

Cultural Competence and Inclusion: Intellectual & Developmental Disabilities

May 11, 2022 - 7:30-8:30 am

Nancy Cronin, MA Executive Director

Disclosure Statement

None of the planners for this educational activity have relevant financial relationships to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.

Objectives

- 1. Participants will be exposed to aspects of the stigma, bias, civil rights movement, self-advocacy, and self-determination in relation to disability and social inequality.
- 2. Participants will learn the basics of developing plain language materials.
- 3. Participants will be introduced to commonly used communication strategies such as social stories and Picture Exchange Communication Systems (PECS)

Objective 1

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First: Let's travel a bit through time.

HISTORY, POLICIES

Town Farms and Alms-Houses

532

RELIEF OF THE POOR.

Overseers of their poor; and where such are not specially chosen, the Selectmen shall be Overseers of the poor.

Overseers to towards them.

Sec. 4. Be it further enacted, That said Overseers shall have the care have the care and oversight of all such poor and indigent perand their duty sons, so settled in their respective towns, and shall see that they are suitably relieved, supported and employed, either in the work house or other tenements belonging to such towns, or in such other way and manner as they at any legal meeting shall direct; or otherwise at the discretion of said Overseers, at the cost of such town.

79 Town Farm Rd, Gray, ME 04039 - MLS 1252610 - Coldwell Banker

www.coldwellbankerhomes.com > ... > Maine Real Estate > Gray Homes for Sale ▼ Feb 29, 2016 - For Sale - 79 Town Farm Rd, Gray, ME - \$258000. View details, map and ... Listed by The Maine Real Estate Network. Lots/Land; Active; 3 ...

487 Town Farm Road, Hartford, ME For Sale | Trulia.com

https://www.trulia.com/_/3200406390-487-Town-Farm-Rd-Hartford-ME-0422... * Trulia *

Jan 28, 2016 - This property is listed by The Malne Real Estate Network for \$79,900, 487 Town Farm Rd has 6 beds and 4 baths. The property has a lot size of ...

79 Town Farm Road, Gray, ME For Sale | Trulia.com

https://www.trulia.com/.../3227663252-79-Town-Farm-Rd-Gray-ME-04039 - Trulia -

Sep 24, 2016 - Photos, maps, description for 79 Town Farm Road, Gray, ME. Search homes for sale, get school district and neighborhood info for Gray, ME on .

Lot 2 Town Farm Road, Anson, ME | Trulia.com

https://www.trulia.com/.../3215036810-Lot-2-Town-Farm-Rd-Anson-ME-0491... • Trulia • Photos, maps, description for Lot 2 Town Farm Road, Anson, ME. Search homes for sale, get school district and neighborhood info for Anson, ME on ...

284 Town Farm Rd, New Gloucester, ME 04260 | Zillow

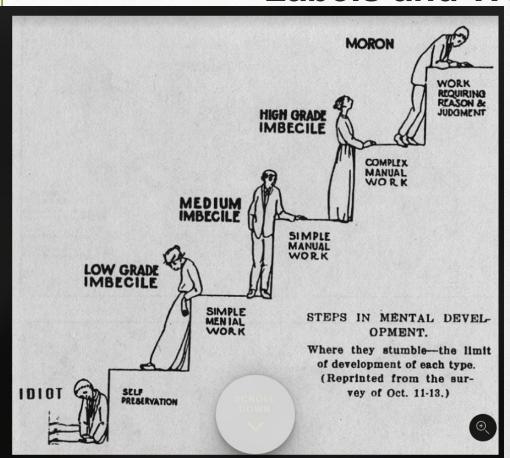
www.zillow.com > Maine > New Gloucester > 04260 ▼ Zillow * My Notes. Edit. This 2634 square foot single family home has 4 bedrooms and 3.0 bathrooms. It is located at 284 Town Farm Rd New Gloucester, Maine

