I am honoured to be here with you this morning and I acknowledge that we are on the unceded territory of the Coast Salish People.

It is a great honour to receive the Rosemary Brown Award for Women. I am accepting this award on behalf of the families and staff I worked with over many years as we created and then improved services for children with developmental challenges. Our work was always a team effort and our accomplishments, and there were many, were realized because of our commitment to working together.

We worked across boundaries that had been, in the past, rarely crossed. Boundaries that kept parents and professionals apart, professional disciplines apart, government ministries apart. And key to our success was the driving advocacy of parents. Parents, whose sons and daughters were for the most part completely excluded from normal community life and activity, parents, who stood up and demanded exclusion stop.

So this morning I would like to share some stories of transformation in the parent movement with you, what I learned as I worked in this field. I will end with a few words about the pressing concerns facing us today. But first a few words about Rosemary Brown.

This award has special meaning for me. I knew Rosemary, initially as most others in BC knew her, as a brilliant orator, politician, and passionate champion for human rights. I also knew Rosemary supported the development of better services for children with disability, my field and was engaged in that in her early work as an MLA in BC with her colleague the late Norman Levy.

For many years, I knew of Rosemary Brown, from afar. I was lucky though. Rosemary and I had close friends in common so I had the privilege of getting to know her personally, as a mentor, as a friend. I was one of thousands I assure you, she was so loved and admired. And today I receive this award in her honour. I hope she would be pleased.

Before I begin the more serious part of my address let me share a few stories about getting to know Rosemary personally.

Our mutual friends included a couple who owned a beautiful, rustic, waterfront resort on Salt Spring Island. Knowing that I had such admiration for Rosemary Brown my friends invited me over for a weekend. They had a big, big surprise for me. I had been to their place many times and was very at home there. So when I arrived I did not knock I just called out and walked into their living room, and Rosemary was sitting there. Nearly fainting, I quickly turned and staggered out to the kitchen. She had that impact on people.

My hosts escorted me back into the living room and that marks the beginning of getting to know Rosemary on a personal level. But know that even with a friendship she commanded awe. Years later we were sharing a cabin at the resort and Rosemary was in the bedroom, I was on the sofa bed in the living
room. Actually, I had pulled the mattress onto the floor. I was younger and could at that time get up off
the floor and my dog was sleeping beside me. I woke up in the middle of the night and Rosemary was
leaning over me. My first thoughts were “Rosemary Brown has come for me. I must follow” But no, it
was not a call to political action, it was a request to get my dog off her bed and back into mine.

The focus of the Rosemary Brown award this year is disability. I am not an expert, but I see it from
different sides. I have lived with disability, a significant hearing loss from birth, I have parented a child
with disability, and I have worked with many parents of children with disabilities and with many adults
who live with disability. I consider disability to be a completely normal part of the human condition and
if we live long enough we will all experience it, in its many forms. Indeed it seems at times at my age
now, that I am adding a new condition to my reality daily. But it is also difficult for me to think of
disability without considering disability as a social construct, as a stigma. Without considering that much
of what happens in the world of disability happens because of our value systems and decisions that we
make based on these values. Values shaped for the most part by fear and ignorance. I have witnessed,
been part of, amazing changes in how we view disability in our society, the words we use to define it
and how we provide or do not provide services and access to people who live with disability, based on
these views. How we can deny the most basic of human rights based on our construct of disability.

I grew up and went to school in BC a very long time ago, in the 1950’s and 1960’s and there were no
children with developmental disabilities in any school I attended. Many children with intellectual
disabilities were in institutions like Woodlands or Tranquille or at home, not allowed to attend school.
There were no children with physical challenges, many of these children were in hospitals like Sunny Hill,
children with severe hearing or vision problems went to Jericho Hill School for the Deaf and Blind.

There was no discussion of differences, of disability, that I remember at school or home. Even in my
family, my hearing loss which was moderate, was never discussed. Except once, my father said that it
must have come from my mother’s side of the family, her uncle by marriage had become deaf at 80. I
did not have hearing aids and passed without accommodation as a hearing child. I took teachers training
at UBC and taught elementary school for a short while. And then with absolutely no knowledge,
experience or skill I was hired in 1973 to run a small program in Vancouver for families with infants with
severe developmental challenges.

I was hired by the Vancouver Richmond Assn for Mentally Handicapped People, as it was then known, in
the language of the day, to run the Infant Home Care Program which had started the year before. This
was I believe, the first example in Canada of home based support to parents of infants with intellectual
disability and other developmental challenges. And I walked into a world that was as foreign to me as if
it were another country with another language. The world of intellectual disability. I began a learning
curve that encompassed knowledge of disability, early childhood intervention, and attitudes and values,
including mine, which needed change. I also had the privilege of working with parents and learned the
most from them.

