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Helping disabled children



“My kids need what they need”

**Additional family costs for meeting
the everyday, non-specialist needs of
children on the autism spectrum**

Dr Chloe Blackwell



Background

It is broadly recognised that children on the autism spectrum and their families face high financial costs. Previous estimates have shown that extra spending on specialist items and private fees for therapies as well as lost parental income contribute both directly and indirectly to family-level financial pressures. Yet, until now, estimates have not included a detailed analysis of everyday non-specialist goods and services.



The term 'everyday non-specialist goods and services' is used in this report to refer to those items which all children are assumed to use (for example, non-specialist bedding, technology, clothing and furniture items). The research reported here asks if the needs of children on the autism spectrum translate into different specifications from such everyday items.

This study set out to test if parents raising children with a range of experiences of autism could agree on what everyday non-specialist goods and services children would need. The study was informed by the Minimum Income Standard (MIS) approach, which is explained below. Parents of children on the autism spectrum met in a series of deliberative focus groups to discuss needs and how they could be met. In-depth family interviews helped to identify a list of key goods and services important for households with children on the autism spectrum. Descriptions and specifications of the corresponding items from the UK MIS budgets were presented to groups of parents who worked together to decide whether they would meet the needs of a child on the autism spectrum and, if not, what would need to change about them for the child to be able to meet an acceptable standard of living.

The findings summarised in this report were produced as part of a PhD study. Full details of the research findings and methodology can be found in the original thesis. See further information on page 23.

The Minimum Income Standard

The Minimum Income Standard (MIS) is the income that people need to reach a minimum socially acceptable standard of living in the UK today, based on what members of the public think. It is a budget standards approach, specifying baskets of goods and services required by different types of households to meet needs and to participate in society.

MIS budgets, which set out what is needed for a minimum socially acceptable standard of living – are the result of hours of group deliberation – during which participants negotiate and reach consensus on the goods and services that individuals and households need both inside and outside the home for this living standard. These include tangible items such as furniture, bedding and clothing, as well as the resources needed to feel able to participate in society – such as being able to take part in activities outside the home. The research process involves several stages of groups; 'Task groups' make the first set of decisions and then 'checkback' groups and 'final groups' check the list of goods and services. MIS research is updated annually and produces a costed basket of goods and services for different household types which can be used to calculate the income required to meet a minimum acceptable standard of living, according to the following definition developed with members of the public:

'A minimum standard of living in the UK today includes, but is more than, just food clothes and shelter. It's about having what you need in order to have the opportunities and choices necessary to participate in society.'

As set out in the definition, a minimum is about more than survival alone. However, it covers needs, not wants; and necessities, not luxuries: items that the public think people need to be part of society. Groups refer to this definition when deciding on the list of goods and services and the specifications (such as quantity, quality and replacement rate/frequency) needed to meet the minimum acceptable standard of living. MIS for the UK (also referred to as main MIS) assumes that none of the household members are disabled, but offers a baseline that enables us better to understand additional and different needs of those in different situations.

Note on terminology

This research refers to the child or children 'on the autism spectrum'. While it is acknowledged that many advocates and self-advocates prefer autism-first language, not all young people and parents participating in this study felt comfortable with this language. To mediate the different terminological preferences within and outside the study, 'child/ren on the autism spectrum' was chosen on the basis that it presents the child first but in a way that is considered more neutral in comparison to other person-first alternatives (1).

1 See Bottema-Beutel, K., Kapp, S.K., Lester, J.N., Sasson, N.J., & Hand, B.N. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, 3(1), 18-29. <http://doi.org/10.1089/aut.2020.0014>

Headline findings

Everyday non-specialist goods and services cost at least an additional £51.10 per week to meet the needs of children on the autism spectrum. This figure (based on a small selection of household items, personal items and everyday services) is indicative of significant resources required for households with children on the autism spectrum to meet a minimum acceptable standard of living. It was calculated for a hypothetical 14-year-old child named 'Holly' who attends a mainstream school and experiences some aggression. Another hypothetical child named 'Tom' was found to need at least an additional £53.58 per week to meet his needs as a seven-year-old who uses minimal verbal communication and attends a specialist school. More information on the use of hypothetical vignettes can be found in the methodology section.