293 Town Farm Rd, New Gloucester, ME 04260 | Zillow

www.zillow.com > Maine > New Gloucester > 04260 * Zillow *

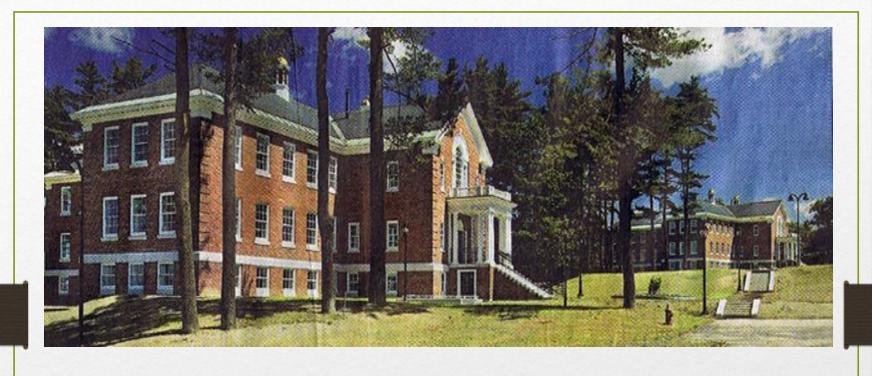
This 1930 square foot single family home has 3 bedrooms and 2.0 bathrooms. It is located at 293 Town Farm Rd New Gloucester, Maine

Early 1900s - Codifying Intellectual Ability Labels and Words



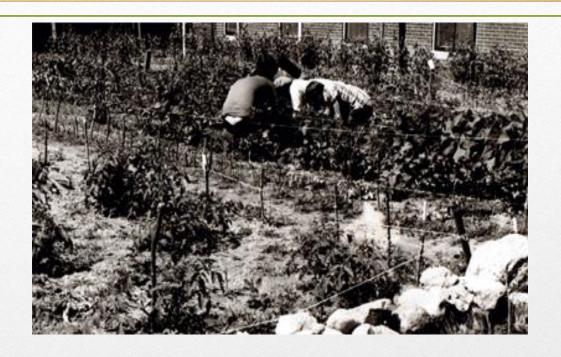
From Mental Defectives in Virginia: A Special Report of the State Board of Charities and Corrections to the General Assembly of 1916, on Weak Mindedness in the State of Virginia; together with a Plan for the Training, Segregation, and Prevention of the Procreation of Feeble-Minded

The idea that some of those with developmental disabilities could be trained, and also that they were dangerous or unfit for society if they could not be, led to the rise of the institution. The earlier rise of the asylum or "hospital for the insane" fed this notion of building spaces away from the rest of society, to protect upstanding citizens from the influence of the "degenerate" – until such time as those degenerates could be trained to perform useful work and act according to the morality of the time.



Maine School for the Feeble Minded aka Pineland Farms 1909 – 1996

For a complete history go to www.shadowsofpineland.org



The goal was a colony that would be self-sufficient and self-supporting, with staff and residents alike living on the grounds.

All of the residents were known as children, regardless of age. The most capable "working boys" worked in the gardens and farms while the "working girls" worked in the dormitories, kitchen and laundry.

But – people needed to be able to work.



Myth of Menace and the Rise of Eugenics

During the late 1920s and early 1930s professional statements about the dangers to society from "the menace of the moron" became more alarming.

Segregate Feeble-Minded to Stop Petty Crime, Urges Judge Sanborn

"Segregation and sterilization of feeble-minded women and girls, and industrial occupation under government guidance for those of both sexes of limited mentality was advocated by Lauren M. Sanborn, former judge of the Cumberland County Superior Court, speaking yesterday before the Kiwanis Club...."

- Portland Press Herald January 6, 1926



By the time of World War II research had disproved earlier theories and exposed the myth of the dangers of mental retardation. With the change in attitude and beliefs Pineland itself began to change. A program was implemented for those working boys and girls who could be placed with families and work in their community. As a result, hundreds of Pineland residents went on to be discharged and live successfully "on the outside".

Feeble-Mindedness Often is Not Hereditary

Dr. Fernald Points Out Mental Defectiveness Many Times is Due to Destructive Brain Diseases in Infancy

".... We have been far too sweeping in some of our generalizations and deductions concerning the feeble-minded."

