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Human Worth

A Matter of Value

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what we do, what we say, what
happened to us and our collective past*

We wonder why it is so difficult, if not impossible, to get sufficient resources to help people who have intellectual disabilities to get the supports they need, and we know how to provide, so that they can take their rightful place alongside us in our communities. It is just a matter of value.

What is someone who has an intellectual disability 'worth'? How much is society willing to pay to help get someone 'better'? If a person needs intensive behavioural intervention to ameliorate self-injurious behaviours, how much is 'enough' to effect the change? The answers are a question of public and private values. Is it worth over \$100,000 for one person to have a necessary heart transplant? The answer is obviously 'Yes', because we do it. The public generally supports transplants ... but would it if the person needing the transplant was a thirty year old who had Down Syndrome? Values do not just come out of the air like clouds or mists, they are shaped by what we do, what we say, what happened to us and our collective past.

Let's take a look at the much-maligned Medical Model, not as it pertains to people who have intellectual disabilities, but its application for the general public. Physicians use an 'individual programme plan'... they do sufficient 'assessments' (blood tests, X-Rays, injections, etc) to individualise a treatment plan based on the presenting situation. Every complaint is seen as a new one, so your appendix is not just a collective of a thousand similar ones, but just yours. What you need, and what you get is dependent upon an assessment of YOU. If the average length of →

hospitalisation is four days, and you haven't healed as quickly as the person in the next bed or had some other complication, you don't get sent home because you did not get well as fast as the doctor thought you were supposed to. Would we limit the hospital stay and intervention strategies of someone severely injured in an auto accident? What about someone who has cancer? In the real world of hospitals you stay until the intervention is completed. Patients don't 'get blamed' for not meeting the doctor's expectations and get kicked out of services and treatment because they are difficult to manage, cost too much, take too long, or are of little professional interest. To do so would generate a sense of repugnance and moral outrage and would lead to negligence and malpractice suits and the inevitable media circus. **Except if you wear the label 'retarded'.** Then, I guess, it is not only acceptable but rationalised as appropriate for 'some' people. Did you ever hear of a negligence or malpractice suit in the field of developmental services for not using available and accepted technology? For not providing appropriate treatment?

It's just a matter of value. Let us tell it like it is. People who have intellectual disabilities have been discriminated against, denied basic human rights, denied 'treatment', and denied equal access to the sort of decent life we want for ourselves because they are seen to be second class citizens ... maybe even sub-human. Would we treat them the same if they were film stars or sports celebrities? If they were us?

In the medical field they talk about CAT-Scanners, thermography, lasers, transplant teams and esoteric diagnostic and treatment strategies that most of us have never even heard of, while for us it's a big event to have someone who was forgotten and forsaken in the back

ward of an institution to stop hitting himself. To dress appropriately. To make a meal. To move into a flat. To have a friend. To become a person, not just a patient. The health system talks Star Wars while we do not even begin to routinely use available, let alone new, technology that can liberate people. We accept, even glorify, segregation ... called self-contained classrooms, developmental centres, sheltered workshops, day activity centres. Do we segregate them because their mere presence offends us? Or do we do it while hiding behind virtuous words like "it is for their own good" (it never was), or "they like being with their own kind" (as if their kind was different from our kind). Our treatment suggests that if people who have intellectual disabilities are not sub-human (ugly thought, that) they are at best inferior. Our double standard becomes even more apparent when we look at what we do to or for them that would never be acceptable if it were happening to us.

We talk rights and freedom while practising apartheid. We knowingly accept government sponsored and funded incarceration of a group of people who have done nothing 'wrong' ... and what is worse, who look to us as their advocates and their lifeline. And we remain polite ... and mute. If we were Amnesty International, we would righteously focus the spotlight of public attention and outrage at the treatment of these hostages and demand they be liberated. We tolerate, and often participate in, segregation and then wonder why the public are prejudiced, deny rights, do not allocate sufficient resources or get →

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upset when a few 'different' people want to live in the neighbourhood. We have taught the public how valuable people who have disabilities are and where they belong, not from our words, but from our deeds.

