



## **The Suffolk Parent Carer Role of an Expert by Experience**

### **Working in Partnership**

Working in partnership with local authorities may mean that you work with groups of Senior Managers, Commissioning groups, or Health Boards or in sub groups of these (sometimes called working groups, task and finish groups etc). These types of sub groups may have a mix of professionals from Health and Local Authority services focussing on one particular service such as transport, short breaks or transition. You will be an important and **equal** member of the team and your role will be to share:

- common problems and experiences of families with children with a range of Special Educational Needs and Disabilities and caring situations.
- ideas and solutions from forum discussions and surveys.
- key plans and topics with the forum for feedback to other parents.
- blocks and barriers to the planning group acting on what parents say and share this with the forum and chair to identify strategies and solutions.
- be aware of **confidentiality** – not all discussion and ideas can be shared widely at all times – so you will need to be clear with the chair about what can and can't be shared.

As an Expert by Experience you will need to be able to both draw on your experience and the knowledge of other family's needs and circumstances (without identifying those parents!). Ensure that you put your own views to one side to put across the views of a wider range of parents.

There are over 1000 conditions and rare disorders that make up the basic groupings of disabilities such as learning and physical disabilities, sensory and communication needs, long term medical conditions, etc. There are also a range of caring situations that need to be considered when planning services such as lone parents, low-income families, fathers, Black and Minority Ethnic families, working parents, families with more than one disabled child, families caring for other adults/older relatives, disabled parents etc. We need to make sure that we are the voice for all.

### **Top Tips for Experts by Experience**

- Don't feel obliged to say anything at your first few meetings.
- Be prepared: do your homework, read the papers, get ideas from other parents.
- Feel confident in your own knowledge: adopt a positive appearance, attitude and body language.

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- Be on time or early – it gives you a chance to meet people beforehand, introduce yourself, network.
- Be polite but assertive.
- Make sure your views are heard and minuted.
- Be open to new ideas.
- Be clear whether you are speaking from personal experience, or presenting views you have gathered from other parents.
- Remember **confidentiality**: do not mention another parent by name but if they want something raised, raise it as a general issue: remember to respect your own child's and family's confidentiality when speaking from your own experience.
- Be prepared to give feedback to your parent carer forum about what happened in the meeting – any outcomes of your involvement and decisions taken. You will be asked to complete a feedback sheet.
- Take time after the meeting to reflect on how you think it went – are you being taken seriously, are you able to have an impact, do you need to gather more information or ask more questions.
- It's ok to ask to meet with someone beforehand to go through the purpose of the meeting, who else will be going, how the meeting is run and the process of making decisions.
- Look after yourself and see if you can have another parent representative at the meeting – two heads are often better than one!
- Don't be afraid to ask for clarification especially if acronyms are being used throughout the meeting

*There will be times when upsetting topics will be discussed in a meeting. This can be particularly hard if it triggers a trauma either yourself or your family have experienced. We are all human and be sure to take time if you need it or reach out to a team member after the meeting should you need to talk.*