- Portland Press Herald January 6, 1926



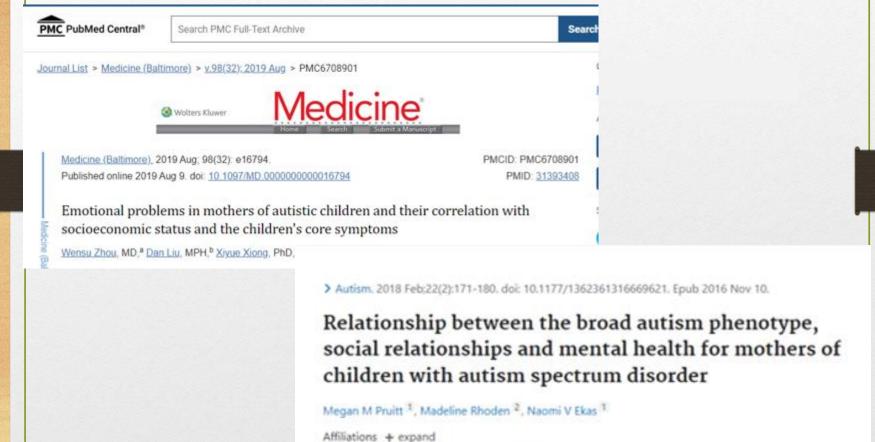
Families



Families were often caught between their love and concern for their child and the social stigma of having a "defective" child in the family. Friends, neighbors, and professionals were all likely to persuade the parents that it would be best for everybody if they placed their child in the institution. Parents were discouraged from visiting for several months after admission so that their child could adjust to its new surroundings. Families were often advised to forget that they had the "defective" child and were even encouraged to have another baby as soon as possible to replace the one they had "given up".

Refrigerator Mothers – A Dangerous Legacy

https://www.youtube.com/watch?v=TQY2oB3Rqdg



PMID: 29490487 DOI: 10.1177/1362361316669621

And yet...

"Mothers of children with autism may be prone to depression if they feel responsible for the cause or outcome of their child's disorder...". Fifty percent of mothers with children with <u>autism</u> had elevated depression scores, compared to 15 percent to 21 percent in the other groups. Single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with a partner.



Pineland History: Reform and *Rejection* of Medical Model

- Teeth Pulled as Response to Behavior
- Belief that pain felt differently
- Sterilization: The law was changed in 1983

Chapter 275.

AN ACT to Regulate the Sterilization of Inmates of Institutions.

Be it enacted by the People of the State of Maine, as follows:

Sec. 1. Provisions for recommendation for sterilization in certain cases. Whenever it appears to the medical staff or institution physician of any institution in this state which has the care or custody of insane or feeble-minded persons that any inmate under the care or custody of such institution would be likely, if released without sterilization, to produce a child or children who by reason of inheritance would have a tendency to serious mental disease or mental deficiency, said medical staff or institution physician shall submit to the governing board of such institution a recommendation that a surgical operation be performed upon said patient for the prevention of parenthood.

Multigenerational distrust of doctors

Maine 1931 Public Law Chapter 275

In the next decades, at least 326 people were sterilized in institutions across the state, 189 of them at Pineland.

Long Battle to Independence

Institutionalized at age 10, she's now one of Maine's leading advocates for Mainers with developmental disabilities

BY ALLEN PIERLEONI

I hen Maryann Preble's mother died, her father willing to throw committed his daughter to the notorious Pineland Hospital and Training Center in New Gloucester. It opened in 1908 as the Maine School for the Feeble-Minded

Maryann Preble was 10 years old.

Today, 60 years of self-determination later. Preble is a often can't speak highly respected advocate for people with developmental disabilities, a pioneer in her field who has lived independently for years.

Her accomplishments have been remarkable. For instance, she's a leader in the self-advocacy group Speaking Up For Us, serves on the consumer advocacy board of the University of Maine's Community Inclusion and Disability Studies department, and has testified multiple times before the Maine State Legislature, advocating for those with developmental disabilities. Preble is a member of the executive committee of the Maine Developmental Disabilities Council.

"A lot of people in group homes want to be out on their own, to have an apartment, to set married." she said. "When I testify at the state house and tell them about [other people with developmental disabilities], I'm taking their voices with me. [Advocates] wouldn't be on committees if it wasn't for me speaking up. It makes me feel good to do that."

"Maryann's life embodies possibilities," MDDC Executive Director Nancy Cronin said. "The system was me anymore."

her away, but the fact that she was able to continue on and speak for people who for themselves, is amazine."

Preble was 16 and still in Pineland when an aide took her to lunch at a local restaurant. Incredibly, she ran into her brother, who soon engineered her release and moved her in with him and his wife.

"I thought, 'Good, I'm out in the community and with my family," Preble recalled.

