

Project Overview

- 12 Month Pilot project
- NHS Employed Youth Worker Roles
- Supporting young people with long term health conditions
- Holistic support as young people prepare and move into adulthood and transition to adult services.



Introduction

The NHS Youth Worker pilot project, supporting young people, aged 13–25 years with long term health conditions, is delivered across the four Black Country areas. The 12-month project is primarily funded by NHS England with an additional post funded by Black Country ICB in Sandwell.

Nationally, NHS England (NHSE) are currently running a Youth Work two-year pilot project. Despite Black Country not being successful with the bid for the national project, as timings aligned, the Black Country Youth Workers and Managers actively attend the NHSE regional and national meetings for shared learning.

The short-term funding of 12 months does not appear to allow sufficient time to measure impact or establish and provide a settled service with vulnerable young people. It presents risk of loss of support service to young people who are already struggling living with a long-term health condition and managing transition to adulthood.

Healthwatch Sandwell and **Diabetes UK** have published reports highlighting the increase in type 2 diabetes cases, including at younger ages, and serious concerns around gaps in diabetes support services. Around **60%** of the young people currently receiving support through the pilot project in Sandwell have diabetes. Therefore, insight from these reports and a focus on diabetes has been used to illustrate the benefits of the NHS youth worker service. However it is important to highlight the Youth Workers are also supporting young people with different long term health conditions across paediatric and adult services.

Healthwatch Sandwell have collaborated with the NHS Youth Worker Team Manager in Sandwell and West Birmingham NHS Trust to create this report highlighting the pilot project and time-line concerns.

The request is consideration be given to funding an extension of the pilot project timeframe.

“If they explain to me what the steps look like being moved over as I won’t even be an adult yet, so that’s a bit scary! But if the Youth Worker stays with me along the journey, because it will be a lot of new people, I will have someone I know from before moving and will feel more comfortable.”

“Having a Youth Worker would have helped me with the changes, as well as coping with day to day, as I had a lot of stuff going on at the time.”

Transition from paediatric to adult services

Transition is a planned and purposeful process that address medical, psychosocial, education and vocational needs of young people with long term health conditions as they move from child oriented to adult oriented healthcare services (Blum, 1993).

Adolescence is a time when risk taking behaviours begin and lifelong health behaviours are potentially set. The effects of poor healthcare in adolescence can last a lifetime (AYPH, 2023). There is evidence that morbidity and mortality increase for young people following the move from paediatric to adult services (Nagra et al, 2015).

A poor transitional experience can lead to poor health, social and educational outcomes. Transition can coincide with multiple life transitions at a time of emerging independence and changing role of parents. This can further coincide with challenges adhering to the management of a young person’s health condition and/or engagement with health care appointments, impacting on health outcomes (such as HbA1c blood sugar levels for diabetes).

Health Youth Workers

Health Youth Workers have a positive impact on young people’s lives described as “making life easier” and someone who “made heavy stuff feel lighter” (Marshall & Waring, 2021). Evidence suggests adolescent brain development continues to at least mid-twenties and therefore Youth Workers support the delivery of developmentally appropriate healthcare.

The NHS Youth Worker roles are intended to help address the health outcome risks for long term health conditions, including diabetes, which is one of the priority clinical areas identified in Core20PLUS5 to have the greatest potential to narrow the gap in life expectancy due to health inequalities (NHS England). Sandwell is the 12th most deprived local authority area in the Country and most deprived in the Black Country. The Black Country has higher than national average child poverty, obesity and mortality rates.

The young people supported by the service are those who are at risk of disengaging from services and failing to manage their health condition and transition successfully into adult hood. Youth Work referrals are via health care professionals with the young person’s consent.

Sandwell and West Birmingham NHS Trust currently have two fixed term contract Youth Workers. They commenced in post January 2024 with their current contracts due to end the start of January 2025. They are part of a Black Country project with Dudley Group NHS Trust, Walsall NHS Trust, Royal Wolverhampton NHS Trust also having one fixed term Youth Worker in post with contracts ending November 2024–March 2025 (individual start dates varied). (The substantive full time Diabetes Youth Worker at Royal Wolverhampton is a separate post to this pilot project).

Diabetes and young people

Diabetes is a long-term health condition where life choices and risk-taking behaviour will impact diabetes management (for example with type 1 diabetes alcohol consumption can be dangerous if steps are not taken to manage the diabetes when drinking alcohol), therefore support in transition from paediatric to adult services is vital.

Diabetes outcomes are shown to decline at adolescence and transition age, with an increase in diabetic ketoacidosis (DKA) and repeat DKA admissions (NHS RightCare, 2024). Data shows a steady deterioration of HbA1c levels between 15 and 20 years old and decrease in care processes between 17 and 20 years old (NHS RightCare, 2024).

Sandwell and West Birmingham NHS Trust will shortly be commencing a large audit on diabetes care processes and management from 15-25 years.

The **Healthwatch Sandwell [Diabetes in Sandwell report \(March 2024\)](#)** highlighted:

There is insufficient information, education and support available to help inform, enable and empower individuals to manage diabetes as a condition and reduce health outcome risks.

Diabetes UK published a report highlighting concerns about the increase in type 2 diabetes in children.

