

<b>Institution:</b> University of East London (UEL)		
<b>Unit of Assessment:</b> 23 Education		
<b>Title of case study:</b> Seeing beyond the wheelchair: Pioneering education and higher aspiration promotion for boys and men with Duchenne Muscular Dystrophy		
<b>Period when the underpinning research was undertaken:</b> 2014 – 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Dr Janet Hoskin	Senior Lecturer	2014 – present
<b>Period when the claimed impact occurred:</b> 2014 – 2020 (ongoing)		
<b>Is this case study continued from a case study submitted in 2014?</b> No		

### 1. Summary of the impact (indicative maximum 100 words)

Duchenne Muscular Dystrophy (DMD), is a rare genetic impairment, affecting one in 3,500 male births worldwide, with 2,500 patients in the UK. The mean age of death has recently increased to 30 years, yet current research focuses almost exclusively on medical treatments, ignoring broader wellbeing dimensions. Hoskin's research has focused on the educational and related psycho-social issues faced by disabled young men with DMD. The research has resulted in 1) improved parental and professionals' knowledge of the educational needs of people with DMD and how to access appropriate resources 2) reducing social exclusion through personal and community empowerment.

### 2. Underpinning research (indicative maximum 500 words)

Hoskin's pioneering research into the lesser-known co-occurring educational and related psycho-social risks that are associated with DMD such as dyslexia, Attention Deficit and Hyperactivity Disorder and Anxiety (R1) further develops her earlier ground-breaking work on DMD and reading difficulties prior to 2014. This is particularly timely now that children with DMD are reaching adulthood for the first time due to improved medical interventions such as ventilation and cardiac care. Hoskin's work highlights the need for early educational intervention and high expectations to ensure young people with DMD have better life choices, and the same opportunities as any other young person as they grow into adulthood (R1, R2, R4).

Hoskin's body of work has been instrumental in supporting clinicians, parents, young people and professionals in the UK and internationally to understand: a) the importance of early educational and psycho-social intervention for children with DMD and b) the need for appropriate support and aspirations particularly when transitioning to adulthood (R1, R2, R3, R4). This research has resulted in work being carried out in UK schools to support the learning and behavioural needs of children with DMD through assessment and specialist advice, and the training of educational professionals and parents.

Hoskin's research explored for the first time the impact of the 2014 Special Educational Needs and Disability (SEND) policy in England on young people with DMD (R3). Her findings demonstrate that although the new Education Health and Care plan process enables young people with DMD to have aspirational goals for the future, funding cuts and the lack of appropriate professional training has made these goals difficult to achieve. This highlights the need for guidance as parents and professionals navigate new policies to gain appropriate educational and social care resources.

Her research in 'Transition to Adulthood' in DMD shows both young people and parents are keen to reach normative educational and life goals such as employment or living

## Impact case study (REF3)

independently, and as a consequence illustrates the need for schools and services to offer appropriate support in order for this to happen (**R2, R4**). This research is highly original in that it utilises qualitative and co-produced approaches and foregrounds the voices of young people and their families (**R2, R4**).

Her research has found the role of adults with DMD in the UK to be central in raising aspirations through sharing their lived experiences (**R2**). Furthermore, Hoskin's comparison of life with DMD in Denmark and England (**R4**), found men in Denmark are supported to have 'normalised goals' such as getting a job, living independently and having sexual relationships, whereas young people in England often experience a lack of support and aspirations (**R2, R3, R4**). Hoskin's work in collaboration with adults with DMD led to the establishment of the first user-led charity in the UK for adults with Neuro-muscular conditions called Pathfinders Neuro-muscular Alliance. This has led to increased visibility, empowerment and social inclusion of adults with DMD who can now access peer support for the first time and gain relevant advice to achieve their life goals.

