



The cost of bringing up a child with autism ESRC DTP Collaborative Studentship

Loughborough University and the Family Fund

Full Project Summary - The cost of bringing up a child with autism

The cost of bringing up a disabled child is an important empirical question relevant to social policy, influencing the structure both of public support for families and of third sector activity. Yet there is currently a serious lack of usable research in this field. Previous research on the cost of a disabled child in the UK (Dobson and Middleton, 1998) has been highly influential but is out of date. Moreover, a growing recognition of the importance of autism spectrum disorder as a source of disability and childhood disadvantage has not been matched by adequate research on its demands on families and the costs that they face.

Since 2008, the Centre for Research in Social Policy at Loughborough (CRSP) has established the Minimum Income Standard (MIS), a pioneering, internationally acclaimed research technique for assessing minimum household costs. This provides a new means of measuring additional costs of disability, using non-disabled costs as a baseline, so far applied for the case of adults with sensory impairments (Hirsch and Hill, 2016). Charities supporting families with disabled children have made it clear to CRSP that they would greatly value the extension of this work to explore the cost of a disabled child. The Centre is ideally placed to host such research, given its unique expertise in the MIS method and its application to disability. Moreover, Professor Jo Aldridge, based in the same Department, brings a deep understanding of the issues raised, having conducted research with people with profound learning difficulties and with complex cognitive and health needs, and having previously supervised post graduate research on young people with autism and their experiences of the criminal justice system.

This PhD project will initiate this strand of research on the cost of childhood disability, focusing on autism as a particular disability type. This will provide valuable findings as well as knowledge and perspectives on which subsequent/parallel work could build.

The key research questions are:

- What issues do families with children with autism face that contribute to their living costs?
- What are the most important needs of children with autism that require additional spending – seen through the eyes both of children and adults in these families?
- How much do specific needs faced by children particular forms of autism add to a minimum household budget?

The main techniques employed will be (1) thorough exploration of literature and concepts related to autism and its costs (2) gathering of perspectives of organisations working with children with autism (3) interviews with such children and their parents and (4) deliberative focus groups to agree on what additional expenditures are required in a given case.

The literature review will examine definitions and classification of autism in ways relevant to living costs. McKay et al (2013) argue that it is necessary to “microsegment” conditions on the autistic spectrum in order to explore their economic costs. The lack of settled definitions of autism condition “types” means that such classifications can best be explored with reference to outcomes - in this case relating to everyday living requirements. Medical classifications of autism will be taken into account, but not be the main focus.

Literature conceptualising and measuring disability costs includes econometric modelling, surveys of spending on disability-related items and direct identification of additional needs (Hirsch and Hill, 2016; Morciano et al, 2012). Cost studies on childhood autism have been limited in scope, focusing on spending directly linked to disability, such as on care services and special sports clubs (Knapp et al, 2008). In contrast, the Minimum Income Standards considers what additional spending is needed on both specialised and general requirements for everyday life (eg transport; replacing household goods) due to disability.

Informed by this literature, the project’s fieldwork will explore perspectives of children with autism, their parents and organisations working with them. An internship of about one month at the Family Fund will give an initial appreciation of the issues facing such families. Approximately 20 in-depth paired interviews with children with autism and their parents will seek perspectives about aspects of daily life from the child and their family. This fieldwork, involving vulnerable subjects (see Aldridge, 2016), will be carefully set within ethical guidelines. Finally, three experimental focus groups will use the MIS method to assess what additional amounts a family with an autistic child with a particular condition needs to spend in order to maintain an acceptable living standard.

The research will aim to estimate additional costs faced by families containing children with autism, and more widely to give qualitative insights into the types of expenditures involved - including indirect or “hidden” costs.

This evidence will contribute to policy and practice. Charities helping children with autism will be able draw on it both in structuring their support for families and in arguing for public policies supporting families in meeting these costs and ensuring that children’s needs are properly assessed. This evidence will be valuable to the Family Fund and the National Autistic Society, as well as to other organisations working in this field.

Furthermore, the project will aim to stimulate and inform further specific measurement of the cost of childhood disability. It will demonstrate how this can be approached methodologically, and how such measurement can be related to prior research and conceptualisation of this theme.

The location of the project at CRSP will both allow it to draw on the Centre’s expertise in this field and help inform the Centre’s future research.

REFERENCES

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