



Væk med tavshed, tvivl og  
tabu om psykisk sygdom!

8th International Stigma Conference  
21. September 2017



No more doubt, silence and  
taboo about mental illness!

**ONE OF US ambassador survey**

Project Coordinator Anja Kare Vedelsby

**ONE OF US... a campaign for all of us**



Væk med tavshed, tvivl og tabu om psykisk sygdom!

# Agenda

- Briefly about ONE OF US
- Ambassador in ONE OF US – recruitment and training
- Evaluation among ambassadors – essential findings
  - Background data
  - Motivation
  - Activities
  - Personal benefit
  - Recommendations
- Questions?

# Vision of ONE OF US



No more doubt, silence and  
taboo about mental illness!



To create a better life for  
all by promoting inclusion  
and combating  
discrimination connected  
to mental illness

# ONE OF US – in Danish: EN AF OS

- **Project period:** 2011-2020
- **Funding:** National Board of Health, Danish Regions and philanthropic foundation TrygFonden
- **Organisation and Interventions** at both national, regional and local level
- **Five target areas:**
  1. Service users and relatives
  2. Staff in the psychiatric, health and social sectors
  3. Labour market
  4. Youth
  5. General population and the media





No more doubt, silence and  
taboo about mental illness!

# Partners behind ONE OF US



## **Mandate:**

Focus on knowledge, attitudes and behaviour related to anti-stigma

## **No mandate for:**

Criticising structure, services and financing services for people with mental illness

1. phase: 2011-2015
2. phase: 2016-2020

# At least three important reasons to work with anti-stigma



## 1. Sensational and negative portrayal of mental illness in the media

- e.g. "Mentally ill commit more murders"...

## 2. Mental illness affects more people

- and more people get a psychiatric diagnosis

## 3. Spread the message of recovery

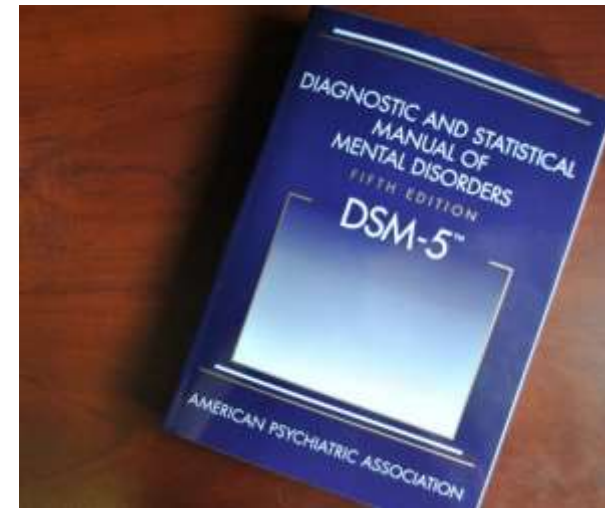
- break with the story of chronicity "once mentally ill, always mentally ill"



# Anti stigma methods

## What **doesn't** work

1. Traditional communication about **illnesses and symptoms**  
- not enough and can lead to pseudo diagnosing
2. **Simplifying problems and challenges**  
Comparing mental illness to e.g. a broken leg or diabetes.  
It leaves out the fact that self perception and relations are notably affected when you have a mental illness. And this is where uncertainty and distance can occur in social contexts.
3. **Moralising** – creates distance and resistance



# Anti-stigma methods

## What works

- 1. Facilitating identification and empathy without moralising by e.g.:**
  - ✓ **Social contact:**  
Meeting people with lived experience of mental illness and dialogue about mental illness
  - ✓ **Film, pictures, tv, radio and theater** with people with lived experience of mental illness
  - ✓ Dialogue via **social media** (facebook etc.)
- 2. Challenging myths with facts**
- 3. Intrude with messages without being intrusive**





# Ambassador in ONE OF US

## Criteria:

- ✓ People with **lived experience of mental illness** recruited among people volunteering in ONE OF US through the website, the national secretariat or the regional coordinators.
- ✓ An ability to put their personal experience into perspective. Vital that the ambassadors are well on the way in their **recovery** process or in a good place in their lives.



