

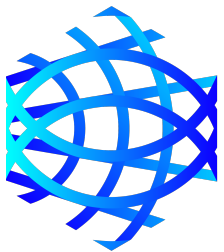


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# Well Being, Learning and Behaviour in DMD

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University of East London

- **Snap-shot of interim results** from small scale study to support the Psycho-social working group of Care DMD ie Well-Being, Learning and Behaviour

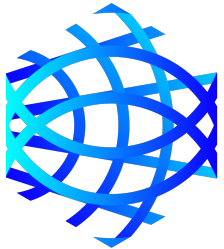


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# The aim of this project is to explore:

- the impact of psycho-social difficulties in DMD on young people with DMD and their families in the UK.
- the barriers to effective psycho-social assessment in DMD in the UK
- the quality of psycho-social support for DMD currently accessible in the UK

Predominantly qualitative to find out the stories behind the data

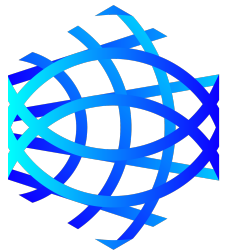


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# Focus Groups with parents and interviews with clinicians

## **5 focus groups involving 29 parents and 1 adult with DMD**

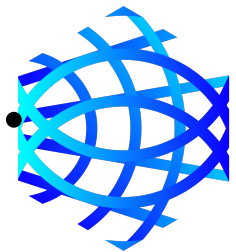
- Group 1: parents of under 6 years
- Group 2 and 3: parents of 7-13 years
- Group 4: parents of 13 – 19 years
- Group 5 : parents of 19 years +, and an adult with DMD
- Currently recruiting clinicians for interviews



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# What we already know from published literature about DMD and Psycho-social issues:

1. Speech and Language delay/impairment (Parson's et al 2004)
2. Short term/working memory –linked to reading difficulties (Hinton et al 2000; Hendriksen and Vles 2008;etc) ,numeracy problems (Hinton 2004)
3. ADHD or ADHD-type behaviour ie impulsivity, and /or attention difficulties (Hendriksen and Vles 2008; Banihani et al 2015; Pane et al 2012)
4. Anxiety (Ricotti 2016) and adjustment difficulties
5. Social Communication eg. Autism (Hinton et al 2009; Darke et al 2006)
6. OCD (Hendriksen et al 2010;)
7. Underlying cognitive ability (Cotton et al 2001; Muntoni 2003)
8. Lack of support and resources/ low expectations for disabled people



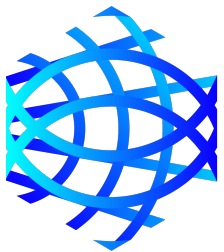
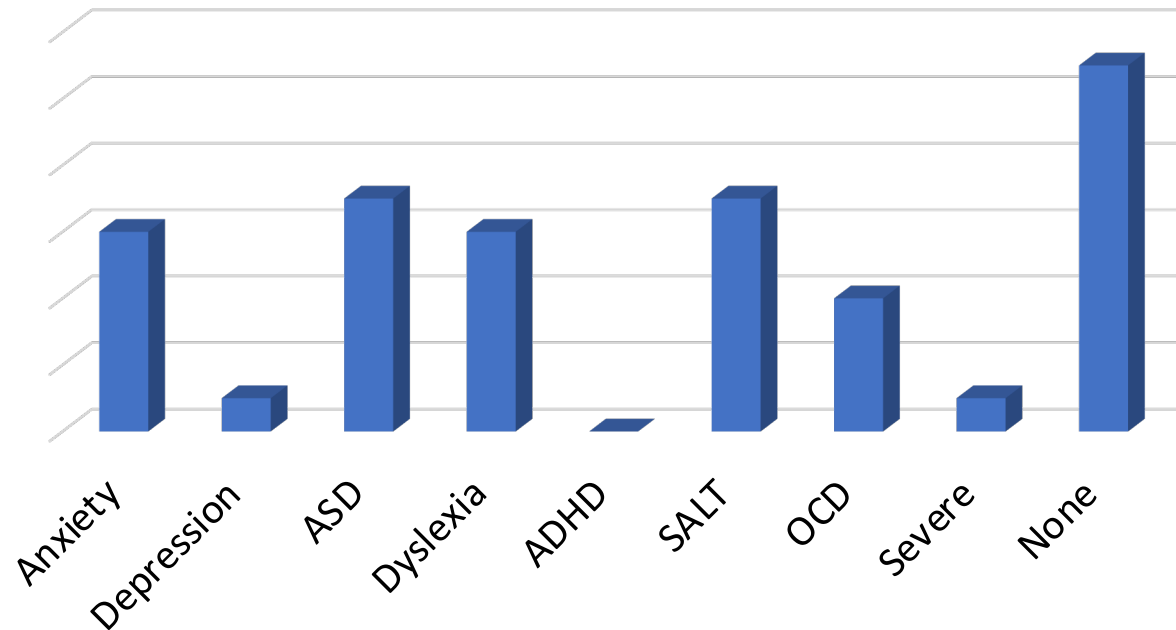
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# Questionnaire n=30

