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## Editorial

## Getting It Right First Time and Every Time; Re-Thinking Children's Rights when They Have a Clinical Procedure



Children who need a clinical procedure such as a medical examination, blood test, radiological investigation, vaccination or the administration of treatment can often feel worried and anxious about what will happen. Even minor procedures can be worrying for children who will often be entering an unfamiliar clinical environment full of new people, sights, smells, sounds and equipment (Krauss & Krauss, 2019). Those with long term conditions may experience anticipatory anxiety (Racine et al., 2016) as they may be revisiting a place where they have previously experienced pain, discomfort or medical trauma (Morton, 2015, 2020).

There are many health professionals (for example, nurses, doctors and play specialists) who work in a child-centred way and go above and beyond to provide children with positive interactions and experiences. However, there are also many occasions when children, especially younger children, are not prepared, are not listened to, are upset and are held against their will to complete a clinical procedure (Bray et al., 2016; Svendsen et al., 2018).

Over the past 20 years, in many countries, the terminology of 'holding' children for clinical procedures has changed from restraint to include more 'positive' or politically correct terms such as clinical holding, therapeutic holding and comfort positioning. However, regardless of what terminology is used, the practice of holding children for procedures continues to be a frequent, unchallenged and accepted part of paediatric practice (Bray et al., 2018; Brenner, 2007; Kirwan & Coyne, 2017; Leroy & ten Hoopen, 2012; Lombart et al., 2020; Svendsen et al., 2017). Although some procedures where children are held may be deemed clinically urgent or an emergency, many procedures in which forceful holding is used, such as administering eye drops or removing a dressing are not (Bray et al., 2016). The use of procedural holding is not routinely documented or 'flagged' in health records or medical notes and a purposeful discussion or debrief after a child's procedural event is not standard practice (Bray et al., 2016). Often there are no structures in place to support health professionals to critically reflect on these procedural encounters or opportunities to ask themselves questions such as, what could have been done differently or what impact will that experience have on that child? This lack of debrief and documentation can result in a missed opportunity for a child's individual procedural needs and preferences to inform future procedures and treatment.

As adults and professionals, the overruling of children's expressed calls to 'stop' or 'wait' may have previously been justified by arguments such as 'they are too young to sit still on their own', 'they will get more upset if we stop' or that 'they will not remember'. Even health professionals who report being aware of the need to prepare and support a child through a procedure can be challenged when faced by a reluctant child, an anxious parent, a busy department and a procedure to be

completed and can "adopt the Nike approach and 'just do it'" (Bray, Appleton, & Sharpe, 2019a). This approach may even be supported by parents who can feel pressured due to time and concerns for their child and suggest that 'it is best to get it done quickly' (Bray et al., 2016; Bray, Appleton, & Sharpe, 2019a). Yet, whilst the completion of the procedure may seemingly serve a child's best interests, there is an emerging body of literature that considers the longer-term harmful impact upon the child of sub-optimal procedural experiences (Racine et al., 2016; Svendsen et al., 2018). In acknowledging the potential for harm to a child as a result of unsupported and distressing experiences, there is a need to appreciate that every interaction a child has with a health professional is important whether it is their first contact with health services or if they have had multiple procedures. Each and every interaction or procedure can shape every subsequent procedural expectation and experience. Children do remember poor procedural experiences for a long time, especially those where they have felt fear or threat during a procedure (Forsner et al., 2009) and when procedures 'do not go well', this experience can taint all future interactions with health services and professionals. Further, not being listened to can heighten feelings of vulnerability and powerlessness which can increase risk of medical trauma (Morton, 2020). Children look to their main caregivers for support, comfort and feelings of safety, especially during adversity. Therefore, when parents are asked to hold their child against their child's wishes this may further exacerbate a trauma response (Morton, 2020). Parents can also carry this trauma forward (Brenner, 2013; Svendsen et al., 2018).

There is a considerable body of research that has accumulated over a number of years showing how to support children's positive procedural experiences and how to engage with and respond to a child who is upset or reluctant to undergo a procedure. Despite this, practice has been slow to change and is inconsistent within and across settings. Despite the known benefits of pain relief, distraction and preparation on children's procedural journeys, many children are poorly prepared and informed about what will happen and what they may feel during and after procedures (Bray et al., 2021; Bray, Ford, et al., 2019) and are inadequately supported to cope throughout their procedure (Bray, Appleton, & Sharpe, 2019c; Jaaniste et al., 2007).

