'PATERNALISM AND DISABILITY' WORKSHOP

PATERNALISM, HEALTH, AND PUBLIC POLICY PROJECT

https://paternalismhealthpublicpolicy.org/

DAY ONE: 26TH APRIL

13.00 - 13.30 BST	**Welcome and Introduction** Angharad Beckett, Jessica Begon	
13.30 - 14.30	**Jonathan Wolff** University of Oxford Discussant: **Alex Pearl** University of Leeds	*Minority Minds and the Social Model of Disability*
14.30 - 14.45	Break	
14.45 - 15.45	**Dana Howard** Ohio State University Discussant: **Gillian Loomes-Quinn** University of Leeds	*The Value of Non-Domination in Supported Decision-Making for Research Participation*
15.45 - 16.00	Break	
16.00 - 17.00	**Joe Stramondo** San Diego State University Discussant: **Radoš Keravica** University of Leeds	*Paternalism and the Presumption of Problematic Motivations when Choosing Disability*
17.00	End	

DAY TWO: 27TH APRIL

8.45 BST	Zoom room opens	
9.00 - 10.00	**Linda Barclay** Monash University Discussant: **Peter Ochieng** University of Leeds	*Paternalism, Supported-Decision Making and Expressive Respect*
10.00 - 10.15	Break	
10.15 - 11.15	**Marie Tidball** University of Oxford Discussant: tbc	*Paternalism, Inclusive Governance and the UNCRPD Implementation Gap: 3 Case Studies*
11.15 - 11.30	Break	
11.30 – 12.30	**Alex Gregory** University of Southampton Discussant: **Leonora Gunn** University of Leeds	*The Range of Adaptive Preference*
12.30 - 13.00	Lunch break	
13.00 - 14.00	**Roundtable** Participants: **Miro Griffiths** University of Leeds **Stephen Hallett** University of Leeds **Anna Lawson** University of Leeds	*The Impact of the UNCRPD*
14.00	End	

ABSTRACTS

Jonathan Wolff (Blavatnik School of Government, Oxford University): *Minority Minds and the Social Model of Disability*

Much discussion of disability – both academic and in policy terms – has focused on issues of physical disability, and within that problems of mobility, even to the point where the international symbol for disability is an image of person in a wheelchair. Social policy, accordingly, has given a great deal of attention to issues of accessibility, especially in relation to the built environment. Such policies mark a very welcome change over the decades to social attitudes to disability, often, implicitly or explicitly, drawing on elements of the 'social model' of disability. In one version of this model the experience of disability is conceptualised as a type of 'mis-fit' between the person and the world around them, and the remedy is to act to change the world, rather than 'repair' the person, as the older, 'medical model' – presupposes. However, there is a question of how much the social model can be extended to other forms of disability, and in particular the very broad spectrum often referred to as 'cognitive disability' although, following Thomas Schramme, I prefer the term 'Minority Minds'. My question in this talk is the degree to which the disadvantages experienced by those with minority minds can be mitigated through social and cultural change.

Dana Howard (Ohio State University): *The Value of Non-Domination in Supported Decision-Making for Research Participation*

The historic abuses of biomedical research on intellectual and developmentally disabled people are marked by relationships of extraction and exploitation. This paper looks at the underlying structural context and power relations that gave rise to these abuses and considers what values need to be in play to counteract these structural forces. The paper defends the view that while exploitation is the abusive outcome, domination is an underlying condition that makes such outcomes possible. How do we engage in research practices that are inclusive and non-paternalistic, but also guard against the potential abuses of vulnerable populations? Our answer, developed in the paper, is the non-domination approach. The central objective of our non-domination approach is to treat supported decision-making as a fundamentally collaborative decision-making process between the prospective research participant

(who we will call the subject), their trustee, and the researchers – a collaboration that is grounded in and justified by the subject's evaluative perspective.

Joseph Stramondo (San Diego State University): *Paternalism and the Presumption of Prudentially Problematic Motivations when Choosing Disability*

Arguably, one of the most uncritically accepted instances of medical paternalism is a tendency to discourage or even prohibit "choosing disability." The institutions and practices of medicine often just assume that one ought not choose to become or remain disabled. Likewise, it is often assumed that one should not intentionally cause another to become or remain disabled. One common reason for maintaining that one ought not choose disability is a belief that such a choice always or at least usually entails some sort of problematic motivation on the part of the chooser. Namely, one might believe that anyone who chooses disability for themselves is motivated in a way that is bad for them, or prudentially problematic. Further, one might then hold that it is wrong to aid another in acting upon such a prudentially problematic motivation as a third party, like a physician. In this paper, I will reconstruct and then critique this "prudentially problematic motivations argument" against choosing disability. The argument holds that one ought not choose disability since it is an action that is problematically motivated by: a non-autonomously formed reason, an object that is not worthy or less worthy of value than others, uncertain knowledge, flawed reasoning or bias, a fleeting desire, a mental disorder, or an object that is very unusual. For my part, I will challenge the prudentially problematic motivations argument against choosing disability on the grounds that none of these motivations should always be presumed to be prudentially problematic nor should they be presumed to be always or typically at the root of choosing disability.

Linda Barclay (Monash University): *Paternalism, Supported-Decision Making and Expressive Respect*

Some philosophers argue that the nature, and presumptive wrongness, of paternalism is the distrust the paternaliser shows towards the judgement and will of the paternalised agent. Such distrust, along with the paternaliser's belief in their own superior judgement, is said to insult the paternalised agent by expressing disrespect for their agential capacities. On the other hand, a number of philosophers have argued that refraining from paternalistic intervention can also express serious disrespect towards those who should be subject to such intervention. In this presentation I will

discuss these competing claims in the context of cognitive disability and supported-decision making. I will suggest that while the shift from substituted to supported decision making is largely positive, for those with 'severe' or 'profound' cognitive disabilities an insistence on supported decision making can also licence an array of seriously disrespectful attitudes. We should value agency; but we should also value the lives, interests and unique identities of all people. I will argue that overreach with respect to the possibilities of supported decision-making run the risk of masking the all too common disrespect for the lives, interests and unique identities of people with 'severe' or 'profound' cognitive disabilities.

