

A. CHILDREN'S RIGHTS IMPACT ASSESSMENT

The Rights of Children and Young Persons (Wales) Measure 2011 places a duty on the Welsh Ministers to pay due regard to the [United Nations Convention on the Rights of the Child \(UNCRC\) and its Optional Protocols](#) when exercising any of their functions.

1. Policy objectives

- What decision are you impact assessing?
The decision to implement a statutory organisational duty of candour on NHS bodies in Wales. The duty applies in respect of health care provided to children.

2. Gathering evidence and engaging with children and young People

There have been UK inquiries and reports calling for the introduction of an organisational duty of candour,^{1 2 3 4} those which specifically relate to children and young people are as follows:

- In his public inquiry report into children's heart surgery at the Bristol Royal Infirmary, Kennedy, I¹ (2001) stated "We consider the need for a culture of openness and honesty within the hospital as a whole, and we argue for a duty of candour towards patients when things go wrong or concerns are raised."
- An independent investigation commissioned by the First Minister of Wales into

¹ Kennedy, I. The Bristol Royal infirmary inquiry. Learning from Bristol - The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995 [Internet]. Crown; 2001. Available from: https://webarchive.nationalarchives.gov.uk/ukgwa/20090811143822/http://www.bristol-inquiry.org.uk/final_report/the_report.pdf

² Donaldson, L. Making Amends - A consultation paper setting out proposals for reforming the approach to clinical negligence in the NHS [Internet]. Department of Health Publications; 2003. Available from: https://webarchive.nationalarchives.gov.uk/20120809195448/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4060945.pdf

³ Francis, R and others. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry [Internet]. Staffordshire NHS Foundation Trust; 2013. Available from: <https://www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry>

⁴ Evans, K. "Using the Gift of Complaints" - A REVIEW OF CONCERNS (COMPLAINTS) HANDLING IN NHS WALES (2014) Welsh Government

the circumstances of the death of ten-year-old Robert Powell⁵, made a number of recommendations relating to candour under the theme of “*better communication and involvement with patients and their families*” when things go wrong. The charity, Action against Medical Accidents (AvMA) used the Robbie Powell case to campaign for a statutory organisational duty of candour in the UK, “Robbies Law”⁶

Calls for the introduction of an organisational duty of candour in Wales have been made in the following reports:

- The Evans Review of complaint handling in NHS Wales “Using the Gift of Complaints”**Error! Bookmark not defined.**⁴ made a specific recommendation, recommendation 49, for a new “*legal duty of candour*”.
- Ruth Marks’ review of Healthcare Inspectorate Wales (HIW)⁷ published in November 2014 also called for an explicit duty of candour to be introduced in Wales.

A duty of candour was introduced in Scotland in 2018. Inkster, T and Cuddihy, J⁸ (2022) describe clinician and patient experience of a duty of candour and communication on a children’s ward following a significant infection control incident. They state, “The significant learning from this incident is that patients and families should be communicated to in a timely, open, transparent fashion, with frequent updates.”

One of the key points noted by Glasper, E. A⁹ (2018) in his paper about the Bawa-Garba and Amoro case is that “The Royal College of Paediatrics and Child Health believes that a no-blame culture in which the focus is on learning from errors and open and frank dialogue with families affected is the best route to achieve improved

⁵ Jones, N. THE ROBERT POWELL INVESTIGATION - A REPORT TO THE WELSH MINISTERS [Internet]. 2012. Available from: <https://webarchive.nationalarchives.gov.uk/20121105061144/http://wales.gov.uk/topics/health/publications/health/reports/powell/;jsessionid=7715EFC40A4DCD5B5DD28E35A550C584?status=gxbqamrvi&lang=en>

⁶ Walsh, P. (2020) The Duty of Candour – where are we now? [The Introduction of the Duty of Candour | PSA \(professionalstandards.org.uk\)](https://www.professionalstandards.org.uk) Professional Standards Authority for Health & Social Care, Insights into Regulation, Blog, 30 Jan 2020

⁷ Marks, R. An Independent Review of the work of Healthcare Inspectorate Wales. The way ahead: to become an inspection and improvement body [Internet]. 2014.

