

# GABOR GOMBOS

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Throughout the world, people with mental disabilities, elders with dementia, and people of all ages who suffer from psychological illnesses, from depression to schizophrenia, are regularly abandoned to a life of discrimination. They are often locked away in insane asylums where degrading conditions include pervasive inactivity, filthy spaces, and the use of physical restraints, including confinement and cages. Denied adequate privacy, medical and dental care, food, water, clothing, blankets, and heat, rehabilitation and reintegration into society are rarely the goals of their treatment. Medications are chronically overused and misused, and there is almost a complete failure to provide informed consent for treatment and experimentation. The chronic shortage of resources includes a serious lack of trained staff, and few avenues of complaint for violations against one of the most vulnerable and marginalized segments of society. Gábor Gombos of Hungary knows these conditions all too well. Between 1977 and 1990, he was confined four times to psychiatric wards in Hungarian hospitals. He emerged determined to overhaul psychiatric care—first in his country and then across Europe. To this end, Gombos cofounded the first NGO active in Hungarian mental health issues (EGISZ, the National Family Association of the Mentally Ill) in 1993, and the following year, cofounded Voice of Soul, Hungary’s first NGO for ex-users and survivors of mental health facilities, where he still serves as chair of the board. In 2001, Gombos was elected to the Ashoka Fellowship, continuing to advocate for the rights of psychiatric patients and reform of the Hungarian mental health system. In 2010 he was elected to the United Nations Committee on the Rights of Persons with Disabilities.



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“WHAT IS MISSING IS A FLEXIBLE AND REACHABLE NETWORK OF VARIOUS SOCIAL SERVICES FOR PEOPLE WITH MENTAL DISABILITIES: A SHELTERED PLACE TO LIVE, SUPPORT IN FEEDING, SHOPPING, AND OTHER NEEDS. WITH AS LITTLE AS HALF AN HOUR A DAY, THESE PEOPLE COULD BE NOT ONLY EQUAL MEMBERS OF SOCIETY BUT BE ABLE TO EARN THEIR OWN LIVING.”

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AN EXCERPT FROM AN INTERVIEW CONDUCTED BY KERRY KENNEDY IN 2000

In Hungary, there are social care homes for the mentally ill, similar to the old American state mental hospitals. Most of these institutions were started in 1953 by the Communist Party, which maintained that mental illness was a characteristic feature of capitalism and would disappear under Communism. And after a few years they discovered there were still mentally disabled people in society. How to solve the problem? They set up these institutions very far from bigger cities and towns, to make mentally disabled people invisible for the majority of society. If you don't see them, they don't exist.

Even the newest post-1994 facilities reflect the attitude of the society, the discrimination, the prejudice, the stigma against people with mental disabilities. The buildings are modern, but the attitudes are old, designed without rooms for occupational therapy [therapy that helps people perform everyday tasks, such as getting dressed or cooking], without a common eating facility, and with cages for acute cases.

What is missing is a flexible and reachable network of various social services for people with mental disabilities: a sheltered place to live, support in feeding, shopping, and other needs. But there are no outpatient services like that. With as little as half an hour a day, these people could be not only equal members of society but able to earn their own living. But because these services are completely missing, the only choice for the family or for the local authorities is to condemn people to social care homes for the mentally ill. This is really tragic.

The lack of resources is not the main reason for the government's failure to do anything (a much-heard complaint) because an unreasonable amount is spent for services that are ineffective and, by the way, violate basic human rights. On a fact-finding trip to an institution, for example, we noticed a relatively young man was severely intellectually challenged in a cage. We asked the staff how much time he spent in the cage. The answer was all day, except for half an hour when a staffer works with him. And I asked them, why do you keep this person in the cage? And the answer was, "for his own protection".

The average waiting list for admittance to a group home is about three years, and if you consider that the conditions are abhorrent, that they are not rehabilitation institutions but are custodial institutions, it seems surprising that there are people waiting. It doesn't mean that these people want to be there; it means there is no other choice, or that their guardians are forcing them to be there.