# Ambassador training

Three-day oral presentation course developed and carried out by external communications consultants with special expertise from the field:

- Learn to structure their personal stories and to adapt it to different target audiences.
- Training in dealing with the media and an introduction to ONE OF US.
- Protecting personal boundaries and maintaining one's integrity when disclosing.



Currently about 120 active ambassadors from the age 18 and up

Evaluation survey: 54% to a high degree and 25% to some degree have used tools from the training → training makes a difference

# The questionnaire to the ambassadors

- Draft made by the ONE OF US secretariat
- Draft tested by selected ambassadors – relevance and language?
- Items added by ambassadors
- Questionnaire emailed to ambassadors. Email addresses collected by regional coordinators (ambassadors organised regionally)

# Ambassador survey 2017 – *selected* background data: **variated profile**

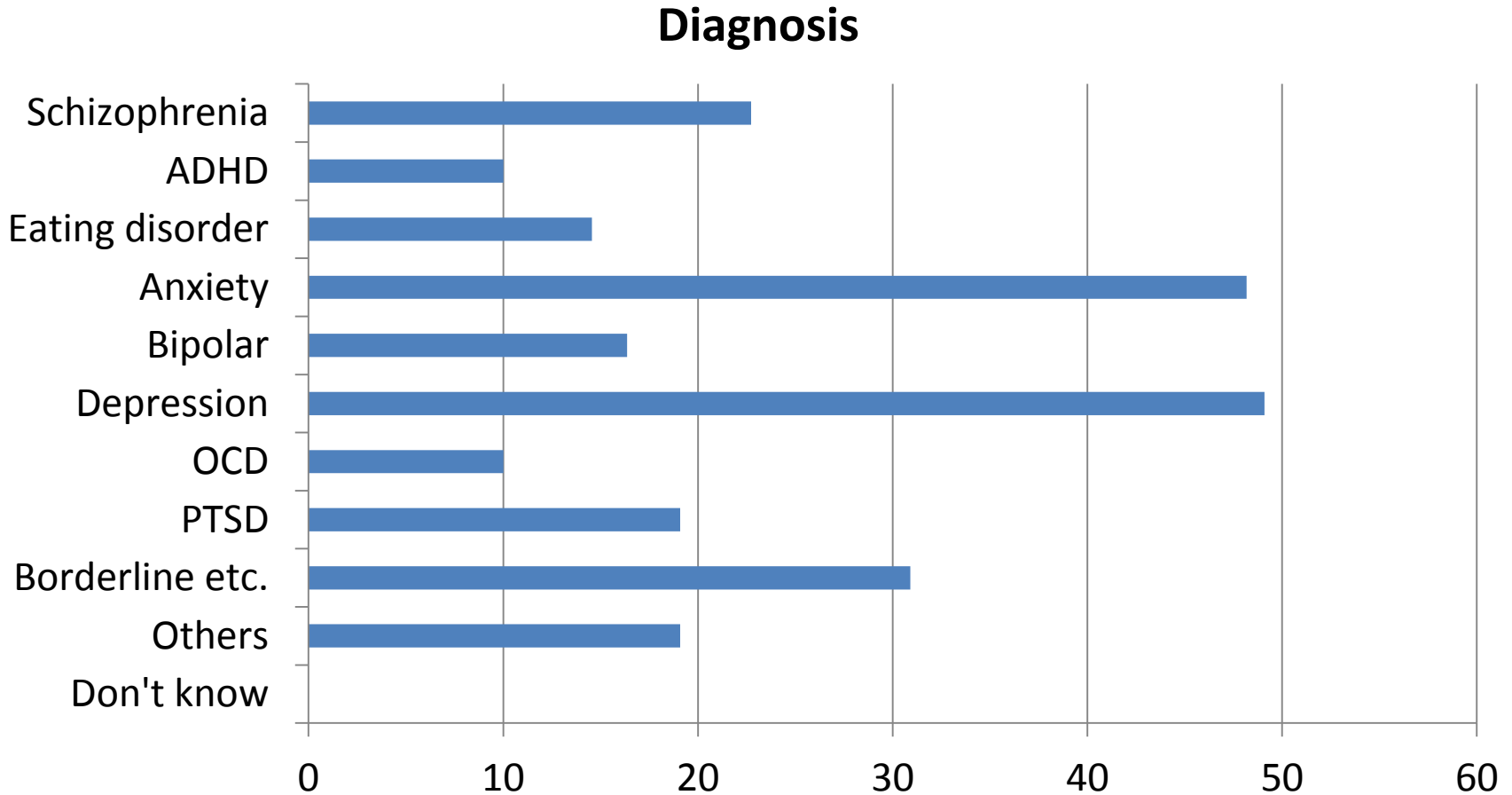
## **Electronic survey:**

- 2014: 72 respondents  
2017: 114 respondents
- Currently about 78 are active in the campaign and more people are joining
- Sex: 77% women, 23% men
- 64% between 26-45 yrs.
- Educational level: 40 % bachelor or masters degree
- Income: 47% currently unemployed (sick leave, social benefits, early retirement)
- Household: 36% single

**2014: Two focus groups** (total of 9 ambassadors)

# Diagnostic representativity

- several ambassadors have more than one diagnosis



# Motivation top 3

- "I want to tell my story about mental illness at schools, workplaces or at events" (n=89)
- "I want to challenge myself and to grow personally" (n=73)
- "I want to participate in the practical work with activities and events" (n=31)



