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Using the Social contact approach in researching marginalized groups

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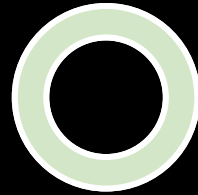
CGMH
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MENTAL HEALTH



Spark



About Me



Supporting African communities
to improve mental health in kids
with developmental disorders



outline



Social contact What, when and why ?



Evidence for this approach



What we planned to do for our project



What we did and learned



Working with Vulnerable groups




Learning from your experiences in this area



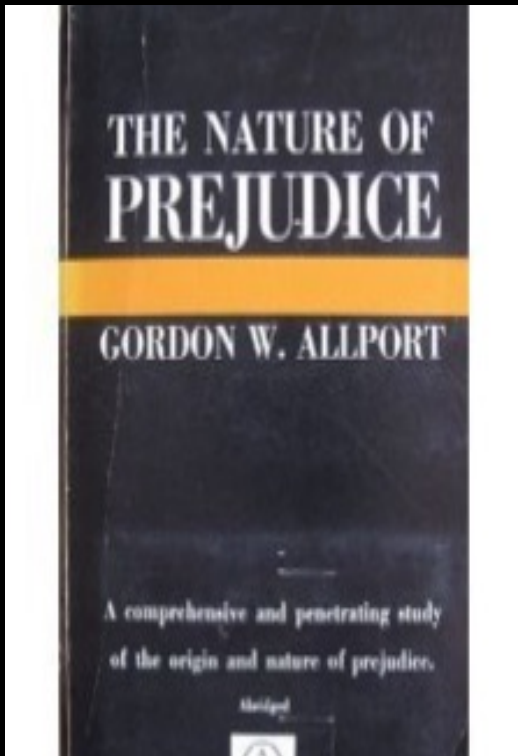
Reflections



History

- Historically writers argued contact between groups under conditions of equality would only breed “suspicion, fear, resentment, disturbance, and at times open conflict” (Baker, 1934, p. 120).
 - Others proposed that intergroup experiences could lead to “mutual understanding and regard” (Lett, 1945, p. 35) and that when groups “are isolated from one another, prejudice and conflict grow like a disease” (Brameld, 1946, p. 245 and Watson, 1946).
 - Us Merchant Marine:- the more voyages the White seamen took with Blacks, the more positive their racial attitudes became (Brophy (1946)
 - White police officers who worked with Black colleagues later objected less to having Blacks join their police districts, teaming with a Black partner, and taking orders from Black officers (Kephart, 1957)
 - Robin Williams’s “The Reduction of Intergroup Tensions” offers 102 testable “propositions” of intergroup contact theory(William, 1947).
- 

Social contact...what is it?



- “The Nature of Prejudice, Allport (1954)” formally proposed the contact hypothesis that social contact between majority and minority group members would lead to changes in attitude.
- For the change in attitude to be favourable towards the prejudiced group, 4 preconditions need to be met.
- Equal status between groups
- Common goals
- Intergroup collaboration and
- Support from authorities






A Meta-Analytic Test of Intergroup Contact Theory

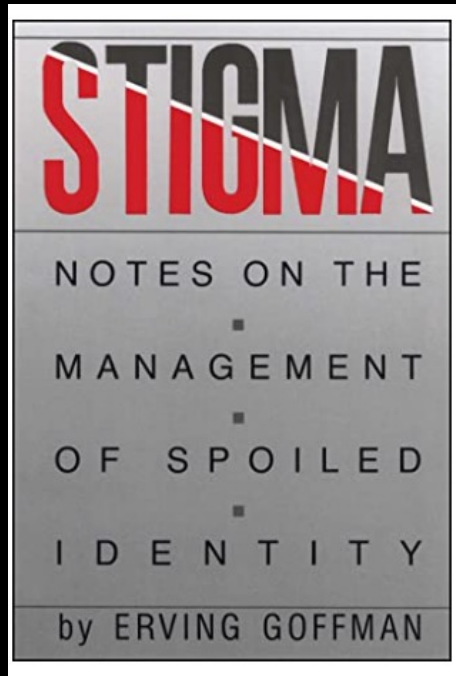
Thomas F. Pettigrew
University of California, Santa Cruz

Linda R. Tropp
Boston College

- Review of 713 independent samples from 515 studies.
 - To test Allport's hypothesis by asking
 1. Does intergroup contact decrease prejudice?
 2. Evaluating the role of Allport's conditions
 - The meta-analytic results clearly indicate that intergroup contact typically reduces intergroup prejudice.
 - A global indicator of Allport's optimal contact conditions demonstrates that contact under these conditions typically leads to an even greater reduction in prejudice.
 - Intergroup theory has been tested with participants of varying ages and with target groups as diverse as the elderly, physically disabled, and mentally ill participants.
- 



