

“I am more than just my label”: Rights, fights, validation and negotiation. Exploring theoretical debates on childhood disability with disabled young people.

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Abstract

Through the creation of safe spaces in which to explore and challenge dominant negative views of disabled children and young people, this co-written paper presents unique insight into the meaning and impact upon disabled young people’s lives of medical lenses and deficit models of disability. Bodies of work and dominant debates in medical sociology, disability studies and childhood studies have so far largely overlooked the experiences and positioning of disabled children and young people and have rarely involved them in the development or discussion of theory. Drawing on empirical data, and through a series of creative, reflective workshops with a UK-based disabled young researchers’ collective (RIP:STARS), this paper discusses areas of theoretical importance identified by the disabled young researcher collective - the validation of their lives, negotiation of their identity and acceptance in society. The implications, and possibilities, of platforming disabled children and young people’s voices in theoretical debates are deliberated and are achieved through the yielding of privileged academic voice and the development of a symbiotic, genuine partnership which resonates with disabled young people and recognises them as experts in their own lives.

Introduction

The relationship between medical sociology and disability studies raises a number of questions for theory, policy and practice, not least in relation to disabled children and young people. Children have so far not had a strong presence in medical sociology, research from a child perspective which aims to understand the meaning and impact of health and illness, disability and chronic illness in a child’s life is much needed and is currently lacking (Brady et al, 2015). In a similar vein, disability studies has also largely overlooked the experiences and theoretical examination of the positioning of disabled children and young people. Thus, a

vacuum has been created whereby disabled children's lives are predominantly viewed through a medical lens of disability. Deficit models prevail and disabled children are viewed as passive recipients of care, charity and philanthropy (Curran and Runswick-Cole, 2014; McLaughlin et al, 2016). This article, based on discussions emerging within our disabled young researcher led collective (RIP: STARS), reveals the ways in which disabled young people make sense of, and therefore theorise, their subjective experience. We argue that there is a need for alternative approaches to thinking about the lives of disabled children and young people that are neither medical nor deficit and we call for the full engagement of disabled children and young people in this process.

The name 'RIP:STARS', devised by the collective, means Research into Practice/Policy: Skilled Team with Ambition, Rights and Strength. The RIP:STARS collective are disabled young researchers and their academic allies, we have passion and drive to fight all forms of inequality, exclusion and discrimination which are impacting the lives of disabled children and young people. As a collective we undertake research directly with disabled children and young people to explore their experiences, using all evidence gained through this process to argue for changes in practice and policy and to develop training. Over the course of five years, through reflective practice, engagement with established Disability Activists, and the development of safe spaces to explore issues of rights, identity, diagnosis, labels, discrimination and an awakening political awareness, the RIP:STARS have been addressing a major gap: the inclusion of disabled children and young people in theoretical debates on disabled childhoods.

Originally funded by Disability Research into Independent Living (DRILL)/Big Lottery in 2018, co-leading and co-producing research into rights and quality in Education, Health and Care

Plans (EHCPs), we have remained together, despite a number of challenges – personal, institutional and financial. Following introduction to theoretical debates about disability by the academic allies (Brady and Franklin, 2019) RIP: STARS discussed a range of areas of importance to them. Moving on from the original focus on inclusive education and disability rights we began to explore mental health, the meaning of diagnosis, neurodiversity and their intersection. Our participatory methodological approach also allowed for this participatory theoretical development. Our co-writing partnership aims to revisit key debates and concepts in the sociology of health and illness and disability studies to encourage a social, cultural and political understanding of childhood disability. Drawing on empirical data about lived experience which has emerged in the course of our working together we aim to connect a social studies of childhood perspective, and childhood disability studies, with the sociology of health and illness; this is an under-developed field and thus far there has been little engagement with disabled young people, least still them being supported to lead such discussions. Knowledge produced by and for disabled young people requires academic researchers to engage in a meaningful way and to democratise the research process. Drawing on influences from disability studies (Oliver, 1992) and childhood studies (James and Prout, 1990; Tisdall, 2012) we argue that participating in research should be about creating knowledge together through mutual dialogue between researcher and participant, allowing for the increased influence of those who would previously have been the subject of study. Working in this way requires yielding the space of privileged academic voice and embracing disabled young people as 'experts by experience', experts in their own lives - partners in the development, and furtherment, of academic fields. The possibilities for participation in every aspect of research then become infinite and the knowledge which is contributed is highly valued. Through a process of reflection

over many weeks (on-line and face-to-face) we have shared our ideas and collectively contributed ideas for this paper. The time given to the process has allowed for percolation of thoughts and layering of reflections, important in deepening knowledge and understanding between all involved. We consider our way of working to be symbiotic in that disabled young people share their life experiences and the academic allies introduce some traditional theoretical understandings, within the space created, exploring the applicability of theory to lives as lived. Here we combine our collective voice as we choose not to privilege academic voice over lived experience.

