

What is parent carer participation?

Parent carers can help to pinpoint challenges frequently experienced by families with children and young people with Special Educational Needs and disabilities (SEND) through their experience of navigating services and support. They are also able to highlight examples of good practice across education, health and care (both children and adult's) in a local area where they are providing support and services that work well. Their insights and knowledge are invaluable to practitioners because listening to, and involving, parent carers helps them to improve how services and support for children, young people and their families are delivered so that they better meet families' needs.

Parent carer participation can happen in different ways:

On an **individual level** - parent carers influence their own child's or young person's journey through services and work with practitioners to ensure the best possible provision and support is available.

Strategic participation via parent carer forums – where local parents have formed a group that aims to ensure that all families with disabled children and young people have their voices heard and that services meet their needs. Parent Carer Forums work together with practitioners to design, develop, review and improve services and support for disabled children in the local area.

What are Parent Carer Forums?

Parent Carer Forums were first funded in 2008 as part of the Aiming High for Disabled Children programme. A Parent Carer Forum is an organised group of parents and carers of disabled children from a local area. Their aim is to work in a solution focused way to make sure that services in their area meet the needs of disabled children and their families. Parents or carers of a child or young person between the ages of 0 and 25 with any type of additional need or disability are welcome to join their local forum. For further information on parent carer forums, and what they do, you can visit Contact's [webpages for forums](#).

What do Parent Carer Forums do?

Parent Carer Forums gather the collective views and experiences of local families and by working in partnership with local authorities, and other providers including across education, health, care and the voluntary sector, highlight where local services, processes and commissioners are working well, or challenge when changes or improvements need to be made e.g. to the local culture.

Parent carer forums might use formal or informal methods or events to survey or consult parent carers in their area to ask their opinions and experience of a service and they will have representatives on local strategic and operational working groups where the views or case studies gathered are fed in, ensuring that they're listened to and considered by service providers. Forums are keen to hear from as many parent carers as possible, this is because forums represent the views of all parent carers in the local area rather than advocating for individual families. Forums feedback progress made to their members via their websites, social media, newsletters and events.

There is usually a steering group or committee of parent carers leading the forum's work and forums are supported by an annual grant of up to £15,000 from the Department for Education. There is one DfE grant available to a parent carer forum in every local authority area in England to support their operational costs, training, parent carers' expenses and their strategic involvement in local service development. The grant is administered by Contact. By receiving the grant, the forum becomes the recognised Parent Carer Forum in the local area, and all forums in receipt of the DfE grant sign a Memorandum of Understanding

(MOU) recognising that they will work in partnership with services in their local area. A local authority representative, usually the SEND lead or their equivalent, also signs up to this MOU which sets out how the Parent Carer Forum and their local partners will work in co-production.

Forums have steadily grown in their membership, influence and impact, being instrumental in shaping the SEND reforms and cementing their place in legislation. Parent Carer Forums have regional networks and are members of the national strategic umbrella group, the National Network of Parent Carer Forums. Forums are largely run by volunteers.

Legislation and why you should work with Parent Carer Forums

Parent Carer Forums are mentioned in the Children and Families Act 2014 part 3, and sections 1, 3 and 4 of the SEND Code of Practice as an organisation that local services must work with to ensure that the voices and experiences of children, young people and their parents are not only heard, but are listened to and considered when services are being planned, designed, implemented and reviewed. [See Appendix 1](#)

Co-production

The Children and Families Act encourages co-production, collaboration and partnership working and for families to be at the heart of the support and services that they receive; and in designing them. Co-production is achieved when all partners play an integral and equal part in the decision-making process and are fully engaged in shaping, developing, implementing and evaluating services and systems. These local partners include the Parent Carer Forum, local authority, health agencies, social care and other local service providers and organisations.

Evidence shows that equal, co-productive partnerships make the best use of people's time and the money available, whilst also improving outcomes for children and young people with SEN and Disabilities. [Watch this co-production video](#) where forums, local authorities, health providers and commissioners share their experiences of working in co-production and how it helped them to improve services.

What are the benefits of co-producing with our local PCF?

Services and support in your local area will better meet the needs of families and therefore be better received. By targeting services and support in the right places, the likelihood is that you will save money, and by involving parent carers in any service developments from the start, it might take longer, but you are more likely to get it right first time and not make costly ill-informed decisions that need to be rectified later. For information on the impact of parent carer forums, please visit the [National Network of Parent Carer Forums'](#) website.