Additional costs arise because children on the autism spectrum require personal and household goods of a higher quality, they need a higher number of many items, and those items need to be replaced more frequently. These specifications are explained by a range of sensory, emotional, developmental and physical needs outlined in table 1.



Table 1: The specifications and weekly costs for selected items

Item	Main MIS		MIS for a child on the autism spectrum		
	Item Specification	Weekly cost	Item Specification	Weekly cost	Focus Group Rationale
Sofa	Two basic fabric sofas with removable, washable covers, and replaced after 10 years.	£1.64	Two sofas made of real leather replaced after 3 years.	£8.94	Higher quality to better withstand sensory-seeking needs. Wipe-clean coverings for cleanliness and maintenance.
Child's bedframe	Single pine bedframe. Replaced every 8 years for primary school age and every 10 years for secondary school age.	£0.28 - £0.43	Solid bedframe (e.g. oak). Single for primary-school age, double for secondary-school age. Bedframe replaced every five years, and bed slats replaced every 18 months.	£1.89 - £2.28	Higher quality to better withstand sensory-seeking needs. Size of bed increases with age of child in consideration of co-sleeping.
Child's mattress	Single mattress replaced every 8 years for primary school age and every 10 years for secondary school age.	£0.47 - £0.63	Single mattress for primary school age and double mattress for secondary school age. Replaced every 5 years.	£0.73 - £0.89	Same quality but higher replacement rate for sensory-seeking needs and physical needs (e.g., incontinence).
Pillows	2 pillows needed from retailers such as supermarket. Replaced every 2 years.	£0.09	Pillows of orthopaedic or memory foam quality. 2 for primary school age and 4 for secondary school age. Replaced every 9 months.	£1.23 - £2.45	Higher quality pillows to help with sleep difficulties and sensory needs. Higher replacement rate for sensory-seeking needs and physical needs (e.g., incontinence).
Pillow protectors	4 needed (2 to use and 2 in the wash), Supermarket, 5 years	£0.03-£0.04	4 needed for primary school age (single bed) and 6 needed for secondary school age (double bed), replaced every year.	£0.23 - £0.35	Higher replacement rate for sensory-seeking needs and physical needs (e.g., incontinence).
Mattress protectors	2 mattress protectors, replaced every 5 years for primary school aged child or 1 mattress protector, replaced every 8 years for secondary school child.	£0.04 - £0.09	Waterproof mattress protectors. 3 needed for primary school age (replaced every 2 years) and 2 needed for secondary school age (replaced yearly).	£0.29 - £0.50	For frequent or infrequent occasions of incontinence. Higher quantity and/or reduced lifetime takes into account more frequent washing.
Bedding	Cheapest cotton bedding, 10 years	£0.15-£0.23	Higher quality, soft bedding (e.g., 100% cotton or teddy/fleece). Replaced every year.	£1.45 -£1.72	To withstand frequent washing. Softness for sensory needs and to encourage good quality of sleep.

Main MIS			MIS for a child on the autism spectrum		
Item	Item Specification	Weekly cost	Item Specification	Weekly cost	Focus Group Rationale
Blankets	Two needed (one per sofa). Cheapest okay, replaced every 2 years.	£0.08	Three blankets per sofa, high quality and soft with waterproof lining. Replaced every 6 months.	£2.87	Higher number of blankets to keep a consistent look and feel around the home and to manage laundry. Waterproof lining to protect sofa.
Child's clothing	Retailers such as Primark, supermarket, H&M, Sports Direct. Clothing items replaced yearly.	£6.18-£8.37	Retailers such as Next or Marks and Spencer. Clothing items replaced every 6 months.	£16.70 - £20.89	Retailers reflect expectations about higher quality of clothing, and choice of softer materials that can withstand frequent washing, as well as greater clothing choice (e.g., seamless socks). Frequent replacement due to wear and tear (whether from incontinence, sensory seeking, anxiety, frustration).
Laundry (detergent, fabric conditioner and tumble dryer)	3 loads of washing per week for a primary-school-aged child and 5 loads of washing per fortnight for a secondary-school-aged child, no tumble dryer included for households with one child.	£1.27 - £1.33	8 loads of washing per week for primary school age and 7 loads of washing per week for secondary school age. Tumble dryer needed for all ages.	£2.03 - £2.12	Higher frequency of washing for physical and sensory needs. Keeping home the same look and feel to ease anxiety. Tumble dryer to facilitate high volume of washing.
Laptop/tablet	1 shared device between partnered parents and one child. Entry level laptop or tablet okay. Replaced every 4 years.	£0.75	1-2 devices needed for child (parents have separate device). High-functioning device, such as iPad needed. Replaced yearly. Plus robust protective case replaced with device.	£5.90 - £12.55	Number of devices depend on developmental or language needs (e.g., 1 device dedicated to communication). High performing devices encourage learning and ease frustration. Replacement rate linked to higher likelihood of accidental damage which could be due to sensory needs, acts of frustration or needing to maintain performance of device.
Leisure activities	£10 per week for 52 weeks of the year (based on 2 activities per week, not necessarily running all year round but leftover used towards equipment/kit)	£10	£25 per week to include one-to-one sessions (such as swimming) or activities designed with autism in mind.	£25	Increased activity budget in consideration of developmental needs, sensory needs and/or cost of traveling to autism-friendly activities which are less common.