Social contact in Psychology research



- Stigma is a social, interpretive, and cultural process, with an interpersonal core.
- Defines stigma as “an attribute that is deeply discrediting” (Goffman, 1963)
- The stigmatized person is reduced “from a whole and usual person to a tainted discounted one”.
- Processes of social construction is central to making stereotypes.
- “a special kind of relationship between an attribute and a stereotype”

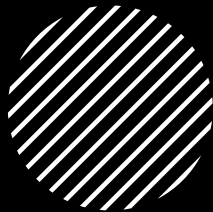


Effects of Structured Cooperative Contact on Changing Negative Attitudes Toward Stigmatized Social Groups

Donna M. Desforges, Charles G. Lord, Shawna L. Ramsey, Julie A. Mason,
Marilyn D. Van Leeuwen, and Sylvia C. West
Texas Christian University

Mark R. Lepper
Stanford University

- 3 stages identified.
- **Expectation stage:**--Initial contact based on negative stereotypes.
- **Adjustment stage:**- negative stereotypes may not be grounded in empirical reality, the outgroup individual may make a more positive impression than expected alleviating the discrepancy by positively adjusting their attitude.
- **Generalization stage:**- the in-group member may apply that positive attitude adjustment to all members of the out-group.





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Schizophrenia Research 69 (2004) 175–182

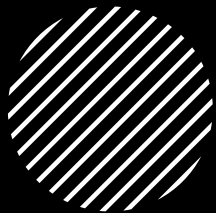
SCHIZOPHRENIA
RESEARCH

www.elsevier.com/locate/schres

Familiarity with mental illness and social distance from people with schizophrenia and major depression: testing a model using data from a representative population survey

Matthias C. Angermeyer^a, Herbert Matschinger^a, Patrick W. Corrigan^{b,*}

- A representative survey involving 5025 adults was carried out in Germany.
- A structured questionnaire presenting a vignette depicting someone with either schizophrenia or major depression was used.
- Respondents were asked to respond to measures assessing familiarity, perception of dangerousness, fear, and social distance.
- Respondents who were familiar with mental illness were less likely to believe that people with schizophrenia or major depression are dangerous corresponding closely with less fear which in turn was associated with less social distance.



The Lancet Commissions


The *Lancet* Commission on ending stigma and discrimination in mental health







- Umbrella review of 216 systematic reviews shows that interventions based on the principle of social contact that has been appropriately adapted to different contexts and cultures are the most effective ways to reduce stigmatization worldwide.
- Evaluation of 10 large-scale anti-stigma programs, indicated that they are most effective when PWLE are involved as co-producers at all levels of development.



Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey

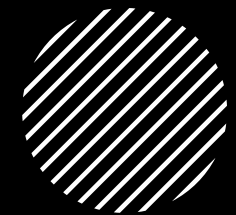
[Dejene Tilahun](#), [Charlotte Hanlon](#) , [Abebaw Fekadu](#), [Bethlehem Tekola](#), [Yonas Baheretibeb](#) & [Rosa A. Hoekstra](#)

Parents' and Professionals' Perceptions on Causes and Treatment Options for Autism Spectrum Disorders (ASD) in a Multicultural Context on the Kenyan Coast

[Joseph K. Gona](#) , [Charles R. Newton](#) , [Kenneth Rimba](#) , [Rachel Mapenzi](#) , [Michael Kihara](#) ,
[Fons J. R. Van de Vijver](#) , [Amina Abubakar](#) 

Why Social contact approach for our project?

- The aim of the project is to co-develop a tool for community case detection and associated training package in order to increase community-based detection of children with DD and promote care engagement in Ethiopia and Kenya.
- One of the most important factors for low detection in these settings is the stigma towards children with DD and their caregivers.

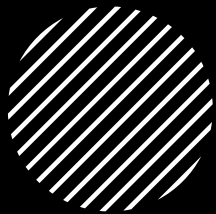




What we did and learned

- 8 stakeholder consultation workshops (2 in each site) to understand the **needs and priorities** of the local community.
- Stakeholder groups included:
 - ✓ caregivers of children with DD
 - ✓ community health workers
 - ✓ teachers
 - ✓ policymakers
 - ✓ health and education professionals





- High stigma and low awareness about DDs in the community.
- DDs often attributed to supernatural causes, spirit possession, and wrongdoing by parents.
- Awareness-raising for the larger community was suggested to promote community engagement and address negative beliefs.
- Involvement of caregivers of children with DD informed by the social contact theory



How?

