PRESENTATION

to

LAKES REGION COMMUNITY SERVICES

on

CONFLICT FREE CASE MANAGEMENT

SEPTEMBER 20, 2017

INTRODUCTION

- Lakes Region Community Services (LRCS) and the other Area Agencies (AAs) within NH's regional service system serve a lot of vulnerable individuals.
- Both the state and federal governments have put in place rules that are intended to protect the rights and well-being of the individuals served
 - The public-at-large, from whom most of the funds for services come, also expects the publicly funded services to insure the protection of individuals
- Regulations cover a variety of topics, such as rights, safety, certification of programs, staff qualifications and training, administrative and funding issues
- There is general recognition that regulations are needed for the benefit of all involved in the service system: individuals, their families, staff, providers and agencies
- The intent of today's presentation is to share information about a <u>federal</u>
 <u>Case Management Services regulation</u>, which is likely to impact how
 NH's system operates
 - The rule is administered by Center for Medicare and Medicaid Services (CMS), which is a unit within the federal Department of Health and Human Services

"CONFLICT FREE CASE MANAGEMENT"

- Simply put, the CMS's expectation is that a provider of federally (Medicaid)
 funded Case Management services must not provide any other service
- Case managers (service coordinators) typically have three general responsibilities:
 - Advocate on behalf of the individual so that his/her needs are met and rights are protected
 - Facilitate the outcomes needed/desired by the individual
 - Oversee the services being delivered to insure quality and service satisfaction
- As a part of their official responsibilities case managers are expected to coordinate service planning efforts and create service plans
- They also serve as intermediaries among those involved: the individual, family/ guardian, staff and providers, and all organizations that are a part of the service arrangement
- Clearly case managers have very important roles to play within the system
- CMS's position is that, to fulfill their responsibilities, <u>case managers must not be</u>
 <u>affiliated with any agency that is providing other services to the individual</u>
 - The federal expectation calls for "independent case managers" so that they can fulfill their responsibilities on behalf of the individuals thoroughly

THE PROBLEM

- Over 4,000 adults with developmental disabilities or acquired brain disorders receive supports from NH's Area Agency service system.
- Some of these individuals and their families/guardians have chosen to receive all of their services, including case management, from their local area agency.
- Based on the CMS view, when an individual receives all of his/her supports from the same agency, there is a "potential conflict" for service coordinators:
 - Case managers may <u>not</u> fully advocate for people when they can be influenced by the interests of their organizations.
- The federal government has informed BDS that NH needs to change its regulations to achieve "conflict free case management" services
 - This change <u>might</u> mean that individuals and their families will <u>not</u> be allowed to receive all of their services from the same agency.

THE USUAL SOLUTION

- The typical solution to the "conflicted case management" problem is pursued in the following way:
 - Putting in place a <u>prohibition at the agency level</u>, which would prevent organizations from offering/providing both case management and other services at the same time
- The above change would mean that there would be two types of provider agencies:
 - a. Those providing just case management services and nothing else;
 - b. Those providing a variety of services except case management.
- What would happen if this solution were to be used in NH?

POSSIBLE IMPACT

- LRCS and 7 other area agencies currently do provide both case management and other services (such as residential and day)
- These 8 NH area agencies would be deemed by CMS to be <u>not</u> in compliance with the federal regulation
 - Two area agencies [Gateways in Nashua (Region 6) and Crossroads in Atkinson (Region 10)] primarily provide case management and family support and nothing else
- When NH's system was originally conceived in 1981 the intent was for all area agencies to provide just case management and subcontract out all other services
- The idea was abandoned when it was recognized that:
 - There was not a sufficient number of subcontractors
 - Some AA Boards wanted the area agency to be able to provide all services and offer "one-stop shopping" options

POSSIBLE IMPACT IN REGION 3

- A <u>prohibition at the agency level</u> would mean major changes for a number of individuals, families and LRCS:
- If LRCS chooses to continue as an "Area Agency":
 - a. It will keep providing all of its Case Management Services and continue to receive about \$1.0M;
 - b. But it will have to give up its other services and stop earning about **\$18.5M** of revenues.
- If LRCS chooses to give up its standing as an Area Agency and become a "provider agency":
 - a. It will keep providing day, residential and other services and continue to receive about \$18.5M;
 - b. But it will have to give up all of its case management services and stop earning about **\$1.0M**.

You may wonder whether NH has ever considered the issue of potential conflict in Case Management Services?

And, what has it done about it?

