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# Why the intellectually disabled in the *Evans* case continue to hold the DC government neglectful after 40 years: a history of differing views about disability rights

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**Abstract:** This article is about Washington, DC's intellectually disabled and the history of their struggle for habilitation rights, which for them includes gainful employment and having a family. Against them has been a conservative local and national government and the US District Court in its rulings over the past 40 years in the *Evans et al. v. Bowser* case. The disabled have had only limited success in their expansive interpretation of their rights, but by exploiting differences between the government and court, they have obtained concessions concerning basic food, clothing and shelter. For this reason they advocate for an indefinite continuation of the *Evans* litigation.

**Keywords:** genocide; habilitation rights; intellectual disability history; over-medicating.

## Introduction

This essay discusses the differing views about the rights of Washington DC's intellectually disabled and the history of their resistance against the neglect of their rights by the DC government. The focus in discussing the differing views will be on DC's "Persons with Intellectual Disabilities Constitutional Rights and Dignity Act of 1978" (Constitutional Rights and Dignity Act), as interpreted in the DC Federal District Court's *Evans et al. v. Bowser* case (*Evans*) [1, 2]. The act claimed to protect the rights of the intellectually disabled. From its beginning the courts, government and the disabled have interpreted the act in different ways. These different interpretations are seen in the long-running *Evans* case, which began in 1976 and continues to be a battleground. The *Evans* plaintiffs are the 1100 living

and dead individuals who were residents at DC's facility for the intellectually disabled, Forest Haven, when the case commenced.

By way of background, psychologists using standardized intelligence quotient (IQ) tests define the intellectually disabled as that 3% of the population who score two standard deviations below the statistical mean. By this definition, DC, with a population of 670,000 in 2016, has 20,000 intellectually disabled. The DC government's Developmental Disabilities Administration (DDA) provides services to about 10% or 2100 of them, which includes the 600 surviving *Evans* plaintiffs [3, p. 21; 4]. The scholar Duane Stroman notes that in 1973 the IQ norm was redefined by conservatives to exclude government assistance to half those formerly eligible [5, pp. 12–13]. According to US Congressional testimony in the 1970s, when the DC population was 722,000, there were 29,000 developmentally disabled, of which 23,000 were intellectually disabled. Of these, 1100 were served by the Department of Disability Services (DDS). In addition the DC public schools served 9000 and the Social Rehabilitation Administration (SRA) served 14,000. The latter included Aid to Families with Dependent Children (AFDC-PA) and services for alcoholics, drug-addicts and public offenders [6, p. 18].

The current presiding judge in the *Evans* case, Ellen Huvelle beginning in 2001 and before her Judges John Pratt from 1976 to 1995 and Stanley Harris from 1995 to 2001, have been in agreement with the plaintiffs' (the disabled) views concerning the government's culpability in neglecting to deliver basic necessities which results in deaths and hospitalizations that the government's own investigators find preventable. Nevertheless, all the judges, from the perspective of the disabled, have followed a conservative interpretation of the 1978 statute, viewing it as extending not much beyond food, clothing and shelter. The disabled and their advocates take an expansive view of the act, arguing it protects their rights concerning habilitation. A history of their habilitation accomplishments, as will be outlined, will help explain their differences with the conservatives.

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## Habilitation

Habilitation from the perspective of the disabled equates with gainful work at a living wage so that they can raise families in security like the non-disabled. The D.C. Code § 7-1301.03(14) (2001) defines habilitation as follows:

“Habilitation” means the process by which a person is assisted to acquire and maintain those life skills which enable him or her to cope more effectively with the demands of his or her own person and of his or her own environment and to raise the level of his or her physical, intellectual, social, emotional and economic efficiency. “Habilitation” includes, but is not limited to, the provision of community-based services [1].

The disabled’s view of habilitation is summarized by Terry Carroll. He was director of the National Institutes on Rehabilitation and Health Services (NIRHS) between 1960 and 1971. The NIRHS was a federally-funded, labor union-backed advocacy organization. Carroll wrote:

The principle element in a national habilitation and health program is a full employment program that would provide socially useful, non-hazardous jobs at a living wage to every worker. One of the first steps toward achieving such a program would be the repeal of the 1947 Taft-Hartley Act and its sequel, the Landrum-Griffin-Kennedy Act and an anti-union NLBR, which have impeded workers’ efforts to unionize and obtain fair working conditions and wages [7, p. 211].

From the disabled standpoint, what the conservative court and government attempts to offer them and their direct caregivers is permanent poverty.

Illustrative of disabled thinking about jobs is a 2012 report prepared by DC’s University Legal Services Protection and Advocacy Program (ULS), which organization is one of their defenders in the *Evans* case. By way of background, ULS has been DC’s Protection and Advocacy (P&A) agency since 1996. It is funded by grants from the US Department of Health and Human Services and the US Department of Education. It is required by law to ensure the enforcement of constitutional and statutory rights of people with disabilities. It does this through administrative, legal and other appropriate remedies that address complaints of abuse, neglect and rights violations on behalf of people with intellectual disabilities who live in city-funded group homes and may be at risk of abuse and neglect, individuals with mobility impairments seeking accessible housing, mental health patients at St. Elizabeths Hospital, people who are homeless and mentally ill and people with disabilities who live on their own.

ULS documents how DC’s intellectually disabled in large numbers seek gainful work, but the government

gives them a near-zero work option. Jane Brown, executive director at ULS comments, “In D.C. in the 2011 fiscal year, the vast majority of individuals receiving both RSA [Rehabilitation Services Administration] and DDA services (332 of 355 people) did not achieve an ‘employment outcome’ through RSA. Only 23 individuals entered or retained any type of employment” [3, p. 25]. A ULS report summarizes:

Regardless of where ULS presented, whether it was a day program, prevocational program, or supported employment program, ULS heard repeatedly from individuals that they want to work. Nevertheless, these individuals encounter a myriad of obstacles to employment... Some individuals are told over and over again that they are not ready for work. They are told this by providers and representatives of DDS [DC DDS]. This seems to be true nationwide. One study found that “state and federal policy do not consistently prioritize employment.” It also found that community rehabilitation providers have not reallocated resources to community employment [3, pp. 20–21].

The study referred to in the above quote is from the Institute for Community Inclusion (UCEDD) University of Massachusetts Boston [8, pp. 10–11].

It is of interest that in the past the DC government has been helpful in providing employment to the disabled. This help included the early era of Forest Haven-District Training School, which was a residential institution for the intellectually disabled at Laurel, Maryland between 1925 and 1991, the Occoquan Workhouse for a century until it closed in the 1970s, the DC unit of the Works Progress Administration (WPA) and the Civilian Conservation Corps (CCC) during the Great Depression of the 1930s, the World War II full-employment era and over the last 30 years the Mayor’s Summer Youth Employment Program (SYEP) and the Job Corps.

## District training school

An account by journalist Pablo Maurer describes Forest Haven’s full-employment economy in its early years in the 1920s to 1950s, when it was called the “District Training School for the Feeble Minded.” He writes:

Forest Haven was a progressive farm colony that taught people with intellectual disabilities useable skills and aimed to get them gainfully employed. Residents milked cows, planted and tended to crops, and lived in dorms surrounded by trees, with peaceful, pastoral names like Beech or Elm cottage. Their routine included exercise and recreation: a gymnasium, swimming pool, athletic fields and basketball courts filled some of the green space between buildings [9, pp. 10–11].



Figure 1: DTS Farming [10].

The Training School's 900-acres and 86-head of dairy cattle, at various times provided the residents and staff with eggs, milk, cheese, pork and vegetables. While some chores, as depicted in Figure 1, were daily events, such as milking the cows morning and evening and feeding the livestock, there was an agrarian cycle that brought variation and provided jobs for everyone. The cycle began in the spring with multiple crews plowing the fields and planting corn, soybeans, potatoes and vegetables. May and June were spent in strawberry picking and weeding. Starting in July the fruit orchard and vegetable gardens were harvested, with the busiest period from September to November, when they did corn husking, loaded the silos with grain, mowed the hay, bailed it and stacked it in the barns and dug up the sweet potatoes [11]. From December until March they did hog butchering.

The heavy work was done by the males, but the females joined in the gardening, in the strawberry, fruit, and potato harvests and in the butchering [12]. They had a US Department of Agriculture-sponsored 4-H Club (head, heart, hands, and health), whose motto was "learn by doing". Each fall they exhibited their livestock and produce at the Maryland state fair [13].

Besides the farming the disabled helped build and operate a foundry that produced metal that was used in the facility [14, p. X19; 15, p. 24; 16; 17]. This involved making impressions in sand molds and filling them with molten metal. Coming under the category of industrial arts, it prepared those involved for employment in Baltimore's nearby steel industry. Other on-the-job training was obtained in

the power plant, which provided light and heating, and in the carpentry, plumbing, painting, electrical, machine and masonry shops that kept the institution in repair [18, p. 424]. In 1940 the disabled helped build and operate a 50-bed hospital that served the facility's 500 members. The American president's wife, Eleanor Roosevelt, took part in the hospital's dedication ceremony, which featured performances by their 30-member band and 50-member women's chorus [19, p. X15; 20, p. 17; 21].

Unlike the outdoor jobs, the disabled women, as illustrated in Figure 2, did much of the indoor work, such as laundry, baking, cooking and sewing. The institution was self-sufficient in baked goods with bread and doughnuts made daily. For celebrations such as May Day 1941 they baked 6000 rolls, 13 sheet cakes and 2400 cookies [22]. The facility similarly aimed at self-sufficiency in its sewing, weaving, crocheting and embroidery. For example, in February 1940 they made 6750 pieces of wearing apparel and mended 806 pieces of clothing. On a single day they mended 84 blankets [23]. They also made quilts, embroidered curtains and on their looms they wove rugs and hot pads [24]. During one period they were crocheting 60 blue caps per month which the women wore as part of their uniform [25].

The disabled had a school which was in 1961 named after Mary Ziegler, a popular teacher who served them for 34 years from 1928 to 1962. Along with the school there was a library, occupational program, drivers' education program and chapel [26, p. 7; 27, p. 9; 16]. The manual training shop had table saws, laths, band saws, drill presses and other wood and metal working tools. Those who completed





**Figure 2:** Needlework: making and repairing their clothes, rugs, bedspreads, towels, potholders, tablecloths and napkins [53].

elementary school commuted to junior and senior high schools in DC [28, p. 25; 6, p. 24]. In the 1930s the education and psychology program was supplemented by practicum students from Antioch College in Yellow Springs, Ohio and Catholic University in Washington, DC [29, p. 8].

Among the disableds' unusual possessions was a zoo which at various times had a bear named "Maggie", a race horse, monkeys, squirrels, raccoons, owls, rabbits, white rats, guinea pigs, ground hogs, 12 species of pigeons and aquariums with turtles and fish [30]. Their theater and drama company staged productions for the holidays such as the "Hansel and Gretel Opera" by Engelbert Humperdinck, "Why the Chimes Rang", by Raymond MacDonald Alden and the "Sleeping Beauty Operetta" by Oliver William Robinson. The plays generally had social themes that appealed to the disabled, such as poverty, employment and victory for the underdog. The casts for each performance consisted of 30 to 40 actors, singers, dancers and others that worked as stagehands and made the scenery and costumes. The accompanying orchestra added another 25 participants [31–33]. In the orchestra were trombones, saxophones, clarinets, cymbals, drums, trumpets, baritones and sousaphones [34]. Less formal were the minstrel and talent shows that were staged

several times per year [12]. Parents, friends and others from the outside community attended the performances.

Until the 1950s the "Trainers", as they were called, also had several uniformed baseball and other athletic teams that played against institutions in Pennsylvania, Virginia, the Eastern Shore and local facilities such as Rosewood at Owings Mills, MD, Briarley Military Academy at Beallsville, MD and St. Mary's Industrial School in Baltimore [35, p. 25; 36, p. 18; 37, p. X5; 38, p. X6; 39, p. SP2; 40, p. 7; 41, p. 24]. Babe Ruth learned to play baseball as a resident of the latter facility, but by the 1930s when the Trainers were playing them, he was playing against the Washington Senators at Griffith Stadium. A star Trainer team-member, Edward White, later played with the Washington Grays [29, p. 8]. During World Series' week each fall the harvesters suspended operations to listen to the games [13].