Alex Gregory (University of Southampton): *The Range of Adaptive Preference*

What are adaptive preferences? Who might have them? This paper lays the groundwork for answering these questions. It explains some problems in Serene Khader's account of adaptive preference - such as that it wrongly categorises too many kinds of mistaken preferences as "adaptive", and that it neglects the adaptive preferences of the well-off - and offers a theory without those problems. It also explains some problems with Elizabeth's Barnes pessimistic claims about adaptive preference, showing, against Barnes, that there are good reasons to try to diagnose adaptive preference. The underlying thought in both cases are that adaptive preferences are in some ways more common, and in some ways less common, than they might seem.

DISCUSSANTS

Alex Pearl is a PhD researcher based in the School of Law at the University of Leeds. Her research interests centre around disability and human rights, feminism, discrimination and equality law, jurisprudence and moral personhood. Alex has written and spoken on the impact of the right to Legal Capacity in Article 12 of the UN Convention on the Rights of Persons, and the Capabilities Approach. As a member of the Centre for Disability Studies and the Centre for Law and Social Justice, Alex has contributed to consultation and policy documents. Alex has taught English Legal System and Constitutional Law and is a keen non-academic book reviewer.

Gillian Loomes-Quinn is a disabled scholar-activist with a background in disability advocacy, peer support, and community building. Her ongoing PhD research, supervised by Professor Anna Lawson at the School of Law, University of Leeds, is entitled "The Mental Capacity Act 2005 and Disabled Voice: A Socio-Legal Exploration". It is concerned with the operation in practice of the Mental Capacity Act 2005 (a ground-breaking piece of Anglo-Welsh legislation setting out a framework for the assessment of mental capacity and decision-making in the best interests of adults deemed to lack capacity); focusing particularly on its socio-legal and practical impact on the individual and collective 'voice' of disabled people. Her key areas of interest include: the views of disabled activists on advance care planning; participation in research of adults lacking the capacity to consent; and the work of the Court of Protection. Gill is also proud to be Co-Director (with Professor Celia Kitzinger) of [The Open justice Court of Protection Project](#) and a convener of the Participatory Autism Research Collective ([PARC](#)). She tweets @GillLoomesQuinn.

Radoš Keravica is a disabled researcher from Serbia and a doctoral candidate at the University of Leeds, Centre for Disability Studies in the School of Sociology and Social Policy and works as an EU Marie Sklodowska-Curie Early-Stage Researcher within the Disability Advocacy Research in Europe (DARE) project. He holds a master's degree in human rights law from the Central European University and a master's degree in international economics from the University of Novi Sad. His doctoral research project uses socio-legal analysis and focuses on disabled children's participation in healthcare decision-making in the context of impairment-related elective orthopaedic treatments. It further explores the relationship between the UN Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with

Disabilities (UNCRPD) in the area of child participation. He serves as a Board Member of the European Network on Independent Living (ENIL) and worked previously for the UN OHCHR in Serbia as Disability Rights Specialist.

Peter Ochieng is a Commonwealth PHD student at the University of Leeds. He comes from Uganda, and he has cerebral palsy. His research is on what can be done to make rights enshrined under UNCRPD Article 12, Persons with Disabilities right to legal capacity and equal recognition before the law a practical reality for all People with Disabilities in Uganda. His area of research interests includes the implementation of the United Nations Convention on the Rights of Persons with Disabilities in the global south, equal personhood, disability law and policy and the equal participation of persons with disabilities in all aspects of life including education, employment, community development, health, among others. Peter is passionate about challenging negative, stereotyping attitudes that negate people's personhood based on their physical or mental characteristics.

Leonora Gunn is a philosophy PhD candidate at the University of Leeds. Her research takes an ontological reading of the social model of disability as a starting point for building a theory of disability, and considers the epistemological, moral and political significance of such a theory and of the social model itself. She also serves on the committees of Leeds Disabled People's Organisation and Chronic Illness Inclusion.

ROUNDTABLE PARTICIPANTS

Miro Griffiths is a Leverhulme Early Career Research Fellow at the University of Leeds, as PI on the project 'Disability Activism in Europe: Young Disabled Activists Views and Experiences'. He completed a PhD at Liverpool John Moores University in 2018 investigating the young disabled people's experience and views of the UK Disabled People's Movement. In May 2014, he was awarded an MBE as recognition of his service to disabled people. Since 2007 he has worked as a Human Rights Adviser, currently including as a policy adviser for the European Network on Independent Living, as an adviser to Government, the British Council, and the Equality and Human Rights Commission.

Stephen Hallett graduated in Chinese Studies from the University of Leeds and has worked in the field of disability rights in China for over 20 years. In collaboration with Chinese disability rights advocates, he has set up and run numerous projects to strengthen awareness of disabled people's rights in China and East Asia. He is director of the charity China Vision and, since 2018, has managed the U-Lead East Asia Disability Rights Forum for the Centre for Disability Studies at the University of Leeds.

Anna Lawson is a professor of Law and Joint Director of the Centre for Disability Studies at the University of Leeds. She is a Fellow of the Academy of Social Science and an honorary Master of the Bench at the Middle Temple Inns of Court. Her research focuses on disability equality and human rights, with a focus on issues of discrimination, accessibility, access to justice and public space.