

# Disability and economic disadvantage: facing the facts

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This in-depth article presents evidence and detailed reflection on the ill effects of inequalities on children's health and well-being. We have known about these issues for generations. Indeed Public Health work since the 19th century, and the drive behind the Post-war Welfare settlement creating the NHS, were informed by that knowledge. That we seem unable to close the gaps and right the wrongs is a continued concern.

Variations in health affect a child's whole-of-life-course outcomes. Variations become inequitable when children are denied fair access to the determinants of good health, including in services' responsiveness.

This paper explores some of these issues through the lens of child rights given that poverty and inequality compound and are compounded by physical or learning disabilities.

Too many children in England do not have access to an adequate diet, a warm coat, new shoes or a quiet place to do their homework. That disability adds to the weight on a family's financial position is a stark reality.

In our research, one disabled young person told us; "I don't get a lot of money, although I do get DLA. Right now I've got no money for food."<sup>1</sup>

This article reflects evidence from those affected; discusses inequality as a wider determinant of health outcomes in the children and families concerned; and presents some challenges.

The view of the Office of the Children's Commissioner (OCC) is that our society must make a firmer commitment to improve all children's life chances. The approach should be to protect children from hazards known to have a negative impact, and to actively provide positive experiences to enhance the child's and family's assets and resilience.

Children with disabilities present challenges to the health, education, social care and benefits systems, made more acute by the fact that they cannot level the playing field for themselves but need us to do so.

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The social model of disability says disability is created by barriers in society, generally in three categories:

- ▶ The environment: including inaccessible buildings and services;
- ▶ People's attitudes: stereotyping, discrimination and prejudice;
- ▶ Organisations: inflexible policies, practices and procedure.

Services working with children for whom these barriers exist often cannot respond adequately, meaning children themselves present as the problem. Specific, proactive, evidence-based preventive programmes should be implemented to address these issues, enabling children and young people to have a secure and nurturing childhood.

Health providers and commissioners must be aware of the many determinants of health and well-being in children with disabilities. Such knowledge should inform planning and commissioning, how both are communicated, and how providers respond in practice. Children and young people rightly expect adult society to create and maintain services that respond to their circumstances.

Statistics in the public domain, and accounts by children and young people living with disability and in poverty, show inequality in health outcomes is related to measures of how well they fare for life. There is a doubly negative effect of poor experiences born of disability combining with other impacts of deprivation. These factors working together have significant impacts on children's resilience, agency, family life, learning, behaviours, attainment, physical and mental health, gainful employment, and engagement in further and higher education.

Children most affected by health inequalities are also significantly affected by other inequalities. They include children in areas of deprivation, with poor childhood experiences, suffering abuse, neglect or exploitation, those who are physically or mentally ill, those not in school, and those marginalised by society because of learning or physical disabilities. Being physically or learning disabled does not make a child immune from harm neglect or abuse, or mental illness. That society is uncomfortable about that reality must not allow us to deny it.

Often a child's disability is the first thing adults see. It can be easy to overlook

other issues in the child's life unless they manifest in a crisis. For example, one of the most common childhood mental illnesses, early onset persistent behavioural difficulties, can be misinterpreted as bad behaviour rather than an outward sign of emotional distress. Such difficulties are compounded if a child's disability means he or she cannot express what is amiss, meaning professionals see only the presenting disability and may either miss the problem, or ascribe it to the disability.

Only a quarter of children with mental health problems receive specialist help, even when they can articulate what is wrong. The lack of appropriate responses and services at the onset stage add to their problems rather than allowing them to recover. The likelihood that such children will present longer-term burdens on themselves and services is obvious. That disability compounds the problems may strike the reader as obvious. That too often their experience is anything but positive leaves us with a challenging question: why is it not being dealt with?

Not every child living with a low standard of living and a disability leads a life of unremitting bleakness. Outcomes for such children and families depend on interplays between individual, disability-related, family and community factors. Some deal with poverty and disability and have positive health outcomes, due to individual or family resilience and protective factors. But the research that informs our study<sup>2</sup> also indicates that, where circumstances outlined below are found in combination, the effects on health for these children and young people are multiplied. The circumstances are reflected at community levels, but they live in personal stories.

