

Isles of Scilly – Working with health, education and social care to improve services

Forum: Isles of Scilly parent carer forum,
Web: www.iosparentcarers.org.uk
Contact: Tracy Smith
Email: scillyonions@aol.com

Background

The forum had a good relationship with children's services, but wanted to build links with education and health.

Living on a small island can bring additional challenges for disabled children and their families. There is only a small health workforce on the island and many universal services are provided by the Cornwall Foundation Trust, based on the mainland. Since the helicopter service stopped, the only method of travelling in winter is by plane. It can take two to three days for families to attend appointments on the mainland – and longer, if bad weather kicks in. Bad weather can also prevent medical professionals travelling to the island to provide clinics, leaving families having to wait a further three months before being seen. Not surprisingly, there can be long delays in children receiving assessments, reviews and getting education statements. A further complication of island life is that, once children are over 16, they have to go to the mainland to continue their education.

It was extremely difficult for the forum to know who to make contact with regarding the problems families faced in accessing health services. From 1 April 2013, there will be one clinical commissioning group for Kernow, Cornwall, including the Scilly Isles. It was important that services commissioned by this group meet the needs of the islanders.

What they did

The forum heard out about Local Involvement Networks (LINKs) after Contact a Family published a report on parent carer forum involvement in shaping health services. This acted as a trigger for the forum to make contact with their local LINK and ask for assistance. Isles of Scilly LINK welcomed the opportunity to have input from the families of disabled children about the unique challenges they faced. They arranged for forum members to meet medical professionals and commissioners when they were visiting the island to attend meetings. Isles of Scilly LINK also invited a member of the parent carer forum to sit on the LINK Isles of Scilly Steering Group and the Healthwatch Isles of Scilly Transition Group.

The forum had a good relationship with the parent carer forum in Cornwall, whose members were happy to raise issues on their behalf with the Royal Cornwall Hospital Trust on the mainland. The forum also began to meet every three months with the island GP, to discuss the issues families faced. This GP reports to the Clinical Commissioning Group on the mainland. The forum also began to have three monthly meetings with education leads.

After having built up a relationship with education and health through individual meetings, the forum persuaded all three services, (health, education and children's services) to have three- monthly joint meetings, with all of them present together. This will facilitate informed discussion between different services on how they interact with each other, as well as reduce the number of meetings parents have to attend.

The parent forum has also been invited to have parent carer representation on the children and young people's committee which scrutinises the work of the children's trust board and monitors the delivery of services as outlined in the Children and Young People's Plan. It also manages home-to- school transport and approves the Council's budgets for children's services.

Outcomes

There had been a good early year's service for children aged 0–8 with input from speech and language therapy, occupational therapy and physiotherapy. However, after the age of eight this disappeared. Some older disabled children had not been picked up earlier and never been properly assessed. After raising this, an occupational therapy (OT) service has been commissioned for these children.

An outreach service has just started, where the community paediatrician, speech and language therapist, physiotherapist and OT all travel together from the mainland to the island. This allows for the children to receive all their assessments on the same day and for the team to carry out 'team around the child' reviews.

A video link to support speech and language therapy is being piloted. Children and young people will still have an initial face-to-face assessment. After that, the speech and language therapist on the mainland can use a video link to discuss how children are progressing with the people involved in their care.

From April 2013, the first the Isles of Scilly Health and Wellbeing Board will become fully operational. This board's responsibilities include making sure that services meet the needs of the local population. Parent carers will be able to influence this through Healthwatch, as they have a place on the Healthwatch Board which in turn has a seat on the Health and wellbeing Board. The forum will also be able to influence the Clinical Commissioning Group having built a good relationship with their GP.

What do you consider your best achievements?

"Having a dialogue – in the past medical consultants came to the island – but no one was consulting with us about how we found the services."

"Getting all agencies to meet in the same room with us."

"Parent carers feel valued and listened to, and children and young people's issues are now being heard."

Tracy Smith , Isles of Scilly parent carer forum