***Wherever the art of medicine is loved, there is also a love of humanity. (Hippocrates)***

**BACKGROUND**

Recent scandals, inquiries and reports into Winterbourne View, Whorlton Hall, Mendip House, Slade House and Yew Trees Hospital have revealed the tragic consequences of dehumanising care for adults with learning disabilities and/or autism (Emerson et a, 2012; Heslop et al, 2013, 2014; Hatton, 2017; Read et al, 2018; BBC News, 2018, 2019, 2010; Kenyon and Chapman, 2011; DoH, 2012; Mazars, 2015; Ryan, 2017; Davies and Plomin, 2019; Birrell, 2019; Heslop and Houghton, 2019). Previous research has evidenced a number of stubborn problems within healthcare (e.g. Kerr et al, 2014; Transforming Care and Commissioning Group, 2014; NHS, 2017, 2020; Dept of Health and Social Care, 2018; LeDeR, 2019; Joint Committee on Human Rights, 2019; Kinney et al, 2020; Shankar et al, 2020; Sun et al, 2020; Lodge, 2020). These include ignorance, indifference and diagnostic overshadowing on the part of professionals (where underlying health conditions such as constipation or epilepsy are missed and symptoms incorrectly attributed to learning disability). Uptake of annual health checks, screening and follow up appointments are low and there is evidence of inappropriate prescriptions of psychotropic drugs. This literature indicates that there is a paucity of accessible easy-to-read information and systemic clinical failures that fail to pick up on changes in personal circumstances and conditions that later present in acute emergency services. A lack of inter-agency partnerships across medicine, education and social care fail to create joined up person-centred care, while families and advocates are under-used in consultations and service development. MENCAP concluded in their 2007 report *Death by Indifference* that the failure of healthcare services towards people with learning disabilities, their families and carers ‘is a national disgrace. We say this is institutional discrimination’. Prior to the pandemic, people with learning disabilities and/or autism already died 20-30 years earlier than their non-disabled counterparts (NHS, 2017, LeDeR, 2019). By Autumn 2020, people with learning disabilities and/or autism were six times more likely to die from Covid-19 than the rest of the population (Public Health England, 2020). Controversies associated with the Clinical Frailty Scale, healthcare rationing, ‘Do Not Resuscitate’ orders, the neglect of care homes and changes in guidance around the vaccination programme, have had the cumulative effect of devaluing the human worth and value of people with learning disabilities and/or autism. Despite attempts to promote empowering, person-centred and holistic care practices (e.g. Jingree et al, 2006; Ross et al, 2013; Wilkinson, 2018), research consistently concludes that many people with learning disabilities and/or autism are dehumanised by healthcare; threatening to render them expendable and disposable.

**THE STRATEGIC IMPORTANCE OF THIS PROJECT**

In these times of recovery and renewal, as we plan for a post-pandemic world, we believe that a new approach to healthcare is required. Responding to the ESRC’s priority call for ‘Innovation in health and social care’, we will develop an approach to 'Humanising Healthcare' that identifies principles and practices of empathy, compassion, dignity, kindness and recognition through a co-produced project with researchers with learning disabilities and/or autism, medical clinicians and social scientists. Uniquely informed by contributions from medical humanities, disability studies, posthumanities and disability activism, we will address two **aims**:

(1) To qualitatively investigate the cultures, conventions, systems, relationships and practices of a neurology service and a learning disability service through co-production, ethnography and narrative interviews.

(2) To identify the ways in which two distinct services and their practitioners deliver humanising healthcare for people with learning disabilities and/or autism.

We propose an innovative approach to co-production, fieldwork, impact and public engagement that addresses six **research objectives:**

1. Identify the key priorities and determinants of health of people with learning disabilities and/autism through a literature review of legislation, policy, clinical guidance and datasets.

2. Identify key theoretical resources from the medical humanities, disability studies, posthumanities and disability activism to conceptualise humanising healthcare.

3. Implement an investigation of the healthcare experiences of 30 people with learning disabilities and/or autism through 300 days of ethnographic research of the two services and 120 narrative interviews with patients, professionals and families/carers.