For many disabled, football, basketball, track meets or boxing was as popular as baseball. They sent their boxing teams to exhibitions at the Washington YMCA, the Police Boys Club and similar venues throughout the area, as well holding meets in its own gym. A match on January 22, 1936 in their gym featured seven different bouts, starting with the 115-pound class and ending with the heavyweights.



**Figure 3:** May Day king and queen (wearing white gloves) reigning over the festivities [46, p. B-4].

In between each bout there was entertainment, such as a mouth organ recital between the first and second bout, an accordion medley after the second, group singing after the third and a vocal solo after the fourth [42]. A memorable event in the fall of 1935, especially for the Afro-Americans, was the world heavyweight championship match between their hero, Joe Lewis and the Nazi Max Baer. They borrowed radios to listen in their cottages to Lewis's blow-by-blow victory [43].

The farm-wide teams were for the more skilled and competitive. For those who were not so inclined, each cottage during the various seasons had its own hiking, playground, tennis, swimming, baseball, football and basketball activities. On Thursdays both the disabled and their staff went bowling [44]. For those that liked fishing, the pond was stocked with bass by the Bureau of Fisheries [45]. In the summer the pond was used for swimming and diving. In the winter it was used for ice skating. There were 12 miles of hiking trails contiguous with the farm that were kept up by the disabled.

In addition to sports, throughout the year the disabled had supervised Saturday night dances and celebrated seasonal and national holidays such as Halloween, Thanksgiving, Christmas, Easter and July 4 with parades, banquets, picnics-lunches, invited guests, baseball games and barefoot dancing. A newspaper report with a photo reproduced in Figure 3 described a May Day celebration complete with a maypole as follows:

It was May Day, the mental institution's once-a-year festival which has been held for as long as anyone present could

remember. For more than 1000 retarded residents, May Day is all the holidays wrapped into one. The parade, the king and queen, visitors, the holiday meal and games all afternoon are looked forward to for days in advance.... The day started early with a two-block parade winding through the field-like campus. Residents and staff who didn't participate lined the streets, calling the names of those riding the floats, sometimes getting a smile or wave of a little flag in return....

The king and queen, who were crowned after speeches at the end of the parade, were the oldest Forest Haven residents, 79 and 80 years respectively. Both have spent most of their lives at the institution. The honor of who rides on the floats is passed around from year to year as much as possible, although a counselor for one cottage said her area chose residents whose parents no longer visit them. "They are the one that really need to feel special," she explained....

Leading the parade, which ended at the athletic field for speeches and games, were Redskin back Larry Brown, who helped organize this year's festival and a daughter of Sargent Shriver... Following a "holiday lunch" which included barbecued spareribs, the residents returned to the athletic field for games and fair booths [46, p. B-4].

Occasionally cottages would go on outings to Washington DC to see a Senator's ballgame or a theatrical performance, such as Cab Calloway at the Howard Theater [47]. For many the most anticipated event of the year was at holiday times when they did overnight visiting with their parents or relatives. On other holidays such as Valentine's Day, they sent cards to their mothers [12].

Employment on the farm was not racially segregated but the cottages were divided along racial, gender and age lines. From the start about half the population was Black, half White, half female and half male. Unlike a kibbutz, there was no provision for those who wished to marry and raise a family. They had to go back to DC for that. As will be seen, the females who chose to stay had to be careful or they would be aborted and sterilized by the maneuverings of eugenic-minded administrators.

There were apartments for those of the 250-member staff who chose to live there permanently. They included five teachers, a shop man, a vocal music instructor, five recreation workers, an occupational therapist, administrators, and assorted medical, dental, social service, culinary, utilities and farm employees [48, p. 20; 49]. They earned standard civil service, trade-union wages, which for an entry-level job in the 1930s was \$1080 annually. They were collectively represented by the Federation of Federal Employees, whose local unit in the 1930s was headed by the Training School teacher, Mary Grolman Ziegler [50]. The union established a credit union and provided group insurance coverage.

The disabled in terms of food, clothing and shelter were self-sufficient, being paid in kind for their labor. However, because they were not a money-making

operation, they relied on public funding to cover staff expenses. The *Washington Post* reporter, Ed Fenton in 1936 described the disableds' habilitation philosophy in terms that are similar to those of a kibbutz or Mennonite community. From the earliest age, the individual was educated for gainful employment.

Upon reaching adulthood the higher functioning could establish their own living arrangements, including employment in sheltered workshops or they could stay in the state institution and work there. The lower functioning that were not employable in the open economy were given employment on the attached farm and factory network. A father commented about his recently-deceased, non-verbal daughter's employment at the laundry:

After all these years she loved it up there. That was her home. It was her life. She worked folding linen in the laundry room and she loved needle point. When she liked something, she'd get very animated, very happy and smile all over [51, p. C4].

Reporter Fenton summarized the facility's job-oriented nature, "Its purpose is in line with the modern line of teaching the mentally deficient to become socially adequate, to be able to carry their weight in the complex community life of the present time" [52, p. X19].

The expansive interpretation of habilitation rights as Fenton outlined was as much an area of disagreement in the 1920s and 1930s as it is currently. As protested by the disabled and their families in the early years, the problem with the District Training School was that only a tenth of those who sought admission were accepted [54, p. X13; 17 p. X19; 55, p. 15; 56, p. X3; 57, p. 7]. A conservative US Congress controlled the funding. The facility's superintendent from 1925 to 1934, Kenneth B. Jones, in his annual report in 1934, complained:

The District Training School for the Feeble-Minded at Laurel Md. from its beginning has been hampered at almost every turn by lack of money to do very essential things. Necessary utilities and accommodations have been provided only long after the need for their existence was pressing. In consequence, makeshifts have been frequent and almost the rule. Never has it been possible to plan adequately for present needs with any hope that such plans would be carried out. The institution is situated far from the eyes of the average District resident. Its inmates are the children of the poor, the unfortunate and the mentally subnormal, and the institution has not had the weight of influential personal contacts that ordinarily demand support in other fields [58, p. 5; see also 59, p. 23; 60, p. 11].

According to reporter Eugene Robinson, by 1981 Forest Haven was receiving \$6 million per year from Medicaid for 400 residents, which was cut off by federal regulations

because the facility was suffering from a lack of habilitation programs [61, p. 1]. In 1989 the facility again suffered a cut off of Medicaid funding, which by then was \$8 million per year in a total facility budget of \$22 million for 250 residents [62, p. C1].

As voiced by the disability activists, their problem was the eugenic-minded conservatives, who, as will be discussed later, preferred to see them sterilized, aborted or dead – not habilitated [63, p. 1]. For a majority of DC's intellectually disabled, Forest Haven and government services were never sought or desired. They found their own gainful employment and took care of themselves. Families provided assistance. At the same time for the fraction who were orphans or whose parents were in prison, aged, invalids or who otherwise abandoned or neglected to feed, clothe, shelter or educate them, the training school community became a family [64, p. DC1]. Illustrative was the thinking of John Thomas, a member of District Training School cottage 6 in the 1930s. He wrote a poem, "Home Sweet Home" about his experience of being jobless, homeless and hungry:

Park benches are quite chilly.  
You've discovered you've been a fool,  
for leaving a place you hate to call home.  
It's the District Training School.

When you get so hungry, you have to steal  
And break the golden rule.  
Your thoughts swiftly turn to the homestead,  
And you're headed back for the school... [65]

## Occoquan workhouse

In addition to Forest Haven, the Occoquan Workhouse was a government jobs-program of which working people made use. Its history dated back to the early 19th century. Until it was closed in the 1970s it helped 20,000 men and women per year, some of whom, like the general population, were intellectually disabled but not involved with DDS and its predecessors [66, p. 7]. In the 1930s the daily capacity at the workhouse was 1000. Working people were committed there by the DC courts for doing petty offenses such as panhandling, public drunkenness and fighting, prostituting and pimping, bootlegging, failure to pay child support, shoplifting and petty larceny. They were what the eugenic-minded founder of Planned Parenthood, Margaret Sanger, called "human waste" [67, chapter 5; see also, 68, 69]. At times they also included activists for trade union, women's voting rights, socialism and veterans benefits.



Occoquan was located 20 miles south of the city and bordered the DC correctional facility at Lorton, Virginia. The workhouse included a brick and tile plant employing 190 people, a construction division employing 210 people, a foundry and furniture, sheet metal and textile factories that sold their products to the federal government [66, pp. v, 7, 10, 22, 37, 63–67]. In addition to its industries Occoquan also employed its residents to run the facility itself. They worked in the kitchen, laundry, electrical shop, carpenter shop, machine shop, hospital, garden, power plant and boiler house. The workhouse offered formal training and on the job training in skills such as auto mechanics, plumbing, steamfitting, electrical wiring and wood working [66, p. 27]. Part of the workhouse system was a farm that employed 140 people in its dairy, poultry unit, orchard, hog raising and wheat raising [66, p. 22].

Occoquan also operated joint projects with the federal government, such as the Works Projects Administration (WPA) programs in 1935–1936 [66, p. 55]. During the 1930s more than half the Occoquan residents had been a year or more without employment before coming to the facility. For many on indeterminate sentences, especially seniors, Occoquan was a home: a place where they could stay sober, work and have a roof over their head. There were no guards, walls or cells [66, pp. 18, 20, 45]. The facility was shut down in the 1970s by the same coalition that deinstitutionalized Forest Haven and St. Elizabeths Mental Hospital.

The DC Department of Corrections ran a second habilitation program similar to the workhouse, of which DC's disabled made use. This was Lorton Reformatory, which existed from 1910 to 2001. It housed 10,000 individuals in the 1990s, of whom 75% had not completed high school and 65% were unemployed at the time of incarceration [70, pp. 232–234]. Scholars Orville Endicott, George Denkowski, Kathryn Denkowski and Jerome Mabli have studied the percentage estimates of intellectually disabled prisoners [71, pp. 232–234; 72].

To assist the prisoners the government ran a number of programs, including the “Second Chances for Improved Education and Job Placement Program”, which provided courses in a range of academic subjects, personal development and work experience to prepare for the General Equivalency Diploma (GED) and for apprenticeship programs. In 1994 there were 4000 enrolled in the program. The facility also gave employment to 1000 men and women in its furniture, upholstery, textile and other industries and in its network of thirteen half-way houses in the city where residents held mainstream jobs including maintenance, landscaping and housing restoration or attended school or drug programs [73, p. 167; 74].

## The WPA and CCC

The District Training School (Forest Haven), Occoquan and Lorton gave employment in a residential setting. During the Great Depression of the 1930s, the disabled gained additional residential and also non-residential employment programs. The CCC during the decade of its existence from 1933 to 1942 was a federal, residential jobs program based on a semi-military organization with uniforms, drills and bivouacs. They worked a 40-h week over a 5-day period, making \$30 per month, of which \$25 had to be sent home to their family. They received food, clothing, medical care and an educational program that emphasized job training. Some one million youth took part in the program.

Among the intellectually disabled who joined the CCC were District Training School alumni [13]. They also joined the non-residential, federally-funded, DC government-run branch of the WPA. It gave jobs to the unemployed. Initially it refused to employ the disabled but their protests, as on May 8, 1936, when 35 of them, as part of a socialist organization, staged a sit-in at the WPA's Washington office, brought concessions. As depicted in Figure 4, they forced Harry Hopkins, head of the agency, to meet



Figure 4: 1930s' activism [78, p. 431].



personally with them and establish a policy that included them in the government's full-employment program [75, p. 6; 76, p. 10; 77].

In studying the 1930s activists, the UCLA historian Jennifer Uhlmann discusses in her dissertation, "The Communist Civil Rights Movement", the influence which developments in the socialist world had on American activists. Following the foreign example, Uhlmann summarizes that they defined civil rights expansively. She explains:

Civil rights in their view included workers' rights to unionize and strike, foreign immigrants' rights to political conscience, radicals' rights to First Amendment freedoms, African-American rights to full, integrated and equal political and civic participation, and finally, inalienable human rights. They felt that all the demands packed into the expression "civil rights" were the inheritance of working people around the world. For this reason, their civil rights movement never narrowly focused on the South, or on African Americans, but included the rest of the United States and globe in an ambitious and multi-faceted revolutionary program [79, p. 6].