Methodology

The research reported here was designed as a proof of concept, using qualitative interviews and deliberative focus groups to explore family-level resources, and to establish whether parents of children with different experiences of autism could reach agreement about what types of goods and services households with children on the autism spectrum would need for a minimum acceptable standard of living. The study used the data from MIS for households with children as a baseline. Parents of children on the autism spectrum were brought together in focus groups to look at the original specifications set out in MIS and to decide what, if anything, would need to be changed to meet the needs of a child on the autism spectrum.

Because of the exploratory nature of this study, groups were not asked to produce a comprehensive list of goods and services, but instead a subset that would help to test the feasibility of the approach. It was important that families were involved from the start to inform the types of goods and services selected for discussion. For this reason, 19 families (including 19 mothers, three fathers and seven children) took part in semi-structured interviews to talk about the financial and broader experiences of families with children on the autism spectrum. Interview analysis identified a selection of goods and services to highlight in the next stage of research with focus groups. Four focus groups of different sets of parents (5-8 parents per group) from across the UK were brought together to discuss household and personal items, specifically sofas, the child's bed and bedding, blankets, clothing, laundry, electronic tablets, toys and leisure activities.

The MIS approach uses hypothetical individuals as a basis for group discussions. This means that researchers are not asking participants to divulge any personal information, and by focusing on the needs of a hypothetical person or 'vignette', parents are better able to reach consensus than if they were trying to specify the needs of their own children. The vignettes in this study were developed from the interview data, where families said that the type of schooling

as well as the presence of child aggression and the minimal use of verbal communication could lead to different experiences and needs, although the interviewed families did not necessarily argue that one version of experience was more severe than the other. The intention of the vignettes was therefore to highlight some variance of experience rather than to explore different levels of 'severity', something which the interviewed families said was difficult to define. In this research the case studies were:

'Holly is 14 years old and has an autism diagnosis. Holly sometimes becomes aggressive. She attends a mainstream school. Holly lives with her parents, Pete and Joanne. All family members are in a reasonably good state of health and live in an urban area in the UK.'

'Tom is 7 years old and has an autism diagnosis. He uses minimal verbal communication, and he attends a specialist school. Tom lives with his parents, Pete and Joanne. All family members are in a reasonably good state of health and live in an urban area in the UK.'

The focus groups were recruited purposively so that the participants within them had experienced at least some aspects of the circumstances presented in the vignettes.

Based on the item specifications agreed upon in the focus groups, goods and services were costed in line with the MIS approach. Costing involves finding real goods and services available from suppliers suggested by participants and calculating a weekly cost, based on the item quantity and lifetime specified. Costs presented here differ from the original thesis to bring them up to date for the publication of this report. Items were re-priced and all costs recalculated by inflation.

More information on the research methodology is available in the original research thesis.



Detailed findings

Focus group participants first looked at the items that were selected from the Main MIS budget for discussion. They agreed that the item specifications (their quality or the materials they were made from, their quantity and their rate of replacement) would not be sufficient to meet the needs of children on the autism spectrum. The groups then worked to reach consensus on what would need to be different about those items. The item specifications were not intended to be prescriptive, rather they were used to identify and explore different types of needs and their implications for financial resources.

