

Parent's Perspectives on the Impact of the Cost-of-Living Crisis upon the Rights of Families with Children with Complex Needs in Northern Ireland

Celia Lynn-Hawkins LLB MSc

Research Questions

- What has been the perceived impact of the cost-of-living crisis upon the rights of families with a child with complex needs under United Nations Convention on the Rights of the Child 1989 and the United Nations Convention on the Rights of Persons with Disabilities 2006?
- Has the cost-of-living crisis caused a deterioration to the standard of living of families with a child with complex needs?
- Has the cost-of-living crisis had an adverse effect on parents' ability to access services and support for their child with complex needs? If so to what extent and in what ways?
- To what extent are parents aware of the rights of children with disabilities as set out in the CRC and CRPD?

Children's Rights Framework

United Nations Convention on the Rights of the Child 1989 (CRC)

The Rights of Children with Disabilities Article 23

The Right to an Adequate Standard of Living Article 27

United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD)

Children with Disabilities Article 7

The Right to an Adequate Standard of Living and Social Protection Article 28

An Adequate Standard of Living

Article 27 CRC imposes a duty on the state to assist parents to ensure a 'standard of living adequate for the child's physical, mental, spiritual and moral and social development'.

Article 28 (c) CRPD places an obligation on the state to ensure access to assistance from the state with disability-related expenses...financial assistance and respite care'

Studies have shown that the factors impacting families with children with disabilities include:

- Parents coming out of work – difficult for parents to combine work and caring responsibilities due to lack of flexibility in employment options, need to attend medical appointments, and the lack of afterschool programmes for children with disabilities (Steill et al 2006)
- Additional costs of disability – additional expenses for heating, laundry and transport. Costs due to disability - incontinence pads and dietary needs (Zaidi and Burchardt 2005) costs of frequent hospital visits (Flynn 2021)
- Studies have shown that the additional costs associated with a family member having a disability are significantly higher than for households without disabilities (Morris et al 2022; Vu et al 2020; Zaidi and Burchardt 2005)
- *The Scope Disability Price Tag Report 2024* - families require an additional £1010 per month to have the same standard of living as those without a family member with a disability
- Austerity measures prior to and during the Covid-19 Pandemic – cuts to benefits, benefit cap, implementation of two child limit and benefit freeze (Webber and Hill 2022)
- Cost-of-Living-Crisis – adverse effect on disposable income, surge in energy prices, rise in rate of inflation (Hourston 2022)

Aim of the Study

This study seeks to address the gap in the literature with respect to the impact of the Cost-of-Living Crisis on the rights of families with children with complex needs in Northern Ireland .

Studies have shown that children with disabilities are often excluded from research with parents and others speaking in the role of 'proxy' (Mitchell et al 2009) The parents of children with complex needs were interviewed as they had the life experience which could provide answers for the research in relation to the financial impact and the impact on services (Clark et al 2017)

Methodology and Study Design

Phenomenology is an approach to social research which research is concerned with human experience and focuses on the obtaining of information from those with lived experience of a situation (Denscombe 2017)

A Qualitative study approach was used this is an appropriate method for social research as the researcher 'seeks answers to questions in the real world' (Rossman & Rallis 2017)