- ▶ Family and community have life-limiting physical conditions, including types 1 and 2 diabetes; cardiovascular and pulmonary diseases; poor nutrition, low physical activity and high rates of obesity, and depressive illnesses.
- ▶ Children and young people in families of moderate or hard-pressed means are more than twice as likely to have conduct disorder—a common childhood mental health problem—than children living in wealthy higher-achiever areas
- ▶ The take-up of—and community trust in—proven protective measures are low. For example we see:

1. High rates of early onset sexual activity; risky behaviours, sometimes with evidence of coercion and abuse, particularly among children who are learning disabled;
2. Infant mortality rates, and numbers of children born prematurely or

with impairments, are higher than average;

3. Take-up of antenatal and immediately postnatal care by expectant and new mothers is poor;
4. Immunisation, including in children with disabilities, lags behind national rates;
5. Lower than average advantage is taken of NHS dental services;
6. Lower advantage is taken of mental and emotional health and well-being services.

Circumstances not directly health-condition-related are also prevalent in these communities. Poor health often stems from a combination of the following life circumstances:

- ▶ Average incomes below 60% of the median, a figure which has fallen in recent years, appearing to indicate a reduction of numbers of children in poverty, when in fact it reflects a fall in incomes and therefore of the 60% figure. Research shows that notwithstanding the resilience and protection factors mentioned, poverty and low living standards are powerful determinants of abiding ill health and drivers of health inequality. A child facing the challenges and additional expenses brought by a disability is likely to be still further disadvantaged;
- ▶ Higher than average numbers of 16–19-year-olds are not in employment, education or training. Young people with disabilities struggle to be taken seriously in employment, and further and higher education, in spite of expectations that they will all make reasonable adjustments under UK law;
- ▶ Professionals in health and other services report citizens' assertiveness (and sometimes aggression or resistance) towards services which other communities might see as being supportive;
- ▶ Where universal services are available, those with the greatest needs are least likely to access support for positive outcomes. Where a child in a poor family also has a disability, this poor access is often due to poor or unresponsive service offers;
- ▶ Many families living in poverty with a disabled child are characterised by, and express the opinion, that they have poor agency and choices, meaning that without sensitive, proactive, tailored intervention their children will have equally poor agency as adults;
- ▶ There is higher than average reported domestic violence and abuse, including that witnessed by and affecting children,

and sadly including where they are disabled.

In some communities, and in the lives of some families with a disabled child, there is a persistent issue of children and young people with multiple risk factors, as providers in social care, education and health services will attest to the combination of factors at work make some children still more likely to suffer inequality in health outcomes. Children who are marginalised and disadvantaged often experience many factors described above in ways that do not relate to health, and other aspects of daily life. Such factors add up to a child or young person being at risk of poor outcomes about which, given their age and stage of maturity, they can do little or nothing.

The children of the poor and those with complex familial histories are likelier than their peers to be excluded from school; to self-exclude through poor attendance; to do less well in examinations; to be in conflict with the law and in contact with the youth justice system, including when incarcerated. That those with a disability are likelier still to face even more challenging and negative issues may seem obvious. Given the unevenness of their experiences, it clearly needs to go on being said. Many disabled children have too few opportunities to voice their views, and professionals may struggle to communicate effectively with them, making their outcomes still poorer.

### THE UN CONVENTION ON THE RIGHTS OF THE CHILD: DISABLED CHILDREN AND YOUNG PEOPLE AS SOLUTION-FINDERS

In 1991 the UK became a Ratifying State Party to this international Human Rights treaty. It is binding on public bodies. Its basic premise is that all children are rights holders, without needing adult mediation or permission. The rights include:

- ▶ *Article 2*: non-discrimination: it applies in full to all children under 18 years, regardless of social standing, ethnicity, family circumstances, abilities or state of mind.
- ▶ *Article 3*: The best interests of the child must be a primary consideration.
- ▶ *Article 6*: Every child has the right to survive, make the best of their potential and grow up healthy.
- ▶ *Article 12*: Every child has the right to have their voice heard in all decisions about their life, and to have their views taken seriously.
- ▶ *Article 23*: Every child with a disability has the right to a full and decent life, to be helped to achieve their potential and to receive services that adjust to needs.

