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# IN/ISBLITY

A visual history of the journey to increase the independence, productivity, self determination, integration, and inclusion of Minnesotans with developmental disabilities and their families. The Minnesota Governor's Council on Developmental Disabilities

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## **INVISIBILITY**

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## GLIMPSES

## From the Past

Images from the Minnesota Historical Society (MHS) from the first half of the twentieth century offer glimpses into the lives of people with developmental disabilities. Most photos focus on children who elicited feelings of pity and compassion. Rarer still are those of infants and adults with developmental disabilities who may have been hidden away.

The first half of the 20th Century was focused on building state institutions in all parts of Minnesota, and the eugenics movement. This was an attempt to build a "better" human race by segregating individuals with developmental disabilities from society. In 1923 the Board of Control urged opening a new state hospital to prevent crime, vice, pauperism, and mental and physical disease, with their untold costs to the state materially, morally, and socially.

The MHS has graciously granted the Council permission to include its images for this project. The MHS retains all rights to images duplicated from the MHS collection. When known, a photo credit to the creator of the original work or the current copyright owner is provided. Photographs may have been cropped to suit design and layout. Special thanks to Jo Erbes who carefully reviewed the MHS records to find historical images of people with developmental disabilities. The material we quote contains historical phrases that are considered offensive. Much of the language has been retained to provide historical context.



Left: Classroom learning was just as much a part of life at the Gillette Hospital as physical therapy, 1905.

Below: These toddlers seemed more interested in the camera than they did in their swing on the grounds of the Gillette State Hospital for Crippled Children, 1905.



Below: Boys learned in the classroom and the work room at the Gillette State Hospital, 1905.

Right: Young girls posed in a horse-drawn carriage outside the front door of the Gillette State Hospital, 1905.

Far right: A large group of young children, using a variety of crutches and braces, stood around a swing on the grounds of the Gillette Hospital, smiling for the camera, 1905.







Families who had a child labeled "feebleminded" were stigmatized as morally bad or genetically flawed. The message given to families was to institutionalize their children or keep them out of sight.

- From Parallels in Time, Part 1, The Rise of the Institutions, 1800-1950



It is rare to see a photograph of a baby with Down Syndrome in 1925.

Below: Michael Dowling succeeded in having the first bill passed providing state aid for children with disabilities in 1919. This photo shows a girl using a wheelchair at the Dowling School in 1925.

Right: The Mayor of Minneapolis, Wallace G. Nye, gave a child a lift, 1915.

Far right: Prize-winning basketry at the Minnesota State Fair, St. Paul fairgrounds, 1926.







Right: The flag was raised at the opening ceremony of the Lindsay School for Crippled Children in St. Paul, 1931.

Below: Christmas was the perfect time to host a tea party at the Gillette State Hospital for Crippled Children, 1930.

Bottom right: Students celebrated the 6th anniversary of the Mary Helen Lindsay School, 1937.

Far right: Boys and girls stayed busy with activities at the Shriners Hospital, 1938.









Below: Students from Dowling School awaited the arrival of President Franklin Delano Roosevelt. FDR was paralyzed by polio in 1921, and privately used a wheelchair he had designed himself, 1940. Far right: Four students using wheelchairs at Mechanic Arts High School, St. Paul. Students were identified as Joe Hill, Bernadette Reich, Margaret Smack, and Gene St. Martin, 1949.







Esther Bjerre Bowles, dance instructor, teaches ballet to a class of youngsters with disabilities in Shakopee, Minn. The children, whose IQs range below 50, are responsive to music, 1956.

We can no longer speak with scientific reverence of the [child with an intellectual disability] as being inherently delinquent or immoral or capable of diluting the general intelligence level of our population through an ascribed abundance of procreative abilities. Nor can we in truth regard them all as hopeless and helpless creatures incapable of positive social adaptations and unable to make useful, though perhaps modest, productive contributions to the community.

– Howard Kelman, social worker, 1958

Below: From *Star*, "Help for Ronnie," Nov. 23, 1957. Ronnie is one of the children who is now able to participate in an expanded program for individuals with developmental disabilities. Last summer Ronnie Lawrence attended the day camp at Glen Lake. Back home helping his mother, becoming a useful member of the family. Photo by Larry Schreiber.



