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Inclusive Education, Person-Centered Planning & Systems Change Challenging Permutations and Opportunities

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Abstract

This article acknowledges there has been remarkable progress in creating opportunities for inclusive education, person centred planning and constructive long term change. However, while the author is optimistic about the possibilities, the themes are words of caution regarding some areas where slippage is already happening, and unchecked, could be very dangerous. In particular, the 'colonization' of the language of inclusion so it no longer has meaning, and the resurgence of the eugenics movement which could undermine much of the progress of recent decades of work. Meanwhile, there are remarkable glimpses of the futures we want in stories from around the world.

Key words

Inclusive education; colonization of the language; eugenics movement

Educación Inclusiva. Sistemas de planificación centrados en la persona, cambio, permutaciones y oportunidades que suponen un reto

Resumen

En este artículo se reconoce que ha habido notables progresos en la creación de oportunidades para la educación inclusiva, centradas en la planificación personal y en un cambio constructivo a largo plazo. Sin embargo, mientras que el autor se muestra optimista

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sobre las posibilidades, advierte que hay que ser cautelosos con algunas áreas en las que se está produciendo un deslizamiento que, si se descontrolara, podría ser muy peligroso. En concreto, si sucediera esta "colonización" del lenguaje de la inclusión, éste ya no tendría sentido, y el resurgimiento del movimiento eugenésico podría socavar muchos de los avances de las últimas décadas de trabajo. Mientras tanto, hay historias por todo el mundo que permiten vislumbrar el futuro que queremos.

Palabras clave

Educación inclusiva; colonización del lenguaje; movimiento eugenésico.

Introduction

Inclusive Education had not yet been invented when many of us began this work. Then, we talked about 'integrated education', but it only takes a moment to realize that the high hopes of genuine integration turned to mush, so we began using the new word – inclusion. Now 'inclusion' too has lost the crisp clarity it had those many years ago. When we thought about implementing inclusion, we knew planning would be required, so we created 'person-centred planning' in order to be sure that the processes always kept the individual 'in the middle' and present for their plan. Now we are pushing for Independent Facilitation because education and social service systems have too often usurped Person-Centred Planning into just another way to market the self-contained 'activities' and places with seriously inadequate attention being devoted to exploring and creating real lives for real people.

It is very simple. Well done, and with a solid values base, the family of Person-Centered Planning approaches can and do assist to create some remarkable, almost unimaginable futures, for people who have traditionally been written off and institutionalized. It can be a core element in a systems change strategy. So the 'possibilities' and power of Person-Centered planning and facilitation have only just begun, and are brimming with enormous promise in schools, social service systems and families everywhere.

However, simultaneously, there is a serious challenge to this potential as large system 'accountability' requirements thin the soup of possibility into a gruel that can barely sustain life. The pressure to deliver 'more' with less and do it faster means that the very core of Person-Centered Planning is often gutted because there is no time to be 'person centered'. In fact, in North America, with economic cutbacks, there is a frightening 'recovery' and 'reinvestment' in larger-group mini-institutions and institutions. After three decades of struggle to close institutions, budgets are gradually shifting to 'large group service systems' - often privatized and more committed to the budget bottom line than to supporting 'people' to have full and contributing lives. In education, too often the first cuts are supports for individuals who need a little extra help – and increasingly congregate students with 'labels' into 'special' classrooms where the major activity is 'waiting'.

This is not cynicism. But to move forward, it is vital that we acknowledge the landscape for this work. In North America and around the world, there are spectacular achievements in 'inclusion' and post de-institutionalization with innumerable and remarkable examples of individuals being acknowledged as full and contributing citizens in communities. All this is at risk. Several 'almost invisible' dangers lurk in the background and must be publicly challenged so they can be reversed. The two I am focusing on here are the colonization of our language, and the resurgence of eugenics.

The first danger is captured by this George Orwell quote:

“Political language is designed to make lies sound truthful and murder respectable, and to give the appearance of solidarity to pure wind.”

Colonization of our Language

In our field, our very 'language' has been colonized and the concepts and words we created to be clear, have been 'repurposed' into jargon-speak. Systems chime with warm sounds that in many cases have mutated the very meaning of 'our words' into their opposites. Examples: Inclusion in schools is twisted to mean 'segregated classrooms, schools and services. More broadly, the Canadian government just completed a national ad campaign for a Youth Job Creation program that did not exist; the "No Child Left Behind" program in United States imposed 'standards' that were devastating to the poor. Countless examples abound in every sector. Our words are not what they seem. We are too often consumed with 'politically correct language' and fail to look at real life consequences. We do snapshot analysis blaming quick fix processes for our failures, and avoid facing the power of the underlying values and systems that generate triviality in the face of real issues. We must be courageous and look underneath the fluff, and examine our actions, and see the actual meanings and consequences.

