



# **From “Imbecile, Idiot, Feeble Minded” to People First”: 150 Years of Struggle**

Presentation to: SDACBS  
September, 2008

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## Introduction:

Someone once said ...“You can never understand where you are going unless you understand where you have been”. As I end my 44 years of work in the disability field...I thought it might be of interest to the SDACBS Directors (both old...some of you have been around almost as long as I have; and new) to review our South Dakota community support network’s historical path. Please bear with me as I try to take you through a 150 year history in about ½ hour.

## We are Shaped by the Past:

From a historical perspective, it is now possible to see the enormous injustice on the “disability movement” in the U.S. and South Dakota that false understandings of “mental disabilities” perpetrated on people with disabilities and their families. These “false understandings” explain why various misconceptions and social policies were developed, and why the applications of many correct and incorrect “remedies” happened...with some of the effects still persisting today.

- **Humanitarian Beginnings... 1846 - 1876:**

In this period...humanitarian efforts were carried out in an effort to educate the “poor idiot” and make him socially competent. As the industrial society developed...conditions of survival in this environment (through work) required a degree of intelligence unnecessary in previous, simpler, cultures. “Intelligence” became a mark of success...a condition of upward mobility. In reverse, limitations of intelligence became stigmatizing and degrading. “Feeble-mindedness” and other terms describing low intelligence epitomized the inability to compete effectively for the good things in life. In fact, this condition stood out starkly as the most dreaded of all disabilities...worse by far than missing limbs, blindness, or deafness. In 1846...Dr. Samuel Gridley Howe, Boston, carried out the first “mental retardation” research in America in determining the number of people and what might be done for them. Dr. Howe determined there were 755 “idiots” in 182 Massachusetts’ towns with a combined population of 392,586 people. From this data, he determined that 2 per 1000 total population (or 33,000 total in United States) would be identified as “idiots”; however, he admits “many, perhaps most, of the idiotic children escaped the notice of the commission’s survey”. As a result of this survey/ study... the Massachusetts Legislature appropriated \$2,500 annually for three years to educate ten “idiots” in order to try the experiment. Thus, the first public residential institution in the United States was born as the Massachusetts School for Idiotic Children and Youth. It is often said that these early, small, and somewhat home-like schools (institutions) were a failure because Howe and his followers were too optimistic, unrealistic, and naïve in their educational expectations; that, in short, they failed because

they expected to restore all "idiots" to normal function through intensive special education. In hind-site; however, they did not fail. From the beginning these "schools" were organized "upon the plan of a family" with "a kind and mother person" in care...their sole concern being with education during the best learning years and people being returned to their families. During Dr. Howe's years of work until his retirement in 1874...he was the first and last voice to speak about rights of people with disabilities and the need for community integration for more than a half century.

## • **From Residential Schools to Custodial Institutions... 1876 - 1950:**

During this period we saw institutional populations in the United States increase from an estimate of 1,282 in 1874 to 128,000 in 1950. This can be translated to .03 per 1,000 general population in 1874 to .83 per 1,000 general population in 1950. How did we get there...and why? First, great bulks of the admissions to the institutions were from very poor families. Secondly, the philosophy of Dr. Howe was challenged and dismissed. An example of this "philosophical challenge" can be found in the Superintendent of the Pennsylvania Institution (1875) report where he stated...*"I repudiate Howe's 'principle of diffusion' (we now label this integration) of the idiotic throughout the community on the grounds that they are, in reality, aliens in their own homes; because, unlike any other child or member of the family, they are foreign to the community, because they are insubordinate to its rules and habits; they are children always, even when men in stature; and of necessity they come to be repelled from home and society"* He, by those statements, summarily dismissed Dr. Howe's suggestion of there ever being anything remotely called: "idiots' rights."