How do we find out more, and what if we have any queries or concerns?

Parent Carer Forums are supported by Contact who are the DfE's contracted strategic participation partner overseeing the development of Parent Carer Forums in England and administering the annual DfE parent carer participation grant. For further information about the work of Parent Carer Forums, or to find the [contact details for your local parent carer forum](#), please visit the [parent carer participation pages](#) of Contact's website.

If you have any concerns regarding your local parent carer forum, you should direct your queries to the forum's Chair via the forum's public contact details in the first instance. If your concern is in relation to the DfE grant, you can get in touch with one of Contact's [parent carer participation advisors](#).

Appendix 1

Parent Carer Forums – what it says in the [Special Educational Needs and Disability Code of Practice: 0 to 25 years](#)

1 Participation in decision making

Parent Carr Forums

1.13 Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families. Parent Carer Forums have been established in most local areas and local authorities are actively encouraged to work with them. More information about Parent Carer Forums is available from the websites of Contact (a Family) and the National Network of Parent Carer Forums.

2.6 Local authorities should involve children, young people and parents (including local Parent Carer Forums and Youth Forums) in the design or commissioning of services providing information, advice and support in order to ensure that those services meet local needs. Local authorities should do this in a way which ensures that children, young people and parents feel they have participated fully in the process and have a sense of co-ownership.

3 Working together across education, health and care for joint outcomes

What this chapter covers This chapter explains the duties local authorities and their partner commissioning bodies have for developing joint arrangements for commissioning services to improve outcomes for 0 to 25-year-old children and young people who have special educational needs (SEN) or disabilities, including those with Education Health and Care (EHC) plans.

It explains:

- the role that children, young people, parents and representative groups such as Parent Carer Forums and Youth Forums have in informing commissioning arrangements

Partnership with children, young people and parents

3.18 At a strategic level, partners must engage children and young people with SEN and disabilities and children's parents in commissioning decisions, to give useful insights into how to improve services and outcomes. Local authorities, CCGs and NHS England must develop effective ways of harnessing the views of their local communities so that commissioning decisions on services for those with SEN and disabilities are shaped by users' experiences, ambitions and expectations. To do this, local authorities and CCGs should engage with local Healthwatch organisations, patient representative groups, Parent Carer Forums, groups representing young people with SEN and disabilities and other local voluntary organisations and community groups.

3.29 Local authorities must review their provision, taking into consideration the experiences of children, young people and families (including through representative groups such as Parent Carer Forums), voluntary and community sector providers and local Healthwatch. Information from such reviews will contribute to future arrangements and the effectiveness of local joint working.

Making best use of resources

3.35 Joint commissioning arrangements should help partners identify scope for working more efficiently together. Partners should assess the extent to which activities contribute to their local priorities and outcomes and decide which services should be commissioned or decommissioned, in consultation with children and young people with SEN or disabilities, their parents, or representative groups such as Parent Carer Forums.

3.44 Local authorities must review the special educational provision and social care provision in their areas for children and young people who have SEN or disabilities and the provision made for local children and young people who are educated out of the area, working with the partners to their joint commissioning arrangements. The local authority must consult with children and young people with SEN or disabilities and their parents and as part of this should consult with family representatives such as Parent Carer Forums. Joint commissioning arrangements must consider the needs of children and young people with SEN and disabilities. Partners should also work with commissioners of adult services to ensure that there are smooth transitions between children's and adult services. This will involve working with a range of professionals in the public, private, voluntary and community sectors and will help those with SEN or disabilities prepare for adulthood, including living independently and employment

4. What is the Local Offer?

Preparing and reviewing the Local Offer - Involving children and young people and parents

4.8 Local authorities must involve children with SEN or disabilities and their parents and young people with SEN or disabilities in:

- planning the content of the Local Offer
- deciding how to publish the Local Offer
- reviewing the Local Offer, including by enabling them to make comments about it

4.9 Local authorities should do this in a way which ensures that children, young people and parents feel they have participated fully in the process and have a sense of co-ownership. This is often referred to as 'co-production'. Local authorities should take steps to ensure that their arrangements for involving children, young people and parents include a broadly representative group of the children with SEN or disabilities and their parents and young people with SEN or disabilities in their area.