This paper arises from the discussions and theoretical developments that have emerged and been led by disabled young researchers over this time. It begins by reflecting briefly on developments in the field of medical sociology, disability studies and disabled childhood studies, before introducing the RIP:STARS methodology and theoretical discussions. We argue that both medical sociology and disability studies have been largely concerned with adults and have overlooked children until recently. We detail the ways in which our lives are 'validated' and our experiences defined by professionals. Next, we show how societal understandings of disability impact our life. Finally, we make links between the theorising of our subjectivity and existing theoretical frameworks. This paper aims to minimise the gap in both professional and academic knowledge of the lived social, material and political experience of disabled children's lives.

Background:

It is not our intention to re-visit at length either sociology of health and illness or disability studies, as the context has been set by the editors of this collection, however, the historical

development of the fields of study is crucial to understanding the contemporary lived experiences of disabled young people. Ideas about disability, health and illness have changed over time and such evolving ideas, discourses and conceptualisations influence the lives of disabled children and young people.

Medical sociology/sociology of health and illness

Medical sociology emerged in response to the dominant model of western medicine, which is biomedical. Atkinson refers to the biomedical as follows:

It is reductionist in form, seeking explanations of dysfunction in invariant biological structures and processes; it privileges such explanations at the expense of social, cultural and biographical explanations. In its clinical mode, this dominant model of medical reasoning implies: that diseases exist as distinct entities; that those entities are revealed through the inspection of 'signs' and 'symptoms'; that the individual patient is a more or less passive site of disease manifestation; that diseases are to be understood as categorical departures or deviations from 'normality' (Atkinson, 1988: 180).

Medical sociology and the sociology of health and illness have critiqued the biomedical model and offered alternative ways of understanding, being concerned with the analysis of the organisation of medicine on several levels and across a range of domains. The questions raised by medical sociology concerning the production of knowledge – how do we come to know what we know about health, well-being and illness? – are highly relevant when considering disabled childhoods. Who has the power to define? Who has least power to define? What are some of the social and cultural factors that influence or indeed determine health, well-being, illness, disability? How is ill-health responded to and what interventions are deemed appropriate and necessary? The sociology of health and illness problematizes

biomedical knowledge and exposes the social construction of health, well-being, illness and disability. What much of the research that has emerged from this tradition has in common is a focus on the adult experience or adult body (Mayall, 1998; Brady et al 2015).

Disability Studies

Disability studies and critical disability studies positions that disability is constructed as a social issue that must be addressed by removing the barriers to participation that people with impairments experience in the world. Disability studies is a wide field and incorporates a number of sub groups. For example, critical autism studies (Davidson and Orsini, 2013; O'Dell et al, 2016), which draws attention to the ways in which power relations are present in the field of autism and strives to promote enabling narratives that challenge a deficit-focus. Scholars in this field are developing new analytical frameworks using inclusive methodologies.

Dominant within disability studies is the social model of disability, which has led to activism and a focus for challenging forms of discrimination and inequality. Such perspectives are important because of the way that the social model of disability differentiates disability from impairment (Oliver, 1990; Oliver and Barnes, 2012). This model enables us to understand the disabling effects of structural, social and attitudinal barriers on disabled people's lives as separate from the individual experiences of, for example, physical or sensory impairments. Difference and identity are two highly contested concepts in critical disability studies (e.g. Shakespeare, 1996; Oliver, 1996). For example, identity has different meanings in different contexts but in terms of disability, Oliver argues that disabled people are those who can be identified by the presence of an impairment, by externally imposed restrictions or those who actively identify as such.

The social model of disability has been highly influential. However, it is not without critique. It has, for example, been criticised for failing to pay attention to the gendered nature of disability (Thomas, 1999).

The relationship between Medical Sociology and Disability Studies

Over time, there have been a number of points of commonality between medical sociology and disability studies. Both fields of study could be said to be relatively fledgling, both emerging in response to the dominance of biomedical understandings of health/illness and disability, presenting a challenge by critically analysing what has been presented as 'scientific knowledge'. Both medical sociology and disability studies have criticised biological reductionism, where bodily biological changes and disease processes are over-focused upon without recognition that bodies are to be found in socio-environmental contexts and material circumstances. Bodies are connected to self and society. Both medical sociology and disability studies have questioned how society constructs the body. Both medical sociology and disability studies have therefore theorised the body, in a range of ways.