NH'S HISTORY REGARDING "POTENTIAL CONFLICT"

- New Hampshire's service system has been aware of the potential problem of conflict and <u>has taken action to</u> <u>address it</u>.
 - Before the CMS regulations sought to address it.
- NH has chosen <u>not</u> to establish a general prohibition at the organization level,
- The state has, instead, put in place <u>multiple layers of</u> regulatory <u>safeguards at the individual level</u>.

- Each individual's services are established through a person-centered planning process and documented in an individualized Service Agreement.
 - The person-centered approach in planning and service provision puts the <u>focus and emphasis on the</u> <u>individual/care-giving family needs</u> and not the provider related issues.
 - The intent is to put the individual and family/guardian in the driver's seat regarding making choices/ decisions
 - This planning process leads to the creation of a formal document that is known as <u>Service Agreement</u>

[Note: The label "agreement" is purposefully used (instead of "plan") to emphasize the nature and level of formal commitment that the provider agencies are being asked to make.]

- Service Agreement contains detailed information regarding the services that the person and his/her care-giving family needs, such as:
 - What services are going to be provided
 - Who is going to provide the services
 - Where and when the services are going to be provided
 - How the services are going to be provided
- If an agency is not addressing the issues that are important to the individual and family/guardian the planning process cannot be concluded until those issues are addressed.
- The Service Agreement <u>cannot</u> be implemented (and payments to providers cannot begin) until the individual or his/her guardian indicate their approval by signing it.

- The staff from the Bureau of Developmental Services carry out a review of each proposed service arrangement and issue a <u>Prior</u> <u>Authorization</u> before services can be provided or paid for.
 - The State is in a position to intercept and raise questions on Service Agreements that are not in line with the identified needs of the individual
- Individuals and their families/guardians have the right to file a complaint and/or an appeal to the state:
 - Anytime they feel their service and/or treatment rights are being neglected or violated by the agencies that are supposed to provide the services identified in the individual's Service Agreement.
- Persons who are direct providers of other services to an individual are <u>not</u> allowed to become the case manager for that individual:
 - "A service coordinator shall not ... have a conflict of interest concerning the individual, such as providing other direct services to the individual." [State Rule He-M 503]

- The individuals and their families/guardians have the right to choose their providers based on their own needs and circumstances:
 - "An individual, guardian, or representative may select any person, any provider agency, or another area agency as a provider to deliver one or more of the services identified in the individual's service agreement." [State Rule He-M 503]
- Specifically to the provision of service coordination, the state regulations include the following:
 - "The area agency shall advise the individual and guardian or representative verbally and in writing within 5 days of the determination of eligibility and each year prior to the annual service planning meeting ... that he or she has a right to choose his or her own service coordinator, including one who is not employed by the area agency. [State Rule He-M 503]

- NH has chosen to address the potential conflict issue at the individual level, as the state has empowered the individuals and their families/guardians to:
 - Decide whether their service coordinator is advocating for and supportive of the individual fully, as she/he should be;
 - Determine whether the "potential conflict" is a real concern for their service arrangement; and
 - Choose an independent case manager if they wanted to.
- NH's approach of addressing a potential conflict at the individual level is based on its longstanding focus on the person-centered approach in service planning, provision and addressing unique individual needs and issues

NH'S APPROACH

- Administratively, a solution at the agency level would be a "simpler solution" than the solution at the individual level.
 - No analysis, thinking or decision making is required; the prohibition at the agency level sorts things out.
- NH has chosen the seemingly "harder solution" at the individual level because, just like its person-centered approach, it is intended to produce better and consumerfriendly results, in spite of requiring more time and energy.
- Ultimately, NH has made its decisions based on the bedrock value and principle that drives its services system:
 - The individuals and their families/guardians must have the opportunity to choose who is going to provide their services.

The strategy that NH has been using is known to CMS

In a 2003 CMS sponsored publication on "Promising Practices in Long Term Care Systems" NH's approach was highlighted as involving and leading to successful systems changes

NH'S APPROACH

• The CMS sponsored publication said this about NH's emphasis on choice:

"Freedom of choice is an inherent focus of this (Medicaid) program and is codified in the State program regulations. Participants and their families can select anyone to be their provider of services if the (provider) meets system's standards and qualifications." (emphasis added)

"Area Agency staff are required to explain the options and participant rights at the beginning of the service planning process. Participant or family signature attesting that they were informed of their choices and rights is part of the Service Agreement process." (emphasis added)

 The CMS funded publication, moreover, notes how NH has gone beyond providing choice and has also been offering control over services and funds:

"New Hampshire was among the first States in the country to modify (its Medicaid program) to allow participants and their families to assume control of their own budget and serve as their own service coordinator, selecting needed services and providers." (emphasis added)

NH'S APPROACH

 There are a couple of more observations that the CMS sponsored publication said about NH's approach:

"Another lesson from New Hampshire is the degree of support for change and improvement that can come from involved stakeholders. Stakeholder momentum has been behind every significant change in the New Hampshire system." (emphasis added)

"Stakeholders have been crucial in the development, implementation, and operation of the New Hampshire (Medicaid) waiver program. Stakeholder involvement has always been the cornerstone of the system, from the first lawsuit that led to the closure of the State institution and forced the question of appropriate alternatives. A State official noted that the waiver program is a community stakeholder program because of the structure in place to respond to the needs of individuals and families." (emphasis added)

 The above observations on stakeholder involvement in NH's system are the reason why we are here today learning about and discussing an issue that could bring about significant changes to our system, including how individuals and families will receive and influence their services.

WHAT NOW?

- If regulatory and systemic changes are being contemplated and required then the stakeholders would need to guide and help the area agencies and BDS make the right decisions on their behalf.
- To BDS's credit, the State has set up a process that includes some stakeholder input, which will enable the system to continue to adhere to the motto that has long been embraced by individuals and their families:

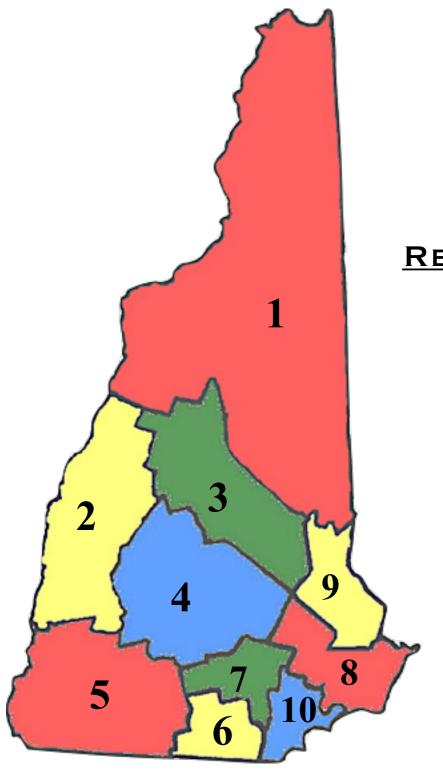
"Nothing About Us, Without Us!"

- With input from individuals/families/guardians the AA BOD will ultimately decide how LRCS will proceed.
- We are here today to share information with you and get your input/suggestions regarding the Conflict Free Case Management issue.

First a short but an important bit of history

The knowledge of this history has influenced the way NH has chosen to develop and run its community-based service system

REGIONAL SERVICE SYSTEM



Area Agencies

REGION AGENCY NAME

- 1 Northern Human Services
- 2 PATHWAYS OF THE RIVER VALLEY
- 3 LAKES REGION COMMUNITY SERVICES
- 4 COMMUNITY BRIDGES
- 5 MONADNOCK DEVELOPMENTAL SERVICES
- 6 GATEWAYS COMMUNITY SERVICES
- 7 MOORE CENTER SERVICES
- 8 ONESKY COMMUNITY SERVICES
- 9 COMMUNITY PARTNERS
- 10 COMMUNITY CROSSROADS

THERE WAS A TIME WHEN NOT MUCH EXISTED IN THE WAY OF SUPPORTS

NH COUNTY FARMS



Strafford County Farm



Cheshire County Farm, Westmoreland, N. H.

Cheshire County Farm

NH COUNTY FARMS

- All vulnerable people needing help were placed at County Farms
 - Elderly
 - Children
 - People with disabilities
 - People with mental illness

[No "service silos" existed at that time!]