"I made up my mind after I got out of Pineland that I was going to get my own place and be out on my own," she said. "I went from my brother's home to a group home. We would cook (as a group) and make our own menus and meals. It was like being on our own. And once I was there, I was able to see my family quite a bit."

Preble left the group home when she was about 30. "I said I was going to find my own apartment and get a job, which I did. I wanted to meet people and earn some money. I worked at a preschool and it was fun working with kids. But they let me go because they couldn't pay

"You know what you want, but other people aren't going to know if you don't tell them.

Marvann Preble Self-advocate and MDDC executive committee

herself and other Mainers with developmental PHOTO BY NIKOLAS HAMPLE

Then, she met "a companion." They married and moved to Litchfield. When her husband had a stroke and was moved into a nursing home, she got an apartment in Augusta to be near him. She commuted from there to Hallowell to visit her husband until he passed away.

Ever ambitious, she got a job as activities director at the nursing home and began advocating for herself and others. "I'd advocate for people who couldn't advocate for themselves," she said. "It brought me closer to doing something for other people, and I felt good about that."

Preble has lived in her apartment for "about 20 years now," she said, "I'm a different person from who I was. I make my own decisions and 20 where I want, when I want. It's like, 'I'm free, I'm out on my own, What am I soins to do next?' I volunteer and it makes me feel sood doing things for other people."

What advice does Preble offer those who struzgle with their developmental disabilities?

"Speak up, don't keep it in," she said. "You know what you want, but other people aren't going to know if you don't tell them."

PREVENTING A STEP BACKWARDS

The Maine Developmental Disability Council is very concerned at the current trend to open larger congregate settings for people with disabilities. The Council believes firmly that Maine has "been there, done that, and it didn't work."

That doesn't mean our community services system is working perfectly - wait lists are growing for services, in addition to a housing crisis and a direct workforce crisis - but the

solution must not be opening large institutions. Some who support institutional living point to people's safety, but the statistics are clear: People are safer in the community and they have history of developmental disabilities in Maine.

It is critical that we learn from our history and fix the problems in our systems without repeating the mistakes of the past because we have forgotten the terrible consequences.

In honor of the 25th anniversary of the closing of Pineland, the Council will be aponsoring podcasts and events to learn the



Check our website for more information: www.maineddc.org.

Very Abridged DD History in Maine and Healthcare Timeline

Before 1908

Town Farm Roads

Attics

1908-1996

Individuals with I/DD were Institutionalized in Pineland

1908-1940s Eugenics

1960-1996 Underfunded, Terrible living conditions.

Experiences taught individuals to fear the medical model,

1996

Civil Rights Movement Closes Pineland

Anti-Medical Model / Social / Community Model

Seek healthcare from community medical professionals

Today

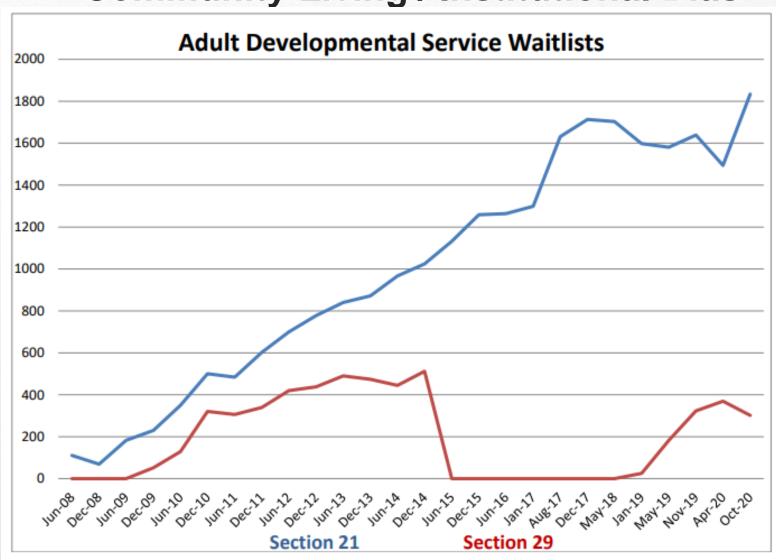
PCPs are responsible to oversee the care of individuals with I/DD and have had little to know training/preparation to do so.