In their expansive definition of civil rights, the academic David Lane comments that for 1930s activists, the full-employment economy was a "sacred element in Soviet social policy" [80, p. 215]. Lane also notes another attractive feature for the disabled. As there was no administrative restriction in the USSR on moving from job to job, management sought to keep employees by having better facilities and payment in kind (housing, stores, recreation). Trade unions likewise helped with encouraging expansive rights because they were not forced to focus simply on wage and hour issues [80, pp. 2–3, 8].

Professor Uhlmann pictures the 1930s' American activists as seeking to imitate the planned labor-shortage of socialism so that labor costs would be high, giving workers strength against management. Because, as Lane puts it, there was no capital under their social model, there was no incentive to increase the profit of capital by reducing labor costs or the number of workers employed [80, pp. 1–2]. Uhlmann and Lane conclude that the labor theory of value was the "lynch pin". Full employment in the socialist state was vindication of the Marxist notion that labor was the source of value and idleness was degenerate. The Bible was quoted on this in the 1936 and 1977 Soviet Constitution: they who do no socially useful work shall not eat. Problems of efficiency, shortages, growth rates and the disability of workers for them were secondary [80]. The same authors go on to observe that the Soviet economy was one of full employment with the highest rate of paid employment known in history. There was an absence of a "reserve army" of the unemployed. Public

ownership and labor shortage were an inherent part of the planned economy that worked to the advantage of the disabled [80, p. 214].

The importance of employment to the disabled in the socialist world was reflected in their educational psychology. An educator commented on the right to work, "This right is not granted because of materialistic-social consideration, but rather from the point of view that work is an essential condition for personality development and the formation of specific personality characteristics" [81, p. 121]. While work was important in educational psychology, the progressives rejected intelligent quotient (IQ) testing. They maintained that the majority of those labeled as disabled received that designation because of the poverty into which they were born, not because of organic, intra-uterine or early lesions of the central nervous system that result in a tendency not to progress and low IQ scores. As the British medical scholar John Wing summed up, because of their full employment economy and resulting lack of poverty, the Soviets had little "psychosocial" intellectual disability [82, p. 433]. Eliminating poverty in his view eliminated most disability.

In another study that parallels Wing, the academic Joseph Wortis, contrasted the progressives lack of IQ testing with the 1930s eugenic approach, which in his view put a burden on the disabled by labeling them, using psychometric testing and low IQ scores [83, p. 1442; see also, 84, 85]. According to the eugenic views, a two standard deviation from the IQ median, as noted earlier, resulted in a disability label, which equated with 3% of the population. In the Soviet system because they did not test, there were no low IQ scores.

There was a final aspect of progressive habilitation that was as Professor Wing discusses, attractive to 1930s disability activists. In addition to the full employment economy and elimination of poverty and IQ testing, they liked the philosophy of training youth for employment from an early age, no matter what their diagnosis. This philosophy was embodied in the Soviet constitutions, which stated, "USSR citizens are obliged to show concern for the upbringing of children, to prepare them for socially useful labor and to rear worthy members of a socialist society" [86, p. 166]. The educator Jean Nazzaro summarized how the disabled implemented their constitutional rights in early education in order to prevent attitudinal and motivation problems that might otherwise overshadow the original disability:

To put a child in a situation where he is exposed to failure, even at the preschool or kindergarten level, is to set things up so that other problems, attitudinal problems and motivational prob-

lems, may soon overshadow the original problem of retardation. They feel it is very necessary to protect the child and help him develop the best functioning level he can with the resources he has and not allow any opportunity for the secondary kinds of emotional problems to develop. The earlier they can pick him up in a special program, the more protected he is from these complications, and the more directly they can get to his retardation and begin to work on it [87, p. 169].

Wing observes that the progressive habilitation training program, which began in Lenin's time, from the start stressed giving help to achieve full working capacity. During the 1920s and 1930s a system of habilitation units, training centers, vocational guidance units, and prophylactic workshops in the factories was established [82, p. 433]. American activists at the time toured these facilities. Wing made the following observations:

Many factories have special workshops for handicapped people – for example, a sewing machine factory in the neighborhood of No. 8 dispensary in Moscow has 300 handicapped people in such a shop, as well as providing sheltered conditions for other handicapped people within the open workshops. The standard of work required is, of course, very much higher in the open factories than in the sheltered workshops (though these have a much higher standard than our British day centers). For example, such workers need to be members of a trade union; they need sickness certificates if they wish to stay away from work. In addition, there are special factories with homes attached [82, p. 434].

Professor Klause Becker in the following passage, describes how the diversified nature of disability employment in the post-World War II period also influenced the German Democratic Republic (East Germany):

The factories can sign a training contract with the student. During the vocational training the students receive a stipend. Partial training can be provided for skilled vocations in various production fields, for example, construction, metal and electronics industry, foodstuffs, service sector, paper industry, agriculture, horticulture. However, the following overall characteristics applies:

- a relatively limited field of activity with essentially unchanging occupational characteristics,
- a high degree of skilled manual labor,
- in relation to the complex skilled vocations a clearly reduced theoretical and practical demand and a reduced degree of responsibility in production or occupational fields.

Graduates of Section II can be employed as sanitation workers, packers, assemblers, transporters, laundry workers, field hands and cattle hands [82, p. 120].

From the conservative perspective, which Wing reflected, the socialist system was too “paternalist”, too protective of habilitation rights. He commented:

The very thoroughness of the service must carry a certain disadvantage. It would require a deeper knowledge of Russian life and custom than I possess to assess how far a certain gentle but insistent paternalism and over-protectiveness is characteristic throughout the whole society. It is plainly evident in attitudes to the mentally retarded. In many cases it brings good results; probably the more severe the handicap the more satisfactory the system [82, p. 435].

Contrary to Professor Wing, from the 1930s' activists' perspective, the socialist system was more about fraternalism than paternalism. It followed working class and biblical idealism: “From each according to ability, to each according to need,” and St. Paul's (*Acts* 4:32–35) slogan, “one for all and all for one” [88].

Despite his anti-paternalism, Professor Wing endorsed and quoted the Soviet academic, Anton S. Makarenko (1888–1939), whose “paternalist” approach to habilitation emphasized the importance for the disabled of collective work during early childhood within the family as the path to employment success as an adult:

Both parents and children engaging in tasks appropriate to their different abilities but always for the common good is necessary for training in later collective living. By observing the example of such cooperative labor and mutual respect, and by himself carrying his proper share of responsibility, the child gradually acquires self-reliance, moral integrity and social dedication [89, p. xiii].

As summed up by Professor Uhlmann, the 1930s' activists found attractive the habilitation of the disabled in the Soviet family and the specialized schools in which they were trained for employment, as this resulted by the time they reached adulthood in them being prepared to be workers and in them being guaranteed full-time employment with the same wages, union membership and benefits enjoyed by the non-disabled.

Similarly, the East German disabled after World War II found attractive and established labor-oriented habilitation. Educator Becker expands on his earlier noted analysis:

The trainable are continuously prepared in their educational rehabilitation institutions for socially useful and productive work. Such acquired skills and capabilities allow the person to be placed into the work process under certain conditions. A regulation sets the pertinent criteria. A person being rehabilitated under this regulation is someone with handicaps of the most severe degree (including the trainable), who cannot be employed under conditions of the normal work process. They are ensured vocational work through sheltered work. Sheltered work means an activity under specifically established conditions, considering the person's guaranteed right to work. Sheltered work is possible:



- in sheltered departments in factories
- in sheltered individual workplaces within factories
  - in sheltered workshops
  - through work at home...

Work at home is permitted only if, on the basis of handicap-specific and/or territorial considerations, there is no possibility for the trainable person to be placed in a collective. The work contract to be entered into with the trainable persons may, in accordance with their handicap, contain special regulations regarding the work place, rights and duties of the contractual partners, the work task, work hours, wage and salary group. The facilities of sheltered workshops have the obligation to train the rehabilitants in accordance with their performance capacity and to create the possibility for further qualification. The factories are fully responsible for carrying out these tasks [81, p. 121].

Professors Wayne Sengstock and Sieglind Ruttgardt deal with the more recent challenges to Germany's expansive habilitation following the 1990 unification. Despite the burden of unemployment and poverty, the disabled continue to advocate for and achieve labor-oriented special education from the time of infancy, vocational apprenticeship, guaranteed full employment, trade union membership and equal wages [90].

## World War II: Expansive habilitation

Besides Forest Haven and the socialist-inspired WPA, World War II was another development that DC's intellectually disabled were able to turn to their advantage in terms of expansive habilitation. The American University law professor Daniela Kraiem has commented that "Capitalism has no role for the elderly and people with disabilities. They are non-productive" [91, pp. 697–698]. But World War II was an exception. There was a full-employment economy with both DC Training School members and staff drafted into the military [92]. Like the Soviet system, the US during World War II dropped IQ testing [93, p. 308]. The social historian Steven Gelb explains:

At the beginning of US involvement in the war, conscription centers operated under constraints that made careful selection impossible. As many as ten-thousand men a day were inducted at the beginning of the war. By years' end, the army was accepting men who were able to understand only simple orders given in English, whether or not they were able to read and write... Military psychologists, becoming far more critical than civilian psychologists working in peacetime at schools, announced that IQ tests were inadequate as a measure of recruits' ability. Staff members attached to the Adjutant General's office, which was responsible for research on the classification of soldiers stated flatly that "the MA [mental age] and IQ are not meaningful in the

Army situations in terms of the evidence available." They and others charged the test with insensitive to relevant social factors in soldiers' backgrounds [93, pp. 310–311; see also, 94, 95].

Experience convinced the military that failures on mental tests were, as the 1930s progressives contended, much more likely due to causes other than mental deficiency. Chief among these, as Professor Gelb notes, was poverty, inadequate education, membership in ethnic and linguistic minority groups, especially Blacks from the South, emotional problems, organic pathology, fatigue (tests were sometimes administered at late as 3 am) and extreme shyness ("bucoliphrenia") in recruits from isolated rural settings. Gelb writes that when compared with figures from the 1978–1979 school year, Blacks were 100 times less likely to be identified as mentally deficient by the services in World War II than they would have been by schools in some southern states more than 30 years later [93, p. 311].

Like the 1930s' habilitation advocates, the US Army in World War II followed an affirmative action philosophy in instituting training courses intended to remedy deficits wherever possible. Such a program for "retarded" soldiers was put into effect in July 1943, at the Engineer Replacement Center in Fort Belvoir, Virginia. The initial recruits included "feeble-minded" individuals, psychopaths, psychotics, drug addicts and the physically handicapped. Many in the DC mental habilitation system had dual and triple diagnoses that incorporated psychiatric problems.

Military remediation included courses in elementary education and military engineering subjects that were designed for illiterates and non-English speakers, a mental therapy class for those who needed it, a physical coordination and elementary military subjects class "for soldiers of low grade mentality who were particularly deficient in the ability to coordinate their muscular movements", and an individual attention and observation course for soldiers whose military potential seemed most questionable, intended to determine whether there might be some way to help the weakest individuals become useful to the armed services [93, p. 312; see also 96, pp. 771–772]. Gelb's article gives a bibliography concerning the military's affirmative action program.

An historian sums up the World War II period for disability employment, "The armed services were more interested in making marginal recruits useful than in labeling them" [93, p. 312]. Professor Gelb goes on to explain that as the war progressed, some of the disabled became heroes, such as the diagnosed "imbecile with

an IQ” of 48 who by 1945 had been promoted to private first class, served in four Pacific campaigns, and received a presidential citation. According to another academic, Dorothy Bassett, an estimated 83% of the disabled did well in the military, 10% had questionable success and 7% failed [97].

It was not only the military that found employment for the disabled during World War II. With the normal workforce in the military, the disabled, along with women, youth and elderly, helped fill the labor shortage. Steven Gelb writes that most obtained their jobs independently and a large proportion had jobs above the unskilled level [93, p. 314]. The scholar William Dunn documents that after the war, both the military and civilian disabled were disproportionately reshuffled back to poverty and dependency by the eugenic-dominated capitalist system [98; see also 93, p. 316].