This was still a time when it was recommended that newborns with intellectual disability be
institutionalized, warehoused. A diagnosis of intellectual disability could take you from a loving family
and house you in a large institution, completely away from community. Thousands of children and
adults were living in large institutions in BC and across Canada and the States. These were, for the most
part, hellish places to live and I had many opportunities over the next years to see these first hand.
There were no community alternatives to the institution for families, no services for infants and few if
any community services for families with older children. And public schools, for the most part, did not
accept children with intellectual disability. Children were either institutionalized or kept at home, often
hidden, deprived of rights we take for granted for other children in our society. And as most people had
no contact with children or adults with intellectual disability this amplified their fear. Fear that had in earlier years led to the provision of draconian laws.

The year I was hired, 1973, BC had laws that permitted the forced sterilization of persons with intellectual disability. Alberta’s sterilization laws had been repealed the year before, but in the 40 years they had been in force, over 4700 Albertans had been forcefully sterilized. The laws had been applied broadly in Alberta, although mainly to persons with disability, but immigrants, Aboriginal people and the poor were also sterilized. An earlier court judgement by the American Justice Oliver Wendell Holmes in 1927, had influence in Canada. His judgement reads in part “the state had the power to regulate the breeding of citizens and that sterilization was appropriate to curb generations of imbeciles from reproducing, and was passed to save the nation from incompetence.”

The eugenics movement, fueled by false science and public hysteria, was in full form in Canada. Eugenics means ‘well born’, a term coined in 1867, by Frances Galton, a cousin of Darwin. It became a social movement with two main objectives. Selective breeding to ensure marriage of healthy adults to produce healthy offspring and the prevention of procreation by those deemed by others as to be not healthy. Prominent Canadians, Alexander Graham Bell, Nellie McClung, in fact all of the Famous Five, Tommy Douglas, were strong supporters of Eugenics. It led to the Holocaust in Germany, was completely debunked as a science but is still with us. Racism in any form is at the basis of eugenics.

And back to a personal note. My parents, like others in society at that time, would have been terribly reluctant to accept a difference in their child. Anything less than normal. Which is a partial explanation for why my hearing loss was never discussed. My mother was a strong supporter of the civil rights movement in the fifties and sixties but never connected, at that time, that movement to the unmet human rights of persons with disabilities. Of course, even to this day disability rights are seldom considered as part of a larger struggle.

But there were other parents who were looking at this differently. By the seventies, when I was hired, huge change was beginning for individuals with disabilities in North America. Many of the community programs that we take for granted today in 2017 had their roots in the seventies. There was a climate of optimism and an interest in creating human services that would lead to change and brighter futures for many people facing social barriers. And change was led by the parent movement in intellectual disability.

After WWII, parents of children with intellectual disability started organizing in North America. They were appalled by the horrors of the Holocaust and learned that in the decades preceding the Holocaust, the Nazi’s had exterminated over 200,000 German disabled or ill children and adults. They were inspired by the growing American civil rights movement. These parents saw the incarceration of their sons and daughters in institutions, the lack of educational opportunities, lack of employment, as the real barriers. That their sons and daughters were denied basic human rights. And through the parent movement, services began to develop. Transformation did not happen overnight. And it would never have happened without the fierce advocacy of parents.

Parent associations grew from small groups of parents meeting in kitchens across the country to an organized movement of local, provincial/state and national associations for the mentally handicapped. They lobbied for community services. For sheltered workshops. For the right for children to attend school. And in places like BC where there were laws that prevented children with intellectual disability from attending public school they raised the money and build their own schools. Parents lobbied Victoria to change the law and Oakridge School in Vancouver was built. It was the first school in Canada that was built with public dollars as a school for children with intellectual disability. It opened in 1961.
The parent movement attracted powerful parent advocates. President Kennedy and his family joined. His sister had intellectual disability and was in an institution. He formed the President’s Committee on Mental Retardation in 1962 with the goal to take intellectual disability out of the shadows and into the public view. His Committee called for better maternal care, community rather than custodial care, research centres for diagnosis and treatment, and special education training for teachers. New scientific knowledge was now publicly available about the importance of the early years in human development and in the United States some universities, with support from the President’s Committee were beginning pilot projects for young children with disabilities. There was the belief that early childhood intervention would lead to cures, that developmental differences could be fixed.