⁸ Inkster, T. and Cuddihy, J. [Duty of candour and communication during an infection control incident in a paediatric ward of a Scottish hospital: how can we do better? | Journal of Medical Ethics \(bmj.com\)](https://www.bmj.com/content/366/n8157/e000000) (2022) Vol 48, Issue 3.

⁹ Glasper, E.A. [Full article: Promoting Honesty and Truthfulness When Things Go Wrong During Care Delivery for Sick Children \(tandfonline.com\)](https://www.tandfonline.com) (2018) *Comprehensive Child and Adolescent Nursing*. Vol.41(2), 2018, pp. 83-88.

patient care and safety.”

The above research indicates the importance of an organisational duty of candour for all including children and young people.

Although the duty of candour applies to all, regardless of age, when considering the impact of the duty on different groups of children and young people, it is considered the positive impact will be greater on those who are likely to have greater interaction with healthcare services ie children or young people who have experienced adverse childhood experiences (ACEs), live in poverty, have a disability or permanent health condition etc.

Evidence demonstrates Romany Gypsies, Irish Travellers, Refugees and Asylum Seekers¹⁰ experience poor access to healthcare and poor health outcomes when compared to the settled population of Wales. This would apply to children and young people in these groups. The lack of a permanent address, poor understanding and lack of skill when communicating their own health needs, poor literacy, and a cultural reluctance to engage with services can all pose different but distinct challenges to delivering services to individuals, including children and young people within these groups. They or their parents may delay seeking treatment until their condition has worsened which could lead to their condition requiring more complex treatment and an increase in the likelihood of more than minimal harm occurring. Being open and honest with children and young people and their parents, if appropriate, will help to improve their confidence in the healthcare system which in turn, may help in the long term to break the cycle of distrust with these groups.

Representatives from the office of the Children’s Commissioner for Wales and the Future Generations Commissioner were invited to the four workshops held with stakeholders in November/December 2021 to participate in initial preparatory discussions on the duty.

Children in Wales were contacted to obtain the views of children and young people on the duty of candour. A small focus group was held with four young people aged 14-20 and a discussion was held on some aspects of the duty. Children in Wales felt that this is a complex subject for children and young people to fully understand. The focus group discussed issues such as whether children and young people who have been assessed as having Gillick competence should be able to make a complaint, what needs to be in place to help a child or young person to complain and how children and young people may be informed of their right to make a complaint.

The group felt that even though a child or young person may be Gillick competent an adult should take the lead in helping them to understand the details and implications of the complaint. Some of the group felt that an advocate would help to speak up for the child or young person and others stressed the need for legal provision to protect

¹⁰ McFadden, A et al (2019) [Gypsy, Roma and Traveller access to and engagement with health services: a systematic review | European Journal of Public Health | Oxford Academic \(oup.com\)](#) European Journal of Public Health, Vol 28, issue 1

the complainant. The group agreed that a health professional should inform them of their right to make a complaint and suggested the information could be included on NHS websites, information leaflets and videos. It was acknowledged that not everyone will want to have a face-to-face meeting and may prefer contact by email. In discussing the levels of harm, the group felt the threshold should be lower and the process wasn't clear if there is less harm. A definite need for support for the person was expressed.

This feedback will be used when developing the candour awareness leaflet for children and young people. Children in Wales have agreed a more focussed approach is needed to help young people understand the subject and they will be asked to provide structured feedback to assist in the development of the awareness leaflet. The children and young people section of the candour guidance has been considered by the Children in Wales multi-disciplinary staff, including the designated safeguarding lead, communications and young people's staff group. It was also shared with parents/carers/children and young people.