The Resurgence of Eugenics

The second undercurrent is the very quiet resurgence of eugenics - without using those words. These sentiments have been repressed in recent decades, but a movement that originated in North America has never been forgotten - just in hibernation. When one combines economic pressures with the ethic of 'high performance', the slippery slope into 'too costly to maintain' with the hidden undertone of 'not fully human' is profoundly dangerous to all of us.

We are choosing to paint this frightening portrait precisely because our societies are going to be making choices, and without awareness and action, the spirit of eugenics and the capacities of modern 'testing' are already slipping into a hidden policy of gradual elimination for those of us who are perceived to be not 'perfect'.

This tension is not inherent in Person-Centered approaches. Rather, it is that the values of the people implementing such processes predetermine the outcomes. Those who deeply believe in possibility and capacity will discover it. But others who may have been overwhelmed and sometimes numbed by system pressures, and the endless struggle to cope with reporting demands, quickly lose sight of 'possibility'. When we allow our focus and attention to be consumed by the pressures of the 'risk-aversion', or the 'insurance-claim' frame of reference, concerns about safety quickly trump living a life, let alone a full life. Such pressures close the windows of opportunity and compress the courage to leap into possibility.

Even with these environmental threats, we believe Person-Centered planning and quality facilitation remain full of promise. But we must be constantly vigilant so that we are not colonized by system-speak and tick-box timed requirements. We must not allow our good ideas to be transformed into disappointing and even harmful illusions.

Re-Learning – Remembering How to Listen

Excellence in communication skills (outputs and inputs) are vital, but these days are more easily sidetracked by the speed, pressure and inundation of information enabled by chip

technology. While our capacity to communicate has grown exponentially, our listening skills have often atrophied. We no longer have the 'time' to listen at the very time when listening may be the key capacity to growing our future! More rules, fewer staff, and more bureaucratic paper reporting demands – all mean we don't have time to listen!! And this is vital to our schools, workplaces, communities – and each of us personally and in our families.

Our stories are a source of hope, inspiration and demonstrate what is possible. Diversity is fundamental to our very survival. Thus, we find hope in the spectrum of stories where people imbued with strong values can take Person-Centered approaches to people, places and possibilities that we can hardly imagine. These stories reaffirm that there are possibilities that include all people - people with disability labels and citizens of every diversity - as powerful creators of the futures they choose, rather than the futures they are given. School stories, family stories, and community stories powerful motivators of possibility – in words, in videos, in stories in every format.

Crisis or Opportunity; Possibility or Despair

We live in interesting & challenging times; times that demand courage and action. We can choose our focus: Crisis or Opportunity; Despair or Possibility. First we must acknowledge the tension – then manage it by investing in our future. Our decision is to scan the landscape, find the fledgling seedlings of possibility and nurture them.

We live in a time when for the first time in Canadian Social Policy History - the right of people living with challenges are being acknowledged and actual policies have principled clauses about full citizenship, full participation, employment, housing, and health. Civil rights and citizen rights for full inclusion in education, work, health, housing, citizenship, have made enormous headway. We see people with disabilities in school, at work, shopping, partying, travelling, and leading us into the adventure of full citizenship and participation for all. There are thousands of advocacy groups that continue to push for full participation for all. These are profoundly positive developments that suggest full lives for all are just around the corner.

We also live in an era when we have seen (the tense is important) the closure of most of the big institutions, and even apologies for the abuse and pain that was too often inflicted there. (The Premier of Ontario delivered an elegant and sincere apology to the institution survivors on Dec. 9, 2013. We believe this to be a first.) (http://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/Premier_Apology.aspx)

Simultaneously, we are acutely aware that there are incredible fiscal restraints that are hammering individuals, families, and service organizations with exponential increases in 'euphemistic accountability paper wars', endless cycles of testing and assessments, financial cutbacks, and technocratic bureaucracy creep. We live in the era of privatization, where care organizations, nursing homes, prisons, and institutional care of all varieties are shifting to profit making corporations with shareholders. The 'apologies' are important. But more important is the implementation – the actions that create genuine opportunities for full inclusion – in schools, workplaces, and communities. We need to SEE action and not just hear the words.

