



National Network of Parent Carer Forums  
'Our Strength Is Our Shared Experience'

**contact** a family  
for families with disabled children

**Strengthening Parent Carer Participation**

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Dear Parent Carer Forum

Contact a Family and the NNPCF Steering Group has recently been working with the Department For Education and the Department of Health to increase the number of children and young people registered on their local GP's Learning Disability Register.

Evidence shows that young people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. Some steps have been taken to improve the situation, such as the introduction of annual health checks for those with Learning Disabilities, but one of the key challenges is that many of this group are not actually known to their local GP. Increasing the number of young people with learning Disabilities who are on their GP's LD Register, will help to ensure that better and more person centred health care will be offered to this group.

Attached to this email is a letter that has been co-produced with the Department For Education and the Department of Health to inform parent carers about this issue. Your Forum can help to increase the number of young people with learning disabilities who are on their GP's LD Register by sending this letter out to your members. Contact a Family and the NNPCF recognise that this will not be applicable to all of your members but encourage you to share this information so that parent carers can act on it if they feel it is applicable to their child.

Over 1million people have a learning disability in the UK but only 200,000 are on the GP learning Disability Register. Learning Disabilities can cover a range of conditions and abilities but fundamentally it means that individuals may have difficulty in;

- Understanding new or complex information
- Learning new skills
- Coping independently

To find out more about what a Learning disability is visit

<http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Whatislearningdisability.aspx>

In addition to encouraging parent carers to ensure that their child with a learning disability is on their local GP LD Register, your Forum could also encourage Local Authorities to include the sharing of

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Education, Health and Care Plans with GP's as part of their local process. Families would need to give their permission for this to happen but this would be a positive step in increasing GP's awareness of young people with disabilities or additional needs in their practice area. Developing a relationship with GP's becomes increasingly important as young people with disabilities prepare for adulthood and move into adult services. The importance of good information sharing and in particular the value of sharing EHCP's with GP's was recognised in the Department For Education's 0-25 SEND Newsletter in July, sent to all Local Authorities. In an article title 'Sharing Information on Children and Young People with Learning Disabilities' the following statement was included;

***"Sharing information between organisations is critical to providing effective, joined-up care, particularly for children and young people with special educational needs and disabilities. That is why we strongly urge LAs to share appropriate information with local GP practices. EHC plans provide an ideal way into this. Please make sure, with the parent's or young person's consent, that you share the plan with the GP and ask that the child or young person is included on their register of learning disability."***

The full newsletter can be found on the following link

<http://www.councilfordisabledchildren.org.uk/10972>

Thank you for your help in this matter. If you have any questions please do contact us.

**Sarah Thomas**  
**Health Manager**  
**Contact a Family**

**Sherann Hillman**  
**Co Chair**  
**NNPCF**

**Maureen Morris**  
**Co Chair**  
**NNPCF**

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