### 3. References to the research (indicative maximum of six references)

---

**R1.** Colvin, M., Poysky, J., Kinnett, K., Damiani, M., Gibbons, M., Hoskin, J., Trout, C., Weidner, N. 2018. Psychosocial management of the patient with Duchenne Muscular Dystrophy. *Pediatrics*, October 2018, 142 (Suppl. 2), S99-S109. <https://doi.org/10.1542/peds.2018-0333L>

**R2.** Hoskin, J. 2017. Taking charge and letting go: exploring the ways a transition to adulthood project for teenagers with Duchenne muscular dystrophy has supported parents to prepare for the future. *British Journal of Special Education*, 44(2), 165-185. <https://doi.org/10.1111/1467-8578.12173>

**R3.** Hoskin, J. 2019. Aspiration, austerity and ableism: to what extent are the 2014 SEND reforms supporting young people with a life-limiting impairment and their families to get the lives they want?. *British Journal of Special Education*, 46 (3), 265-291. <https://doi.org/10.1111/1467-8578.12271>

**R4.** Hoskin, J. 2020. Troubling norms? Adults and teenagers with a life-limiting impairment in Denmark and England talk about their lives, support and future plans. *European Journal of Special Needs Education*. <https://doi.org/10.1080/08856257.2020.1754545>

### 4. Details of the impact (indicative maximum 750 words)

---

#### Improved parental and professionals' knowledge of the educational needs of people with DMD

In 2018, Hoskin edited the Guide to DMD for Teachers and Parents bringing together international experts from the United States and the UK, as well as adults with DMD, to focus for the first time exclusively on educational and well-being issues in DMD (**S1**). This accessible textbook is informed by Hoskin's research that has shown increased educational needs in DMD, families struggling to gain necessary resources through their Education Health and Care Plans, and lack of support and expectations during Transition to Adulthood (**R1, R2, R3, R4**). This book has internationally sold over 1,170 copies, which accounts for nearly half of all people with DMD in the UK, and has helped professionals and families to be more skilled in how they support the learning and behaviour needs of their children. It offers information and support strategies about lesser-known educational and behavioural risks associated with DMD such as reading difficulties, Attention Deficit and Hyperactivity Disorder and Autism Spectrum Disorder. The charity Duchenne UK buys a copy for every family that is diagnosed in the UK. Therefore, families and teachers are better advised and children with DMD have improved support, intervention and life chances. In 2019 Hoskin was invited to the European Neuromuscular Centre Workshop on 'Dystrophin and the Brain' where she presented to DMD clinicians and scientists on learning

## Impact case study (REF3)

difficulties in DMD. The paper produced from this workshop (**S2**) links scientific research in the brain with real-world impact on learning for children with DMD and is for an audience of Neuro-muscular clinicians enabling them to address learning and behaviour difficulties in their patients appropriately.

### Improved psychosocial wellbeing and mental health needs

Hoskin was invited to join the Psycho-social Working Group for the International Care Considerations for DMD published in 2018 which informs clinicians globally on all aspects of care for DMD (**S3**), and a 'lay version' has been produced for families. This means that all doctors treating boys with DMD, and families, are now aware of best practice psycho-social care and can ensure boys are referred to mental health or specialist education teams where appropriate.

### Accessing Education support services

Hoskin's research directly informs the work of the Special Educational Needs (SEND) Community Interest Company (CIC) Decipha CIC of which Hoskin is a director. Hoskin's research found that families struggle to gain appropriate support at school (**R3, R4**) and Decipha CIC has been funded by Duchenne UK since 2017 to help families to navigate SEND legislation and produce relevant and appropriate Education Health and Care plans to support learning and behaviour (**S4**). Decipha CIC has worked with 199 children with DMD, 13 local authority officers, 40 Special Educational Needs Co-ordinators, 38 teachers and 7 head teachers attending 2 tribunals, 4 appeal meetings and running local workshops for professionals. Hoskin and Decipha CIC have presented to parents at Parent Information Days at Liverpool Alderhay Children's (92 participants), Great Ormond Street (75 participants), and Guys and St Thomas hospitals (66 participants) (**S5**). This means that children with DMD now have more appropriate support at school, and therefore more opportunities for the future. Hoskin presented at a user-led conference in Switzerland about Education and Transition to Adulthood where 100 delegates were parents and professionals. (**S6**)

### Support for DMD during Covid 19

Decipha CIC ran two 'Support Through Lockdown' webinars for families with 500 views collectively (**S7**). Hoskin helped Duchenne UK to write Advice to a Parliamentary Inquiry on the impact of Covid 19 on children and education (**S8**).