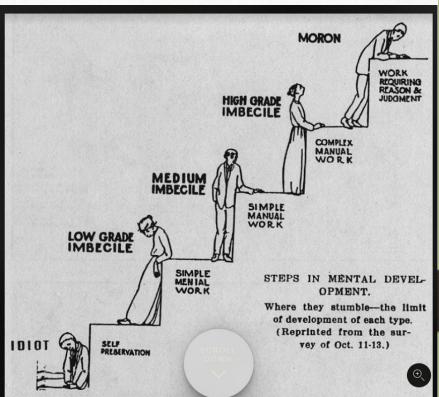
Standing up to STIFFE



Community Living / Institutional Bias









the advocacy monitor

Independent Living News & Policy from the National Council on Independent Living



The Advocacy Monitor is a project of the National Council on Independent Living, a leading crossdisability, grassroots organization run by and for people with disabilities that represents Centers for Independent Living (CILs). Statewide Independent Living Councils (SILCs), individuals with disabilities. and other organizations that advocate for the human and civil rights of people with disabilities throughout the

You are here: Home / Civil Rights & the ADA / Marriage Equality Is Still Not a Reality: Disabled People and the Right to Marry

Marriage Equality Is Still Not a Reality: Disabled People and the Right to Marry

November 14, 2019 By theadvocacymonitor - 20 Comments

By Eryn Star, NCIL Summer Policy Intern

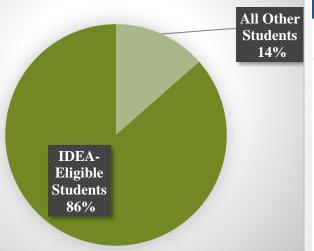
"We're done fighting for marriage equality; we have it now, so we have to focus on other issues instead!" is something I've been hearing a lot in queer spaces for the past couple of years. I understand where many people are coming from; marriage is an institution that has been used as a tool of oppression against marginalized people, and the focus on marriage equality did lead to many LGBTQ+ rights issues getting pushed aside. However, that should not be used to deny that marriage equality remains an issue in the United States for disabled people. It is necessary for us to address this because it is both a healthcare and civil rights issue.

A major reason why many disabled people are unable to marry is because of SSI and

Marriage Struggles Continue

https://shadowsofpineland.org/marriage-statutes-revised/

Maine Students Restrained or Secluded: USDOE Data 2013-2014



National Library of Medicine
National Center for Biotechnology Information

Search PMC Full-Text Archive

Journal List > Front Psychiatry > v.10; 2019 > PMC6673758

Front Psychiatry 2019; 10: 491.
Published online 2019 Jul 16. doi: 10.3389/fpsyt.2019.00491

Effects of Seclusion and Restraint in Adult Psychiatry: A Systematic Review

Marie Chieze, 1.* Samia Hurst, 2 Stefan Kaiser, 1 and Othman Sentissi 1

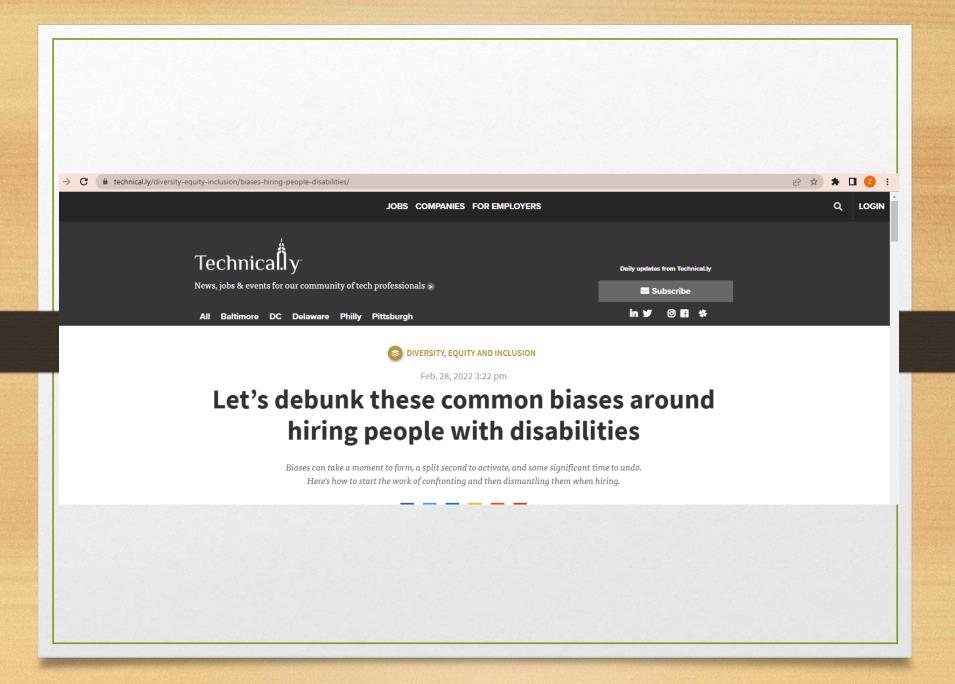
► Author information ► Article notes ► Copyright and License information <u>Disclaimer</u>