One important achievement has been that both medical sociology and disability studies have challenged the notion of patients/clients/service users/lay people being passive recipients of care and emphasised interaction between people and professionals or experts, drawing attention to the location of power within such interactions. Both perspectives humanise the patient, client, service user – people have a role to play and a perspective to bring, the language used to describe them is important too, reflecting their status and relation to the professional who is attending to their need.

In calling for an embodied sociology Williams and Bendelow (1998) required a shift in theorising about bodies in a largely disembodied, typically male way (e.g. a sociology of the

body, which 'objectifies' and 'subjectifies' the body from 'outside' to a new mode of social theorising 'from' lived bodies' (p3). To do so challenges the dominance of social constructionism, seen as necessary to 'appreciate the importance of embodiment to the processes through which children participate in social life' (Prout, 2000).

As Williams argues, 'it is not a question of choosing between either biology or society but of re-envisioning this very relationship – and the former dichotomies it entails – in new (emergent, irreducible) ways which go beyond these existing terms of debate [...]' (2002: 14)

Crucially, whilst both medical sociology and disability studies highlight the social construction of 'health', 'illness' and 'disability', adopting a more holistic viewpoint than that of the biomedical and contextualising the experiential aspects of these states of being, they do so largely taking for granted adult bodies and experiences, rendering the experience of children and young people invisible. Invisibility of experience leads to gaps in knowledge of the views of children and young people relating to their illness or disability and a lost opportunity to understand the approach that children take to managing their daily lives.

Childhood studies

In childhood studies children and childhood are the central feature yet still relatively little research focuses on their own experiences of health, well-being or illness, with most accounts traditionally being gathered from their parents and carers. Parents and carers have an important perspective to contribute and can provide insight to their child's interaction with their health or disability status, however, to be able to advance understanding children need to be afforded the opportunity to recount their lived experience. Research from a child perspective which aims to understand the meaning and impact of health, illness, chronic illness, pain and disability or impairment in their own life is

still relatively limited and although gradually increasing is often disparately located across disciplines. In 2015 a Special Issue of this journal aimed to address this gap by bridging developments in the sociology of childhood and the sociology of health and illness, locating children as constructors of their own world of illness or ill health. This collection of international papers built directly on the groundbreaking work of Berry Mayall in calling for a sociology of child health. In 1998 Mayall argued:

'To elevate children to the status of a social group whose activities are to be considered within a sociology of health requires a concerted programme of work' (Mayall, 1998:273)

To do this justice Brady et al (2015) argued that whilst issues of child health can be contemporary and emerging it is important to look beyond issues identified as child health issues and take account of more general debates in medical sociology in order to develop the familiar theories and concepts of the sociology of health and illness. Alanen (2014) notes that internationally childhood sociology remains marginalised from mainstream sociology, the ultimate aim of childhood sociology should be the full incorporation of childhood into the body of the sociological discipline (Alanen, 2014). Bringing children and childhood into visibility has been a key aim of the sociology of childhood, therefore much oriented to the empirical, but the field needs to move towards further theorizing of childhood. In a similar vein, we argue here that there is also a need to look beyond disability studies more generally to focus on children's lived experience of being defined as disabled or impaired and their drive to theorize the childhoods which they are living.

Scholars within the tradition of social studies of childhood have highlighted how traditional accounts of childhood are individualistic and biologically determinist. They problematised the notion of children as immature becomings on their way to adulthood, emphasising

children as social agents, actors, influenced by and influencing their social worlds (James and Prout, 1990, 1997; James et al, 1998; Qvortrup 1994). The central concepts of the social studies of childhood have been much debated and developed over the past thirty years, in particular, attention has been drawn to the need to be inter-disciplinary in thinking about children and childhood and to recognise that much theorising has been excluding of the Global South, lacking recognition of diversity. Living in different contexts, being of different ages, gender, ethnicity, dis/ability, sexuality, socio-economic circumstances subjects children and young people to different structures and discourses on children and childhood. Homogenising and decontextualising discourses of children and the child are problematic, particularly when conceptualisations developed by Northern scholars are imposed elsewhere. The social model of disability when transported to societies which are organised differently, perhaps more collectively, does not take account of historical and political context (Singal and Muthukrishna, 2014). Disabled, individualised identities are more likely to be linked to a collective in the Global South and a localised approach to researching disabled childhoods is needed.