We had powerful parent advocates in Canada. One of those parents was Pat Vickers. When her daughter Pamela was born in 1969 in Vancouver and diagnosed with Down syndrome, Pat approached the Vancouver Assn for the Mentally Handicapped. At that time it was running a preschool program for children aged 3 to 5, a school program for school age children and vocational and recreational programs for adults and a few group homes. Pat became a strong advocate for Pamela for her rights and worked with other parents and professionals to start a new service, a home based service for infants with developmental challenges and their families. The initial program objective was to teach parents ways that they could encourage the development of their infants. It was the first such program in Canada and was truly the inspiration of parents and professionals who believed in a better world for their sons and daughters. A world that did not include institutions, but did include support for families and education for children. Community living.

So there I was in 1973 with very little research available and even fewer resources to guide my work and I was completely unprepared. I took on a caseload of 13 infants with serious challenges and their parents who wanted information and support. The parents were a wealth of information about their children, as all parents are. We had a wonderful advisory committee of parents and professionals through the Vancouver Richmond Association and they too were a wealth of information and support. But it was clear to me that we needed much more.

Duthie’s Bookstore, the largest book store in Vancouver had exactly 5 books on child development and nothing on disability or delay in infancy. I turned to UBC and the Special Education Department, I started taking courses but again, not much there, the emphasis was on the school age child, and there was nothing in the courses that related to infants. Further, the emphasis was on pathology, disability as disease, little on interventions that might make a difference, and nothing on family support.

So we connected with American researchers, and with the support of the BC Association for the Mentally Handicapped, again the language of the day, today the BC Assn. for Community Living, and UBC, we started a series of training programs to begin to acquire the skills and knowledge needed to make a difference for children and their families. We set up evening meetings for parents in Vancouver on areas they identified as needing help, feeding, walking, and language development. Parents came from as far away as Hope. There was nothing else. We encouraged parents who lived outside of Vancouver to press for services like our home based infant program for their communities.

I mentioned that Rosemary was involved early in her role as MLA in supporting disability related initiatives. Her colleague Norm Levy was the Minister of Human Resources and the NDP government in 1973 decided to move the administration of institutions for persons with intellectual disability from the Ministry of Health to Human Resources. This had a huge impact on service delivery in this province, it altered perceptions, and it helped to change the policy focus of intellectual disability from a medical model to a social and educational model, opening some minds to possibilities of community rather than institutional living. The Ministry of Human Resources saw the need for services for parents as
alternatives to the institution. I was asked to help develop the Infant Development Program across BC in 1975, and was appointed Provincial Advisor, under the direction of a Provincial Steering Committee chaired by Pat Vickers initially. We had provincial champions from the professions as well, Ann Reiner, Physiotherapist, Dr. Elinor Ames, Psychologist, SFU, Dr. Geoff Robinson, Paediatrician, Dr. Bert Perry, Chair of the BC Medical Assn Committee on Intellectual Disability, Dr. Hillel Goelman Educator, UBC and others who worked with us to set the standards for this new human service.

Parents in communities across BC worked with us and community professionals, public health nurses and physicians, to develop Infant Programs in their community. Within five years we had 15 Infant programs running in BC with 25 staff serving 500 children and their families. Parents who had never before become involved in community work or advocacy got involved. They sat on committees, wrote briefs to government requesting funds to start a program, and interviewed staff to run the program, made decisions as to training staff. And all of this while attending to the developmental needs of their infant, fighting for the right of their child to the most basic of services. And in the face of extreme prejudice. Parents would tell me that they had never spoken up before, in any setting, but now, on behalf of their son or daughter and with the encouragement of the Infant Program and other parents, they had a courage they did not know they possessed.

Parents at that time were often given very grim and unrealistic prognosis for their children. Health care professionals based these prognoses on the development of children who had been institutionalized or had not attended school or developmental programs. Parents of children with Down syndrome were told their child would never walk or talk. One parent, in recounting to a UBC researcher the least helpful thing shared by a health care professional, stated, “He told me my son was functioning at the level of an alligator”. Another mother who was told her infant daughter with Down syndrome was a vegetable brought her daughter in to see the physician two years later. Her daughter who was walking at that time and had a few words ran around the office and the parent said to the physician, “Lively little potato isn’t she”. Another mother, whose daughter was attending a special school, told me, “What a pity she can’t read at school, she reads so well at home”

Lifesaving medical interventions were routinely withheld. Open heart surgery available to other infants was not generally available for infants with Down syndrome until the 1980’s. Pamela Vickers was one of the first children with Down syndrome in Canada, possibly the first, to have open heart surgery. So parent advocacy was needed on all fronts. We worked with UBC Faculty of Medicine to create a program for 1st and 2nd year medical students, to take them on home visits. Parents had the chance during the home visit to share their experiences with the students, what was helpful for them, what they needed as parents to support their children. These home visits were powerful instruments of reform. Years and years later I was approached at a conference by a specialist physician who told me that he never forgot his home visit with Kenny and his family in his 2nd year of medical school and that his entire career was influenced by that opportunity.