The minimum additional expenditure that a family would have to make for the areas of goods and services discussed was calculated from the detailed information provided in group discussions. This section first describes the different needs that inform the additional expenditure required for a child on the autism spectrum. The section then briefly discusses the item specifications in relation to autism variance, and finally, highlights the implications for low-income families.

Areas of need

The summaries of participants' discussions are organised under the headings: sensory needs, physical needs, developmental needs and emotional needs. This is because rationales informing the specifications for goods and services were centred around the different needs of a child on the autism spectrum. Although the findings are presented in this way, it is acknowledged that needs will overlap.

Sensory needs

Certain sensory experiences (including sounds, smells and textures) can be very uncomfortable for children on the autism spectrum, and subsequently they may try to avoid encountering them (sensory avoidance). Feeling sensorially overstimulated can be a very

negative experience for the child, making them feel unwell, frustrated or frightened. Families described sensory avoidance as having implications for some items, particularly those coming into contact with the child's skin such as clothing or textiles for bedding and furniture.

"(I don't like clothes) when they're a bit scratchy or they feel like really puffy and heavy...I have a dress that I really, really...like but...where it's sewn, it's got all plastic running (through it) ...and it keeps scratching on my shoulder...I never wore it because it was just like that. I wore it about twice."

(Child)

"I really don't like much of the materials... (They are) itchy in a bad way. Uncomfortable."

(Child)

If a child felt uncomfortable because clothing was too tight, too loose or too rough, it would go unworn. Parents in the interviews and focus groups therefore described needing to be very careful when buying clothing. Focus group participants said that household textiles (such as throws or bedding) and children's clothing needed to be of a higher quality to ensure softness. This made it more expensive than the clothing and textiles included in the main MIS budgets, which generally came from low-cost stores such as Primark or from supermarkets.

Children on the autism spectrum may also seek out certain sensory experiences (sensory seeking). A child on the autism spectrum may "stim" (repeat phrases, flap their hands or flicker their eyes) to engage with their surroundings and/or to self-regulate. As part of the need to "stim", a child on the autism spectrum may also pick or pull different items (for example, picking at clothing or textile threads), chew on clothing or household items or climb, jump or rock on furniture.

"After five hours (of sleep), Leo (son) is awake. He doesn't need any more sleep than that...he wakes up because he needs to move. He needs that sensory (stimulation). So, what he does in bed is he rocks and rolls...throwing (himself) from side to side. There's only so much that beds can take of that. "

(Parent)

To meet these sensory-seeking needs, groups described the different item specifications that would be required. For example, they said that furniture items would need to be sturdier and constructed of higher quality materials to withstand regular movement. The lifetime of many household and personal items was also much shorter because of greater wear and tear.

Physical needs

Children and parents talked about regular or infrequent instances of incontinence as well as different physical needs associated with cooccurring diagnoses, such as hypermobility or dyspraxia, which could lead to accidental damage around the home. Groups said that accidental damage was likely to shorten the lifetime of household items. Parents talked about trying to minimise accidental damage through buying items such as protective cases for electronic tablets, large quantities of bedding or waterproof-lined throws.

"...we have a lot of issues of washing and trying to protect sofas... frequently have accidents all the time...so we put a lot of throws and blankets on things..."

(Parent)

Groups said that a household with a child on the autism spectrum would need a leather sofa (2) or an equivalent quality of fabric sofa with at least three sets of removable, washable covers to withstand frequent spillages and other accidental damage. Frequent washing of sofa covers, throws, clothing items and bedding was also cited as reducing the lifetime of these items significantly. Adding further expenditure, higher laundry demands necessitated a tumble dryer, a household appliance that is not already included in MIS, unless the household has at least three children.

Developmental needs

The communication abilities and preferences among children on the autism spectrum can vary greatly; with some children on the autism spectrum who are non- or minimally-verbal and others who are fluently verbal. Aside from communication, children on the autism spectrum may benefit from resources that support with learning. Devices, such as laptops and tablets, were often discussed in relation to developmental needs (used, for example, with communication software or other software for assisting with homework).