Below: Aide Sue Becker talked about sizes of clothes, how to put them on and fold them neatly, 1958.





Boys and girls with cerebral palsy were entertained at a party in the Cerebral Palsy center by high-school kids. David Hawley, 14, and Robert Pihl, 14, of the Hi-Fi's, provided some rock 'n roll while Judy Schaub and Steve Stevens, 18, danced for the amusement of the youngsters, who did not often get out to many social functions for their age group, 1958.



## Brought to Light

Throughout the 1960s and 1970s, participants in the Parent Movement collectively fought for legislative changes, initiated critical court challenges, worked with the media on exposés about poor living conditions for people with disabilities, pressed for their children's educational rights, and sought access to vocational training for them.

The two major cases in Minnesota were the *Welsch* case from 1972 to 1989 and the *Jensen* lawsuit from 2009 to 2020.

The *Welsch* case alleged that conditions in the institutions violated the constitutional rights of residents under the Eighth and Fourteenth Amendments to the U.S. Constitution. In February 1974, the court

held that people with intellectual disabilities have a constitutional right to treatment in the least restrictive environment. There are trial exhibit photos from both 1973 and 1980.

The *Jensen* lawsuit was filed in the U.S. District Court for the District of Minnesota alleging that the former Minnesota Extended Treatment Options (METO) program used restraint and seclusion in a way that violated residents' constitutional rights. These rights include the Eighth Amendment (to be free from cruel and unusual punishment), under the Fourteenth Amendment (under the Due Process Clause), as well as their rights under federal and state statutes, including the Americans with Disabilities Act and Section 504 of the Federal Rehabilitation Act.

In 1962, members of President Kennedy's Panel traveled to Denmark to view residential services. Denmark had enacted a national law about normalization in 1959. The director, Niels Erik Bank-Mikkelsen showed the American experts a residential setting and the windows were open. The Americans were startled and asked, **"Aren't you afraid the people will leave through the windows if they are opened and not locked?"** Bank-Mikkelsen replied, "No, our residents prefer to leave by the front door."

President's Panel, 1962, as told by Rosemary Dybwad



From A Major Minnesota Problem, 1965. Photos by Earl Seubert, Minneapolis Tribune. Young boys with nothing to do, Iolling in chairs.





From A Major Minnesota Problem, 1965. Photos by Earl Seubert, Minneapolis Tribune. Far left: Lack of programming and treatment cause patients to regress; left: Confined in isolation for months; and below: The unhappy figure of a girl in soiled clothing sitting on a bare floor.



The black, the poor, women, [people with intellectual disabilities] and their families are knit together in this tradition of lawsuits not merely by historical accident but by social fact. These citizens share common experience, and a perspective and their resort to the courts is in significant part a result of the similar position each of them occupies in society. Society's response is grounded in the judgment that "they are inferior, and we are superior" ... The person subject to the judgment that they are inferior comes to believe it and internalize it, from which flows feelings of guilt, shame, timidity in action and unusual selfdenying acquiescence to authority.

- Tom Gilhool, plaintiff counsel, described the Pennsylvania class action lawsuit that began on January 7, 1971 with twelve individuals with [intellectual disabilities] claiming they had an equal right to a free public education. From September 1971 Conference Proceedings sponsored by the U. S. Department of Health, Education and Welfare at the Belmont Conference Center in Elkridge Maryland.

Exhibits at the *Welsch* Trial, 1973. In 1972 Richard Welsch sought help from the Legal Aid Society of Minneapolis for his daughter, Patricia Marie, a resident of Cambridge State Hospital. On August 30, 1972, with the support of The Arc Minnesota, they sued state officials charging that the residents at Cambridge, Faribault, and four other state institutions were denied their rights to habilitation and to live in less restrictive community settings.

Below: Man with cut on eye, Cottage 3; top right: Bathroom, Cottage 8; and bottom right: Girl with a bloody nose, Cottage 12.











Exhibits at the *Welsch* Trial, 1973.

Boswell Hall: top left: Man being fed; bottom left: Contractured legs; bottom right: Crib enclosures.


How old were you when you went into Faribault? Five years old. Do you remember what that was like? No, I just hated it, just a hell. We were hit with sticks, dunked in cold water, stretched, guys could not talk with girls, girls couldn't talk with guys, you couldn't have contact with each other. Daylight was in your own building or maintenance if you worked around, they get paid. But there was lousy pay, two cents a day. Two cents a day. We did the work; employees sat around and look at what they were getting.

