

Bridging the gap between diagnosis and intervention



Foundation for the Sociology of Health & Illness



Introduction and setting the agenda

- Thanks!
- Speakers – Sarah Nettleton, Celia Roberts, Oonagh Corrigan
- Objectives of the workshop
 - 1. Introduce the Health, Technology & Society (HTS) research group
 - 2. Explore connections between the sociology of diagnosis and the sociology of intervention
 - 3. Identify research questions/agendas for possible future bids and/or collaborative work



Dr Michael Morrison (comparative technological innovation; sociology of diagnosis)

Dr Anna Harris (DTC GT; culture & medicine)

Dr Hannah Farrimond (diabetes & pre-diabetes in families)

Dr Daniele Carrieri (NF1; complex, variable genetic conditions in families)

Dr Ginny Russell (diagnosing childhood disorders; mental health group PCMD)

Christopher Elphick ('Utilities' of psychiatric genetic tests)

Mila Petrova (philosophy of science perspective on health research synthesis)

Dr Susan Kelly – Director (Genomics & medicine, e.g., non-invasive prenatal diagnosis and next generation sequencing; consent for research; sociology of intervention)



HTS group: Indicative questions

- How do novel technologies affect diagnostic practices?
 - How are increasingly complex pathways to diagnosis experienced by patients?
 - What are drivers and consequences of innovations in diagnostic technologies?
 - Can a critical sociology of diagnosis speak to conventional health technology assessment programmes?
 - How can we foster interdisciplinary collaborations to address these questions?
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- ESRC Seminar Series on Sociology of Diagnosis

What is this gap?

- A gap in understanding between (the sociology of) diagnosis and (the sociology of) intervention which needs to be theorised and researched. Possible questions include:
- If changing diagnostic methodologies can reframe the boundaries and meaning of disease categories how does this affect the meaning and choice of available interventions, and the subsequent trajectories of disease management, for patients and physicians?
- Do new diagnostic technologies affect existing organisational practices and if so how and with what outcomes? For example, if a new diagnostic technology allows diagnosis earlier in the life-course or earlier in the medical management of a life event such as pregnancy, does this give new responsibilities to particular professional groups (e.g. nurses, midwives, lab technicians), and does it reduce or alter the role of other groups (e.g. genetic counselors)?
- Is earlier (diagnosis) leading to earlier (intervention) always better? In what ways or under what conditions might different outcomes occur? Can we theorise this?
- To what extent, if at all, are changing diagnostic technologies, which may entail new levels of diagnostic accuracy and specificity, incorporated into the healthcare technology assessment procedures for pharmaceutical or other interventions?

Sociology of intervention

- Phenomenology of impairment (Hughes and Paterson 1997)
- Social production of childhood impairment (Leiter 2007)
- Socio-historical contexts of research on families and disability (Ferguson et al. 2000)
- Literature on parents' decision making and genetics emphasises autonomy and risk
- Literature on parents, health, risk and behaviour – 'responsibility' central theme
- Scant literature on 'intervention' – risk again prominent framing concept (e.g., Shim et al. 2006)

Early Intervention

- Screening childrens' health and development during well child visits in US began in the 1920s (Halpern 1988)
- Early Intervention (EI) programme created by the US Congress in 1986 under the Individuals with Disabilities Education Act (IDEA) and fully implemented in the 1990s
- 2001 American Academy of Pediatrics policy statement recommended pediatricians regularly screen children for referral for early intervention services

**Ashley X – parents’
controversial choice to
‘intervene’**

**‘The case of Ashley X -
the American child with
learning disabilities who
has had surgery and
other treatment to keep
her body "childlike" - has
triggered a debate about
medical ethics’. (Adams-
Spink 2007 BBC)**



Parents' experiences of childhood impairment

- In-depth narrative interviews with parents (80)
- Interviews with geneticists and genetic counsellors
- Field and clinic observations
- Parents' narratives of decisions concerning biomedical, rehabilitative and social interventions into childhood impairment
- Secondary analysis of narrative data
- Trajectories and stories of impairment, intervention decisions and outcomes

Case A

- EE: I always have a feeling that I should, you know, *I should be doing more....though. I always have that feeling*, you know, that that...that, but I think that...
- ER: And his surgeries are to do what?
- EE: He was born with club feet, where his feet would turn in, and that...we were cor...he's had...surgery for his feet, and he's had knee surgery...to correct the... tried to correct the, uh... contractures, the contract...like he was born with his...knees bent.

Case A

- ER: Does...how does he do with the surgeries?
- EE: Um...he, he does okay. He it, is...they give him medicine when we go in there to...to make him calm, you know, to try to help him be calm when he goes back. Um...sometimes it works. Sometimes it doesn't, you know.
- ER: Uhuh.
- EE: Sometimes it...I think he fights against it and...he...he...um...it's like when you have surgery...it's like it puts him back...so many months.
- EE2: Uhuh.
- EE: You know, physically and, I think, mentally it affects him, too, as far as his attitude.
- EE: It makes him mad.

