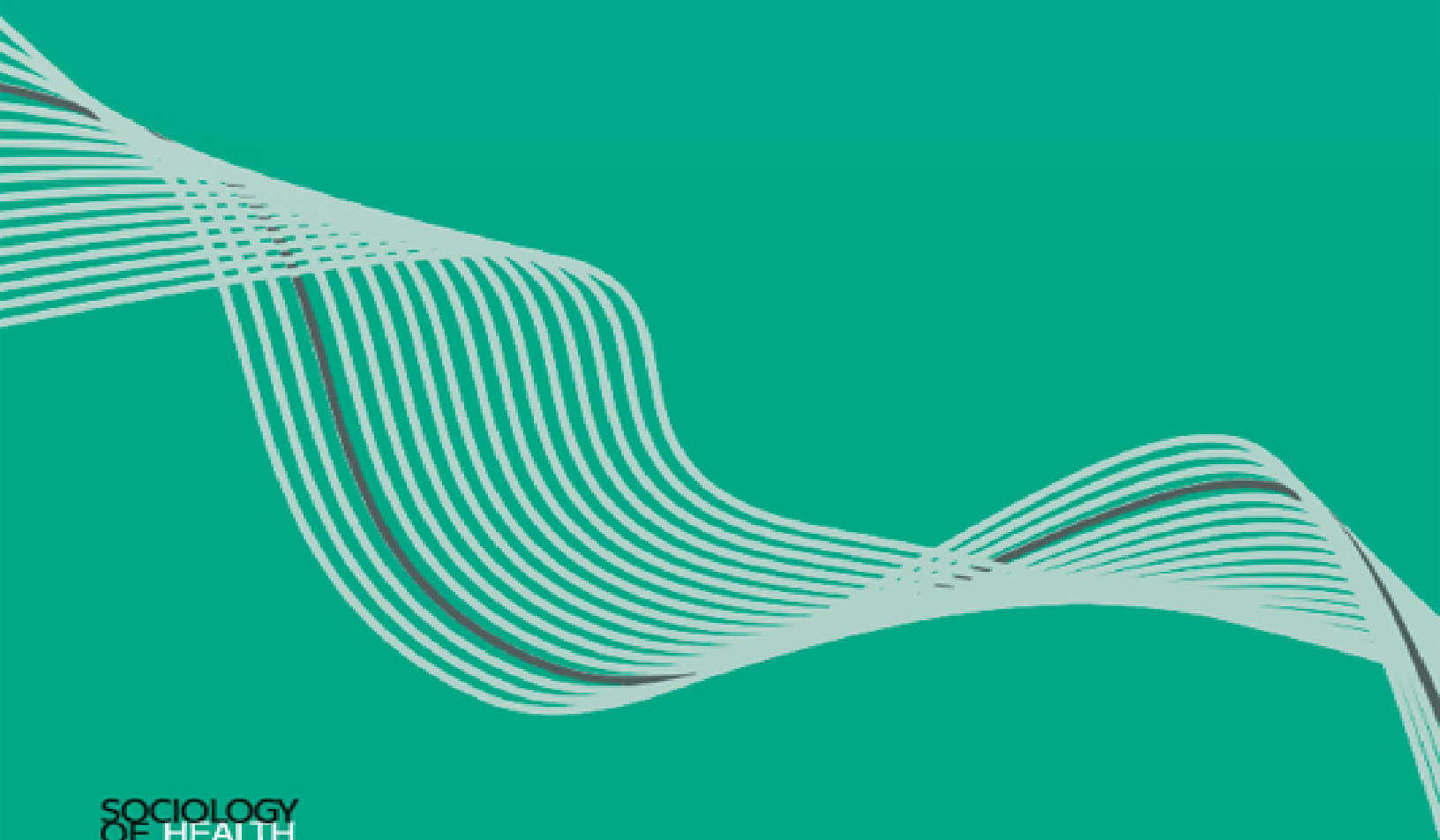# Children, Health and Well-being

Policy Debates and Lived Experience

Edited by

Geraldine Brady, Pam Lowe
and Sonja Olin Lauritzen

Sociology of Health and Illness Monograph Series

Edited by Professor Ian Rees Jones
Cardiff School of Social Sciences
WISERD
46 Park Place
Cardiff
CF10 3BB
Wales, UK