– John Johnson, Minnesota, 1978



John, restrained to a wheelchair, Brainerd State Hospital, 1980.

John was 30 years old in February 1980 and he lives with 15 other men. The staff ratio is 2 staff for 16 men. He has lived at the state hospital for 13 years. John has developed behavior problems and is both selfinjurious and aggressive. He is not physically [disabled]; he can walk. But each morning, cuffs are put around his ankles and are attached to a wheelchair. Cuffs are also put around his wrists, and these are attached to the wheelchair. When he goes to bed each night he is also restrained. The hospital keeps detailed records on the time he spends in restraints. For 22 hours he is restrained hand and foot. He has not, according to the data, spent more than 10 consecutive minutes out of restraints. His school program includes gross motor development and fine motor skills but it is difficult for a person to develop any skills when he is restrained to a wheelchair.

<sup>–</sup> Michael R. Fargione, plaintiff's attorney, Welsch v. Noot, May 5, 1980

There's a man at Brainerd State Hospital named Dennis. He was 29 years old in February 1980. He has been living at Brainerd for the past 18 years. He is in a residential area with 15 other residents. The staffing pattern during the day is routinely sufficient to meet a 1:8 ratio.

Dennis has developed self-injurious behaviors. Part of his approved program to deal with the behavior requires that his right hand be put in a paddle cuff and be pulled back around his left side. A similar thing is done to his left hand. Then his hands are fastened.

When witnesses have observed him in these restraints, he is generally sitting on the floor. Folded in half. His head is resting on his ankles.

On Tuesday, March 25, 1980, he was bound like this 22 times. He spent 5  $\frac{1}{2}$  hours that day in restraint. That was his best day in March. His worst day was on a Monday when he was bound for more than 12 hours. The average for March 1980, was 8 hours and 50 minutes a day in restraints.

Dennis has a scheduled school program operated by the Brainerd State Hospital. But it contains primarily things which occur in large groups: a movie, a bus ride, a popcorn party each Monday, Tuesday, and often on Friday. The activities are scheduled for groups of 35 or more from his building. He does have a smaller classroom activity scheduled for Thursday; but he was absent from that class 3 out of 4 times in March.

<sup>–</sup> Michael R. Fargione, plaintiff's attorney, Welsch v. Noot, May 5, 1980



Dennis S., Brainerd State Hospital, 1980.

Photos submitted from the Faribault State Hospital, 1980.



Four point restraint chair in SLP Household II.



North side of living room area for 8 females.



Household for 11 males in Holly Building.



Time out restraint room West Cottage.



Bathroom in Fern Building.



Work Activity Center in Rose Building.



Richard Welsch and his daughter, Patricia, at the residence where she lived in Brooklyn Park, 1989. Photo by Regene Radniecki.

Residents' records at the Minnesota Extended Treatment Options (METO) facility indicated that mechanical restraints were used in response to what the staff termed "aggressive behavior," including such actions as touching a staff member's shoulder, touching a pizza box held by staff and talking about running away.

– Just Plain Wrong, Minnesota Ombudsman for Mental Health and Developmental Disabilities, 2008



Jim Jensen with his son, Bradley. Photo courtesty of Lorie Jensen.

Well, Judge, this case moves in mysterious ways and it is through the tireless exertions and passions of everyone. So, there are families here today, Your Honor, that struggle in quiet solitude, with pride and compassion in their own lives that deal with these issues. There are thousands of people that work in our State Government, in our Federal Government, and in our local agencies, who have provided justice by choosing a career that highlights the care and treatment of people with developmental disabilities.

It is important to recognize that it is just not on one side of the aisle, it is on all sides of the aisle that justice is done. And with people who have tirelessly worked on these issues for years upon whose shoulders we stand today that brings us to an agreement that I think is unprecedented that will benefit hundreds of thousands of people in this state.

<sup>-</sup> Shamus O'Meara, plaintiff counsel, at a Fairness Hearing presided over by Judge Frank to approve the *Jensen* Settlement Agreement, December 1, 2011

The termination of the Court's jurisdiction over the Jensen Settlement Agreement should in no way imply that the Court feels that justice has been served. At some point, the purpose of the Agreement was lost... at the expense of making meaningful lasting improvements in the lives of people with disabilities.

