

# Thinking big with Type 1 Kidz: Regional events, residential trips and charity status



**Chloe Brown**

Project Officer, Investing in Children

**Helen Mulhearn**

Co-Director, Investing in Children

**T**ype 1 Kidz (T1KZ), which is facilitated by Investing in Children, is an initiative that supports children and young people (CYP) living with type 1 diabetes and their families. It is a large project with many different aspects. Here, we discuss how T1KZ has adapted to challenges and how we have worked creatively to ensure funding for the expanded project over the past 5 years.

## Investing in Children

Investing in Children was set up in 1995 as a partnership between Durham County Council and the strategic health authority. In May 2013, it became a community interest company. The organisation works to create a range of effective ways in which CYP can have a say, discussing issues and developing arguments about how things might change. Since 2001, it has worked in partnership with County Durham and Darlington Paediatric Diabetes Team, where many changes have been made to the service based on the views of CYP.

## T1KZ: facilitating mutual support

CYP with type 1 diabetes informed us that they had really benefited from the support they had received from each other at meetings and that this was something that they wanted to pursue further. As a result of this request, in 2012 a monthly group was set up to offer CYP with type 1 diabetes and their families the chance to come together, share stories, learn from one another and take part in interactive activities, as well as continuing to work with us to encourage better dialogue and to review and improve services. T1KZ, as it was named by the CYP, had three overall aims:

- To help CYP feel more confident
- To help CYP feel more positive about the future
- To improve health outcomes.

This holistic model was very successful and because of this there was interest from clinical teams across the region as well as nationally. As a result of

this interest, we began to look for funding to expand the project.

## Initial expansion

In 2014, in collaboration with the Bright Ideas Fund, we secured funding from the Academic Health Science Network in the North East and Cumbria to:

- Explore the rollout of a simple telehealth system (Mulhearn and Brown, 2017a)
- Expand T1KZ into four new areas – Gateshead, Newcastle, Sunderland and South Tyneside (Mulhearn and Brown, 2017b).

The partners in this venture (the paediatric diabetes teams from Newcastle, Gateshead, Sunderland, South Tyneside, County Durham & Darlington and Cumbria) set up a steering group, which included young people. Initial discussions highlighted the close geographical areas and crossover in patient lists, which informed the decision to establish two groups – Newcastle/Gateshead and Sunderland/South Tyneside – to cover four areas. The plan was to replicate the same format as had successfully been used in Durham.

After the first 12 months, it was apparent that we were having limited success with this approach in the Sunderland/South Tyneside group. Family engagement was not as high as in other T1KZ areas and not as many families attended the monthly meetings. Although research was undertaken with CYP with type 1 diabetes and their families in clinics and via digital messaging to find out why engagement was poor, no apparent reason was established and it became clear that holding monthly groups was not practical. This meant we were not achieving our aims and objectives, so we reconsidered our approach.

## Regional events versus monthly meetings

During discussions between Investing in Children, patients and their families, and the local diabetes teams, some CYP with diabetes and their family

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members fed back that they wanted to have bigger events to encourage more people to attend. They felt that this would enable more in-depth discussions, sharing and learning. We therefore decided to trial quarterly sessions in 2017. These proved to be a big success, with an average of 30 families attending each session. This equates to 25% of the patient population in Sunderland. A huge 46% of patients in South Tyneside attended these events; higher than the four other regions.

With the success of the quarterly events, we thought big and agreed to organise larger regional events. We have held several regional events over the past 4 years, including our summer fun days and Christmas parties. This has led to the organisation of away-day trips. In 2017, 170 people went on a day trip to Lightwater Valley Theme Park. Families have told us that these regional events and away days are really valuable, providing the opportunity for CYP with type 1 diabetes to try new activities in a safe space.

### The residential trip

Following the success of the larger events, last year we organised a 2-night residential trip to Dukeshouse Wood, Hexham, which 70 people attended. Activities offered aimed to improve CYP's confidence and self-belief and included high ropes, climbing, abseiling, 3G swing and group games. CYP said that this was extremely empowering, as many families had not had the confidence to try these types of activities before. CYP said that they felt more confident in managing their diabetes and some told us they had made changes to the way that they manage their diabetes while doing activities, such as taking different amounts of insulin and eating different snacks to avoid high and low blood sugar levels. One young person also did her own injection for the first time ever because she watched others doing it during the trip. In an online questionnaire assessing the outcomes of the trip, all of the CYP said that they felt more confident, felt more positive about the future, and that the trip had helped them to improve health outcomes.

The residential trip was supported by the local diabetes teams, who encouraged families to attend. One nurse attended for the whole trip to help and offer support to families. The teams also

provided documents and advice regarding diabetes management and overnight activities, so the trip could be a success. A positive consequence of bringing families together from different clinical teams/areas was that they were able to discuss the care that they received from their paediatric diabetes team. Hearing about the different treatment options offered in each region and seeing the support CYP receive has empowered families to challenge their teams to provide alternative types of support and ask for different treatment options, which has ultimately improved families' experience with the teams.

Another residential trip is booked for August 2019, with the goal of making it an annual event. To find out more visit [www.investinginchildren.net](http://www.investinginchildren.net).

### Tackling funding challenges

Investing in Children involves CYP in dialogue and change. Our approach informs how we develop projects or groups and responds to the wants and wishes of CYP involved in the debate. Raising funds to be able to provide child/young person-led services is always a challenge and having to rethink an approach 1 year into a 2-year funding stream is limiting. Although this approach has been extremely successful, it has meant financial support for projects has quickly been exhausted.

As an organisation we are constantly looking for funding. Gathering sufficient proof of our concept for clinical commissioning groups to clearly see that providing safe spaces for CYP with type 1 diabetes, their peers and their families has a positive long-term impact on the health and well-being of CYP with type 1 diabetes is hard and takes time. We are nothing if not creative in our approach, however.

We realised very early on in our development that families were keen to support us, engage in fundraising and make donations. This challenged us as an organisation to examine whether our governance was best suited to this. It was clear after years of successful fundraising – totalling approximately £8,000 per year over the past 3 years – that Investing in Children T1KZ is better suited to being a charity. We have recently been successful in registering the Investing in Children Foundation and look forward to being able to sustain the current groups and events while seeking more long-term funding to develop and expand. ■

*“Families have told us that regional events and away days are really valuable, providing the opportunity for children and young people with type 1 diabetes to try new activities in a safe space.”*

Mulhearn H, Brown C (2017a) The Type 1 Kidz project. Part Two: Introducing a simple telehealth system. *Journal of Diabetes Nursing* 21: 32–35

Mulhearn H, Brown C (2017b) The Type 1 Kidz project. Part 1: Engaging children and young people with type 1 diabetes in their own health and wellbeing. *Journal of Diabetes Nursing* 21: 28–31