During the early years of this period, the over-all attitude still remained one of "humanitarianism"...that being providing a better environment and opportunity for improvement to these individuals. However, it became evident that costs were rising and expansion of institutions was meeting with resistance from legislatures and public officials. Things were about to change...and in about 1874, a young National Organization was starting that would greatly lead to this change. The National Conference of Charities and Corrections was organized as a result of the fact that, at this time, most states controlled their institutions (charitable and corrections) through their "State Boards of Charities and Corrections". As you can understand, South Dakota, pretty much from statehood, had its "Board of Charities and Corrections" and, in fact, did not dissolve this Board until 1989. This National Organization (along with all of the state Boards) constituted the major policy maker for activities related to people with mental retardation for well over 40 years. Increasingly, the mood of "humanitarianism" began to change. A major paper was delivered at the 11th National Conference of Charities and Corrections. Listen carefully to a statement from that paper: *"There is no field of political economy which can be worked to better advantage for the diminution of crime, pauperism, and insanity than that of idiocy. The early recognition of some of its special, upper, and more dangerous forms should be followed by their withdrawal from their unwholesome environments and their permanent segregation before they are pronounced criminals, and have, by the tuition of the slums, acquired a precocity that deceives even experts. Only a small percentage should ever be returned to the community."* This paper, also stated that *"American institutions, having been already in existence 30 years, it may be asserted that the experimental period is passed, and that, when States shall proceed to legislate for these defectives, it will be done on a permanent basis"*. With a sweeping brush, this paper transformed the institution from a school from which the "improvable" may return better fitted for social living, and an "asylum" for the profoundly impaired who have no community home... into instruments of permanent segregation of the *unfit* from the community to which they are a *menace*. The "institution" had now become the established model where "education" was subordinate to "custody" with clientele firmly linked to poverty, crime, insanity, prostitution, alcoholism, and immorality in general. The "mildly retarded" should be indentured to work, to earn their own support, and to support, by their labor, those more helpless. The cost of institutional care should be drastically reduced by use of this labor. Sad to say...things would get even worse.

We now enter what I call "The Dark Period" where there developed a campaign of control of people with mental retardation. This period lasted until about 1950. One cannot do justice to a history of mental



retardation without dealing with the various scientific developments that occurred that helped to paint the final image of the “feeble-minded” individual as that of a depraved menace to society. I will not take a lot of time in this period; but I do want to highlight a few important societal changes taking place:

1. The evolutionary theories of Charles Darwin promoted “survival of the fittest”. The obvious flipside of Darwin’s theory is...a species wants to perpetuate the strong and do away with the weak. One can easily see where the “idiot” fell in this theory.
2. Increasingly, the corrections side of “Charities and Corrections” began to see criminal tendencies in the “feeble-minded and idiotic” population.
3. A myth began to form that the “feeble-minded” had abnormally strong and totally uncontrolled sexual drives.
4. Genetic studies became important at this time with the most famous being the “Kallikak family study”.

When society begins to hear about evolution, criminal tendencies, uncontrolled sexual activity, and the alleged fact that feeble-minded traits are significantly genetic in nature...it is easy to see how the “campaign to control” attitudes and policies can begin to take over. For many years, (in South Dakota until the 1950s), a major strategy for dealing with mental retardation was identification and registration as a means of control. The control factor of sterilization was also widely used. It was not until the early 1960s that the law creating the South Dakota Commission for Mental Retardation was repealed, which included this registration, sterilization and listing of people with mental retardation on county listings. So, how did we come to get our large institution at Redfield? Obviously, with the State following the “control” and “segregation” policies described above...it becomes pretty clear how the Redfield population grew. For many years, the only way parents could assure their son or daughter would be “protected” and “cared for” by the State after they could no longer care for them was to register (in effect commit) them to the South Dakota Commission for the Mentally Retarded. Also, during this time...the consensus of the people working in this field was that people with mental retardation died early in life (many still believe this). In reality, science prolonged life and most people with mental retardation have, and are living much longer than expected. At this point, it might be a good time to remind you that, on your *College of Direct Support* site, you have a Course titled...*Introduction to Developmental Disabilities*, which provides an excellent and more extensive history of our field.

## • **The Parent / Special Education Movement Period... Starts in 1950:**

These two movements pretty much paralleled each other through-out the ‘50s and ‘60s. In 1950, children with retardation and their parents were still very much stigmatized. Institutions were, for the most part, too large, with very poor living conditions, and had extensive waiting lists. Within the education system, there were very few special programs and those few were mostly for the wealthy. In September, 1950, the National Association of Parents and Friends of Mentally Retarded Children was organized in Minneapolis, MN. There were 44 delegates at this convention representing 13 states (South Dakota was one of those states). This organization has had a number of name changes over the years... from the name mentioned above to...National Assoc. for Retarded Children to National Assoc. for Retarded Citizens (the ARC). Of interest to South Dakota is the fact that Dr. Henry Cobb (Vermillion; USD Professor) was very instrumental in starting this organization, becoming its’ President in 1966. Dr. Cobb went on to become President of the International League of Societies for the Mentally Handicapped during the period 1966 – 1970.