– Senior United States District Judge Donovan W. Frank (Doc. 879, p.15) September 4, 2020

## EDUCATION

## Training to Learning

Students with developmental disabilities were systematically excluded from education during most of the 20th Century. When students began being included in school, enrollment expectations were low. In 1965 teachers were directed to focus on fine motor skills such as using scissors, crayons, forks, and spoons. Teachers were told that the paper punch and stapler were favorite skill builders. An educator noted, "It was nothing to go through 5000 staples a month because it was cheap and the child could learn how just the right amount of pressure on the stapler would do the job." There was little academic work except recognizing names and words such as exit, stop and go.

Since the mid 1960s, educational practices have advanced from fine motor skills to full access to the general education curriculum. According to Patrick Schwarz, an educational consultant, "Inclusive education means everyone belongs everywhere in our school community and the community beyond. Curricular design means meeting the needs of all students."

## Those who are trainable and sub-trainables (IQs

**below 50)**: Cannot manage their lives with ordinary prudence; Cannot enjoy ordinary social interaction in the normal world; Cannot take responsibility for financial aspects of their lives; Cannot compete with satisfaction to themselves in any area of normal living; and require considerable protection by family or family substitutes ... through protected community facilities or through institutional facilities.

Sheltering Arms Training Program Lecture Series, carried out under a contract with the U.S.
Public Health Service, presented to 39 trainees, 1964–1965



Metro Work Center, 1965.



From Let A Thousand Flowers Bloom, 1976.









Far left: Children with developmental disabilities at school. Mrs. Rita Grismer, their teacher, is at center. Photo by Dwight Miller, 1963.

This page: Integrated classrooms. Photos by Ann Marsden, 1990s.









Left, above and top right: Photos by Ann Marsden, 1990s.

Bottom right: Early Special Education, 1989. Photo courtesy of Hank Bersani.





Enjoying college experiences. Photos courtesy of Bethel University BUILD Program, 2021. Photos above and below right by Scott Streble.





There is an unmet need for students with intellectual and developmental disabilities to have access to inclusive postsecondary education options in Minnesota. Expanding postsecondary education options for students with intellectual and developmental disabilities creates a pathway to meaningful credentials, competitive integrated employment and independent living with appropriate supports and services. Students with intellectual and developmental disabilities who attend college are twice as likely to be employed, earn \$400 more per month than a peer who did not attend college, rely less on Supplemental Security Income (SSI) and achieve a higher level of independent living. Students with intellectual and developmental disabilities who attend postsecondary education are prepared to enter the workforce and talent pool to meet the needs of businesses in Minnesota and contribute to statewide economic growth.

<sup>–</sup> The Minnesota Inclusive Higher Education Consortium (MIHEC) statement, December 2020

# POSTONS

## Employment

In the 1950s and 1960s parents grew increasingly frustrated with the slow development of services in local communities as an alternative to state institutions. Unwilling to wait any longer, these parents came up with their own idea for creating services and began developing day programs. These programs, as noted in a 1967 publication by The Arc Minnesota, provided "care, training and stimulation of people with developmental disabilities for whom there are no public school classes or other facilities available because of age, mental ability, or behavioral traits. The primary care rests with parents." The images in this section show how work and employment have changed from the 1950s through today—from the early day programs and sheltered workshops, to job sharing and work crews, to meaningful employment in the competitive workforce. Businesses now recognize the talents and skills of employees with developmental disabilities. Employment means individuals with developmental disabilities will have greater economic self-sufficiency, an opportunity to use their skills, and more actively participate in community life. Below and right: The Opportunity Workshop, in a Richfield, MN home. People with developmental disabilities were given the opportunity to learn piecework, such as folding popcorn boxes (right), yard care (below), and woodworking, "and be helped to step out into the world of industry if they are capable," as reported in the *Star* article, "New Life for Individuals with Developmental Disabilities – They'll learn work like this at Opportunity Workshop," June 3, 1953.





We live not only our own lives but, whether we know it or not, also the life of our time.