The main MIS budget includes one tablet or laptop shared by the parents and one child, where it is assumed that all family members are neurotypical (with an additional device needed for each additional school-aged child). However, participants in the current study said that this would not be appropriate for a child on the autism spectrum, who would need their own device set up specifically for their needs:

“...it’s about not having too many changes. So once...the iPad is set up for my little one...they tend to know exactly...where everything is. And so that gives them some sort of consistency, which helps with their learning.” (Parent)

2 Linked to sensory needs, it was important to have a genuine leather sofa rather than imitation leather because although this was the cheaper option, it was more likely that the child would be able to scratch and pick the PVC material.

Participants noted that sharing a device with other people could impact the consistency and predictability of the display and performance of the device, which could become a considerable frustration for the child, as well as a hindrance to their development if it was being used to aid their learning. Sometimes a child on the autism spectrum would also need access to multiple devices:

"Speech therapists will always tell you to have a completely different device for communication, versus a play device for them...it has to be communication specific...it makes it more dedicated for what it is."

(Parent)

The quality and functionality of devices was also important for motivation and to encourage learning and development. Groups talked about devices needing to be fast enough so that the child could have "instant feedback" so that they could identify the effect of the buttons they pressed when interacting with a programme.

"Especially when learning something, that immediate this causes this to happen, especially when it comes to communication... [If the device is slow] my daughter sees it as wasting time and she will not stick around for it. So, [the device] needs to be of a decent standard to work and be consistent."

(Parent)

Therefore, groups agreed that digital devices, especially laptops and tablets, were not sufficient at entry-level as specified in the main MIS basket. Rather, a child on the autism spectrum would need one, if not two, high-performing devices.

Groups also discussed the specifications for leisure activities, linking them to the developmental needs of the child, as well as highlighting the benefits for physical and mental health and social and cultural participation. Groups agreed that a child on the autism spectrum would likely need to access a one-to-one activity, and this could be the case even if the child was fluently verbal or attended a mainstream school:

"We had to stop the group swimming lessons that she was going to...she can't retain any more than one instruction at a time...she'd get halfway down the pool and then forget what she was meant to be doing...she was still stuck at this level and it just, she just wasn't progressing and...[the teacher has] five kids that they've got to teach and she just needed more support, so we found a one-to-one lesson for her."

(Parent)

Groups often talked about swimming, saying that occupational therapists frequently recommended it as a beneficial activity for children on the autism spectrum. Groups also talked about autism-friendly trampoline sessions, equine therapy or art clubs for children with special educational needs. Leisure activities for children on the autism spectrum presented extra costs, either because they were expensive activities in themselves, because the child needed a lower child-to-staff ratio or because the activities were less common and therefore required travel.

Emotional needs

Families described many children on the autism spectrum as needing consistent surroundings and routines for their emotional and mental wellbeing. The need to maintain a home environment that consistently looked and felt the same had an important bearing on the number of items families would need to purchase. One focus group participant used the example of throws to demonstrate this point:

"When you get these waterproof [throws], and these things that change the sofa...I'm very mindful that these then become habit... if I decided to put a [throw] on the sofa, then I need to know that I'm going to have a constant supply of those."

(Parent)

Having items like a tumble dryer was also important for quickly drying items and keeping the child's routines the same, such as making sure that a child's favourite cuddly toy was washed and dried and ready for when the child went to bed.

Participants also talked about the high prevalence of anxiety among children on the autism spectrum and how this could translate into different needs or item specifications. For example, behaviours related to anxiety could have implications for the lifetime of clothing items:

"...on trousers, across the seams, they'll start being pulled apart and... I remember looking at him and one day I thought, I only bought those pants this week... He's starting to pull them and half the time it's subconscious...It's almost like a nervous kind of thing."