Current titles

Children, Health and Well-being: Policy Debates and Lived Experience
edited by *Geraldine Brady, Pam Lowe and Sonja Olin Lauritzen*

From Health Behaviours to Health Practices: Critical Perspectives
edited by *Simon Cohn*

Pandemics and Emerging Infectious Diseases: The Sociological Agenda
edited by *Robert Dingwall, Lily M Hoffman and Karen Staniland*

The Sociology of Medical Screening: Critical Perspectives, New Directions (2012)
edited by *Natalie Armstrong and Helen Eborall*

Body Work in Health and Social Care: Critical Themes, New Agendas (2011)
edited by *Julia Twigg, Carol Wolkowitz, Rachel Lara Cohen and Sarah Nettleton*

Technogenarians: Studying Health and Illness Through an Ageing, Science, and Technology Lens (2010)
edited by *Kelly Joyce and Meika Loe*

The Sociology of Health Inequalities (1998)
edited by *Mel Bartley, David Blane and George Davey Smith*

The Sociology of Medical Science (1997)
edited by *Mary Ann Elston*

Health and the Sociology of Emotion (1996)
edited by *Veronica James and Jonathan Gabe*

Medicine, Health and Risk (1995)
edited by *Jonathan Gabe*

Children, Health and Well-being

Policy Debates and Lived Experience

Edited by

Geraldine Brady, Pam Lowe and Sonja Olin Lauritzen

WILEY Blackwell

Wiley also publishes its books in a variety of electronic formats. Some content that appears in print may not be available in electronic books.

Designations used by companies to distinguish their products are often claimed as trademarks. All brand names and product names used in this book are trade names, service marks, trademarks or registered trademarks of their respective owners. The publisher is not associated with any product or vendor mentioned in this book. This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is sold on the understanding that the publisher is not engaged in rendering professional services. If professional advice or other expert assistance is required, the services of a competent professional should be sought.

Contents

List of Tables

List of Illustrations

Notes on contributors

Geraldine Brady   Centre for Communities and Social Justice, Coventry University, UK

Pam Lowe   School of Languages and Social Sciences, Aston University, UK

Sonja Olin Lauritzen   Department of Education, Stockholm University, Sweden

Disa Bergnehr   Department of Child Studies, Linköping University, Sweden

Karin Zetterqvist Nelson   Department of Child Studies, Linköping University, Sweden

Ellie Lee   SSPSSR Cornwallis Building, University of Kent, UK

Jan Macvarish   CHSS, University of Kent, UK

Gillian M. Martin   Department of Sociology, University of Malta, Malta

Stephanie A. Alexander   School of Public Health, l'Université de Montréal, Canada

Caroline Fusco   Faculty of Kinesiology and Physical Education, University of Toronto, Canada

Katherine L. Frohlich   Institut de recherche en santé publique de l'Université de Montréal, University of Montréal, Canada

Terese Wilhelmsen   Norwegian Centre for Child Research, Norwegian University of Science and Technology, Norway

Randi Dyblie Nilsen   Norwegian Centre for Child Research, Norwegian University of Science and

Technology, Norway

Lise Mogensen   Medical Education Unit, School of Medicine, University of Western Sydney, Australia

Jan Mason   School of Social Sciences and Psychology, University of Western Sydney, Australia

Sarah Bernays   London School of Hygiene and Tropical Medicine, UK

Janet Seeley   London School of Hygiene and Tropical Medicine, UK and MRC/UVRI Uganda Research Unit on AIDS, Uganda

Tim Rhodes   London School of Hygiene and Tropical Medicine, UK

Zivai Mupambireyi   Centre for Sexual Health and HIV/AIDS Research, Zimbabwe and University College, London, UK

Marie-Louise Stjerna   Södertörn University, School of Culture and Education, Sweden

Laura Jenkins   University of Sheffield, UK

Berry Mayall   Social Science Research Unit, UCL Institute of Education, University of London, UK

1
Connecting a sociology of childhood perspective with the study of child health, illness and wellbeing: introduction

Geraldine Brady, Pam Lowe and Sonja Olin Lauritzen

The health and wellbeing of children and young people has been studied from a range of different perspectives in social science and the health sciences as a whole. Much of the research to date has been for or on children and has focused on promoting health, detecting illness and its causes or investigating the social determinants of health. While these make vital contributions to making the world better for children and young people, we would argue there is also a need for research with children, research from a child perspective, to fully understand the meaning and impact of health and illness in children's lives. Furthermore, there is a need to explore the social and cultural contexts of child health that frame the lived experiences of children and their parents. More specifically, there is a need to interrogate the explicit as well as the implicit perceptions of childhood and the child in health policy, perceptions that are reproduced in various health and social practices. The purpose of this issue is to contribute to a further understanding of these issues by bridging developments in the sociology of childhood and the sociology of health and illness.

