Autism Diagnosis as a Social Process
An exploration of clinicians’ diagnostic decision making

Supervisors:
Dr Ginny Russell
Prof Rose McCabe
Prof Tamsin Ford
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
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
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
Some changes in how we think about autism

- Caused by ‘refrigerator mothers’ (Bruno Bettelheim, 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
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
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?

Study one: review of documents

Study two: interviews with clinicians

Study three: observation of MDT meetings

Informed by:
- Behavioural scales
- Observation
- Developmental History
- Interview
- Documentation

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

Informed by:
- Government policy
- National and regional strategies
- Local protocols

Diagnostic symptoms

Clinician interactor (formal and informal)

Beliefs and Practices

Institutional Framework

Clinical Decision

Social factors and influences

What are they and where can they be observed?

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


References


Thank you!

Questions and comments welcome....