# Motivation

“I want to be part of breaking down the prejudices about mental illness og make outsiders much more informed about the reality of living with a mental illness, and give other people with mental illness proof that it is possible to have a good life with a mental illness.”

Participant in focus group

# Reasons for becoming an ambassador

My illness would be a little more meaningful if I can use it to help others so that things would not have to be quite so difficult for them. I love to be able to turn my experience into something positive.

Being able to spread the message that even when you have schizophrenia and have hit bottom it is still possible to come back to life and have a real every day life. Even though it takes a lot of hard work and lots of tears. I am clear when I say: I AM not my diagnosis!



# Social contact activities - categories

- Presentations for different target groups
- Festivals
- Workshops and training
- Conferences
- Stand
- Development of materials
- Other creative events



# Meaningful activities top 3 (to a high degree)

- Activities directed at staff within health and social sectors (77%)
- Activities directed at young people (72%)
- Activities directed at people with lived experience of mental illness and their relatives (70%)

“I have learned to control it but there is a risk. Of course there is. But it’s a risk that I’m willing to take if I can go out and tell my personal story. If I can share my experiences and maybe help just one person to get help or give a little bit of hope, then my shitty life will have been worth it.”

# Ambassadors turning points

A class of high school students "forgot" about their smartphones for a full hour. Then you know that you are on to something right.

There is so much confidence in my skills. I feel very much like a professional when I am out doing presentations.

