Children North East Poverty Proofing© Health Care Common Themes Poverty Proofing© Paediatric Diabetes Care



Poverty Proofing[©]



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Background & Context



About Children North East

Children North East (CNE) is a large North East children's charity, with work extending across England, Wales and Scotland. CNE exists because growing up can be hard. We want all babies, children and young people to be happy and healthy and to grow up feeling:

- Safe and loved
- Resilient to the challenges they may face
- Valued and confident

At CNE we are national leads on Poverty Proofing© and since developing this work in schools, we have further developed this into a programme that spans Healthcare, Culture and the Arts, Education, Early Years, VCS and Employers.

Context

Poverty has a significant impact on communities across the UK, with over 14 million people affected by poverty, including 75% of working households and 43% of families with three or more children particularly affected. With increasing healthcare inequalities experienced by those living in poverty, it is imperative that as healthcare providers we are in a position to ensure that our services meet everyone's needs.

This work supports the NHSE focus on the Core20PLUS5 framework, specifically supporting individuals and families living in the most deprived circumstances. Poverty Proofing© Healthcare has already proven to make an impact within different departments across the NHS, and we are building on this work developed in the North East of England by developing a delivery partner model so local people can inform and influence service delivery in the years to come.

Project Delivery

In 2021, Children North East was commissioned by the North East and North Cumbria Child Health and Wellbeing Network to 'Poverty Proof' a variety of Health settings in the North East and North Cumbria, starting with pilot work undertaken in Gateshead Paediatric Diabetes Service. We were then commissioned by the Children and Young People's Yorkshire & Humber Diabetes Network to Poverty Proof two settings within their network – paediatric diabetes services based at Hull Royal Infirmary and Diana Princess of Wales Hospital in Grimsby.

Expertly trained Poverty Proofing© Coordinators provided a comprehensive report and set of recommendations for each of the three settings, on how to reduce and remove barriers to health care faced by people experiencing poverty. Developed collaboratively through a programme of training, scoping and user group consultations each report was bespoke to the setting and recommendations came directly from the voice of staff, patients and community groups.

The work concluded in the production of this Common Themes Report drawing out and bringing together the overall learning. Over 280 delegates working in Paediatric Diabetes joined together across seven Common Themes Training Events to explore what this means for practice.

Poverty Proofing© Principles

The Poverty Proofing© delivery model is founded on three core principles that underpin all Poverty Proofing interventions:



Voice

At CNE we recognise that to see real social change it is imperative that the voice of those affected by poverty are central to understanding and overcoming the barriers that they face.



Place

Alongside hearing from people we need to understand the context of the community and place which we seek to Poverty Proof. We recognise that poverty impacts places differently, and so understanding place is vital in our response. Organisationally we also need to be clear about why and how decisions are made. This understanding of context is essential.



Structural Inequalities

While tackling poverty can feel like an impossible and unachievable goal, the knowledge that the root causes of poverty are structural give us reason for hope. If poverty can be addressed or at least alleviated by making structural changes within society, then what structural changes can we make at an organisational level to eliminate the barriers that those in poverty may face?

Introduction

Additional Cost of Diabetes

Diabetes is an expensive disease to have. In 2019, SCOPE estimated that people with disabilities have an average of £583 per month in extra living costs for expenses relating to disability, and one in five living with a disability had costs of more than £1,000 per month (SCOPE, 2019).

Regardless of their socio-economic position, service users we consulted with all highlighted 'additional costs' as one of the key challenges impacting their life, decision making and health behaviours.

- Cost of travel, fuel, parking, bus/train fares, taxis.
- Lost earnings, reduced earning capacity of families/carers.
- Food bills, cost of food associated with visits at hospitals if there for long appointments, vending machines, hypo treatments and the need to have a balanced nutritional diet.
- Computers, smartphones and in-app purchases in Carbs and Cals apps.
- Phone contracts and costs for WIFI, phone data, phone calls.
- Up-to-date/compatible phones and devices.
- Specialist medical equipment and clothing (Weighing Scales, Bags and Pouches to keep equipment in), adhesive patches, stationery.
- Costs of Physical Activity e.g. sports equipment, swimming pool entrance.
- Childcare costs for siblings when accessing appointments.
- Employment instability, taking time off to attend appointments, attend school to care for a child.

