# Recollections
## of the
# Institution

## Parents' Perspectives
## STUDY GUIDE

# Introduction

*Recollections of the Institution: Parent's Reflections* documentary presents the stark realities of past institutional treatment of people with disabilities and points to the hope and benefits of inclusive community living today.

Focusing on the experiences and views of parents who placed their child in the institution, what makes this documentary so compelling is that it is almost entirely presented in the words of the parents.  In their own words and voices they tell of their experiences, the isolation and the lack of supports that forced them to the institution and the untold pain.  Sometimes in shocking detail, examples of abuse and neglect, which were all too often absent from the "official records" are described.  These records avoid the prosaic and obfuscated acknowledgements of abuse that was often part of daily life. The parents tell of their experiences with a directness and veracity that commands attention and provides a powerful imperative for community inclusion.

The purpose of this video and study guide is to educate people concerned about individuals with disabilities. This documentary is dedicated to individuals with disabilities, their families, staff, future staff, community leaders and all who care about an inclusive community which will support and benefit all of its' members.

Those interviewed in this video are from New York.  Their experiences, however, are representative of institutional experiences across the country.  There are of course, individual differences; however, it is the depersonalization and dehumanization that is the common thread and was fundamental in forming the basis for the conditions that prevailed.

The reflections of the parents whose children lived in the institutions provide an important perspective without which we would only have the side of the history preserved in the "official record" of the institutions.  The parents provide another view which must be considered along with the first hand reports of their children, the annual reports and other preserved archives of each institution.

Times have changed and the services have evolved. Institutional placement, once the dominant means of societal care for people with disabilities, is dwindling.  Yet, there are still those who would argue that people with disabilities should be with "their own kind", that inclusion is not good for people with disabilities or the general public.

These people seek to ignore or minimize the past.  Recognition and acknowledgement of the negative effects of institutionalization is an important safeguard to preventing a return to those antiquated models and ideas responsible for creating the institution in the beginning.  Parents of those who were caught in that system provide a unique perspective, different from their relatives but as direct and compelling of our attention.

If it is true that those who don't know their history are doomed to repeat it, then surely we must never forget what occurred in these institutions. This video is an effort to preserve this aspect of the history as the participants experienced it.

# The Rise and Demise of the Institutional Era in the United States

Institutions for persons with intellectual disabilities emerged in the United States in the mid 19th century. Compassion and optimism were driving sentiments for the creation of the institutions. Following on the heals of the successful efforts to educate those who were blind and those who were deaf, these new humanitarian efforts focused on that group of individuals who were too often seen in jails and alms houses where it was not uncommon for them to be taken advantage of by other inmates. These people were not considered able to be effectively helped in those settings and indeed, many were harmed.

Initial efforts were aimed at eliminating the abuse of individuals with intellectual limitations and to provide training permitting them to become productive members of society as was happening in the new schools for the blind and deaf. First in Massachusetts, then in New York and gradually across the nation, institutions were created to address their educational needs.

Almost immediately, a conflict arose between the educational needs of " higher functioning" individuals and those with more significant intellectual and other impairments who were deemed "uneducable" and in need of custodial help. Some institutions refused those with custodial needs but eventually most ended up attempting both education and provide custodial care. Sadly, the result of too little education **and** poor care was repeated from institution to institution across the nation.

The numbers of institutions and the institutions themselves grew during the difficult times of the Civil War and its' aftermath. Severe economic conditions, at that time, in the country had a tremendous effect. As more and more demands were placed on serving more inmates with less public support, conditions grew desperate.

Models of institution design and management emphasized self-sufficiency.  More capable inmates were forced to care for those unable to care for themselves. Too few direct care staff, too few professional staff and insufficient public funding created a rapidly deteriorating environment.  Frequently, farms were established as part of the institution to reduce the cost of food and also provide training for the inmates. Unfortunately even these measures all too often resulted in drawing from the few existing resources available to provide care, thus further worsening an already bad situation.

Fear and rejection gradually replaced compassion as sentiments towards those with intellectual disabilities.  By the end of the 19th century, people with intellectual disabilities came to be viewed as a threat to the health and vitality of society.  The *Eugenics Alarm* sounded dire warnings that the cause of intellectual disabilities was "weak genes" and those genes could be spread throughout the general population and the result would be an entire country of inferior citizens.

Families were suspect, as it was believed that people with these weak genes had more children than others. Hence if unchecked they would overpopulate the country. To make matters worse, these weak genes were also considered to be responsible for other social ills such as drug and alcohol addiction, prostitution, criminal behavior and poverty itself.