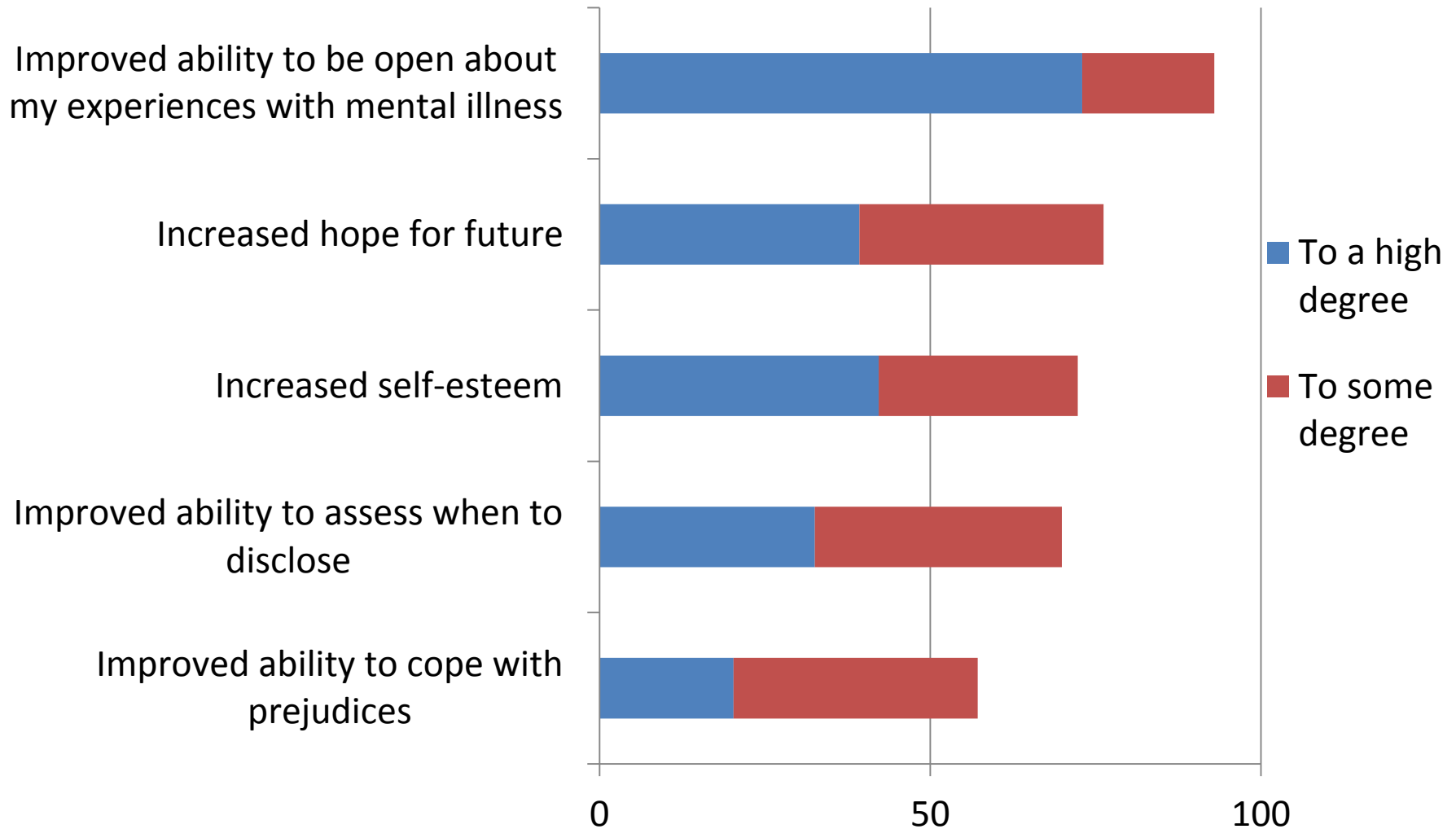
# Difficult experiences as an ambassador



