarchal notions of body and appearance. Despite growing discourses about diversity issues, ideologies of the body remain embedded within binary oppositions of "normal" and "abnormal" (Davis 1995, 1997). Physical differences and disabilities frequently are positioned as personal tragedy, a burden to self and others, deformity, and inferiority (Rogers and Swadener). Because of medicalization, differences in appearance and ability typically are interpreted as illness or disease. As a result, public dialogue and medical discourse tend to focus on physical difference and disability as something to be shunned or overcome (Zitzelsberger, Odette, Rice, and Whittington-Walsh).

*People feel that you owe them an explanation because you don't look like everyone else. They ask, "What*

*happened to you?"*

Postmodern and feminist perspectives emphasize how body images and identities are produced and experienced through social interactions. Cultural meanings given to bodies become a basis for identity in interpersonal exchanges. People construct a sense of their bodily self from messages, spoken and unspoken, that they receive from other people throughout their lives. This occurs when they grasp how others perceive their bodies and understand the personal and social significance of these perceptions to their sense of identity and possibility.

One of the ways women with facial and physical differences and disabilities are marginalized in our society is through cultural and medical messages about the abject body, such as bodily fragility, dependency, contamination, and sickness, interwoven in their everyday interactions. Many experience negative or inaccurate perceptions about their bodies and lives, encountering judgmental comments, intrusive stares, and questions about their bodies (Keith). These are commonplace, occurring in interaction with family, friends, medical practitioners, strangers, and others.

*Sometimes the way health care providers respond to me can have a big impact on how I feel about myself. If I hear words like "deformity" used to describe me then I feel really shitty.*

Women with physical differences and disabilities frequently internalize negative judgements about their bodies and lives. They may have learned to view their body as inadequate, unacceptable, and a source of stress and anxiety. This can make it difficult for individuals to develop or maintain a positive sense of self and has important implications for physical and emotional health. For example, many women have experiences of health care interventions marked with a lack of privacy and respect,

where difference or disability is the sole focus and other aspects of their identities and health care are not acknowledged (Leigh, Powers, Vash, and Nettles; Veltman, Stewart, Tardif, and Branigan 2001a, 2001b). Stresses involved in encountering negative perceptions can deter women's decision-making to access services in health care settings and can leave them feeling vulnerable in social situations (Nosek, Young, Rintala, Howland, Foley, and Bennett). At the same time, however, many develop creative strategies to navigate challenging interactions. Women tell how

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**"Surgery is wonderful and it can give people new opportunities, but it is only part of the answer. You still need to find ways to be able to go out there and not let people's stares or comments stop you from doing what you want to do."**

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rejecting looks, critical comments, and intrusive touch are everyday experiences, yet they also speak of affirming messages that are features of their relational lives. Through interactions and connections characterized by support, validation, and affirmation, women come to understand and resist cultural meanings of their bodies that position them as "other" within social and medical discourses and relations.

*I was objectified as a child. At eight years old, they stood me up against a wall in the cold to demonstrate*

*how tall I was, and they were snapping pictures. I didn't start realizing that I was in textbooks until I was a teenager and I was really taken aback.... I went back as a teenager and destroyed all the pictures that remind myself where I was as a child.*

In this article, we describe our involvement with *Building Bridges*, a project that examines everyday experiences related to appearance and ability of adult women with disabilities and other body differences. We outline project activities such as workshops and art-making groups that have been designed to create opportunities for women to share stories, knowledge, and practical ideas with others who have similar concerns and experiences; look at the significant skills that they already use to negotiate stressful and challenging interactions; and build on their existing knowledge and skills together.

### **Impetus for Our Initiative**

*I have so much to say ... a voice muffled by the fears of others. I refuse to stay quiet. I will be heard.*

In August 1999, *Building Bridges*, a partnership project

of AboutFace International, the only organization in Canada providing services to persons with facial differences, and the Body Image Project, Sunnybrook and Women's College Health Sciences Centre, was developed. Supported by the Ontario Trillium Foundation, this project was created with, by, and for women living with facial differences, physical differences, and/or disabilities. Quotes and artwork embedded throughout this piece are the voices and images of women who have participated in the project.

