

## Family Fights For Inclusion of Down Syndrome Daughter

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As far as 9-year-old girls go, Ellen Scheel is 'typical.' She loves her family, hanging out with friends, belting out Hannah Montana tunes and riding horses. She plays Monopoly with her mother, Kelly, in the middle of the family's Timonium living room floor. She is the apple of father Jamie's eye and reads books to him. None of this has come without struggle. "The day she was born, I said to my husband, 'I think she has Down syndrome,'" Kelly remembered. When doctors confirmed that Ellen did have Down syndrome, the Scheels decided limitations weren't going to be placed on Ellen. Ellen didn't start walking until she was 3, an age when many children start preschool. She discovered how to run quickly. "She's very high-functioning," said Kelly, 45. "My goal for her is to get a job, get married if she chooses to and support me when I'm old and gray." The Cathedral of Mary Our Queen, Homeland, parishioners have found not everyone is ready for people with disabilities. Ellen became the first student with Down syndrome in the Cathedral's school of religious education and the first at Timonium Elementary School, where she is a third-grader. Her school, Kelly said, originally said it did not have a place for Ellen. "I didn't expect it to be this hard," Kelly confessed. "For the most part we are still fighting. I don't want anyone else to have a hard time." Kelly was battle-tested before Ellen. During the 1990s, Kelly was in a relationship and gave birth to a son named Christopher, who doctors at The Johns Hopkins Hospital in Baltimore discovered had spinal meningitis. He was blind, and he had cerebral palsy and many complications from pressure to his brain. "He loved going to church," Kelly said. "He couldn't say a word, but he would sing with the choir." A year after Christopher's birth, Kelly had another son with no medical issues and gave him up for adoption. "I always joke that God only gives me a child with a disability because he doesn't think I can handle a 'typical' child," she said. "The 'typical' one was meant to be given to someone else." Christopher died at the age of 5. "That is what made me what I am today," Kelly said. "For me, he was kind of like the guidance to give me the voice for Ellen." She married Jamie 13 years ago. Jamie leads one of the biggest teams entered in the annual Polar Bear Plunge at Sandy Point State Park. The money from the event goes to Special Olympics Maryland. Co-workers and friends from the plumbers and steamfitters local union 486 participated and raised \$85,000. "I knew I had to do something," Jamie said. Ellen loves a photo from this past January's event. "That's me and my dad," Ellen said. "My dad got in the cold water!" Ellen will ride horses in the Maryland Special Olympics June 5-7. When Ellen read to a recent visitor, she told her parents to "zip it!" Her parents laughed hysterically. "That's your side coming out," Kelly said to her husband. "That's you," Jamie teased back. The Archdiocese of Baltimore is trying to perfect outreach to families like the Scheels. Auxiliary Bishop Mitchell T. Rozanski recently met with pastors, directors of religious education, youth ministers and persons from the deaf and disabled communities to formulate a plan

to assist parishes in welcoming those with disabilities. Kelly participated in the group. "I think we have made great strides in incorporating people with disabilities into the life of the parish thanks to the courageous witness of people themselves and their family members," Bishop Rozanski said.

Bill Fleming, the archdiocese's coordinator of catechesis for persons with developmental disabilities, said many parishes are unsure how to reach out to families. "We're trying to break down barriers," he said. Fleming said Kelly had influential ideas for the archdiocese's annual Family Fun Day, hosted at the Monsignor O'Dwyer Retreat House in Sparks for people with disabilities. "People like Kelly are crucial," Fleming said. "Just to see her faith is so wonderful. What a model of parenting." Ellen received her first Communion last year, bringing her parents to tears. Bishop Rozanski said the archdiocese rejoices in such moments. "People with disabilities bring such an enthusiasm and love of the church and the sacraments," Bishop Rozanski said. "They also bring it to fellow students to heighten their own awareness and their ability to reach out." Kelly and Jamie Scheel know their daughter is a gift. "Ellen," Kelly said, "is going to teach people how to love who never knew the true meaning of it.