Within a landscape of a cost-of-living crisis and some of the worst child poverty statistics for a generation, a useful starting point for this report is just to pause to reflect on just how much the complexities of everyday life in poverty are compounded by the additional costs of having diabetes.

The Five Common Themes

The report is broken up into the five areas that make up the common themes, these are:



The report takes each theme in turn and covers:

What Works: Highlighting existing good practice, things patients told us that they appreciate and helps to make their lives easier.

Barriers to Accessing Care: This section outlines the elements within each theme that prevents those living in poverty from accessing diabetes care. These are in addition to the usual complexities associated with managing the condition. They have a negative impact on health outcomes and are as a direct result of low socio-economic status.

Key Considerations: This section reflects on what the sector can be doing now based on the learning from this work to mitigate the impact of poverty and give a more equitable experience of care.

Role of the NHS

The theme of diabetes support and education across all settings came out on top in terms of strengths-based, socially engaged practice excellence. As the theme is most obviously related to clinical practice, it is easy to see why this would be the case. Travel, appointments, financial guidance and technology on the other hand are areas that generally, would be considered to be outside of the remit of the clinical practitioner. Although good practice emerged and is detailed within each thematic area of this report, the overall conclusion is that because they do not traditionally fall under the remit of clinical practice - in the same way as patient care - the burden of responsibility for these elements sits more with the individual.

However, what this report shows is that for people living in poverty excellent clinical practice is pointless when you can't afford to get to travel to the appointment, when you are excluded from the technology, the food and the self-confidence to manage the condition effectively independently and maintain a dignified quality of life.

Getting more money in people's pockets is an overarching theme running throughout this report. We believe there is a real role for the NHS to play in delivering diabetes care that is structurally focussed on reducing expenditure (efficient appointments in convenient, accessible locations), maximising income (signposting, prescriptions, welfare support, community and VCS support) and facilitating patient engagement and participation in a way that advocates for more inclusion, diversity and equitable access of care to underserved communities.

Common Themes



What Works

Settings that are in familiar locations and close to home helped to alleviate many of the travel-related barriers. Although not always possible 'being able to be seen at home', 'getting seen in school' or 'somewhere local to us in the community' helped reduce transport costs. During the pandemic, service users reported bloods were done on their driveways and this was praised by families as a model for 'saving us money on fuel', 'saving us going in and stressing on with what his levels were'. Where community outreach was not an option participants valued hospitals and clinics that were 'easy to get to' in centrally located, accessible locations that were 'on or near a bus route' with 'plenty of easy and free parking spaces'.

We observed that in settings where clinicians had a level of understanding and appreciation of the costs, complexities and realities of travel this translated to a more empathetic, flexible and accommodating approach.

The NHS operates travel reimbursement schemes for people on low incomes. These worked well when staff knew about them, could locate the forms easily, and proactively supported and promoted patients to claim back any travel-related expenses.

Barriers

People struggled with the costs and inconvenience of public transport, especially from underserved communities where transport poverty was a very real issue. One patient told us it took her three buses each way to get from where she lived to the hospital, 'it's forty minutes on the bus and I miss an afternoon's salary to come to clinic'.

Those with cars complained about unfair and excessive parking charges, for example, 'you're only here 45 minutes and you pay for 3 hours parking'. People also told us how they needed to allow much more time than the allotted appointment just to find somewhere to park, 'we spent most of our time finding a parking space', 'most of the time we have problems with the parking. There's a pay and display but limited spaces. We needed to wait in line for a long time to get a space', 'I can't afford £4 for the car park', 'I just can't afford to park the car - I've had to leave a note on my car to say I'm in and hope that I won't get a fine on the parking'.

We heard from service users opting for more expensive transport options to avoid the stresses, strains and uncertainty of public transport and hospital parking, 'we usually get a taxi', 'we spend £18 on the train because it's not an easy hospital to get to, we didn't want to drive and pay for parking and risk missing my appointment'.