## Summer Youth Employment Program

In the DC history of expansive habilitation, there is an area of achievement, the Summer Youth Employment Program (SYEP), which continues to provide employment to the disabled. In the tradition of the WPA, it was established in 1979 as part of the DC government’s Department of Employment Services. It is an affirmative action initiative in which the youth work for private businesses and the government pays their wages. SYEP is funded by the Job Training Partnership Act of 1982 (JTPA), which is also the source of the Job Corps [99]. JTPA was signed into law by Ronald Reagan and was the successor to the Comprehensive Employment and Training Act (CETA), which was signed into law by Richard Nixon in 1973.

Historians Harry Jaffe and Tom Sherwood contend that DC mayor, Marion Barry, built his political career by bullying the government to fund the youth employment [100, p. 29]. The youth employment started in 1967 when US Department of Labor secretary Willard Wirtz gave Barry’s newly-established Pride, Incorporated \$250,000 to fund 5000 summer youth jobs. The 1967 grant was followed the following summer with a \$1.5 million grant. The summer jobs lasted 5 weeks and led Pride into adding a number of other employment programs that gave permanent jobs in landscaping, gas stations and other services [100, pp. 59, 64, 66].

DC disability activists such as Stokely Carmichael (aka Kwame Touré, 1941–1998) believed Barry’s job programs were not enough. Historians Jaffe and Sherwood commented about Carmichael:

In the mild-mannered world of Washington politics, Marion Barry was a militant. But to Carmichael and other radical black nationalists, Barry was a collaborator with the white ruling class. They saw Pride as the federal government’s way of buying peace in the ghetto. Barry, in that analysis, was a tool of the oppressor [100, p. 29].

But for the intellectually disabled, including VR who is now 49-years-old, the SYEP, which has been VR’s only paying job, it ranks in importance with the birth of her four children [VR. Transcript of interview with: author. 2015 June 29, p. 2]. During the summer of her 17th-year in 1983, when she was in the ninth-grade at McKinley Tech, she and several of her siblings had jobs as part of SYEP. She was a file clerk and photocopy operator in a large office building near Gallery Place and China Town. At her job, VR’s fellow-workers were “nice” to her. They treated her as an equal. Her step-father, who was a taxi driver, dropped her off and picked her up each day. She made “good money” and paid her dad for the transportation. She also paid to have her hair done and buy clothes and school supplies [VR. Transcript of interview with: author. 2015 June 29, p. 2]. In her view, the job allowed her to be like everyone else.

VR’s summer job contrasted with her adulthood, during which she has never been employed. She dropped out of school in the tenth-grade and spent her adulthood until age 38 on-and-off a ward at Washington, DC’s St. Elizabeths Mental Hospital. She did not have a significant mental problem, but without employment she was homeless and had a number of children whom she could not raise. Because she was gullible, her acquaintance with the first three of the fathers of her children was only a single encounter. She never obtained their addresses. Theoretically, because of intellectual disability, she was eligible for help from the DDS, but this was provided only in 2003 and by chance when she met a lawyer from ULS, Jennifer Lav and a ULS advocate, Celeste Valente. They demanded an administrative hearing and forced the government to locate her school records to verify that she had been in special education when growing up. Because of this help, VR obtained a subsidized apartment though a housing certificate [VR. Transcript of interview with: author. 2015 June 29, p. 4].

ULS also attempted, but without success to help VR obtain a job. According to VR, in 2005 she obtained an appointment with a D.C. government agency, the Rehabilitation Services Administration (RSA). Their mandate is to help residents find employment. She went to a classroom setting where there were about 15 others seeking help. The RSA official began asking questions. When it was VR’s



turn, the others laughed at her answers. She left and never went back [VR. Transcript of interview with: author. 2015 June 29, p. 4].

## Full habilitation spectrum advocacy: 1950s–2000s

As outlined above, the disabled have been successful at various times in obtaining accommodations to their habilitation demands. Since World War II, if not earlier, the struggle both nationally and locally has focused, from the perspective of the disabled, on the fight against what the conservatives called “fiscal retrenchment”. Historians Jaffe and Sherwood maintain that the DC business community, represented by the Board of Trade, was the power behind DC’s elected and appointed governments, judiciary and their retrenchment policy.

On the occasions before home rule that began in 1973, when the local politicians fell under more popular control, the Board of Trade would go directly to the Dixiecrat-controlled Congressional House District Committee. Jaffe and Sherwood comment, “Congressman John L. McMillan of South Carolina as chairman of the House District Committee treated the city as if it were his plantation... He kept the city’s social service budget low, held down local taxes, and applied taxes to construction projects at the behest of the white business community” [100, p. 28]. Forest Haven’s budget in 1972 was \$9 million dollars and projected to be \$18 million by 1982 [6, p. 5]. In 1976 the government was paying \$28 per day per Forest Haven resident. To keep the city budget low, Walter Washington, who served as the mayor from 1973 to 1978, imposed a hiring freeze [100, p. 93].

At the national level politicians like Ronald Reagan used libertarian “freedom” ideology to justify the replacement of the country’s public habilitation facilities with homelessness and prisons [101, p. 6; 91, endnote 129]. But from the perspective of the disabled, there was little difference between the political parties. As one advocate put it, the deinstitutionalization program against the disabled had influence in both parties and was a “sibling” to the drive to privatize Social Security, to privatize public education with vouchers, to replace free higher education with school loans and to substitute “consumer directed” insurance company dominated health care for free universal healthcare [91, p. 696]. Professor Kraiem comments on the deceptive nature of the conservative Medicaid disability terminology:

A number of Medicaid consumer directed long term care programs pointedly and deliberately use the term “consumer” rather than “beneficiary.” This creates a powerful framework that hides the means-tested nature of the program. In the “ownership society,” market participants, those who own and control their retirement portfolios, homes, and small businesses, reign supreme [91, p. 697].

Over time fiscal retrenchment was also associated with other programs that hurt the disabled, such as the above-mentioned deinstitutionalization of the mentally ill with their re-institutionalization in the prison and homeless system, the foreclose and eviction of low income home mortgage consumers and the movement to deport immigrants.

The DC disability resistance to retrenchment brought a 40-year campaign against the starvation and privatization of Forest Haven, which continued the militancy that dated back to the institution’s early years. Their public events, such as the parades that were covered by the newspapers included protests against the starvation, as depicted in Figure 5 and as in a float depicting the old lady that lived in a shoe (Forest Haven) with more children than she knew what to do. The Evening Star newspaper reported about the floats in the parade:

Yesterday the farm workers won the prize for the best float – an unabashed farm wagon driven by a couple dressed as Amish farmers, carrying crates of turkeys and a calf. Second prize was taken by “Cottage One” with a truck carrying a cardboard shoe and an old woman. The cottage residents who could not get into the crowded truck followed along behind on foot, showing the sort of crowded conditions experienced by the Old Lady Who Lived in Shoe and by themselves [102].

At another parade a reporter summarized the message on the floats, “There were two themes to the red, white and blue, crepe paper-decked floats and cards decorated with signs, one festive, the other a sad reminder of the inadequacies which have resulted in a growing scandal... Members of the King and Queen’s court displayed such signs as ‘Even I Care. Why Can’t You?’ and ‘We are concerned.’ The theme of a float representing Curley Building, home of the severely retarded and source of some of the most troubling tales to emanate from the institution, was ‘Staff and Funding Are the Key’” [46].

The journalist Pablo Maurer in a 1976 article described the starvation policy:

In the 1960s, Forest Haven languished. Funding for its athletic and recreation programs dried up, and residents suffered greatly. Among the worst affected were residents who weren’t mentally disabled at all – some were severely epileptic, others had similar disabilities that kept them from being functional outside the asylums gates. Once physically able, their bodies withered away



**Figure 5:** Central Labor Council foster godparents march in 1970s FH protest parade [46].

from lack of activity, and many became bedridden. It got worse. Forest Haven's population grew far beyond its means... In 1976, it became too much to bear. Families raised a class-action lawsuit, detailing the abuses at Forest Haven... The District balked. Joseph Yeldell, D.C.'s director of human resources, remained defiant. "The innuendo here is stifling," he told members of the press. And Yeldell and Mayor Walter Washington rattled off myriad excuses for issues at the asylum, from budget limitations and unsympathetic city council members to media members reporting "patently false" allegations [9; see also, 103, pp. 279–280]

Congress person Clair Burgener from San Diego, California, who had a child in the disability system and became a disability advocate, gave the following description of Forest Haven at a 1976 Congressional Hearing:

The best cared for are the most profoundly retarded. The most profoundly retarded are the bedridden. They lie in bed. One young man had lain in bed for some 25 years. That is understandable. He is slightly non-ambulatory. But the ones in this particular ward, I thought, having looked at hundreds of institutions worldwide and nationwide, I think he was getting excellent care.

They were bathed and washed. The bed sores seemed to be at a minimum, and the nurses and the attendants were making the rounds doing their best to keep them clean and changed and well cared for. These were the ones in bed. That is the bottom end of the spectrum.

At the top end the young adult ones live in their own rooms, the only ones with any kind of privacy that I saw, rooms they had painted themselves in an old, old building, they were doing pretty good.

They have speech. They can talk to each other. They go into the community. They have jobs. At both ends of the scale, they are doing quite well. But the ones that are ambulatory but that is about all, that don't have communication, can't help maintain the place and have jobs of responsibility.

They can't earn any money, they are stuck there. They are in a large room with a TV set that may or may not work. The program

cannot be academic. You are not going to teach them to read or write but there are all kinds of other learning. They can groom.

I am getting far afield from your question, Mr. [Charles] Diggs, but it sounds like an unaccountable, hopeless bureaucracy, and we collectively must have more imagination in this. We have a lot of unemployed people willing to work. We are on grounds that must be maintained. Why in the world can't we match those up? Why do we have to live with this system that won't match need to desire? [104, pp. 76–77].

The activists were not against private apartment and group homes. These had always been available. But a publicly-controlled institution that offered training and employment in multiple careers to large numbers with a faculty staffed by civil service and trade union-protected employees had also always been available. They did not want to lose it. [6, p. 18; 5, p. 169; 101, p. 6]. Conservative policies had been opposed during the Civil Rights Movement of the 1950s and 1960s. Activists voiced demands for substantive rights and the expansion of state services.

Illustrative of the disability militancy were demonstrations at the White House in 1972 against President Nixon's veto of what is now the Rehabilitation Act of 1973. There were similar protests in New York City, which were led by Judith Heumann. Eighty activists stopped traffic with a sit-in on Madison Avenue. As a result of the 1973 disability protests, President Nixon was forced to reverse himself and sign the Rehabilitation Act. Section 504 of the act was the first federal civil rights protection for those with intellectual disabilities. It stated:

No otherwise handicapped individual in the United States, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance [105].



At the national level the disabled had the support of “Voice of the Retarded” (VOR) and the American Federation of State, County and Municipal Employees (AFSCME) which represented direct care workers. They sponsored research, organized politically, managed public relations, and participated in litigation [6, p. 122; 106]. The Greater Washington Central Labor Council, AFL-CIO gave its help by establishing a foster-grandparent program in which 55 trade union families established an “adult-child” relationship with Forest Haven youth who had no parent.

The combined local and national agitation in the 1970s resulted in increased funding and an expansion of Forest Haven’s employment programs. The funding included an “Eight Year Plan” that won the support of US Senator Hubert Humphrey, which brought \$8 million dollars from Congress to increase the Forest Haven staffing ratio from 20 to 1 toward the goal of 1 to 1 [107, pp. 172, 175]. The plan started in 1975 with a \$900,000 grant. The activists also expanded several Forest Haven disability employment programs. One of them was a 1973 HEW “Career Development Program” grant of \$125,000 for 43 residents to work in housekeeping, food-service and building maintenance. Another grant funded the wages of 229 residents without whose work, a Congressional report stated, the institution could not operate. Their wages, hours and conditions of labor of the residents were compliant with the Fair Labor Standards Act (FLSA) and their monthly payroll amounted to \$22,000 [108, p. 125]. This contrasted with the history of exclusion of the disabled from labor law protections, which is frequently publicized by their Workers World leader, Edward Yudelovich [109, p. 26].