# **Mental Illness and Justice Issues**

<http://www.miministry.org/justiceissues>

1

## MENTAL ILLNESS AND JUSTICE ISSUES

*“As individuals and as a nation, therefore, we are called to make a fundamental "option for the poor". The obligation to evaluate social and economic activity from the viewpoint of the poor and the powerless arises from the radical command to love one's neighbor as one's self. Those who are marginalized and whose rights are denied have privileged claims if society is to provide justice for all. This obligation is deeply rooted in Christian belief.”*

*THE CHURCH IN THE MODERN WORLD, #69, SECOND  
VATICAN COUNCIL*

*Deacon Tom Lambert*

*Catholic Archdiocese of Chicago – Commission on Mental Illness*

2

### **Scope of the Issue**

Mental illnesses include such disorders as schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, borderline personality disorder, and other severe and persistent mental illnesses that affect the brain.

o “These [mental illnesses] can profoundly disrupt a person's thinking, feeling, moods, ability to relate to others and capacity for coping with the demands of life. Mental illnesses can affect persons of any age, race, religion, or income. Mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. Mental illnesses are treatable. Most people with serious mental illness need medication to help control symptoms, but also rely on supportive counseling, self-help groups, assistance with housing, vocational rehabilitation, income assistance and other community services in order to achieve their highest level of recovery.”<sup>1</sup>

Mental illnesses are common in the United States and internationally.

o “An estimated 26.2 percent of Americans ages 18 and older — about one in four adults — suffer from a diagnosable mental disorder in a given year.”<sup>2</sup>

One in 17 suffers with severe mental illness.

- o Mental [illnesses] are the leading cause of disability (lost years of productive life) in the North America, Europe and, increasingly, in the world. By 2020, Major Depressive illness will be the leading cause of disability in the world for women and children.<sup>3</sup>
- o Mental [illnesses] account for 4 of the 10 leading causes of disability in the United States.<sup>4</sup>
- o In 2002, 31,655 (approximately 11 per 100,000) people died by suicide in the U.S, 90% have a diagnosable mental [illness]. <sup>5</sup>
- o Each year, almost 5,000 young people between the ages 15 to 24 take their own lives. The rate of suicide for this age group has nearly tripled since 1960, making it the third leading cause of death in adolescents and the second leading cause of death among college-age youth. <sup>6</sup>
- o At least six million American children have difficulties that are diagnosed as serious mental [illness], according to government surveys — a number that has tripled since the early 1990's. <sup>7</sup>

3

### **THE DIGNITY OF THE INDIVIDUAL.**

Catholic social teaching calls us to recognize that each person has dignity and all life is sacred. In Pope Benedict XVI's message for the 2006 World Day of the Sick he specifically addresses the issue of mental illness. He states "Every Christian, according to [their] specific duty and responsibility, is called to make [their] contribution so that the dignity of these brothers and sisters may be recognized, respected and promoted."<sup>8</sup> Pope John Paul II's 1997 message to healthcare workers states that "Whoever suffers from mental illness 'always' bears God's image and likeness in [themselves], as does every human being. In addition, [people with mental illness] 'always' have the inalienable right not only to be considered as an image of God and therefore as a person, but also to be treated as such."<sup>9</sup>

One of the greatest obstacles for people with mental illness and for their families is overcoming the stigma the general public associates with mental illness. Stigma erodes the dignity of the person and hinders us from seeing a person as an image of God.

Stigma detracts from a person's dignity and keeps people from receiving the treatment and care they need for recovery.

- o The Surgeon General's recent report on mental health argues that the stigma around mental illness is one of the most significant challenges to the development of effective mental health policy<sup>10</sup>
- o This stigma has intensified over recent decades, despite the advancement of scientific knowledge about the causes of mental illness and the effectiveness of certain treatments; studies show that a greater portion of people associated mental illness with violence in the 1990s than the general public did in the 1950s.<sup>11</sup>
- o Nearly two-thirds of all people with diagnosable mental [illness] do not seek treatment<sup>12</sup>
- o Stigma pushes people to the margins of our society. People fear what they do

not know and the stigma of mental illness exacerbates the misconceptions people have about who the person really is.