▶ *Article 24*: Every child has the right to the best possible health and access to services that will ensure it.

▶ *Article 26*: Governments must provide additional resources for children and families in need.

▶ *Article 27*: Every child has a right to an adequate standard of living and to the state's help where it falls short.

When children are well or only occasionally unwell, they can be experts in their own health and well-being. The older they grow, the more they wish to be treated as service users rather than having interactions filtered through an adult. Those with a recognised physical or mental health condition or disabled disability are often still more expert. Their personal expertise does not always lead to agency and control.

The OCC has published on children and young people as stakeholders in the planning, delivery and evaluation of health services, on their experiences, and their ability to have their voices heard and taken seriously.

Our report on neurodisability in young people in secure settings *Nobody Made the Connection (OCC 2011)*<sup>3</sup> highlighted the increased vulnerabilities of young people with neurodisabilities who are in the criminal justice system. It recognised some biopsychosocial aspects of living in poverty, including the impact of foetal alcohol syndrome and its correlation with antisocial behaviour, seen especially in disadvantaged areas. It emphasised the strong association of antisocial behaviour with adversity— influenced by parenting style, school attendance and family breakdown; it noted young people with learning disabilities are common in custodial settings (23–32% compared with 2–4% of the general population). About 37–46% of men in youth custody have a traumatic brain injury acquired through risky behaviour, gang violence or poor supervision with significant impacts on memory, ability to learn, cognitive function and social skills.

*"We Would like to Make a Change: children and Young People's Participation in strategic health decision making"* (OCC 2013)<sup>4</sup> highlighted the need to actively include children's voices in strategic health decisions by Health and Wellbeing Boards, Clinical Commissioning Groups and Local Authorities. This report has particular relevance to the rights of children to a strong voice in Education, Health and Care plans under the 2014 Special Education Needs Code of Practice.<sup>5</sup> This sets out the duty to support children with medical needs in school, and the meaning of a 'local offer' requiring Education, Social Care and

Health to work together in the best interests of the child.

The Department of Health and NHS England emphasise that children and young people should be actively involved in decisions made about them. The Friends and Families Test has, to date, had little relevance to children although they represent 25% of our population. If they all find it hard to get their voices heard, it is inevitably all the more difficult for marginalised children to do so. Our research found that only 28% of local health plans referenced the needs of children and young people. We recommended Health and Wellbeing Boards, CCGs and Local Healthwatch should ensure clear arrangements for promoting and explaining their work to children, and monitoring outcomes. We emphasised the imperative to provide opportunities, including to children with poor outcomes and complex needs.

The OCC has also published research on the experiences of children with a disability living in poverty. Disabled children and young people played a central role in directing the research, helping us understand the impact low income has on their health. The report highlighted the challenges.<sup>6</sup>

Based on the findings and recommendations from the young people the OCC recommended that Government should:

- ▶ Undertake an independent review of the adequacy of support for disabled children;
- ▶ Ensure disabled children's views are reflected in decisions on welfare reform;
- ▶ Publish clear, accurate and reliable information about rights and service;
- ▶ Provision for disabled children;
- ▶ Ensure Government departments have greater awareness of disabled children's rights, and
- ▶ Use inspection and training to encourage awareness of disabled children's right across local services and statutory bodies.

Local authorities should:

- ▶ Audit accessible youth provision and publish plans on how services will be provided and sustained, with adequate facilities for disabled children and staff with the knowledge and information to meet their needs, and
- ▶ Ensure all disabled children who wish to have short break provision can access it, and
- ▶ Ensure disabled children from low-income families can access play, sport, leisure and cultural opportunities, including through improved transport services.

These are the things our young researchers consider would give them, and successive generations, a chance to close the gaps between those who do well, and those who do not. We wholeheartedly agree.

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- 3 All OCC publications are freely available and copyright free at [www.childrenscommissioner.gov.uk](http://www.childrenscommissioner.gov.uk)
- 4 Available on the OCC website, at [www.childrenscommissioner.gov.uk/publications](http://www.childrenscommissioner.gov.uk/publications)
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