Introduction

A recent internal audit highlighted a relatively high number of cases where parents initially declined intervention following the diagnosis of a permanent hearing loss. As a result the team hope to improve the uptake of children’s hearing services within our community through several agreed ‘action plans’. One action was to better understand parents’ experience of the newborn hearing diagnostic process at Bristol using arts based methods. This information would inform service development plans including producing information for the website and various other mediums.

Method

We worked with the patient experience team within the trust and Beth Calverley, poet in residence. Parents of children were invited to work with Beth to express their experiences of having a child identified with a hearing loss as poems. Beth hosted a gentle conversation with each parent. They were free to share as much or as little as they wished. Beth wove their words into a poem, live in the moment, and invited each co-creator to shape the poem as they wished. Some sessions took place in person while others took place via phone/video call. Each person received the original typewritten poem to keep as a memento of their experience. In addition, staff members also shared their feelings and experiences of diagnosing hearing loss and supporting families through childhood.

Discussion

Four parent volunteers described their journeys as family members of a baby or child with a permanent hearing loss. The created poems (with permission) will be displayed:

- visually and with audio recording on the Children’s Hearing Centre website
- UHBW social media sites (Facebook, Instagram, Twitter and Linkedin)
- a poetry gallery within the department will be created to display all of the poems in a quieter area for private reflection
- visual snippets from the poems on the diagnostic test room walls

Taking part in the poetry session was really useful to me. It gave me the opportunity to pause and reflect on how I felt at the beginning of our journey with hearing loss (parent)

I feel a wave of privilege to have spent time with family members, listening to their experiences. They expressed many emotions: shock, worry, uncertainty, guilt, connection, pride, love, joy. Throughout the poems, there’s a thread of trusting intuition, tuning into a deeper rhythm, and finding creative ways to connect with the world. These connections seem all the brighter for it (Beth, poet in residence)

I was listened to and I got a poem out of it. The fact a clinician sat in and listened as well meant she got to hear how difficult it is for parents, and that is so beneficial (parent)