Just Another Fad or Historical Revisionism?

We are deeply concerned by emerging rumors that frame Person-Centred Planning and the related family of approaches are passé - just another passing fad. The truth is that Person-

Centred Planning a vital part of our history. Labeling critical value based initiatives as passé has a1984 (George Orwell) feel - when we just 'airbrush' our history so some things 'disappear'.

We call this historical revisionism - historical denial. It is profoundly dangerous in policy and in thought. We are gravely concerned because historical revisionism was a key strategy in creating the holocaust and holocaust denial. Most will react saying this is overly dramatic. However, the experience of First Nations (Aboriginal peoples) everywhere is a powerful parallel case that bears sober review.

In Canada, after well over a century of oppressive policies, one of the key elements of suppression is finally being revealed. Indian children (from as young as age 3) were 'stolen' from their families and put in residential schools operated by the government and churches. An estimated 150,000 children were institutionalized away from their families, punished for using their languages, and often abused physically and sexually. Some records suggest 30,000 children died! Currently in Canada, The Truth and Reconciliation Commission (on Residential Schools) (<http://www.trc.ca>) has ended its five year mandate, and still, even after Supreme Court decisions mandating full access, survivors have been unable to free up the archival documents - the actual records from the residential schools. The relentless obstructionism continues. We highlight this example because as the 'Court Settlements' for institutions for the developmentally disabled are now being implemented, and in spite of an apology from the Premier of Ontario, the bureaucracy manages to constrain access to records in precisely the same way. The parallels are one to one. Our federal government is deeply engaged in historical revisionism - denial that this happened. Their hope is that by 'stalling' for another generation, the awkwardness of this truth will avoid some of the court challenges, and more insidiously, allow future Canadians to adopt the perspective "it never happened". Court records of torture using a home built electric chair in one residential school are still being suppressed even though school personnel were convicted and imprisoned. Hard to believe, but true! In Canada you say??

In the disability sector the same historical revisionism is also active. Institutions, group homes, day (wasting) centres and a litany of other 'innovations' are part of our history. Regardless of the intent, the implementation was and is rife with horror stories. Institutions, organizations and individuals thinned the values and principles into a meaningless broth that has done enormous harm to many. The current court settlements with the survivors of Huronia (and other Ontario institutions) reaffirm the depth of our concern. The fact that 'many files cannot be located' is yet another nail in the historical revisionism coffin. Stall tactics once again: we could not find the files; it never happened. Apologies and 'Meaning well' are simply not good enough in the face of the enormous pain that has been inflicted on individuals and families. We must put a finger in the dike of denial. We must not relegate our values and principles to the historical dustbin because some people mutilated them in implementation. We must not forget that families created group homes as an alternative to institutions because they were a dramatic improvement over institutional abuse. Person-Centred Planning and Independent Facilitation are part of this continuing evolution, and while some would say this is merely semantics, I am gravely concerned that simply declaring it passé is dancing on the razor of justifying death making.

If we deny our own history, we are part of the justification for the profoundly dangerous economic and political decisions that many of us feel are already in the ether. Some people are looking for how to and who to 'cut' - who to 'excise' from our society. 'Non productive citizens', those who cannot speak for themselves, and inconvenient people are quickly

reabeled as 'non-humans', thus 'expendable' because they are not worth the investment in tight economic times. If we are not careful, Person-Centred planning will be abused to choose who is worthy of life or elimination.

In short, we live in scary times. The deeply held values underpinning the origins of much of this human rights struggle (to include Everyone in full citizenship) are simultaneously being heralded internationally at the United Nations, and while wonderful phrases are featured in banner headlines, basic rights are being set aside, trivialized, mechanized, and even replaced.

What do we do? What can we do, in these 'confusing times'? Collapse in despair, or rally to the opportunity for incredible change. We opt for creating change, since the historical systems we have created and live within are unquestionably well beyond their 'best buy' date'. We need to create the futures we want. And as has been said: "It is tragic, but we are the people we've been waiting for." Why us? –Because we are all we have.

And there is good news; we are not alone. We have allies... all over the world. The 1% of the ruling class is doing very well, but the majority of people, the 99% (including ourselves) are potential allies. And the further down the poverty and exclusion roster, the more powerful the potential alliances. People with only the future to gain (and nothing to lose) have unlimited energy and creativity. When we ally with them, the fiscal and grant control systems that twist our lives in knots are incidental to their world picture. It is time that we take charge.

