The educational journey of individuals with MPS IVA Morquio Disease

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Introduction

- Morquio syndrome (MPS IVA) is an extremely rare lysosomal storage disorder which is caused by deficiency in the enzyme N-acetylgalactosamine-6-sulfatase.1
- Individuals with Morquio experience progressive skeletal and non-skeletal manifestations, including respiratory disease and cardiac disease, which can impact upon their functional capacity, mobility and quality of life.2
- The aim of this project was to determine the educational and employment history of individuals with Morquio.

Methods

- Ninety-nine individuals with Morquio, identified by the MPS Society, were invited to take part in the survey via postal questionnaire in April and May 2014.
- A specifically designed questionnaire was used to assess the individuals educational attainment and need for support from primary through to further education as well as their employment history.

Results

- Forty-six individuals completed the questionnaire (46%).
- There was an equal number of male and female respondents, aged 4 years to 56 years (mean 21.8 years).
- The number of responses received varied at each educational stage (Figure 1); data were calculated using these values unless otherwise specified.
- The majority of individuals with Morquio attended mainstream schools and followed the National Curriculum (Figure 2).
- Seventy percent of individuals needed additional help at primary school compared to 63% at secondary school.
- The most common requirements at primary school were help moving around the school (40%), getting ready for physical education (PE) (37%), and writing (26%).
- Similar needs were reported at secondary school: moving around school (37%), getting ready for physical education (PE) (35%) and with writing (25%).
- Of those currently employed, or who had previously been employed the roles were computer programmer/software engineer (14%), civil servant (12%), Social media project officer (8%), bid coordinator (8%), graphic designer/web designer (8%), business mentor (8%), higher information analyst (8%), outreach nurse (8%), speech and language therapist (8%), translocation officer (8%), one-to-one support worker (8%), and advisory teacher (8%).
- They do their best to accommodate my needs.
- Positive work environment – I am treated like everyone else.
- I do not have to make up time taken off for medical appointments.
- I loved working and had many friends.
- They can attend meetings remotely from my desk if I am too tired or in too much pain.
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Conclusions

- The educational needs for most individuals with MPS IVA were met by mainstream schools.
- Individuals received very little specialist input in primary school, but were well supported in secondary school.
- Although half of the individuals surveyed felt that medical appointments impacted into their education most had gone onto further education and a high proportion attended university and entered employment.
- Most individuals had a positive experience in the workplace.

References


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