In the last decades we have seen a growing interest across disciplines in research on children's own experiences and

understandings of health and illness. It can be argued that this increasing interest has been stimulated by developments in the sociology of childhood. Through the 1990s a body of work emerged which criticised dominant notions of child development where children were largely depicted as immature and passive objects of socialisation (Burman 1994, Halldén 1991, James and Prout 1997, Qvortrup 1994).

Scholars of the sociology of childhood problematised these notions of the child by theorising the ways in which childhood is socially constructed and understandings of the child vary across different sociocultural contexts. Importantly, the focus was shifted from seeing children as immature becomings on their way to adulthood to a focus on children as beings and as competent actors with a social agency of their own, not only influenced by but also influencing their social worlds (James *et al*. 1998, James and Prout 1997, Qvortrup 1994). Moreover, by understanding children as a specific social group, attention could be directed at children's rights and the structures that enabled and restricted control over their lives (Alanen and Mayall 2001).

Since these early years, the theoretical positions and central concepts in the sociology of childhood (and its place in sociology) have been, and are, debated (see, for example, Alanen 2014, James 2010, Moran-Ellis 2010). At the same time, empirical studies of children and childhoods have been burgeoning in sociology and in other disciplines. Although a full account of these developments and disciplinary differences falls outside the scope of this issue, here we want to draw attention to some of the central concepts and theoretical points of departure in this tradition that we find of particular interest for studies of child health and wellbeing.

Firstly, seeing children as a social (minority) group draws our attention to the ways this group is placed and perceived in the structures of societies. Children as a social group need to be understood in relation to other social groups. Importantly, work on children as positioned in intergenerational relations has added to understanding of the dynamics in relations between children, parents and adult society (Mayall 1996, 1998). This involves power relations and the ways children (as a group) are listened to and taken account of in different social settings, such as in healthcare settings and at school, but also prevailing discourses and images of the child in social and health policy and health promotion interventions addressing children and young people.

Secondly, understanding children as social agents and as co-constructors of their social worlds is fundamental to studying their experiences and ways of dealing with health and well-being in everyday life. Child agency is a core issue in the sociology of childhood, but it has also been debated in this tradition in recent years. Agency is not to be seen as just something positive, or a personal competence, but as a more complex and multidimensional concept (Valentine 2011). Children's agency is bounded by and in intergenerational relations as well as in wider socioeconomic contexts and bodily, social and material resources. This raises questions about whose actions should impact on whom (Tisdall and Punch 2012). Power and participation are situated and changeable, which calls for attention to how children's agency is perceived, facilitated and restrained in specific settings.

Thirdly, in recent years, there has been a turn towards seeing children as beings (not just becomings). However, it is also argued that all humans are becomings; subjects who develop and change as they experience the world and in relation to different social contexts (Lee 2001, 2005, Prout

2005, Uprichard 2008). Further, there is an issue with diversity and variation in children's lives. There is no typical child. Children are of different ages, gender, ethnicity, socioeconomic circumstances and capacity. They live in different national and cultural contexts and attend different educational institutions. Thus, they are subject to different structures and discourses on children and childhoods (Prout 2005). Increasingly, conceptualisations of the child that homogenise and decontextualise children and their lives are being viewed as problematic (see, for example, Singal and Muthukrishna, 2014).