4. Analyse the data from our ethnography and narrative interviews through the deployment of our theoretical resources.

5. Identify and share healthcare practices - including referrals, assessments, diagnoses, clinical judgements, investigations, treatments, service management, commissioning, medical training and continued professional development - that are under-pinned by humanising principles of empathy, compassion, dignity, kindness and recognition.

6. Increase public awareness of the healthcare realities and aspirations of people with learning disabilities and/or autism.

Each objective will be informed by co-production workshops and humanising healthcare practice will be shared via a website, manifesto, toolkit, practitioner training materials, journal articles, conference presentations and co-production research resources in consultation with an experts-by-experience advisory board and clinical and practitioner expert group. Public engagement will be met through the curation of festivals, a digital exhibition, a social media campaign and a podcast series. Our interdisciplinary team includes people with learning disabilities and/or autism - members of self-advocacy groups and a workers cooperative - who will work with a neurologist, psychiatrist, psychologist, sociologist and educational researcher. We have been meeting over the last 18 months to co-produce this application (see ***Accessible Introduction***). To focus our research we will investigate two services that support 1300 patients. The ***neurology service***, based in South Wales, specialises in providing a unique offer to patients with learning disabilities and/or autism with neurological presentations (including epilepsy, spasticity, dysphasia, mobility issues). The service works closely with local learning disability teams, carers, GPs, social workers and advocacy organisations and offers clinics (series of individual consultations), joint multidisciplinary team meetings (planning care around patients) and individual casework (supporting people with their neurological conditions in the community often at times of crisis). The ***learning disability service***, based in Cornwall, seeks to offer high quality, evidence-based, person-centred care to people in their homes and communities. Patients have access to care coordination, casework and multidisciplinary teams which are organised around seven distinct pathways (inc. mental health, epilepsy, profound and multiple labels, neurodiversity, dementia), drawing in psychiatrists, psychologists, nurses, speech and language therapists, physiotherapists, occupational therapists, support workers, dieticians and clinical psychologists. Adult Learning Disability Community Health and Specialist Epilepsy teams work alongside primary care liaison, intensive support and mental health nurses to access GP practices, hospitals and mental health services. By focusing on these two research sites we will be able to investigate specialist and holistic forms of service provision; draw in people with learning disabilities and/or autism with a number of additional complex needs (e.g. autism, mental health, poor diet, epilepsy) and assess primary and secondary outcomes of their interventions. Primary outcomes relate to improving physical health and well-being and secondary outcomes include enhancing quality of life, educational participation, social networks, skills acquisition, work opportunities and community engagement (Spreen, 1981; Rittey, 2003; Galaburda, 2005; Sharpe et al, 2019; Niven et al, 2020). The Clinical Directors of these two services - CoIs C.Lawthom and Shankar - are committed to improving their service offer and sharing good practice with other services in England and Wales.

**THEORISING HUMANISING HEALTHCARE**

Our research will develop new concepts, principles and practices of humanising healthcare that are informed by four theoretical perspectives that span the clinical, social science and activist domains of our team. These approaches reveal intellectual possibilities and gaps that we will address. ***Medical Humanities*** draw on the arts, humanities and social sciences to explore interdisciplinary questions of the human condition in the context of healthcare knowledge and practice (Whitehead el, 2016). Healthcare settings are cast as dynamic spaces in which the roles of practitioners and patients are constantly in flux; undergoing changes in terms of status, power and positionality (Meakin and Kirklin, 2000; Fisher, 2006; De Plessis, 2013). Patients often explain that they feel empowered or denigrated by their encounters with practitioners (Khetarpal and Satendra, 2012; Stoddard Holmes, 2015; Peimonte, 2017). Salisbury (2020) argues that healthcare practitioners often struggle to combine a relational approach (building rapport, knowledge, trust and empathy with patients) alongside transactional demands (focused on identifying specific needs, diagnosis, treatment and referral). Indeed, because professionals are often judged by the efficiency of their transactional practice - adhering to quality and clinical outcomes frameworks, following guidance and keeping within prescribed budgets - little time is left for more relational encounters (Iles et al, 2009). This raises questions about the extent to which humane healthcare is possible. For Gupta (2011), while healthcare practitioners are trained through a biopsychosocial approach, there is still a tendency to emphasise individual over social determinants of health and illness. Empathy, compassion and care are often understood as being incompatible with the underlying values and performative demands of the contemporary healthcare system (Youngson and Blennerhassett, 2016). Relational qualities are often more difficult to measure than transactional outputs. What is required, according to Sim et al (2017), is a new approach to medical humanities that promotes empathy, dignity, respect, caring, kindness, compassion; recognising the person before the patient. We will address gaps in the literature including:

* Excavating the ways in which healthcare practitioners combine clinical/transactional demands with relational/empathic commitments to their patients;
* Identifying examples of compassionate healthcare at a time when transactional demands have multiplied as a consequence of the public health crisis marked by the pandemic.

To inform our investigation of humanising principles and practices of healthcare we turn to ***Disability Studies***. This field considers disability as the object of study and the driving subject of inquiry (Siebers, 2008; Meekosha and Shuttleworth, 2009; Shildrick, 2012; Goodley, 2016). Foundational work has interrogated social and cultural practices that constitute learning disability as a stigmatising category and the consequential impacts on those who live as human subjects with this category (Goffman, 1963, Edgerton, 1967; Bogdan and Taylor, 1976, 1982; Langness and Levine, 1982; Ferguson, 1987; Jarrett, 2020). People with learning disabilities and/or autism often occupy a peripheral social status in our current period of cognitive capitalism which values intellectual abilities and self-sufficiency (Bérubé, 2010; Rindermann and Thomson, 2011). Cognitive ableism refers to the process whereby people with learning disabilities and/or autism are deemed to lack ethical, moral and human worth (Carlson, 2001, 2016; Johnson and Walmsley, 2010; Kittay, 2005, 2019). Researchers have called for research to probe the emotional and psychological consequences of these dehumanising discourses (Thomas, 1999, 2007; Goodley et al, 2018) and to generate more humane discourses, in contexts such as healthcare, that emphasise personhood over a preoccupation with labels (Ryan, 2017). Learning disability is still too often framed in terms of tragedy and deficit. Disability studies pushes us to embrace more enabling social and relational approaches that assume and build on the capacities of people and their families (Goodley, 2014; Ryan, 2020). We will draw in disability studies into an investigation of healthcare as a key institutional, social and cultural site for the reproduction of learning disability/autism knowledge. We will address a number of outstanding concerns including:

* Interrogating the de/humanising ways in which learning disability and/or autism are diagnosed, defined and represented by healthcare cultures and practitioners;
* Attending to those moments of compassionate healthcare practice that emphasise the human worth, value, rights and aspirations of patients with learning disabilities and/or autism.

To deepen an understanding of the cultural constitution of the human, we will draw upon the emerging field of the ***Posthumanities*** (Braidotti, 2013, 2018; Braidotti and Hlavajova, 2018). This field maintains a focus on the human subject but situates it in what Serres (2003) terms a 'logic of relations'. Humanness is always contextual, relational and distributed. Our codependence with non/human others is a defining feature of what makes us human. Many posthumanists engage with a ‘missing people’s humanities’ (Braidotti, 2019): reclaiming the lives of those whose worth and value have been compromised by processes of racism, sexism, colonialism and disablism (McRuer, 2006; Goodley, Lawthom and Runswick-Cole, 2014; Vandekinderen and Roets, 2016; Saur and Sidorkin, 2018; Goodley, 2020). Gilroy (2018) advocates for a ‘re-enchantment with the human’ through a commitment to those who have been dehumanised. A fresh approach to research and scholarship is required that drops academia’s tendency for nihilistic deconstructionism and embraces a perspective that seeks out affirmation, hope and possibility (Bargués-Pedreny, 2019). This literature reveals a number of outstanding concerns that we take up in our research which include:

* Investigating healthcare as a potentially liberatory site in which the humanities of people with learning disabilities and/or autism are affirmed, celebrated and enhanced;
* Illuminating the ‘missing people’s humanities’ of people with learning disabilities and/or autism as an opportunity to embrace more equitable conceptions of what it means to be human.