The Hungarian guardianship system itself is a severe violation of basic human rights. If someone has a psychiatric diagnosis or one of mental retardation and if someone therefore believes that person is incompetent, then they can initiate guardianship procedures, and some local official makes a decision about a temporary guardianship, lasting sometimes for two or three years. It means all your civil rights are controlled by your guardian, including your property, house, and money. Abuse is common.

Medically you can be forcibly treated or hospitalized against your will only if you have been admitted voluntarily. The guardians circumvent this by proclaiming the patient incompetent and then condemn them for life to "voluntary" care. In the new social care homes for the mentally ill, more than 90 percent of the residents are under guardianship, and this is shameful.

One of the issues we address is occupational therapy. There is very little, and what exists is not very therapeutic. On the other hand, patients do real work for the institution, cleaning bathrooms and washing floors—for free. They should be paid the minimum wage for this real custodial work they perform, instead of being exploited by the institution. The fact that they perform these services indicates that they can survive perfectly well in society with minimal support.

I must tell you that, on average, the human rights violations in the institutions for people who are intellectually challenged are much more severe. It's not a question of money and a shortage in financing. It's a question of attitudes. For example, it's very often an everyday practice in many of these institutions that the staff beats some of the patients.

The last time I was in a mental hospital was in 1991. At that time I was very, very depressed, and I was a voluntary patient. But when I wanted to leave I was not allowed. Since we had no real legislation about this, the doctor simply changed my status in the medical documents to involuntary, because he decided I'd become agitated or confused—I don't know. The courts had nothing to do with this. The court made several visits to the wards. They interviewed some selected patients, most of whom were over drugged, and some of them had just been electroshocked. After the electroshock, your memory is not really clear. So they said, "Yes, yes, it's okay."

My contact with psychiatry began when I was three years old. My uncle committed suicide. A few months later, my mother became very depressed and delusional. She was hospitalized many times when I was a child, and when not in the hospital she worked outside the home to care for me and my grandmother. So I was raised mainly by my grandmother, who was also mentally ill. She died when I was ten. Being afraid that I'd be put in an orphanage, my mother married. But my stepfather drank a lot, which did not help my mother's emotional stability. Her hospitalizations increased, and she tried to commit suicide several times.

My mother lost her autonomy, her social contacts and her social roles over time and applied for a disability pension. She lost her job, which was devastating for her. So her life was narrowing and narrowing and narrowing. And the only goal which remained for her was for me to grow up successfully. As soon as I became more or less independent, my mother died. Her death was mysterious because she was an outpatient at the mental health hospital where she was an involuntary subject in a double-blind drug experiment.

When I discovered the true cause of her death, I went really crazy, completely psychotic, with threatening hallucinations. So psychotic, that I didn't go to the psychiatrists. I didn't eat. I didn't leave my home. I couldn't. The reason that I am here is that one

of my friends unexpectedly visited me. But he was an old friend and didn't think that the answer to my state was hospitalization. He could understand my situation. I had lost my mother. He knew something about her very doubtful autopsy. So he moved into my apartment for weeks, spent all his time with me, forced me to eat something. After three weeks, I recognized that I had passed my deepest crisis.

That was the beginning of a new life. I had the self-confidence that, with the proper support from people who are close to me, I could survive. I felt that I did have some control over my illness.

[Eventually,] some people contacted me and asked me to help them organize a nongovernmental organization for the families of people with mental disabilities. I joined because of my mother. And after a time, [I] became more and more involved. And this was the moment when I realized that I would be seriously committed to helping people who share my terrible experience of so-called psychosis, and changing the way society reacts to it, and so changing the world.

For years I believed that it was my mission to do research in physics. There were extremely heavy competitors there, but not supporters. In my private life, my mother was the only person who was a supporter. In the world of human rights advocacy for people with mental disabilities, I discovered people who shared my experience, who gave me all their support, all their expertise, all their knowledge. And I tried to return that in kind. Solidarity, you know? This was the first time in my life when I experienced solidarity.

