



Autism Diagnosis as a Social Process

An exploration of clinicians' diagnostic decision making

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Autism and Neurodiversity
Exploring Diagnosis

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Context of study

- Growing literature on the sociology of diagnosis and how economic, social, political and cultural practices shape diagnosis (Nadesan, 2005)
- Shifts in diagnostic criteria and resulting clinical guidelines impact on the meaning of autism as a condition
- Significant increase in rates of diagnosis to about 1% of population

A sociological view of diagnosis

- A way of categorising people (as ill or healthy)
- An intervention in itself with consequences for health
- A **social transactional process** which clinicians, patient and carers may negotiate

Jutel & Nettleton, 2011

Diagnosing Autism

- Defined by behaviourally-defined symptoms (wide and diverse range)
- A spectrum
- Lifelong condition
- Early presentation of symptoms
- Causing significant impairment in social, occupational etc. areas

Traditionally a 'triad' with persistent patterns of difficulties in:

- Social communication
- Social interaction
- Repetitive and rigid behaviours and interests



Some changes in how way we think about autism

Caused by 'refrigerator mothers' —————> Aetiology (mostly) unknown
(Bruno Bettelheim, 1967)

Classified as childhood schizophrenia —————> Classified as a pervasive neuro-
(prior to 1980) developmental disorder

Three symptom domains (triad) —————> Two symptom domains
(prior to 2013)



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

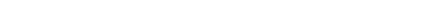
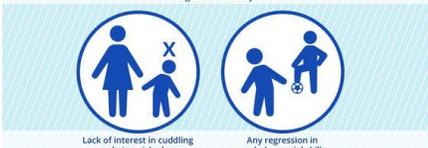
THE NUMBERS BEHIND THE **AUTISM TSUNAMI**

In March 2013, the Centers for Disease Control and Prevention (CDC) released a new study, estimating now that **1 in 50 children in the United States have autism**. Previously, this number was 1 in 88. Some have dubbed this increase an "autism tsunami."

CARING FOR AN AUTIST
HIS OR HER LIFETIME
\$3.2 MILLION

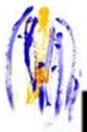
DEFINE
'NORMAL'

SHEKNOWS CANADA **AUTISM WARNING SIGNS**



Source: Autism Speaks Canada

We're
Autastic!