A vital part of the project was the series of workshops held across Ontario from 1999 to 2004. Women who joined our workshops have included those with visible or hidden differences, such as women with facial and other physical differences or disabilities, which may be present at birth (such as a spina bifida or cleft lip and palate) or acquired later in life through injury (such as a burn or spinal cord injury) or illness (such as facial cancer). Some women may not identify themselves as having a disability, however, there are often overlaps in issues regarding body and self-image.

*I have learnt the benefits of having a cross-disability workshop. Not only did the participants become sensitive to issues of cross disability but they learnt that their "community" is greater than they had previously thought. I believe that this awareness will create a stronger base for change in society.*

Impetus for *Building Bridges* came from the recognition that there are few spaces for women to explore their subjective and social experiences of living with physical differences and/or disabilities. It was also recognized that there are few places for individual and group resistance to dominant views of body difference. Our objective in the *Building Bridges* workshops has been to provide a place for women to acknowledge their bodies and lived experience as sites of knowledge. The project builds bridges between and across participants' perceived differences and among established and emerging communities of those with disabilities and differences. Liminality situated between a mainstream health care institution and a grassroots community organization, the project also creates opportunities for building bridges between health providers and women with and without differences and disabilities. This is critically important. Active presence of women with disabilities and differences as facilitators gives hope that not all health providers accept conventional accounts of difference conveyed in training. In addition, women living with physical differences and disabilities have insights about operations of cultural meanings of body normalcy and body abjection within everyday life that position them as sites of knowledge for health providers and for all women.

*We all have issues around appearance. Let's stop looking*

*at each other like we're supposed to be something other than who we are and start realizing we are on this continuum of difference.*

### **From Skill Development to Skill Discovery**

The workshop sessions used individualized exercises, art making, journaling, small group work, discussions, and large group activities including drama, and story telling. Whatever the modality, a key aspect of our workshops and art-making groups has been the cultivation of a positive identity, not in spite of difference and disability, but through incorporating one's body difference into one's positive sense of identity.

*Surgery is wonderful and it can give people new opportunities, but it is only part of the answer. You still need to find ways to be able to go out there and not let people's stares or comments stop you from doing what you want to do.*

While we began workshop and support group sessions using traditional "skills development" and "solutions-focused" methods (Fiske; Metcalf), we increasingly adopted a "narrative approach" in our facilitation (Drewery and Winslade; White and Epston). This method is a therapeutic application of postmodern theory. Within health promotion, it has emerged as an effective approach for facilitating alternative meanings, identities, and worldviews excluded by dominant accounts and for fostering affinities and actions among marginalized people (Williams, LaBonte, and O'Brien). Facilitators working from a narrative perspective view participants as having expertise and skills in the challenges of living with body differences, but understand that this knowledge may be hidden by dominant stories that portray them as inadequate or incapable (Silvester). For example, individuals with disabilities and differences often hold important insights about their bodies, health care, needs, and lives that are derived from their everyday experiences but which may be devalued by greater authority given to expert knowledge. From our perspective, because a narrative stance views participants as possessing unrecognized skills in living with difference, it more fully supports them in discovering their own knowledges, and in building on capacities for action that may already work for them in their own lives.

A workshop facilitator sums up her perspective on the workshop process:

*Speaking as a woman with a facial difference, I believe that it is essential that women living with disabilities/facial differences understand that being different is not only negative, but that it has many positive sides (i.e., empathy, strength, courage, etc.). Through the Building Bridges Program, the participants are reminded of what they already know and possess—their survival skills,*

*their inner strength, their communication skills, and their ability to adapt to challenging situations. Women have lived this far in a society that condones attitudinal abuse, and in the workshop context are encouraged to look at the consequences of this abuse and to hone their knowledges derived from their experiences. We offer support so that women may become more comfortable with their bodies and their lives. Through our program, they understand that they are not alone.*

Over time, we have reworked and refined our workshop method to encompass five strategies for helping participants' discover and build on individual and communal knowledge and strengths: telling our stories; taking a not-knowing stance; asking purposeful questions; de-centering our expertise; and creating communities across difference.