I can understand those who are on the other side of this mental health care. I don't suppose that they are less valuable human beings. And by understanding, we can influence each other, at least on a personal level. And I really believe that change, social change, can happen only if it happens in various levels. If decision makers, as human beings, embrace human relationships with people with mental disabilities, and with other disabilities, this will advance change and understanding like nothing else.

# HUMAN RIGHTS AND PSYCHOSOCIAL DISABILITY

## GAMBOR GOMBOS

LESSON GRADE LEVEL: 9-12  
HUMAN RIGHTS ISSUES: RIGHTS OF THE DISABLED

### UNIVERSAL DECLARATION OF HUMAN RIGHTS:

- **Article 2:** All of the rights and freedoms within the UDHR
- **Article 12:** Right to privacy
- **Article 25:** Right to adequate Standard of Living

### GUIDING QUESTIONS:

- How would you define 'disability'?
- There are many kinds of disabilities, some very profound, others much less so -- what are some examples of disabilities that you know of?
- What kind of help do people with psychosocial disabilities need? Who should provide the help (family, society, etc.)?
- Should people with psychosocial disabilities be able to make choices about the kind of treatment they receive?

### TIME REQUIREMENT:

90 Minutes

### OBJECTIVES:

After the lesson, students will be able to:

- Give examples of and describe the symptoms of a range of different psychosocial disabilities
- Discuss and evaluate different kinds of possible treatment for psychosocial disabilities
- Consider if, how, and when a person's choices should be limited due to a psychosocial disability and how this relates to one's human rights

### STUDENT SKILLS:

- Empathy (ability to put oneself fully in the shoes of another, no matter how uncomfortable those shoes may be)
- Sensitivity to particular people in their unique situations, a resistance to make hasty generalizations
- Reflection and evaluation after looking closely at individual stories and experiences

### CONCEPTS:

- Stigma
- Normal
- Emotional, intellectual, physical, social health
- Individual and social responsibility
- Paternalism
- Autonomy
- Isolation
- Informed consent
- Coercion
- Human rights

### MATERIALS:

- NYT article: [http://www.nytimes.com/2013/05/27/health/when-hoarding-morphs-into-a-safety-hazard.html?](http://www.nytimes.com/2013/05/27/health/when-hoarding-morphs-into-a-safety-hazard.html?mtrref=undefined&gwh=A2874DD846576A5DA0A98DA94E8AEA9F&gwt=pay)
- 'The Yellow Wallpaper': <https://www.nlm.nih.gov/exhibition/theliteratureofprescription/exhibitionAssets/digitalDocs/The-Yellow-Wall-Paper.pdf>
- Eleanor Longden in a TED Talk [http://www.ted.com/talks/eleanor\\_longden\\_the\\_voices\\_in\\_my\\_head.html](http://www.ted.com/talks/eleanor_longden_the_voices_in_my_head.html)
- Gabor Gombos interview: [www.rfkhumanrights.org](http://www.rfkhumanrights.org) / click on **Speak Truth to Power** / click on "Defenders" tab

### VOCABULARY:

- Psychosocial disability\* (\*commonly viewed as mental illness)
- Depression
- Schizophrenia
- ADHD
- Obsessive compulsive disorder
- Eating disorder
- Dementia
- Bipolar disorder
- Stress, anxiety
- PTSD
- Suicide
- Therapy (psycho, cognitive, behavioral, group, drug)
- Psychologist, psychiatrist, social worker, neurologist
- Mental institution/psychiatric

### CONCEPTS:

- Empathy
- Fairness
- Cultural Norms
- Systemic Change
- Values
- Justice

### TECHNOLOGY REQUIRED:

- Internet

## STUDENT ACTIVITIES

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### ANTICIPATORY SET:

Make a circle in the classroom so that students face each other. As a group, discuss the following questions:

- What does it mean to have a psychosocial disability? Give some examples of psychosocial disabilities you've heard of.
- How is having a psychosocial disability different than having other kinds of disabilities?
- When/ in what circumstances do we tend to come in contact with people with psychosocial disabilities?
- Imagine your cousin has a psychosocial disability (e.g., severe anxiety, an eating disorder, etc.) and that s/he came to stay with you for a weekend. How would his/her disability influence what you chose to do?