[Reverse the Trend - Reducing type 2 diabetes in young people- \(May 2024\) Diabetes UK](#)

When type 2 diabetes develops at a younger age, defined here as under 40, it is more acute and aggressive. It is associated with an increased risk, and more rapid onset, of devastating complications such as heart disease, kidney disease, sight loss, and even early death. Developing type 2 diabetes at a younger age can also bring additional challenges to managing blood glucose levels.

Recommendations include:



4 Implement an enhanced support offer – working hand in hand with Diabetes UK – for people newly diagnosed with type 2 diabetes to support self-management in the first year after diagnosis.

6 Provide sustainable longer-term investment and prioritised programmes of targeted support for those most at risk of diabetes complications, such as that provided through the T2Day programme.



Collaborative working (focus on diabetes)

The NHS youth worker roles help connect and enable a wider support offer to young people with long term health conditions and increase positive outcomes for the patients. They support wider determinants of health by supporting access to partners such as social care, housing, education, youth justice and the Voluntary Community Faith and Social Enterprise sectors.

The Sandwell and West Birmingham NHS youth worker pilot project have received 35 referrals for young people with type 1 or type 2 diabetes. 135 one to one sessions have taken place with young people with diabetes, with the level of intervention varying for each young person depending on engagement and need. Referrals are continuing to be identified on an ongoing basis as young people attend routine outpatient appointments or during hospital admissions. It is anticipated the youth workers will also work with increasing numbers via the delivery of a range of diabetes support groups.

The Youth Workers worked in partnership with Diabetes UK to deliver a Tree of Life session at Sandwell Hospital. They have worked in partnership with the Adult Psychologist in the Trust to deliver a “Thriving not Surviving” workshop to a small group of young adults with Diabetes to share experiences of moving from struggling with diabetes to thriving with it. Feedback included:

“I learnt that Diabetes does not define who I am and that I should try to thrive with it as much as I do with the negative moments.”

“I want to remember I am not alone with Diabetes, and I have support and guidance whether it is at home or the Hospital.”

The Youth Workers are commencing a group for young people with Type 2 Diabetes to engage in “Walk & Talk” sessions at Sandwell Valley over the summer holidays. It is anticipated this will be the start of such activities with the aim to work collaboratively with other community organisations in the future.

Measuring outcomes

Measuring the impact of youth work, particularly in health-based settings, is more difficult in comparison to other clinical services. **Consideration needs to be given to extending the timescales for the project to enable outcomes and impact to be measured.**

Young people’s voices and experiences best highlight the difference youth support work can make in their lives as they transition to adulthood.

The next pages share some young peoples stories (names have been changed)

Young people's experiences

"It's good to get out and go for walks and talk about life, although I do wish I could see them more often!"

Keisha (18 yrs) Type 1 Diabetes

Keisha was referred to the Youth work service as she was emotionally struggling, impacting on family relationships and engaging in the community. The youth worker focuses on approaches to help Keisha manage her emotions and hold positive conversations. Keisha now actively participates in sessions and reaches out when she feels overwhelmed and unsure how to manage her emotions.

Last year, Keisha missed five appointments, this year she has not missed any.

"They are trying to help me talk to the Diabetes Specialist Nurse and help me find a solution to be more comfortable"

Rebecca (23 yrs) Type 1 diabetes

Rebecca was referred to the Youth Work service for support with independent living skills as she was having difficulty accepting her diabetes diagnosis and in building positive relationships, particularly with new professionals. Rebecca has been building a positive rapport with the Youth Worker, enabling wellbeing support, she has engaged in 14 sessions to date.

Rebecca felt she had negative experiences with health professionals when she was first diagnosed which resulted in poor hospital appointment attendance and trust issues. With support, including a multidisciplinary approach with the adult diabetes team, Rebecca attended an appointment to meet a new Diabetes Nurse, which was a huge step forward! Rebecca went on to attend a Psychology appointment independently.

Rebecca is currently unemployed, ongoing support is being provided.

Aisha (16 yrs) Type 1 Diabetes

Aisha was referred to the Youth Work service due to issues with bullying and struggles at school resulting in a severe lack of confidence. Plans were put in place to create a safer and more supportive environment to enable challenges to be addressed. The youth worker has supported Aisha to more confidently hold conversations and address life's challenges.

Aisha is now more accepting of her diabetes diagnosis, continuing to work with the Youth Worker on improving her overall wellbeing.

“They have visited me in School but thought going for walks would be better for me and it is now we go on walks together which helps me get healthier and have someone to talk to. Because I want to feel that I am trying to make a difference in my life that makes me healthier and happier, and they are doing that. So, I will get my weight down and manage my type 2 diabetes because I do not want to have this forever”

Jack (23 year) Type 1 Diabetes

Jack was referred to the Youth work service as he was struggling to manage his Diabetes and his mental wellbeing. The Youth Worker has engaged with Jack in over 16 sessions to date to help Jack to make more positive healthy life choices, including reducing alcohol consumption which had been impacting his diabetes management.

The Youth worker has encouraged Jack with regular walking activities which have improved his sense of wellbeing and relationships at work, resulting in a promotion.

“They give some good advice on what to do and how to stop overthinking.”

Conclusion

This document has outlined the value and impact of the NHS Youth Worker posts in supporting vulnerable young people living with and managing long term conditions. However the pilot project funding was for 12 months, end timelines are fast approaching, and to date ongoing funding to continue a Youth Worker support service has not been identified. **The request is for consideration to be given to funding extension of the timescales for the project to enable outcomes and impact to be measured and an ongoing sustainable service to be implemented.**

Please send responses to this paper to

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