

## What's the Evidence?

# Reducing Distress & Improving Cooperation with Invasive Medical Procedures for Children with Neurodisability

- Evidence suggests that children require individualised approaches to reduce distress and improve their cooperation with invasive medical procedures.
- Research is needed to identify effective strategies to support children who have had a previous traumatic experience of invasive medical procedures.
- How professionals interpret the reasons for challenging behaviour is crucial. Strategies that parents use to manage children's behaviour can inform interventions to reduce distress.
- Introducing standard protocols for invasive procedures and sharing them with families empowers parents and professionals to know what good practice looks like.
- Wider changes to NHS policies are likely to improve children's experience of health care, but research is needed to see if they are implemented and effective.

### What were we asked?

A parent asked which interventions are effective for children with neurodisability to reduce distress and improve cooperation with invasive medical procedures carried out in hospital by health professionals.

Such procedures include taking blood, placement of cannula into veins (to take samples or administer fluids or drugs), and insertion of tubes into the nose or mouth to aid feeding. These procedures can be particularly challenging for children who have had a previous bad experience.

Neurodisability describes a group of long-term conditions that create functional limitations with movement, cognition, hearing and vision, communication, emotion and behaviour.<sup>1</sup>

A specific diagnosis may not be identified but conditions include autism, cerebral palsy, Down syndrome and many others.

### What did we do?

We searched a range of academic health databases (Cochrane, TRIP, PubMed, NICE, NHS Evidence). As we were looking for psychological outcomes, we also searched PsycINFO. We used a mix of search terms relating to clinical or medical procedures, adherence or cooperation and children generally. Then we looked specifically for studies relating to children with neurodisability.

### What did we find?

#### *What is the need?*

Children have described invasive medical procedures and anticipatory anxiety about them as the most distressing aspect of being in hospital.<sup>2</sup>

Children with neurodisability are more likely to be admitted to hospital, and they may experience a greater number of invasive medical procedures than their typically developing peers.<sup>3</sup>

Children with neurodisability may face particular challenges as an inpatient. Some may be unable to

move independently, be visually impaired, or unable to communicate verbally. Others may find changes in routine or unfamiliar settings difficult.

Anxiety about invasive medical procedures may manifest as distress, challenging behaviour or a lack of cooperation.<sup>3</sup> Children with developmental delay and/or autism have also been found to have higher levels of anxiety relating to medical procedures than other similar aged children.<sup>4,5</sup>

Reducing distress and improving cooperation is important as it can (i) reduce anxiety for the child, family and hospital staff (ii) improve safety of the procedure and recovery times (iii) enhance trust between families and health professionals.<sup>6</sup>

Sometimes it is not possible to avoid discomfort but poor practice that causes avoidable discomfort is likely to adversely affect future care.

### ***What are interventions to reduce distress and improve cooperation?***

Interventions are things that are done purposefully to achieve some specified outcome.

Medical interventions include drugs to reduce pain and anaesthetic creams applied to the skin to reduce sensitivity.

Psychological interventions aim to help individuals develop and use coping skills to manage distress. They can include:

- Distraction or diverting attention (e.g. watching a movie, singing).
- Hypnosis.
- Relaxation techniques such as breathing exercises.
- Positive reinforcement e.g. demonstrating to a child how a task can be completed successfully (called modelling), using positive statements.
- Behaviour preparation such as rehearsal using dolls/puppets, taking a tour of the hospital ward, using consequence-based strategies such as giving tokens for cooperation.
- Play or music therapy.

- Social stories/picture schedules to explain situations more simply, to increase understanding and/or establish a routine.

In practice, interventions are often a combination of these strategies and are provided by families and/or hospital staff, or by specialists. These specialists include [learning disability liaison nurses / health play specialists](#) (UK) or [child life specialists](#) (USA).

In addition to these medical and psychological interventions, changes to hospital policies and practices have the potential to reduce distress and improve cooperation with medical procedures. For example, in the UK:

- The NHS has recognised that children's positive experience of health care is an important health outcome in itself.<sup>7</sup>
- The introduction of the Equality Act 2010 requires 'reasonable adjustments' to be made for disabled people. This includes offering first or last appointment to avoid wait times and making information accessible.

### ***Which interventions work?***

- Topical local anaesthetic creams and drugs to reduce pain have shown to be effective for common medical procedures and to be well tolerated by children.<sup>8,9</sup> Although some children still report discomfort from procedures.<sup>10</sup>
- A lot of research has evaluated psychological interventions to reduce distress for children undergoing medical procedures. [Systematic reviews](#) of studies suggest that distraction,<sup>10,11,12</sup> hypnosis,<sup>11</sup> and music<sup>13</sup> can be effective to reduce children's distress.
- Evidence from these reviews suggests that finding an effective approach requires identifying individual preferences and learning about a child's temperament.<sup>10</sup> Then, adopting an appropriate customised intervention.<sup>13</sup>

- The effectiveness of psychological interventions depends on the child's attention capacity,<sup>12</sup> and developmental stage. Younger children may respond better with behavioural strategies and older children to more cognitive strategies.<sup>11</sup> However, this may not be the case for children with neurodisability.
- The World Health Organisation recommends adhering to a strict limit to the number of attempts to draw blood from a child.<sup>14</sup> While this 'three strikes' approach can be found in some hospitals<sup>15</sup>, there is no standardised NHS protocol.

