

# Reflections

A series of insights from our day to day practice

## COLLECTING SENSITIVE DATA

Organisations are generally quite well equipped to collect information about their activities and participants. But sometimes they need help to collect objective evidence about the difference they make and to make sense out of that data. **Marie Goss** of Brain Injury Matters and **Nicola McIldoon** of CENI contemplate how they gathered useful data in ways sensitive to the circumstances of participants.

### Brain Injury Matters

Brain Injury Matters (BIM) is a charity dedicated to supporting people with Acquired Brain Injury (ABI) to rebuild their lives and reach their full potential in the community.

In 2014, the organisation established the Younger Persons Network (YPN), a programme funded by the Big Lottery Fund to provide physical activity and personal development opportunities for young people with an ABI. The aim was to help participants increase positive experiences across different aspects of their lives, including relationships, daily activities, leisure, work and training



## Marie: What we wanted

We were already collecting a raft of data including information on service delivery and outputs, user feedback and clinical outcomes for individual participants. That was useful in reporting on activities and tracking individuals' progress, but we wanted to be able to communicate what impact the project was having on young people and their families.

**We knew from what we could see and hear that it was making a difference to them, but we felt that we needed some external support to get objective evidence of that difference.**

We asked CENI to help us gather 'stories' from the young people, and to present them in a way which would clearly communicate the impact of the project from the beneficiaries' perspectives.

## Nicola: Being aware of circumstance and nuance

Our first step was to ask the YPN staff to tell us what difference they thought the programme was making to participants. They had already set out a number of outcomes in their funding application and together, we revisited these and explored what they hoped to achieve in more detail.

We agreed the high level goals for

the programme - reduced isolation, improved health and wellbeing and enhanced life opportunities. Working back from these, we identified more deliverable outcomes and the specific changes or outcomes for young people and set out some indicators - the types of things which would show that the outcomes had been achieved.

**We knew that young people might experience the outcomes to different degrees depending on their individual circumstances and level of engagement with YPN,** so the exercise provided us with a core framework around which a set of questions could be structured.

Given the nature of the challenges faced by participants, we worked closely with programme staff to plan and carry out the consultation; they were familiar with all of the individuals and could provide us with guidance on engaging them in the process. They helped us to identify a sample of eight young people and to obtain consent from their parents or guardians.

They also provided us a briefing on each person - the history of their ABI, their engagement with the project and any particular challenges (for example, communication) which needed to be taken into account. Using this intelligence, we were able to adapt each of the interviews to the needs and circumstances of the young person taking part.

We carried out the consultation with the young people face-to-face and via telephone interviews, using a common set of questions linked to the outcomes framework. A number of parents were also consulted. The information collected was then analysed and presented in a report to BIM.



### **Marie: The benefits of this approach**

All of our YPN participants have had very personal journeys and so this was a piece of work which needed to be done sensitively. Developing and using an outcomes framework as the basis for the research allowed us to take a thematic, rather than an individual case-by-case approach. It meant that the feedback from the young people and their families could be aggregated and we were able to see patterns about what had been achieved. This way, the confidentiality and anonymity of the young people and

their families was protected – the report was about the overall picture of what was being achieved, rather than their personal stories.

It was important to ‘Brain Injury Matters’ that a third party was asking the questions. We were able to provide our own professional insights and observations about how the project was helping the young people, but this process lent some objectivity and gave participants the space to talk freely about their experiences’.



**BRAIN  
INJURY  
MATTERS**

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We provide training, support and consultancy to help with:

- **Outcomes planning**
- **Collecting and making use of data**
- **Communicating outcomes, impact and learning**
- **Using findings to improve and develop**

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