Social constructionist accounts of childhood, which negate the importance of the body, are also problematic. Prout (2000) states that social constructionist accounts of childhood provide a necessary and useful counterpoint to biologically reductionist accounts but wishes embodiment to be taken seriously, incorporating rather than excluding biology in the process (Williams and Bendelow, 1998). Mayall (1996; 1998) argues that children can be better understood as active participants in the management of both their bodies and their minds, rather than being regarded as passive recipients of processes which are imposed upon them in the form of 'civilisation', 'regulation' and 'surveillance'.

In order to understand the processes described above in an empirical sense we need to access disabled children and young people's own accounts, rather than accessing accounts from parents or professionals who are in contact with young people and speak on their behalf. This may or may not require the adoption of particular, specialist or adapted methods. Researchers often adopt a range of methods in order to access diverse childhood experiences and learn about the views of children, with a drive to be innovative, creative and relevant. Punch raises the question of whether special 'child-friendly' methods are necessary if our starting point is to consider children as competent social actors (Punch, 2002). A further reason for adopting such methods is to attempt to reduce power imbalances between researchers and their child participants, taking into account the diverse ways that children might communicate with adult researchers. A starting point that allows for children to describe their lives as lived and to set the agenda helps to diminish existing power relations and offers new ways of conceptualising that researchers may not have previously considered.

Disabled childhood studies: disabled children and young people's voice on disability and illness

Disabled childhood studies is an emerging field borne from attempts to make disabled children visible within often homogenous studies on children's lives, and to counter deficit narratives and the problematising of disabled children's lives. Drawing upon childhood studies and disability studies, disabled childhood studies does not problematize the lives of disabled children but rather it values, and seeks to understand, the holistic, diverse and intersectional lives of disabled children from the perspectives of disabled children, their families and allies. Thus, countering the often medical and developmental discourses which

dominate the research landscape for disabled children (Curran and Runswick-Cole, 2014). Connecting the principles of childhood studies and disability studies in research can significantly contribute to understanding the lives of disabled children and young people from their own experiences and perspectives (Davies et al, 2003; Connors and Stalker, 2007). This is important as much of the work in disability studies has been concerned with disabled adults, Watson calls for the development of new models ‘that can allow us to explore what it means to be a disabled child’ (Watson, 2012:199), acknowledging the heterogeneity of experience and allowing disabled children to contribute ‘fully and actively’ to the research agenda. The success of the social model lays in its ability to be utilised as a rallying call for the inclusion of disabled children in childhood studies and calls for methodologies to be more inclusive. A focus on disability as a sociological issue and a social construction, rather than an individualised problem, has galvanised lobbying and activism across a range of issues for disabled children including for inclusive education. The power of the model to liberate from oppressive, individualised notions of deficit forms the reasoning behind it underpinning the RIP:STARS methodology – it empowers and unites.

As argued above, when combining the principles of childhood studies and disability studies and moving to research methodologies which undertake research ‘with’ and increasingly research ‘by’ disabled young people, we are starting to understand how disabled young people are actively involved in constructing their lives and in making sense of life. By applying a health-care-division of labour lens (Stacey, 1981; Mayall, 2002; Brady, 2014) it becomes clear that disabled children and young people take responsibility for their health and well-being. A lived experience (of disability) provides children and young people with relevant knowledge with which to inform their decision-making in issues pertaining to their lives, yet rarely is such knowledge and expertise recognised by professionals.

In Stjerna's research with children who have a food allergy children are characterised as being in a state of liminality, being between categorisations of, for example, states of being healthy or ill (Stjerna, 2018). The liminality for disabled children is not necessarily that their bodily state might vary from healthy to ill but that perceptions and assumptions and ways of categorising them vary between, highly dependent on the model or framework of explanation in use, e.g. the medical model, social model or bio-psycho-social model. This then permeates through macro, meso and micro-levels in the ways in which disabled children are seen, treated, prioritised, included and so forth, impacting their everyday lives. Within the concept of embodied sociology, the 'lived body' is viewed as socially embedded, relational and a vehicle for challenging seemingly 'natural' dualisms, such as biology/society, healthy/ill. Monaghan and Gabe (2018) argue that embodiment of health identities has largely been an adult field, not focused on young people's understandings. Knowledge gaps prevail – including of chronic illness diagnosis early in life. Disabled children must also be recognised as active, interacting and shaping the social order.