3. Analysing the evidence and assessing the impact

It is not considered the duty will have a negative impact on the lives of children and young people.

The notification process under the duty of candour will ensure that as soon as the responsible body becomes aware the duty has been triggered, they will inform the child or young person (or someone acting on their behalf). The child or young person will receive an apology, information and support if required. This approach supports and promotes article 13 of the Convention (*"Article 13 - Children have the right to get and to share information as long as the information is not damaging to them or to others."*) as set out in the below table.

The approach also positively supports Articles 1, 2, 3, 4, 12, 23 and 24:

Article 1: Everyone under 18 years of age has all the rights of this Convention.

Article 2: The convention applies to everyone whatever their race, religion, abilities, whatever they think or say and whatever type of family they come from.

Article 3: All organisations concerned with children should work towards what is best for each child.

Article 4: Governments have a responsibility to take all available measures to make sure children's rights are respected, protected and fulfilled.

Article 12: Children have the right to say what they think should happen, when adults are making decisions that affect them, and to have their opinions taken into account.

Article 23: Children who have any kind of disability should have special care and support so that they can lead full and independent lives.

Article 24: Children have the right to good quality health care, to clean water and good food.

How does your proposal enhance or challenge children’s rights, as stipulated by the UNCRC articles and its Optional Protocols? Please refer to the [articles](#) to see which ones apply to your own policy.

| UNCRC Articles or Optional Protocol | Enhances (X) | Challenges (X) | Explanation |
|-------------------------------------|--------------|----------------|--|
| Articles 1, 2, 3, 4, 12, | X | | The duty strengthens the requirement to be open and honest with a child, or someone acting on their behalf, if something goes wrong. |
| Article 13 | X | | Ensuring that a child, or someone acting on the child’s behalf and representing their interests, will be informed if something goes wrong with the child’s care and will be kept up to date with the results of the investigation into the child’s care and treatment. This supports Article 13. |
| Article 23 | X | | The duty applies to all children but is likely have a more positive impact on those who have greater interaction with healthcare services in support of Article 23. |
| Article 24 | X | | In the long term, learning from incidents will improve the quality of healthcare, including for children and young people, in support of article 24. |

The following EU Citizen Right relates to young people up to the age of 18 in accordance with the Citizens Rights Agreements implemented by the European Union (Withdrawal Agreement) Act 2020.

iv) **Co-ordination of Social Security Systems** - these include benefits, access to education, housing and access to healthcare.

4. Ministerial advice and decision

- How will your analysis of these impacts inform your ministerial advice?

The Ministerial advice is that the duty of candour applies to all, regardless of age. When considering the impact of the duty on different groups of children and young people, it is considered the positive impact will be greater on those who are likely to have greater interaction with healthcare services.

5. Communicating with Children and Young People

Children and young people groups from Children in Wales will be informed of the launch of the duty of candour via Children in Wales. The Children's Commissioner for Wales will be informed of the launch.

A duty of candour awareness leaflet for children and young people will be developed to explain the process when the duty is triggered for a child or young person. Feedback from the Children in Wales children and young people focus group will be taken into consideration in the development of the leaflet as outlined above. For example, young people felt that an adult should help them to understand how to make a complaint and it was suggested that an advocate may be able to aid.

Young people will provide structured feedback when the leaflet is being developed to ensure it explains the duty in a way children and young people understand.

An electronic version of the leaflet will be sent to Children in Wales and the Children's Commissioner to add to their websites. It will be available electronically via the Welsh Government and NHS body websites. Copies will be available in hard copy from NHS bodies.

6. Monitoring and Review

The CRIA will be monitored according to the implementation of the duty by NHS bodies. A working group has been set up in Welsh Risk Pool comprising of NHS body representatives. They will be asked to monitor and report to Welsh Government any impact of the duty on children and young people. **An evaluation of the Health and Social Care (Quality and Engagement) (Wales) Act 2020** will report annually over a 5-year timeframe.