As Church we are called to counter the sinful effects of stigma by:

- o Using “people first” language to reinforce the dignity of the person, e.g., “people with a mental illness” not “the mentally ill.” This allows people with mental illness to be recognized as a person not a disease.
- o Recognizing that everyone has something to contribute. We value the individual for who they are and what gifts he or she brings to the community.

4

- o Debunking myths and mental illness characterizations that portray people by generalizations that have no basis in fact and are negative and demeaning.
- o Welcoming and including all people into our faith community and treating each person with dignity and respect. Finding ways to proactively include people.
- o Educating and informing faith communities about the facts concerning mental illness

#### **PREFERENTIAL OPTION FOR THE POOR**

Another theme of Catholic Social teaching is our priority for those who are most vulnerable and pushed to the edges by society. A basic moral test for our or any society is how the most vulnerable members are treated. Our society is flawed by a widening gap in health care and services between the rich and the poor. We look to the story of the Last Judgment which instructs us to put the needs of the poor and vulnerable first -

*...Lord, when did we see you hungry and feed you, or thirsty and give you drink? When did we see you a stranger and welcome you, or naked and clothe you? When did we see you ill or in prison, and visit you? And the king will say to them in reply, Amen, I say to you, whatever you did for one of these least brothers of mine, you did for me. (Mt 25:37-40*

Prisons and Jails have become the largest deliverers of mental health services in the United States

- o Largest mental health “provider” in the country is Los Angeles County jail
- o At midyear 2005 more than half of all prison and jail inmates had a mental health problem, including 705,600 inmates in State prisons, 70,200 in Federal prisons, and 479,900 in local jails. These estimates represented 56% of State prisoners, 45% of Federal prisoners, and 64% of jail inmates.<sup>13</sup>
- o Very few prisoners in general prison and jail populations receive the treatment they need

Only ---- “Over 1 in 3 State prisoners and 1 in 6 jail inmates who had a mental health problem had received treatment since admission.<sup>14</sup>

Death penalty

- o The majority of countries except the U.S. prohibits the death penalty for people with mental illness
- o Although precise statistics are not available, it is estimated that 5-10 percent of people on death row have a serious mental illness.

5

- o In 1986, the Supreme Court ruled that people with mental illness can be executed if they understand the punishment that awaits them and why they are being put to death. This ruling has prompted some states to provide psychiatric treatment to offenders with mental illness on death row in order to “restore their competency.” Also some states are medicating defendants involuntarily in order to make them competent either to stand trial or to be executed.

Homelessness

- o Deinstitutionalization of public “mental hospitals” created an increase in homelessness because of poorly funded community programs.
- o Lack of an array of services and affordable housing in the community adds to the mental health crisis.
- o At least 20 to 25% of homeless people have a mental illness.<sup>15</sup> Mental illness among people who are homeless is generally acknowledged as much higher.

As church

- o We are called to change the systemic problems that result in prisons and jails being the largest mental healthcare provider in the country. In addition to individual acts of compassion and caring for people with mental illness we are called to work for better laws and policies that end discrimination and marginalization of people with mental illnesses, cause homelessness, and add to the high recidivism rate for people who are in prisons and jails.

**FUNDAMENTAL RIGHT TO LIFE AND A RIGHT TO THOSE THINGS REQUIRED FOR HUMAN DECENCY.**

Another major theme of Catholic social teaching is that human dignity can be protected and a healthy community can be achieved only if human rights are protected and responsibilities are met. Every person has a fundamental right to those things required for human decency including healthcare. It is our responsibility to protect these rights. The mental healthcare system in the United States is often described as dysfunctional and uneven in its care for people with mental illness. Mental Illness is a treatable brain disease with better success rates than many other diseases. Studies have shown that proper diagnosis, medication, and an appropriate range of community psycho-social rehab support services will deliver cost effective results that are actually less expensive than the current disconnected delivery system now in place. Yet the needs of many go unmet which is unconscionable.

Poor Health Care systems foster continuous “cycles of crisis” for people with mental illness and their families.

