

Forums working effectively with campaign groups – Herts Parent Carer Involvement and the Nascot Lawn Campaign

The forum in Hertfordshire (Herts Parent Carer Involvement) worked with a parent-led protest group who aimed to save Nascot Lawn, an overnight short breaks facility for children with complex health needs. The forum also worked with strategic partners to improve processes around consultation, evidence gathering and strategic planning while maintaining their role as the collective voice for parents of children with additional needs.

The Issue

In Carers Week June 2017 one of the two CCGs (Clinical Commissioning Groups) in Hertfordshire announced they would be closing Nascot Lawn (an overnight respite centre for families of children with complex health needs). This caused huge stress and anxiety to families whose children attended the centre.

Parent carers had not been consulted and the impact on families using the service and how their needs would be met had not been sufficiently assessed. This had also been done without proper consultation with other strategic partners (e.g. the other CCG in Hertfordshire LA and parent carer forum).

The forum felt there had been insufficient assessment of what the impact of this would be on other families of disabled children in the county, services and budgets; or parents of children with complex health needs in the future.

What the Forum did

The forum mobilised quickly and dedicated two reps to work with the campaign group and keep their membership informed. They gave out clear information about the campaign, how parents could be involved and have their voice heard while being clear on their independent role.

They helped facilitate a wider consultation on the impact closure would have on families and services and on appropriate provision for families of children with complex health needs in the county.

The forum represented the views of parent carers at strategic meetings e.g. at scrutiny meetings and helped councillors understand the impact of the cuts on families and other services. They clearly communicated their findings and how they were working with partners to find a way forward and to ensure the specific needs of these children were met alongside the needs of all children with additional needs in the county.

The forum facilitated discussions with all partners to find a way through the crisis and to find new solutions.

What were the main challenges?

This was a long, high profile and complex legal case and involved working with a range of partners and groups. Capacity was also an issue for the forum, as they had to try and maintain a countywide and pan disability role, as well as represent these children (a small but important group) alongside the needs of other children. One of the other challenges was helping ensure

parents understood procedures and processes so their energies were directed in most effective way.

What difference did the forum's involvement make?

Ultimately the decision was made to close the centre but the forum are now fully involved in ongoing discussions around improving provision for children with complex healthcare needs across health, education and social care.

By working with families and other partners the forum was able to help strategic partners be clearer on their responsibilities. Looking at the issue strategically enabled the forum to identify gaps in provision for these families e.g. EHCP plans for children attending the centres. Also working at a countywide strategic level meant the forum was able to highlight other related issues and identify other services that were needed or would be impacted by the decision e.g. the impact of lack of specialist school places was having on other provision and the lack of provision for children under 5 and young people with health needs?

There are now clearer process for how the CCG and LA should be working together and with the forum. And the forum is fully involved in discussions around how the needs of children with health needs can be met going forward. Meeting with parents directly (& meeting their children) helped councillors fully understand the complexity of these children's needs & the importance of high quality medical care & regular breaks.

The forum & campaign group working together provided evidence that supported the High Court ruling which recognised that short break services such as those offered at Nascot Lawn are indeed a health service & therefore the NHS has a role to play in funding this type of provision.