No research into the lives of people with learning disabilities and/or autism would be credible without an engagement with the knowledge that people so-labelled have created themselves: ***Disability Activism.*** Disabled people and their representative organisations have created a literature through their expertise-by-experience that emphasises the desires and aspirations of disabled people (Campbell and Oliver, 1996; Bergs et al, 2019; LDE, 2020; Ryan, 2019). People with learning disabilities and/or autism have organised through their self-advocacy; informing public discourse, service provision and professional practice (Atkinson and Williams, 1990; Dybwad and Bersani, 1996; Goodley, 2000, 2005; Disability Rights UK, 2015; Learning Disability England, 2018). A key motif of the self-advocacy movement is that members are ‘People First’ and a key maxim is ‘nothing about us, without us’ which demands that people with learning disabilities and/or autism are placed at the centre of any decision-making processes about their lives. Too often research fails to engage with the organic intellectuals of disability activism: disabled people. Therefore, our research will:

* Work in collaboration with people with learning disabilities and/or autism as co-researchers, theorists and analysts to conceptualise their healthcare experiences and aspirations.
* Appraise healthcare cultures of their potential to promote positive articulations of people with learning disabilities and/or autism that are in tune with the aspirations of self-advocacy.

**METHODOLOGY, ANALYSIS AND DISSEMINATION**

Our research is informed for two methodological approaches. First, a **Co-Production Model** **of Research** centralises co-researchers with learning disabilities and/or autism (who boast national reputations for research and innovation in disability advocacy and healthcare research) drawn from self-advocacy groups (Sheffield Voices, Speakup, Sunderland People First) and a workers cooperative (Barod). This approach, which we have adopted to write this application, is a burgeoning area of social scientific and health research (Walmsley and Johnson, 2003; Bigby and Frawley, 2010; Read and Maslin-Prothero, 2011; Durose et al, 2012; Abbott and Carpenter, 2014; Strnadová et al, 2014), though projects often fail to locate people with learning disabilities and/or autism as research leaders (Kaley et al, 2019). We position our co-researchers as research managers, social theorists, methodological provocateurs, analysts and impact experts who, through their expertise-by-experience, will encourage us to think critically and productively about healthcare (Nind, 2012; Goodley et al, 2019). In month 7, two full time PDRAs will join our team (one in Sheffield, the other in Plymouth). PDRAs will carry out fieldwork, analysis and knowledge exchange, supported by the PI and CoIs. At the centre of our co-production model is **The Executive Team** - composed of the PI, CoIs and eight co-researchers with learning disabilities and/or autism - who will meet online(twice a year), chaired by Goodley, utilising breakout rooms and focused activities to develop inclusive models of co-produced research leadership. The Executive will have oversight of the project - from conception to completion - through a series of blended face-to-face/online **Co-production Workshops** organised around four themes: Theory, Methods, Analysis and Impact. We will deploy participatory, accessible and arts-based methods; building on the PI Goodley and CoI Runswick-Cole’s [ESRC funded research](https://whycantwedream.co.uk); to demystify ethics, enhance research design, inform data collection analysis, public engagement and co-authorship (Liddiard et al, 2019; Goodley et al, 2017; Whitney et al. 2019). We will use Easy Read, infographics, film, cartoons and arts-based methods to ensure transparency around research design, empower co-researchers with learning disabilities and/or autism and promote interdisciplinary dialogues about healthcare across medical, social scientific and expertise-by-experience of our Executive Team (Atkinson and Williams, 1990; Goodley and Moore, 2000; Fancourt, 2017; Lawthom et al, 2017; Montgomery et al, 2019; Wilcox, 2020).