The days of institutional life in BC were numbered. Parents with older sons and daughters in institutions worked tirelessly to convince government that the institutions must close. Tranquille, in Kamloops, was the first to close, possibly the first to close in Canada, and in 1984 people moved from that institution to the community. Every single person who was moved from an Institution for Intellectual Disability left with a community plan, a place to go, a home and a community of people to support them. By 1996 the last institution in BC had closed down. And people who had never lived in community were finding joy in community life.

Our work in Early Childhood Intervention during these years was also changing focus. Initially, the work had been driven by the hope of cure, of fixing. There were some professionals who believed that if you
worked hard enough the extra chromosome in Down syndrome would disappear. There were early childhood intervention programs elsewhere in Canada and the states where professionals and parents charted hundreds and hundreds of behaviours a week. These programs were usually attached to research projects at Universities, and had the resources to provide such intense intervention. But I can tell you no one, parent or child, was having much fun in those programs. We did not have those resources, so we never got to a place where we expected families to spend hours instructing their infants daily. This was to our good fortune and to the families and children we served.

Of course certain interventions, specific activities, approaches to teaching skills to young children are beneficial but the important work is in supporting the family to manage. To help them acquire the skills and knowledge that they consider important for themselves and their family, to tailor interventions individualized to the child’s abilities and interests. And to incorporate as much of this as possible into the regular routines of family life. And to have some fun as a family. And our programs grew into a family centred model of service. This was from the understanding that families were strong and capable, and that children with disabilities are not broken, to be fixed but benefit from different ways of learning. Our work in part was to help the family and community environment accommodate to the child. Not to change the child to fit the environment.

We grew to understand that if the family and community were nurturing and welcoming and if barriers to participation were removed this would create learning opportunities of great benefit to children and their families. Of course, there are some children with specific conditions that do benefit from intensive interventions, and it is of critical importance that these interventions be available as early as possible. We supported the development of the BC Early Hearing Program for example. Our task in an infant program is to ensure that each and every child and family served is offered the right supports and interventions at the right time and that these are offered in the most inclusive setting possible.

And the families that worked to create infant programs in their community continued to work as their children grew older, they influenced the inclusion movement in BC, pressing for their children to attend community preschool, to attend public school, in regular classes with support. Inclusion. Parents led an Education Committee through the BC Assn for Community Living in the 1970’s and 80’s. This committee advocated for education from birth to adulthood for all persons with disability. That a disability may for some make it important to have education start earlier and end later, to have that advantage. We advocated as well that all children be educated in public schools, in regular classes with special assistance when needed.

We lobbied to have education continue after high school as well. This was a completely new idea, that persons with intellectual ability attend college. But we believed that this was possible and right and needed to happen. We had many meetings at colleges to discuss this possibility. I remember preparing for one such meeting, in Vancouver. We were to a person nervous. Expecting rejection of the idea. We prepared a lengthy presentation in favour of a special program for adults with intellectual disability to attend this college. We delivered this in the board room to the president and his board and waited for the argument. We waited. The President of the College took his time to respond and then said. “Of course. All adults are welcome here. What do we need to do to help this happen”. Times were changing.

So over many, many years, we have seen amazing transformations through the advocacy of parents, parents as advocates for their children in speaking up for their rights to services, in creating services for them when none existed. And we know that the impact of disability can be reduced through family support and interventions that help the child reach his full potential. And this advocacy has had a significant impact on how we view disability in our society.
When I started in the field, I remember getting on a bus once with some adults with intellectual disability and their staff from the group home. I knew some of them so sat with them. I saw how others in the bus moved away, averted gaze, were uncomfortable, fearful, anxious. A few years ago, I got on the bus and watched a young man with Down syndrome get on, sit down and take a copy of Harry Potter out of his knapsack and start reading, he was half way through. I was the only person on the bus who noticed him. He was just another passenger.