We argue that there is a need to reflect more broadly on learning from the sociology of childhood in research on child health. This tradition is now well established and there is much evidence to indicate that children are competent social actors, yet we are in agreement with Tisdall and Punch when they state that:

> Focusing on children and young people's perspectives, agency and participation is no longer sufficient; greater emphasis is needed on the intricacies, complexities, tensions, ambiguities and ambivalences of children and young people's lives across both Majority and Minority World contexts. (2012: 22)

These issues also raise questions about research methodology. The risk of homogenising and decontextualising children also applies to the context of research on children's lives. If it is important to do research with children, how do we locate children at the centre of knowledge production? How can we access children's perspectives and lived experience? One avenue suggested is to use a range of methods to take account of diversity between children (see, for example, Christensen and James 2000) or to involve children as actors in research as a way to overcome the power imbalance

between the child and the researcher (Alderson 2000, Mason and Hood 2011) which, however, might create new methodological problems (Harden *et al.* 2000). On the other hand, whether research with children is necessarily different from research with adults is also being questioned. 'If children are competent social actors, why are special "child-friendly methods" needed to communicate with them?' (Punch 2002: 321). These, and other methodological issues are part and parcel of research with children and need to be addressed to obtain a child's perspective on health and wellbeing.

So, what are the child health issues and concerns in contemporary society? Children are diagnosed with an increasing range of conditions and are subject to more and more elaborate child health and welfare interventions, reflecting a medical perspective on the changing panorama of illness and health risks in the 21st century. We see today a growing concern with mental health (for example, the autistic spectrum), as well as emerging contested illnesses (attention deficit hyperactivity disorder [ADHD]), life-style related conditions (obesity and allergies) or 'new' infectious diseases (HIV/AIDS). However, we would argue that in trying to bridge the sociology of childhood with that of health and illness, it is important to look beyond what is discussed as child health issues and take account of issues currently debated in the sociology of health and illness more generally. Health behaviour approaches have almost universally been adopted by those involved in healthcare research, with little critical attention paid to the conceptualization of health behaviour (Cohn, 2014). The assumption that there are easily identifiable and observable forms of health behaviour can be difficult to challenge, not least because the way in which health behaviours are seen as the outcome of individual choices has become established as the norm. This model also draws on ideas

about agency, particularly in relation to choice and personal responsibility, often devoid of the social, economic and political context in which such agency is being enacted. In addition, a focus on health risks and surveillance medicine, as well as on lay understandings and patient perspectives, are relevant in the study of child health. However, research on these health issues, similarly to the old issues of chronic or life threatening illness, have largely been limited to the taken-for-granted adult person (Williams 2000). Expanding research to other phases of the life-course to include childhood is important not only to understand the meaning of child health and children's experiences but also to add important knowledge at a more general level to the understandings of health and illness.

Themes of this issue

As outlined above, in this issue we focus on the ways that socially and culturally constructed understandings and conceptualisations of childhood impact on issues of health and well-being and on the ways in which children exercise agency and competence in dealing with health and illness. A further consideration is how agency is bounded in intergenerational relations; while the focus of this issue is on children, the role of parents as mediators and facilitators in the healthcare division of labour (Stacey 1988, Mayall 1996) cannot be underestimated. Further, health, we argue, can be understood only by locating children as embodied beings (Bendelow 2009) in different social and cultural contexts. To advance our understandings of child health, it is necessary to situate child health issues in wider social, economic, cultural and national contexts as well as in the variety of public and social policies that will impact on dominant ways of

understanding childhood and on children's lives and opportunities.

Children's daily lives play out across the social contexts which structure their lives. The settings of school and home largely organise children's lives, while their movement between such settings straddles the public and private domains. Messages about health are communicated to children both explicitly and implicitly so that they begin to learn social norms around health and, sometimes, change their behaviour in response to such messages. Mayall has argued that 'child health is not a neutral, factual concept; notions of child health are constructed out of essentially political considerations' (Mayall 1996:22). It may be assumed that children are relatively passive and conforming when faced with illness or diagnoses, yet children do exercise choices. Children have an active role in the management of health risks, their conditions and interactions with healthcare services. Moreover, they develop a repertoire of strategies to cope and sometimes to resist adult defined agendas (Bluebond-Langner 1978, 1996). Adults can be unaware of the ways in which children are interpreting information on health and making it meaningful to their lives. Previous health research has shown that even chronologically young children are competent reporters of their illness experiences (Alderson 1993) and that children can understand complex information if it is presented in appropriate ways (Alderson and Goodey 1996).

Since Mayall's 1998 article in this journal calling for a sociology of child health, research published in this area has increased but is sometimes disparately located. In this issue, the aim is to contribute to the development of a sociology of child health by bringing together current research that draws on the sociology of childhood and to address three cross-cutting themes that we have identified

as being important in the study of child health and wellbeing:

Theme 1: situating children within health policy, which sets out the significance and pervasive influence of health policy in shaping the lives of children and their families.