### **Building Bridges Workshop Methods**

*What is positive for me about the group is to see that I am not alone and I can share my life experience with others.*

#### **Telling Our Stories**

One of our most significant workshop methods has been use of storytelling within a group context. Storytelling invites description and explanation on the who, how, why, what, and then what (LaBonte and Feather). It enables women to see themselves as authors in their own lives. Most activities are designed so participants can look at what has worked well in social and health care interactions and what they could do differently. Through telling stories and witnessing storytellings, participants are able to remember and reclaim the knowledges and skills that they already possess, gain insights, and identify alternative actions in challenging situations. Others' reflections on their stories amplify participants' awareness of knowledge and skills

they already use to handle difficult interactions. When women recognize the ways their stories resonate with each other, this creates movement, or new understandings of common experiences and new energy for action. Telling stories within a group context moves participants to recognize the collective knowledges and skills that are present within the group. Many women have commented that they have felt more empowered through recognizing

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**Individuals with disabilities and differences hold important insights about their bodies, health care, needs, and lives that are derived from their everyday experiences but which may be devalued by greater authority given to expert knowledge.**

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their abilities to make choices and by expanding their choices within interactions.

*When I was younger, how I got through those experiences was by developing a sense of humour.... I was tired of these solemn faces looking at my body. Why did I have to make them comfortable? But I did. That has always been the way that I approach the world in terms of dealing with some really difficult times.*

### **Taking a Not-Knowing Stance**

Using a narrative approach to group work, facilitators begin from the assumption that women in the workshop have knowledge, skills, and insights about moving through difficult situations, and that these knowledges can provide alternatives for actions. Narrative facilitators uncover people's stories by taking a curious or "not knowing" stance, asking questions without having preconceived ideas or theories about what the outcomes should be (Drewery and Winslade). The facilitator's expertise lies in looking for the meaning and effects of problems in people's lives and listening for alternative stories, or examples of their responses and actions in constraining circumstances.

Facilitators use questions to assist participants in accessing what they know about dealing with difficult social and medical encounters and to share this knowledge within the group. For instance, those who have experienced a high degree of medicalization and institutionalization often have been placed in passive roles in health care interactions and given limited opportunities to share information with providers and others about their bodies, health, needs, and lives. This can undermine women's confidence and abilities to access and communicate their knowledge and to collaborate with others in their health care. In *Building Bridges* workshops, facilitators are influential not by imposing interpretations or making interventions that could reinforce participants' relinquishing of agency but through using their questions and reflections to guide women toward the knowledge and skills they have of their lives that are relevant to addressing the challenges at hand.

*The exercises were ones that we could apply to everyday life. Also, looking at things the way others see them, was very valuable to me. Thus, I learned not to make myself the victim before I enter a situation.*

### **Asking Purposeful Questions**

A key aspect of the method is to support participants in recognizing and validating their own knowledges by the questions facilitators ask and the ways they phrase these questions. Rather than giving emphasis solely to the problem, this approach to asking questions stresses the multiple facets of each person that they bring when dealing with challenging clinical and other social interac-

tions. The method assists participants in deconstructing oppressive identities and in claiming subjugated knowledges marginalized by dominant medical and cultural views. Questions facilitate generative processes of exploring other possibilities of embodiment and preferred accounts of selves.

*A wheelchair can be seen as something positive. It's a tool that's liberating. I always thought of it as a prison on wheels. Now I see it gives me freedom.*

### **De-Centering Our Expertise**

Facilitators have found that the more they "decentre" themselves by not taking the expert role (White), the more participants in the group speak openly, and direct the focus according to their own interests, desires, and solutions. When facilitators are "decentred," women are recognized as having expertise and "primary authorship status" over their own lives. Participants, not facilitators, hold knowledge and skills generated over the course of their lives that can become important tools for addressing the predicaments they face (White).

*My goal was to see myself as a sexual and beautiful person. Now when people flirt with me, I accept it as a compliment and I don't automatically think that it's impossible for someone to flirt with me.*

### **Creating Community Across Difference**

The facilitator's role is to build a collaborative group learning process. Group responses are structured to give participants the tools to witness, affirm, and inspire each other. While most participants are initially more conscious of differences within the group, openness to safely ask questions eventually sparks interesting conversations about people's affinities. Encouraging individuals to share with others who have similar concerns and experiences helps end feelings of isolation. This is important, as many people with differences and disabilities may have limited opportunities to learn or talk about their bodies and lives or examine possible intentions and actions within social situations.