The RIP:STARS young disabled research collective

The RIP:STARS disabled young researchers are from the Midlands of England in the UK. Young people came together over five years ago to learn from our academic allies how to become young researchers (See www.ripstars.net for our first research project final report and framework for practice). In this original project we developed our name RIP:STARS, our identity and our leadership skills. At the outset we were a group of eight and are now a group of four, our current ages are 21-24 years, although with renewed funding we are expanding our group once more to include a wider number of young people who are younger than us and are looking for an opportunity for development. Our collective

experiences, passion and drive motivate us to collect, collate and use research evidence to lobby for equality, equity and inclusion for disabled children and young people. We undertake research directly with disabled children and young people to learn about their experiences and we work in partnership with policy and practice stakeholders to facilitate change. We passionately believe that all disabled children and young people have a 'voice' and should be supported to express their views, in whichever way they choose, about decisions which affect their life. We also know from our own experiences that disabled children and young people are rarely given the space to 'voice', nor are listened to.

The RIP:STARS methodology is premised on the social model of disability and underpinned by a rights-based framework for decision-making – notably Article 12 of the United Nations Convention on the Rights of the Child (1989) which supports a child's right to be listened to and taken seriously. The social model of disability enables us to work together to identify and address any individual or collective barriers the group might face to being a young researcher and leader. By adopting this model we recognise that disabled children and young people are disabled by social, physical and attitudinal barriers in society and that these need to be addressed to enable full and equal participation (Oliver, 2013). We create a space where everybody feels included and empowered to fully participate in all research activities as they choose and we recognise each others' strengths and work as a team to achieve our aims. This means that we are supported to access any stage of the research process we wish to and that we have choice and control over how we engage in each activity.

We have been trained to work ethically and our first research project received a favourable ethical opinion from Coventry University in 2018. The process of consenting to take part in

research, in discussions and in grant proposals and publications is on-going at each of our meetings and is addressed by making each a rolling agenda item. We are informed and involved in all decision-making.

Over the course of our regular workshop-based meetings we create space to reflect on our lives, the lives of those we have researched and what we have learnt about disability activism, disability theory and disabled people's fights for equality. Just as previous sociological research has explored the health beliefs of children, which in turn inform health behaviours and influence health status (Pridmore and Bendelow 1995; Oakley et al 1995; Monaghan and Gabe, 2018; Webster, 2020) in our research workshops we explored the meaning of disability, impairment, physical and mental health, ideas of normality and difference, through our focus on research topics. Our voices are present in this writing, we hope that this contributes to making academic theory accessible and furthers the inclusion of disabled children and young people in research in the academic fields of health, illness, disability, childhood, education and social care.

As stated above, traditionally in health and indeed social research, much research has been on rather than for children, and rarely, as in this case, in partnership with young people. Adult categories are used, classifications and taxonomies have been developed with adults in mind and children are expected to fit, they are regarded as incompetent or as immature adults (Mayall 1996; James and Prout 1996).

Identified area of theoretical importance defined by RIP:STARS

Taking as the point of departure that frameworks of understanding provided by sociology of health and illness and childhood disability studies have much to offer, the rest of this paper will address the significant gap which exists in understanding the specific needs and

experiences of disabled young people who are neuro-diverse, from our own perspectives.

These rather more 'hidden' disabilities are often misunderstood or misinterpreted, sometimes because various frameworks of understanding are contested.

Despite increasing attention being paid to mental health amongst children and young people more generally, this group of disabled, neuro-diverse young people are often invisible, silenced or their specific needs are not addressed in generic mental health and well-being services. Little attention has been devoted to examining the potentially complex interacting factors which can affect their mental health and well-being.

Obtaining a clinical diagnosis which meets official criteria, and subsequently a response to need from services, can involve lengthy processes and long waiting lists. This can both lead to and exacerbate poor mental health and well-being. Professionals rarely have training in understanding how disability and/or mental ill health affects the daily lives of neuro-diverse young people, nor how to communicate and involve them in decisions about their support and potential treatment. Thus, interventions are rarely developed in partnership, or developed and adapted appropriately. This can lead to higher levels of unmet mental health need and crisis which can often lead down a pathway to inpatient services at significant personal cost to the young person and their family, resulting in financially costly placements.

As one of us experienced:

'When I got really ill, they kept saying it was just an autistic meltdown. Disability and mental health are taboo subjects and they need to be brought together and understood from the perspectives of disabled young people'.

Valid lives – validation by whom?