Theme 2: practices of children's health and wellbeing, which focuses on health policy in action by looking at interactions between professionals, parents and children.

Theme 3: children as health actors, with a specific focus on the lived experiences of children and young people themselves.

Taken together, these three themes can offer examples of differing contexts and encourage reflection on current and culturally specific ways of knowing and understanding children's health.

Theme 1: situating children within health policy

The health of the child is seen as a signifier for the current and future health of the nation, placing their bodies at the intersection of ideas about social order. Armstrong's (1995) influential work on surveillance medicine clarified how this new 20th century medical paradigm became particularly concerned with the child and child development, over time and into the future. Children are thus a critical object of state policy, where the main focus is on children as future citizens (Mayall 1998), (which raises questions as to whether the future-focus of policy is always in the best interests of children in the here and now). The health policy focus is on risks and includes a preoccupation with children's body size, development and behaviour. These developments are reflected in an increase in preventive

medicine and various programmes for health promotion as well as early detection and intervention in groups of people considered to be at risk, to a large extent directed at children and their parents. While surveillance of child health is not new, it is important to understanding the ways in which children are categorised as healthy or ill, normal or deviant; categorisations that contribute to shaping the embodied lives of children and young people. For example, research on medicalisation as well as psychiatrisation of child development and behaviour (Le Francois and Coppock 2014), followed by pharmaceuticalisation (Williams *et al*. 2011) has raised the question of how categories of child deviance are constructed in the process of health surveillance and also how diagnosis can function as a tool to categorise individuals (Jutel 2009).

Health promotion information aimed at parents often raises awareness of risk and also of protective factors – it is professed that knowing about risks can help parents to consider the best ways of supporting and optimising the wellbeing of children. The risk is usually described as potentially increasing the likelihood of a child or young person developing physical, mental or social difficulties. One main issue with this kind of approach is that many of the factors that put children at risk are not amenable to change by families as they are structural factors such as poverty, stigmatisation and the poor provision of education and welfare. Not being in a position to minimise such risks, coupled with the emphasis on their long-term consequences for children, can leave parents feeling inadequate and also contributes to the depoliticisation and individualisation of social problems (Conrad 1976, Zola 1972).

Against this backdrop, and in a world of health and social inequalities, a critical engagement with the ways in which health policy and practice impacts on children is required.

It is also important to analyse the ideas and images of children and childhood present in policy documents and health interventions. Such ideas and images are typically taken for granted, but in-depth analyses of child health policy documents and programmes tell us something about the prevailing understandings of the child in our societies. It also reveals the ways in which deviance from perceived norms becomes a matter for concern and intervention. The ways in which child health and normality are reflected in health policy and practice thus have implications for children and young people as well as their parents and carers.

Theme 2: practices of children's health and wellbeing

In a sociological approach to health, health care is recognised as part of a social process, carried out in the public domain by paid professionals and privately by unpaid, lay carers (Stacey 1988). Health may also be understood variously; for example, professional beliefs may differ from lay beliefs, adult beliefs may differ from children's beliefs and all are variously influenced by a range of factors. Understandings of child health are thus to be seen as relational and constructed in communication between different actors in everyday life. Also, ideas about child health and how children should be treated vary across social and cultural contexts both in and between different societies, not least between the global North and South, which stresses the importance of seeing children's health and wellbeing as contextually embedded (Singal and Muthukrishna 2014).

As we cannot assume a linear relationship between policy and practice, it is important to consider how health policy becomes translated into practice in healthcare encounters at different levels: in surveillance and intervention

programmes directed at children and young people (or those considered to be at risk) – initiated and carried out by the social and health services – and at the level of the clinical encounter initiated by parents (or others) to deal with the health and illness of the individual child.

Sociology of health and illness research has shed light on the impact of surveillance medicine and has demonstrated how messages of normality and deviance are communicated explicitly as well as implicitly when carried out in health practice (Olin Lauritzen and Sachs 2001). But we still need to know more about the content of these messages. What are the ideas about childhood and the child as well as ideas about normality and deviance inherent in surveillance and intervention and communicated to children and parents? Also, the changing panorama of what is considered a deviance from normal development and behaviour in children needs to be addressed, as well as the fact that the surveillance and monitoring of children's minds and bodies is carried out from an adult perspective and children are not always asked about their views or included in decision-making about their care.