Twenty Five Years After Pineland's Closure: Striving Towards a Restraint-Free Future for All Adults with Intellectual and Developmental Disabilities in Maine

Posted on March 02, 2021

by Barrett Littlefield, Esq.

https://drme.org/resources/restraint-seclusion-in-maine-schools-reviewing-the-first-four-years-of-data-required-by-mdoe-rule-chapter-33



People with intellectual disabilities twice as likely to suffer preventable death, study finds



April 1, 2020

When Maureen McLuhan's daughter Michelle was discharged from hospital on a cool autumn night in 2009, she never imagined the 28-year-old would be dead in the family home just hours later. "[The doctor] put in her notes, on her discharge notes, that Michelle had a temper tantrum, that was more upsetting, that she wasn't sick, she had a temper tantrum, it was because she had an intellectual disability," she said.

Michelle was sick with an ear infection and was acting out of character. The young woman, who loved singing and dancing, was barely able to speak.

She was rocking back and forth on the floor of the hospital, covering her ears and screaming.

"I said, can't she stay, she needs to stay, she needs treatment, I thought the doctor would say yes, I was worried about her and it was a hospital," Maureen McLuhan said.

"Eventually the doctor passed through and said, 'oh, you are still here?', she said 'do you want security to help you out?' I just turned around and the security guards were there."

Michelle died of meningitis on May 19, 2009, after a middle ear infection spread to her brain.

https://www.abc.net.au/news/2017-02-08/study-finds-intellectually-disabled-two-times-preventable-death/8248772#:~:text=Preventable%20deaths%20twice%20average%20rate&text=Researchers%20at%20UNSW%20found%20people,compared%20to%20the%20general%20population.&text=His%20research%20also%20revealed%20people,expectancy%20of%20just%2054%20years.

Most OB-GYN practices fall short in caring for women with disabilities



Physicians' lack of knowledge and training remain significant barriers to effectively caring for women with disabilities. In a recent study that surveyed 1,000 ob-gyns on awareness, attitudes and training around the care of women with disabilities, only 17.2% of respondents reported receiving any information or training on providing care to women with this population. Therefore, providers felt incompetent regarding this population for several reasons, including, but not limited to, a lack of understanding regarding how best to communicate effectively with patients, inadequate knowledge about specific disabilities, and uncertainty about patients' decision-making capabilities. The study was published in the journal *Health Equity*.

The barriers are physical and attitudinal. Most exam rooms, for instance, are not equipped with adaptive scales or exam tables. "Some of these women have never been weighed," Mitra said. There are also less overt but equally challenging barriers, explained Mitra, like the widespread notion that women with disabilities should not and cannot be giving birth.

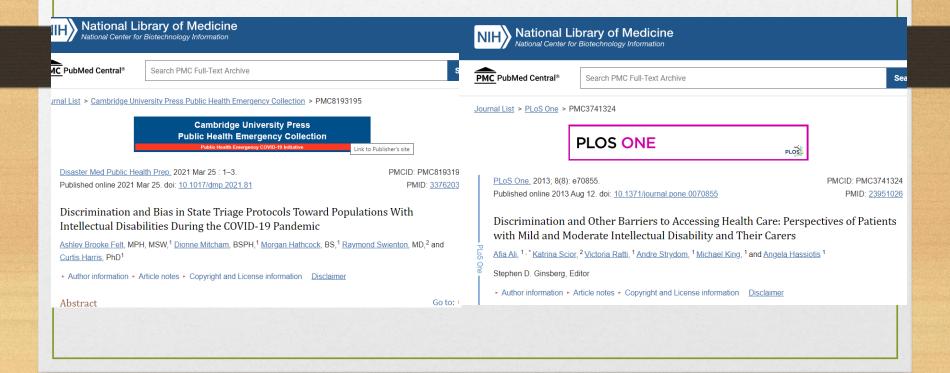
https://ctmirror.org/2019/12/15/most-ob-gvn-practices-fall-short-in-caring-for-women-with-disabilities.