Recent work has gone into the study of stigma. It is understood that stigma, one lens through which we can view disability, can be altered. We know it needs to be altered. Stigma brings stereotypes, prejudice, and discrimination. Efforts to reduce it have been in three main areas. Language, education and contact. Changing the language does not help much to change attitudes. Language is critical of course, and the People First movement developed some early guidelines that were very helpful. But the research shows it does not do much to change attitudes and values. Another method to change attitudes is education, helping people understand the causes of disability, or how it can impact development, or the importance of inclusion, the law, human rights etc. Education is also vital but it also does not do a lot to change attitudes.

What does the most to change our attitudes and values is contact. Getting to know someone personally who lives with a disability. Playing soccer with Henry, sitting with George in a classroom, working with Jennifer in a restaurant. Getting to know people who live with a difference, changes attitudes and values. I do not have time to address the self-advocacy movement but that powerful movement has been critical. People themselves are the instruments of change.

I started the talk with mention of Pat Vickers whose daughter Pamela was born with Down syndrome. Pamela was an instrument of change. Her birth inspired her mother, who started with others, the Infant Development Program of BC which to date has served over 100,000 families in BC and influenced work in many other provinces and countries. Her father, David Vickers, went to Ottawa in 1982 and managed to convince Jean Chretien to include physical and mental disability into the Charter of Rights and Freedoms, making it the first country in the Commonwealth to do so.

And Pamela. Well, Pamela was a friend of mine and this is the kind of friend she was. When my cat died, Pam was the only person who wrote me a letter of sympathy. She was a terrific friend. She had a short life but one with great meaning. She went to a community school, she went to high school and college, and she got a job after graduating. Her heart condition was very serious and she did not have a lot of energy but she worked part time as office support for the Ministry of Finance for the BC Government, doing Xeroxing and collating materials for them. She was working for them when her health deteriorated and she died following her last open heart surgery. At Pam’s funeral, the Deputy Minister of Finance spoke. He told us how his office had benefitted from having Pamela there. She brightened up the office. Everyone now said ‘good morning’ and ‘how are you’. When February 14th rolled around everyone got a Valentines Card.

We have seen amazing changes through contact, through relationships built like Pamela’s that have altered our understanding of intellectual disability. We read great stories on FaceBook and see people with many different disabilities represented in film and through other media. Not just the stars, but regular people with regular lives. Disability Pride held a parade in Richmond last month and everyone had a terrific time. Self-advocates are in places where parents once were, speaking up for their rights, their lives.

But we live in interesting times both terrific and terrible, and not only are we witnessing the rise of white Supremacism with roots in the Eugenics movement, but we are also dealing with massive
technological changes in science and medicine. And we need to consider the future impact of technological change and medical advances and what this means for our society. Iceland has announced that it will eradicate Down syndrome in the very near future. What does it mean to us or say about us as a society when we celebrate eradicating differences. As the ethicist David Jones reminds us, it is one thing to use technology to help people to make them better but it is a very, very different thing when you start on the road to make better people.

I was driving back from a meeting in the interior late at night, years ago. I was listening to Ideas on the CBC and heard the scientist interviewed marvelling that they had identified the genes for obesity and for hearing loss. Marvelling that with prenatal diagnosis no child need ever to be born with those conditions. Well I’m toast I thought. I do wonder what my parents might have chosen had they been given that information and decision.

It is true that we have made great gains over the past decades, in terms of services and supports in the area of disability. But how quickly gains are eroded and lost when our values and attitudes about what is important, shift. When the basic human rights of people are overlooked. When the human rights of persons with disabilities are unrecognized, when child rights are rarely acknowledged.

We have lost a lot in the last years in this province. We now have huge waiting lists for the most basic of services for children and adults with disabilities; long waiting lists for early childhood intervention services and with the closure of the Provincial Office for the programs we lost the mechanisms to document how long families wait. There is loss of special education services in our schools, there were thousands of specialized positions cut. It is near the end of September and there are still children waiting to attend school. There are children with disabilities overrepresented in the foster care system, families without the supports needed to keep their children at home. There are long waiting lists for supports for community living, for training, for employment. Just think about the bus pass. Something as simple, as fundamental as a bus pass was ripped away.

The legacy of Rosemary Brown is to ensure that history does not repeat itself, that progress is maintained and strengthened for those in our society who are most vulnerable. We do have a new government and reforms are coming. The bus pass is coming back!!! We need to honour Rosemary by speaking up for and for supporting these reforms, by holding Conferences like this to facilitate dialogue about these important issues. I look forward to our discussions this morning and the perspectives of the next speaker and our panel members. Thank you so much for your interest and for the great honour of this award in Rosemary’s name.

Dana Brynelsen, Vancouver, September 23, 2017