6

- o Over 40 million people in the United States have no healthcare insurance
- o While effective treatments exist for most common mental [illnesses], studies have shown that many consumers seen in primary care settings do not receive them. Even in the 1990s, most adults with depression, anxiety, and other common mental [illnesses] did not receive appropriate care in primary care settings. Older adults, children and adolescents, individuals from ethnic

minority groups, and uninsured or low-income patients seen in the public sector are particularly unlikely to receive care for mental [illnesses].<sup>16</sup>

Reasons for not receiving care vary:

- Stigma
- Lack of Insurance
- Lack of services in the community
- Ineffective services
- Lack of knowledge about the illness
- cultural
- o Quality treatment and flexible supports for adults with a serious mental illness lead to employment and recovery, reduced substance abuse and incarceration, and greatly improved quality of life.....Multiple Barriers Impede Access to Effective Treatments, Services and Supports. The array of programs that deliver or pay for treatments, services and supports are offered by multiple levels of government and the private sector. The varying missions, settings and financing of these health, housing, disability and employment programs create a mental health maze instead of a coordinated system. Navigating this maze is left to the people with the mental illness and their families, who are least equipped to deal with the complexities of the system. As a result, it is often impossible for families and consumers to find the care that they urgently need. Overall, one in two people who need mental health treatment does not receive it. For ethnic and racial minorities, the rate of treatment is even lower than that for the general population and the quality of care is poorer..... The Commission has identified five barriers in the interim report that needlessly impede access to care: "Fragmentation and Gaps in Care for Children, Fragmentation and Gaps in Care for Adults, High Unemployment and Disability for People with Serious Mental Illness, Insufficient Attention to Older Adults, and Mental Health and Suicide Prevention are not yet National Priorities." <sup>17</sup>
- o Since the Healthcare system is inadequate people do not receive the continuity of Care needed to remain healthy. The range of services varies widely from community to community, from urban settings to rural settings.

7

Need to offer full array of services in all communities

Need to overcome the "not in my backyard" syndrome that keeps people from getting services and housing close to their families and in their own neighborhoods.

NAMI, National Alliance for the Mentally Ill, in a 2006 survey rated the United States with a "D" for its care of people with mental illness<sup>18</sup>

- o Parity legislation

People with mental illness deserve the same coverage as people with physical illnesses. Currently many insurance plans discriminate against

people with mental illness by limiting benefits for mental health care.

#### Housing

- o Affordable housing for people with mental illness is a major problem. If a person is unable to work, obtain a job with a decent wage, and/or on disability housing options are very limited.
- o In 1999, the Court ruled in *Olmstead v. L. C. by Zimring*. that Title II of the ADA requires individuals with mental disabilities to be placed in the least restrictive treatment possible, since excessive treatment can be stigmatizing and is a form of discrimination. 527 U.S. 581. While the *Olmstead* decision was qualified (i.e. there must be a doctor's order that the individual is appropriate for less restrictive treatment and program resources are to be taken into account) the decision was still a benchmark in the history of protection from discrimination.<sup>19</sup> Although the Supreme Court decision outlined what should be done it did not set a timetable leaving the states to work out the implementation. This requires advocates to push for change as funding and change is at a slow rate.

#### Employment

- o People with mental illness need supportive employment opportunities so they can make the transition to full recovery.

8

### **THE ROLE OF THE CHURCH IN JUSTICE FOR PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES**

The people of God, the church, are called to be communities of compassion, hope and justice for people with mental illness and their families.

- o As Church, we are called to respond to Pope Benedict XVI's message for the 2006 World Day of the Sick "I therefore encourage the efforts of those who strive to ensure that all [people with mental illness] are given access to necessary forms of care and treatment..... I commend pastoral workers and voluntary associations and organizations to support in practical ways and through concrete initiatives, those families who have [people with mental illness] dependent upon them. I hope that the culture of acceptance and sharing will grow and spread..."
- o As people called to witness Christ to the world **we** must first examine our own views and actions toward people with mental illness and their families. Do we have misconceptions, prejudices, or attitudes toward people with mental illness that are based on irrational ideas or myths unsupported by fact?
- o Since mental illness is often hidden, it takes on an even greater urgency for a proactive ministry - especially since people with mental illness are vulnerable and discriminated against in the workplace, in housing opportunities, and in the healthcare system.
- o Parishes can address mental illness needs through already established ministries in the life of the parish and by incorporating mental illness issues into the ministerial agenda. It is important to recognize that the disease is rarely talked about due to the stigma associated with the disease and lack of



understanding about mental illness. Therefore it is critical for church leaders to recognize their own misconceptions and/or prejudices, conscious or subconscious, toward persons with mental illness. This can be done through education and training on the facts concerning mental illness. One does not have to become a mental health professional but it is important to get accurate information about mental illness in order to effectively minister to and advocate for those suffering with these diseases.