If quietly, we devalue our constituency by accepting unacceptable standards and practices and decide to paternalistically placate and pacify the people we claim to advocate for (who now often tell us they do not like what we do for them), then it should be no surprise that they are held in low esteem by the general public. Our practices are the public's teacher. And we, all of us who piously claim to be advocates, we parents, professionals, governments, academics, who participate, tolerate and often advocate mediocrity in what we accept, provide, fund, and teach have taught the wider community to become prejudiced by our sorrowful examples. Since we, the workers and advocates in the field of intellectual disability services, supposedly "know what's best", our examples of 'best' are too often segregated and unfulfilling programmes and services. How many times have we heard, "they like doing boring work!" This Frankenstein of negative expectations about the potential for a full and meaningful life in the community for all of our constituency has been created by us.

Enough! If the public learns from our actions, and they do, let them learn of dignity, self-empowerment, normalisation, equal treatment and opportunity, full integration and social participation, and individualised supports. Let them learn from their new neighbours

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and workmates who, unfortunately, are often not there yet. Actions speak louder than any words. What does the presence of a sheltered workshop teach the public? What does real paid employment, supported if needed, teach? What does the public learn from twenty-six people milling about aimlessly in the day room of an institutional ward? What message is conveyed by a television mounted high on a wall out of arms reach? What does living in a flat teach? What picture of common humanity is created by someone living in a 'behaviour unit' for ten years? Especially when currently known technology is not used ... too costly or too troublesome, perhaps?

The late Burton Blatt (1976) talked about the Family: the professionals, parents, academics, organisations and governments that, through a conspiracy of silence and secrecy, condoned and promoted the isolation and segregation of people who had intellectual disabilities. He talked about the **"hypnotic language of humanitarian concern (that) encapsulates the victims of institutionalisation and seals their world off from examination or understanding or even hope. An elaborate camouflage of benign vocabulary - rehabilitation, treatment program, normalisation, therapy, modularised privacy ... is thrown over the reality of idleness, segregation, neglect Thousands continue to be locked up on the pretext of receiving care, training, education, and we continue to speak as though the pretext were reality. We call for more money and resources to implement the pretext rather than confess it was all a terrible mistake."**

Our good intentions have, whether or not by design, taught that the people we claim to be concerned about are not worth the same as the person on the operating room table waiting for a →

surgeon to implant a new heart. The Family continues to isolate and segregate, even today, though we know (and have the research to prove it) that it does not work for anyone - the consumers, staff, professionals, and the public. The Center on Human Policy, Syracuse University in the USA, stated in the Community Imperative (1979):

"To allow for continued segregation of retarded persons ... can only lend credence to the many fears of, and myths and prejudices against, people with disabilities. And no amount of scientific language can mask the fact that segregation benefits no one. We find no reasons ... to support ... isolating or segregating retarded persons from the mainstream of communities. If people need services, let them receive them in typical communities. Rational scientific inquiry and moral convictions can support no other conclusion.

The issues of (segregation) like the issues of slavery and apartheid, strikes at the very core, the very essence of our common humanity. Just as the emergence of Jim Crowism, the Ku Klux Klan, and theories of black inferiority do not and cannot justify the conclusion that Black Americans were better off under slavery, neither can exclusionary zoning codes, neighbourhood resistance, expert claims that some people cannot learn, or even firebombing of prospective homes combine to justify the conclusion that mentally retarded people are better off in institutions. What is at issue here is fundamental human rights and the quality of the lives of human beings. To claim that some people cannot learn, to place these same people in isolated institutions, and then suppose that the dignity and well being of those people can be protected, let alone enhanced, is to deny history. And to suggest that some people cannot and should not live amongst

their fellow human beings is to deny our shared humanness.

It is time we all took the pledge. We, the Family. We, the Family, can no longer accept, condone, rationalise or participate in any activity, programme or service that isolates, segregates or congregates people who have intellectual disabilities. The Family must speak out against an immoral apartheid of people who have disabilities, even if we are impolite or thought by our colleagues to be unprofessional. If we accept low expectations, it makes low expectations acceptable. If the Family segregates, it teaches segregation is necessary and appropriate. If we accept unfair, unequal, or unjust treatment at school, work, in recreational facilities, in places to live, and in programmes, it teaches that 'these' people are second class and deserve, or worse, need, what they get. It is time we, the Family, speak out rather than remain silent, and say, "No more!"

Pogo, Walt Kelly's cartoon opossum philosopher, said "We have met the enemy, and it is us!" It is time now to give less importance to reflection and good manners and opt for passion and commitment. Our constituency is dying for us to do what we know is right. ✱

References

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