

## Research Summary

# Resources for Parents Raising a Disabled Child in the UK

This research summary was written by PenCRU and PenCRU Family Faculty

PenCRU was invited to write a paper for the journal Paediatrics and Child Health on resources for parents raising a disabled child in the UK that has recently been [published online](#). The paper aims to inform UK paediatricians and child health care specialists about resources that can help to support and empower parent carers of disabled children so they can signpost families to them. Key resources which were identified within the paper are categorised below according to whether they relate to the wellbeing of the parent, medical condition(s), research about treatments and therapies, guidance and support or policy.

### Parent carer health and wellbeing

Carers' assessments [nhs.uk/conditions/social-care-and-support-guide/Pages/carers-assessment.aspx#parents](https://nhs.uk/conditions/social-care-and-support-guide/Pages/carers-assessment.aspx#parents)

Carers Club (includes a support guide and advice on healthy eating, physical activity, mental health and relaxation for carers) [carersclub.org/](https://carersclub.org/)

Carers Trust [carers.org/help-directory/taking-care-yourself](https://carers.org/help-directory/taking-care-yourself)

Carers UK (advice about health and nutrition for carers) [carersuk.org/help-and-advice/health](https://carersuk.org/help-and-advice/health)

Contact a Family (advice on parent support groups and guidance on improving parent carers' and children's sleep) [cafamily.org.uk/advice-and-support/](https://cafamily.org.uk/advice-and-support/)

Peer Support [scope.org.uk/support/services/befriending/about-face-2-face](https://scope.org.uk/support/services/befriending/about-face-2-face)

PenCRU (childhood disability research) Healthy Parent Carers programme resources [pencru.org/projectsmeetings/researchprojects/hpcproject/hpcresources](https://pencru.org/projectsmeetings/researchprojects/hpcproject/hpcresources)

Wellbeing for Parents and Carers (Australian guide) [ndis.gov.au/sites/default/files/documents/Wellbeing%20Resource.pdf](https://ndis.gov.au/sites/default/files/documents/Wellbeing%20Resource.pdf)

### Information about conditions:

Contact a Family [cafamily.org.uk/medical-information/conditions/](https://cafamily.org.uk/medical-information/conditions/) also provides links to condition-specific support groups

NHS Choices [nhs.uk/pages/home.aspx](https://nhs.uk/pages/home.aspx)

Rare Diseases [rarediseases.org/for-clinicians-and-researchers/resources/rare-disease-information/](https://rarediseases.org/for-clinicians-and-researchers/resources/rare-disease-information/)

### Research summaries for treatments and therapies:

CanChild [canchild.ca/en/resources/#/?type=27](https://canchild.ca/en/resources/#/?type=27)

Cerebral Palsy Alliance [cerebralpalsy.org.au/about-cerebral-palsy/interventions-and-therapies/](https://cerebralpalsy.org.au/about-cerebral-palsy/interventions-and-therapies/)

PenCRU [pencru.org/evidence/](https://pencru.org/evidence/)

Research Autism [researchautism.net/autism-interventions](https://researchautism.net/autism-interventions)

## Guidance and support

Cerebra (UK charity for children with neurological conditions) [w3.cerebra.org.uk/](http://w3.cerebra.org.uk/)

Cerebra guide to the Disability Living Allowance (DLA) Claim Form [w3.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide/](http://w3.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide/)

Contact a Family [cafamily.org.uk/](http://cafamily.org.uk/)

Communication Matters [communicationmatters.org.uk/](http://communicationmatters.org.uk/)

Communication resources [thecommunicationtrust.org.uk/resources/resources/resources-for-parents/](http://thecommunicationtrust.org.uk/resources/resources/resources-for-parents/)

Council for Disabled Children's Expert Parent Training [councilfordisabledchildren.org.uk/expert-parent-training-course-1](http://councilfordisabledchildren.org.uk/expert-parent-training-course-1)

Grants for families of disabled children [familyfund.org.uk/](http://familyfund.org.uk/)

I Can (child communication) [ican.org.uk/](http://ican.org.uk/)

Information, Advice and Support Services Network (IASS Network) [iassnetwork.org.uk/](http://iassnetwork.org.uk/)

Legal Help [w3.cerebra.org.uk/help-and-information/legal-help/ask-for-legal-help/](http://w3.cerebra.org.uk/help-and-information/legal-help/ask-for-legal-help/)

MenCap (UK charity supporting people with a learning disability, their families and carers) [mencap.org.uk/](http://mencap.org.uk/)

Portage (a home visiting educational service) [portage.org.uk/](http://portage.org.uk/)

SENDirect (information about services available for families of children with special educational needs) [sendirect.org.uk/](http://sendirect.org.uk/)

Scope [scope.org.uk/](http://scope.org.uk/) who also coordinate Face2Face Peer Support programme [scope.org.uk/support/services/befriending/about-face-2-face](http://scope.org.uk/support/services/befriending/about-face-2-face)

Transition to adult services [w3.cerebra.org.uk/information-and-advice/transition-a-guide-for-parents/](http://w3.cerebra.org.uk/information-and-advice/transition-a-guide-for-parents/) and Transition Guides [councilfordisabledchildren.org.uk/transition-information-network/information-and-support/transition-guides](http://councilfordisabledchildren.org.uk/transition-information-network/information-and-support/transition-guides)

## Influencing policy and practice

Council for Disabled Children [councilfordisabledchildren.org.uk/](http://councilfordisabledchildren.org.uk/)

Every Disabled Child Matters [edcm.org.uk/](http://edcm.org.uk/)

National Network of Parent Carer Forums [nnpcf.org.uk/](http://nnpcf.org.uk/)



## Other resources

These resources are national resources and have a UK wide focus – please do also look locally if you are looking for support in your area. The Local Offer may be a good starting point for this information [thelocaloffer.co.uk/](http://thelocaloffer.co.uk/)