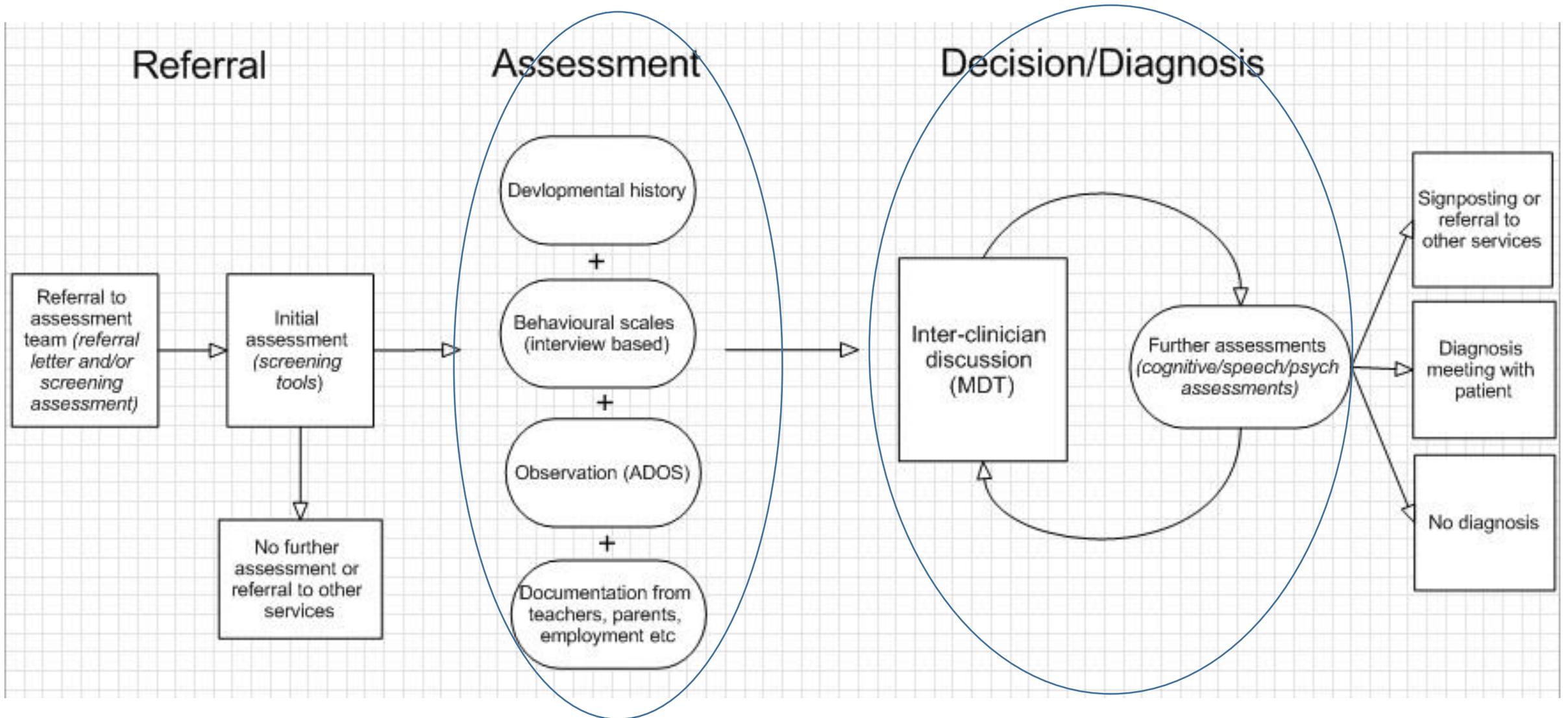


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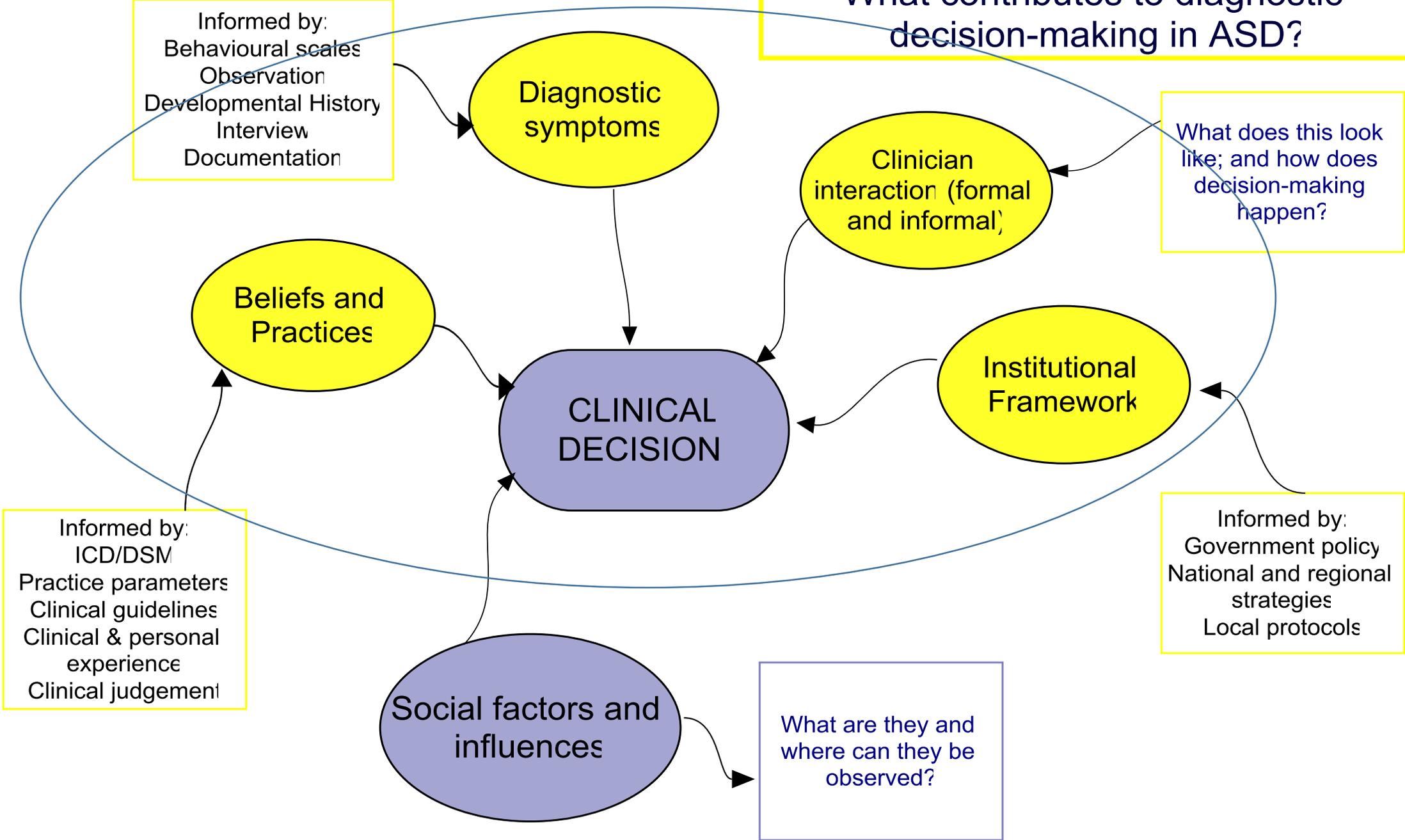
Diagnostic assessment process in UK