Second, we will use **Qualitative Research Methods** toexplore the healthcare realities and experiences of 30 people with learning disabilities and/or autism accessing either a neurology or learning disability service (15 in each). We will include patients who are aged between 18-65 years old, span mild, moderate and profound learning disabilities and/or autism, including those living with 24/7 support and others living independently, while capturing those with challenging behaviour and complex needs (e.g. autism, epilepsy, non-verbal, mental health issues). We will ensure fair representation of socio-economic status, gender, rural and urban living, while actively seeking BAME participants. 30 participants provide sufficient data saturation and sample size (Guest et al, 2006). Participatory methods will be deployed to explain ethics and research participation and we will tailor research design if needed to our *Covid-19 Contingency Plans* (see ***Ethical Information***). We will utilise EasyRead in our information sheets (see ***Accessible Information*** attachment) - stressing to participants that their involvement in the research will not influence the services they receive. A *Distress Protocol* will flag up availability of external counselling services (if required) and, throughout the project, we will work with our clinical CoIs and service directors to monitor and exclude those who express concerns that their involvement is impacting negatively on their healthcare. Each PDRA will be embedded in one service. Collectively they will carry out 10 days of **ethnographic research** with each of the 30 participants (informed by previous research, Goodley, 2000; Pink, 2001; McLaughlin et al, 2008; Read and Maslin-Prothero, 2011; O’Reilly, 2012; Strnadová et al, 2014; Kaley et al, 2019). Ethnographic data will be anonymised, recorded, archived and shared with the team in line with our ***Data Management Plan***. Ethnographic research will access clinical, community and home settings; exploring consultations and contact points between people with learning disabilities and/or autism and the two services. Ethnographic observation will include un/structured, face-to-face/online encounters within the two services during mundane moments and crisis points. We will attend to the embodied, psychological, relational, systemic and cultural elements of these institutional encounters; exploring form and content of appointments, consultations, assessments, interventions and waiting times. We will identify productive encounters, generative cultures and constructive relationships that contribute to our emerging approach of ‘humanising healthcare’. We will also undertake 120 **narrative interviews**(lasting no longer than two hours) with each of the 30 participants from the ethnography and three of their significant others inc. professionals and families/carers (4 x 30). We will use accessible, participatory narrative interviewing methods (Booth and Booth, 1998; Goodley et al, 2004; Banister et al, 2011; Bai et al, 2014). Interviews will have introspective and aspirational elements: as we explore the emotions, memories, stories and hopes associated with humanising forms of healthcare. Anonymised transcribed interviews will be archived and shared across the team (see ***Data Management Plan***). Our research addresses six **Objectives** (also see ***Timetable)*** supported throughout by an **Experts-by-Experience Advisory Board** (see ***Justification for Resources***).

**Objective 1: Literature Review (months 1-12)**

The PI/CoIs will identify the key priorities, individual and social determinants of health for people with learning disabilities and/autism including structural, institutional and service factors; e.g. registration numbers for local authorities; measures of poverty, mental health, employment, care dependency, quality of life; comorbidity (including epilepsy, constipation, dysphagia); hospitalisation, detention, segregation and restraint; hospital admissions; pain thresholds; diagnostic overshadowing; reasonable adjustments. We will review legislation, policy, clinical guidance and key datasets (e.g. Office of National Statistics, Public Health England, NHS Digital, Longitudinal Cohort studies, Covid-19 research) and write two journal articles on the findings.

**Objective 2: Co-producing theory** **(months 1 - 24)**We will hold four two-day *Theory Workshops* attended by The Executive Team; reflecting on the findings of objective 1 and, in response, introducing and debating contributions of medical humanities, disability studies, posthumanism and disability activism. PDRAs, PI and CoIs will compile theoretical reviews - translating these into accessible documents (using participatory and arts-based methods) - to identify a number of conceptual ideas that might inform empirical work and analysis. Workshops will explore conceptual clarity, theoretical utility and empirical adequacy as criteria for choosing theories that affirm disabled lives. We will clarify ‘epistemology’, ‘ontology’ and ‘methodology’; establishing co-researchers with learning disabilities and/or autism as co-theorists. We will write two journal articles reflecting on theorising humanising healthcare.

**Objective 3: Co-designing methods and implementing fieldwork (months 1 - 30)**

We will hold four two day co-production *Methods Workshops* - before and during the time of the empirical work - to ensure consistent oversight of the project by The Executive. We will write interview and observational schedules and plan the logistics of fieldwork. NHS ***ethics*** approval will be gained to ensure access to the two NHS trusts (see ***Ethical Information***). The ***Data Management Plan*** will be reviewed and a ***Publication Terms of Reference*** drafted. We will use participatory methods to co-construct ethnographic and narrative methods. PDRAs will undertake fieldwork and report back to The Executive in the workshops. We will co-author two journal articles focused on co-production methodologies in the appraisal of healthcare.