– Laurens van der Post, 1976

Below and far right: Metro Work Center, 1960s. Far right: Trimming surplus wax from a candle was Dennis Acker, who works for the Opportunity Workshop. The workshop is one of 12 sheltered workshops in the country selected to manufacture the John F. Kennedy "Flame of Hope" candle. Photo by Jack Geilese, 1966.



Balloon and string craft.



Frustration.



Basketry.



In the woodworking room.



Braiding.



Rug weaving.









Far left and this page, photos from A New Way of Thinking, by Ann Marsden, 1987.



Person centered planning means to have dreams, big dreams, and to keep your dreams. To achieve your dreams. You could have a dream all the way up to going to college if you haven't gone to college. You can get your own driver's license. You can run your own meetings. You can have friends over. You can go out to the movies. You can dance. You can have parties. You can be with your family, with your friends. It means to take charge of what you want in your life and dream big.

– Mary Raasch, Minnesota, 2011



Man working in a dairy barn. Photo by Ann Marsden, 1987.





Photos by Ann Marsden, 2000s.








Top and bottom left: Photos by Ann Marsden, 2000s. Top right: Bradley Olson, 2008; bottom right: Digital Imaging, photo by Sherie Wallace, 2009.







Kristen, MSP International Airport, 2014.



Nathan, Menards pianist, 2017.



Mark, Sun Ray Lanes Bowling Alley, 2015.



Candace, Urban Air Adventure Park, 2018.



Jim, Cub Foods, 2016.



Precious, Red Lobster, 2019.

Inclusion in the community is my biggest goal, because everybody should be able to have a job and live where they want to live in the community.

– Lea-Sue Sandberg, Minnesota, 2018



## Champions of Rights

For the richest, most diverse account of human experience, history must include evidence of everyday accounts of life rather than a simple timeline of events.

Enacting change is hard—and often uncomfortable work. Challenges to the status quo of how people with developmental disabilities have been treated takes many forms, with each voice adding strength to a message. Bernard Carabello, an early founder of selfadvocacy in New York State, declared in the 1980s, "I believe people with disabilities have a right to speak out. Have a right to have a voice. They have the right to say what's on their mind. Even if you and I do not agree with what they have to say, they have the right to say it. I want you to hear what I have to say and what I have to contribute to this conversation."

At the 1995 Fourth World Conference on Women, one speaker with a disability declared, "A disability can be endured but the lack of human rights, the deprivation of equal opportunities and the institutional discrimination cannot be endured and should not be tolerated." *Tribune,* Sept. 29 1972. "Working: 110 Outreach Clients. Five clients participate in a Panel Discussion." Photos by Pete Hohn.



Gloria Gunderson, 28, works in the sewing room of the United Cerebral Palsy workshop in Minneapolis. She says, "People with disabilities will have hang-ups when they get married, but I want to marry Larry," (a young man with disabilities whom she met at Outreach). "Normal people have more hang-ups," she continues, "but I don't have any statistics to back that up."



Cliff Poetz, 23, is not ashamed to say he is "MR," although he detests the word. And he is not too modest to say he is doing all right for himself. He is working at a "pretty good job," earning money (30 cents an hour), living in his own apartment, cooking his meals and serving on the board of directors of a state organization concerned with people who have disabilities.



Carol Robinson, 27, strips down computers at a sheltered workshop: "I tell people I'm not really that bad (badly disabled). I tell them. But I don't know if they believe me."

They told me they could only pay me eighty-eight cents per hour. They said they were a rehabilitation facility, and that they were training me to do what I would do in a factory job. I told them I didn't want a factory job. In eleven years, they didn't teach me anything. I told them to go to hell and quit the workshop. I started devoting my time to Advocating Change Together (ACT), a self-advocacy group I helped found. Since that time, I think supported employment has made things better, but there are still people being trained for jobs they don't want. Who is this helping? We need to work on changing attitudes and telling people about our abilities. We need to make our own decisions.

Gloria (Gunderson) Steinbring, founding member of ACT, Minnesota, 1979





Far left: Capitol Crawl, Washington D.C., courtesy of the Tom Olin Collection, March 12, 1990. Above: Partners in Policymaking, 2001.



Photos from Partners in Policymaking, a leadership training program for parents of young children with disabilities and adults with disabilities. Created in 1987 by the Minnesota Governor's Council on Developmental Disabilities, the program teaches leadership skills and the process of developing positive partnerships with elected officials and other policymakers.









