The role of the youth worker in improving outcomes in young people living with type 1 diabetes

Diabetes transition refers to the time when a young person moves from paediatric to adult diabetes services, typically at 16–18.5 years of age. Owing to a coming together of personal challenges and healthcare barriers, the highest risk of losing patients from specialist diabetes care, to either no diabetes care or being managed by their GP, exists during this period.

The diabetes team at Alder Hey Children's Hospital in Liverpool recognised this and worked to get funding to employ a full-time diabetes youth worker for the transition age group, with a view to combatting the issue of losing individuals between child and young adult services. This is the position that I am now employed within.

At 17 years of age, the diabetes service at Alder Hey starts to invite all patients to attend joint transition clinics with our two closest adult hospitals, Aintree University Hospital and the Royal Liverpool University Hospital. Each has a young adult service for those aged 16–25 years, and we look to transition patients to their care at around 18.5 years of age. To improve their experience of this process and to maintain engagement, joint clinics are held at Alder Hey, which are attended by our consultants, nurses and dietitian. We aim for patients to attend 3 or 4 of these clinics before they transition to a young adult service. I attend these joint clinics as a youth worker and am also the point of contact at Alder Hey for the young adult teams. The young people under my care are asked if they would like me to attend their first appointment in the adult hospital with them.

At each hospital that employs a youth worker in diabetes care, the focus of their work differs, depending on the needs of that cohort of patients. When funding was approved at Alder Hey, it was to focus on providing additional support to transition-age patients, to encourage them to engage in their diabetes care and to transition successfully to young adult care.

When I started my role at Alder Hey, it was as the first youth worker in the diabetes team. This provided me with an opportunity to help shape the service. My experiences of living with type 1 diabetes and of being under the care of the children's service when I was younger helped guide my ideas. Asking the young people currently in the service what they needed from it, and being led by them, was also important. The diabetes team had previously had to put in a referral for youth work support for their patients, so I was also able to draw on the data held on referral numbers and the reason for them.

I spent an initial few months going to clinic appointments, so that patients got to know me and I got to know them. I sat in on insulin pump starts to support those that would be using this technology, I joined the nurses on the ward providing diabetes education for those newly diagnosed and, subsequently, met regularly with the nurses and consultants to discuss how we could work jointly to provide a wraparound support for that patient. I now meet all new patients on the ward, so that they are aware of the support on offer. For those we have admitted at a crisis point for them, I ensure that I am available for a one-to-one session, if they are willing.

Referrals to the youth worker typically were coming in for patients who were out of education, were looking for employment, whose families were under children's social care and required additional support, who were disengaged from the diabetes service for one reason or another, or who required more intensive support than other healthcare professionals in the team had the capacity to give.

During the first 12 months following the implementation of the diabetes youth service at Alder Hey, 15 young people (seven male and eight female) were identified as requiring extra support. Their mean age was 14.8 years (range 11–17 years), their mean time since diagnosis was 3.8 years

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Citation: Hallam K (2025) The role of the youth worker in improving outcomes in young people living with type 1 diabetes. *Journal of Diabetes Nursing* [Early view publication]

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(range 0.3–9.0 years) and 87% were in the most socioeconomically deprived quintile.

For a lot of young people, diabetes is the last thing on their priorities list, and what comes above it is extensive and often intensive. I saw that these young people need help with their lives, before they can begin to approach their diabetes management. Often they do not have the space or support that they need to deal with outside influences, before they can start to prioritise their health.

Every young person is different, and the work and approach to each of them needs to focus on this. This is reflected in how much contact and support you give any young person, how you communicate with them and how you handle the areas they feel they need support in, with the involvement of other professionals in the team and their families.

The most important thing youth work can aim to work on is empowering a young person to take control of their choices and decisions, and to be able to speak up for themselves. I see the most important aspect of my role as being to advocate for that young person, until they can advocate for themselves. This may be in an educational setting, with children's social care or in the clinic environment, with the rest of the team. I work with the rest of the multidisciplinary team to provide wraparound support for each young person I work with. Sometimes, this means that an individual feels comfortable to reach out to me asking for help with their diabetes, so I work alongside their key nurse to help with their management.

Building relationships with these young people was different with each of them. For some, it took 12 months of building trust by working alongside their family before they started to engage with me. For others, it was some WhatsApp messages and a clinic or two, and they were happy to engage. I am very open in clinic, with the young people I work with and anyone in the service I meet, about having type 1 diabetes and the struggles I have gone through with it. I have personal experience of the burnout they go through with their diabetes; I have stories of my own childhood and young adulthood going through transition into the adult service. I know that diabetes is exhausting and that you never get a break. Being able to relate to these challenges brought a lot more young people "onside".

For those engaging with the youth work service, the "did not attend" clinic numbers started to reduce. Sometimes this required me to go and pick up a young person and their parent up from home, as they had no transport or way of getting to the hospital for their clinic appointment. If I knew that someone needed reminding of an appointment, I would text them the week before, a few days before and on the day. Building strong foundations for a relationship with these young people and their families allowed me to understand why they were sometimes missing or avoiding appointments.

For me, the focus of this role is letting these young people know that, even if they don't message back or don't turn up to clinic, the level of support will not diminish. The expectation is never for a young person to have to come into the hospital for sessions – I go to where it is more comfortable or more accessible for them. Whether that is a home visit, seeing them in the community or attending their school, they choose where they want to meet. I provide one-to-one sessions for those who want just to chat or want to offload about life or diabetes or school. I attend clinical appointments, in and out the hospital, for other services that are not diabetes related, if that support is what they need. I also help families to be at a place where they can support their young person.

Prior to the implementation of the youth work within the diabetes team, the median and mean HbA_{1c} measurements of the 15 young people referred for intervention were 93 and 97 mmol/mol, respectively. Amongst 13 young people who had been diagnosed for over 12 months, there were three hospital admissions in two patients for diabetes ketoacidosis (DKA). Twelve months after implementation, median and mean HbA_{1c} had fallen to 70 and 81 mmol/mol, respectively, and there were no DKA admissions. Additionally, diabetes clinic attendance per person improved from a mean of 4.2 per year to 4.8. Feedback from the young people in the service was also positive.

The challenge with any work with young people is their engagement, which will fluctuate. They have outside influences that are taking up their time, and you can never be completely confident that they will show up when they have said they will, that they have taken medication as they said they have, or that

they will engage with other healthcare professionals as they agreed to. I learnt this early on, resulting in me being more flexible to suit their needs.

For those of us working in the NHS, time during our working day is limited, but these young people need an abundance of it. Not having a set number of patients when starting fresh in the role was my saving grace, as I had time to really invest in building strong relationships with the young people. I still maintain much lower patient numbers than that of the nurses and doctors, so that I can provide them with the time they need. The role of youth work at Alder Hey involves working with our young people collaboratively to empower them to take control of their diabetes care, lives and futures with confidence, while feeling as supported as they can be.

Incorporating the youth worker role should be an important consideration for any diabetes service working with young people. Youth work can offer a more intensive level of support to young people transitioning to adult care. The less formal relationships that a youth worker seeks to build can make young people feel more comfortable talking about issues that affect their lives, as well as raising questions relating more directly to management of their diabetes. Feeling heard is of great importance and can raise the morale of young people.

For those who are struggling and need that extra help during transition of care, a youth worker can offer wraparound support alongside other healthcare colleagues. This can result in higher attendance, greater engagement with adult services and improved diabetes outcomes. ■

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