

## **By embracing challenge, politicians can reap the benefits in better policy and public services**

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When things are going well, the relationship between charities and government is easy. Everybody loves a nice, cuddly charity. We do good work and it's mutually beneficial for governments to be associated with us – kudos, profile, and photo opportunities all round!

If only everything in society was going well all of the time. Sometimes, things are more difficult. For some charities, it seems to be difficult much of the time. How should we – charities, government, and civil society as a whole – respond to the challenges that inevitably arise?

The National Deaf Children's Society was representing a family in the Lothian area of Scotland who thought that their child's deafness had been missed by the NHS. We supported them to seek a re-assessment and then to complain, first to the health board and then to the Scottish Ombudsman. Eventually, in late 2021, it was confirmed that NHS Lothian had been systematically failing to identify deafness in babies born in the area and that this derived from poor professional practice, lack of scientific and managerial oversight, and the absence of an independent quality assurance system.

This was devastating news. The National Deaf Children's Society was instrumental in the introduction of newborn hearing screening, knowing the importance of early identification as the catalyst for prompt support from both families and statutory services. Deaf babies identified in the first months of life will receive amplification devices such as hearing aids/cochlear implants and/or sign language support, as appropriate to the families' needs and aspirations for their child. Families will be advised and supported in bringing their children up in a rich language and communication environment. Deaf children who are not identified may experience delays in developing language and – without support – may not develop the communication capability that they will need for the rest of their lives. It's hard to exaggerate the importance to deaf babies and their families of getting this right.

And then things got worse. We asked for a data review of the position in England and five more NHS sites were identified as having the very same issues as NHS Lothian.

On one level, an important part of our job had been done. The child in question had been identified as deaf and was receiving support. NHS Lothian had apologised, redeployed their Head of Audiology, and committed to improve. Lothian families whose children had been failed could now be supported. Other toddlers could be called back for re-assessment and the National Health Service could pick up the lessons and move forwards.

If only it was so easy! NHS Trusts (and Boards in Scotland) have multiple challenges, some of them even bigger than resolving the damage being done to deaf babies' lives. We had to ask ourselves: could we be confident that the NHS would sort this mess out?

Or should we do everything in our power to ensure that no deaf baby, anywhere in Scotland or England, would have their deafness missed and their futures blighted by the lack of consequent support? In short, we had to determine what was in the ultimate interests of deaf children and their families – as our beneficiaries and our members. And we were supported in this by our trustees – the majority being parents of deaf children themselves – whose absolute commitment was not to allow other deaf babies to fall by the wayside.

It's not always easy or comfortable to speak truth to power, to hold the powerful to account. Critical friendship can be interpreted as more criticism than friendliness. When you embarrass people who made mistakes, they tend not to thank you. Often confidentiality is raised as a blocker and – at least in the short-term – relationships are damaged. The senior official who welcomes challenge as a necessary means to improve is, sadly, a rare beast.

But charity law and regulation, and successive compacts between government and civil society, insist that charities must remain independent. We need to be simultaneously ally and antagonist; collaborator and thorn in the side; cheerleader and critic. We would always praise a government minister or NHS official for doing the right thing. If they agree with us, we say thank you – and do so publicly. So, when mistakes are made, we should feel able to go public too.

In Lothian, we issued a [press statement](#) expressing our horror at the damage done to deaf babies' lives. We were invited onto the television news and we called on the Scottish Government to step in, to give families an assurance that such catastrophic errors would never happen again. We asked for a formal review of audiology services in Scotland and we met the Cabinet Secretary to press our case. We were lucky at that stage – Humza Yousaf MSP was horrified by what had happened and he ordered a full and independent review.

In England, the position was more difficult. The English NHS benefits from much greater devolution than in Scotland. UK Ministers simply lack the wherewithal to tell NHS Trusts what to do. Were we expected to write politely seeking meetings with 200 or so NHS trusts? Campaigning is more efficient and more effective. We challenged NHS England. We encouraged the families complaining to us to tell their stories to an investigative journalist. Shaun Lintern of the Sunday Times is rightly regarded as a strong and passionate voice on behalf of patient safety. The story he wrote was hugely influential. And NHS England kicked into gear with a vengeance.

With improvement processes in place each side of the border, we couldn't relax. But the appropriate tactics changed. We had won the reviews that we wanted – the task now was to help them get to the right answers. So, we accepted seats on each review body. We contributed the experience of families and of their deaf children. We brought our evidence and expertise about what good services look like. We debated what was desirable and what was possible, and we contributed to a healthy consensus.

Has our approach – being first a critical then a constructive friend – worked? Last August, NHS England issued vigorous and firm advice to its local systems, the Integrated Care Boards. Just before Christmas, the new Scottish Minister accepted all the findings of the independent review. We are not in any way resting on our laurels, but we're pleased with the progress.

The analogy, I think, is that of the insider-outsider spectrum. Charities need to be able to move along the spectrum, challenging from outside where necessary, but on the inside where possible, in what their trustees believe is the interests of their beneficiaries. We sometimes have to create the visibility of a problem in order to be able to help governments solve it.

There are risks in this approach – potentially the noisiest challengers could get their problems resolved first. But the mitigation is that all charities who wish to, can campaign – using all the tools that will help their beneficiaries – and that they can learn to do it well – so, as a sector, we need to ensure that training and advice is both affordable and accessible.

It's right and proper that we work with and stand up for our beneficiaries, that we pursue the objectives in our charitable constitutions. It may not make us popular every day and can undoubtedly be an uncomfortable dynamic for decision-makers to embrace. But, in the long run, we'll help create the better world that we all want to see. And we'll sleep better at night too!

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