### ***What works for children with neurodisability?***

- The evidence is currently limited. We found a few studies that examine interventions to reduce distress and improve cooperation with medical procedures for children with neurodisability. We also found a few studies which can inform the context in which the intervention takes place.
- Medical interventions can take 30-45 minutes to take effect and therefore need to be planned in advance. Some children find the sensation of applying cream distressing,<sup>4</sup> and the use of Entonox gas requires wearing a mask.<sup>8</sup>
- We found small case studies which report techniques to prepare children with autism<sup>16,17</sup> or ADHD<sup>18</sup> for a medical procedure. While describing the interventions that worked for the individual children concerned, these studies do not tell us what will necessarily be effective for other children.
- A study involving 62 children aged 3-8 years with autism examined the cooperation of children with autism having medical procedures as part of a research study. They reported that children with high-functioning autism tended to cooperate more with modelling, distraction with conversation, and rewards for cooperating. Children with learning disabilities often required rewards for small steps, distraction with singing and safe-holding techniques.<sup>19</sup>
- Two studies have looked at the use of 'coping kits'. The first study of 58 families found that a coping kit (including a social story individualized for the child, instructions and equipment to rehearse taking blood at home) meant children were five times more likely to cooperate.<sup>4</sup>
- In the second study, nurses' views of coping kits were surveyed. The kits included communication cards, social script and distraction items. 19 out of 24 nurses perceived the kits to be effective for calming and increasing cooperation during procedures for children with developmental disorders.<sup>20</sup>
- In a small study involving two focus groups, strategies to prevent challenging behaviour of children with autism differed between mothers and health professionals due to different interpretations of the behaviour. Health professionals attributed challenging behaviour to self-stimulation and aggression while mothers attributed it to self-calming, hyperactivity or communicating frustration.<sup>21</sup>
- We found no evidence for interventions to reduce distress or improve cooperation for children who have had a traumatic prior experience of a medical procedure.
- In a review of research on phobic avoidance (going to great lengths to avoid something which is overwhelming frightening), the authors suggest that exposure to the feared stimulus and reinforcement for appropriate behaviours are important strategies for individuals with intellectual disability.<sup>22</sup>
- As a result of the policy changes in the NHS, hospitals have introduced some new processes which have the potential to reduce distress in hospital generally. These include checklists which explore ability and communication of each child,<sup>23</sup> training for hospital staff,<sup>24</sup> and use of hospital passports.<sup>25</sup>

- A hospital audit of how 59 children with autism were managed when admitted for medical and surgical procedures found the following improved cooperation: planning in advance (particularly early communication with families), flexible admission processes with minimal waiting, and having a quiet room to reduce noise, movement and light.<sup>26</sup>

#### **Our recommendations:**

- The evidence suggests that interventions to reduce distress and improve cooperation with invasive medical procedures are tailored to individual children.
- This individualisation means interventions vary widely and are not described consistently. It is therefore difficult for research to recommend which approaches will be effective for children. Health professionals and families need to be aware of the different strategies available and to work together to create acceptable individualised approaches.
- Coping kits offer promise as a strategy for children with neurodisability as they focus on child's individual ability and interests rather than expectations of behaviour based on age.
- With such little evidence on interventions for children with neurodisability, further research into the different meanings for behaviours and the strategies that parents use to improve children's cooperation and reduce distress could be used to inform hospital practices.
- Research is also needed to find effective interventions for children who have had a traumatic experience.
- Standardised protocols (such as max three attempts to try a procedure) could be introduced and shared with families. This would empower everyone to know the steps involved and what good practice looks like.
- The wider changes in NHS policies are likely to improve care, but require auditing to show they

are implemented, and evaluated to see if effective.

- Families should ask about local arrangements prior to invasive medical procedures or admission to hospital. Please see the signposting section for further resources.

#### **Signposting:**

- WellChild provide support and services in hospitals and homes for families caring for a child with a long-term or complex health condition:  
<https://www.wellchild.org.uk/families-area/>
- Me First website provides resources for improving communication between children and health care professionals:  
<http://www.mefirst.org.uk/>
- Monkey Wellbeing provides resources to help children understand hospital admission:  
<https://www.monkeywellbeing.com/>
- Contact a Family have examples of how parents have worked with hospitals to improve care:  
<http://www.cafamily.org.uk/what-we-do/parent-carer-participation/improving-health-services/>
- Autism Speaks has guides for parents and health workers on strategies to make medical appointments go more smoothly:  
<https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/blood-draw-toolkits>

We would like to hear your feedback on this summary – please email [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk) if you have any comments or questions.

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25. NHS Hospital Passport – going into hospital with a learning disability. See: [www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Going-into-hospital-with-learning-disability.aspx](http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Going-into-hospital-with-learning-disability.aspx)
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Note: This information is produced by PenCRU researchers and reviewed by external experts. The views expressed are those of PenCRU at the University of Exeter Medical School and do not represent the views of the Cerebra charity, or any other parties mentioned. We strongly recommend seeking medical advice before undertaking any treatments/therapies.