

# Through their eyes: building resilience and well-being by listening to children and young people with complex needs about their health preferences

by Jane Coad (FRCN 2013)



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**T**his article seeks to draw out exploratory approaches that I have used but, at the same time, it will add to the debate about how children and young people have been involved in co-creation approaches to support adults (families and health professionals) in shaping healthcare services.

Children's and young people's participation in research work and developing services has had a high profile in health, social

and political arenas for at least 15 years (Gibson et al 2010, Clark and Moss 2011, Coad and Hambly 2011, Lundy et al 2011, Carter et al 2012, Christensen and James 2017, Blaisdell et al 2019, Coad et al 2020, McKay et al 2020).

At the same time, children and young people have taken advantage of this societal change and want a voice and to be part of the decision-making processes that govern their lives.

## Building resilience through listening to children and young people about their health preferences using arts-based methods

### Abstract

Many writers over the past 20 years have reported that in order to listen and act on children and young people's views, we need to use age and development-appropriate approaches. In research and in developing clinical services, papers have focused on arts-based methods, participation and more recently co-creation to name only a few (Christensen and James 2017, Blaisdell et al 2019). In this article, they will be termed exploratory approaches. While there have been advancements made in using different approaches, there is less critical evidence about children and young people with complex health needs and how that translates and has transformed healthcare services.

This article captures all that has gone before in terms of my work and draws specifically on how exploratory approaches have been used to effectively elicit the views of children and young people with complex health needs, irrespective of age, development, culture and complex health needs. I am including critical discussion not only of using exploratory approaches in real world settings, but how I believe they can be used to positively impact on children's resilience, development and well-being now and in the future.

This work is important in advancing the practice and science of nursing in this growing group as they develop (or survive) into adulthood. It builds their resilience and directly links to the sustainable development goal of good health and well-being. But more than that – it is about having their voices heard and listened to.

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### Introduction and background

Firstly, what is meant by exploratory approaches and how have they influenced my own work? When we explore what is meant by exploratory approaches, key words such as participatory, consultation, involvement and co-creation emerge in many papers. I had a background in both art and nursing, which influenced me a great deal.

Background aside, what is important to me is that I know as much as I can about the children, young people and families who will be involved in research and that throughout, I am respectful in capturing their voices.

According to Lansdown (2001), the founder and director of the Children's Rights Alliance for England, the levels of research range from 'consultative processes', where children have no control, and activities are adult initiated, led and managed, to full 'participatory processes', which involve collaboration with adults and inclusive sharing.

In my work, I have used these levels of research across a wide range of projects spanning over 20 years. How do I and others use such approaches? The list is extensive, and each must be considered in the context of the child or young person's age, development and abilities (Coad 2020, McKay et al 2020). Suggestions for arts-based approaches used with children and young people:

- » Arts and design-based: Examples could include drawing, colouring, painting, clay, making masks, pottery, 3D insulations, woodwork, collages, scrapbooking and an extensive list of arts-based materials.
- » Writing-based: Examples could include diaries, journals, poster-making, letter activities, storytelling, graffiti walls, symbols or post-its and use of symbolic language.
- » Film and digital-based: Examples could include the use of technology/mobile applications/on-line, photographic imagery and film making.
- » usual person-centred: Examples could include performance arts including role play, singing, dance or any form of human expression and movement.

However, there is nothing quite like seeing an example working in practice. For this article I am drawing on three case examples to show how exploratory participatory techniques have been used in different healthcare settings to ensure children and young people had a voice in shaping services.

- » **Example 1.** Using photographs in building young people's resilience around their views of community health care services (Coad 2007).

I have used photographs in several settings because they offered an interactive approach and also illuminated in-depth views and feelings, particularly in school-age children and young people (Coad 2012). In particular, photographs were used to evoke a response such as a viewpoint or memory, or to enable participants to talk about more difficult, abstract concepts. These are known as photo-elicitation techniques.