HISTORY

- On February 9, 1893, there was a devastating fire at the Strafford County Farm.
- The fire killed 40 of the 44 people living the County Farm.
 - A monument was erected in memory of the victims.
- A controversy arose about the conditions in the County Farms.
- In 1895 the State Board of Charities and Corrections was created by the Legislature to provide oversight.
 - The Board recommended that radical changes be made in the methods of caring for the vulnerable residents of the State
- In 1901 NH Federation of Woman's Clubs petitioned the NH Legislature regarding children with intellectual disabilities

1903

THE STATE ASSUMES RESPONSIBILITY

- Ten years after the Strafford County Home tragedy the State took action to support its vulnerable citizens.
- The State opened an institution for people with intellectual disabilities in Laconia, NH.
 - "NH School for the Feebleminded"
- "In 1903 the New Hampshire Legislature passed an act assigning to the state the responsibility for the care of mentally ill patients throughout the state." (emphasis added)
 - "Many of the state's (severely) mentally ill were indigent and cared for by the counties at country farms or almshouses. With the new act, all patients were transferred to the State Hospital..."
 - "NH Asylum for the Insane"



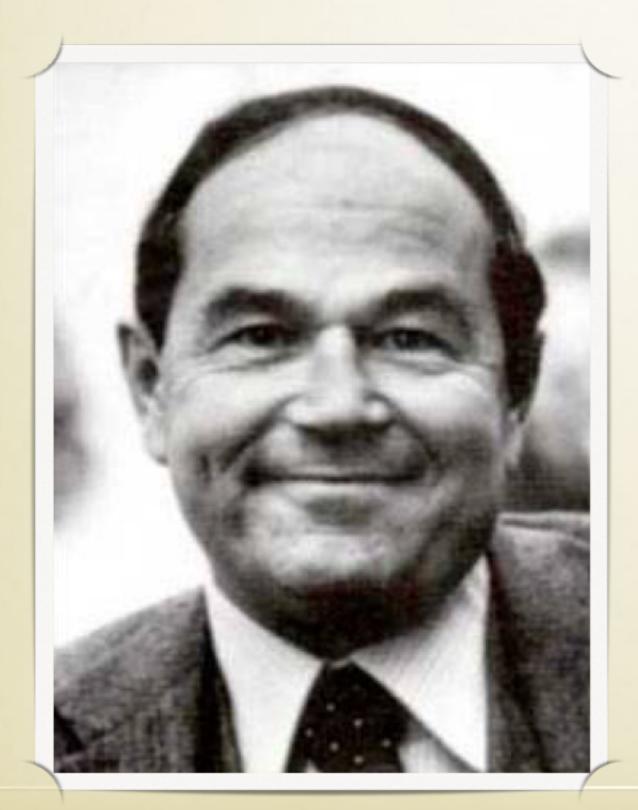








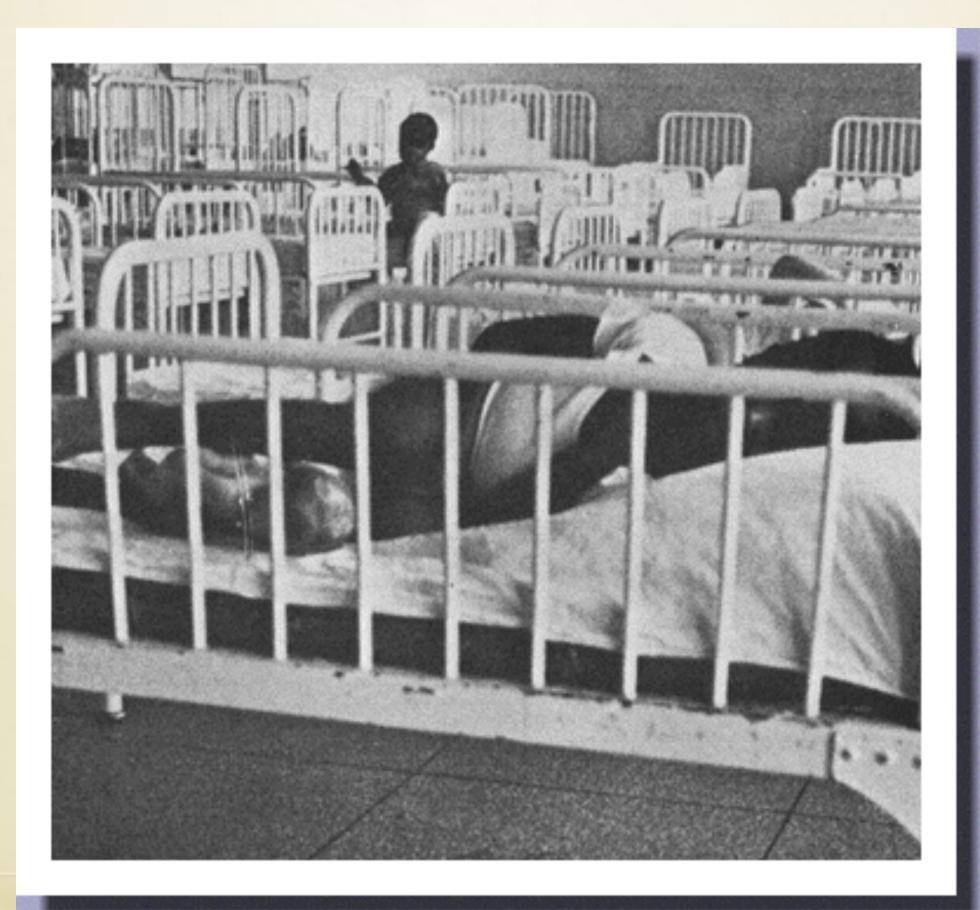
A PIONEER OF THE MODERN DISABILITY FIELD



