Autism Diagnosis as a Social Process

An exploration of clinicians' diagnostic decision making

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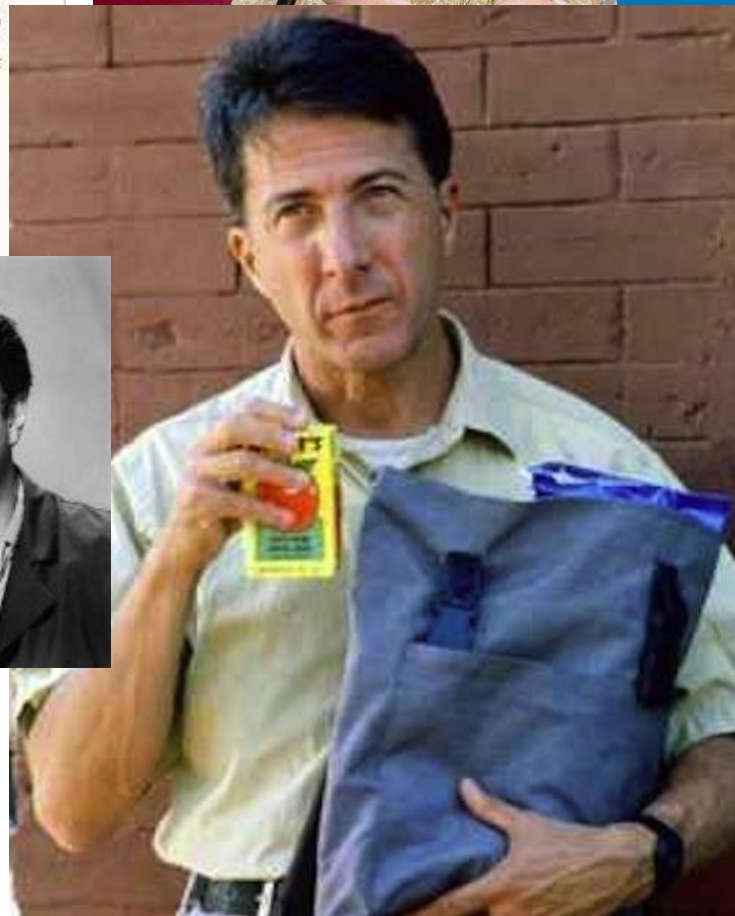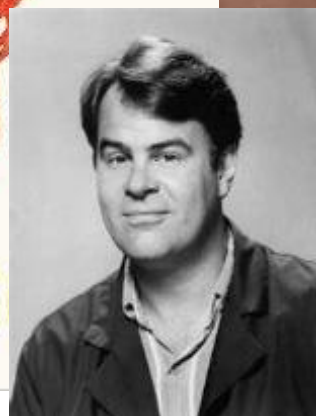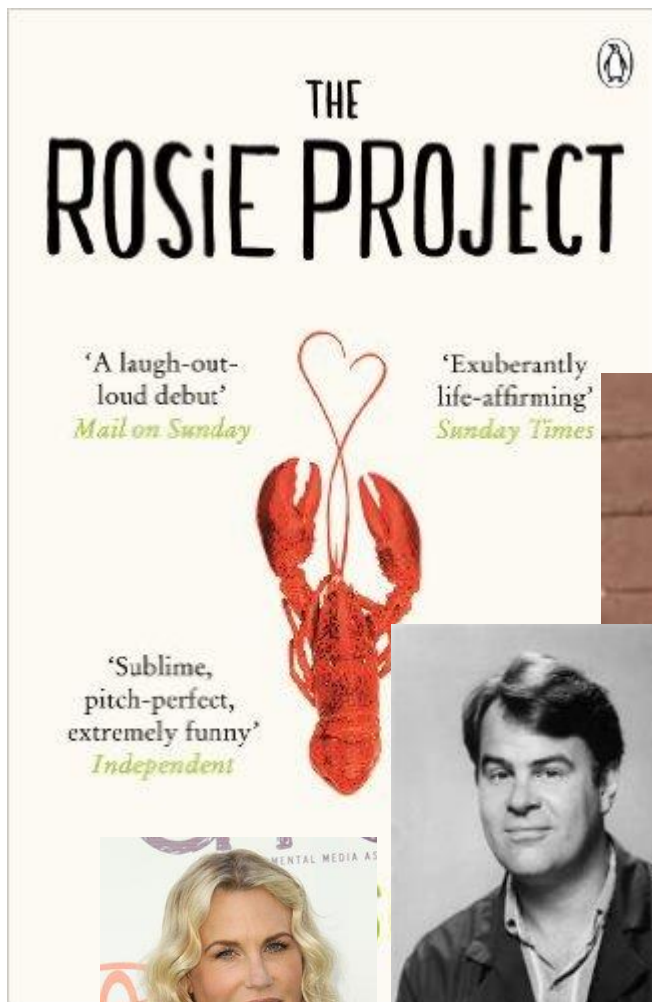Prof Tamsin Ford