At the level of clinical encounters between professionals, parents and children in various healthcare settings, the different voices of these parties can be identified and intergenerational aspects and power relations of the interaction can be laid bare and examined. Early work by Strong (1979) and Silverman (1987) explored the details of how the degree of 'medical doubt' concerning the health of the child patient created different formats of the clinical encounter. This has been followed by studies of how professional and moral understandings and disciplinary frameworks, as well as the structural organisation of healthcare, shape healthcare encounters and the power relations in these encounters (White 2002).

Detailed micro analyses have shed further light on the dynamics of the interaction and power relations between health professionals, parents and children – including the ways in which children contribute to or are excluded in these processes (Aronsson and Rundström 1988, Clemente 2009). Dimond (2014) argues that research on the triadic relationship between children, parents and healthcare professionals in clinical settings is much needed to help to enhance understanding. From what is known about the role of adults in health encounters they often dismiss or reframe children's own bodily sensations and experiences (Carter 2002) to fit existing frameworks of understanding. When it comes to children's voices and agency in healthcare interaction, important contributions have been made, for instance, on children's consent to treatment (Alderson 1993, Alderson and Goodey 1996) but more knowledge is needed to explore children's experiences and capacities. Importantly, patterns of interaction and power dynamics in health practices need to be explored further from a child perspective and across different sociocultural contexts.

Theme 3 – Children as health actors

The third theme of this issue focuses specifically on children's own experiences of health and illness, of living with a condition and on children's active participation in the management of their bodies and minds. Exploring the lived experience of children brings to the fore their role as healthcare actors. We acknowledge that in the field of child health, the views of children, as service users, are beginning to be sought, often through consultation or evaluation. However, perhaps unsurprisingly, the social and political context of lay/professional, adult/child interaction and embedded social relations and structures are often not explicated thoroughly enough to provide a deeper understanding of the experience of children. Consequently,

the data gained from such exercises can be superficial. Crucially, we cannot fully understand the impact and meaning of health and illness in children's lives without bringing in children's experiences, understandings, competence and agency in dealing with these issues (Mayall 1996, 1998). Examples that show this is possible include studies that have accessed the views of children over a range of areas such as in relation to doctor–patient consultations (Rindstedt 2014), the design of children's health services and spaces (Birch *et al*. 2007) and treatment preferences and their impact (Coad 2010). It is clear that by using a range of different methodological approaches research can show how children's concerns often differ from adult-centred ones.

One important issue in the lives of children and young people is the social implication and impact of receiving a medical diagnosis. This can have both negative and positive effects on children's identity and embodied lives, both from their own perspective and the way that they are seen by others. Earlier research in this field has indicated that children's competence and understanding in dealing with a medical diagnosis is often underestimated (Berntsson *et al*. 2007, Brady 2005). This may particularly be the case where definitions are contested or there are debates over prevention or treatment. Questions are raised about children's own priorities, concerns and agendas and how they can be in conflict with those of adults (Brady 2014, Williams *et al.* 2007).

Children's and young people's experiences and understandings of health, illness and medical interventions are interesting per se. Moreover, children's understandings also have implications for how they act to promote health, how they deal with illness and manage risks to their health in everyday life. On the one hand, 'Children use their resourcefulness to stretch adult-imposed boundaries to

limits more acceptable to themselves' (Punch 2001: 34), a fact that is especially evident in research into children's management of risks and of medication. On the other hand, children's dealing with health and illness has to be understood relationally: being healthy or ill, competent or not, takes place, so to say, in relation to others and in the complexity of local contexts. There is also a spatial dimension to consideration of children's health in that a number of sites of health practices, including early year childcare settings, school (the classroom and playground), the family home and wider public space are of importance.

Introduction to the collection

The following chapters, all anchored in a sociology of childhood perspective, include contributions from a range of disciplines, countries and sociocultural contexts as well as different methodological approaches. They address different cases of health policy and practice as well as children's (and parent's) experiences of a range of conditions and ways of 'doing health.'