Burton Blatt (1927 - 1985)

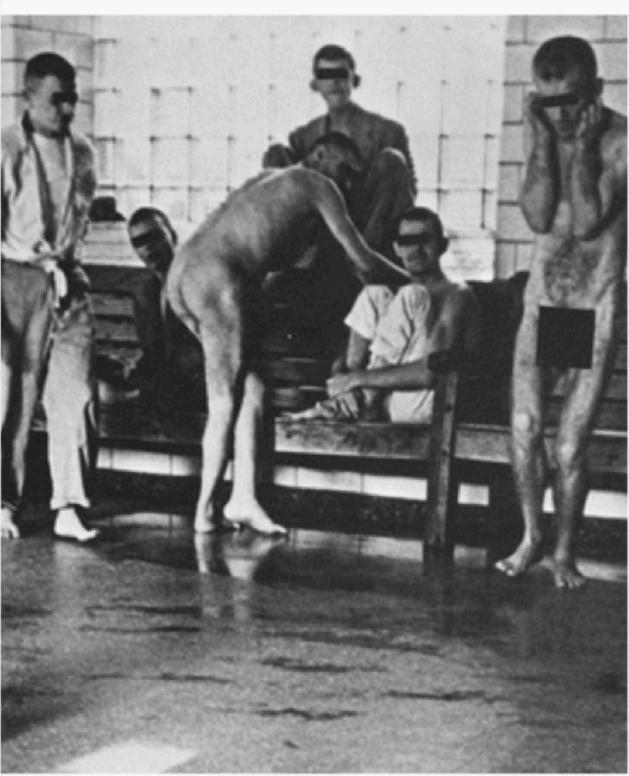
- Educator
- A national leader in special education
- Strong advocate of deinstitutionalization
- In 1966 published his book, Christmas in Purgatory, providing a pictorial account of conditions in state institutions for individuals with ID/DD in four eastern states
 - -As a result, the horrible conditions at state institutions was publicized by the general media

CHRISTMAS IN PURGATORY



CHRISTMAS IN PURGATORY





CHRISTMAS IN PURGATORY



Some people assert their humanity

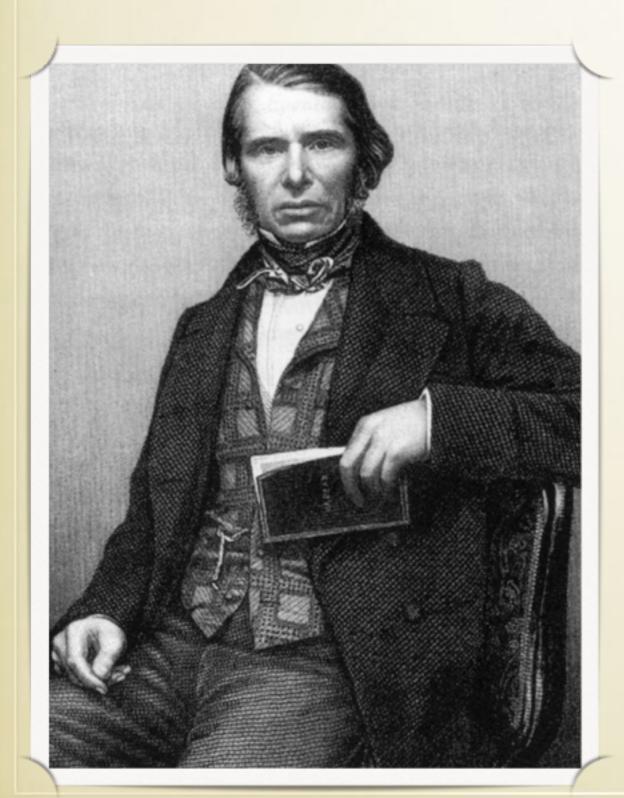
regardless of

what the conditions are

HOW COULD SUCH CONDITIONS EXIST FOR VULNERABLE PEOPLE?