- Caregiver training using the **photovoice approach**.
- This approach trains PWLEs to tell their stories using pictures that represent their recovery journey.
- They will be trained on how to use cameras, how to take good quality pictures, public speaking skills, empowerment, and how to tell a recovery narrative.
- PWLEs who completed the training will then tell their recovery journey using photos(images) that represent their experience before, during, and after the condition they are living with.
- 3 caregivers of children with DD were trained on this approach in rural Ethiopia.

SOCIAL CONTACT VIDEO (Life Testimony) CHECKLIST

Introduction

Orientation to the audience: Introduction and summary of what they are going to say

Introduce yourself and what you are going to talk about. Give background context. Please give information about the following as comfortable as you are, you can give or skip a particular question based on the level you want to share with the audience. This will help orient and contextualize for your audience to contextualize

- Who you are
- Where you live
- What you do for a living
- How many children you have
- The child you are going to talk about, how old the child is e.t.c
- Why you are doing the video recording or testimony

2 REALIZATION and IMPACT

2.1 Identification

- What are some of the challenges your child faces?
- How did you come to know about these challenges? Comparison with other children/ Hospital visits/ Concerns from other members of the family/ concerns from school/ a combination of these or other

2.2 Emotional response

- What did you feel about this realization?
- Reflect on both positive and negative emotional responses

2.3 Impact on daily functioning for your child?

- Activities of daily living
- Making friends
- School
- Participating in social activities such as birthdays

2.4 Impact on in family functioning

- family, marriage (optional)
- friends and colleagues
- work

2.5 Stigma and discrimination:

- What is your experiences been in your community?
- What impact have these stigma experiences had on your relationships, participation in social activities and access to services and support

3 ACCEPTANCE and COPING

What was your experience like?

What helped you cope Any challenges you faced?

What worked well?

4

Treatment/ Interventions

Describe any kind of formal or informal support you have received in your journey

What kind of help they were you able to get to get help/assistance to support your the child with DD? (Talk about all that apply from list below)

- Medical and rehabilitation services
- Educational
- Support groups
- Family
- Religious institutions
- Financial aid
- Legal support

What was the impact of the help/assistance you get for where you are now?

5 NOW – AFTER GETTING ASSISTANCE/ASSISTANCE/TREATMENT

5.1 What are the concrete change in relation to decrease of their symptoms?

What has improved in your child functioning?

What has improved in family functioning?

Positive reflection on child's abilities

5.2 Impact in their family, friends and colleagues

5.3 How are they functioning? Home, Work

6 Empowerment and appreciations

What have you learned from your and your child's journey?

What are you most proud of?

What are you most thankful for during your journey?

e.g Thanking the health workers and counselors who helped you them and what it means in your their life

Or family members/ people in your life who helped you through this

7

Reflection on the testimony

Please reflect on what it has been like for you to give this testimony.

How was the process?

Reflection on the impact this testimony might have in your own words

Any message you have to other families going through similar experiences

Thanking them for listening to their stories and telling them they have the power to bring changes in people like them

8

Closing

Thanking the audience for listening to their stories and telling them they have the power to bring changes in people like them

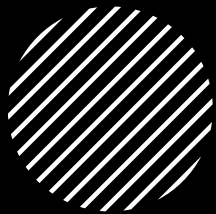
Thanking the audience for their time and attention ADD CAREGIVERS PART

Any message they have to other families going through similar experiences



When?

- We conducted 4 community sensitization events at each site inviting members of the local community, religious and village elders, women and child affairs representatives, and health and education officers.
- In each sensitization event, a caregiver of a child with DD shared their lived experience of stigma, discrimination, and their recovery story.
- Stigma is also prevalent among health care and education providers.
- We trained health care and education workers (Community support workers) to conduct community-based detection and caregivers were invited to give testimonies in these trainings as well.
- Qualitative data being collected to evaluate the effect of these testimonies on negative beliefs towards children with DD and their caregivers.







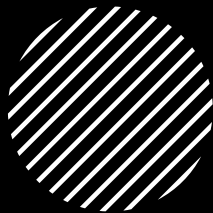
Working with vulnerable groups

The Lancet Commissions

The *Lancet* Commission on ending stigma and discrimination in mental health



- The Lancet Commission on ending stigma surveyed 391 respondents among which 181 were involved in a direct anti-stigma social contact intervention.
- 3 main categories of survey questions were asked.
- What was most difficult with your involvement in the anti-stigma programs?
- What made your involvement in anti-stigma programs more rewarding?
- Recommendation on how to best involve PWLEs in anti-stigma program development



Illustrative quotations

What was most difficult with your involvement in anti-stigma programmes?