The RIP:STARS aim to provide an insight into disabled children and young people's lives in the UK through our research. Our own experiences of education have often been ones of exclusion from education, and from spaces and places where discussions of academic debates such as these might take place. Our experiences in the group have shown that this exclusion is not because of a lack ability or capacity to understand these issues – *“we live them”* – and on a daily basis we actively try to make sense of our lives in a world with high levels of discrimination faced by disabled children and young people. We try to negotiate our place in the world as individuals and, now we have come together, we negotiate as a group. However, we have discussed how our lives are impacted by how valid our lives are seen, and who validates our experiences. We want to rebalance this and validate our own lives from our own perspectives.

Our experiences of diagnosis of neurodiversity and our encounters with Child and Adolescent Mental Health Services (CAMHS) is our starting point. Many disabled children and young people have experience of encounters with the mental health system. The increase in biomedical perspectives in psychiatry is particularly concerning, being individualising and pathologizing and evidencing particular dominant discourses and frameworks of understanding. Whilst such ideas have become established they can still be challenged. As one of us expressed on behalf of all:

‘I am not a file or a spectrum, I am my own person’.

Whist another feels:

‘We will never get past it (mental health) unless we talk about it’

We have experience of being referred to CAMHS and of the long wait for a diagnosis, leading to stress and uncertainty for us and our families. Some amongst us received a diagnosis in our teens after years of battling services for recognition of our needs, and of being labelled as 'naughty', 'trouble-makers' or receiving completely wrong 'labels' of medical or psychiatric conditions by unqualified, but perhaps, well-meaning professionals. When a diagnosis was received it did not answer all of our problems but it was felt '*it can open doors*'. We discussed how receiving an 'official' diagnosis felt. For some it was a relief as it proved what we had always known and maybe hope of some support was offered. For others it meant nothing as we had known all along that we felt 'different' and did not really feel the need of a label for who we are.

These discussions correlate with findings from Mogensen and Mason (2015) who undertook a study with five autistic teenagers (aged 13 – 19) in Australia. They too shared experiences of their diagnosis and how they integrated a 'diagnosis' knowledge with a sense of self, negotiated issues of identity, and the meanings that feeling 'different' had for them. In this study, whether the diagnosis was experienced as advantage or disadvantage depended on the extent to which it facilitated knowledge and control. The young people variously described their diagnosis as 'oppressive', 'positive' or even liberating, and for some it facilitated their having some control in their lives.

Our own discussions led us to talk about what happens once you have been given a diagnosis, a label of 'neuro-diverse' or 'has mental health needs' by a mental health care professional. The 'label' was not a golden ticket to services or recognition of need. Instead it led to a new status, a new identity defined by others and in some cases a loss of what we were before. The group expressed that people form perceptions of disabled young people,

based on their diagnosis, they often assume that 'people with a certain diagnosis' all have the same needs.

'people look at you differently once you have a label, they make assumptions. Having the diagnosis is like losing your past self, before 'this person' and after 'this person with DIAGNOSIS/AUTISM'.

As a group we also reflected that having been 'validated' by medical professionals through the process of receiving a diagnosis, our own 'valid lives' were no more. Medication and adaptation often followed to make us more 'acceptable', we questioned in whose interests this was for?

'You take medication for acceptance, to be normal, to fit in. It is for everybody else's comfort. You ask yourself, is this the real me? Medication cannot fully take away the disability'.

'Medication also feels like it is shutting up the kid, the fun person'.

This resonates with research carried out by the first author here into the lived experience of children and young people who had a diagnosis of ADHD. Attitudes to diagnosis and to medication were complex and multi-layered and for some young people medication had an effect on who they perceived themselves to be, describing in detail that when taking medication it was not 'the real me' (Brady, 2005). This has implications for the ethics of medicating young people and also influences their desire to take or not take medication; they have valid reasons for not complying which are often not taken into account. For example, in the case of ADHD, emphasising the negative consequences of not intervening or offering treatment (school failure, poor mental health, risks associated with 'troublesome'

behaviour) justifies the practice of diagnosing and moving immediately to prescribe medication. An issue of further concern is that one medication can lead to another being prescribed. For example, stimulant medication may be helpful for symptoms associated with ADHD but mean that medication to help with sleep is then needed.

Our awakening to the social model of disability, which moved us away from problematising and blaming ourselves, and using learnt negative terminology to describe ourselves, empowered us to think differently about the reactions and responses we receive. Yet in many ways, as disabled young people, we are still quite powerless to challenge a dominant medical model which infiltrates every aspect of our lives. As an example of this some of the group shared how, now as young adults, asking for parental support in ordering a repeat prescription of medication is difficult, we *'do not want to burden our family members'*. This reluctance to ask for support has had some serious consequences when we have then been without our medication, including deteriorating physical and mental health and the need for treatment in hospital. As disabled young people we want acceptance, understanding, support and the ability to learn and live independent, full lives, yet: *'We are left to struggle'*.