- None: 37%
- ASD: 23%
- SALT: 23%
- Dyslexia: 20%
- Anxiety : 20%
- OCD: 13%
- Depression: 3%
- Severe learning disability: 7%

Has the person with DMD received any additional diagnoses?



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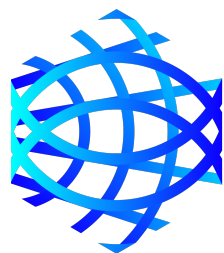
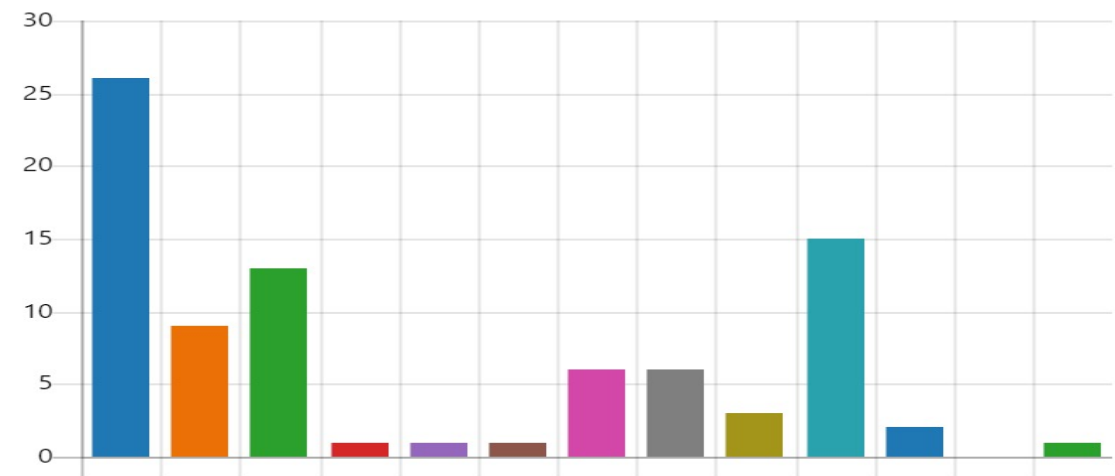


# Support for psycho-social needs

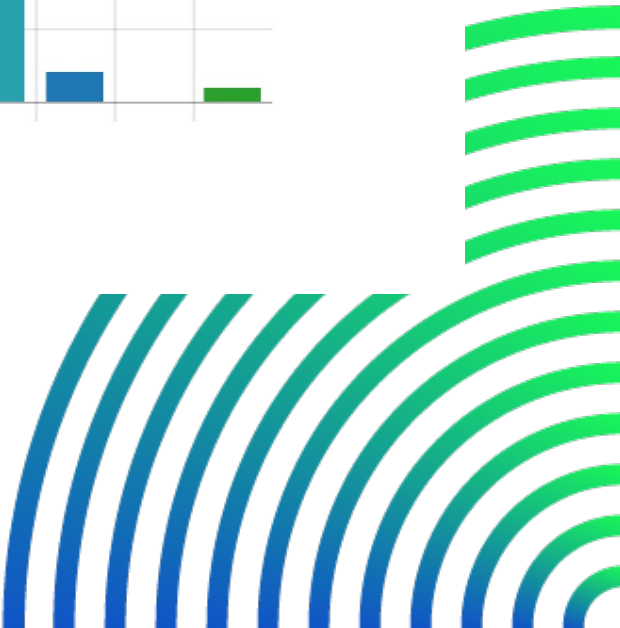
10. Has the person with DMD ever been offered any of the following interventions?