### ACTIVITY 1:

After an open discussion of the questions above, students should sit back, close their eyes and listen, as the teacher reads aloud the following scenario:

- You've had a very busy winter at work and you are depleted and exhausted. When your boss sees this, she suggests you take some time off. Hoping for some serious relaxation, you decide to visit an island where the weather is warm, the food is good, and the beaches are white and sandy. This is the first time you've travelled by yourself, and you feel both nervous and excited. The flight is long, and you sleep almost the entire time. In fact, when you wake up, the last of the passengers is far up the aisle, already deboarding. Quickly, you gather your things and get off the plane. Your legs feel stiff from the cramped seating, and your head is groggy from sleep as you make your way through the airport and towards baggage claim. You follow the people from your flight, barely noticing your surroundings. However, as you start to wake up more fully, you realize that something is wrong. All the signs in the airport are illegible: their script is not only foreign, but utterly mysterious. You scan your mind of different alphabets you've encountered, but this is like none you've ever seen. To make matters worse, the pictorial symbols that identify things like bathrooms and bus/taxi service are equally indecipherable. You blink your eyes hard a few times hoping that this unfamiliarity is merely temporary. Nothing changes. You stop and listen to the sounds around you, hoping to hear a language that you recognize. But everyone is speaking in a strange combination of whistles and grunts. You head to an official looking counter, hoping to find an airport employee who might speak a different language. However, when you begin to talk, she looks at you quizzically and whistles impatiently. You repeat your question: 'Where am I?', but the woman behind the counter merely smiles patronizingly, grunts briefly, and looks down at her work, effectively dismissing you. You walk away, feeling increasingly lost and desperate. Then thankfully, out of the corner of your eye, you spot your suitcase next to an office you assume is for left luggage. Quickly you head over to your bag, intending to collect it and get the first flight out. But as you reach out to pick your suitcase up, someone in the office nearby shouts incomprehensibly but accusingly. Before you can ask any questions, you have been grabbed on both sides by two large men in uniform. They hold you tightly and continue to speak

at you, grunting and whistling, and expecting a response. You try to explain yourself, to ask what is going on, but the more you speak the angrier they become. Finally they take you to a small, windowless room, lead you in, sit you down and then exit. The door closes and you are completely alone.

### DISCUSSION QUESTIONS

Break the class into groups of 3-4 students. Allow 15 minutes for groups to discuss and write down their answers to the following questions:

- How did you feel when imagining yourself in this hypothetical situation?
- What would you have done? What can you do more generally in circumstances where you feel confused, alienated and unable to communicate?
- What would have been helpful to you? What actions could you take to improve this difficult position?
- Come back together as a group, discuss different responses groups gave, and then, as a class, consider the following question:
- How does this situation relate to psychosocial disability?

### ACTIVITY 2:

Read Gambos interview, NYT article on hoarding, and essay 'The Yellow Wallpaper', and watch the TED talk by E. Longden

### DISCUSSION QUESTIONS:

- What kinds of psychosocial disabilities did you encounter in these three readings and talk? How are they different/similar? Which seems the most severe? Which seems the most threatening?
- Do you think people with psychosocial disabilities need to be protected from themselves? If so, when and how?
- Does society need protection from those who are psychosocially disabled? If so, when and how?
- What are effective ways to treat psychosocial disabilities? What are ineffective ways? What is essential to any effective treatment?
- How does culture/society tend to treat people with psychosocial disabilities? How should it treat them?
- Should psychosocially disabled people be given the right to make choices about how and where they want to live? Why/ why not?

