

Transition to Adulthood: the experiences and needs of young men with Duchenne Muscular Dystrophy – and their families and carers. David Abbott & John Carpenter

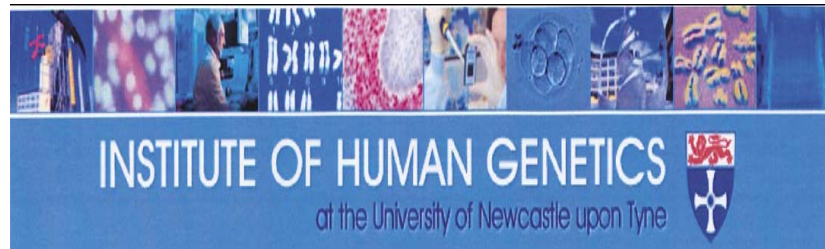


Partners in research



Duchenne Family Support Group

A support group for families affected by Duchenne Muscular Dystrophy



action 
duchenne

**Muscular
 Dystrophy
 Campaign**


 School for **Policy Studies**

The Research



1. Maximising health and well being at transition.
2. Understanding relationships between people with long term conditions and services/staff.
3. What can we learn for a wider group?

How are we doing it?



1. Postal questionnaire to all families with a son with DMD aged 15+ in 3 areas of England: 38 returns – nearly 40% response rate.
2. Interviews with 50 young men and their families: 40 completed with 102 individuals.
3. Staying in touch with 5 families experiencing a ‘big transition.’
4. Talking to professionals and service providers.

Emerging findings



Current day time activities n=38:

| | |
|-------------------------|-------|
| At home/nothing | 35% |
| Local FE college | 21.5% |
| Local mainstream school | 16% |
| Local special school | 13.5% |
| University | 5.5% |
| Day service | 5.5% |
| Special/residential FE | 3% |

Information



Do you have enough information about:

The options for what your son does next with his life

Yes 27% No 70%

The services that are available for your son?

Yes 32% No 65%

The roles and responsibilities of professionals who might support you as your son gets older?

Yes 24% No 73%

How your son's condition will develop in the future?

Yes 78% No 22%

Transition planning?



As far as you know, was there/is there any planning at school for your son's future?

Yes 43%

No 30%

Don't know 15.5%

(11.5% did not answer)

Headlines from one-to-one interviews



- Absence of post-16/post-19 choices
- Absence of helpful transition processes
- Lack of meaningful day time activities and lack of social life/friendship network:

“I go out with my mum for my dinner on a Tuesday. Sometimes I go to bingo. That’s about it. That’s all we can think of doing. We don’t know what else there is out there for us. We want to do more. I don’t just want to go to the pictures all the time or out for my dinner.”

- Barriers to work

Planning ahead – v – living for the day



“You live for today. It’s not to deny it’s there but you can’t dwell on the end else you’d be depressed all the time.”

“It’s as if people think, ‘Oh, you’re still around, you shouldn’t be, we don’t know what to do with you’, and I’m sure there’s more and more boys lasting longer, but after college, no-one knows....”

Emerging issues



- Is Transition a red herring?
- Do statutory services make things worse?
- Is the future individualised budgets?
- Do medical needs swamp social needs?

“Currently, I write and say what [son] needs, get a back up letter from the consultant - she’ll fall in line – it goes to panel – the more technical and medical names you put in the more it will bamboozle the panel and they will agree to anything, which is not a very good system, but works to our advantage.... he’s got one of the best care packages of any Duchenne boy in the [region]”.

- Things that go unsaid?

Further information



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