Clinicians told us that in some cases patients did not show up to their appointments because they '**literally didn't have the money for the bus**'. We found there were missed opportunities to make these people aware of how to access the Healthcare Travel Costs Scheme, either because the staff themselves weren't aware of the administrative process and additional time spent '**filling in forms and finding the right office**' was deemed to be off-putting.

| Top Takeaways | Other Considerations |
|--|---|
| Promote the claiming back of travel expenses normalise it in everyone's roles and make the process as straightforward as possible. Wherever possible deliver clinics in places close to where people live, in community settings, schools and outreach locations. | Make staff aware that the NHS Travel Costs Scheme exists who can apply and what they are entitled to claim for. Understanding what the process is for your setting and communicate this to families. The scheme works on a reimbursement basis. Consider introducing pre-loaded travel cards or similar for people who don't have the money upfront. Once you know someone has claimed once, is there a way for the system to remember this to save making a new claim each time? The scheme also includes 'unavoidable car parking charges' this may help car users. |





Giving as much notice and flexibility as possible helped people better plan their budgets, arrange time off work and put in place childcare and any other necessary arrangements. Arranging appointments with people in person or over the phone worked much better than allocating pre-determined slots. Best practice as shown here was achieved when booking was conversational and allowed patient choice; 'it is easy to rearrange appointments if there is something important he doesn't want to miss and at times he has been offered after school appointments, I'm a teacher and I work full time. I do sometimes have to leave early but the clinic is understanding and try to have appointments later in the day'.

Giving advance notice of how long the appointment would last and sticking to time really helped reduce indirect and unforeseen/unplanned expenditures.

Having multiple communication channels to book and talk about appointments, as well as sending out appointment reminders, worked well. The main learning relating to communication is that what works for one may not work for another and what is most convenient or efficient for the clinic does not always suit the need of the families.

Barriers

One barrier that arose was related to what we understood to be 'clinic flow' issues. Delayed appointments, long waiting times, appointments that overran beyond what was expected and being unexpectedly required to 'stay the whole day' or 'wait around for the reviews, they can be an hour and a half and we need to get them food, although we try not to eat here, it's really expensive'. As we listened to stories from parents their frustrations became easy to understand: 'They are often running late with appointments, when you come to clinic you're here all afternoon it takes a long time', 'I don't work but I provide childcare for my older daughter's children. In order to bring [child] to clinic, I need to arrange cover and get the grandchildren looked after so I can bring her'.

'You just get what you're given. It's how it benefits them. It has to be a Thursday and you do get plenty of time to make sure there's time to take time off, but no flexibility'.

'I'm working full time and it's hard to get an appointment. Sometimes they just give me the appointment and they don't ask the day, but they know when I'm not available. We both have full time jobs'.

In each case, it became apparent that the unpredictable nature of appointments really impacted families. Unplanned time incurred additional and unexpected expenditure such as extended parking, the need to buy food, lost wages, added childcare. This was especially stressful and difficult to cope with when managing on a tight budget.

Research by Public Health England (2015) shows that those in poverty often have lower levels of health literacy and this can 'undermine people's ability to take control of their health and conditions that affect their health (p4)'. We saw this in relation to appointments where people just didn't speak up about things that are inconvenient to them, 'you just get what you're given. It's how it benefits them. It has to be a Thursday and you do get plenty of time to make sure there's time to take time off, but no flexibility. We need consistency with the same nurse and doctor. The letter said you'd see Dr. [redacted name] but we haven't. The dietician was different today and you've got to repeat yourself'.

| Top Takeaways | Other Considerations |
|--|---|
| Give as much notice, flexibility and autonomy over booking appointments as practically possible. Let people know they can change their appointment if they need to and how to do it. Communicate appointment length in advance and have measures in place for if they overrun. | Offer and promote a range of ways to book and talk about appointments that include text messaging and WhatsApp. (Free public wifi is often the only means of communication for people without phone credit). Where appointments are delayed or they overrun, check-in and see if they are okay to stay. Explore whether food, drinks, snacks or vouchers can be offered to patients with long stays at clinics. Make clear the process for rearranging appointments with clear guidance on how to do this if needed. |



Time and again we heard thanks and gratitude to the NHS from parents who 'couldn't believe the amount of support [they] got. To have a doctor on call 24 hours a day, I've never experienced that, and it was like talking to another mum'. Continuity of care stood out as a key feature of this theme 'having one primary nurse from day one has made it a much more personal experience, and that's significant when you struggle without money, from day one, any issues, even if I was having a bit of a breakdown, I'd ring [staff member] and she'd listen to me and signpost me to where I need to be. If it was a different nurse every time it would be hard'.