HEALTH AFFAIRS FOREFRONT HEALTH EQUITY

RELATED TOPICS:

DISABILITY | MEDICAL EDUCATION | QUALITY OF LIFE | HEALTH DISPARITIES | HEALTH CARE PROVIDERS | DISABLED | ACCESS TO CARE

Misperceptions Of People With Disabilities Lead To Low-Quality Care: How Policy Makers Can Counter The Harm And Injustice



You only count...if you are counted During COVID – in Maine – People with DD were not counted / nor prioritized. We don't know how many died.

New cases by date

Cases by age trend

Case rates by county

COVID-19 data by race

Toggle race / ethnicity

Race

▼



People with Down syndrome who get COVID-19 are four times more likely to be hospitalized—and 10 times more likely to die—than the general population.

ANY AGE

https://www.maine.gov/dhhs/mecdc/infectious-disease/epi/airborne/coronavirus/data.shtml

In our survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5 percent strongly agreed that they welcomed patients with disability into their practices, and 18.1 percent strongly agreed that the health care system often treats these patients unfairly. More than thirty years after the Americans with Disabilities Act of 1990 was enacted, these findings about physicians' perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could contribute to persistent health care disparities affecting people with disability.

HealthAffairs

TOPICS

JOURNAL

BLOG

RESEARCH ARTICLE

DISABILITY

HEALTH AFFAIRS > VOL. 40, NO. 2 : VITAL DIRECTIONS, QUALITY & MORE

Physicians' Perceptions Of People With Disability

And Their Health Care

Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressalam, Dragana Bolcic-Jankovic, ... See all authors

AFFILIATIONS

PUBLISHED: FEBRUARY 2021 No Access

The right to <u>live</u> like everyone else

- Community living
- Employment
- Education
- Relationships
- Healthcare
- Right to try to better one's situation











Life in the Community Today

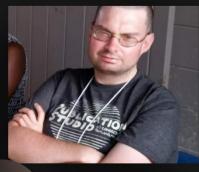
People with developmental disabilities are living fuller lives in their communities today. While our systems still have much room for improvement, the stories below show how life in the community makes for more self-determination and better choices.



Regina Bowie is an artist, musician, and self-advocate. She is a fierce fighter for her own rights and for those of others with disabilities.



Robbie Garland loves to volunteer in community and do many different a He has overcome much to be an out self-advocate for himself and others.



Philson is not afraid to speak his d stand up for the rights of all with developmental disabilities. He current Chair of the Speaking Up For Is hoard, and recently testified to help end



Sarah Trites is a poet, a board member of SUFU, and a member of the Maine Developmental Disabilities Council. When she is not working to advocate for herself and her fellow citizens with develonmental























SCROLL DOWN













Objective 2

Participants will learn the basics of developing plain language materials.

What is "Plain Language"?

From PlainLanguage.gov:

Communicate in a way your audience can understand the first time they read or hear it

The Plain Writing Act of 2010 required all federal agencies to use clear, concise, well-organized information appropriate to the subject and audience.





What is "plain language"?

- Plain language makes sure people can act on information.
- Plain language is about both the words you use and how you organize information.
- Plain language considers context and makes ideas concrete. It makes sure **your meaning is clear.**



Information can be a barrier or a bridge.

Plain language tips



- Keep sentences short.
- Give each fact or idea its own sentence.
- Use bullet points/lists whenever possible.
- Use an active, conversational tone.
- Understand your audience

More on that in a minute!

Plain language tips



- Avoid jargon and acronyms.
- Use visuals to support your meaning (remember alt tags/image descriptions!)
- Best practice: Have members of your intended audience review

Choose the simplest word

FROM

Stakeholders

Individuals

Access

Manage

Cover

Facilitate/Convene

TO

Groups

People

Get

Do

Pay for

Bring together/Lead

Medicaid Open Door Initiative

This example was created for training and is not official agency text.