Case B

- EE: Well, I really look at the person. And if they're not optimistic about my child then I'm not at all interested in speaking with them because I don't think that she needs that. And they weren't at all optimistic about this disease.

Case B

- ER: What are your greatest concerns at this point for A_____?
- EE: *My greatest concerns are that I'm not going to find all of the things that she deserves for me to find for her, that's my biggest concern, that I'm going to miss something. You know, I still grieve myself over not finding the medicine for her when she was first born, because, I mean, they fly babies in that are six weeks old and give them the medicine. And if she had gotten that we would be seeing a lot -- you know, we lost 11 months that were critical. So I'm really upset with myself for that. And no one told me what was going on, no one gave me any hope so I didn't know what to even look for.*

Case C

- EE: ... So now we're going to go to a workshop next week where they teach about magnetic therapy. Of course, the mattress pad was a thousand dollars. But you know, you get to a point where -- I mean, I can't pay a thousand dollars for a mattress pad right now but just having the information when you get desperate enough you'll go into debt, I guess, for the stuff.
- EE: *I operate on big time guilt, just that's it. If it's there and I don't do it and she don't develop it could be because I didn't go do what I could have done.* So I went down there to begin with because everybody went there with their kids who have Down syndrome.

- EE: We keep talking about how -- how much to do on therapies because what if she's two years old and she can't walk yet *it could be because I didn't do enough in therapy, I didn't take enough services*, I didn't take her enough during the week or -- instead of she's not going to walk at two years old, most kids don't. Well, I think some of them do but –
- And moms didn't have this feeling until First Steps came along and offered them everything under the sun. And they come to your house so you feel guilty. How could you say no, they're going to come right to your house for you, you don't even have to leave the house, you know. But still when you're just -- it does, you're scheduling five people a week to come or go or whatever.

Discussion

- Narratives reflect many aspects of Ashley X intervention decisions – the social contexts of care, the blurring of ‘medical’ and ‘social’ justifications, parental responsibility and negotiations of authority, public/private nature of intervention decisions
- Parents of children with impairments at intersections of biology and culture, particularly at the social, cultural and technological boundaries of human variation, normality and pathology, capacity, and plasticity
- Expectations of the *transformative* nature of ‘biomedicalization’ (Clarke et al. 2003)
- Phenomenologically, impairment is understood as malleable and ‘unique’ (and embodied), prognoses are not certain but frequently contested, and contexts of intervention (therapeutic, medical, developmental) suggest that the ‘will to health’ (Rose 2001) is translatable to a ‘will to change’ - an imperative to intervene ?

BIOMEDICALIZATION: TECHNOSCIENTIFIC TRANSFORMATIONS OF HEALTH, ILLNESS, AND U.S. BIOMEDICINE

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The first social transformation of American medicine institutionally established medicine by the end of World War II. In the next decades, medicalization—the expansion of medical jurisdiction, authority, and practices into new realms—became widespread. Since about 1985, dramatic changes in both the organization and practices of contemporary biomedicine, implemented largely through the integration of technoscientific innovations, have been coalescing into what the authors call biomedicalization, a second “transformation” of American medicine. Biomedicalization describes the increasingly complex, malintegrated, multidirectional processes of medicalization, both extended and reconstituted through the new social forms of highly technoscientific biomedicine. The historical shift from medicalization to biomedicalization is one from control over biomedical phenomena to transformations of them. Five key interactive processes both engender biomedicalization and are produced through it: (1) the political economic reconstitution of the vast sector of biomedicine; (2) the focus on health itself and the elaboration of risk and surveillance biomedicine; (3) the increasingly technological and scientific nature of biomedicine; (4) transformations in how biomedical knowledges are produced, distributed, and consumed, and in medical information management; and (5) transformations of bodies to include new properties and the production of new individual and collective technoscientific identities.

THE GROWTH OF medicalization—defined as the processes through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems—is one of the most potent social transformations of the last half of the

twentieth century in the West (Bauer 1998; Clarke and Olesen 1999; Conrad 1992, 2000; Renaud 1995). We argue that major, largely technoscientific changes in biomedicine¹ are now coalescing into what we call

Sara Shostak, and especially Leigh Star, Herbert Gottweis, Vincanne Adams, and the ASR Editors and anonymous reviewers. This paper is part of an ongoing collaboration initiated by Clarke; co-authors are listed in random order.

¹ Following Latour (1987), we use the term “technoscience” to indicate an explicit move past scholarly traditions that separated science and technology conceptually and analytically. We argue that these two domains should be regarded as co-constitutive; we thus challenge the notion

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Biomedicalization:
Technoscientific
Transformations of Health,
Illness, and U.S.
Biomedicine

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Bridging to diagnosis?