Why now... because the bureaucratic rape of morals, language and meaning is extremely dangerous. The systems so many of us have worked for and with have not-so-hidden roots in eugenics. That never died, it just went into hibernation. Eugenicians are waking up again and are making highly successful bureaucratic decisions to regain control. They have a clear ethical framework and crisp measurement standards: "dollaromics". Everyone can be commodified and given a dollar value. And only one millimeter further, everyone can be commodified and assigned a cost/benefit ratio. Take a moment's pause: If you were assigned to 'assess' people who need assistance as commodities, how would they do? And then what policies would you create? Look around slowly and soberly and you will realize that the Eugenics movement that designed the very systems we live within are rapidly regaining control and setting up the infrastructure to 'put away', eliminate and dispense with 'commodities' that are 'too expensive', not cost effective, useless. We can re-institutionalize such people who are 'inconvenient truths'. Better yet, we can make them disappear genetically by enforcing genetic testing. In short, big brother is not only watching, but is already engrossed in his chosen work. And remember: eugenics is a moral perspective - just a very different one than so many of us espouse. We believe in people first. Many others see 'commodities' and profit margins, and some commodities just aren't a good investment.

Where to begin...Here; Now; Today

All of this is seriously sobering. So some of us flee to distractions in despair. But some of us, and we hope you will join us, see this challenge to our very being as an invitation to create the future WE want. We have little to lose, and a universe of possibilities to claim.

We have described a complex and enormously frustrating big picture reality because it is vital to have a clear understanding of our landscape. But there is wonderful news. The key to inventing the future is entirely in our hands in the small daily relationships we build and nurture. Life is about relationships. And if we choose, regardless of all the bureaucratic

regulatory frameworks, we can choose to be humane with each other. That is the starting point. And we can begin now, nurture what already is and build more, today. No budget required. No systemic permission needed. We can choose to build (and rebuild) relationships around ourselves and with the people we know and care about.

When Systems claim and mutate our carefully crafted concepts, we can decide to ignore and disagree with their re-definitions. We (not the system) created a whole family of approaches for planning and support that had a very simple and elegant foundation. They were created to collaborate with people to be full and contributing citizens, living and participating IN their communities. The fact that Systems have mutated terms like Inclusion and Person Centered Planning into techno-driven brands that ignore the foundations built on relationships does not mean that systems are right. The system did not create Inclusion or Person-Centered Planning. They do not own it. It is OURS. WE can use our terms carefully and with the deep respect that was and is still intended by the many creators. So when systems colonize our language, we need to recognize and name it as a 'colonial abstraction' and continue to work to implement the deeper moral commitment that came from a deep engagement with civil and human rights for ALL.

How do we do this...by treating people as people? And that means ALL people: people we employ, people we work for and people we work with. All means all!

It is a daunting challenge to work to create more humane policies, viable support structures and welcoming neighborhoods. We can reclaim neighborhoods rich in diversity, with thriving associations, networks of friendships, community gardens, markets, music, coffee houses, art parks, where a spirit of hospitality permeates the air. We build it by doing it!

Happily, there are simple ways to assess if we are on track. They are not fancy top down statistical models and surveys implemented with huge budgets and regulatory systems. Rather, over coffee or tea, we can ask each other, 'how is it going?' If we begin with and maintain a clear focus on 'a person' and listen to gain clarity on how their life works... we will discover daily adjustments and possibilities to begin creating the future we want. This will involve a lot of coffee, tea, perhaps a few beers, and occasionally creating a poster on the wall. But all these are simply listening aids to help us listen deeply to everyone, and then to strive to take small daily steps in the direction of the better life we envision together.

This gentle, relentless, mass movement to give full lives to all is entirely doable. All we have to do is do it. We can choose it. We can have tea, plant a garden, listen to music, take a bike ride, join a book club, and drop a person at a worship service with new friends you have helped to identify. We can work to reduce 'dependency' and build relationships. We can move beyond and outside of 'systems space' and invade the personal loneliness of millions of citizens with new connections and friendships that will be the lifeblood of the future we want.

A tipping point is not far away. Systems technologies and budgets are out of control and unsustainable. We all know it. So our task is to begin building the new world where everyone belongs, no one's gifts are unappreciated - where loneliness is a memory because we have 'remembered' how to support each other in blood families and water families that are beyond the reach of bureaucratic systems and controls. When Kofi comes to dinner, he is my guest, my friend - not a client, a billable minute, or an expendable commodity.