ON WHAT BASIS
SUCH TREATMENT
WAS "JUSTIFIED"?

CONTRIBUTORS TO OLD DISABILITY VIEWS & LABELS



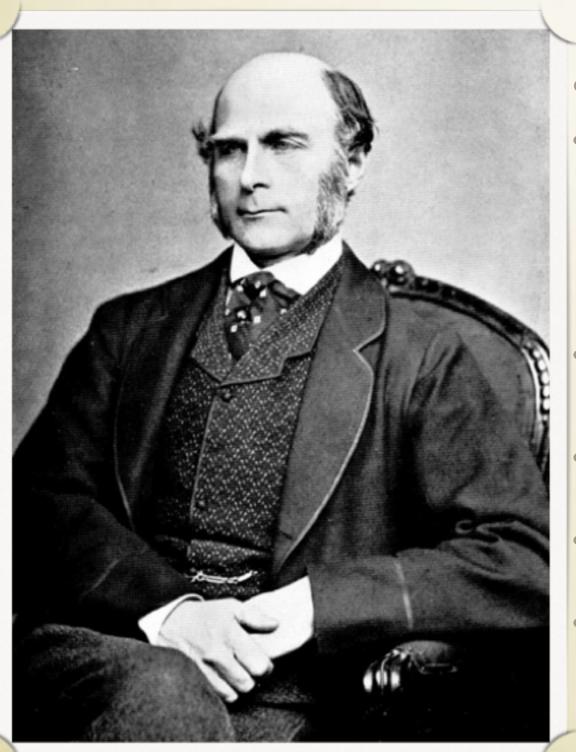
- Sir Charles E. Trevelyan, (1807-1886)
- British civil servant
- Used the intelligence ranking of:

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"Feeble-mindedness"

"Imbecility"

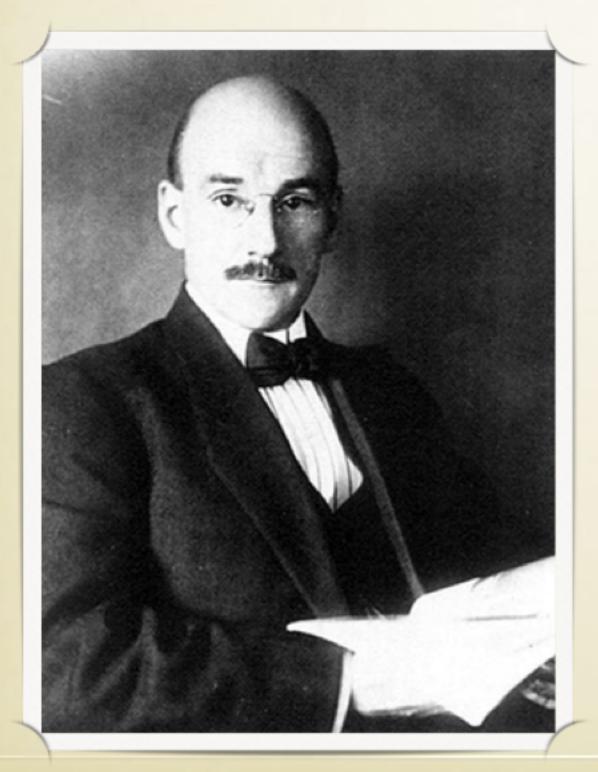
"Idiocy"
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CONTRIBUTORS TO OLD DISABILITY VIEWS & LABELS



- Sir Francis Galton, (1822 1911)
- Polymath (sociologist, psychologist, inventor, anthropologist, tropical explorer, geographer, meteorologist, statistician psychometrician, and geneticist)
 - Half-cousin of Charles Darwin
- Was a pioneer in modern "eugenics"
 - Originated the term itself
- <u>Eugenics</u>: A belief in "improving the genetic quality of the human population"
- Positive Eugenics: the promotion of higher reproduction of people with desired traits
- Negative Eugenics: reduced reproduction and or sterilization of people with lessdesired or undesired traits

MEET THE PSYCHOLOGIST WHO COINED THE "DIAGNOSTIC TERM" "MORON"