*It is fascinating how powerful we feel with each others' support; there's nothing like knowing we have shared experiences and outlook. I really think that since we have a social problem, having social support is part of the solution—both in the workshop and afterwards.*

Within the workshop settings, participants have opportunity through activities and discussion to question and resist cultural meanings related to their bodies that position them as "other" in interactions. Through seeing themselves as members of a group that is rejecting its position as marginal, many participants move to cultivat-

ing new or preferred views of their difference. As they revisit medical meanings received in clinical settings, collective recollection of past responses and actions often motivates women to revision the value and possibilities of living with disabilities and differences. While enhancing individual agency within and without health care situations, women develop connections that build bridges with other women and create commonality around physical difference and disability. This not only helps participants to challenge perceptions of themselves, but it builds a sense of community across physical difference and disability.

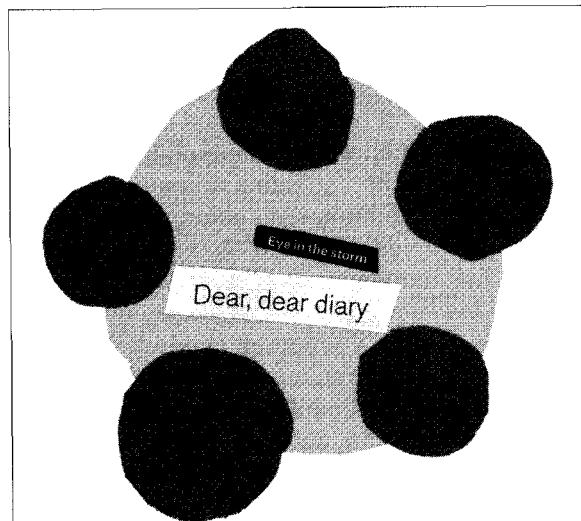
### Importance of Facilitators with “Insider Knowledge”

*In our culture we're all raised with the idea of being independent and being strong and especially people who have facial differences. I know a lot of times when I grew up I got these messages all the time, "oh you are so strong and coping so well." So that kept me from wanting to talk about any problems or issues.*

In our workshops, women with physical differences and disabilities are facilitators. Having facilitators who can become part of the group, while remaining aware of group process, is highly effective. For example, many people with physical differences and disabilities have learned that they should not speak of the difficulties that they encounter in their day-to-day lives. Friends and family members often feel they have little experience to draw upon when responding to women confronting stressful and challenging interactions. It may be difficult for friends and family to know their loved one is experiencing daily intrusions they can do nothing to change. Consequently, when trying to discuss a troubling social moment, many women have encountered subtle cues suggesting that it was a topic best avoided. In communicating their stories to a facilitator and a group who also live with body differences or disabilities, women do not have to succumb to societal pressure to make their story telling more palatable.

Facilitators who share their own challenges of living with a difference and/or disability can support participants to speak of painful situations and vulnerabilities. In this way, facilitators with “insider knowledge” can act as role models, mentors, and advocates (White). Participants in our workshops have commented on how comfortable they were made to feel by the facilitators and how much they appreciated the personal sharing by the facilitators.

*I am so glad to have had this quality experience with a group of women of all ages and backgrounds. Their diversity made it a rich learning experience. Also, it is amazing that this was free! I value that the facilitators*



### The circle can be unbroken by Christene Rowntree

The colours and smaller circles represent the cycles of a woman's life. The yellow circle means there is always something good in your life if you look for it, even though you might be living in the middle of a storm. The yellow also represents the warmth of the sun and joy and the good things in life like sitting on my balcony in the sun. The blue represents the colours of the earth, which is life. The reason I chose felt for this piece is that felt is matter, it has texture; I felt paint was too calm for this piece.

Sometimes for me, my life is like living in the eye of the storm. Even though I don't cause the hurricane, there are people around me that *are* the hurricane. In the morning, some of the people that have to help me with my daily needs, are like a hurricane getting you up. "Good Morning Sunshine!" Their pace is so quick, and sometimes they come in really anxious. So that's what I meant by "Eye in the Storm"; my sense of space is gone.