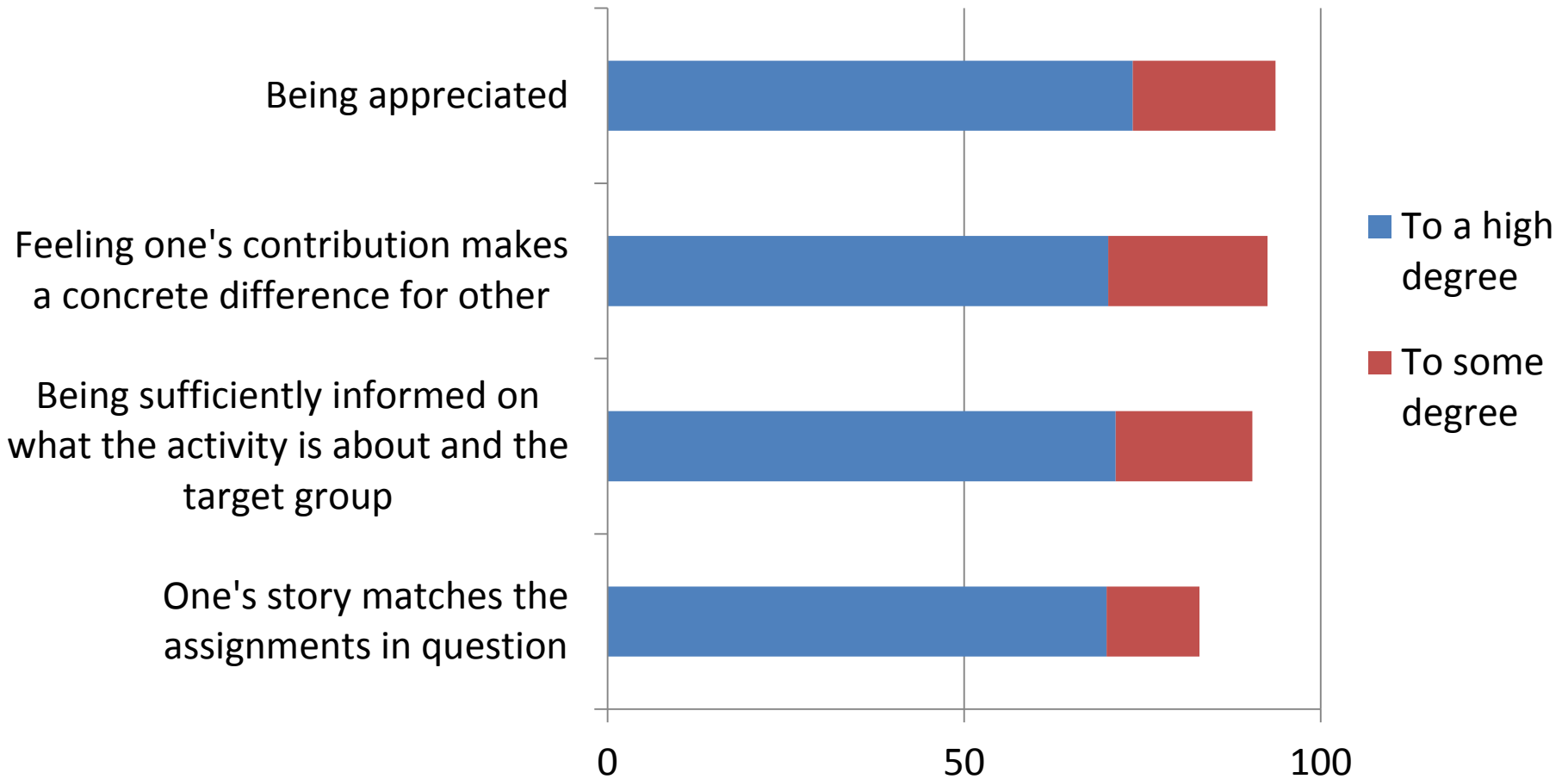
I have met a varied group of people. But the ones that are the most stigmatising are the mental health professionals which is very scary.

I was at a high school where a group of boys certainly did not hide the fact that they had prejudices. It was scary but I managed to create an opening and some understanding. Mission completed.

