## Chloe Brown Project Worker, Investing in Children

Type 1 Kidz - The Impact of Engaging Children and Young People with Type 1

Diabetes and Their Families to a Peer Support Project



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### **Type 1 Diabetes**

- A life-long condition where the body produces **no** insulin, meaning the person affected has to have multiple daily injections or wear an insulin pump. Requires blood glucose tests up to 8 times a day.
- Cannot be prevented in any circumstances and has no cure.
- Requires intensive management to avoid / reduce short and long term complications, therefore affects the whole family and all aspects of life.





### Background

- Investing in Children (IiC) established in Durham in 1995, now a Community Interest Company and works nationally and internationally.
- In 2001 started to support children and young people (CYP) to have a say in their care and service provided by the Paediatric Diabetes Team in Co. Durham and Darlington.
- In 2012 the group took on a new dimension and group sessions start to run monthly. The CYP named this project 'T1KZ Type 1 Kidz.'





### **Sharing Information**

- Monthly group sessions across the North East for families (parents, siblings, grandparents, aunties, uncles, cousins, close friends ...) to help families manage Type 1 Diabetes the best they can to improve health outcomes now and in the future. The Paediatric Diabetes Teams attend group sessions 'informally' to build a better relationship with families.
- This allows continuous sharing and access to information both from families to the diabetes teams and vice-versa.
- Dedicated Project Worker sits on the County Durham & Darlington Multi-Disciplinary Team Meetings to share information.





In the early days ...

- Children & young people said they wanted more support and because of this
  a Psychologist was employed and is now a core part of the team.
- Children & young people expressed an interest in insulin pump therapy; they
  visited a pump clinic in Sweden and brought information back. County
  Durham & Darlington Trust were the first clinic in the UK to offer insulin
  pump therapy.
- Children and young people designed and updated display boards to share information with one another.

More recently ...

During a peer mentoring session children and young people said they
wanted to direct their own appointments so they could get the most out of it.
This is now been trialled at Newcastle Hospital and children / young people
are given a sheet to fill in before their appointment and see the clinical team
at the beginning without parents/carers.





#### More recently ...

- Young people said that they wanted more realistic information about complications, this now happens.
- Children said they wanted more support to reach their goals and be recognised when they do; children are now given certificates when they achieve their goals.
- Families said they want more information about managing their condition while doing sports, this has happened.

Access to information in this way enables the hospital to offer more effective and efficient clinical appointments and allows children & young people to manage their diabetes the best they can to stay healthy now and in the future.







### **Sharing Information**

Information that is gathered is shared:

- Quarterly at a Professional Steering Group
- Through the North East and North Cumbria Families Diabetes Network
- Journal Articles: Nursing Times x 2 (Jan 2017) and Practical Diabetes Guide (June 2017).
- Presentations: Diabetes UK, BSPED, PharmaTimes, AHSN ....
- Awards: Bright Ideas in Health Awards, Quality in Care x2





### **Evaluating Type 1 Kidz**

- ▶ 182 children and young people with T1 Diabetes have attended a Type 1 Kidz session in the last two years. On average this is 20% of the patient population.
- ➤ C&YP who attended more group sessions had more knowledge, worried less, relied on fewer people to help them, were more motivated to lead a healthy lifestyle and were more independent than those who attended fewer group sessions.\*





<sup>\*</sup>This data was analysed by Newcastle University and Newcastle Hospital Trust

### **Evaluating Type 1 Kidz & Flo**

- ➤ Children, young people and parents who attended Type 1 Kidz for a longer time reported to have more understanding of managing diabetes in the following situations:
- Hyperglycaemia (high blood sugars)
- Different ways to manage diabetes, injections, pumps etc.
- Had a higher overall Score (understanding T1, how it affects the wider family, treatment options, hypoglycaemia, hyperglycaemia, illness, exercise, food and carb counting, on holiday and at school).

Than those who had attended for a shorter time.

(September 2017, analysed by Sunderland University).





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### Any Questions?