This project was conducted to explore what young people believed about health and what preferences they had for their community healthcare services. We used a two-phased project with young people aged 13 to 17 years in two locations in England ( $n=62$ ). While there were two locations, each area and group of young people had the same aims and a consistent approach. Access and recruitment included three secondary schools, one youth club, one child and adolescent mental health (CAMH) facility, one children's home and one health-based advisory group.

All of the young people had used healthcare services in the community at least once, and many of them multiple times. We ensured full communication was sent to all the families and that we obtained informed consent from each participant and, if they were aged under 16 years, also from the parents/guardians.

We invited the young people to be the photographers and planned two participatory workshops for each group. Workshop one included an introduction to the cameras, and ground rules for taking photographs, including safe behaviours. In workshop two, the young people were invited to display their photos and talk about what they were and why they had taken them. Analysis included the development of themes, which were initiated by the young people in workshop two. The report was sent to each location to check it represented what they had said.

We were able to draw out some important and novel findings using photographs in this way. The young people felt the process was different from normal school or college activities, and their energy was captivating. The process involved building their personal strategies for resilience and gave them choice as they engaged with one another, and perhaps also with the team in a way they might not have done using another method.

The photographs provided an opportunity to have group discussions around a visual prompt and was easier than interviewing them about their health beliefs and what they felt about community health services.

» **Example 2.** Building resilience through exploring young children's views in a developing a new hospital (Lambert et al 2014a, 2014b)

As part of an excellent team (Lambert et al 2014a, 2014b) in Ireland, I was invited to contribute to the development of an ongoing, multi-stakeholder consultation initiative conducted by the development board of a proposed new children's hHospital of Ireland.

The aim of the project was to explore school-aged children's (aged 5-8 years) perspectives of hospital environments so that the physical places and social spaces of the new hospital would be responsive to their needs. Led by Professor Veronica Lambert, we used arts-based exploratory approaches and actively engaged in three existing children's hospitals in Ireland to generate data.

We used verbal and visual participatory methods, such as semi-structured interviews, to which we added arts (pens, colouring, paper) and crafts (such as stick on fabric; shining materials) to stimulate the children to talk and interact. Young child participants (aged 5-8 years) were purposively recruited from inpatient, outpatient and emergency departments and consent was obtained from parents/carers and from all the children. Interviews and exploratory activities took place at the bedside or in small workshops.

Thematic analysis was employed, following which we were able to draw out novel and interesting findings. These included findings about personal space, physical environments and social spaces, which emphasised that young children have very strong views on what their hospitals should look and feel like. They could express this opinion once given the opportunity, using appropriate participatory mediums such as arts-based materials. They were resilient and expressed strong views on what home meant and how the hospital should reflect them as individuals in the context of their family.

» **Example 3.** Building resilience through engaging young people in developing cancer services.

Delivering cancer care for young people is highly specialised because it involves paediatric and adult settings and includes all cancer disease sub-specialties.

Coad, Thomas and the research team used appreciative inquiry (AI) to underpin the exploratory methods to learn what young people wanted from cancer services. AI is an emerging research methodology that has theoretical and philosophical underpinnings in action research, organisational learning, and organisational change (Cooperrider and Whitney 1999).

Novel approaches were used by the team to extract the information, including exploratory interviews, arts-based workshops, surveys and blogs. We obtained informed consent from each participant and collated data from two regional specialist units and 18 NHS general hospital trusts in England. A key aim was to ensure that young people with cancer were given a 'voice' in the design and delivery of their treatment, clinical care and pathways and management.

We used the innovative, arts-based methods in four half-day focus groups to capture their views, and we did this in different settings, including hospitals and social spaces, such as a bowling club and a local ski slope. Participants shared their views on what was working well, what could be better and the future of cancer services from their experience.

Data analysis included framework analysis where we agreed a framework for each set of data. Results were transformative in that young people asked for improved communication within and across services; improved use of information technology; improved psychological support specific to young people and improved facilities in outreach areas.