**Objective 4: Co-producing findings and analysis (months 13 - 36)**

We will consistently co-produce analysis with The Executive Team through four two day *Analysis Workshops* (blending zoom/ face-to-face). Participatory methods will be used to extract data from transcribed interviews and ethnographic case studies in order to deploy a *thematic analysis* approach (Braun and Clarke, 2006, 2019a, 2019b; Banister et al, 2011; Nowell et al, 2017), supplemented by the theoretical understandings generated in relation to Objective 2. We will develop recommendations for co-producing analysis; a research stage described as ‘a step too far’ for people with learning disabilities and/or autism (Nind, 2011; Feldman et al, 2014). We will explain thematic analysis, consider inductive/deductive approaches and develop an innovative *affirmative analytical approach* (drawing on objective 2) with the express aim of defining and elaborating upon the key facets of humanising healthcare: care, compassion and dignity.  
  
**Objective 5:** **Co-creating impact (months 7 - 36)**We will hold four co-production *Impact Workshops* with our Executive Team to co-create impact activities. We will set up a *Humanising Healthcare Website* to house news, blogs, policy briefings and empathic,compassionate and caring ethnographic case studies and narratives (drawn from the fieldwork). The website will also include a *Humanising Healthcare Toolkit* focused on improving professional practice and service provision. A **Clinical and Practitioner Expert Group** (see ***Justification for Resources***) will meet six times to help inform the writing of the toolkit, review the literature review (objective 1) and emerging findings (objective 4); helping us to identify and disseminate recommendations across England and Wales Clinical Commissioning Groups, NHS Trusts, Learning Disability Mortality Review and NHS Learning Disability and Autism Programmes, Welsh Government Learning Disability Ministerial Advisory Group, Learning Disability Ministerial Advisory Group, Healthcare Inspectorate Wales and Care Inspectorate Wales, Royal Colleges/Societies (Psychiatrists, GPs, Medicine), NHS/Public Health England/Cymru, NIHR, NICE, Care Quality Commission, National LD Senate. We will model the toolkit on the award winning National Confidential Inquiry into Suicide and Safety in Mental Health and NHS Benchmarking; producing two page Easy Read/infographic ‘Humane Practice Summaries’ (also shared across social media). Our experts will liaise with care commissioners to check the utility of summaries. Possible areas of advice might include humane management of epilepsy, prescriptions of medicine, diet and exercise, positive behavioural change and working in collaboration with families. A *Reclaiming the Human in Healthcare Manifesto* will set out a declaration of humanising healthcare (following Youngson and Blennerhassett, 2016) aimed at patients, families and professionals. *Practitioner Training Materials* will be written for the two services’ practitioners; shared across national groups via our website and Experts Group. Materials will respond to Gupta’s (2011) pedagogies of critical thinking, empathy and situating patients’ clinical conditions in the background of socio-demographic factors. We will also produce materials for medical students; delivered by Speakup to the students they teach (University of Sheffield) and shared with medical educators on our Experts Group. *Co-production Research Resources* will be written to raise capacities of academic, practitioner and patient researchers, two *Journal articles* and *conference presentations* will report findings (see ***Academic Beneficiaries***). Our **Experts-by-Experience Advisory Board** will inform impact to ensure reach across self-advocates, families/carers.   
  
**Objective 6: Public Engagement (months 1 - 36)**

We will raise public awareness about the healthcare experiences and aspirations of people with learning disabilities and/or autism. *Festival Events* in Cardiff, Sheffield and Plymouth will target the wider public. *A Digital Exhibition* will share artistic outputs from co-production workshops and crowd-sourced arts from people with learning disabilities and/or autism. A *Social Media Campaign* will raise public discourse in relation to #humanisinghealthcare. A *Podcast* *Series* *‘The Art of Medicine: Love of Humanity’* will share anonymised ethnographic case studies and narratives of compassionate humanising healthcare and include interviews with influential self-advocates, families/carers and professionals (external to the project).