- Encountering stigma (eg. ignorance, lack of sympathy, blame, pity)
- Reliving past difficult experiences
- Coping with others becoming upset
- Challenging interpersonal encounters during and after programme involvement, and with health professionals
- Tokenistic involvement
- Practical challenges (eg. time commitments)
- Feeling anxious or nervous
- Lack of awareness and recognition of mental health
- Engaging the intervention target group

- "The most difficult thing is the moralisation and condemnation of people with health problems. False beliefs of ordinary people about vulnerable people. It is often said that [they are] to blame for their own problems" (Republic of Kyrgyzstan)
- "The hardest bit is being asked to describe your own experience as this means reliving at least some of how you felt through that and it is painful to do so" (UK)
- "I think it's to share past experiences that might bring back some unpleasant memories" (Hong Kong)
- "[It is] hardest to share a story or deliver a workshop if a safe space is not created first" (Norway)
- "...when organised by professionals, they don't know how to work with us" (Spain)
- "One of the most important barriers that I have found, are the people who consider that mental illness does not exist, it has been difficult for me to work with this population. They become fundamentalists and it is very difficult to establish a dialogue" (Uruguay)

What made your involvement in anti-stigma programmes easier or more rewarding?

- Training and support with shaping one's narrative
- Practical support at an organisational level
- Receiving payment for the involvement
- Having expertise through experience validated
- Feedback on the impact of the programme
- Peer support
- Personal sense of satisfaction

- "It takes training to turn one's own experience into a story of hope" (Hong Kong)
- "Certainly, payment offers a way of validating how serious the sponsoring group is in their message" (USA)
- "Critical to pay people if possible. Sharing a lived experience is a vulnerable thing, and a skill. It should be paid in the same way other work should be paid" (Norway)
- "It's the confidence in my skills, and the fact that I'm treated like a teacher. Like another" (Switzerland)
- "I believe feedback on what I've delivered has been the most beneficial and rewarding" (Ireland)
- "I also treasure the peer support within the organisation. We need a safe organization to grow and learn" (Hong Kong)

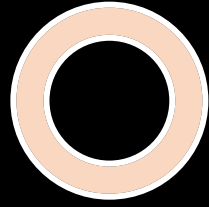
Recommendations for how to best involve PWLE in programme delivery

- Including PWLE at every stage of programme
- PWLE in leading positions of programme activities
- Participation arranged on terms of PWLE
- Involving people at appropriate stage of recovery
- Involving diverse range of people
- Provided a platform to share their lived experience
- Include facilitative factors: training, payment, and instrumental support
- Prepare for challenges

- "Be convinced that people with lived experience in mental health are essential for the execution of programmes" (Spain)
- "Include them [PWLE] in the design of the programme and not as recipients or participants of something already decided" (Argentina)
- "Include them [PWLE] from the beginning of the process in the reflection on the programme (not just like 'testimony machines')" (Switzerland)
- "Participants can stop sharing at any time, and can choose the content they want to share, which is protected and cared by the provider to avoid pressure from third parties [institutions, groups]" (Hong Kong)
- "Support helping people who are reluctant to share or fear retribution to feel empowered and to deliver their message in a way that resonates with the intended audience and also makes the sharer know how important their candour is on so many levels" (USA)
- "Provide training and workshops to make it easier for me to reflect such as searching for my soul" (Hong Kong)


PWLE=people with lived experience of mental health conditions.

Table 2: Key findings from the lived experience survey about participating in anti-stigma programmes




- Distress from disclosures and testimonies.
- Feeling the negative impacts of being exposed to stigmatizing audiences and co-workers.
- The importance of training, feedback, and peer support was emphasised.
- Providing a safe space to share and exit.
- Importance was placed on the need for PWLE to be involved in every step of program development.





Working with Vulnerable groups

- When working with vulnerable groups like caregivers of children with DD, we need to take into account some factors.
 - Are we predisposing participants to an increased risk of stigmatization?
 - Are we taking into account the power dynamics?
 - Are participants benefiting from the experience?
 - Do the benefits outweigh the risk?
- 



Your experience and reflections

- Have you been involved in an anti-stigma program?
- What was your experience?
- What can we learn?
- Reflections????





Thank you !!!