### Increasing social inclusion

Hoskin's ground breaking research has highlighted the role adults with DMD play in inspiring and advising young people and parents about adulthood (**R2**). Her research supported the establishment of the first user-led organisation for adults with neuro-muscular conditions, DMD Pathfinders, (now Pathfinders Neuro-muscular Alliance) and continues to inform their activities. The Alliance runs leadership and mentoring projects for young people with DMD, produces a range of support guides for example managing care, work and education (**S9**) and has hosted annual conferences from 2016 – 2019 in parallel with the Action Duchenne international conference, attracting 500 delegates of men with DMD, families and clinicians. This has resulted in reduced social isolation for adults with DMD, increased friendship and peer support networks that are in person or on-line as well as increased expectations for life. Hoskin's work has directly informed the creation of a film co-produced with members of Pathfinders highlighting the need for raised aspirations for those living with DMD with 721 views (**S10**).

## 5. Sources to corroborate the impact (indicative maximum of 10 references)

---

**S1.** Hoskin, J.(eds) 2018. *A guide to Duchenne Muscular Dystrophy: information and advice for teachers and parents* Jessica Kingsley publishers. <https://www.jkp.com/uk/a-guide-to-duchenne-muscular-dystrophy-1.html> Amazon reviews: <https://www.amazon.co.uk/Guide-Duchenne-Muscular-Dystrophy-Information/dp/1785921657>

## Impact case study (REF3)

**S2.** Hendriksen, J., Thangaraib, M., Hermien, E. and Muntoni, F. 2020. 249th ENMC workshop: The role of brain dystrophin in muscular dystrophy: Implications for clinical care and translational research, Hoofddorp, the Netherlands, November 29th – December 1st 2019, *Neuromuscular Disorders*: <https://doi.org/10.1016/j.nmd.2020.08.357>

**S3.** Birnkrant, D., Bushby, K., Bann, C., Apkon, S., Blackwell, A., Colvin, M., Cripe, L., Herron, A., Kennedy, A., Kinnett, K., Naprawa, J., Noritz, G., Poysky, J., Street, N., Trout, C., Weber, D., Ward, L. 2018. Diagnosis and management of Duchenne Muscular Dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *The Lancet Neurology*, 179 (5), 445-455. [https://doi.org/10.1016/S1474-4422\(09\)70271-6](https://doi.org/10.1016/S1474-4422(09)70271-6)

**S4.** Testimonials for Decipha CIC from:

**S4a.** school: Zoe Carciere, Principal of Clutton Church of England Primary School, Clutton, Cheshire.

**S4b.** parent: Alex Clarke, father of a 7 year old child with DMD, Buckinghamshire.

**S5.** Evaluation forms from Hoskin's and Decipha presentations at Duchenne UK Parent Information Days at:

**S5a.** Session 6: *Having a good transition to adulthood*, Alderhay Children's Hospital, Liverpool 2017. <https://www.duchenneuk.org/Handlers/Download.ashx?IDMF=df83d55d-bce1-4599-8c2c-939274c70893>

**S5b.** Session 6: *Challenges and success at school*, Great Ormond Street Hospital, London 2018. <https://www.duchenneuk.org/Handlers/Download.ashx?IDMF=af6125b7-7c04-47e3-a328-b7b9a9abc2a0>

**S5c.** Session 5(A): *Having a great life with Duchenne - strategies and support for Home School and beyond*, Guys Hospital, London 2019. <https://www.duchenneuk.org/Handlers/Download.ashx?IDMF=bcd7f762-cdaa-4d41-8a3f-155acfd7c830>

**S6.** Testimonial from Maria Fries, Conference Manager, Progena Swiss Duchenne Foundation.

**S7a.** Lockdown webinar 1: Education with Decipha, 360 views. <https://www.duchenneuk.org/news/webinar-with-decipha>

**S7b.** Lockdown webinar 2, Back to school with Decipha, 143 views. [https://www.youtube.com/watch?v=8XvfGpTXpnw&t=174s&ab\\_channel=DuchenneUK](https://www.youtube.com/watch?v=8XvfGpTXpnw&t=174s&ab_channel=DuchenneUK)

**S8.** Duchenne UK Parliamentary advice. <https://www.duchenneuk.org/news/education-select-committee-inquiry-covid-19-on-education>

**S9.** Pathfinders Neuromuscular Alliance website with advice guides. <https://www.pathfindersalliance.org.uk/info-advice/>

**S10.** Raising the bar in Duchenne film. [https://www.youtube.com/watch?v=k10GN-XYrRM&ab\\_channel=DeciphaCIC](https://www.youtube.com/watch?v=k10GN-XYrRM&ab_channel=DeciphaCIC)