

# 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.<sup>1</sup>
- 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.<sup>2</sup>
- The aim of this project was to determine the educational and employment history of individuals with Morquio.

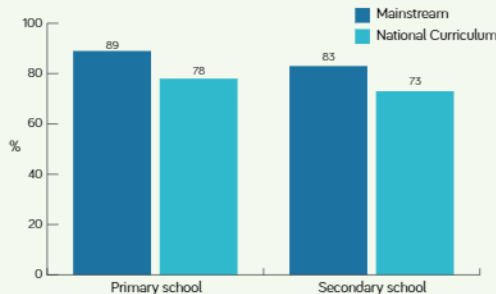
## Methods

- 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).

Figure 2. Most individuals with Morquio attended mainstream school and followed the National Curriculum



- Sixty-one percent of individuals were issued with a statement of educational need (SEN) in primary school; the mean age at issue was 5.3 years (range 3–12 years).
- By secondary school 66% of individuals had a SEN; the majority of which had been issued in primary school.
- 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 (37%), getting ready for physical education (PE) (35%) and with writing (26%).
- Similar needs were reported at secondary school moving around school/carrying things (43%), personal care/dressing (40%), writing (27%), PE (20%) and one to one support (17%).
- A range of specialist equipment was used in primary and secondary schools, alike (Figure 3).

Figure 3. The range of specialised equipment used in primary and secondary school

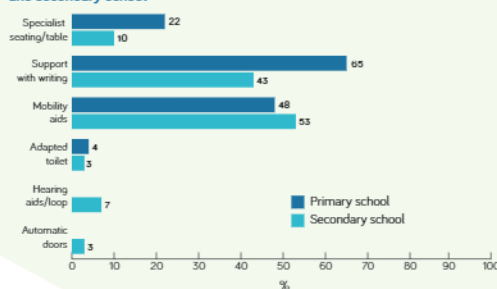


Figure 7. Experience of the workplace in individuals with Morquio

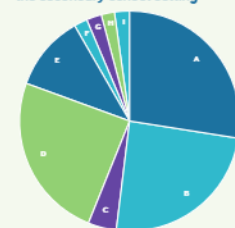


- Support with writing in primary schools included the use of typewriters/laptops/word processors (35%) and pencil grips (20%); typewriters/laptops were commonly used in secondary schools as well (30%), although the use of pencil grips had fallen (7%).
- In primary school 13% of individuals used wheelchairs, 20% used rise and fall chairs, 7% used scooters/buggies and 4% had walking frames.
- Wheelchair use (including rise and fall wheelchairs) was 40% in secondary school and 10% used scooters.
- There was considerably less input from professionals in primary school with no reports of occupational therapist, physiotherapist, special educational needs co-ordinator (SENCO) or educational psychologist involvement.
- In primary schools the most frequently seen professionals were advisory teachers (hearing and physical disabilities) (Figure 4).
- The most frequently seen professionals in secondary school were: occupational therapist, physiotherapist, SENCO and educational psychologist (Figure 5).

Figure 4. Professional involvement in the primary school setting



Figure 5. Professional involvement in the secondary school setting



- Fifty-four percent of individuals felt that the number of medical appointments impacted on their primary education, versus 46% (13/28) on secondary education.
- Overall 91% reported their experience of primary school as positive, compared to 86% (24/28) positive for secondary school.
- Eighty-five percent (23/27) of individuals were studying for, or had gained, GCSE qualifications. A further 11% had gained other secondary school qualifications and only 1 individual had not taken exams at school.
- Twenty-one individuals were in or had completed further education, of which 47% were studying for or had gained honours or higher degrees (Masters and PhD).
- Only one individual had gone straight from secondary school to employment.
- Of the 16 individuals who had completed their education, 81% were currently employed or had previously been employed.
- Of those currently employed, or who had previously been employed the roles were varied (Figure 6).
- On the whole, individuals felt that they were well supported by their employers (Figure 7); workplace adaptations were in place and time off for medical appointments/infusions was permitted.

## 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 on 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

1. Hendriksz C, et al. 2015. *Am J Med Genet A*;167A(1):11.
2. Hendriksz C, et al. 2014. *Orphanet J Rare Dis*;9:32.

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Primary school (n=46)

Secondary school (n=30)

Further/higher education (n=21)

Employment (n=16)

Figure 1. The number of responses received for the educational and employment journey of individuals with Morquio.

Figure 6. Employment history of individuals with Morquio