The first major break towards gaining Federal help to general education came in 1950 through a program to help educate children of Federal employees in “impacted areas”...Federal lands, military installations, etc. A special education clause was added to this legislation a couple of years later...the first time “special education” was specifically identified. In 1954, Congress combined the Federal Public

Health Service, Office of Education, and Social Security Agencies into the Dept. of Health, Education, and Welfare...an agency with Cabinet ranking. This Department became the major resource for future Federal programs for people with mental retardation.

I was fortunate to have had the opportunity to begin my career in this field in 1964 as the Asst. Director of the South Dakota Mental Retardation Planning Program. This was truly "the ground floor" in the community MR/DD efforts. In 1963, President Kennedy signed PL 88-156, the Federal Mental Retardation Planning Act, which framed the beginning of the community mental retardation support system movement. President Kennedy, at the time of his election, made it widely known that he had a sister with mental retardation, and along with Sen. Hubert Humphrey of Minnesota, became the major national political forces in this new community effort. To show what a tough sale had to be made by the ARC in our state at this time...the only way South Dakota was able to get the initial, (approximately \$30,000), Mental Retardation Planning grant for 1964 was for the ARC to donate their Executive Director (at ½ time) to the project using his salary as match for the federal funds. Neither the South Dakota Executive nor Legislative Branches were willing to come up with any funds. Also, at this time... there was no "home" for a mental retardation program since the only "state agency" was the Redfield Institution administered by the Board of Charities and Corrections and the South Dakota Commission for the Mentally Retarded (responsible for commitment and other "identification activities"). There was a "mental health section" of the South Dakota Dept. of Health, and, for lack of a better place...the mental retardation planning program was placed with that agency. The primary reason for this placement was the fact the Federal MR Planning Program was initiated at the same time a Federal Mental Health Planning Program started...so the two planning programs began at the same time in the same agency within South Dakota. This MR Planning Program was truly a "grass-roots" effort in South Dakota. County planning committees were organized within all counties in the state. Also, state-wide planning committees were organized to deal with specific issues needing attention...i.e.: special education services, institutional services, medical / early diagnostic needs, etc. The planning within South Dakota lasted for four years (two planning periods) and resulted in a series of planning documents titled "Space for the Mentally Retarded". This planning effort laid the foundation for the beginning of our community support system and the "de-institutionalization" movement. At the same time the South Dakota Association for Retarded Children was striving to get the MR Planning Program into our state... four communities (Sioux Falls, Rapid City, Mitchell, and Aberdeen...through their local ARC Chapters) were not waiting for the State to act; but, rather, they were starting community alternative programs to support their sons and daughters as an alternative to the state institution at Redfield. These were to become your first "ATCs". At the same time as the Federal MR Planning Legislation was being passed, Congress also passed PL 88-164 which provided construction funds to assist in the development of community facilities and aid in training personnel in special education (S.D. Achieve was one of the first to obtain some of these funds). There are limited copies of these early "Space for the Mentally Retarded" planning documents around and deserve some time to read to gain a better idea of the thinking and struggles being addressed at that time.

As a result of our State and the Nation going through the four years of Mental Retardation Planning efforts...things really began to happen (often not as fast as most of us wanted).

- **Highlights of Major Federal / State Legislative Actions Since the End of MR Planning in 1968:**

1. The base, or foundation, for most of this new Federal Legislation was the 1935 Social Security Act.
2. 1970...the Federal Developmental Disabilities Services and Facilities Construction Act was passed, primarily as a direct result of the MR Planning activities. This legislation laid the foundation for what was to come after...that being, the development of the State DD Councils; the Protection & Advocacy System; and the network of University Centers of Excellences. On a personal note...I had the unique opportunity to be appointed and serve as a member of the National Task Force to