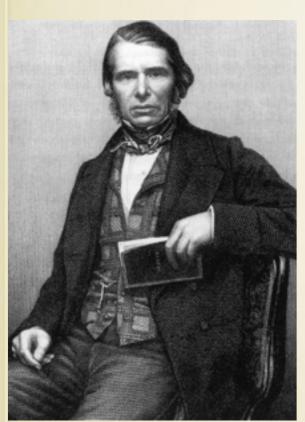


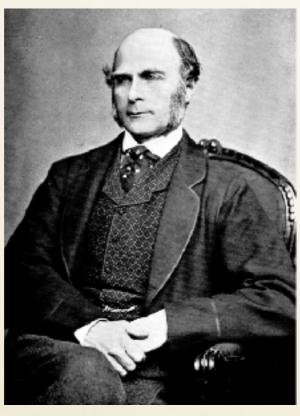
- Henry H. Goddard (1866 –1957)
- A 20th centuryAmerican psychologist
- Introduced the term "moron" into the field of psychology
 - From the ancient Greek word "moros", meaning "dull"
- Goddard's Intellectual classification based on IQ scores:

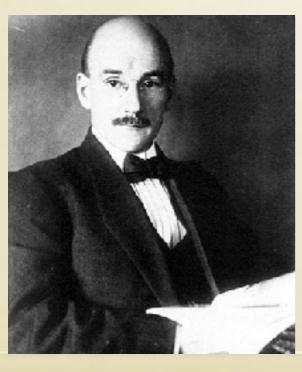
"Moron"
"Imbecile"
"Idiot"

• Goddard came from a Quaker family [Quakers are known for their opposition to hierarchical structures in society; yet Dr. Goddard embraced this one!]

WHAT DID THESE LEARNED MEN "CONTRIBUTE" TO THE FIELD OF DISABILITY?







- The labels they used reflected their beliefs and perceptions about people with disabilities
- They believed that individuals with disabilities were:
 - Deviant and sub-human
 - Unfit for society
 - Burdens to society
 - To be removed from society, either through
 - institutionalization
 - sterilization,
- Buck v. Bell, (1927) the US Supreme Court ruled that a state could use forced sterilization on a woman with ID (18 yr old Carrie Buck)
 - It was seen as justified intervention for "the protection and health of the state"
- Historical reports indicate that the first victims of the <u>Holocaust</u> were people with disabilities
 - It is estimated that about 300,000 individuals with disabilities were killed

SOME PARENTS DID NOT NEED
TO SEE THE PICTURES OF
"CHRISTMAS IN PURGATORY"
TO KNOW WHAT WAS GOING
ON IN INSTITUTIONS

A NH PARENT WITH A DIFFERENT CONVICTION



Freda Smith

- Parent of Janet Smith
- Could not accept the dreadful conditions at the State School
- Along with several other parents took the State of NH to court to improve the conditions
- Although her daughter is no longer alive, Freda gives lectures around the State regarding the importance of providing supports to individuals and their families

A "BUREAUCRAT" STEPS UP



Donald Shumway

- Was the prime architect of the community-based AA system
- Understood the importance of "local control" in NH's culture
- In spite of improving the conditions at the State School he closed it down in 1991
- He was also instrumental in deinstitutionalization of the individuals with mental illness and creation of the current APS (NHH)

A FAMILY WITH A DIFFERENT VIEW



- Katie Beckett, (1978-2012) &
 Her parents Julie and Mark
- At age 4 months Katie contracted viral encephalitis
 - She was partly paralyzed, unable to swallow and could barely breathe on her own
- Her parents wanted to care for her at home with a ventilator
- But Parents' income made her ineligible for Medicaid and for in-home services
- An appeal to the Reagan administration to waive the income requirement was successful and created the <u>Katie Beckett</u> eligibility category under the Medicaid program

DUE TO THE EFFORTS OF A LOT OF PEOPLE -ESPECIALLY FAMILIES-THINGS HAVE CHANGED FOR PEOPLE WITH DISABILITIES

THE UNDERLYING REASON FOR THAT IMPROVEMENT IS THE FACT THAT "WE HAVE CHANGED" (NOT THE PEOPLE WITH DISABILITIES)

There have been three major fundamental changes in the disability field

HOW WE SEE PEOPLE

- We have come to see individuals differently
- The societal attitudes toward individuals with disabilities have gone through a grand transformation
- In general the community-at-large is seeing individuals as valuable members - "as one of us"
- The shift in attitudes toward people has resulted in significant changes at the state and federal level
 - Progressive laws and regulations
 - Allocation of funding for services
- Lessening of stigma means that individuals with disabilities have a <u>chance to live</u>, <u>go to school</u>, <u>work and contribute</u> <u>in their local communities</u>