This was an important exploratory study for this group. We were informed hospitals had re-planned some services specifically around the outcomes of this work. Young people felt empowered to have a voice and at least two were later invited to be in expert stakeholder teams, thus offering knowledge to ensure holistic support and treatment for their individual needs. It was hugely rewarding to be part of building some of those skills.

### **Influence and impact**

Having set out three case exemplars, I will now reflect on using such approaches with children and young people in terms of influence and impact at the time, and over time. There are many writers who reflect on and discuss the influence of using well-designed exploratory approaches in building resilience, from planning to exiting the field or event.

I hope the case exemplars discussed here have highlighted a range of approaches but also provided new insights into children, young people and their family's views and experiences. The work has informed and influenced healthcare services on resilience and optimism, empathetic awareness and altruism in mutual support, and a need to reflect on the child's autonomy.

In terms of building resilience and a sense of well-being, feedback and reward are fundamental to the valuing the child or young person's contribution to the activity. However, any reward needs to be appropriate to the age/cognitive development and needs of the child. At the end of the activities I always give feedback to participants about what will happen to the work and how it will be used.

Further, using exploratory approaches can help children and young people communicate to you in ways they might not otherwise use. Some things might be too difficult to express. This is especially true if you are adult strangers to them. Using exploratory appropriate activities can help support positive psychological well-being, both of which are core components of resilience and well-being. In short, they are the real lived experience of that child or young person through their eyes.

### Current and future relevance

I have been using such approaches for over 20 years and they continue to have relevance. However, there are also some challenges that I faced that should be considered. Children and young people, like us all, are individuals and so a 'one size fits all' does not work. In the case exemplars in this paper, some children and young people had learning difficulties and/or mental health problems which could have affected their cognitive ability to develop abstract conversations and concepts when using direct interview techniques (Gibson et al 2010, Coad and Hambly 2011, Manning et al 2018, Coad et al 2020).

Using exploratory approaches meant that the tangible nature of the approach in most cases helped children and young people to articulate their ideas and gave them control. Some children and young people had life-limiting conditions and for some they said that their participation in the workshops was their legacy, their voice after their lives had ended. This was indeed powerful.

In all the teams, and cases here, we needed to be considerate of the type of approaches, the purpose for which we were using them and then be doubly prepared for all eventualities. We did this by clearly communicating across the teams, much preparation and practices beforehand and having a range of arts-based tools to hand which I call my Just-in-Case resources. But this needs to be balanced against available resources, including funding. In my experience, children and young people enjoy the spontaneity, but if the materials are old or do not appear well considered they will tell you, or even worse quickly lose interest. I always 'practice' using them with team members from start to finish, so we are fully prepared, comfortable and it all appears to 'naturally' flow.

This article referenced consent and assent in each of the case exemplars. Children or young people's consent (or assent) should be ascertained on an ongoing basis in all research as part of good ethical practice in research.

In terms of exploratory approaches, children and young people need to fully understand and agree before you start any activity. But once you start, the activity can be all consuming, energetic and a lot of fun. It builds rapport in a relatively short time, and resilience. I have found that the most difficult part is ending the activity because the children and young people and the team are often so engrossed. I always tell them at the start how long any activity will take and give them notice of the end at various time points.

Building resilience through using exploratory approaches with children and young people is innovative, fun, rewarding and an immense privilege. I have used these approaches for the past 20 years and have worked with some very talented nurses and health professionals. Many are cited in the reference list. Many are cited in the reference list. For me, it exploratory approaches can be the child or young person's platform in having a 'voice' so they had relevance 20 years ago and still does today.

Such learning has been so powerful and is important in advancing the practice and science of nursing in this group as they develop (or survive) into adulthood. It builds their resilience and directly links to the sustainable development goal of good health and well-being. But it is more than that; it is about hearing and listening to children and young people's voices directly, rather than through an adult acting as their representative.

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