Partners graduates.







It's important to be your own advocate because you never know when you're going to need to use your own voice. It's your voice that is telling your story, and you are the best narrator for that particular story.

– Margaret Weiss, Minnesota, 2018

## Right: Justin Smith fist bumps David Durenberger, 2017

Below: Robins Kaplan Disability Justice Seminar, 2011. Faculty members, left to right: Shamus O'Meara, Chris Messerly, Tiffany Sanders, Karen Loven, Jim Backstrom, and US District Court Judge Donovan Frank.

Far right: The 2012 National SABE Conference held in St. Paul, Minnesota. Photos courtesy of Tom Olin, National Disability Rights Photographer.













I was involved with the Modernization of Language bill, and it got rid of the 'R' word from Minnesota Statutes. I spoke at the introduction, and I testified at all four of the committee hearings, two in the Senate, two in the House, and I even showed up for a Senate floor session and a House floor session to show my support for the bill. I was at the White House on October 8, 2010, for the celebration, the enactment of Rose's Law. It got rid of the 'R' word from federal laws so it will say "intellectual disabilities" instead of "MR."

– Roberta Blomster, Minnesota, 2011



Ambassadors for Respect presents to fourth graders at Otter Lake Elementary School, 2019.





Ambassadors for Respect at, left, Little Canada Elementary School, 2015, and at right, Webster Elementary School, 2020.

I want to be treated equally. I want to be treated with respect, with dignity. I don't want anybody to make me feel bad and ... Don't judge who I am.

– Brian Jensen, Minnesota, 2011

# VIBRANCY

# Community Living

In the 1980s, Ed Roberts, founder of the Independent Living Movement, advised "In order to change old attitudes, we have got to get out into society. We have got to be seen. We have got to be neighbors. We have got to be friends. We have got to be seen in a very natural way."

The time has arrived when people with developmental disabilities should be able to make decisions about where they live.

As Justin Smith, Minnesota Partners in Policymaking graduate and disability advocate, told an audience at the Capitol reopening in August 2017, "I imagine a future for myself as one where I choose where I want to live, who I want to hang out with, what I will do each day and how I contribute to making the world a better place, the decisions that many of you take for granted. It takes every one of us to choose the infinite possibility to create a more inclusive society where we see value and dignity in all people."



From Let A Thousand Flowers Bloom, 1978.





Top: from Let A Thousand Flowers Bloom, 1978. Bottom left and right: by Ann Marsden, 1987 and 1993, respectively.





Left and right: Families, by Ann Marsden, 1991.



Dancing boy by Ann Marsden, 1997.

Your story matters, your voice matters, you may just be one voice, but that one voice has the propensity to change everything. You never know who your story is going to impact, and who they know, and what they're going to change, and that if you just sit quietly and you don't ever speak up, and you don't ever tell anyone your story, or what you want to happen, you're taking something valuable from the world that you have to offer. Self-advocates, we have the chance to direct our history and create the path of where we want our community to go.

<sup>-</sup> Jillian Nelson, Minnesota, 2017 on the reopening of the State Capitol



Photos by Ann Marsden for *Stories of Leadership*, 2002. Top left: Jo Ann Bokovoy and her son, Brad; bottom left: Sharron Hardy; and right: Richard Mathison and his mom.



Photos by Ann Marsden for *Stories of Leadership*, 2002. Top left: Tom Schwarz and his son, Nick; bottom left: Sharyl Downwind and her sons; and right: Karen Gorr.

You really must advocate very hard and in some ways protest and **really** have to do a lot to wake **up others** in the State of Minnesota and across the country.

– Reid Scheller, Minnesota, 2018

People with disabilities have made huge contributions to our communities, and just deserve the right, with the amount of support that they need, to continue to do so. So, we are proof of what can happen with diligence and persistence, that independent living can be a reality for anybody that wants it, and I do not want to see that lost for anyone that is currently doing it or anyone that's younger than I am and coming up in the future.

– Jason Blomquist, Minnesota, 2018



Dupree Edwards, a Council member and Partners in Policymaking graduate, was recognized as a Census Hero. His image was featured on a poster encouraging people to participate in the 2020 Census. Photo by Stephanie Rau. Lost lives Lost rights The Pandemic Lost education Lost work Lost relationships

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