The solution to the threat posed was one of prevention of propagation by segregation, sterilization or both.  From the original goal of protection of people with disabilities from mistreatment and abuse, the institutions role evolved to one of protection of society from the threat purportedly posed by the "feebleminded": from that of benevolent protector to incarcerator and jailor.   As institutional placement grew, involuntary sterilization of persons with intellectual disabilities was practiced in many states. Tens of thousands of

people with disabilities, in the United States alone, would be sterilized from the 1920's to 1970.

In 1931, Justice Oliver Wendel Holmes, stated in Buck vs. Bell, that "three generations of feebleminded is enough". His words reflected the bias of the times and were supported by the dominant thinking of the scientific community. Studies of the *Kallikak Family* and the *Jukes* were greeted world-wide as definitive proof of the genetic basis of intellectual disabilities and of many social ills. These pseudoscientific classics demonstrate the power of self-fulfilling prophesies.

Today we view these works and readily see the inadequacies of the research that was so widely accepted at that time. Some the same research and the work of some of the same scientists formed the basis for the eugenics program that came to being in Nazi Germany and led directly to the Holocaust.

Even as institutions continued to grow throughout the mid 20th century, parents of individuals with disabilities joined together to create their own supports for their children and then to advocate for just and equitable treatment for their children.

Emboldened by the civil rights movement of the 1950's efforts were made to extend the same rights to people with disabilities. In many ways the Civil Rights movement formed the beginning of the end of the 'Institutional Era'. Parents, told their children would be 'better off with their own kind', now could see the evidence that it was simply not the truth. Increasingly, throughout the 1960's and 70's public exposes´ of the abused and inhumane conditions of the institutions begin to capture the public's attention.

It was during this time that the individuals featured in this video placed their relative in the institution. With little support available in the community, families in need of help all too often had the

institution as their only option.  Many were encouraged to place their child for his or her 'own good' as well as the welfare of the rest of the family.  A vast array of special services was usually promised. Yet the reality was quite the opposite. The therapeutic needs of those children placed in institutions greatly outnumbered the trained staff that was available for them. The result was the special needs of those children were unmet and parents were not informed of the poor conditions or lack of services.

Eventually, parents began to advocate for supports allowing their children to stay at home with them and be treated like all children.  In successful lawsuits, the rights of children to a free public education regardless of level of intellectual functioning were upheld.  Legislation was passed ensuring available funding and the equitable treatment of individuals with disabilities.

By the 1970's institutions for persons with intellectual disabilities housed over 250,000 people.  As community supports and options increased, people with disabilities began to have alternatives to the institution and admissions to institutions began to slow.  At the same time increased demands for the release and deinstitutionalization of those already placed were being heard.

Both judicial and legislative efforts created community alternatives for those institutionalized in the past.  Institutions rapidly reduced in numbers and size. With few admissions and with greatly expanded community opportunities, the institution alternative has not been frequently chosen. By 2005 the number of individuals remaining in institutions was 30,000.  Several states have no institutional services at all.

A wide array of supports and services abound to assist people so they can have their needs met right in their own community.  Group homes are only one type of support.  No one type of support meets all needs. Rather, the focus is on crafting individualized supports

most effective in addressing the unique needs and aspirations of both the person with a disability and their family.  When well done, these supports are most satisfying for the individual as well as cost effective. This is a winning combination. These are the arrangements that are emerging as the best means to respond to the needs of persons with disabilities. The institutional era appears to be near its' end.

Yet, there are still some who view these changes as undesirable, who see the presence of people with intellectual disabilities in the mainstream of community life as inappropriate and in fact destructive for either people with disabilities or society or both.  In different words but with the same idea, they believe these people are genetically inferior and represent a threat. And yet others seek to overprotect people with disabilities from potential harm. They do not accept that there is dignity in risk.  To be a member of a community is to risk disappointment and failure, but failure to make the effort results in disappointment and lost dreams every time.

To realize one's hopes, dreams and aspirations, you must risk failure, as the alternative is always the greater loss.  People with disabilities simply want the same chance as everyone else.

# Suggestions for Planning Effective Group Discussions

Group discussion of a topic is not always easy.   If you are not a trained or experienced presenter, you may find the following suggestions helpful in planning and in facilitating a group discussion.