Underlying principles of study

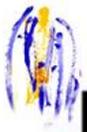
- There are **social influences and social processes** in diagnosis which might be possible to see in ASD diagnostic processes due to:
 - lack of clear threshold for diagnosis within the spectrum (diagnosis as classification requires boundaries) (Jutel, 2009)
 - lack of biomarkers and uncertainty about underlying biology
 - diagnostic criteria being partly based on social interaction and levels of impairment
 - the way in which diagnosis is negotiated between clinicians in MDTs
 - dependence on clinical judgement and consensus to resolve uncertainty
 - the role of the patient's family in assessing the impact of behavioural symptoms

What contributes to diagnostic decision-making in ASD?



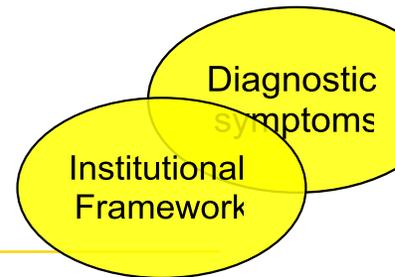
Research Questions

- What is the institutional and policy framework for autism diagnosis in both adult and child diagnosis?
 - What are clinicians' beliefs, practices and decision-making processes when undertaking assessments of people who may have an assessment of ASD in secondary care?
 - How are diagnostic decisions around autism formulated?
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Study one: policy framework

- Review of autism policy and strategy documents in UK; NICE clinical guidelines; National Autism Strategy; statutory guidance; practice parameters
- Content analysis to pull out the social-contextual factors and social processes in ASD diagnosis



Study two: clinicians' beliefs, practices and decision-making processes

- Clinicians' interviews
- Consideration of factors included in diagnostic process with a focus on:
 - Uncertainty ('borderline' cases)
 - Disputed cases
- Thematic analysis

Beliefs and Practices



Study three: formulation of diagnostic decisions

- Observation of Autism Assessment Team's MDT meetings
- Focus on clinician interaction towards the decision-making process
- Conversation analysis

Clinician interaction (formal and informal)



Purpose of study

- To identify what (if any) social factors influence the diagnostic process
- To identify the key social ‘tipping points’ for diagnosis
- To consider the implications of the ‘meaning’ of autism as a medical category and the impact on diagnostic practice



Thank you!

Questions and comments welcome....

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