Part of the problem for many professionals is a sense of uncertainty during a procedure of when what is perceived to be a supportive clinical hold, 'tips' to become restraint. Just as children remember procedures that did not go well, health professionals also report an undercurrent of discomfort and negative impacts of being involved in restraining a child against their will (Lombart et al., 2020; Svendsen et al., 2018). Yet, this practice persists and happens frequently. Clinical holding is an everyday practice that occurs in many healthcare settings across the world and highlights how easily children's rights are being

overruled by the priorities and agendas of adults and health institutions (EACH, 2016; Sahlberg et al., 2020). This overshadowing of children's rights is at the heart of the iSupport collaboration that started from the question; What would procedural practice look like if children's rights were acknowledged and prioritised in *all* procedural interactions?

The iSupport collaboration (International collaborative standards to support paediatric patients during clinical procedures; reducing harm and establishing trust), is an international group of over fifty members including; health professionals, academics, young people, parents, child rights specialists, adults with lifelong experience of medical procedures, psychologists and youth workers and patient and public involvement experts from around the world (Australia, Brazil, Cambodia, Canada, Indonesia, Ireland, Jordan, Korea, Malawi, Netherlands, New Zealand, Spain, South Africa, Sweden, United Kingdom and the United States of America). Throughout 2021 the members adopted a rapid consensus method approach aligned to the World Health Organisation (WHO, 2014) method of group decision-making as a cognitive, collaborative process to develop the 'Rights-based standards for children undergoing clinical procedures'. The collaborative development of the standards involved ongoing and extensive consultation and critical challenges from established youth and parent forums and through an international online survey gaining feedback from health professionals, parents/carers and children and young people.

The core of the iSupport work was to define and promote supportive holding as an approach to prioritise children's rights and well-being and challenge the use of restraining holds for clinical procedures. Throughout the collaborative process, children and parents challenged iSupport to 'think wider than just the holding' and to consider 'the whole' of a child's procedural experience; the before, during and after. The children and parents also motivated and encouraged the collaboration to co-create versions of the rights-based standards for children and their parent(s)/carers. They also were the stimulus for the creation of a preparation sheet to help children and their parents plan, prepare and have a say in what would support them to have a positive procedural experience.

The iSupport standards are based on internationally agreed children's rights set out by the United Nations Convention on the Rights of the Child (UNCRC) (UN, 1989). The UNCRC is the most widely and rapidly ratified human rights treaty in history with 196 countries around the world, with the notable exception of the United States of America, having ratified it all.

The iSupport standards propose an approach where the rights of all children, aged up to 18 years of age, undergoing a clinical procedure are foregrounded to minimise their anxiety, distress and harm. The standards aim to support health professionals, health or care workers and parent/carers to advocate for children's rights and positive procedural experiences grounded in a psychologically informed approach to healthcare provision (Morton, 2020). Ultimately, an outcome of the standards is for children to know and be able to action their own rights when they are having a clinical procedure. The standards are purposefully broad to enable adaptation in accordance with a child's individual needs, developmental capabilities and preferences, cultural practices, regulations, laws and resources within a particular country or clinical situation. The standards are constructed around seven key elements of procedural practice, each of which is supported with specific detail and four case studies to show what the standards could 'look like' when applied in practice:

1. A child has the right to be cared for by professionals who have the appropriate knowledge and skills to support their physical, emotional and psychological well-being and rights before, during and after their procedure;
2. A child has the right to be communicated with in a way which supports them to express (verbally or behaviourally) their views and for these views to be listened to, taken seriously and acted upon;

3. A child has the right to be provided with meaningful, individualised and easy to understand information to help them prepare and develop skills to help them cope with their procedure;
4. A child has the right to be supported to make procedural choices and decisions and for these choices to be acted upon to help them gain some control over their procedure;
5. A child has the right for their short and long term best interests and well-being to be a priority in all procedural decisions;
6. A child has the right to be positioned for a procedure in a supportive hold (if needed) and should not be held against their will; and.
7. A child's health record shall include clear documentation of a procedure and any use of restraining holds.

The standards advocate that if a child needs to be held for a procedure, their rights and interests are best served by the use of supportive holding. Supportive holding occurs when a child is provided with meaningful information about their procedure, offered choices about their procedure and positioning and knows that when they say or show 'stop' the adults around them will listen and act on their wishes. The standards recognise that restraining holds may be necessary to provide life-saving or emergency care for children but sets this in the context that holding a child against their will can be traumatic and have far-reaching consequences.

The members of the iSupport collaborative believe that health professionals and institutions need to be brave and acknowledge when children's rights are being overruled or diminished in relation to clinical procedures and to take action to remedy this in the future. At every interaction with a child who is undergoing a procedure, health professionals need to ask themselves key questions; Am I prioritising the child's short and long-term best interests and rights in our decisions and actions? In short, is this the best we can do for this child?

The 'Rights-based standards for children undergoing clinical procedures' are currently open for consultation on the following webpage: <https://www.edgehill.ac.uk/health/research/rights-based-standards-for-children-undergoing-clinical-procedures/>.

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