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Social Justice and Individuals with Significant Intellectual Disabilities

Lou Brown, University of Wisconsin

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Before humans could speak, draw or write they had rules, determinants and propensities that guided their actions and led to consequences that defined and delivered justice. Genes and other biological phenomena probably had the most influence on those actions. As groups evolved and moved across the planet, so did theories, hypotheses, suggestions and commandments related to the nature and parameters of justice. For thousands of years the few who determined justice for the many were the strongest, the smartest and the most powerful. Sometimes they were magnanimous and sometimes they were mean spirited and brutal. In some cultures justice was actualized by cutting off an arm for stealing a blanket. In others, justice was winning a war and then forcing those conquered into slavery. Over time, cultures became more complex and better organized into functioning governmental components. Local constructions of justice were then applied to commerce, schools, law, public gatherings and militaries. Additionally, justice was applied to greater numbers of individuals with increasingly different characteristics. In many places, components of justice enjoyed by males were extended to women and to citizens of other races and sexual orientations.

Compassionate, Humane and Supportive Social Justice

We cannot choose when, how or with what we enter the world. Accidents of nature, social and economic circumstances and many other factors we cannot control or are not

responsible for can limit our options and place great burdens upon our families, fellow citizens and us. In such instances we are in need of the assistance of others who are better situated. The application of helpful and nurturing egalitarian principles has led to the development of a wide array of taxpayer-supported social services in many countries. Unemployment and medical insurance, social security benefits, vocational rehabilitation services and universal public education are examples. We agree with those who refer to justice as an uncompromising virtue entwined with fairness and the equitable distribution of opportunities and other resources among community members (Rawls, 1999). Central to these and most other egalitarian constructions is the notion that everyone has capabilities that must be honored with reasonable opportunities to realize them (Nussbaum, 2006; Terzi, 2008; Walker, 2006).

Social justice” is an extremely seductive and robust construct for many who function from a variety of perspectives. Many feel good when they advocate for opportunity, fairness, individual freedom, dignity, worth and shared resources. Unfortunately, others advocate for what we consider social *injustice*. They claim that it is not their responsibility to pay for costly services for others; that individuals are personally responsible for their status and wellbeing; that the unequal distribution of resources is natural and acceptable; that caring for others is voluntary and discretionary; that the role of government in the lives of individuals must be minimized; and, that it is extremely important they are taxed as little as possible. To individuals who cannot advocate for themselves or who have neither the voice nor the means to survive or live decent lives without the financial and other supports of those who are more endowed they say “Tough. Not my problem. So be it. Life is not fair.”

Our construction of social justice is compassionate, humane and supportive in nature. Indeed, any credible construction of social justice must clearly acknowledge the humanity of

individuals who might not be able to secure it by themselves and that everyone must have at least the minimums needed to survive and thrive. These minimums include, but are not limited to, food, shelter, medical care, education, personal privacy, opportunities to actualize meaningful choices and the means to work and travel about a community. Without these and related minimums, decent or socially just lives cannot be experienced. If we all have access to the minimums, then talents, skills, individual choices and other factors will determine how the additional fruits of society are distributed. To us, an equitable distribution of resources does not mean equal distribution.

We love to hear about individuals who have taken risks, achieved much and realized hard earned rewards. We encourage them to enjoy their successes and salute them when they do. However, we feel those of us who have more than the minimums have a responsibility to set aside a portion of our bounties to assist others who are also deserving of decent lives. We can have our boats, time-share resort apartments, jewelry, stables of cars, fine wines and many other “things” we can afford, but we must not deny the basic minimums to others who are unable to actualize such options. In short, all we ask is that those with means help others live, basic, meaningful, productive and purposeful ordinary lives.

Individuals with Significant Intellectual Disabilities

For purposes here “disability” means not able to do something. If you can do everything everyone else can, you are not disabled. Disabilities of all kinds are real and important parts of human experiences. Ultimately, all families and individuals will be directly touched by the penetrating realities of some form of disability.

Twenty-five years ago in an essay entitled, “Then and Now” Brown (1986) addressed several important issues related to the lives of the lowest intellectually functioning one percent of

our fellow citizens, the individuals of primary concern here. One issue was the critical need to emphasize the “personhood” of those individuals. Why? Because at that time, most claimed license to refer to and treat them as syndromes, objects, vegetables, less than human and diseases that did not have the rights and protections afforded those who were more intellectually able. They were segregated, sterilized, denied medical treatment, shocked with electricity, taken away from their families and loved ones, secluded even in segregated settings, restrained, denied access to public schooling and otherwise treated in ways we consider “socially unjust.” No longer could we tolerate one group realizing close approximations of lives that are “socially just” and concurrently accept the unjust treatment of others. No longer could their humanity or capacities be denied, minimized or ignored. It was hoped that by emphasizing and demanding the acknowledgement of “personhood,” more constructive and humane expectations, values, goals, pressures and opportunities would evolve into normalized protections and decent lives within integrated communities. Since 1986, much progress has been made. Almost all school age children individuals with disabilities in the United States are now experiencing taxpayer supported educational and related services (Agran, Alper & Wehmeyer, 2002). Each year more and more are performing real work in the real world (Brown, Shiraga, and Kessler, 2006). The numbers who live in public and private “institutions” has been reduced from over 350,000 to less than 40,000 (Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004; Coucouvanis, Prouty, Bruininks, & Lakin, 2006). Small but increasing numbers are living in apartments with not more than one other person with disabilities and with individualized extra support. (Extra support refers to that which an individual with disabilities needs in order to survive and to thrive that she/he would not need if not disabled).

