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<td>Hennessy, Eilis</td>
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How to tackle stigma and bias: Lessons from childhood diseases and disabilities

Eilis Hennessy
ASOI Conference, Belfast, 7 May 2014

A systematic review of childhood interventions to reduce stigma towards peers with disabilities and chronic health conditions
- Charlotte Silke, National University of Ireland, Galway
- Diarmuid Stokes, James Joyce Library, University College Dublin
- Caroline Heary, National University of Ireland, Galway
- Lorraine Swords, Trinity College Dublin
Structure of the talk

- The importance of tackling the stigma of obesity.
- How stigma develops
- The components of stigma
- The nature of anti-stigma interventions
- Do interventions work?
- Limitations of anti-stigma interventions to date
- How to move forward

Why tackle the stigma of obesity?

- Stigma has implications for help seeking (Puhl, Peterson & Luedicke, 2011).
- May result in victimization (Griffiths et al., 2006)
- Has negative academic consequences (Krukowski et al., 2009)
- May increase unhealthy eating habits (Benas & Gibb, 2008)
- Social justice
The importance of tackling stigma early in life

- Attitudes form early (Bigler & Liben, 2007)
- Once formed, attitudes are difficult change
- Children and adolescents learn important social skills from their peers and this learning will be threatened if they are rejected

Many conditions are stigmatized

- Obesity
- Mental health problems (e.g. ADHD, depression)
- Developmental disabilities (e.g. autism, Tourette’s)
- HIV/AIDS
- Epilepsy
- Sickle cell disease
- Facial disfigurement
Conditions necessary for stigma to develop (Bigler & Liben, 2007)

- Become aware of the way in which the stigmatized group are different:
  - Notice physical/behavioural differences
  - Hear the group being labelled
  - Notice that group are treated differently
- Use that difference as a basis for classifying new people
- Learn negative stereotypes and prejudices about this group
  - Hear people make explicit negative statements
  - Note differences in presentation/roles

The components of stigma

Hinshaw & Stier, 2008
Stereotypes

She is lazy

He is unhealthy

He could lose weight if he tried

Prejudice

I feel disgusted

She makes me angry

He makes me feel frustrated
Discrimination

- I don't hang out with him
- I wouldn't want to be seen with him
- It is okay to call him names

Stigma is not only a personal issue

- The conditions that are stigmatized vary from country to country.
- Stigma can change over time.
- Therefore it is important to consider the social context of stigma: this is most evident in the way in which people’s stigma responses are influenced by their perception of other people’s beliefs.
Classifying anti-stigma interventions

- Which aspect of stigma are they trying to change?
  - Stereotypes
  - Prejudices
  - Perception of others’ beliefs

- How are they trying to change it?
  - Education
  - Contact
  - Social norms
  - Social activism

Changing stereotypes

- Challenge stereotypes (manipulation of beliefs about causes & controllability):
  - Contact: structured encounter with someone with the stigmatised condition.
  - Video-based contact: video depiction of someone with stigmatized condition.
  - Education: interventions that present factual information about the nature of the condition and frequently challenge stereotypes
Changing prejudices

• Evoke empathy, acceptance and liking through:
  – Contact: structured encounter with someone with the stigmatised condition.
  – Video-based contact: video depiction of someone with stigmatized condition.

Changing (perceptions of) society’s views

• Challenge social consensus and social norms
  – Provide information on normative beliefs
  – Counter the negative images
Do interventions work?

- Bozkaya (2010): Intervention to counter the stigma of epilepsy.
- Single lecture + discussion that provided info on types and manifestations of epilepsy, diagnosis, first-aid, and causes. Practice with a simulated patient, video of seizure and case-based discussion.
- Concludes that there were changes in knowledge and attitudes but more change in the former.

Do interventions work?

- Holtz et al. (2007) School based intervention to counteract stigma of Tourette’s. One 45 minute intervention (video presentation + Q&A).
- Random allocation to experimental or control (saw different unrelated video) groups. Post-testing carried out immediately after the intervention.
- Change in knowledge, positive attitudes, and behavior intentions or social acceptance was significantly greater in experimental group than the control group.
Do interventions work?


- Review of ‘anti-fat’ stigma interventions
- 16 articles found – generally pessimistic about the ability of the methods designed to change beliefs about causes and controllability or to evoke sympathy. More positive about social consensus and combined approaches.

Do interventions work?

- Corrigan et al., (2012), meta-analysis of (72/119) interventions to challenge the stigma of mental illness: compared education; contact; social activism.
- Social activism did not produce change; for adults contact effect > education; for adolescents education > contact. Some variation depending on outcome variables (attitude, prejudice, discrimination).
Serious problems with almost all anti-stigma interventions

- Many do not have a strong theoretical structure guiding intervention design.
- Flaws in design: dearth of RCT investigations; many studies do not include control groups; failure to measure long term changes in attitudes/behaviour.
- Flaws in research methods: use of unvalidated measures; no measures of behaviour change; use of measures with potential for social desirability bias.
- Flaws in reporting: failure to adequately describe interventions, populations, implementations, evaluations, outcomes and results.

Do interventions work?

- Probably!
- We have evidence of the kinds of intervention that hold the greatest promise.
- We have evidence of interventions that are acceptable in different settings (schools etc.)
- We have suitable measures of outcome.
- We know the kinds of research designs and data that are needed to answer the question.
Way forward:

• Interventions need to start early in life because stigma and prejudice become established early.
• Interventions should be on-going throughout the year and should build on empathy and understanding of others’ feelings and lives, as children develop cognitively, socially and emotionally.
• Should ideally involve parents, teachers, school administrators.
• Interventions should be evaluated in real life settings using RCT design and valid, reliable measures.
• Evaluations of RCTs should include behaviour as an outcome measure.
• Evaluations should routinely involve checking for the possibility of harm.

References