# Personal benefit from involvement in the campaign top 5 – recovery elements!

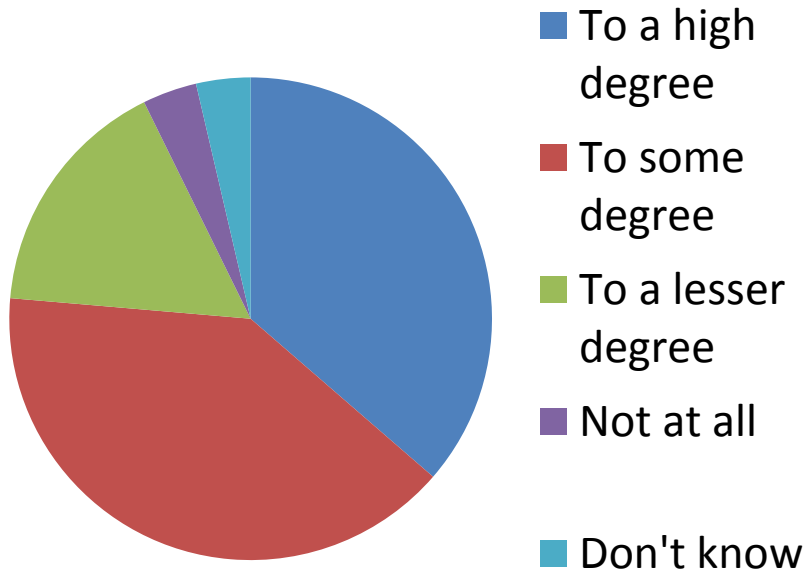


# Maintenance of commitment – important elements top 4

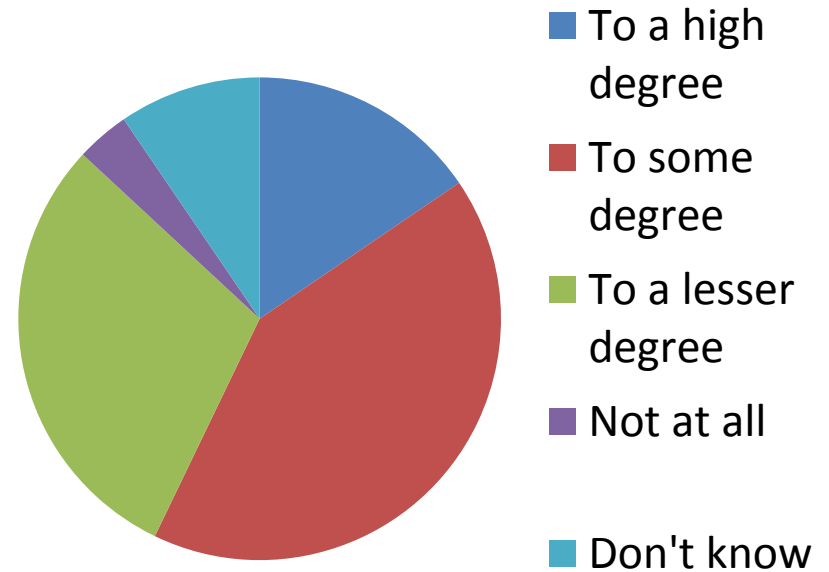


”To which degree did/does having a mental illness dominate your self-perception – before and after becoming an ambassador in ONE OF US?”

## Before



## After



No more doubt, silence and taboo about mental illness!

# Ambassadors turning points

My first presentation was at a school for social and health assistant students in 2011. The teacher was also there for a presentation that I did at the end of 2016 at a different school for social and health assistant students. The response I got from her was about the enormous self-confidence that I have gained since I first started – and that was golden. She could see a gigantic development in me from A to B. I think it was also a turning point for her because in 2011 I was in a rough spot. And now I am a different person so I think it proved to her that a person with schizophrenia can get well.



## Reduced self-stigma

I have become more confident because I'm in no way ashamed to say that I have this diagnosis which was hard for me to say before. Maybe because I was a little ashamed of it. I'm not at all anymore. In any way.