Increasing numbers of individuals with significant disabilities, in concert with family members and others, are demonstrating the ability to make choices that lead to remarkable achievements in integrated employment, residential and general community environments and activities.

What is compassionate, humane and supportive social justice for an eight-year old girl with Down syndrome who is among the lowest intellectually functioning one percent of individuals her age? In 1929, her life expectancy would have been nine years. In 2011, it is around fifty. She attends the same school and classes she would if she was not intellectually disabled. In her integrated school and classes she enjoys the benefits of individually appropriate extra supports, without which she would not be able to benefit from the activities she experiences. She lives at home with her mom, dad, sister and brother. She participates in integrated activities with her family in their faith community. She is involved in integrated swimming classes at the local Y. She is an enthusiastic member of a Girl Scout troop with her sister and neighbors. She enjoys sleepovers with classmates who are and are not disabled. She goes to integrated Girl Scout camp each summer. She...

She functions more effectively in these safe and enhancing integrated environments and activities with the assistance of family members, teachers, paraprofessionals, therapists, taxpayers and other community members. In the recent past she would have been denied access to public schooling and she would be confined to a segregated “institution” or left to sit at home all day. Her life is not perfect, but it is relatively good. Now we must ensure it remains so, because when she exits public school and when her parents die, she will rely on all of us for different kinds and amounts of extra support.

Cost

One of the reasons it is hard for many to consider the provision of individualized extra supports in integrated settings and activities as the best option for individuals with disabilities is because the majority of those who appropriate and allocate the necessary financial and other resources have rarely interacted with them directly and frequently over long periods of time. If

individuals with significant intellectual disabilities grew up in an integrated society, all members therein would get to know them and would understand the extra support they need. Then, the vast majority of taxpayers, legislators, business leaders, coworkers, neighbors and others would join the quest to actualize compassionate, humane and supportive social justice in their lives.

What is compassionate, humane and supportive social justice for a 17-year-old young man with autism and who is among the lowest intellectually functioning one percent of all students in his school district? He attends the same high school he would attend if he were not intellectually disabled. In his school and classes he enjoys the benefits of individually appropriate supplementary aids and services, without which he would not be able to benefit from the integrated educational environments and activities he experiences. He lives at home with his mom, dad and sister. He participates in integrated activities with his family in their faith community. He is in a weightlifting class at school with schoolmates who are not disabled. He lifts and works out with them at the local Y after school Tuesdays and Saturday mornings. He goes to and from school and to the Y in a car pool with his friends. At other times he uses public transportation to travel about his community. Two school mornings per week he goes to a bank to learn work skills and how to function in an integrated work setting. He...

He could not enjoy the benefits of these safe and enhancing integrated environments and activities without the extra support of family members, teachers, paraprofessionals, therapists, taxpayers and many others. Chances are great that he, and millions of others within his functioning range, will outlive his parents. If and when that happens, he still will not be able to survive or thrive by himself. In a socially just society, where will he live? Who will he be with? What will he be doing all day? How much should we spend on him? Compassionate, humane and supportive actions are wonderful, but there are associated costs.

Options

Five of many options that could be actualized for the lowest intellectually functioning individuals within our society are delineated below.

Option # I. The selective killing and harvesting of individuals with disabilities is not just a phenomenon that took place in antiquity or in Nazi Germany in the 1930's and 1940's

(Berkson & Taylor, 2004; Hudson, 2011). The World Health Assembly first adopted an amendment that condemned profiting in the trade of human organs in 1989 (WHO, 1991). Recent reports indicate this horrible practice is still pervasive (Wilkinson, 2003; Garwood, 2007; Hudson & Wheeler, 2008). While killing those with significant disabilities would reduce taxpayer costs, it is rejected here as an unbearable extreme that creates very dangerous and slippery slopes. Specifically, as killing the lowest intellectually functioning five, ten or thirty percent of the population would result in even greater cost reductions. At what point would it stop? Who would stop it?

Option # II. Some would *require* the prenatal testing of all pregnant women and then the abortion of fetuses that have undesired characteristics. No choice. Justifiable homicide. Many who are likely to be among the lowest intellectually functioning one percent would be selected. In the United Kingdom the termination rate of pregnancies after a prenatal diagnosis of Down syndrome is 91-93% (Mansfield, Hopfer, Marteau, 1999; BBC News, 2008). Unfortunately, some of those who strongly oppose these policies and practices also strongly oppose generating tax dollars to help the young survive and thrive after requiring or allowing them to live. Compartmentalized social justice.