The activists also built on Forest Haven’s farm labor tradition. Seventeen female residents ran several greenhouses and obtained a federal grant for “Horticultural Training”. They provided plant material both to landscape the facility and for sale to the public. They coordinated with several male crews which handled the facility’s landscape gardening and ground maintenance [6, p. 122]. In addition to the Forest Haven employment, 90 residents participated in by-weekly trips into Washington, DC for on-the-job training in budgeting, work attitudes, proper dress and manners on the job. Between 1974 and 1976, 50 of them obtained full-time employment and established residential accommodations outside the institution.

Unfortunately from the view of the disabled, the increased federal funding was soon targeted by Washington Board of Trade-connected contractors, their big law firms and their lobby group, the DC Association for Retarded Citizens (ARC), whose director was Vincent Gray [107, p.

174]. The contractors’ program initially focused on starving Forest Haven and directing the disability budget to themselves. They advocated splitting the intellectual disability program off from the Department of Human Resources (DHR). As perceived by the disabled, this would give the contractors more influence over the disability budget.

However, the disabled and their service workers had enough support with the city council to prevent the contractors from significantly re-directing the budget. Reporter Joann Stevens wrote of the opposition voiced by family members about closing Forest Haven and redirecting the budget to contractors:

Charles Inlander spoke to a group of 30 skeptical people, most of them relatives of Forest Haven residents, at a recent community meeting on the proposals... The relatives, who apprehensively questioned the plan, sought guarantees that their relatives would not live in contract homes such as one in Mount Pleasant where a fire recently resulted in the death of 10 mental outpatients... And they asked about the DHR. Would DHR be any more responsive to their relatives needs in the community? As for DHR’s responsiveness, Inlander said, “I’ll be honest with you. I have as great a question as you do whether the government is going to do it right.” As they left the meeting, bewildered relatives shook their heads in dismay. One man, Robert Tilghman, said his 34-year-old brother has been at Forest Haven for 26 years. Tilghman said his brother can’t speak, but through the evaluation process psychologists are finding his intelligence is greater than they had expected. There’s hope in the plan, Tilghman said. Yet, he said he doesn’t feel the complexities of it have been fully comprehended. “I’m not at all optimistic about this contractual living arrangement,” he said, mentioning one of his chief concerns [64, p. DC1].

Law professor Samuel Bagenstos refers to the parents organizations and labor unions as “traditional adversaries” of deinstitutionalization [101, p. 6]. Among the local trade union militants who opposed the privatization scheme was Thomas Eaklor. He belonged to the AFSME and was a vocational education teacher at Forest Haven. He helped run its Stipend Work Experience Program (SWEP), which provided jobs in housekeeping, laundry, counselor aides, messengers, transportation aides, cosmetology, horticulture, gardening and landscaping [110]. He voiced the trade union sentiment:

I’m mad as Hell, and I am not gonna take it anymore. I have reached the point with all the negative newspaper reports, the heart-throbbing TV soap opera style accounts, the degrading statements made by “well-meaning” officials and the general lack of self-esteem reeking it’s ugly head from most staff working here. I will concede only one item about Forest Haven. It needs improvement. But that’s it.

I’m tired of being lumped into the group of apathetic, non-professional, personnel portrayed by all the detractors of Forest

Haven. It's time people begin to realize that indictments against Forest Haven are personal attacks against their ability to function in their job, effectively. I, for one, have logged too many hours of training and years of experience to allow someone with limited, selected knowledge to challenge my ability to perform effective work.

I challenge everyone to begin to fight back. Prove to those who have placed the cloud over Forest Haven, that we can and are doing our job everyday. Who knows more about what we do, but we who do it. Recently a group of teachers and educational staff attended a program presentation at Woodhaven Center at Temple University in Philadelphia. After the conference, most of the staff concluded that program-wise, we could match or even better their system of adult preparation for community placement [111].

Because Forest Haven was popular, the conservatives in 1976 employed DC ARC to initiate what became the *Evans* (Gray) litigation in US District Court [103, 112, pp. 23–25]. This followed a nationwide neo-liberal strategy against public institutions which was accompanied by libertarian legislation that, for the disabled, culminated in the Americans with Disabilities Act (ADA), which George Bush signed into law in 1990. The libertarian ideology was that their privatized system would habilitate the disabled at budget prices. What it actually meant, from the disabled perspective, was that the public would be spending more money for less services with the contractors being the beneficiaries.

Twenty years after the ADA enactment, a disability scholar summarized what he viewed as the negative accomplishments of entrepreneurial legality:

In a series of decisions the Supreme Court has read the statute's [ADA] provisions very narrowly. In all federal courts, ADA plaintiffs lose their cases at astounding rates – the only litigants less successful than ADA employment plaintiffs are prisoner plaintiffs, who are rarely even represented by counsel. The statutory provisions that require businesses to be accessible are wildly underenforced. And the employment rate for people with disabilities remained stagnant at best [113, p. 1; see also, 75, pp. 112–113; 114, pp. 83–84; 115].

In their interpretation of their rights, which was eventually incorporated into the 1978 Constitutional Rights and Dignity Act, the activists maintained that privatization of Forest Haven and its accompanying elimination of civil service and trade union jobs for direct care staff would make impossible their habilitation. They pointed out that Forest Haven gave them training and a work life they could not have in privatized group homes and apartments. The government contractors and landlords would have no incentive to provide them with jobs and would have the City Council to back up their neglect, while at the

same time the disabled would be isolated from working together politically to obtain jobs [91, p. 700].

In addition to job loss, a second argument used by the activists was that closure of Forest Haven would expose them to physical danger because the private facilities could not be properly monitored. Professor Kraiem remarked about the negative consequences for monitoring and quality control that result from home and day-program privatization:

Decreased state control over care is linked in the American legal system with decreased state regulation over all aspects of the caretaker-care receiver relationship. If the state is no longer the employer, it does not bear liability for abuse of the beneficiary or responsibility to monitor quality of care. In the free market, the consumer should simply choose another caretaker if the care offered by one is inadequate [91, p. 700].

The presiding judge in the *Evans* case later commented on the decline that came with the closing of Forest Haven, which the trade unions had warned about:

The findings noted that defendants' [DC government] compliance with the prior Court Orders had deteriorated following the closure of Forest Haven in 1991 and that defendants were not complying with many of the requirements of those Orders. The findings also identified numerous "fundamental problems," including problems with respect to staffing, staff training, and monitoring; management; reporting of and response to unusual incidents, safeguarding of class members' funds, the budgeting process; and the District's Medicaid Home and Community-Based Services waiver [116, p. 287; see also, 117, p. 258].

In addition to the *Evans* litigation, other legal cases repeatedly held the DC government liable for the violation of the disabled individual's due process rights as the result of the lethal neglect of contractors such as Symbral, Inc. [118].

The disabled in opposing the Forest Haven shut down, also argued that privatization and union liquidation would turn their biggest asset into their biggest liability. The non-union work force that would take over would be unskilled and little motivated because it had none of the government protections existing for workers in other professions, such as the eight-hour day, forty-hour work-week protection of the FLSA, the union protections of National Labor Relations Act, or the protections of the Family and Medical Leave Act and DC workers compensation statutes [119]. In 1974 domestic workers came under federal wage and hour protection, but this did not include paraprofessional home health workers, home-care workers or companionship workers [120]. In addition employees of businesses with under 15 workers were excluded from



the act's Title VII coverage [121], employees of businesses with under 50 workers were excluded from FMLA coverage [122] and all in-home employees were excluded [123]. The scholars Charles P. Sabatino, Simi Litvak [117, p. 289], Peggie Smith [124, pp. 1839, 1860] and Hila Shamir have documented the exploitation of homecare workers by the various labor and employment laws [125].

The result of the privatization would be a constant staff turnover. The government would engage the lowest-bidding, most politically-connected contractors, who would make their profit by underpaying and over-working these individuals. University of Michigan law school professor, Samuel Bagenstos discusses the turnover and low-pay aspects of privatization:

Jobs in state institutions have typically been unionized in this country, while most jobs in community programs have not. Community programs are generally run not by the state itself but by private non-profit or for-profit agencies that contract with the state. Those private agencies are rarely unionized, and they typically pay substantially less (and have much greater turnover) than the state does for work in its institutions. Indeed, unions have found it exceptionally difficult to organize the small, decentralized, often non-profit and faith-based agencies that provide community services [101, p. 18; see also, 126, 127, p. 289, 295; 128, p. 969].

Along similar lines in advocating that the 1978 Act required unionized government employees in order to meet the needs of a skilled, motivated, professional work force, Professor Kraiem pointed out:

An autonomy paradigm – even one deeply rooted in human rights – that rests on a system in which women of color and family caretakers receive wages and benefits so low that they themselves are eligible for public benefits, with little or no health and safety regulations despite dangerous working conditions, is ultimately not rooted in social justice... For a progressive movement based on human and civil rights principles, ignoring the worker on the other side of the equation should not be possible. Much like we cannot countenance a feminism blind to the injustices of race and class. I argue that we should not ground a movement for the rights of persons with disabilities in the exploitation of others, especially when those others are overwhelmingly low-income women of color and low-income female members of all races [91, p. 702].

## Privatization and excessive drugs

In defending their rights under the 1978 Constitutional Rights and Dignity Act the disabled voiced a second argument in resisting the shut down of Forest Haven besides the dangers that result from poor monitoring. This concerned the expanded substitution in the private system of psychotropic and seizure medication for habilitation. This

was a nationwide problem going back to the 1960s. In the 1976 Forest Haven Congressional Hearings, there was testimony that 50% of the residents were already being given psychotropic drugs as a substitute for adequate funding of habilitation.

About the drugging abuse the following exchange took place at a Congressional hearing between the DC Congressional Committee chair, Charles Diggs and the Forest Haven superintendent, Roland Queene:

Mr. Dellums. It is your perception that 50 percent is a rather substantial percentage of the clientele? Where psychoactive medication is administered to them, what percentage of that is used because of the need to restrain patients because of inadequate staff or are all of these instances therapeutic or can they be justified on therapeutic ground?

Mr. Queene. Many of our residents have very serious health problems and they fall into the profound and the severe levels of retardation. Therefore they require considerable medication. Certainly to admit that these – this kind of program, that the medical involvement here is one in which we want to control residents, is not one that I am particularly fond of.

Certainly there may be situations – and I think there are very few, really – where we have to use drugs to control.

Certainly when we reach a point where we have to do something like that, that resident is referred to D.C. General or it sent to St. Elizabeths. But as you pointed out earlier, there are some people that are inappropriately placed at Forest Haven whose problems are not mental retardation but are either emotionally disturbed or have some other physical problem.

Therefore, I think that the drug problem is not as intense as you alluded to it, we are not using it as a way to control our residents [6, p. 90].

Disability activists responded to the drug abuse with a provision in the 1978 Constitutional Rights and Dignity Act that outlawed the overuse of medication. It read, "All customers have a right to be free from unnecessary or excessive medication... Medications shall not be used as a punishment, for the convenience of staff, as a substitute for programs, or in quantities that interfere with the customer's habilitation program" [1, § 7-1305.05(h)]. This provision was incorporated into the DC Department of Human Services policy guidelines [129].

Despite the statute, the disabled maintained that the medication would be used as a type of chemical straight-jacket to restrain their resistance to a meaningless lifestyle. As such, the drugging would also violate their First Amendment right to speech and lock them into a prison without appearing to do so. They would not be able to speak spontaneously, take initiative or voice demands, preoccupations or preferences. They would, as they put it, be submerged in a sweet indifference, divorced from their environment by an invisible partition [130, p. 459].

For the disabled the privatized home life of sitting in front of the television would be little different than the life of a DC jail prisoner. The proposed day programming of sitting at a table for six hours per day was analogous to being in a permanent preschool or elementary school, except that the teachers had none of the qualifications, curriculums, wages or protections of their public school counterparts. The programming would not be subject to government quality control and would be offered in facilities that, unlike Forest Haven, were literally warehouses, with no windows, outdoor recreational playgrounds or other provisions mandated for public schools.