Autism and Neurodiversity
Exploring Diagnosis

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Context of study

- Significant increase in rates of diagnosis to about 1% of population

- Evidence that there are geographical 'clusters' of people with a diagnosis

- There is a relationship between socioeconomic status and rates of diagnosis

THE
ROSIE PROJECT

'A laugh-out-
loud debut'
Mail on Sunday

'Exuberantly
life-affirming'
Sunday Times

'Sublime,
pitch-perfect,
extremely funny'
Independent

THE CURIOUS
INCIDENT
OF THE DOG IN THE
NIGHT-TIME

END OIL

MMR DOCS
IN U-TURN
Dramatic retraction KOs autism link

ANTI-MMR SCIENTISTS
CHANGE THEIR MINDS
Major U-turn on triple jab risk

Colleagues withdraw support for
doctor who sparked MMR scare

Retraction
from MMR
authors

Jab scare
climbdown

MMR research
scientists retract
link with autism

MMR authors deny
finding autism link

MMR doctors disown Wakefield study

Diagnosing Autism

- Diagnosed by behaviourally-defined symptoms (wide and diverse range)
- A spectrum
- A lifelong condition
- Early presentation of symptoms
- Must cause significant impairment in social, occupational or other important areas

Persistent patterns of difficulties in:
- Social communication and interaction
- Repetitive and rigid behaviours and interests

APA, 2013
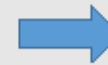
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A sociological view of diagnosis

- Examines how and why particular clusters of symptoms are 'lumped together' or split apart to conceptualise particular conditions

- Sees diagnosis as a social transactional process which clinicians, patients and carers may negotiate

- Sees diagnosis as socially contingent
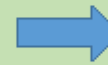
Jutel & Nettleton, 2011

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Some changes in how we think about autism

Caused by 'refrigerator mothers' (Bruno Bettleheim, 1967)	➡	Aetiology (mostly) unknown
Classified as childhood schizophrenia (prior to 1980)	➡	Classified as a pervasive neuro-developmental disorder
Three symptom domains (triad) (prior to 2013)	➡	Two symptom domains

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The meaning of autism?

- Autism means different things to different people at different times in different places

