

# How can we make the assessment journey easier and less stressful for families?

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## Objectives

- Understanding “assessment” from family perspective
- Understanding why families find the journey stressful and difficult
- Understanding what makes a difference to families

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## Assessment from a family perspective

- We don't know this new landscape
- We are having to come to terms that things are “not right”
- Wider family may not be understanding or supportive (“shame”)
- Practical problems of people staring and commenting before you know answers (“bad parent”)
- Pressure to look for answers from unqualified sources (“filling a void”)
- Think about the needs of the whole family and how to support

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## My own experiences of assessment

- Red book assessments not completed, lack of Health Visitors
- Horrible buildings with no positivity
- Late diagnoses, not multidisciplinary and no help in the meantime
- Scary silences (in talking to people and in continuity of care)
- Fought for everything (therapeutic support, eating disorder, neuromuscular)
- Gaps and crises
- Lack of understanding in education, health and social care e.g. of autism, learning disability, neurodisability and behaviour, Equality Act and reasonable adjustments
- Lack of life long planning

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## What makes a difference – environments that give hope

- Buildings and environments should be positive and nice
- Families should feel valued and that they matter
- Need to feel a sense of hope and positivity now and for the future
- Pictures and images of what is possible in relation to lives and employment

## What makes a difference – prevention and early intervention

- Focus on early identification and prevention
- Care pathways need to find the CYP and get them the right help at the right time (for community/specialist etc, using the Dynamic Risk Register effectively)
- Problems only get worse not better
- Positive and open communication, so that families know what to ask and where and when to get the right help

## What makes a difference – avoid delays

- Avoid delays and long waiting lists, as impacts on
  - development of child,
  - family stress and distress,
  - pressure to look at unproven supports
- Don't make excuses, ensure better commissioning
- Learning from Ofsted/CQC local area inspections
- Learning from NHS Long Term Plan

## What makes a difference – be family centred

- For most parent carers this can be the most difficult stage. Knowing or being told your child is different or has a disability can be hard to take in. It can take time to come to terms with the news. Parent carers will do that in different ways and at different times.
- Families may or may not have had previous experience of disability. Families also come in all shapes and sizes and have different make-up and levels of support. You should never assume by looking at a family what support they have or how resilient they are.

Disability Matters, “Caring for Parent Carers Matters”

## What makes a difference – be family centred

- Think about the journey and who's going to support and how at home and in school
- Especially if assessments may not be complete by school start
- Don't sit in your silos of health, education and care - be joined up and child/young person and family centred
- Don't set the family up to fail by making totally unreasonable demands on them, think about sharing responsibilities across education in particular (eg for therapeutic interventions)

## What makes a different – tell the whole story

- Knowing the full story matters and shows you care
  - eg impacts on sleep and eating, learning, concentration (don't be selective in what you say)
- One or two big labels will not be enough: families need to know and understand practical implications of the big labels
- Understanding what labels mean and do not mean, and use of language
- Multidisciplinary teams
- Explaining the issues in ways families can take in and understand

## What makes a difference – trust

- Give the help to meet the needs
- Sort out your EHC differences behind the scenes
- Don't tell families about your financial rows or poor joint working
- Don't make us have to fight for it (e.g. therapies, SEND Tribunals, LGSCO complaints etc)
- Maintain hope and trust by families
- Understand the impact of trauma caused by lack of support and crises

## Families will also:

- Go through different stages of acceptance and learning to live with the news
- Need clarity about who all the different professionals are in the life of their child and who will be doing what (e.g. in ongoing reviews)
- Need to know what health, schools and other professionals can do to support the child so they can reach their potential
- Need help for signposting to and maybe accessing other help – e.g. counselling (if needed), short breaks/social care (including carer assessments), signposting to groups/support networks

Disability Matters “Caring for Parent Carers Matters”

## Ask Listen Do – feedback and coproduction matters

- Imperative to improve experiences of families in commissioning and in all services (education, health and social care)
- NHS England led work, with 11 other partners including Ofsted, CQC DHSC and NMC
- Assessment systems and processes and staff need to listen to families, and be committed to coproduction
- Ask Listen Do tools and approach coproduced for EHC services and incorporated into Friends and Family Test

<https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>

<https://www.england.nhs.uk/fft/>

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## Summary



- Think about the family journey and how it feels for us
- Invest to save, early intervention and prevention
- Family centred, understanding trauma
- Tell the whole story
- Avoid delays
- Build and maintain trust
- Seek family feedback and listen to concerns – Ask Listen Do

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• Any Questions?





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