In resisting the medication problem over the years, the disabled argued that acting up against the neglect of their overwhelmed staff was not a psychotic or seizure disorder. An activist noted that “diagnostic approaches are imperfect and imprecise even when done by the most qualified psychiatrists,... misdiagnosis may be as high as fifty percent” [131, pp. 1036, 1039; see also, 132]. Disability advocate Peter Breggin called it “medicating normality” [133; see also, 134]. In his view, to be anxious, depressed or rebellious when not allowed to have a job and family was a realistic response. Their scholarly ally Rory Sheehan found that at the international level, using a study of 33,000 intellectually disabled adults, some 71% of those being drugged did not have the kind of serious mental or seizure illness for which the drugs were designed [135].

In their opposition to privatization DC’s disabled forced accommodations to their habilitation demands, including those involving medication. In this they exploited the spectrum of differences that existed in conservative interpretations of the Constitutional Rights and Dignity Act. While the government generally took a minimalist view of disability rights, the judges in the *Evans* case, while not taking an expansive view, was less minimalist. Judge Huvelle in a 2007 “Opinion” summarized the minimalist history of *Evans* for its first 30 years, including the background, the 1978, 1981 and 1983 consent orders, 1991 closure of Forest Haven, 1995 appointment of a special master and 2001 Plan [116, pp. 280–294].

In taking a less minimalist view the judges at some points attacked the government’s psychotropic medication program for not having an overall treatment plan, counseling, therapeutic strategies for coping without drugs or efforts to wean the disabled off the drugs [136, pp. 37–38]. In a 2009 *Evans* case review the judge rebuked the government because a resident at a group home owned by Westview Medical and Rehabilitation Services, Inc. was being prescribed ten different psychotropic medications [136, pp. 37–38].

Judge Huvelle was open to the argument of disability activists that the drug problem stemmed from the government being caught in the pharmaceutical industry-dominated Medicaid web, which reimbursed money only for medication, not habilitation. Out of this in the view of the activists, came the tendency to misdiagnosis and, as the court documented, having a medication rate for the disabled at twice that of those not under contractor care. In a 2010 *Evans* “Opinion”, the judge remarked that a random survey of the disabled in group homes and apartments found 19 of 37 receiving one or more psychotropic drugs [136, pp. 15–16]. The DC government-funded Quality Trust, using a larger sample, found that 71% (162 of 228) of the disabled were being prescribed psychotropics [137, p. 6]. While 50–70% of the disabled in group homes and apartments were drugged, the rate in the general population for mind-altering drugs was 20% [138, pp. 19, 21–22; 139].

Illustrative of over-drugging was the Melonie Nelson case. She was a 41-year-old who choked to death from food and drugging in the kitchen of her group home in 2007. During the investigation Marshila Davis, an employee of the contractor, D.C. Health Care, which operated Nelson’s home, gave testimony. Davis had cared for Nelson several days prior to her death, but was on duty at another group home at the time of the death. A report of Nelson’s drugging stated:

Davis says she last saw Nelson three days before her death when Nelson was so drugged up on medications she could barely walk... Nelson was prescribed nine different medications in the months before her death, according to a ULS report. A side effect from her psychotropic medications – which could cause clenching and abnormal movement of the jaw – may have increased her risk for choking [140].

Over the 40 years of their resistance to Forest Haven privatization and excessive medication, the disabled obtained multiple court orders in their favor. In 2001 they forced the *Evans* court to establish a monitoring system based on the prior litigation. They arranged the earlier orders into a list consisting of nine different basic service areas, which continue to serve as a guide to the present. The nine subject areas were Budget, Case Management, Individual Habilitation Plans, Protection from Harm, Quality Assurance and Fiscal Audits, Residential Vocational and Day Services, Restricted Control Procedures, Safeguarding Personal Possessions, and Staff Training [141, pp. 4–5; 103, p. 296].

Unfortunately, as the monitoring list was implemented, the disabled complained that it too often followed the conservative “medical model”, and its focus

on pathology, Medicaid-reimbursement, charity and entrepreneurial contractors, not the holistic, trade-union, full-employment approach. Nevertheless, it was seen as better than the government's starvation model. To implement the monitoring the disabled constructed specific outcome criteria for determining compliance along with data collection methods. Illustrative of the data collection methods for assessing compliance were those developed for "staff training". As listed in a report by the *Evans* court's special master, Clarence Sundram, they were:

1. Review of documents to verify attendance at training and evidence of competencies in the skills taught.
2. Review of grievances and unusual incident reports and related investigations and other quality assurance documents to determine whether lack of training is identified as a cause of incidents and grievances, and if so, whether correction actions were taken and were adequate.
3. Interview a random sample of 10 percent of consumers, their families, guardians and staff of the residential and day treatment programs regarding training issues.
4. Interview a random sample of advocates and case managers assigned to the consumers in the sample regarding staff competencies [141, pp. 16–17].

Called the "2001 Plan for Compliance and Conclusion of *Evans v. Williams*" (2001 Plan) [142] and later the "2010 Revision to the 2001 Plan for Compliance and Conclusion of *Evans v. Fenty* [136], the nine service area as list was backed up with financial penalties, contempt sanctions and the threat of endless litigation for failure to comply. The Plan provided for the case to be terminated when the government came into compliance with the plan's nine areas. As each area is certified as compliant, it is removed from the court's supervision.

Using the 2001 Plan, one of the first strategies the disabled, as represented by ULS, adopted against the excessive medication was to make the government establish a systematic review program over its contractors. This involved the creation by the DC government's DDA of a "Restrictive Controls Review Committee" (RCRC) [143]. The RCRC implementation was frequently a conservative rubber-stamping of the medication abuse, as illustrated by the government's own statistics. The disabled advocated for non-governmental reviews, complaining that the RCRC, including its DDS Rights and Advocacy Specialist (RAS) who coordinated the program, along with everyone else involved in it were government employees and contractors. There was a conflict of interest, a bias for the least expensive way of controlling the disabled [VR. Transcript of interview with: author. 2015 June 29, p. 2].

Besides the RCRC the disabled developed another strategy based on the 2001 Plan and the earlier court

orders concerning the privatized medication. This involved establishing a "Behavior Support Plan" (BSP) for each person who was prescribed psychotropic medication. The aim was to make contractors through the BSP use more active programming and less chemicals. The plans had to list "proactive, positive strategies... and benchmarks for reducing the restrictive interventions including a titration plan for medication" [143, pp. 3–4].

But, as the disabled complained, the BSP implementation was, like the RCRC, too often contractor-dominated, which resulted in little protection [VR. Transcript of interview with: author. 2015 June 29, p. 2]. In constructing the BSPs, the government was contracting with a handful of entrepreneurially motivated psychiatrists and psychologists who understood their main role to be enforcement of servility. They turned the BSPs and 1978 Constitutional Rights and Dignity Act requirement of monthly scrutiny of psychiatric medication into a *pro forma* exercise. The D.C. Code, § 7-1305.05(h), states, "All prescriptions for psychotropic medications shall be written with a termination date, which shall not exceed 30 days." As noted, Medicaid paid for drugs, not talk therapy. It forced even professionals who would like to be helpful to the disabled to focus on volume work, with consultations lasting only minutes and with no counseling.

Despite the limited nature of the BSPs and the *Evans* court oversight, this helped the disabled's medication resistance, as witnessed by the effort of the contractors to dodge it. One of the dodges was to use the probate division of the DC Superior Court to undermine *Evans* oversight. Those who chronically refused to consent to the medication were taken to the probate division where the contractor's psychologist testified that the disabled were not competent to make medical decisions. A ULS publication comments on the poor representation offered by court-appointed lawyers in hearings to determine if a guardian should be established:

Advocates unanimously identified the quality of legal representation for individuals alleged to be incapacitated or under guardianship in a post-petition proceeding as a serious problem in the Probate Court system. Attorneys regularly observe Court-appointed counsel hollowly representing his or her client's interests; counsel merely articulating the client's expressed interests while implicitly informing the Court with tone and language that counsel believes the client needs a guardian... On occasion guardians have explicitly forbidden their "wards" from talking to legal advocates such as ULS and Quality Trust for Individuals with Disabilities about assisting with termination or modification of guardianship [144, pp. 25, 34].

The result of the disabled's encounter with the probate court was that a medical "guardian" was assigned to them whose rubber-stamping of the psychiatrists overruled the



*Evans* court and the wishes of the disabled. The latter had no had no voice in choosing the psychiatrist or guardian. From the contractor's perspective the existence of a guardian both allowed it to dodge *Evans* and also avoid the limited protection against forced psychotropic medication provided by the "Health Care Decisions Act," D.C. Code § 21-2201 *et seq.* (2007). Before forcibly medicating, the Act required the contractor to obtain the consent of two physicians, one of whom is a psychiatrist. The act states:

Mental incapacity to make a health care decision shall be certified by two physicians who are licensed to practice in the District and qualified to make a determination of mental incapacity. One of the two certifying physicians shall be a psychiatrist.

Illustrative of how the guardianship system was used to avoid the Health Care Decision Act concerning forced medication was the case of VR, who was discussed above. In 2007 the DDS admitted VR to their intellectual disability services. She had a dual diagnosis – both mental health and intellectual disability. As she explained it, because she did not voluntarily take medication or go to a day program, the contractor went to the probate court and had a medical guardian appointed. When she did not go to the office of the contractor, Anchor Mental Health (AMH), to obtain a Haldol injection every third Friday, the contractor's Assertive Community Treatment (ACT) team filed a missing persons report with the police. The police went to her apartment, handcuffed her and took her to the Comprehensive Psychiatric Emergency Program (CPEP). There she was threatened with commitment at St. Elizabeths Mental Hospital if she did not "consent" to the medication. VR complained that the practice of a DC contractor calling out the police and having her arrested without probable cause gave her less rights than a common criminal [VR. Transcript of interview with: author. 2015 June 29, p. 4].

There was also another contractor scheme, in addition to the medical guardians, which was used to undermine the disableds' resistance. This was the practice of group home and apartment contractors who obtained a seizure rather than a psychiatric diagnosis for their residents. With a seizure diagnosis, there were no BSPs or monthly monitoring requirements. Yet the same mind-numbing medications were used for either a seizure or psychiatric diagnosis. Contractors obtained seizure diagnoses simply by alleging the individual had a seizure [SL. Transcript of interview with: author. 2015 May 1, p. 1]. The disabled complain that they are given no choice about medical contractors. They are restricted to a handful of eugenics-minded practitioners, including several neurologists who legitimize the seizure medication dodge

[CH. Transcript of interview with: author. 2015 Jan. 4, p. 4]. Some unfortunate individuals, such as the late CH (1944–2015), were kept on these medications for 40 years without having a seizure and despite repeatedly requesting to be titrated off as they experienced the toxic chemicals destroying their bodies [CH. Transcript of interview with: author. 2015 Jan. 4, p. 4].

An example of the seizure medication problem is the saga of 56-year-old SL, an *Evans* plaintiff [SL. Transcript of interview with: author. 2015 May 1, p. 3]. Discharged from Forest Haven in July 1981, he lived for 25 years in a group home managed by VOCA, Inc., which was the only city contractor with a union (SEIU) work force [145, p. 3]. The philosophy at VOCA, under its Qualified Mental Retardation Professional (QMRP) Todd Sticler, for whom SL had a high regard, was active programming, if not gainful employment, rather than using medication to keep the residents quiet [SL. Transcript of interview with: author. 2015 May 1, p. 3].

According to SL, his medication problem started in 2005 when the government shut down VOCA and put him in another group home whose owner in SL's view, treated the disabled and their care givers as market commodities. Warehousing was substituted for active programming. A psychiatrist, urologist and their medications were employed to deal with SL's resulting mutiny. At a psychotropic review meeting in the summer of 2006, SL with the help of a militant ULS legal intern, threatened the psychiatrist with a medical malpractice suit over the medication issue. The practitioner was already involved in a Medicaid fraud investigation and terminated SL's medication on the spot. The government later prohibited for a short period the psychiatrist from acting as a contractor [146].

