



What is Participation?

Parent carers can help pinpoint problems frequently experienced by families with disabled children. This knowledge is useful to professionals to help them improve how services are delivered, so they better meet family's needs. When parents and professionals work together, recognising each other's expert knowledge, informed decisions are made which make the best use of people's time and money. Including parents in their decision making processes has helped Local Authorities and Health professionals develop services that are relevant and right for the disabled children and their families in their areas.

The PIPS focus on four main areas of Participation which we believe makes a positive difference. The role of each Parent Carer Forum is to become involved at the appropriate stage or progress of local policies to develop these four areas on behalf of the parents and carers they represent.

Information: The more informed that parents are, the more they will feel confident and able to make appropriate choices for their children and families. A local constituency of well-informed parents develops knowledge of what works best for all disabled children and young people. Such knowledge is an essential ingredient in shaping effective services that best meet local needs. It underpins successful consultation and parents' participation.

Consultation: Consultation is a step up from simply giving information as it requires a two-way communication. Professionals should consult with parents on existing services, seeking their views on how services can be improved and good practice shared from other areas. Another reason for consultation could be when changes to services are planned. In this instance, as many parents as possible should be informed about proposed changes to a service and invited to give their ideas and raise any concerns about the proposals before final decisions are made. The professionals who are carrying out the consultation will then need to reply to the parents' responses, setting out clearly what has changed as a result of parent feedback and where it has not been possible to make changes, explaining why. Many parents do not have the time or choose not to get involved in full participation. However, all parents have opinions about the services their children receive. Consultation is an important and relatively simple way of capturing a wide range of views.

Participation: The purpose of parent participation is to enable parents to get involved in service planning and decision making so that services meet the needs of families with disabled children and resources are not wasted on services which parents and families do not take up. Effective parent participation happens when parents have conversations with and work alongside professionals, in order to design, develop and improve services. This conversation benefits everyone. Working with parents helps professionals to understand what needs to happen to develop services that meet families' needs. Working with professionals helps parents understand the complexity involved and the challenges faced by the professionals who have to bring about that change. Working together and sharing knowledge enables parents and professionals to find solutions that work.

Co-Production: 'Co-production is about trust', (parent carer) and builds upon transparency, open communication and equal value being given to each participant's contribution. Co-production happens when all team members together agree outcomes, co-produce recommendations, plans, actions and materials as a collective. It is an approach which builds upon meaningful participation and assumes effective consultation and information sharing. In its essence, co-production is a dynamic group process and happens in the room when there is equal value for each participant's contribution and when there is a meaningful proportion of participants who are service users (in this case parent carers) present. Parent carers are not there just to illustrate the experiences of services users but rather to take responsibility to help shape future experiences and be an active part of delivering the solutions.