

# The experiences of diagnosis for people with Usher syndrome

Usher syndrome affects people who are deaf and then lose their vision later in life. This obviously has a significant effect on their experience of life and a need for a different outlook on opportunities and experiences. It is one of the most significant causes of deafblindness in the UK.

In this research we examined the lives of people with Usher syndrome, types 1, 2 and 3. We talked to people at different stages in their lives to understand their experience of diagnosis and the impact this has on planning for life and identity. This research into Usher syndrome was timely for a number of reasons -: changes in attitude to disclosure to children; the possible introduction of more sensitively targeted genetic diagnosis; screening in relation to cochlear implantation, and the impact of the internet.

The key data collection for this research was collected by talking to people who have Usher syndrome, (some of who use British Sign Language) and through this gaining an insight into their lives. Through this we identified key themes from their own experience of life.

## Impact and Dissemination

We are keen to share the findings with people with Usher syndrome, and with other professionals and researchers. The findings cover research issues such as the identification of people with Usher syndrome, and also the life stories of people with Usher syndrome, including their perceptions of the diagnosis on their lives. We hope that the findings may have significance for those working in education, treatment, and counselling for people with Usher syndrome. We hope to publish a variety of reports, including in peer reviewed research journals, and also to make our findings available to the Usher community through interactive signed material on the web.

## Project Reports

We are pleased to share with you our final report for dissemination to the deaf community and to those with Usher. Further reports both for this audience and more research focused outputs will follow.

### Final report

For the University of Birmingham's final report on Usher Syndrome "Life and Change with Usher" please download either the WORD or PDF document below.

[Life and Change with Usher \(WORD 97-2003 document, 882KB\) \(/Documents/college-social-sciences/education/projects/final-report--life-and-change-with-usher.doc\)](#)

[Life and Change with Usher \(PDF, 1.30MB\) \(/Documents/college-social-sciences/education/projects/final-report-on-life-and-change-with-usher.pdf\)](#)

For a summary of the final report on Usher Syndrome, please download either of the documents below

[Life and Change with Usher - summary \(WORD 97-2003 document, 45KB\) \(/Documents/college-social-sciences/education/projects/summary-usher.doc\)](#)

[Life and Change with Usher - summary \(PDF, 167KB\) \(/Documents/college-social-sciences/education/projects/summary-usher.pdf\)](#)

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