Staff who enabled and empowered families and communities to build their skills, capacity and resource helped people to build confidence and manage more independently. 'There was one incident where I gave her the wrong insulin... and I had to bring her into A&E. It was the middle of the night and the doctor was on the phone to me and to the ward advising us. She made me feel like I hadn't done anything wrong and didn't need to worry, even though I had done something wrong. They're always quite reassuring like "you're doing amazing; you're doing the right thing." That encouragement really helps'; 'they really make you feel empowered and boost your confidence because my confidence was on the floor, thinking how am I gunna manage all this. You make a silly mistake and they say "everybody does that" and virtually every phone call they would say "you're doing really well and his levels are good, whatever you're doing is great"... it all seems like double-dutch at first so when you ask a pertinent question they're like, "oh that's great", they tell you how great you're doing'. Where nurses had established close working relationships with schools they were able to build the confidence of teaching staff to provide care that otherwise a parent would have to come in for. This parent quit her job as a teacher 'because the school can only administer one correction an hour and then I have to go in'.

Having strong referral and signposting pathways to a wide range of diabetes-specific and universal support services helped give patients as much autonomy and choice over who and how they engaged with support and education. The idea of employing youth workers was raised on more than one occasion to support transitions and to add capacity to teams in areas where medical knowledge was not needed. Patient and peer support groups worked well and families reported valuing informal opportunities such **'as using the waiting room for young people to do cooking', 'to open up and get peer support'**, as well as providing opportunities for patient feedback.

Barriers

Medical staff themselves can be a barrier when engaging families most in need of support and education. We identified a point at which already stretched staff who felt like they were doing as much as they could had exhausted all the avenues open to them for getting interventions in place.

From their perspective: 'No amount of effort can get them to manage it right'. 'These dysfunctional families, there's a poverty to the family but it's their behaviour that's the issues. School attendance will be poor and they'll blame their diabetes for it. Relationships between dysfunctional families and clinic staff are poor. There's low engagement, they don't pick up the phone or they don't have the money to top up their phones. 99% of these issues the nurses are involved in it'.

'I've got complex families with not much money, domestic abuse, drug abuse, poor diet, I've got [children] that engage with me, but don't come to clinic always. Some come to clinic because they're scared of trouble if they don't come. Some don't come back because of the consultants so I have to change their appointments to another day. Some consultants think differently to different types of family and the offer more to middle class families who they have different expectations for'.

'Unless you ask, they won't tell. You have to proactively explore. It's assumed they're lazy and that's not always the case'.

This is a very honest portrayal and reflects what has been evidenced in the growing academic literature on the impact that poverty has on people's decision-making processes and how this leads to health inequalities and poorer health behaviours (JRF, 2017, Marmot, 2018). Although the individual circumstances were not fully divulged the evidence points to there being a likelihood that the difference between how these two parents perceived and approached the health care that was equally available to them may have been linked to their socio-economic status.

In both cases, the children were diagnosed within the last month and both were attending their first formal clinic appointment.

| Scenario One | Scenario Two |
|--|--|
| Lone parent, unemployed and in receipt of Universal Credit. | Married parent to partner with a good job and a 'decent income.' |
| Experience of support: | Experience of support: |
| 'I haven't really asked for any help, as I can manage everything myself and I understood everything that I need to do, everything has been fine. It wasn't great having to do finger pricks and injections but we got used to it. I was offered support when he was diagnosed but I didn't want people to think I couldn't cope or that I wasn't smart enough'. | 'The support I received was amazing I can't believe how incredible the service had been. They visited me at home to give me support, they just made themselves so available. I could even call them in the middle of the night if there was an emergency. They had spoken to me with such genuine empathy I could just tell how much they cared, not only about me but also about my son'. |

The parent in scenario one, 'didn't want people looking down on her', so she didn't ask for any help and she managed by herself.

