



By Vickey Kowal

Parent Carers report February 2021



Current difficulties faced by parent-carers

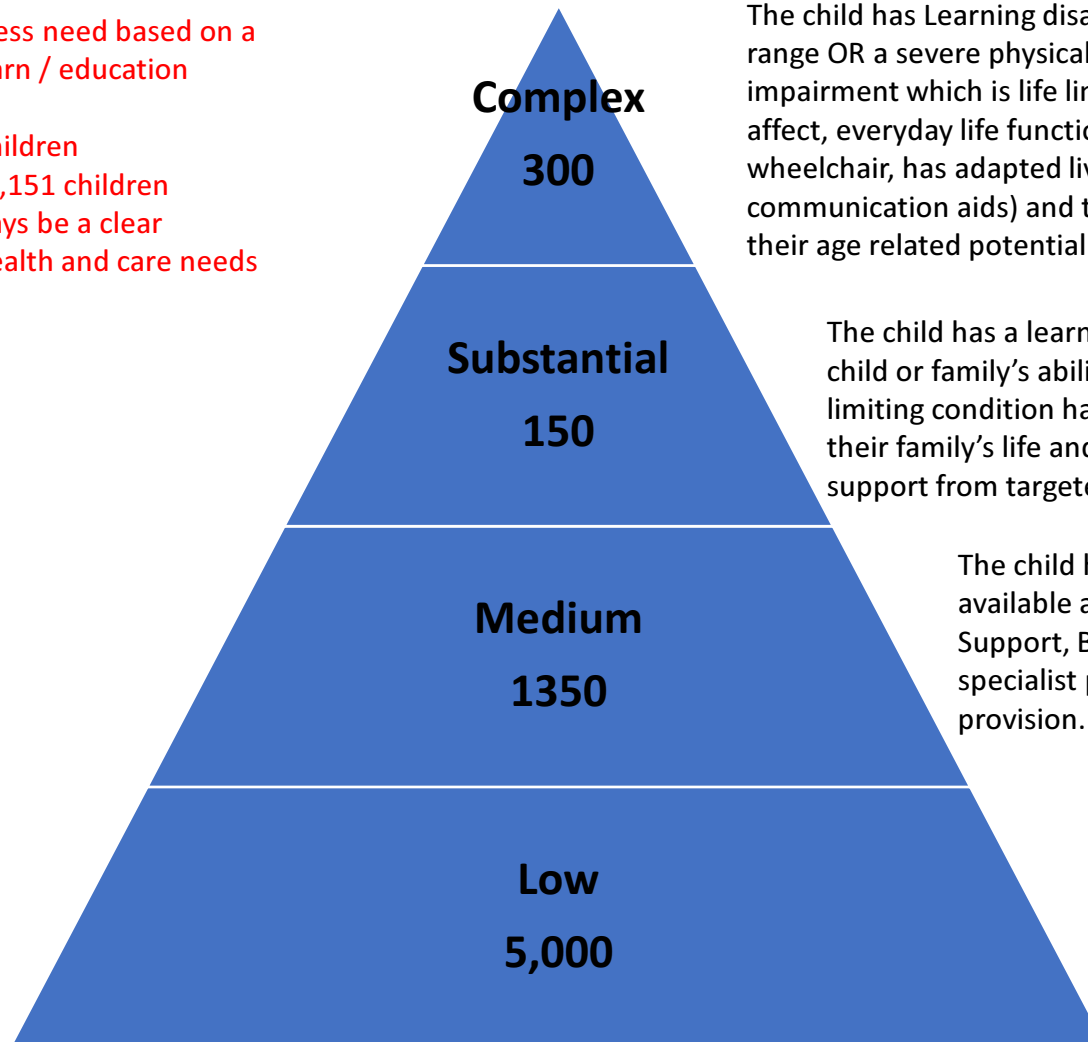
- Lack of easy access to information
- Lack of recognition of needs of parent-carers
- Lack of emotional support
- Lack of practical support
- Financial and housing support
- Breadth of SEND and therefore challenges faced by parent-carers
- Only small percentage of parents able to access carers assessment (statutory requirement) those that do access aren't involved in their own assessment
- Communication
- Parents not seen as experts in their child
- Many families have more than one child with SEND
- For many this is a lifelong role, different needs at different times

Current model for support

NB. Education assess need based on a child's ability to learn / education outcomes:

- EHCP – 1,411 children
- SEN support – 5,151 children

There will not always be a clear correlation with health and care needs



The child has Learning disabilities within the moderate, severe or profound range OR a severe physical (including visual and hearing) health condition or impairment which is life limiting, or significantly affects, or is predicted to affect, everyday life functioning or a child's access to education (e.g. in a wheelchair, has adapted living, requires total personal care support, requires communication aids) and their ability to achieve outcomes appropriate to their age related potential.

The child has a learning or physical disability that significantly impacts on a child or family's ability to function. The impairment, chronic health or life limiting condition have a substantial impact on the quality of the child and their family's life and child would be unable to achieve outcomes without support from targeted services, coordinated by a lead professional.

The child has additional needs where parents require support above what available at universal level e.g. Special Education Information, Advice and Support, Benefits, carers rights and short breaks from caring through specialist play schemes and clubs, or enhanced/adapted mainstream provision.

The child has low level additional needs that parents are able to meet through universal services and a network of family and friends. Parents may require signposting to the SEND Local Offer for information, advice and guidance about the universal services available.

Proposed model

Known as the iThrive model, it is often used by CAMHS services and places families at the center of the model with a needs based approach rather than a service led approach.

Families can move within approach more fluidly

Description of the THRIVE groups



Input offered





Recommendations

- Ensure all parent-carers have access to carers assessment that they have an active role in
- Parent-carers treated equitably with other carers whilst recognizing the differences between the two.
- Cultural change from 'service led and child focused' to 'needs led and family focused'
- Increase the number and variety of parent support groups across different areas of SEND and geographical areas of the city
- Support proposed changes to adopt iThrive model
- Provide Parent support for managing children and young people with challenging behaviour
- Ensure timely access to an increased range of parent training and education courses
- Improved communication between professionals/agencies as well as with parents

What parents say



- 'On the identification point. Our GP surgery won't recognise me as a carer because he's under 18!'
- 'Took me a while to even understand that parent-carer was a role in its itself, for ages I thought we were talking about parents and/or carers. But once I understood it, I wanted everyone to 'understand and acknowledge it too. Its real! It does take a while to acknowledge you are a parent-carer - we all thought we were just going to be common or garden parents and then had to adjust to our new lives, roles and responsibilities.'
- Covid has meant...if I'm completely honest, more trapped....'
- 'The only time I get a good night sleep is when my son is in hospital'
- 'One time we were in hospital a nurse sat down and spent time talking to me about DLA it was only 10 minutes but it made a huge difference'
- 'Carers in Southampton are brilliant, a lovely organisation and I do feel I could turn to them to ask a direct question. But they don't feel like "my" service after the confusion about Carers assessments I guess I gave up a bit and sorted myself out.'
- 'I had a breakdown following the fight I had to get suitable special ed place for my boy whilst trying to sustain a teaching career. I have no childcare options for my lad due to his disabilities, no family nearby to take on any caring role and have had to take at least a £20k cut in salary, ending a 20 yr career in teaching.'