1.  **Clarify your goals for the discussion**
    In addition to your own goals you should consider the existing knowledge and experience participants have with the issue. For example, with a group of church members with very little knowledge or experience with people with disabilities, the goals should be to increase their sensitivity and awareness of the capabilities and rights of people with disabilities. This is a great opportunity to dispel many of the negative stereotypes of disabilities.  When addressing a group of teachers or administrators who have some basic knowledge of people with disabilities, a different goal may be appropriate.  Here, the goal might be to increase awareness of the impact of expectations, or lack thereof, on individuals, in this case those with disabilities and in supporting actions to include people with disabilities in community activities.

2.  **Insure the program & facilities facilitate participation of people with disabilities**
    Make sure that the building and the rooms used are accessible to wheelchairs. Nothing is more embarrassing than to have a program whose purpose is to advance the community participation of people with disabilities and to find that a person with disabilities can't access it. Physical access is not the only concern. Preparations should also include the availability of someone to support an attendee who is blind or sign language interpretation for attendees with a hearing impairment.

3. **Arrange for local partners or discussants**
   It is always beneficial to have the active participation and support of local experts or other local leaders. One good resource for this might be to invite someone who is active with a local self-advocacy organization. There are also parent organizations and service organizations whose staff or members may be resources for help. They might function as small group discussion leaders/facilitators or as speakers after the video is presented to inform the audience of the current state of services and supports in the area.

4. **Provide a table for the display of pamphlets and other public information**
   A vast array of informational pamphlets both locally produced and nationally produced are available from many sources. This kind of information that participants can take home with them can provide an excellent means for directing someone to additional information.  National and state agencies often provides this free of charge or for a small fee.

5. **Become as knowledgeable as possible on the topic**
   You don't have to be an expert but knowledge of the issues and the current status is important. If time permits, the resources listed in the Suggested Reading sections are excellent background sources.

6. **Examine your own attitudes about disabilities and community participation**
   We are all a product of our environment and experience. Many of us grew up in environments where there were no people with disabilities. We went to school where people with disabilities were excluded.  Seek out help to get information and become aware of the local resources which can help you learn more of the potential and possibilities of full community participation for people with disabilities.

7. **Examine the nuts and bolts!**

   Will the room fit the participants?  Is it too small? Is it too large?  A group of 10 participants can be a very workable group but if it is in an auditorium which can hold 500, it may seem disappointingly tiny.

   - Make sure restrooms are available and accessible, for the group.

   - If the group size is more than 20 a 24" TV monitor will not suffice. Either additional monitors or some kind of projection system should be considered.

   - Do you need break out room for small group discussions after the video?

   - Do you need a flipchart or blackboard for the small group discussions?

   - Will you provide a sign-up sheet including addresses and phone numbers? (This may be most helpful if future activities are anticipated.)

# Managing Effective Group Discussions

There is no one way of working with groups. There are many successful approaches and we all have our own preferences. Yet there are some suggestions that can help the inexperienced discussion group leader.

1. **Introductions**

   First things first. If the group is small a go-around for introductions is possible. Each person can introduce themselves and state their interest in the topic. The facilitator, resource people and other helpers should all be introduced. If the group is large and of varied background, this is more difficult. One way of introduction can be to openly ask some informative and amusing questions that only require a show of hands.

   - How many of you have been involved with people with disabilities?

   - How many of you have no exposure to these issues?

   - How many of you were forced to come here?

2. **Clearly state the goals of the meeting**

   Make sure people share the same expectations. The goal needs to be appropriate to the awareness of the participants.

3. **Encourage participant expression**

   Be ready to reinforce and reward group participation. Even negative and prejudicial views should not be cut off or demeaned. Let the group itself handle the wayward comment.

   A negative or demeaning response from the group leader can discourage comments from the rest of the group. It is important to correct misimpressions, but it should be done in a way that still values the contribution of all members. Give the person

the benefit of the doubt. Don't assume you know all about what the individual means. Ask them to explain and elaborate. Fully explore their point of view and you will often find other members actively participating.

If the members don't feel that you are fully listening to what they are saying, they will stop contributing and the discussion will end.

4. **Pull the discussion together and provide for a discussion wrap-up**
   The facilitator's role is to organize the discussion and to summarize it. This can be done in many ways. A verbal summary can be provided or a printed summary can be created. If there are next steps planned, now is the time to articulate them and to establish expectations for future activities.

# Reactions to the Video
## Suggested steps and discussion points

Prior to the video, ask the participants to write down two statements about individuals who lived in institutions for people with intellectual disabilities.

a)  People who lived in institutions for individuals with intellectual disabilities were placed there because . . . and

b)  leaving the institution to live in the community has these benefits.

Show the video.

After the video, if you have a larger group, you may want to divide into smaller groups.  Either way, give a few minutes to allow the participants to absorb and reflect on their feelings and reactions.