### EXTENDING AND REFINING STUDENT LEARNING

- As a class consider together the following questions. Be sure to record student responses on the board and reserve the last 10 minutes of the lesson to draw conclusions from the previous activities.
- Where do our ideas of what is normal come from? How have these lessons made you rethink what it means to be 'normal'?
- At what point does being 'odd' or 'wacky' or 'out there' become being psychosocially disabled?
- Do you think that every human being no matter what his/her intellectual state, should be free to make at least some decisions about his/her life? (Such choices may be seemingly minor, such as the color of one's shirt or the choice of one's breakfast cereal; or more significant, such as whether or not to go on medication or be hospitalized.)

### UNIVERSAL DECLARATION OF HUMAN RIGHTS (UDHR)

- **Article 2:** Non-discrimination
- **Article 12:** Privacy
- **Article 25:** Adequate Standard of Living

Since the creation of the Universal Declaration of Human Rights (UDHR) by the United Nations (UN) in 1948, many other international documents—also called treaties, covenants, resolutions, or conventions—have been drafted to develop these rights further. Countries commit to protect the rights recognized in these treaties by ‘ratifying’ them and sometimes a specific institution is created within the UN to monitor their compliance.

Here are examples of relevant international documents:

### CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

- **Article 5:** Equality and non-discrimination
- **Article 8:** Awareness-raising
- **Article 14:** Liberty and Security of Person
- **Article 19:** Living independently and being involved in the community
- **Article 22:** Privacy
- **Article 23:** Health
- **Article 28:** Adequate Standard of Living and Social Protection

### INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS (ICCPR)

### INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ICESCR)

### CONVENTION AGAINST TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT (CAT)

*For more information, visit the Office of the High Commissioner for Human Rights’ website: [www.ohchr.org](http://www.ohchr.org)*

## BECOME A DEFENDER

- Go to the website of organizations that advocate for the psychosocially disabled, such as NAMI (<http://www.nami.org>), Rethink psychosocial disability (<http://www.rethink.org>), Mental Health Foundation (<http://www.mentalhealth.org.uk/get-involved>), and search there for concrete ways you can help them fight for human rights for the psychosocially disabled.
- Look up Intellectual health facilities in your state/region and gather information: where are they? Outside city limits? Accessible by public transportation? How many patients do they house? How old are the facilities? Are they well kept? Overcrowded? Investigate, and follow up by writing to your congressman/woman with questions and concerns, or to your local paper, or a blog about human rights issues and have mental health be your first entry!
- Talk to your school counselor about having an annual psychosocial health day at your school—create a table with information about different disabilities and suggestions for where to find help.
- Become a mental health advocate:
  - Mental Health Advocacy  
<http://www.mentalhealthadvocacyinc.org>  
Mind, UK based  
[https://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/#.Wej5umWG\\_ow](https://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/#.Wej5umWG_ow)

## ADDITIONAL RESOURCES

### Nami

<http://www.nami.org>

### Rethink Mental Illness

<http://www.rethink.org>

### CBM International

<http://www.cbm.org/Community-Mental-Health-terminology-314111.php>

### Pace Manual

[http://www.power2u.org/downloads/pace\\_manual.pdf](http://www.power2u.org/downloads/pace_manual.pdf)

### Users, ex-users, and survivors of the psychiatry movement

<http://www.enusp.org>

### Mental Health Foundation

<http://www.mentalhealth.org.uk>

### Mental Health America

<http://www.mentalhealthamerica.net/go/mission-vision>

### The United Nations Enable

<https://www.un.org/development/desa/disabilities/issues/mental-health-and-development.html>  
An article on mental health and development

### Disability Rights International

[www.driadvocacy.org](http://www.driadvocacy.org)

### Robert F. Kennedy Human Rights

<http://www.rfkhumanrights.org>