Lack of self-belief, high levels of stress, stigma and power dynamics all contribute to how a person in this situation might feel about themselves and their status when speaking to health professionals (JRF, 2017). This is likely to spread to engagement with peer participation and support groups too, 'there weren't many there and everyone was affluent – the people that need the support wouldn't have fit in and would have been isolated, I mean, it takes place at David Lloyd'.

| Top Takeaways | Other Considerations |
|-------------------------|---|
| <list-item></list-item> | How do medical staff and patients find out about the charitable and community support that is available? How is this shared with service users universally - do you have a welcome pack or posters in clinic? Is there a local community partnership, network or website that can provide this information? Think about language, 'can I put you in touch with,' 'can I get [organisation] to get in touch with you.' Look at JRF report on 'How Poverty Affects People's Decision Making Process'. Consider how patient participation groups and peer support groups include equity, diversity and inclusion in their roles. Consider the roles receptionists and assistants can play. |



We found that where direct conversations were opened up about finances right from the very start it helped to normalise the fact that diabetes is expensive and will affect everyone's finances. Doing it in this way helped to remove stigma and most importantly get people the financial assistance they were entitled to. 'The DWP have given a form to fill in for some allowances for [child]. Because I've always worked and do have a good job, I was a little bit embarrassed about applying for it. [The clinic] encouraged me to do it for her long term but it's not something we would necessarily need financially so it took me a while to apply, but [staff member] really encouraged us to apply for it and we did in the end'.

We heard about 'pre-appointment forms that specifically asked about financial circumstances' and staff going above and beyond to 'get DLA forms and doing a home visit to help fill them in'. This was an exceptional case but having a broad awareness and understanding of what financial support is available, especially for Disability Living Allowance (DLA), helped create direct referral pathways and signposting to organisations like Citizens Advice Bureaux (CAB), Carers UK, SCOPE and Diabetes UK who were able to help people access welfare benefits advice, support and advocacy. Signposting to food support and having information and resources available in the waiting room like this clinic who provided 'free fruit and veg'.

Barriers

Staff confidence to approach the topic of money with families, although completely understandable was a barrier to families accessing the financial help that was available to them and that they were entitled. 'It's a real awkward sticky thing to talk about, money, with patients. I'd need to know about if there was an issue with money before I asked. It's awkward if there isn't a problem with money because I have to work with these families for 19 years. Coming from someone with money, it's difficult isn't it, when the person asking has money, and they don't'.

The length and complexity of application processes, 'we have applied for DLA, but I don't know where we're going to stand with it, I know we're going to be entitled to something but the form was so hard, it was treacherous. It took me three to four weeks to get round to it. I don't know if I put enough detail in it. There is quite a bit of extra expense. The process of applying for it is a nightmare. The forms and things...It's draining, when the letter arrives you think, oh god. You feel like you have to justify everything and be so careful about how you word things'.

Inconsistency and uncertainty about what patients could get free on prescription presented as a barrier. People told us they were struggling to pay for things that they'd once had funded through a prescription, that had now stopped or that they are no longer able to access that other people are; 'hypo treatments aren't available on prescription, although I've heard some people are getting them'. When he's having a hypo he used to get glucojuice from the doctors but they don't tend to prescribe them anymore. We were using Lucozade but now we're having to buy more because it's not as sugary and stuff like that adds up, 'we used to get Gluco-juice free on prescription. At first, it was "we didn't have them in". Then they just said they stopped doing it'.

| Top Takeaways | Other Considerations |
|---|---|
| Open up the conversation directly and intentionally as part of their care. Explain to people that they may be entitled to financial support and encourage them to take it. Have a range of ways for people to let you know about their financial support needs. Create a positive culture within teams. Celebrate and be proud in your achievements. Getting money in people's pockets has a direct impact on health outcomes. | Openly acknowledging the additional costs of diabetes as a universally recognised condition is a good way of opening up money conversations with everyone and helps to remove stigma. Make links with organisations and charities such as CAB, Carers UK, SCOPE and Diabetes UK and explore mechanisms for direct referrals. Again, think about language in this. Not everyone is comfortable with the word 'referral' (RCPCH, 2022) In most cases children with Type 1 Diabetes are entitled to some form of DLA award. The NHS Low Income Scheme can provide financial support. Including questions on pre- assessment forms about financial circumstances can be a discrete way of letting care professionals know. Consider offering as many channels as possible - not everyone is comfortable talking about money. |
| | <image/> |