The first chapters address the ways in which children are positioned in health policy. In their chapter, Bergnéhr and Zetterqvist Nelson take mental–health-promoting interventions to explore the ways in which children are situated in health policy; how young people are viewed, understood, thought about and positioned. While this research analyses the Nordic context, such public health interventions are increasingly being introduced to children and young people across the world. Two themes thread through the analysis – that the child is largely assumed to be passive and formed by adults and that ideas about health and wellbeing are often highly individualised and decontextualised. These themes appear throughout the book. The study draws attention to school as a site of

health promotion and maintenance and argues for a need to know more about children's experiences of such (mental) health interventions, which are largely normalised and seen as part of school life in some countries.

In the next chapter, Lowe, Lee and MacVarish focus on images of children and parents in health policy documents, more specifically on 'brain claims' in English health and welfare policies from 1998 to 2012. The authors describe how determinist ideas about brain development, drawing on quasi-neuro-scientific discourses, are becoming prevalent in understandings of children and child development. They discuss this development as a drive in policy that amounts to understanding children's development and growth in increasingly narrow terms. Although focused on England in this instance, it is argued that such brain claims are impacting on policy and practice across the western, neoliberal world. Taken together, these two chapters demonstrate how a detailed analysis of health policy documents and programmes can reveal implicit ideas about the child; ideas that will impact on practice and are translated in communication with parents and children.

The chapters that follow focus precisely on such practices, and on the complex dynamics in the translation and communication of notions of the child as well as the divides between health, illness or deviance from the norm. Research undertaken by Martin focuses on public health messages of concern and panic about childhood obesity and explores how the issues of obesity and additional weight are understood by children and their mothers in Malta. By ethnographically studying the children in a primary school setting she is able to identify the subtle ways in which children understand and depict their own bodies (as fat or not), as well as highlighting interesting differences between the bodily accounts given by younger children (5-year olds) and those somewhat older (10-year olds). She

argues that the younger children are buffered by robust protective strategies in their group, while children in the older group perceive themselves to be different and are indeed so labelled; they develop private coping strategies to manage the levels of exclusion often felt. In doing this, Martin draws attention to the ways children's bodies are both biologically and socially constructed.

Also in this collection, Alexander, Fusco and Frohlich begin by acknowledging increasing public health concerns about childhood obesity. In Canada, public health institutions are emphasising active play as a way of combatting obesity. The chapter highlights the contrast between public health discourses and children's own diverse, lived experiences of playing. They show how some children adopted the understanding of active play, while others highlighted the importance of other more sedentary activities. They argue that there may be unintentional consequences in limiting understandings of play to an active mode. This chapter again highlights the need to properly understand children's lives before interventions are planned and executed. Both of these studies relating to obesity highlight the ways in which messages on one of the major public health issues in the Western world are communicated, taken up and understood by children and their parents.

The following chapter, by Wilhelmsen and Dyblie-Nilsen also explores the practices of children's health and wellbeing. In this case the focus is on how normal child development is communicated to parents in an early years setting, in a Norwegian day-care centre. The chapter addresses the processes and tools used to assess and define children's behaviour as either normal or deviant. The chapter shows the complexity of parents' experiences of pathways towards a diagnosis of a 'non-normal' condition, such as ADHD, and a 'special-needs' designation. Parents have their everyday understanding of their child, which

may agree or disagree with the professional perspective. In their study they also show how forms and charts used to map behaviour serve to provide a visual representation of deviance and difference and are regarded as evidence, legitimating the forms of power at work in the social construction of knowledge.

The following three contributions address the understandings and experiences of children and young people who are living with different conditions. Mogensen and Mason consider the label of autism and the meaning of this diagnosis to a group of five young people in Australia. The young people were able to choose how they communicated with the researchers, who used participatory research methods, and were able to share their understandings of autism and its impact on their sense of self and identity. More specifically, the authors show how the young people integrated their understandings of the autism diagnosis with their sense of self, and the different positive or negative meanings the diagnosis could take on in this process. Also, these young people clearly desired to be in control of the ways in which they dealt with their diagnosis, and Mogensen and Mason suggest that ways of minimising stigma and marginalisation associated with a diagnosis of autism need to be considered at a policy level.

Bernays, Seeley, Rhodes and Mupambireyi also explore children as health actors, in this case the illness narratives of children living with HIV and accessing antiretroviral treatment (ART). They note that in previous research into HIV, adult views have been the focus, acting as proxy representations of the experience of children. The narratives told by the children themselves reveal a complex picture of illness stories, resistance to being defined as ill, and what the authors identify as protest talk – where children strive to come to terms with the ambiguities of