Unfortunately from SL's perspective, the psychiatrist was only half the problem. One of SL's resistance strategies during times of distress was enuresis or bed-wetting. Instead of implementing a less restrictive response, such as a toileting schedule, the contractor employed a urologist to prescribe a psychotropic medication, namely Tofanil plus two other incontinence medications. Tofanil is an off-label tricyclic anti-depressant, anti-psychotic drug. Because it is a sedative, it slowed down all SL's bodily functioning, including his intestinal muscle contractions or peristalsis. SL's stomach is particularly sensitive to sedative-type medication. Over the next several years he went to the emergency room 20 times because of the medication-induced constipation that left him curled up on the floor moaning in pain. Finally, on April 5, 2008, his peristalsis stopped completely, a condition called paralytic ileus. Intestinal gangrene set in, which resulted in the cutting out of the infected intestines [SL. Transcript

of interview with: author. 2015 May 1, p. 3]. The surgeon called the procedure “an exploratory laparotomy with resectioning of what had become his gangrenous sigmoid colon.” SL also had a colostomy which he wore for 6 months. The alternative to the surgery would have been a painful death within 2 days. For a month after the surgery he was kept tied to a hospital bed in four-point restraints with only a TV in front of him. For someone who hates TV, as he puts it, it was torture.

SL’s constipation crisis set the stage for his seizure medication problem [SL. Transcript of interview with: author. 2015 May 1, p. 3]. At the time of his intestinal surgery, the hospital required the contractor to obtain the appointment of a medical guardian to give consent for the surgery. Following her appointment the guardian confronted the urologist. She pointed out that the medications were supposedly being prescribed for incontinence, but he was not incontinent. He used the toilet during the day. He had a different problem, bed-wetting, especially late at night. The medications did nothing to address this, but rather came close to killing him because of their side-effects. The urologist was sufficiently intimidated that he gave up the medicating.

A year later in 2007 the government closed down the contractor for unrelated reasons and moved SL to another facility whose idea of habilitation was also the TV. When SL rebelled the contractor turned to the earlier-appointed medical guardian for psychotropic medication. Still mindful of SL’s near-death experience, she fought the contractor for a number of years. In the end he went over her head. As she surmised, he fabricated that SL had had two seizures [SL. Transcript of interviews with: author. 2011 Aug. 29; 2012 Jan. 19; 2012 Aug. 12; and 2013 Jan. 17]. The seizures were alleged to have taken place while he was in bed at night, one in March 2011 and the other in August 2011. They were reported to have lasted 2 or 3 min, after which SL went to sleep. Later he was tested with an electroencephalogram (EEG) to measure his brain electrical activity. No abnormality was detected.

The contractor’s allegation was all the neurologist needed to start SL on Tegretol. The neurologist’s order stated, “advised to start Tegretol as prescribed, effective for seizure and mood” [SL. Individual Support Plan for SL in possession of author. 2012 Feb. 9, p. 56]. SL pointed out that a newspaper report quoted the neurologist as being surprised by an FDA study that found that Tegretol put those who take it at twice the risk for suicide as those who take placebos. The same article also quoted an Epilepsy Foundation as stating that the increased suicide rate was something that had been known for a long time [147].

In the period since the seizure medication was prescribed, SL repeatedly went to the emergency room because of constipation. Most recently in February 2016 he spent a week at Sibley Hospital amid talk that surgery would be necessary [SL. Transcript of interview with: author. 2016 February 22, p. 3]. When questioned, the treating physician at the hospital was not aware that SL was being prescribed seizure medication and insisted, despite the manufacturer’s warning label, that the medication had nothing to do with his constipation problem. In a similar situation, writer Upton Sinclair (1878–1968) in *The Jungle* (1906), commented, “It is difficult to convince someone of the truth of an argument when their livelihood depends on not understanding it”.

Despite the medication, SL continues to resist. From his perspective, whether or not he had two seizures in 2011, they were not a danger, but the medication is causing significant on-going harm and is life-threatening. Realizing its toxicity and that epilepsy can go into spontaneous remission, a common practice is for the medication to be weaned down (titrated) if there has been no seizure in 2–5 years. This allows for a determination as to whether there has been a spontaneous remission and a termination of dangerous medication [148, p. 123]. But as SL points out, the contractor allows no such weaning off because the medication is not for seizures but mind control.

Similarly in failing to wean off of dangerous but useless seizure medication is the case of JC, another group home resident. She had a catamenial epilepsy disorder during her reproductive years. Her seizures began at puberty and ended with menopause. During times when she was taking no medication and during times when she was taking four medications at once, she always averaged three seizures per month. The medication had no influence. The seizures came at night during her menstrual period when she had hormonal changes. She was usually in bed at the time of the seizures, which lasted for a few minutes. Over the years she had 1000 seizures; they did her no harm, but the medication has resulted in gastrointestinal and bone damage. JC has the holistic belief that since osteoporosis is a particular problem for those who have reached menopause and the medication only increases bone demineralization, it would be prudent for the neurologist to consider weaning her off the medication and abandoning his zero-tolerance approach for seizures. But the contractor controls, which means she will be taking seizure medication until she dies from its side-effects [JC. Transcript of interview with: author. 2015 June 27, p. 2].

## Privatization and genocide

Added to the trade union and medication issues, the disabled voiced a third argument against the closing of Forest Haven. This was that privatization would increase what disability advocates allege are the government's traditional genocidal policies against them. The Polish-Jewish professor, Raphael Lemkin in *Axis Rule in Occupied Europe* first used the term "genocide" in 1944 to describe the Nazi destruction of Jewish and Slavic ethnic and national groups. The historian Mark Srebnik maintains the Nazi medical professionals followed a similar policy against the intellectually disabled starting in 1939 [149]. He defines genocide as the elimination of those groups that are seen as "undesirable" and that mental disability was seen as undesirable.

The genocide policies included sterilization, abortion, infanticide, euthanasia, execution in the criminal justice system, assisted suicide and premature death from neglect of their health, safety and economic welfare [63, p. 1]. The scholar Richard Eyman points out that intellectual limitation is not unhealthy, but failure to train a person to use a toilet, to self-feed or to walk leads to death before age 10 [150, pp. 2–3]. Immobility restricts proper expansion of the lungs and ingestion of food, which makes inhalation difficult. When the basics are taught, the survival rate is better, but those in institutions still die at twice the rate of the non-disabled [150, p. 1].

Multiple studies have traced the genocidal ideas about the disabled to the eugenics, literally "good birth", movement in the first part of the twentieth century. The Rockefeller, Carnegie and other capitalist foundations financed eugenic campaigns [69, 151–159]. Following Darwinian theory, the Harriman railroad fortune was used to sterilize the disabled. Feminist and Black organizations supported it. Among the feminist groups that lobbied for eugenic legislation, as documented by the historian Mary Ziegler were the National Federation of Women's Clubs, the Women's Christian Temperance Union, and the National League of Women Voters [160]. The historians Gregory Dorr and Aangela Logan write that W.E.B. DuBois, Thomas Wyatt Turner and academics at Tuskegee, Howard and Hampton Universities believed, as DuBois put it, that only "fit blacks should procreate to eradicate the race's heritage of moral iniquity" [161]. Some 28 states enacted laws to legitimize forced sterilization of the disabled. Those who dominated the DC government could not obtain a sterilization law, but starting in 1933 they commenced sterilizing, arguing that since it was not prohibited, it was legal [63, p. 1].

Both locally and nationally the disabled resisted. Prison riots forced the abandonment of attempts to sterilize

prisoners [162, p. X19]. A 1945 newspaper article reported a DC protest involving 16 women from the District Training School who had been involuntarily sterilized at DC's Gallinger Hospital [63, p. 1]. In a 1973 protest, hospitals were targeted that performed the sterilizations, including Howard University's Freedmen's Hospital, George Washington University Hospital and the Washington Hospital Center. The more popularly-controlled hospitals, such as DC General and St. Elizabeths, refused to do such practices. A newspaper report summarized the 1973 protest:

Government officials were obviously sensitive to sterilization's controversial aspects, especially in a largely black city where many citizens are suspicious of any government invasion of their rights... Georgetown University Hospital's Dr. Andre Hellegers said, "Maybe we've become more conditioned here by talk about rights. Maybe Washington blacks are more militant on issues like this, and maybe rightly so, and we're more aware of it" [163, p. A1].

The 1970s' resisters were helped by Ralph Nader's Health Research Group, which publicized that the Department of Health, Education and Welfare's Office of Economic Opportunity was funding the sterilizations despite federal regulations against it. As the Nader group put it, the government was able to do this because of "a crucial loophole." A newspaper summarized, "the loophole permits physicians to convince women to have what are non-therapeutic sterilizations merely by writing specious medical therapeutic reasons in a patient's records" [164, p. A2].

From the beginning of the *Evans* court involvement in the 1970s and over the next several decades 1800 "elective surgeries", including abortions were done on the disabled against their will [165, 166, p. 26]. Their resistance to the forced procedures included litigation, such as a series of cases in the 2000s. In one of these cases, *Does I Through III v. District of Columbia*, the DC Federal District Court Judge, Henry Kennedy, ruled in 2005 in favor of three women, two of whom had been forced to have abortions. He stated that the government's involuntary abortion policy violated their due process right to refuse medical treatment [165]. The government had argued that undertaking an inquiry into the wishes or interests of an individual with intellectual disability was an impossible charge. To this the judge responded that such an argument "offended both common sense and the dignity of retarded citizens" [165]. The court ordered the government to obey its legal obligation to undertake an inquiry as to the wishes of the disabled.

Unfortunately from the women's perspective, a more conservative Federal Appellate Court in 2007 overturned the 2005 decision, ruling that the government could



forcibly abort them. To this decision law professor Catharine Blackburn objected that the appellate court was over-ruling the common law which respected the right of competent persons to make wrong or unwise decisions concerning health, or simply to differ with their health providers on the best course of action. Blackburn wrote, “The common law has long recognized that only the individual experiences disease; only the individual experiences the effects of treatment for that disease; and only the individual can choose between the effects of disease and the effects of treatment” [130, p. 459].

Blackburn and others also voiced the disabled complaint that while genocidal procedures can be forced on them to prevent life, life-saving procedures can be withheld from them, such as in the Supreme Court decision, *Bowen v. American Hospital Association*, 476 US 610 (1986). That case legitimized infanticide by striking down the federal “Baby Doe Law”, which was part of a 1984 anti-child abuse statute. The court stated that standard medical treatment can be withheld, including treatment for a correctable gastrointestinal birth defect, even if withholding the procedure would lead to death by prevention of nutrition and hydration [167].

With the adverse 2007 federal appellate court abortion decision, the disabled were forced back on an enactment they had won in 1998, the earlier-mentioned “Health-Care Decision Act”. It prohibited the government from consenting to abortions or sterilizations against the disabled without a court hearing. The act did not prohibit forced abortions or sterilizations, but required the government to give evidence that the procedures were in the person’s “best interests” [168, 169, p. 3; 170].

In addition, the disabled used the more friendly *Evans* litigation to gain concessions against what they viewed as the genocidal neglect of their health, safety and welfare. An example was when the *Evans* judge conceded that “protection from harm”, which was covered in one of the nine service areas in the “2001 Plan”, was a constitutional right. The disabled used this decision against the government’s 2015 request that the *Evans* court certify that it (the government) was in compliance with the “protection from harm” requirement. This would have meant that the government would no longer be subject to court monitoring concerning this area.

The *Evans* judge refused the government’s request because the disabled rebutted the request with evidence of governmental neglect to protect them from harm in areas such as nutrition and health care. The judge’s nutrition standard was not high. She made no objection to the widespread obesity, diabetes and other diet-related maladies among the disabled. But choking to death for which

the disabled were shown to have a history, was not acceptable. Included in the disabled’s nutrition rebuttal was the recent case of an individual with a swallowing disorder. He had a meal protocol of chopped and ground food and a court monitor found him choking on a McDonald’s chicken sandwich and French fries. When the individual’s “active treatment specialist” was questioned, she stated she did not know that the individual had a swallowing disorder or where the written protocol was located. When the written protocol was located, it was found not to be the most recent [171, pp. 15, 21, 25–27]. In a similar rebuttal case, a disability advocate gave evidence that untrained group home staff were neglecting to develop and update mealtime protocols for individuals with eating disorders and were ignorant of the procedures related to choking episodes [171].