Can this be done? We have personally walked out and walked on from systems land and survived. Some of us will do that. But not everyone needs to, or is in a position to walk out. But each of us can 'walk on' starting today. We can reach out, start or renew, strengthen a

relationship, create an opening for friendship. Invite someone for coffee. Invite someone to dinner. Go to a game or a movie with a new buddy. But most important - don't wait.

If we don't act now, the accelerating growth of the industrialized machine will drive over us and we will be discarded long before the system implodes. So do it now, because our collective momentum to invent alternative futures will create a tipping point - and these choices will create the futures we want.

Look around...

There are some remarkable and inspiring developments everywhere - but usually - on the 'margins' where people are driven and choose to push the boundaries of possibility. In Alaska, the school system is using Person-centered planning with primary school students, to minimize 'dropping out' and ultimately to reduce the suicide rate! A parallel in Nunavut on the other side of the Arctic in Canada, the school system is injecting PATH planning into schools where older students will be mentoring younger students in their plans, and the plans are revisited at intervals throughout their high school careers. There are no 'special' classrooms - just classes for all. At a student's transition from high school, not only fellow students, but also their families are included in the planning.

In many First Nations Aboriginal communities throughout Canada, creative PATH inspired types of planning are being used with students, agencies, community planning, and elders.

Similarly, and perhaps most dramatically, the Maori (First Nations) community in New Zealand are utilizing PATH planning for individuals, families, credit counseling, village planning, Women's rights, 'the quit smoking' campaign, Abuse prevention, hip hop competition teams, and on, and on and on. Critical to its very dramatic success has been that most of the planning is done in the Maori language and the graphic recording uses Maori myth and imagery. (<https://www.facebook.com/PATHFacilitatorsAotearoa>)

In India, Adapt India, a leading agency leading the struggle for full inclusion in India, Person-Centered approaches are being used to create incredible opportunities.

In Toronto, two remarkable variants are particularly noteworthy. SKETCH is an arts development program for street involved youth. PATH is often a component in assisting youth to discover their capacities and create new futures. (<http://sketch.ca>)

Similarly, the Toronto Newsgirls Boxing Club (www.torontonewsgirls.com) trains women to box. The majority of the boxers have endured sexual discrimination and/or abuse. One of the components in the training regimen is the opportunity to create a new PATH for your life.

Person-Centered approaches are being developed, adapted and implemented with creativity, deep values and enormous skill all over the world. The tipping point is approaching. The good news is that as more and more students and families have had a 'taste' of inclusion, they will continue demanding full inclusion. But in the 'systems' push to implement faster, with less, and document it to death, there are innumerable perversions that strip our words of meaning and are insulting and dangerous to the fundamental integrity of the Person-Centered family of approaches. In contrast, locally in Ontario, there are 75,000 recent 'graduates' who are unable to find employment. And there are 12,000 families on 'waiting lists' for support services. By thinking differently, we could match these talents and energy with folks who need a hand to realize full participation in the community. Although such options would cost money in the short term, the investment in creating full and participating citizens who are healthier, use services less often, are happier

and cost less over time, seems like a better choice. It is a matter of vision and will. It is possible. And we can begin with the little people in schools – starting today.

There are wonderful examples of excellence blossoming every day. Find them; publicize and celebrate them; learn from them, join them. And beware the false gods of fast-footed claims of miraculous 'cures', and instant solutions. Person-Centered planning approaches have always been about relationships - and have a foundation of integrity based on a personal relationship with each person. It is not easy, simple or quick. But it is essential and a core component in the way to build a future for us all.

Together we are better! All means all!

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Jointly with his wife and partner, Lynda Kahn, Jack conducts workshops and consults with organizations and collaborates with people with disabilities and their families, to engage in positive change that honours the gifts and contributions of all. Earlier, Jack, his late wife Marsha Forest and John O'Brien, collaborated to create several person-centered approaches such as PATH, MAPS and Circles of Friends. The collaboration continues now with John and Lynda.

Jack's forty years of organization experience include seven years in Africa implementing post-war reconstruction; sixteen years as President of Canada's oldest literacy organization, Frontier College; and nearly two decades as a full-time publisher and presenter.

Jack is the founding director of the Marsha Forest Centre: Inclusion, Family and Community and remains its Executive Director. Jack and Lynda Kahn work internationally and have expanded their network beyond Canada and the United States to include people in Australia, England, India, China, the Netherlands, New Zealand, Scotland, and Uganda.