The development of digital technology for families caring for children with diabetes significantly enhanced and improved their quality of life, 'with the technology, it's easier to check her bloods through the night without having to wake up my daughter, and I can keep an eye on her levels when she's not with me'. People reported better relationships with school, with each other, greater peace of mind and better quality of sleep. For families who couldn't afford this themselves NHS assistance was greatly appreciated; 'in the earlier days we couldn't get the funding for certain things so we paid that out of our own pockets. Obviously it's quite unfair for some children who can't do as much because they can't get the funding. Now all the technology is covered on the NHS and the insulin pump means we don't have to spend as much through the day on snacks," "it was a struggle before the clinic paid, it was £50 per sensor and the sensor lasted 7-10 days but sometimes it would come off in as little as three hours or it could come off at the swimming pool. It was hard to afford that and we did struggle'.

Taking a proactive approach to providing families with assistance, support and signposting on how and where to get diabetes-specific technology whether via the NHS or a diabetes charity helped to alleviate the impact of poverty. Giving the option to download BG monitoring data and access free WIFI in the clinic as a universal service helped to prevent identifying or stigmatising those who may be doing this out of necessity because they lack their own technology or data.

Barriers

Families talked at length about the main barriers, preventing them from being able to take full advantage of the technology so crucial to managing their health. 'high costs of data' 'unreliable internet', 'incompatible phones for the tech', 'not knowing how to work the computer', 'no internet', 'not being able to get on WIFI', 'running out of data', 'needing the latest versions of tech to access the data'. We heard about how the processes for involving technology in management of diabetes could be very difficult. Charitable support, although available, was often unable to meet the demand 'charities that provide phones but they're so small and there's not enough'.

Even where families had the kit from the NHS or a charity often their skills, capacity and resource to work with it effectively was impeded because of IT literacy and digital poverty. The quotes below help to paint a picture of the reality of the patient experience: 'We got a laptop but we returned it because we didn't know how to use it', 'we don't understand what we're looking at', 'it's okay giving the devices but they haven't got the means to download what they need', 'it was mandatory to have a Samsung phone for Libre. We can't keep changing phones'.

'We feel like we don't know what we're doing, there's so much information to look through and to be honest I've never been much good maths...he's the one who can do it but what you really need is all the information in one place, you don't know what apps do what or what they're gonna cost you or what the updates do or what and it just goes in one ear and out the other'. The same barriers that applied to Accessing Diabetes Support and Education also applied here in learning about and accessing technology. Families doing their absolute best but just unable to get to grips with the technology told us of their frustrations of not understanding, not being shown properly and often having to make do with second hand, shared or outdated kit and of course this added to the stress and discomfort that those with money were better equipped to mitigate. '[Financial disadvantage] it's never spoken about. They just don't ask. When we went on these gadgets it was just assumed you had a laptop. We got given a laptop from the school. I bought a second hand laptop for my other little girl. We don't know how to download the data. We learn by seeing. If you give us a leaflet, we'd go home and panic', 'The [diabetes] control could be better, but I'm up in the night changing his ratios every 2 hours. I could get more sleep if I just had the tech to get him his insulin'.

Having the facilities to download data in clinics does help, but not having it available at home means more inconvenience and costs associated with getting to the clinic to use the facilities there.

We saw a reward and recognition scheme that awarded kids stickers for maintaining their blood sugar levels effectively. While positive for those who monitored well, settings need to be mindful of how reward, recognition or encouragement is received by those experiencing poverty who do not have access to the technology or resources required to do this.

| Top Takeaways | Other Considerations |
|--|--|
| Work with charities who can offer educational and financial support in getting access to technology. Have opportunities available in clinic to access WIFI and download data. | Charitable support and access to technology for families although much needed is under resourced. Is this something that can be addressed perhaps in partnership with the business or tech sector? |

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