

**Evidence from an expert witness for review question: How can the views of babies, children and young people be best represented by independent advocates?**

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<b>Contact information:</b>	
<b>Guideline title:</b>	Babies, children and young people's experience of healthcare
<b>Guideline Committee:</b>	Topic specific committee for above guideline
<b>Subject of expert testimony:</b>	Independent advocacy
<b>Evidence gaps or uncertainties:</b>	How can the views of babies, children and young people be best represented by independent advocates?
<p><b>Aim of review:</b> The Care Act 2014 and Mental Health Act 1983/2007 place a duty on UK councils to provide an independent advocate for a baby, child or young person who has substantial difficulties being involved in their own healthcare or who may not have an appropriate person to represent them. In addition to this, independent advocates may be used in healthcare situations where babies, children and young people cannot agree with their parents or healthcare professionals over a healthcare decision, or where it is not appropriate for their parents or carers to represent them.</p> <p>Independent advocates may be obtained from a range of providers, with a range of experiences and remits, and there may be variation in practice.</p> <p>The aim of this review is to determine how children and young people can be best represented by independent advocates. This may include ease of accessing independent advocacy services, and how the services can be helpful, supportive and useful.</p>	

**Evidence gap:** We conducted a systematic review of qualitative literature and found no evidence relating to babies, children or young people's experience of independent advocates.

We also conducted a grey literature review of national healthcare surveys for babies, children and young people and found no evidence relating to babies, children or young people's experience of independent advocates.

The committee are interested in the views of an independent advocate and reported testimony from children and young people who have used an independent advocate. The committee are particularly, but not exclusively, interested in the following themes:

- Access to records of healthcare staff discussions
- Adequate training for independent advocates including knowledge about developmentally-appropriate approaches
- Appeal to, or use of, advocacy groups
- Availability and accessibility of appropriate advocacy services
- Awareness of independent advocate services
- Encouraging and supporting self-advocacy when possible
- Sensitivity and responsiveness of independent advocate to feedback from child or young person
- Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support

### **Summary of testimony**

A true advocate will be independent of the organisation/health care setting they may be working in. Coming from an independent place allows a trusting relationship. When a child knows you are not part of the health care system, they are freer to share their thoughts, feelings and wishes.

My experience as an advocate spans 25 years. Advocacy organisations introduced a qualification by City and Guilds around 2011, prior to this advocacy did not have any formal training mechanisms. I became a qualified Independent Mental Health Advocate then. I worked with children for four years in a mental health unit in Colchester for 13 – 18-year olds, and used the Mental Health Act in my practice.

When a child is detained under the Mental Health Act it is the responsibility of the hospital to let them know they are entitled to an advocate if they wish. The advocacy provider must respond to a request for advocacy within a specific time frame agreed by the commissioning body for that contract. It is the responsibility of the advocacy provider to make this as accessible to the children as possible. Posters are placed on the wards and time for drop-ins to make the service available are also used.

Access to advocacy for children not detained under the Mental Health Act depends on the commissioning bodies of the counties, and the contracts that deliver advocacy to children.

In my relationships and meetings with each child I would explain who I was and what my role was, this would include an explanation about how I was independent from the staff and all other professionals. I would reassure them that they could share anything with me, and it would stay with me. I would include in this an explanation of the only situation where this confidence would be broken and who I would have to speak to. This laid the foundations of trust. It was important to ensure that they were aware of our independence of the hospital to enable them to feel they could talk freely knowing that we would not share anything unless they agreed, which also helped them.

The skills I used was knowledge of the Mental Health act and hospital processes. I would observe body language and actively listen to answers and paraphrase to gain knowledge of them and build an understanding. This would always be at their pace remaining calm.

The rights of patients detained under the act was also something I had to explain to them to ensure they were met. It is the responsibility of the advocacy provider to ensure an Independent Mental Health Advocate is available for all requests. Cover for advocacy absences is arranged by the advocacy provider. There is a requirement of the hospital to ensure all advocacy requests and referrals are made. The use of the Human Rights act was also something I held in mind if necessary. Often these rights are written down which can be harder to understand, it was important that they were explained in a way that the young person could relate to so I developed a method of explaining them in a way that was less frightening and easier to understand. I had resources I had researched that had been written for children that are detained. They explained the section appeal process and tribunals. Advocates use information they find to help clients understand their situation in a more accessible way.

A lot of the work I did was to support clients at Care and Support meetings (CPA's). These were meetings held with everyone to do with the care of the child in hospital. Often there were eight or more adults in the room and the child. An advocate can help a child feel they have someone on their side in the meeting, as they can be intimidated by the number of people and feel overwhelmed. My role was to help the child prepare for their meeting so they could have their say and ask questions about their treatment. I would meet with the child ahead of the meeting to go through the reports that had been written about them from the Dr, Therapist and school. I provided an independent view and an opportunity to understand the system and their rights. Parents would attend and support the child also; I would explain my role and independence. What viewing the reports ahead does is empower the child to know some of what will be discussed and to have their say. We would read them together and I would help them understand and prepare questions. I would empower them to do this themselves but if they were unsure, I would agree with them what I would say. They were always in control. This helped them connect with the process they were in and feel they had a say. I also made sure the professionals gave the child information in a way they could understand.

Another part of the work I did was around support at Dr reviews. I would spend time with the child before the meeting to help them work out what they wanted to say.

Talk about questions they might like to ask about their treatment. In the meetings I made sure the child understood what was being said and that they had an opportunity to have their say. Independent Mental Health Advocates have the right to view medical records. Patients and parents also have the right too. The data protection act sets the age of thirteen for children to have access to their records. There is an administrative process that is used to request these. Dr can have view if they feel it would be detrimental to the patient for them to see them.

Advocates are not decision makers, we are people that empower people including children to have their say over their situation, whatever that is. We help children to understand their rights and feel they have some control. We measure this through outcomes we add to the case before and after. In addition, we use feedback questionnaires for both children and stakeholders. The information is collated by the provider and shared anonymously.

When the child leaves the unit generally the Independent Mental Health Advocate role ends. It ends when the child comes off section and the entitlement is no longer there. If a child goes into adult services, and is detained and local, then the same service can continue if there is an advocacy contract in place to do this. If appropriate, signposting is provided to other advocacy providers. Children receiving support from Social Care could be eligible for other statutory advocacy.