The only time that I feel spiritual or alone is when I'm writing in my journal which explains the "Dear, dear diary" in my piece. Other people can just go drink a glass of wine and put their feet up to relax, but I have to have someone to help me to pour the glass of wine, so I can't escape the same way other people do. Keeping a journal is important for my sanity. It is my sense of privacy. I can use it to vent my anger when I have to. Before my CP got worse, I used to drive around when I needed to vent. I also use my journal as source material for the comedy that I write. I turn situations around and put it right back in their faces. I take things and turn them around and make them funny.

were women with physical differences.

### Imagining New Meanings of Difference

Over the past two years, we have held several creative expression workshops, including an art making series called *Being and Becoming* and a photography workshop series entitled *See Me*. *Being and Becoming* featured four themes: love, sexuality, spirituality, and possibilities. In the *Being and Becoming* workshops, women were encouraged to do anything that came to mind relative to each theme with any of the art materials available, including paint, clay, magazines for collage, textiles, and other craft materials. The *See Me* workshop sessions focused on participants' examining, through photography, social and clinical moments of looking and being looked at; exploring what was concealed and revealed in interactions; and recollecting old and imagining new ways of seeing their bodies and themselves. For many women with disabilities and differences cameras have an association with pictures taken in medical settings. In *See Me* workshops, participants have opportunity to take their own pictures, creating images that resonate with and reflect on their different senses of self.

In our art and image making groups, participants are introduced to a process for witnessing and participating in the group. Facilitators introduce this process by telling group members that it is not their role to give opinions, or place positive or negative judgements on other participants' art or images. As witnesses, their task is to engage with others about what they have heard and seen, and link and build on each other's expressions. Participants are also encouraged to reflect on what they have learned and/or how they have shifted as a result of viewing others' artwork and listening to them talk about their expressions of creativity. This approach helps facilitators and participants to shift from evaluating or interpreting the artwork to allowing themselves to be affected and moved by each other's art making. For example, one participant who created two clay sculptures of her body differences said about her art pieces, "my nose and my spine are issues that are very hard for me to look at." Once her pieces were done she expressed to the group: "it felt so liberating to feel the clay nose, and to trace my clay spine with my finger." Another participant who depicted a woman in a wheelchair voiced of her work, "that woman is in action, with her arm out showing movement."

In many images created throughout the sessions, the women illustrate how possibilities for their lives are constrained in some ways by body limitations. Yet, the more recurrent locations of the limitations they encounter are external barriers, including attitudinal and literal walls others have built to exclude them. Unlike traditional support group exercises that are highly structured, the creative processes women partake in are more fluid, without sharp beginnings and endings. Often participants

undertake exploring possibilities for their bodies and lives in informal conversations as they pick out a paint colour or learn how to set up a shot with the camera. Comments from workshop evaluations suggest that while women view the art and image making as valuable, the most meaningful feature of these groups is the sense of connection they feel in sharing their images, artwork, and stories with other women. One woman wrote what inspired her most was "the joy" she felt in witnessing participants discuss their creative work, where others wrote that they were most moved by learning other women were dealing with similar issues.

*Building Bridges* creates an opportunity for shifts in meaning of difference and disability to occur. Shifting meanings of difference has important implications for increasing individuals' capacity to collaborate in their health, and for enabling them to expand their options and choices in challenging health care interactions. When women perceive health providers' increased openness to understand their unique experiences of disability and difference, this enhances practitioner-client communication, comfort, and competency in clinical situations. The project does not deny the challenges of others' and our own perceptions of body difference, but it does open up the possibility to imagine. Imagining becomes a resource that allows women to make new meanings and create new connections through art, image, and metaphor, and in so doing, envision new images and interpretations of difference.

*The Building Bridges Project has produced two resources: Talking About Body Image, Identity, Disability, and Difference: A Facilitator's Manual and Building Bridges Across Difference and Disability: A Resource Guide For Health Care Providers. If you are interested in ordering your own copies of the Resource Guide or Facilitator's Manual, please call AboutFace International at 416-597-2229 or toll-free 1-800-665-3223 or email: info@aboutfaceinternational.org.*

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