× Before

The Open Door Initiative is a program based on a simple and fresh attitude: that the CMS desires to better hear and interact with those beneficiaries, providers, and other stakeholders interested in the delivery of quality healthcare for our nation's seniors and beneficiaries with disabilities. This increased emphasis on responsiveness is captured through an ongoing series of 'Open Door Forums' that provide a dialogue about both the many individual service areas and beneficiary needs within CMS.



We want to hear from you!

Help us improve our service to you.

Attend an Open Door forum near you.

For information about upcoming forums, visit cms.gov ...

Before and after

Application Due Date

This example was created for training and is not official agency text.

Before

The application must be completed by the applicant and received by the financial office by June 1st.



We must receive your application by June 1st.

Objective 3

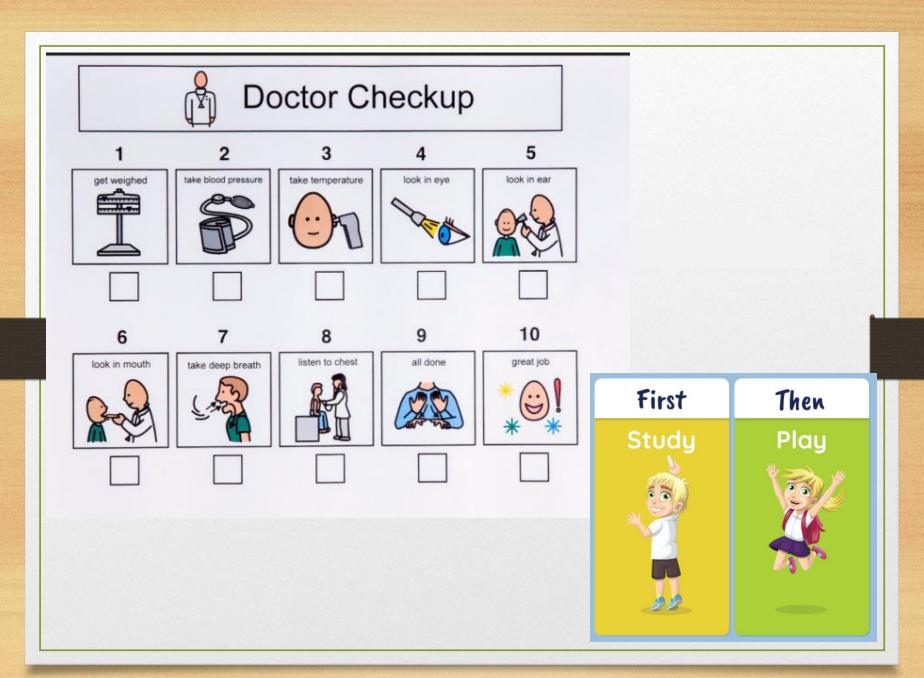
Participants will be introduced to commonly used communication strategies such as social stories and Picture Exchange Communication Systems

Communication and prediction tools.

People with limited language ability and understanding rely on familiar routines and environmental cues to understand or anticipate what will happen next.

Visual Schedules

- Useable individual should be able to manipulate schedule. Should not be just a teacher/care giver showing the pictures
- Current / Relevant to the moment If you are working on snack time that "step" is clearly shown as current
- Indicates sequence of steps: the schedule is clear that now is the time, what came before, and what will happen next





Visual Timers

Use First – Next Language
Then use visual timers





Audible Visual Timer 3-has \$29.95 Achievement...



<u>Time</u>
<u>Tracker - Visua</u>

\$27.99

AreYouGame...



Time Tracker
Mini Visual Ti...
\$19.95
One Step Ahe...



Visual Timer... \$34.95 QVC.com



Sponsored (i)

Audible Time
Timer 12-inch
\$33.95
eSpecial Nee...

www.nwresd.k12.or.us/autism/visualstrategies1.html

Picture Exchange Communication(PECS)

- Common language of many with DD. As valid as a foreign language you do not know.
- Language <u>using</u> visual cues, not just visual cues
- (1427) Pinterest

Social Stories

A visual learning tool that provides an opportunity to communicate complex items like, for example, what to expect

https://www.rchsd.org/programs-services/autism-discovery-institute/hospital-visit-tips/social-stories/

Thank you for having me Contact me anytime

Nancy Cronin, MA Executive Director

Nancy.e.cronin@maine.gov