[More Details](#)

support from a teaching assist...	26
Speech and /or Language sup...	9
special intervention for literac...	13
medication for attention diffic...	1
support from an Autism team	1
medication for anxiety or depr...	1
counselling for anxiety or dep...	6
family therapy	6
parenting courses	3
support from hospice	15
no additional support offered	2
not sure	0
Other	1



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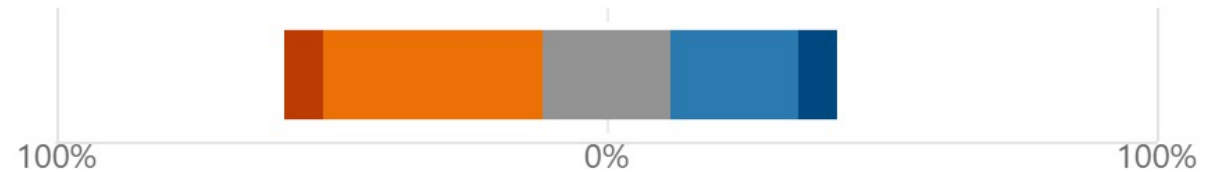


# Are Psycho-social needs met?

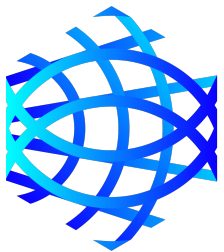
13. Do you think that the person with DMD has their well-being, learning and behaviour needs met? For example, are they well supported at school or home with learning and mental health issues if needed.

[More Details](#)

■ Yes met very well   ■ The are mostly met   ■ They are met sometimes   ■ They are rarely met   ■ No they are not met at all



7% all needs met; 40% mostly met; 23% met sometimes; 23% rarely met; 7% not met at all

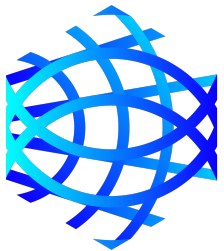


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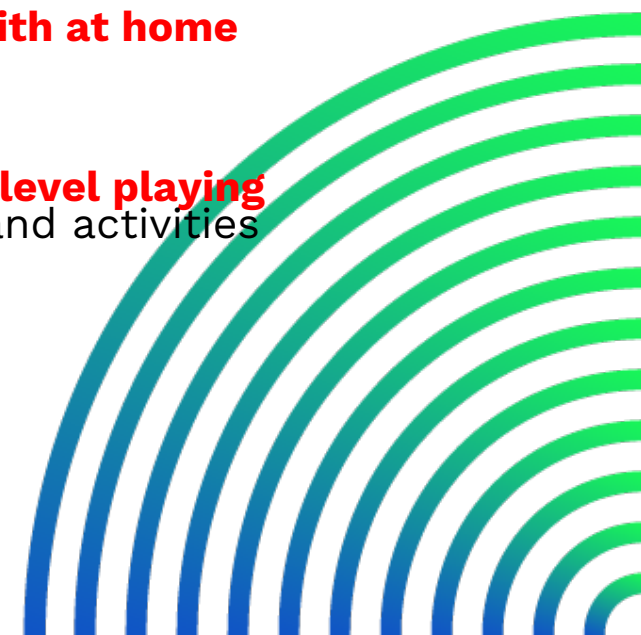


# Qualitative responses from questionnaire:

- **Lack of support:**
- ‘We have **never been offered any support** for our son or family in relation to psycho-social needs. I feel this is a huge gap in support and meeting needs.’
- ‘As a family we **have had no support** except for a family diagnosis session years ago at GOSH.’
- ‘My son was displaying **concerning behaviour** and waiting lists / access to treatment was just so long.’
- ‘I have been prescribed medication for anxiety’
- **Parents’ expertise :**
- ‘Have asked **numerous times about dyslexia** but been ignored.’
- ‘he then comes home in rages from having pent up frustration which **I have to deal with at home** which I self manage’.
- **What works?**
- Extra activities prove invaluable especially when there is the feeling of all being **on a 'level playing field'** – examples are powerchair football, horse riding for disabled and other sports and activities like swimming.



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# Qualitative data collected through focus groups (yet to be analysed) initial headlines

- Not a homogenous group! Even those with same genetic deletion can have very different needs
- Some difficulties seem to be more prevalent at certain ages
- Lack of acknowledgement /knowledge by professionals about different learning risks and learning disabilities
- Ongoing battle for resources



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