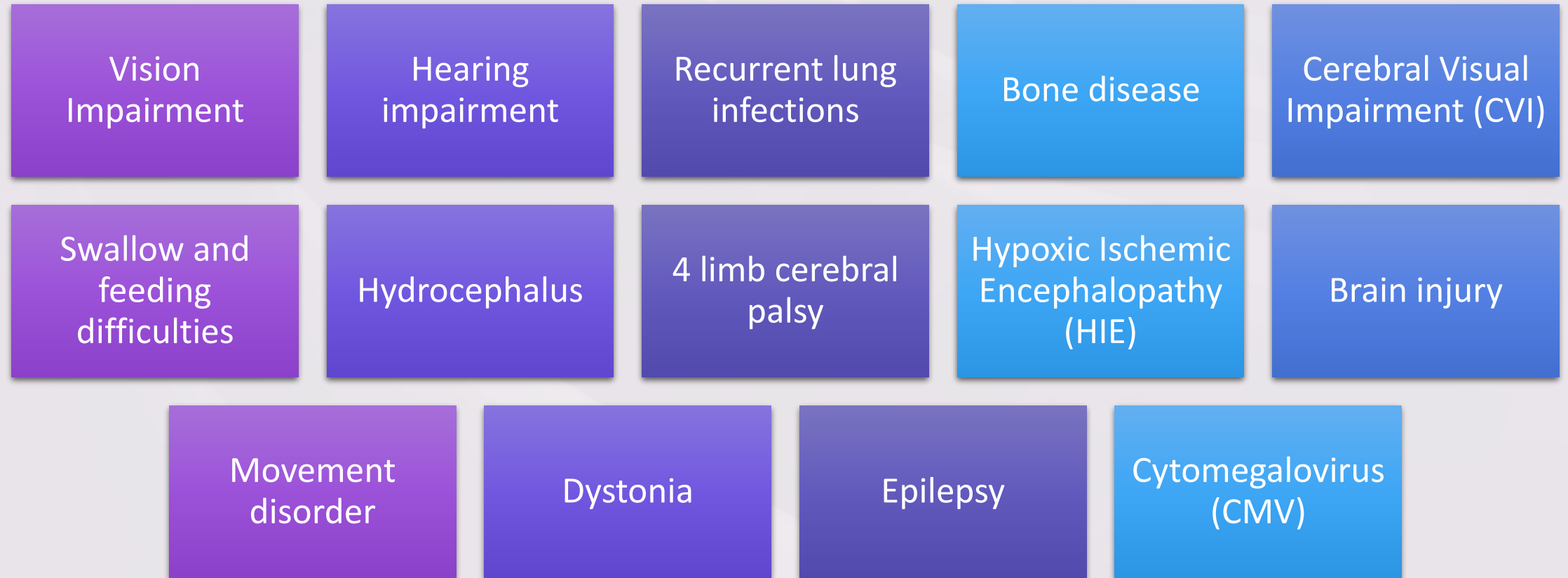
Criteria to be included in the study

- Participants were required to be a parent (either a father or mother) of a child with complex needs.
- Participant must have cared for their child with their child with complex needs during the Cost-of-Living-Crisis (October 2021 to mid 2024)
- Both the participant and the child with complex needs must have lived in Northern Ireland during the cost-of-living crisis.

Recruitment of Participants

- Purposive sampling was used as it is more strategic when targeting a specific group of participants (Miles, Huberman & Saldana 2020) in this case the parents of children with complex needs in Northern Ireland.
- Snowball sampling – useful tool to gain access to participants who may be hard to reach and involves using an interviewee to suggest or recommend other interviewees (Cohen et al 2018)
- A modified approach was used by contacting Non-Governmental Organizations (NGO's) who work with children with disabilities.
- Information was distributed which they were asked to share with members of their mailing list or on the organisations social media.
- Special Needs schools – Parent and Staff Associations
- Sharing of Social Media Flyer on personal social media and shared with friends to distribute information about the study.
- Four participants recruited were from four of the HSC Trusts.

Children with complex needs had multiple diagnosis of various medical conditions and required 24 hour care



Ethics



The British Educational Research Association (BERA) ethical principles and guidelines were referred to in the conducting of the research.



Ethical approval was obtained from the School of Social Science Education and Social Work Ethics Committee QUB



Participant Information Sheet provided to potential participants



Consent Form – Written and verbal consent obtained prior to interviews



Distress Protocol was prepared to support participants if required



Data protection complied with in accordance with QUB Data protection and GDPR legislation.

Methods of Data Collection

Data collection was conducted via online interviews as opposed to in person

Provided greater flexibility to schedule the interviews at a time that was convenient for the participants irrespective of their location

Avoided the need to book a location for the interviews

Avoided travel time and costs or the need to obtain childcare for participants

An Interview question guide was used to gather data during the interviews took place during the month of July 2024 and lasted 45mins to 1hour.

All four
participants
have self-
funded
therapy and
or
equipment

- Self funding of therapy due to waiting lists or unavailability on NHS
- Speech and language therapy, physiotherapy and occupational therapy
- Participants report researching and sourcing of therapies not available on NHS
- Therapies are expensive, not readily available parents travelling with their children to England and the Republic of Ireland to access and undertake training for therapy – increases the cost to parents, significant time commitment e.g. Anat Baniel Method , Advanced Biomechanical Rehabilitation

Additional cost of toys and play equipment for children with disabilities

- Funding for play equipment has been sourced from charities such as outdoor play equipment to indoor sensory and soft play areas
- Bikes, trikes, outdoor swings at affordable prices are not accessible for children with complex needs – specialized modified equipment is necessary which increases the price significantly
- Charities are the main source of assistance for parents who wish to source equipment or seating for their child which is not provided by the NHS
- Equipment/seating which enhances the child's life in various ways such as a learning aid, a source of entertainment, for sensory regulation and comfort e.g. iPads, sensory equipment, sensory lighting comfort seating, therapy pod swings,

Impact on sourcing services and or funding

- Increased waiting times for applications to be processed by charities to source the items including changes to application criteria e.g. from twice a year to once a year
- Charities having a lack of funding and difficulties in fund raising during the cost-of-living crisis
- Effect of Cost-of-Living crisis on obtaining mobility aids and equipment from the NHS - OT's no longer making home visits to repair wheelchairs – one case child had to wait from May to September before her wheelchair could be fixed.
- Increase in waiting times to obtain essential equipment due to timescales to have an assessment completed and further waiting times to have the equipment delivered parents report the process taking over 6 months.
- Significant waiting times from point of referral to receiving an appointment to be fitted for AFO's – 18 months

Impact of Cost-of-Living Crisis on Daily Living Costs

Increase in food and energy costs

Increase in energy prices particularly significant for families with a child with complex needs

Require equipment and furniture to be charged e.g. suction machines, feeding pumps, beds, air mattress, hoists, chairs

Parents resorting to charging portable equipment when out

Difficulties in fund raising to self fund therapy and equipment

Decrease in parents disposable income to self fund therapy/equipment

Lack of Respite Support

Participants did not have access to the Direct Payment scheme as a source of respite

Barriers - lack of Disability Social Worker to complete the assessment to determine the number of Direct Payment hours required – 2 year wait

Change to the Direct Payment Scheme - Carers are no longer permitted to feed a child who is peg fed or permitted to give the child medicine if necessary

Changes to the Direct Payment Scheme have effectively withdrawn the respite service for children with complex needs

NI Children's Hospice is the only provider of substantive respite for families of children with complex needs

Awareness of children's rights under CRC and CRPD

Participants have limited awareness of the rights of 'children with disabilities' or the right 'to an adequate standard of living' as provided in Article 23 and Article 27 CRC and Article 7 and Article 28 CRPD

Participants undertake their own research to access therapies, equipment, funding and assessment to benefit entitlement

Networking with other parents of children with complex needs is a valuable source of information and signposting to services