o It is important that persons with mental illness feel welcomed and supported within the parish. This requires the purest spiritual outreach, i.e., nonjudgmental love and acceptance of the individual. The more that parishes can project non-judgmental love, the more its members suffering with mental illness, or those who have a family member with mental illness, are likely to acknowledge their needs and overcome their fears of rejection.

9

In “*THE IMAGE OF GOD IN PEOPLE WITH MENTAL ILLNESS*” Pope John Paul II says “...the church will not hesitate to take up the cause **people** of the poor and to become the voice of those who are not listened to when they speak up, not to demand charity, but to ask for justice.”<sup>20</sup>

The church needs to be a sign of hope to persons with mental illness and their families, supporting them in every possible way with prayer and friendship—welcoming them unconditionally. Vatican II's document *Gaudium et Spes* calls us as church to "establish a political, social, and economic order which will to an ever better extent serve [humankind] and help individuals as well as groups to affirm and develop the dignity proper to them."

Persons with mental illness and their families are in need and are asking for the Church, you and I, to help in their search for Justice. In Mathew's Gospel story of the final judgment, Jesus tells us “whatever you did for one of these....you did for me.” Our call is clear - our response is not optional.

<sup>1</sup> NAMI-National Alliance for the Mentally Ill, “About mental illness” website [www.nami.org](http://www.nami.org)

<sup>2</sup> Kessler RC, Chiu WT, Demler O, Walters EE. Prevalence, severity, and comorbidity of twelve-month DSM-IV disorders in the National Comorbidity Survey Replication (NCS-R). *Archives of General Psychiatry*, 2005 Jun;62(6):617-27.

<sup>3</sup> NAMI-National Alliance for the Mentally Ill, “About mental illness” website [www.nami.org](http://www.nami.org)

<sup>4</sup> National Institute of Mental Health. (2001 January). *The numbers count: Mental disorders in America* (NIMH Publication No. 01-4584).

<sup>5</sup> National Institute of Mental Health. (2001 January). *The numbers count: Mental disorders in America* (NIMH Publication No. 01-4584).

<sup>6</sup> National Institute of Mental Health. (2001 January). *The numbers count: Mental disorders in America* (NIMH Publication No. 01-4584).

<sup>7</sup> N. Y. Times, *Living with Love Chaos and Haley*, October 22, 2006

<sup>8</sup> “Message of His Holiness Benedict XVI for the 14th World Day of the Sick”, December 8, 2005

<sup>9</sup> “Mentally Ill are also made in God's image,” L'Osservatore Romano Weekly Edition in English 11 December 1996

<sup>10</sup> U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General*, Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999, p. 6.

- 11 Little Hoover Commission, Being There: Making a Commitment to Mental Health, Sacramento, CA, November 2000, p. 31.
- 12 Surgeon General's Report, December 13, 1999
- 13 DOJ Study, Mental Health Problems of Prison and Jail Inmates, September 6, 2006
- 14 DOJ Study, Mental Health Problems of Prison and Jail Inmates, September 6, 2006
- 15 SAMSA
- 16 President's New Freedom Commission on Mental Health, press release 11/1/2002
- 17 President's New Freedom Commission on Mental Health, press release 11/1/2002
- 18 NAMI-National Alliance for the Mentally Ill, "About mental illness" website [www.nami.org](http://www.nami.org)
- 19 [www.nami.org/Template.cfm?Section=Court\\_Watch1&template=/ContentManagement/ContentDisplay.cfm&ContentID=15684](http://www.nami.org/Template.cfm?Section=Court_Watch1&template=/ContentManagement/ContentDisplay.cfm&ContentID=15684)
- 20 "Mentally Ill are