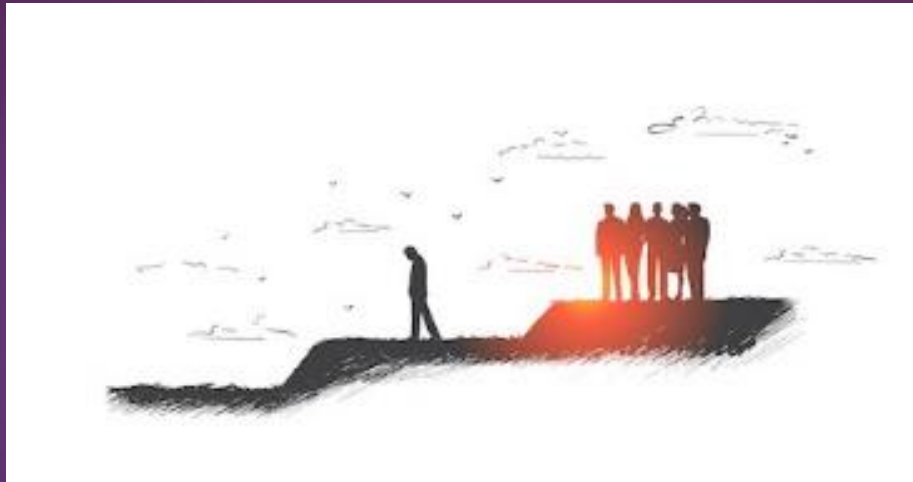


# The Stigma of Tourette's Syndrome



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# Outline of Presentation

- ❖ **What is stigma?**
- ❖ **Why is studying stigma so important?**
- ❖ **Stigma and Tourette's syndrome**
- ❖ **Our study on stigma of Tourette's syndrome**

# What is Stigma?

- ❖ **Visible** or **invisible mark** that reduces the bearer from a whole and “usual” person to a tainted one (Goffman, 1963).
- ❖ The mark separates “**us**” from “**them**,” and people possessing it experience **status loss** and discrimination (Link & Phelan 2001).
- ❖ “Stigmatised individuals possess (or are believed to possess) **some attribute, or characteristic, that conveys a social identity that is devalued in some particular social context**” (Crocker et al., 1998).

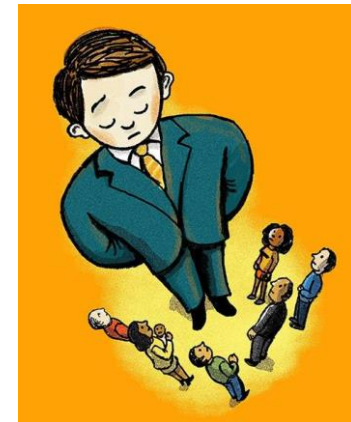


# What is stigma?

Components	Stigma
Cognitive- Stereotypes	<b>Negative belief about a group.</b> For example, all people with Tourette's have coprolalia
Affective- Prejudice	<b>Agreement with belief and/or negative emotional reaction.</b> For example, anger and fear
Behavioural-Discrimination	<b>Behavioural response to prejudice. For example avoiding hiring people with Tourette's syndrome</b>

# Forms of stigma

- ▶ Stigma manifests at an interpersonal interaction (**individualised stigma**) micro-level stigma
- ▶ Stigma is applied by agencies, institutions, and laws inhibiting access to power and resources. It consequently constrains the opportunities, and wellbeing for stigmatised populations (Hatzenbeuhler & Link, 2014). **Structural stigma** can be intended or unintended. Macro-level stigma
- ▶ **Self-stigma**- Negative beliefs about the self, prejudice and discrimination towards self e.g., not pursuing employment or social activities
- ▶ **Courtesy stigma**- devalued through association with stigmatised person



# Why is examining stigma important?

- ▶ Stigma is associated with diminished Quality of Life and negative effects on psychological well-being, self-esteem, self-perception, group-identification
- ▶ We need to be exposed to the narratives of the marginalised.
- ▶ Interventions that aim to combat stigma should be based on what stigmatised individuals highlight as more deprecating and devaluing in the way they are viewed and treated by the society.



# Tourette's syndrome and stigma

- ▶ The study of stigma has been primarily attached to conditions such as mental illness or HIV
- ▶ Beside the hurdles, children and adolescents with TS endure because of the manifestation of tics, narrative testimonies of youth with TS provide extensive accounts of stigmatisation, harassment, bullying and teasing.
- ▶ Research on Tourette's stigma focuses on general public attitudes and overlooks patients' subjective experiences of everyday stigma arising from significant others
- ▶ Tourette's syndrome may be susceptible to distinct types of negative attitudes that necessitates examining TS stigma individually

# Tourette's syndrome and stigma

- ▶ There are no studies that delve into the first hand accounts of the experience of TS stigma.
- ▶ There is also a scarcity of knowledge pertaining to the extent, nature and impact of Tourette's stigma and factors that influence the level of stigma.
- ▶ The coping mechanisms of people with TS



# Our study about the stigma of Tourette's syndrome

- ▶ The overall **objective** of this study is to provide data regarding the stigma of Tourette's syndrome, constructing a preliminary and in-depth picture of the impact it has on the lives of both adults and youths, which will inform current policy and practice.



# Our study about the stigma of Tourette's syndrome

- ▶ 1. Firstly, through an online questionnaire, to assess the prevalence estimates of stigmatisation amongst individuals with TS; and to measure the impact of Tourette's stigma in an individual's quality of life;
- ▶ 2. Secondly, through in-depth interviews to gain a comprehensive understanding of the everyday difficulties individuals experience as a result of stigma, We will also explore how individuals experience access to support.



# Ethics and involvement of service users throughout the project

- ▶ The study was reviewed and given an ethically favourable opinion by the University of Kent Ethics Committee (November 2018).

- ▶ **Advisory Group was set up**

Consulted in how to best word the questions,

Interview schedule

Study recruitment



# Online Questionnaire



## ONLINE SURVEY

- ▶ **Discrimination and Stigma Scale (DISC-12)**-collects quantitative data to provide a rating of the degree to which discrimination has been experienced in various areas of life including work, relationships, parenting, housing, leisure, and religious activities) using a 4-point Likert scale (Brohan et al., 2013) .

1.	Have you been treated unfairly in making or keeping friends?	Not at all	A little	Moderately	A lot
	Not applicable				



# In-depth Interviews

- ▶ The interview schedule was designed by the advisory group
- ▶ Interpretative Phenomenological Analysis will allow us to understand the subjective lived experiences of the participants



# Data so far...

- ▶ 136 individuals have taken part in the online questionnaire (110 adults, 10 children, 16 adolescents)
- ▶ 3 children have taken part in the one-to-one interview
- ▶ 13 adults with Tourette's syndrome have taken part in the one-to-one interview