



Improving Access to Genetic Testing for Adults with Intellectual Disability

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Life QI Code: 108051

Overcoming Unexpected Barriers to Genetic Testing

Aim

We wanted to increase the number of our clients who are offered genetic testing at their initial assessment, to help them find out why they had learning disability.

How did you involve service users and carers in this work?

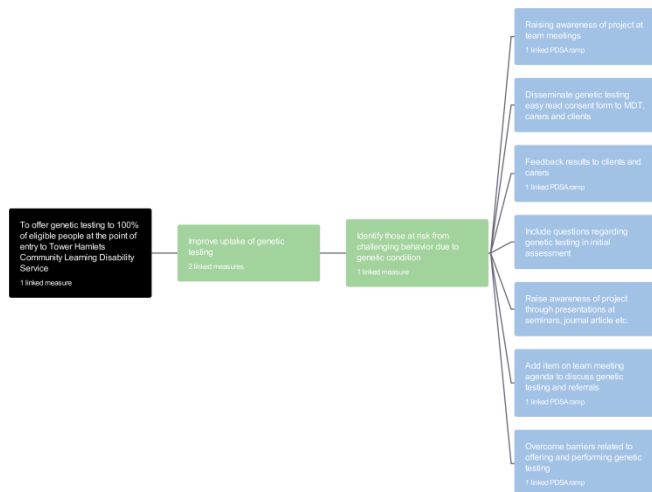
A carer was part of our project team. She helped us devise accessible information, and was invaluable in our staff teaching and presentations to give the family perspective on the process and subsequent benefits of genetic testing.

Tests of Change

We made offering genetic testing part of our initial assessment. We regularly reviewed the number of offers made and asked staff to feedback about their experiences of offering the test. This allowed staff to share their concerns.

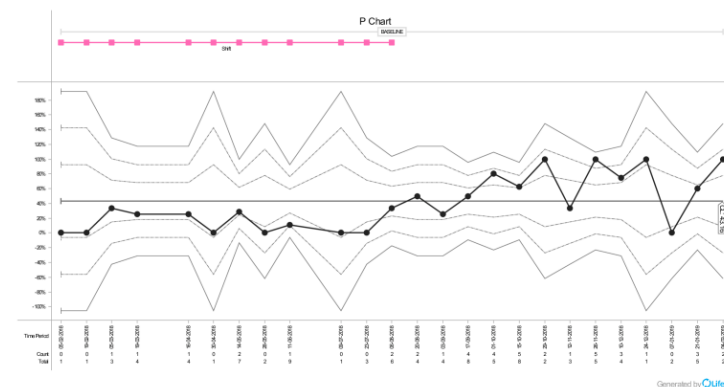
AIM PRIMARY DRIVERS SECONDARY DRIVERS CHANGE IDEAS

Driver diagram



We have increased the percentage of patients offered a genetic test at initial assessment with the implementation of education and support for our staff and GP's.

Data



Learning and what next?

A lot of clients and their carers were very interested in choosing to finding out why they had a learning disability. We were able to identify and overcome many unanticipated barriers to offering genetic testing, including ambivalence amongst team members and GPs. We want to use QI methods to evaluate clients' and carers' experience of having testing to further improve the service for future clients.