HOW WE SUPPORT PEOPLE

- As a result of the changes in our perceptions professionals and agencies strive to support individuals differently
- Taking each person's capacities, challenges, needs and preferences into consideration in providing services
 - Recognition that each person's situation is different and requires unique supports
 - Getting away from "one-size-fits-all" approach
- Community-based and customized supports that are based on the "person-centered orientation"
 - Listening for what is really important to the person
 - Focusing on discovering each individual's skills, capacities and gifts

HOW WE EMPOWER PEOPLE

- Through enactment of new practices, policies, laws, and regulations we have come to empower people
- Individuals, guardians, families can have <u>choice and</u> control over their services
- Individuals, guardians, families have the opportunity to be involved and make decisions in all aspects of their service arrangements
- Individuals, guardians, families share power with agencies and professionals
 - The AAs use "Individual Service Agreement" as a signed formal document for service planning and provision













It is informative and wise to remember this history and its lessons when we consider any future changes within the system

WHAT COULD/SHOULD LRCS AND ITS BOD DO?

- Getting input from individuals and families/guardians and using it in decision making
 - Several AAs are reaching out to families to gather information
- Posing questions to better understand the specifics of the problem and what possible solutions can be implemented; questions such as:
- What is the extent of the "conflicted case management" problem statewide?
 - An initial review indicates that "potential conflict" may exist in 30% to 40% of the case management assignments statewide
 - Two regions are said to have no conflict in their case management services already
- If it turns out that the "potential conflict" exists in only minority of the cases, does it still make sense to force the entire system go through dramatic administrative and structural changes?
- Are there national or NH based data/information to indicate that "independent case management" is more effective?
- Why would the concept of "conflict free" override the NH's longstanding principle of empowering individuals and families to make their own choices regarding the providers of their services?

WHAT COULD/SHOULD LRCS AND ITS BOD DO?

- Questions re Conflict Free Case Management: (continued)
- Why should a family that is satisfied with its case manager's performance and has experienced no indications of conflict be forced to go through a case management change?
- Is a detailed analysis being made to identify the financial implications of a change in regulations and practices?
- If additional funds are needed to make systemic changes why would NH choose <u>not</u> to spend those funds for wait lists?
- Medicaid Waiver programs tend to vary from state to state; if the DHHS Secretary has the discretionary power to approve different approaches in different states, why couldn't NH make a case for being allowed to achieve compliance at the individual level?
- What type of assistance would BDS/DHHS need from the regional stakeholders to persuade CMS to approve NH's approach of compliance at the individual level?
- Other questions...?

WHAT COULD/SHOULD LRCS AND ITS BOD DO?

- Reaching out to the Legislature and Governor to inform them of the issues and preferences of the individuals and families regarding how compliance with federal regulations should be achieved
 - Any change in NH regulations would have to be approved by JLCAR and a public hearing would be a forum where the individuals/families could advocate for themselves
- Reaching out to CMS, the Secretary of DHHS and/or the White House directly to make the case for compliance at the individual level
 - Ask the federal officials to honor and preserve NH's long-standing and fundamental value about consumer choice and control in responding to the issue of conflict free case management

SUMMARY

- There is no denying the fact that a variety of "potential conflicts" can exist in all service arrangements.
- NH has developed regulations to address such concerns.
 - Current NH regulations <u>already empower</u> individuals and their families/guardians to choose "independent" (conflict free) case management services
- CMS's focus on "conflict free case management" gives us a chance to ask an important question:
 - Are all individuals, families and guardians making an <u>informed</u> <u>choice</u>?
 - Are they getting the necessary and full information about having a choice in selecting their provider agencies?
- Is there a way to evolve and improve the current system and practices:
 - By continuing to comply with the federal rules at the individual level?
 - But finding ways to improve the communication with individuals, families, guardians to help them make fully informed decisions?
 - Without making radical changes and limiting the capacity of agencies to provide a variety of services?

SUMMARY

- Having a strong and influential family network has made NH's system open to changes and improvements
- With input and suggestions from individuals, families and guardians:
 - Can we, once again, do a number of things to:
 - Enhance the application of consumer choice, and
 - Improve the selection and provision of case management services?
 - Several AAs have already begun to engage in such activities
- Can we make such changes without undermining NH's fundamental value of empowering individuals, families and guardians to choose their own provider agency?

SUMMARY

Based on its history NH's regional service system needs to:

- Seek input and guidance from its stakeholders in formulating its plan of corrective action;
- Be thoughtful in responding to the federal directive about conflict free case management;
- Preserve the principles and practices that have served people well.

Questions?

Comments?