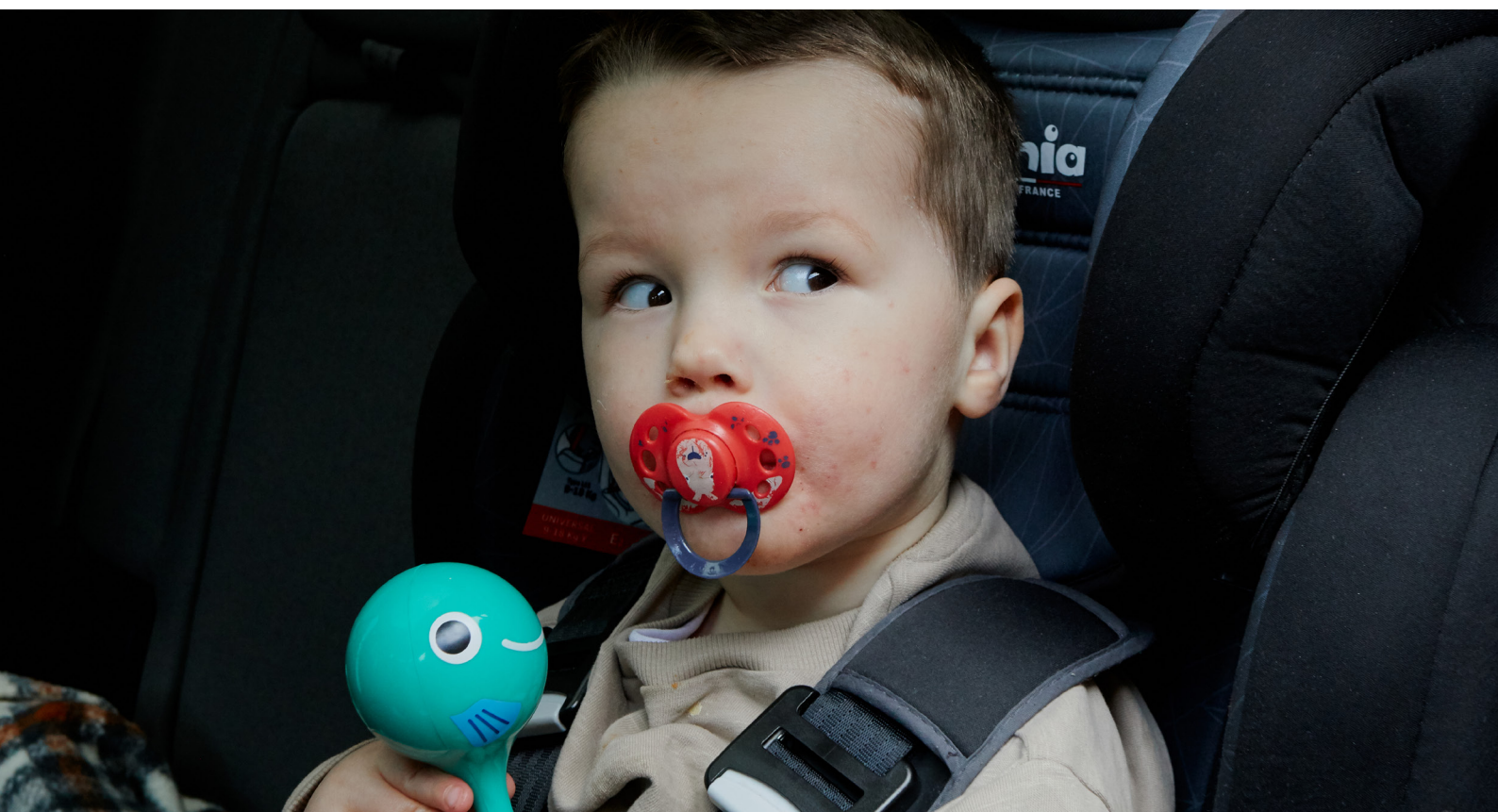
(Parent)

Anxiety could particularly present itself at nighttime, affecting the child's ability to sleep. For this reason, families described that parents could need to intermittently or regularly co-sleep with the child. Co-sleeping could also be a requirement for safety, so that parents could ensure that the child did not wander around the house or attempt to elope (a term used to describe a child wandering or running away from a person or place of safety). They said that while a parent and a small child could share a single bed, an older child (i.e. of secondary school age) co-sleeping with a parent would need a double bed to accommodate this need, something which would require additional expenditure for the bed and mattress, as well as bedding.