- develop the first definition of “Developmental Disabilities.” This Task Force, over a 12 month period of time, went through the very long debate of... “do we develop a categorical (disability listing) definition or do we develop a non-categorical (non-labeling) definition?”
3. In 1971, Federal Title XIX (Soc. Security Act) funds first became available in the Mental Retardation area; but only for institutions such as Redfield.
  4. In 1972 the SSI (Supplementary Security Income) program began. As we have seen, over the years... this funding for people with disabilities has been of tremendous benefit to assist them in moving into the community and becoming increasingly independent.
  5. It was in 1973 that South Dakota passed SB 18... the South Dak. Community Developmental Disabilities Services and Facilities Act. There were, initially, very limited funds available with this legislation; but the important point to remember is... this was the first “specifically directed community DD funds” appropriated by the Legislature.
  6. In 1974, by a fortunate coincidence, Congress passed the Federal Title XX (Social Security Act) program that was initially designed to combine a series of child welfare programs. Because of the unique way the legislation was worded... the South Dakota Community DD Program was able to capture a very large percentage of the State’s allocation to use in the implementation and expansion of the community DD Service Network (especially the residential side of the system).
  7. Also in 1974... South Dakota developed a five year de-institutional plan for both Redfield and Custer to address a National goal of reduction of institutions by 1/3 by 1979. As part of this activity... we were able to get legislation passed in South Dakota setting the following objective for both Redfield and Custer as being... “The ultimate aim of each facility shall be to foster those behaviors that maximize the human qualities of each resident, increase the self-direction of his behavior, enhance his ability to cope with his environment, and return him to the community. (It is interesting how this language takes one back to the Dr. Howe’s days of 1866)
  8. In 1975... the Federal Education for All Handicapped Act was passed by Congress. Of interest here is the fact that South Dakota had passed similar legislation some two years prior to the Federal Action... one of the few times our State led the Nation on an issue. This action was accomplished primarily through the support and efforts of the South Dakota ARC.
  9. During the period 1971 to 1981, South Dakota reduced its’ institutional population by 46% (1172 to 631).
  10. In 1979... the Federal Government expanded the use of Title XIX funds to include community ICF-MR Programs and South Dakota began these programs for 15 bed or less programs in a number of our ATCs.
  11. In 1982, South Dakota became the 4th State in the Nation to receive approval of its’ Home and Community Based Waiver (the newly expanded Federal use of Title XIX Funds for community DD Services).

• **The Big Picture... Facility and Consumer History... 1964 - 2008:**

- 1964: There were the beginnings of four community programs (day only) supporting less than 100 individuals. The state was providing no funds to assist these programs. The total funds available to “plan” for the development of community programs were the \$30,000 of Federal Planning funds.
- 2008: Currently, there are 19 approved “ATCs” providing support services for well over 3,600 individuals in day, residential, and family support program areas. The state is providing

funding in an amount over \$90,000,000 in both state and Federal dollars. The community ATC system is 100% accredited by CQL which demonstrates it is providing supports at a nationally recognized high level of excellence. Obviously, the "community support network" is operating in much different ways than it did in 1964; but, of interest, it is still facing many of the very same problems / issues that it faced back in 1964. The "community support network" remains a "creature" of opportunity...one that continues to rely on changes in the "funding sources". The fact that our initial (and continued) funding source from the Federal government is Title XIX Medicaid (medical model) funding...has provided us continued challenges as we move our system away from a medical model to more consumer control and community integrated system.

## Conclusion:

I hope this "feeble attempt" to paint the picture and draw a map of how we got to where we are today is helpful. If nothing else, my desire is that this document will somewhat explain why yours and my predecessors might have "done what they did" in developing services and supports for people with disabilities. So much of what was developed over the past half century in South Dakota to support people with disabilities was considered "state of the art" at the time of development. It is easy for some to look back and "put down" past services and supports as being "old school", "out-dated" and even "degrading" to people with disabilities. Without being defensive...we must always remember that, for the most part, people who have pioneered the way to where we are today did so with the ultimate goal in mind...developing what they deemed was best for their sons, daughters, consumers, and family members. People with disabilities and their families today could not even dream of obtaining the independence, choice, and control over their lives had it not been for the efforts of those "pioneers" in our field. Lastly, on a personal note...I feel strongly that I had the honor and privilege of being a player in the development of what I consider the very best community developmental disability support network in the Nation. The "pioneers" responsible for this network include many of you sitting around this table today as well as all those many people who participated in our journey of the past 50 years of South Dakota's planning and development activities. As I conclude my "career" in this effort...I can only say "thanks" to all of you for making my part in this fantastic journey so meaningful and worthwhile. I ask each of you to "positively continue the journey" with the understanding that the community system will continue to change, attitudes and policies will continue to change, and your role and your agency's role will continue to change; but, in the end of your career...you to will be able to look back and say... *"I made a positive difference in the lives of many individuals in that the support system today is much better than it was yesterday and I played a major role in making that happen!!!"*

Let me end this presentation by using a quote that I have, perhaps overused, many times through-out my career...that being one by Carl Sandburg: *"The people have come far and can look back and say, we will go farther yet."*