Our examples describe the ever presence of the dominant discourse of medicalisation (Zola, 1972) which ensures that any struggles or difficulties or need for support will not be recognised unless or until children are able to claim a recognised disability or diagnosis – evidence, proof – only an individualistic label will open up the pathway to receiving support. For example, the Education, Health and Care Plans (EHCP) in England, introduced under the Children and Families Act 2014, aims to be one, holistic assessment of the education, health and care needs of children with special educational needs or disability. Adult agendas drive policy, practice and standards of care, with an overarching focus on educational attainment

within these plans. Whilst of course recognising the rights to, and importance of education for disabled children and young people, we argue that such a focus on educational attainment and achievements serves as another form of pathologizing disabled children; reframing, restricting and excluding based on a framework of 'labelling', 'assessing' and 'othering'.

Our own research identified that children's needs and desires are not being fully met within such Plans, and rarely focus on important areas of their lives where support is most needed, including their physical, mental and sexual health needs (Brady and Franklin, 2019). Yet to even achieve the 'status' of having an EHCP in England, where thresholds for support are so high, requires numerous assessments of need, and has led to an adversarial process where families are forced to fight lengthy battles for 'validation' and repeatedly work within a medical model, framing their child in negative ways, emphasising 'deficits' in order to receive support. Curran and Runswick-Cole argue that the Children and Families Act continues to locate special educational needs and disability as a within-child deficit (2014).

Societal understandings of disabled childhoods

As alluded to above, we were aware that predominant views in society concerning disabled children and young people were concerned with intervening to make disabled children more 'normal', to fit into existing society. We had our own personal experiences of this and it became more apparent once we learnt about different approaches to disability and impairment:

'The medical model is about fixing the problem and the problem is me. The social is more about the external and the environment'.

Problematizing a whole group of children impacts on their experience of school and life in general; health, education and social care systems pathologize, diagnose and medicate, individualising and not looking to the structure of the social system and society. A vacuum has been created whereby disabled children's lives are predominantly viewed through a medical lens of disability, where deficit models prevail and where disabled children are viewed as passive recipients of care, charity and philanthropy.

In Bendelow and Brady's account of research into children's experiences of ADHD over ten years ago they state '*[...] the stereotypes used stigmatise and label them and are exacerbated through unsympathetic media coverage and lack of understanding. At the very least, these children are marginalised and excluded and at worst pathologised*' (Bendelow and Brady, 2002). Over-medicalising the disability can lead to not seeing the child or seeing past the disability, children are 'psychiatrised' (LeFrancois and Coppock, 2014), decontextualised from their wider lives and further pathologized.

The 'lockdowns' associated with the Covid-19 pandemic in the UK provide a prime example of the impact of this view of disabled children and young people. The RIP:STARS group kept going through the pandemic, supporting each other as best we could via online platforms. However, online meetings were not accessible to all, and were not a substitute for face to face peer support. The isolation of repeated lockdowns had a severe impact on the mental health of each of us. We discussed feelings of loss of time, confusion, needing to start again, re-learning skills such as independent travelling, social skills or how to manage social anxiety and of rebuilding our confidence. In our discussions we talked about how disabled children and young people were referred to and framed as 'vulnerable' or 'the vulnerables'. And

whilst we accept that this might have protected us from the Covid-19 virus, how did this new 'label' define us? Once more a deficit model, to be pitied and increasingly to be forgotten about. Now that numbers of people infected by Covid are not so high there is a rush to resume 'normality', yet 'normal' (or life as we had before Covid) often excluded disabled children and young people, and rushing back to what we had before is not going to address issues of exclusion, invisibility and discrimination unless attention is paid to the things that matter to disabled children and young people (Franklin and Brady, 2022).

In the field of childhood studies dominant definitions of 'children' and 'childhood' often exclude disabled children, leaving disabled children and young people invisible, overlooked, not asked to contribute their views, or assumed too difficult to include. Therefore, it is crucial that an understanding from the perspective of young people labelled or defined as disabled is gained in a post-pandemic world. We have a lot to say about the experience, including the measures taken that identified us as 'different' and assigned us an identity. Disabled activists have long fought against disabling attitudes of pity, charity, dependence and vulnerability to be able to be regarded as equal citizens (Franklin and Brady 2022). It remains to be seen whether the 'vulnerables' label is enduring and continues to serve as 'othering' us as a group.