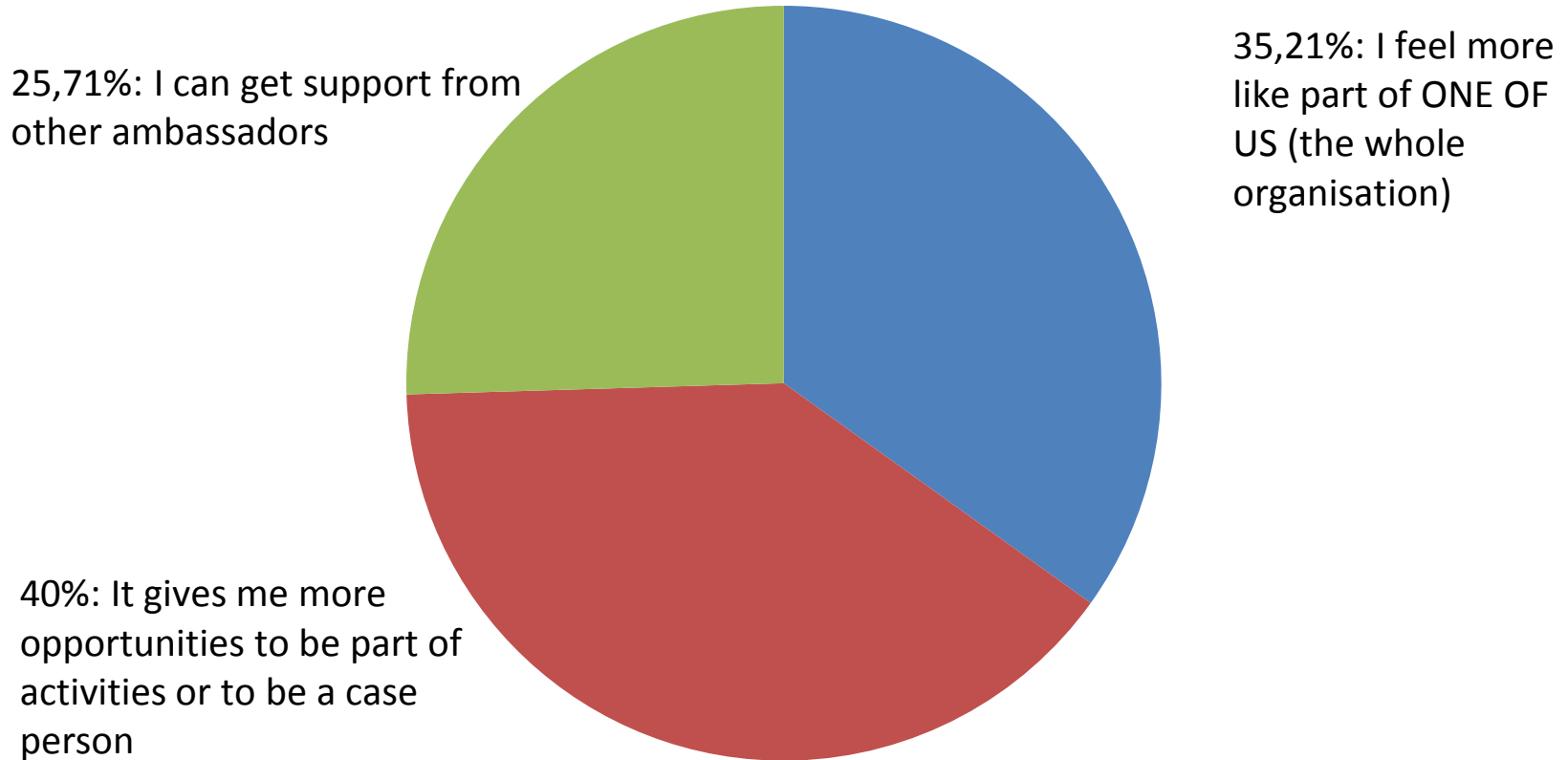
It has gotten much easier to talk about because I have become more serene about being something that people just have to accept. There's no debate. Before, I would think 'oh no, are they ok with it?' I see it in a completely different light now.

# Ambassadors' recommendations

- A good 'welcome' with introduction and training
- Focus on the community in the group of ambassadors
- Recognition of ambassadors' effort and contributions
- All ambassadors should be given a chance to be involved



# Facebook group for ambassadors



**80 % of the ambassadors are members of the ambassador facebook group**

**62 % are active on the public ONE OF US facebook page.**



No more doubt, silence and  
taboo about mental illness!

# Questions?