

Patient engagement and inequality

What are the difficulties that young people encounter in accessing diabetes services and what are the solutions/adaptations that psychologists have developed?

NPDA 2021 survey shows there is trend of widening inequalities in the care of and access to technology in Children & Young People with T1DM from Ethnic minority groups and those living in economic hardship in England and Wales.

Potential barriers include:

- Lack of research to explain inequalities
- Lack of understanding in why there are differences in the uptake of specific support (e.g. psychology) – more research needed.
- Variability in funding between services across the country (postcode lottery) – Why?
- Differences in what information about technology is available to/accessed by minority groups before being put onto a pump pathway.
- Is there unconscious bias amongst MDT teams – differences in who is referred for psychological support and who is offered diabetes technology – are assumptions being made about who will engage?
- English as a second language not necessarily accounted for during diabetes related education.
- The Young person being used as interpreter for parents.

- Carbohydrate counting apps don't necessarily include cultural food or take into account faith based festivals e.g. fasting.
- Staff teams not necessarily representative of population culture and ethnicity.
- Lower literacy and numeracy levels can contribute to lack of confidence in CYP and parents in being able to navigate technology e.g. using pump/CGM apps.
- Being unable to afford the smart phones/laptops needed to support diabetes technology.
- Differences in transport links between urban and rural services and affordability (including hospital parking charges) make it difficult for some families to attend clinics and therefore may be seen as disengaged.
- How do we build trust in patients – how does information from the MDT land with families and how is it valued and how is it influenced by culture?
- How do we know what CYP and families feel about coming to clinic appointments e.g. feeling judged, overwhelming, its all about the numbers – without consideration for what is going on in the rest of their life.



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Potential Solutions/Adaptations

- Getting out of the therapy room and into homes and communities to have insight into the lived experience of young people and families within the context of their culture.
- Using communities & peer support expertise to engage other children/young people/families.
- Offering occasional on-line appointments where appropriate (if family have on-line access, developmentally appropriate, no safeguarding concerns).
- One service has adapted the 'Tree of Life' group to 'Team of Life' group (held in a football stadium) as a way of engaging young people.
- EoE network has created a cook book containing recipes donated by our families which are representative of family cultures across the East of England.
- Offering camps, family activity days, BBQs, sports camps at subsidised rates to bring CYP with T1DM together on a regional basis rather than individual hospitals.
- Having youth workers, family support workers and social workers as part of the team who can support families in accessing financial support, housing etc to give 'head space' to think about diabetes.

- Some services are now engaging in much needed service audits to explore reasons for inequalities, demographic factors between non-attenders/attenders.
- Encouraging service user groups to contribute to service development with a co-creation approach rather than a top down approach.
- North East – 'Poverty Proofing' training and audits designed to minimise the impact of poverty on health care provision.
- Annual Review is an opportunity to ask CYP and families about relationship with MDT (e.g. T1DAL screen asks these questions).
- Offering routine diabetes clinic appointments at satellite clinics to address transport problems for patients under teams that cover wide geographical areas.

Funding opportunities for families living in financial hardship:

- <https://www.scd.uk.com/> - offer a hardship fund to help families buy diabetes related items for the home and vital equipment not available through the NHS, they also provide respite for young people and their families who cope daily with the challenges of T1DM
- <https://digitalpovertyalliance.org/application-form/> - fund to apply for laptops which can help support diabetes technology.
- <https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/> - Families that are on qualifying benefits can apply for the Healthcare travel costs scheme which can reimburse reasonable travel costs