Reflections and implications

This paper seeks to contribute to a growing body of research which is interested in disabled and chronically ill children's lived experience. The examples we have presented are revealing of the ways in which disabled young people are actively making sense of their place in the world. Medical sociology and the social model of disability have frameworks of understanding to offer, each importantly counter dominant biomedical understandings of

difference and/or impairment. However, with the dominance of adult models of understanding in these fields of study the everyday experiences of disabled children and young people have been over-looked by the medical model, medical sociology and disability studies.

Our analysis resonates with the major themes of this special issue, highly relevant to contemporary concerns. We recognise that there are tensions between medical sociology and disabled childhood studies but there are also fruitful opportunities to explore further, if dialogue is kept open. Narrative accounts of young people's subjective experience can contribute what Letherby refers to as 'theorising subjective experience' (2003), providing alternative ways of knowing and contributions to knowledge production. Whilst not necessarily using the academic language of medical sociology or disability studies, the RIP:STARS in describing and discussing experience of life in a body deemed to be impaired, either physically or mentally, are clearly contributing to extending some of the fields of work which are highly familiar to readers of this journal. This lay storytelling of disability chimes with Frank's 'illness narratives' (1995), reflection on encounters with medical professionals speaks to Strong's doctor-patient interaction (1979). Most clearly threading through is an idea central to the sociology of health and illness, the medicalisation of social experiences (Zola 1972) or of deviance (Conrad 1975) and clear examples of iatrogenesis (Illich 1976), where rather than curing, healing or making things better medicine can actually do more harm than good. The negative consequences of psychiatric intervention are evident in the examples given of the outcome of either diagnosis or the clinical interventions used to treat mental ill health.

The embodied perspectives of disabled young people show how we are not passive recipients of health, education or welfare, we challenge perceptions – if not directly with professionals with whom we are in a power relationship – through our actions, activism and refusal to accept a label which defines and limits our potential in life. As we argue, disabled children and young people are experts in their own lives, we want professionals to hear our experiences of living with an impairment, the impact it has day to day but also to recognise our agency, our abilities to be involved in decisions about our lives, bodies, ‘labels’, treatment and assessment of our needs. We would also argue that our lives as lived are valid.

In the field of childhood studies, dominant definitions of ‘children’ and ‘childhood’ often exclude disabled children. As we have argued, this can lead to disabled children and young people being invisible, overlooked, not asked to contribute their views, or assumed too difficult and complex to include. Therefore, it is crucial that an understanding from the perspective of young people who identify as disabled is gained. Yet, as we have previously discussed (Brady and Franklin, 2019), introducing disabled young people to their oppression with an aim of raising critical consciousness needs to be approached carefully and ethically, with the provision of appropriate time and space for reflection and to address emotions which may be raised. Being part of a marginalised group and theorising your own experience has a potential impact, yet children’s rights research can lack critique (Larkins et al, 2015).

Tick-box cultures of medicalising, categorising, psychiatrising and ‘othering’ disabled children and young people lead to making assumptions about young people based on their impairment or label (Brady and Franklin, 2021), including treating children *as* their disability,

or diagnosis, for example, the 'ADHD kid', the 'Down's Syndrome (DS) kid', the 'Cerebral Palsy (CP) kid' or, more generally as simply 'vulnerable' (Franklin and Brady, 2022). The world of disabled children then remains invisible, the impairment remains their dominant identity and they are pathologized through a medical or psychiatric diagnosis. Children who do not fit the biomedical profile of 'the disabled child' can similarly have their impairment-related needs overlooked if they have not been deemed to have a medical or psychiatric diagnosis. In some cases, children are seen as 'bad', excluded from education, on the edge of criminalisation. Their neuro-divergence remains hidden as the focus of attention is on their 'badness' and forms of 'troubling behaviour' (Franklin et al, 2020). Crucially, a medical label can be a precondition of receiving care and support from health, education and social care services. Both medical sociology and childhood disability studies offer alternative ways of knowing and call to de-medicalise current forms of understanding disabled childhoods. Creating space for disabled children and young people to collectively think-through their experience, as we have done as RIP:STARS, allows for full and meaningful contributions. Young people competently speak about health, illness, well-being, disability, impairment. Whilst the lives of disabled young people are often dominated by medicalised talk and understandings our own insights show how we are also resisting dominant narratives and questioning the labels that regard us as lacking, deficient, vulnerable or at risk.

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