- Neurodiversity movement is challenging what autism means - a disorder or part of a 'normal' range behaviours
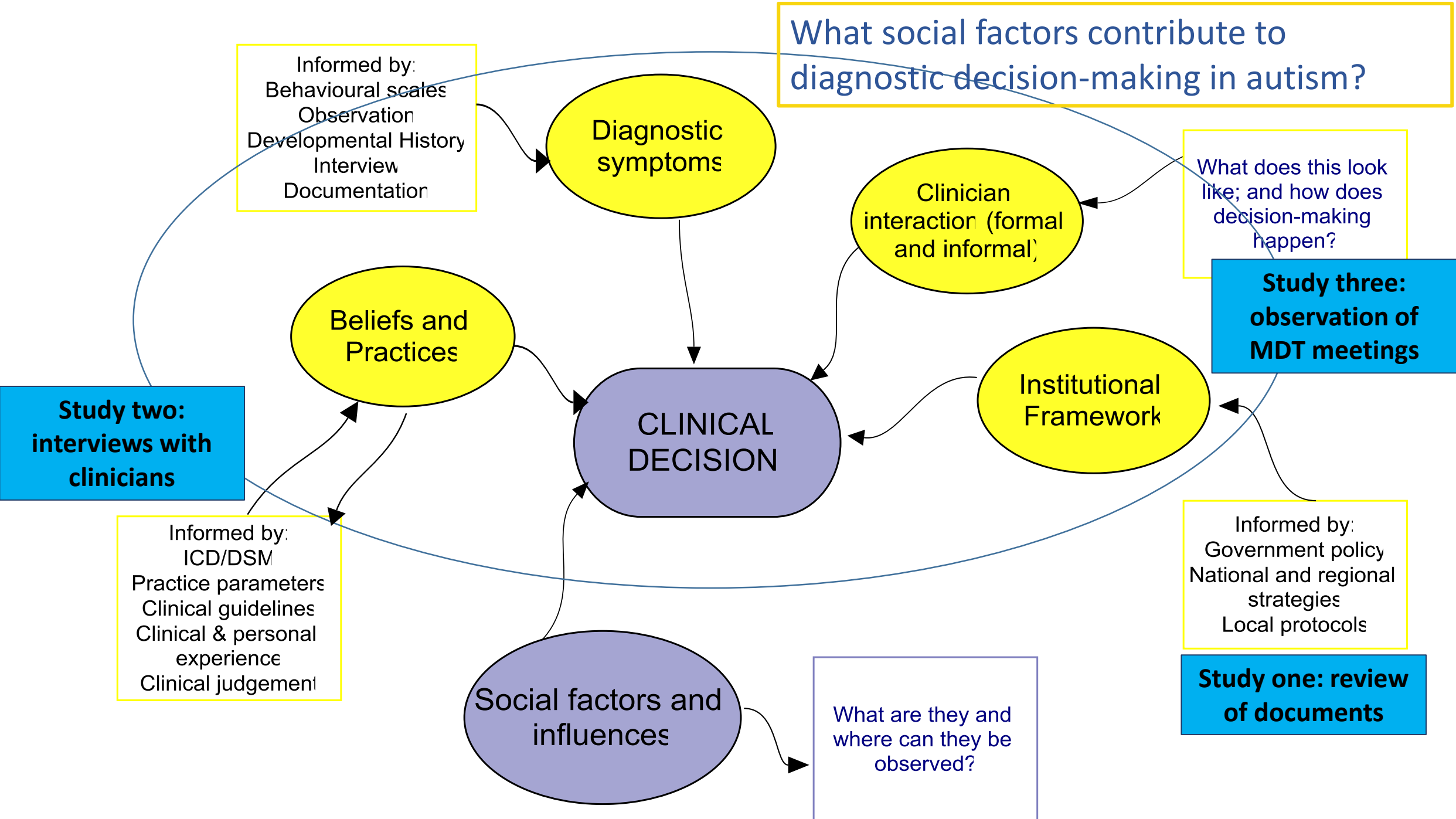
Underlying principles of study

There are **social influences and social processes** in diagnosis which might be possible to see in autism diagnostic processes due to:

- lack of clear threshold for diagnosis within the spectrum (diagnosis as classification requires boundaries) (Jutel, 2009)

- diagnostic criteria being partly based on social interaction and levels of impairment

- dependence on clinical judgement and consensus to resolve uncertainty

What social factors contribute to diagnostic decision-making in autism?

Informed by:
Behavioural scales
Observation
Developmental History
Interview
Documentation

Diagnostic symptoms

Clinician interaction (formal and informal)

What does this look like; and how does decision-making happen?

Study three: observation of MDT meetings

Beliefs and Practices

Institutional Framework

Study two: interviews with clinicians

CLINICAL DECISION

Informed by:
ICD/DSM
Practice parameters
Clinical guidelines
Clinical & personal experience
Clinical judgement

Informed by:
Government policy
National and regional strategies
Local protocols

Study one: review of documents

Social factors and influences

What are they and where can they be observed?

What might social factors be?

- availability of diagnostic resources

- time constraints and patient choice

- perceptions of stigma

Liu et al, 2010; Mazumdar, Winter, Liu, & Bearman, 2013; Fuat, Hungin & Murphy, 2003; Bourret, Keating & Cambrosio, 2011; Whooley, 2010

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The research project

Qualitative study asking:

- What is the institutional and policy framework for autism diagnosis?

- What are clinicians' beliefs, practices and decision-making processes when undertaking autism assessments?

- How do social factors play a role in the formulation of diagnostic decisions around autism in MDT meetings?

Diagnostic symptoms

Institutional Framework

Beliefs and Practices

Clinician interaction (formal and informal)

Purpose and contribution of study

- To identify what social factors influence the diagnostic process

- To identify the key social 'tipping points' for diagnosis

- To make recommendations regarding diagnostic guidelines

- To consider the social processes and consequences of diagnosis

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Thank you!

Questions and comments welcome....