Socioeconomic barriers preventing children and young people living with long term health conditions from achieving optimal outcomes

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Introduction

Children and young people living with a chronic illness (CI) and faced with poverty are less likely to benefit from medical advances than their more affluent peers.[1-3] Clinical outcomes are also poorer[1-4] setting these children on a trajectory of lifelong disadvantage. Inequality may be due to a variety of factors, some of which require action at a political level, while others could be addressed closer to home.

In the Liverpool City Region, more than 80,000 children and young people are growing up living in poverty. In this pilot project, we undertook a scoping exercise in collaboration with Health Junction, an independent, not-for-profit community interest company, to gather the views of parents and healthcare professionals (HCPs) who are involved in managing children with CI living in poverty to identify the barriers preventing them from achieving optimal health outcomes as a means to guide service improvements.

Method

Between April and November 2022, semi-structured interviews were conducted by the directors of Health Junction (CA, JS), involving:

1. ***Health care professionals (HCP):*** HCP were identified using those who responded to an email advert directed to the subspecialty multidisciplinary teams who are involved in managing children and young people with CI from a range of specialities. HCP were asked to participate in a virtual session using the Microsoft Teams platform and two session dates were available.
2. ***Parents and carers:*** Anonymous, face to face discussions were held by Health Junction with parents of children with CI who resided in an area with a postcode in decile 1 of the index of multiple deprivation 2019 (representing the most deprived 10% in the country). The families were approached by their clinical team and the discussion took place after their clinical review, in a private room located next to their hospital appointment. Initial adverts requesting parents and carers to join a virtual engagement event failed to obtain any suitable participants.

Anonymous responses were noted along with relevant quotes. Key themes were extracted. The project was reviewed and registered by the Clinical Audit Department (Alder Hey Children's Hospital) as a service evaluation (reference 6657).

Results

Eleven HCPs, including nurses, psychologists and physiotherapists, took part in the professional focus groups from the departments of nephrology, respiratory medicine, diabetes and endocrinology and ten private parent interviews took place. Fifteen themes were identified and consolidated to generate eight over-arching themes; burden of caring for a child with CI, social isolation, financial cost, transport and parking, suitable housing, access to healthy lifestyles, digital exclusion and links with education (Figure 1). The themes were common across specialties, HCPs and parents. These themes are illustrated with pertinent quotes in Table 1.

Discussion

Our service user evaluation has identified key themes that could be used to prioritise interventions to address the challenge of adverse health outcomes faced by children and young people with CI that are associated with living in poverty. Enhanced access to locally and nationally available community resources, for example assistance with completion of applications to access the Government Benefits system, support and access to technology to overcome digital poverty, awareness of food larders, voluntary drivers, and logistical help to arrange prescriptions, aided by trained professionals with expertise and time to dedicate to such families may provide a fairer society for children with CI living in poverty. This work has led to the design of a proposed well-being hub incorporating a hospital-wide method to screen children to determine who may benefit from such intervention with robust evaluation of its efficacy. Limitations of this study include the small number of participants and single-centre approach however our methods, which required adaptation to engage with this seldom heard, under represented population, have gained sufficient information to inform future interventions to drive change in the trajectory for children and young people living with CI and faced with poverty.

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Figure 1: Themes identified as barriers to achieving good clinical outcomes in children with chronic illness, living in disadvantaged communities

Table 1: Barriers to achieving good clinical outcomes in children with chronic illness, living in disadvantaged communities: Key themes and illustrative quotes