Accounting for children's different needs

Despite the different cases represented by the vignettes “Holly” and “Tom”, the research found more similarities than differences in the final additional costs indicated for everyday non-specialist goods and services. Including experiences and needs which are typically understood to be more ‘internalised’ (such as those relating to anxiety or sensory needs), as well as those which present more outwardly and have therefore received more research attention (such as developmental needs, or experiences of aggression) reveals that a range of needs of children on the autism spectrum present different routes to similar item specifications and therefore cost implications.

So while a diversity of needs were captured in the findings, they often represented various routes to similar resource outcomes. The lifetimes of household goods were reduced in similar and significant ways based on a variety of factors which could lead to increased wear and tear: from internalised behaviours related to sensory seeking and anxiety, to externalised aggression or incontinence.



The stress of not being able to meet needs

The families included in this research were worried about not being able to afford all the specialist and non-specialist goods and services that their child needed. Parents talked about the mounting financial pressures of replacing so many things in the home, in addition to the child's personal items.

At a general household level, parents regularly described difficulties of keeping the home in good repair. They described using household appliances which were only partially working and of not being able to re-carpet or fully furnish the home. More often, families expressed frustration when they could not afford all the specialist and non-specialist personal items that their child needed.

"As a family on a low income, we can't afford that (specialist) stuff... I can't afford it. It's that simple. The list goes on and on, but we can't afford what (they) genuinely need..."

Parents regularly had to make difficult decisions about which goods and services to prioritise and which ones to forego, and the continuous struggle to manage finances was stressful, particularly for families on low incomes.

"My kids...need what they need. Why can't they get the things that are vital (for) them, for their everyday life, without it becoming unbearable?"



Conclusion

How children on the autism spectrum and their families experience and navigate daily life is influenced by the social and political world around them. It is well documented that households with children on the autism spectrum face mounting financial challenges, but it is important to note that these can be deepened or alleviated by policy. Evidence on the needs of children on the autism spectrum, and the required expenditures for meeting these needs is necessary for understanding how policy will likely impact such households. Previous estimates of costs for such households have tended to adopt an 'actual expenditure approach', where participants document what they spend.

While these data are useful, in that they tell us what given household types spend in a given period, they cannot tell us what those households need. Expenditure studies for households with children on the autism spectrum have also been unable to look at costs beyond specialist goods and services, as they do not have equivalent data for households with neurotypical children to compare to. Without comparable or baseline data, expenditure studies focus on specialist goods and services to arrive at areas of cost which can be considered additional to those of households where the child is assumed to be neurotypical.

Using MIS as a baseline, it is possible to extend the method to households with children on the autism spectrum to understand what they need, as well as what they would have to spend to meet those needs. Importantly, this could include not only looking at specialist goods and services, but also non-specialist goods and services assumed to be used by all children on a daily basis (such as non-specialist furniture items, clothing and bedding). To test the feasibility and utility of MIS for households with children on the autism spectrum, a proof-of-concept study was conducted as part of a broader PhD thesis, focusing on the distinct areas of the child's bed and bedding, clothing, sofas, throws, laundry and leisure activities.

These cost areas alone indicate that achieving a minimum acceptable standard of living requires an additional expenditure of at least £51.10 per week. This report has not presented a comprehensive MIS budget standard for households with children on the autism spectrum, however as a proof-of-concept study, it is successful in two areas.

First, the study results demonstrate that it is possible for parents raising children with a range of experiences of autism to agree on children's needs and compile a list of the types of goods and services that would meet those needs to an acceptable minimum level; so, it confirms that the study is methodologically feasible.

Second, it indicates that meeting needs to reach an acceptable standard of living for children on the autism spectrum requires significant additional expenditure; confirming that a full MIS study for households with children on the autism spectrum will prove useful to understanding everyday needs and areas of required costs which have been previously difficult to calculate.

Further information

The original thesis informing this report was titled, 'The needs of children on the autism spectrum and their families: Exploring household costs and factors impacting access to resources'. It was funded by Loughborough University, the Economic and Social Research Council and Family Fund.



Family Fund

Helping disabled children

find us:




Family Fund
3 Alpha Court
Monks Cross Drive
Huntington
York YO32 9WN

talk to us:

Telephone: 01904 550055
Email: info@familyfund.org.uk

online: www.familyfund.org.uk

community:

 @familyfund
 @familyfund
 @family_fund