Playing a role in the nutrition neglect, as the disability rebuttal argued, were the dietitian consultants. To the limited extent they were employed by the contractors, they relied on prepared foods because the disabled were not taught to cook for themselves and the unskilled staff did not know how to cook anything better. This was allowed. The only objection came when those with eating disorders were fed too much, too little or food of the wrong texture that caused them to choke and develop respiratory infections.

A worst-case, food related death that the *Evans* court had to deal with was the 2007 Melonie Nelson incident noted earlier. She died in her group home, gasping for air because she could not swallow an un-chopped piece of food. Her eating protocol required “close supervision and monitoring in order to avoid coughing, choking or aspiration”. The group home contractor, D.C. Health Care, which owns 13 group homes, was understaffed and left Ms. Nelson to eat unattended. When she was discovered choking, the staff did not clear her airway, or properly perform the Heimlich maneuver or attempt CPR. Marshila Davis, a D.C. Health Care employee, stated that the company attempted to use her to whitewash Nelson’s death. Within hours of the death, Davis, who was working at another group home, was told by the company to tell investigators she was the third staff person who was supposed to be on duty at Nelson’s group home. Davis commented:

D.C. Health Care kept bouncing me and other employees through group homes to conceal staff shortages caused by low pay and turnover... None of us have been trained. They just send you to a house [140].

D.C. Health Care was owned by political campaign donors.

Besides the general nutritional neglect, the disabled have sought concessions in their *Evans* litigation

concerning the related medical neglect and drug-side effects with which they are needlessly confronted. These include hypertension, excessive cholesterol, Parkinsonism, akathisia (drug-induced restlessness), agranulocytosis (lowered white-blood cell count, causing vulnerability to infection), skeletal demineralization of bones and osteoporosis. The quadriplegia resulting from demineralization ends with their being frozen in a fetal position prior to early death [150, pp. 1–3]. Their diet, lack of exercise, dangerous drugs and the resulting side-effects, not their disability, reduce their life expectancy to half that of the non-disabled [172, 173].

In litigating against the government's life-threatening medical neglect, the disabled won a number of decisions. As noted one of these was the March 2015 *Evans* declaration that the government was not in compliance with the court's "protection from harm" standard. About medical neglect the disabled put on evidence that in a recent 11-month period, 15 contractors were the subject of sanctions or corrective action because of medical neglect [174, p. 3]. These contractors, such as Comprehensive Care II (CC II), Inc., failed to keep proper medical files [174, p. 11], or Multi-Therapeutic Services which had 220 issues identified, of which 72 were "Health and Wellness" [174, pp. 1–3]. Some contractors were sanctioned for failure to prevent bedbug infestations, unsanitary housing conditions or harassment and threats by housemates [171, pp. 15, 17, 20, 24, 27–28].

The medical neglect, as the above examples illustrate, was shown by the disabled to involve over-worked direct care and nursing staffs in group homes and apartments. Because of their failure to keep proper medical records and take other precautions, wrong medications or doses were given, or medications were not obtained from the pharmacy or medical appointments were missed or occupational therapy and other service assessments ordered by doctors were not being completed, or there were erratic responses to emergencies, such as when to make 911 calls [171, pp. 16, 18–19, 21–22, 24; 175, p. 10]. In the *Evans* court order of March 31, 2015, the judge summed up that the preventive medical and healthcare services and supports that were identified in the disabled's individual habilitation plans (IHPs) were not being provided at the level ordered [176, pp. 12–13]. The court further found that the IHPs were not addressing the "accessibility, quality and continuity of health and medical services" [177, pp. 16–17].

In addition to their "protection from harm standard" in the "2001 Plan" to gain concessions against genocidal medical neglect, the disabled used the periodic reviews in the *Evans* case to advocate against and publicize their preventable, recent medically-related deaths. At a

2007 hearing the judge stated, "Columbus investigators have questioned whether the deaths of at least five class members might have been prevented if health problems had been managed better" [116, p. 304]. The judge then discussed the deaths:

US Ex. 11a at 27 (citing the lack of a "well-coordinated effort by the provider to comprehensively investigate and address the decedents weight loss and significant anemia" even though two other class members with similar weight loss issues also in the provider's care, had died in the past seven months, and nursing staff's failure to adequately assess and monitor the decedent when he exhibited a significant change in status months before his death.

US Ex 11b at 20 (citing failure of decedent's health care team to "adequately address his risk for morbidity and mortality due to his underweight status and GI and pulmonary diagnoses")

US Ex. 11c at 26 (citing lack of a coordinated efforts to "appropriately and comprehensively evaluate, assess, and monitor the decedent when he presented with a change in status" and lack of an "aggressive approach to the decedent's chronic underweight status")

US Ex. 11f at 20–21 (citing failure of provider nursing staff to comprehensively assess or adequately monitor class member when she established a change in status in the week prior to her death)

US Ex. 11m at 15 (citing monitoring and other problems associated with the effort to taper decedent's anticonvulsant medication).

In such defending against the contractors, the disabled have been more successful in using the *Evans* court than in using the DC Superior Court's probate division. They would welcome court-appointed medical guardians from the probate court, if they would help them with their health care, such as having abscessed teeth treated or addressing their obesity or nicotine problem. But this, as a conscientious guardian complains, is obstructed by the contractors and a laissez-faire probate judiciary [MB. Transcript of interview with: author. 2016 March 16, p. 2]. Illustrative is the case of JLJ. In January 2016 he was beaten up in what the contractor, Frontline Community Services (FCS), stated was an unprovoked attack by a direct care staff worker. The assault resulted in an emergency room visit and a diagnosis of a punctured eardrum and a damaged eye. The contractor did not notify the medical guardian. The guardian learned of the incident a few weeks later when, on a routine visit to the residence, he inquired of JLJ why his eye was swollen [MB. Transcript of interview with: author. 2016 March 16, p. 2].

The guardian pointed out that it is impossible for him to do any guarding when he is left out of the loop. Part of the problem, from his view, is that the direct care and nursing staff are in constant turnover, so that even when well intentioned, they do not know the medical situation. In fact, from the guardian's perspective, the staff does little

to care for their own health. The bigger problem, however, is the philosophy of the contractor, who views the role of the medical guardian narrowly, as simply to sign-off on psychotropic medication. Driven by cost-benefit analysis, the contractor makes decisions without consulting the guardian [MB. Transcript of interview with: author. 2016 March 16, p. 2].

The decisions made by the contractor extend to the psychotropic medication, which, at least as provided by in the 1978 Constitutional Rights and Dignity Act, is the guardian's prerogative. The contractor overrides the law by keeping the guardian and psychiatrist in the dark about JLJ's jail-like life-style that drives his resistance. Earlier in JLJ's life, he had gainful employment. The present contractor offers no such option, nor does it bring this problem up for psychiatric counseling. Nor does it bring up the consideration of a titration plan for the medication or a discussion of the medication side-effects as complained of by JLJ.

From the disabled perspective the neglectful health and safety practices brought on by privatization is a national as well as local problem. An advocate James Bakler commented:

Our nation's public health systems largely focus on the prevention of disability rather than on preventive health services for people with disabilities. As a result of this bias... Americans with disabilities are on the whole, in poor health. Again, systemic barriers rather than the medical impairment itself define the disability experience. Many factors contribute to the poor state of health among Americans with disabilities. People with disabilities are less likely to be employed, more likely to live in poverty, less likely to participate in the social fabric of their communities, and, unless they qualify for Medicaid or Medicare benefits, less likely to have health insurance coverage [76, p.19].

Baker goes on to remark that “regardless of who pays, people with disabilities have greater difficulty in accessing affordable, quality healthcare services, including preventive care. As a result, people with disabilities are more than two and half times as likely to be diagnosed with diabetes and experience higher rates of other chronic conditions. They are less likely to engage in leisure-time physical activity and other recommended health behaviors. They are more likely to smoke and have higher rates of obesity. They are less likely to have good dental health. About 28% report symptoms of depression, and when asked, people with disabilities are less likely to report being satisfied with their lives” [76, p.19].

Baker also emphasizes that the nature of disability is not the reason why Americans with disabilities are in poor health. He writes, “Most can or should live long healthy

lives. While it is true that people with disabilities may need more health-related services and supports than the general population, these services are often not designed to meet the needs of people with disabilities” [76, p. 19]. Some advocates would contest Baker's notion that poor health brought on by privatization is unique to the disabled. Yale professors Elizabeth Bradley and Lauren Taylor point out that the whole society is unhealthy:

The United States faces a central paradox in its health-care system: we spend more than any other industrialized country on health, yet we rank among the lowest in many dimensions of health. Our health-care spending is more than 17 percent of our gross domestic product, nearly double the spending in many other industrialized countries. But we rank far below most of these same nations in measures of life expectancy, infant mortality, and maternal mortality, among other key statistics. The huge costs and poor outcomes are difficult for Americans to fathom [178].

For Bradley and Taylor it is the same dysfunctional medical model, as that experienced by the disabled, which is at fault. They advocate for a social model, writing that, “The United States spends, as a percentage of GDP, about half of what some of the other industrialized counties spend on social services (such as housing, employment training, unemployment benefits, old-age assistance, and family support services). The ratio of social-service spending to health-care spending in the United States is less than 1:1, while the average among other Organization for Economic Co-operation and Development (OECD) countries is 2:1. Across the board, OECD countries, including the United States, spend about a third of their GDP on combined health and social services. But the United States has inverted the standard allocation pattern” [178].

Habilitation advocate Terrence Carroll in backing a socialized medicine, single-payer health care system before Congress, summed up Bradley and Taylor's argument more briefly, “I hope you will consider the paradox presented by any proposed system which would be socially funded and privately delivered, with the mistaken assumption that avarice is a motivating factor that inevitably leads to efficiency” [7, p. 213].

## Conclusion

This essay has looked at the habilitation rights of DC's intellectually disabled and the role of the *Evans* litigation from an historical perspective. Most disabled by necessity protect their rights, like everyone else, through self-help, which includes their using trade unions, public schools



and political, family and religious networks. A minority, including the *Evans* litigants, obtain custodial care from the government as admittees or committees in Superior Court's Mental Habilitation Division and in larger numbers in the criminal justice, homeless shelter and mental health systems.

Concerning job rights, the custodial disabled in various periods have forced concessions from a conservative government. The *Evans* court for 40 years has been negative about jobs. It led in shutting down Forest Haven, which had helped several generations of disabled with employment. Its complicity in the privatization process helped destroy the Civil Service and trade union jobs of the direct-care staff. It is laissez faire toward the excessive drugging used against the resistance.

In terms of habilitation the *Evans* court has, in short, not been a friend to the disabled. Nevertheless, given their present status, the disabled, as represented by ULS, do not want to see the case closed because they use it to exploit the divisions among the conservatives. The genocidal minimalists would deny them food, clothing and shelter. The less minimalist court obstructs such maneuverings.

In the past 5 years the *Evans* court has certified the government as being in compliance in most of the nine monitoring areas set up in its minimalist "2001 Plan". However, ULS advocate Sandy Bernstein has pointed out that areas dealing with health, safety and welfare, which in her view are the most important for the disabled, remain neglected and uncertified [179, p. 7]. Bernstein also contends that the government reverts to a neglectful pattern as soon as court supervision is removed. This includes the government keeping secret the data it collects, such as the records of the Incident Management and Enforcement Unit (IMEU), Mortality Review Committee (MRC), Human Rights Committee (HRC), D.C. Health Regulation and Licensing Administration (HRLA), Columbus Organization death investigation reports and MCIS (Mental Retardation Case Information System) records [179, pp. 17–19].

*Evans* Judge Huvelle has complained about the government repeatedly filing erroneous and misleading reports concerning timely payments which negatively impacted the disabled [136, p. 38]. Also among her complaints is that the government seeks to prevent the court from using death, medical and incident records [116, p. 39]. At some points half of the death records given to the court were altered to eliminate evidence of government neglect [116, pp. 94–95].

For that reason, the disabled advocate for the indefinite continuation of the *Evans* litigation as a protection from the minimalists.

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