Option # III. Some recommend that extra supportive services paid for by taxpayers should be drastically reduced or not provided. If families or charities cannot pay for what they need to survive or thrive, so be it. In fact, if tax dollars are reduced or denied to this extremely vulnerable population, many would die, tremendous economic, emotional and other burdens would be placed upon aging parents and family members and the lives of millions with and without disabilities would be terribly and painfully constricted or wasted. In 2000 over 710,000 persons with intellectual disabilities of all ages in the United States were living with caregivers

over age 60 (Braddock, 2007). In addition, if we deny or drastically reduce services for individuals with significant intellectual disabilities and their families, we would have to look at ourselves in mirrors and we would have to explain to our children why we treat people this way.

Option # IV. Some argue for regression to the era when individuals with significant disabilities were confined to large “Handicapped Only” public and private institutions. In fact, at this time individuals with disabilities are being placed in homeless shelters, nursing homes or assisted living facilities at much earlier ages and in vastly disproportionate numbers compared with their same age peers (Charlton, 1998). Historically, the institution option has been extremely costly for taxpayers. In 2002, the average annual cost of confining a person to a state operated institution for individuals with intellectual disabilities in the United States was \$135,000. The cost of serving the same persons in the homes of family members or in supported apartments and in supported employment in integrated work places was \$20,000 (Rizzo et. al, 2004). Price (2012) reported that in 2011 Ohio spent 175 million dollars per year keeping individuals with intellectual disabilities in segregated workshops and only five million dollars keeping them employed in the community. Further, she reported that the cost of supporting individuals in integrated community settings was less than \$9600. Per year. The cost of supporting them in sheltered workshops was \$22,000. Per year. The state of Oregon was found out of compliance with the Americans with Disabilities Act by the U. S. Department of Justice for segregating far too many individuals with disabilities in segregated workshops and thus not affording reasonable access to integrated work opportunities (Perez, 2012). Peterson (2008) reported the cost of housing individuals in institutional settings in the state of Illinois was about \$150,000 per year compared to about \$50,000 for community based housing. Consider the costs of segregating one percent of three hundred million or three million individuals. Also consider

the well-documented abuses and wasted lives endemic in segregated settings (Horner-Johnson & Drum, 2006; Hakim, 2011). No socially just society can tolerate this option.

Option # V. Some, including the authors, strongly believe that we all should pool our resources, talents and notions of fairness and decency and arrange for the lowest intellectually functioning one percent of our population to live, work and play in integrated society. This depiction of compassionate, humane, and supportive social justice can and must be realized.

If environmental factors were held constant across individuals, intelligence, however defined, may not be distributed as is typically depicted by a bell curve, but it would still be distributed unequally. Assume that no matter how it is actually distributed in nature there will always be high and low intellectually functioning individuals. Should social justice be distributed unequally as is intelligence? Are there parameters of citizenship that should be available only to certain intellectual portions of the population? We say no, but how intelligence is manifested and honored in the lives of individuals in each grouping might be substantially different. Individuals with significant intellectual disabilities have the same general needs and rights as all others, but they require many different and specific kinds of assistance in education, health care, domestic living, transportation, social relationships, vocational functioning, personal management and other aspects of daily living.

What is compassionate, humane and supportive social justice for a 30-year-old man with severe cerebral palsy and who is among the lowest intellectually functioning one percent of all citizens in his community? His mother and father have died. He works in the office of an insurance company for the local minimum wage for thirty hours per week. A Job Coach paid by taxpayers ensures that he is successful at his work site. He receives medical benefits from the Social Security Administration. He lives in an apartment with another person with disabilities. A Life Coach comes to their apartment several times each week to help with shopping, cleaning, medical activities and cooking. He is involved in aerobics and ceramics at his faith community. He uses public transit and meals on wheels. He and his roommate like movies and go to a theater together about once per week. He...

He does not make enough money to pay all the costs of his apartment and employment assistance, food or other important basic life needs. The county in which he lives gives him tax dollars for that which he cannot pay for himself. Consider what his life would be like if the extra support he receives is drastically reduced or taken away?

Many families have fought passionately and tirelessly for many years in order to generate opportunities for their children with significant intellectual and related disabilities to survive and thrive in integrated settings and activities. This has resulted in innovative ways of generating opportunities for many others of similar circumstance to do so. New examples of individuals with significant disabilities who lead remarkably productive, safe and rewarding integrated lives surface daily. Thus, we know it can happen and we know how to do it. However, they certainly are part of an extremely small minority. The overwhelming majority of individuals with significant intellectual disabilities are still confined to segregated schools, classes, group homes, nursing homes, shelters and the homes of family members all day as adults.

Sadly, some legislators, union officials, business leaders, parents and a dying breed of professionals are still opposing Option # V, even though it is the one that will lead us to a socially just society. If compassionate, humane and supportive social justice is being actualized in the lives of a few, we must find ways to expand it to millions of others. Each of us must be able to see, feel, hear or otherwise sense that compassionate, humane and supportive social justice is operational in our lives as well as in the lives of our fellow citizens. The challenge now is bringing Option # V to scale (Schorr, 1998).

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