After a few moments you can stimulate group discussion by asking the following or related questions. Remember, the intent is to stimulate group discussion. You don't want to force the questions to stop discussion. They are meant as a guide and support.

- What kinds of feelings did this video evoke in you? (Place the answers on the blackboard/flip chart)

- What did you learn from this that was new to you?

- What has changed since the parents institutionalized their children? (in schools, in the community)

- Why should people live in the community instead of in institutions?

- Do you think that there are advantages for the general public to have an  inclusive community?

- Have you changed your attitudes about people with disabilities or about inclusive living after seeing this video?

Ask if there are particular statements or issues which the participants would like to discuss.

# Sensitivity to General Disability Issues

The focus of this discussion is to develop the awareness and sensitivity to the challenges and possibilities of disabilities. Using the disabilities seen in the video, participant are asked to imagine how they would deal with disabilities.

**Suggested steps:**

Have the participants choose two of the following disabilities and ask them to imagine that they have the disabilities.

- Cannot walk
- Have learning problems
- Are blind
- Have epilepsy

Ask them to think about how they would deal with every day issues and activities.

- What are some of the difficulties you might expect?
- What support or assistance would be helpful?
- How would you deal with this situation if you were of a parent of such a child?
- Ask experts, especially people with the disabilities to discuss the kinds of supports that can be provided.

Develop a list of what things a community could do to assist people with disabilities to fully participate.

# Discussion of issues raised in the video

There are many statements and ideas presented by the people in the video that are rich grounds for further discussion. A sample of such possibilities is listed below but the participants should be encouraged to identify sections from the video that they found particularly insightful or informative.

Marie Mimms was a young mother with four children, one with severe disabilities, when her husband died.  As the only caregiver and sole financial support for her family, Marie was advised to place her child in the institution. What kinds of support might have helped Marie keep her child at home?

The Pichler family had not only a son with severe developmental disabilities but also a daughter with severe mental health problems. They feared that the chaotic home situation would be unhealthy for their typically developing daughter.  How might you react if this were your family? What differences exist today as compared to then?

Mrs. Kohler relates how, despite the existence of some community programs for children with disabilities; these were not widely available to children with more severe levels of intellectual disabilities or to those children with more severe behavior problems. In fact, families dealing with the most severe problems seemed to get the least, if any, community support.  Do you think that was unusual? Why were these children rejected?

The Weisenbergs movingly describe how they were advised to place their son, who has severe developmental disabilities. They make the painful decision only to find out that the expected professional care is virtually nonexistent.

They present an understanding and resigned view of these life threatening failures in the institution. How can they be so compassionate?

Mr. and Mrs. McCourt relate how desperate they were for help that they felt compelled to accept the placement of their daughter into an experiment developing the hepatitis vaccine. Research guidelines for such experimentation require "informed consent". Do you think that their agreement constituted "informed consent" or did the coercive nature of it negate it being freely given?

What were some other statements that caused you to think differently about disability issues?

# Suggested Reading:

Blatt, Burton and Kaplan, Fred (1974) *Christmas in Purgatory: A Photographic Essay on Mental Retardation,* Human Policy Press, Syracuse, New York

Elks, Martin. A. Visual Indictment: A Contextual Analysis of "The Kallikak Family" Photographs. *Mental Retardation* v. 43 no. 4 (August 2005) p. 268-80

Ferguson, Philip, (1994) *Abandoned to their Fate: Social Policy and Practice toward Severely Handicapped People in America, 1820 to 1920 ( Health, Society and Policy)*Temple University Press, Phil. Pa.

Smith, J. David. (2002)The myth of mental retardation: paradigm shifts, disaggregation, and developmental disabilities*. Mental Retardation* v. 40 no. 1, p. 62-4

Smith, J. David., et. al. (Aug.1993), Institutionalization, involuntary sterilization, and mental retardation: profiles from the history of the practice. *Mental Retardation* v. 31  p. 208-14

Trent, James.W. (1994) *Inventing the Feeble Mind: A History of Mental Retardation in the United States,* University of California Press, Berkeley, 356p

# Other Resources:

**AAIDD**:  The American Association on Intellectual and Developmental Disabilities. (Formerly AAMR) www.aaidd.org

**The ARC of the US**:   **www.thearc.org**

**Quality Mall**:   **www.qualitymall.org** A website with information on disabilities intended for persons with disabilities, their families and for anyone interested in more information on disabilities

**TASH**: The Association for the Severely Handicapped, **www.tash.org**

Produced by Michael R. Dillon, Ed.D. for the National Historic
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