

Project Title	Challenging delay in the diagnosis of Autism Spectrum Disorders
School	School of Law
Project Supervisor/ Scholar Mentor	Sorcha Mc Cormack and Professor Luke Clements

1. Project overview

This is an excellent opportunity for a driven undergraduate student to take part in an exciting research project. The project will work in collaboration with the disabled children's charity 'Cerebra'. The research will examine the workings of a specialist NHS service called CAMHS (child and adolescent mental health services). Legislation, government and professional guidance place obligations on the NHS to assess, diagnose and treat children with neurological problems such as Autistic Spectrum Disorders (ASD).

Preliminary research by Cerebra (and other independent bodies) has identified serious delays (often running to several years) in CAMHS's procedures for diagnosing children with symptoms of ASD. The research also suggests that these delays are causing significant harm to the young person and their families (e.g. delayed access to essential support / therapy services and family breakdowns).

The research project will seek to identify the prevalence and extent of such delays and the resulting harms. The research will have several strands including:

The submission of Freedom of Information requests to CAMHS to obtain quantitative data on (1) standard waiting times; and (2) the diagnosis policy for each CAMHS area; Working with a personal injury barrister and national solicitors practice to identify which are the key characteristics that would enable a 'victim' of diagnosis delay to mount an actionable claim for damages.

In conjunction with Cerebra, we will prepare and disseminate a questionnaire to its members. The purpose of which will be to ascertain the following: the extent to which they have experienced delays in the diagnosis of a child with ASD; suffered harm as a consequence of the delay; and might be interested in investigating the possibility of being part of 'test case' litigation to seek compensation for that harm. Families that indicate a willingness to be part of this element of the programme would then be sent a further questionnaire to identify which had the best prospects of succeeding in a claim for compensation. In 2015 Cerebra undertook a pilot survey of parents (limited to questions concerning (a) delay in diagnosis and (b) the resulting harm experienced. The survey attracted 1300 responses in a 3 week period.

The scholarship holder working closely with the project supervisor Sorcha McCormack and the pro bono research students will review the FOI requests and questionnaire responses.

This will involve a 'number-crunching' quantitative analysis of the data. Contact will then be made with a PI firm concerning our findings and the possibility for strategic litigation (i.e. bringing a case on their behalf). All of the information gathered will be compiled into a final report, and presented at a national conference.

2. Key tasks to be pursued by the scholarship holder

The purpose of this research is essentially to investigate the prevalence of delayed diagnoses of ASD and the resultant harms caused to both the child and their family. The scholarship holder will be involved throughout every stage of the project and will play a key coordination role as well as shaping the research project, overseeing the gathering of the essential data and its evaluation.

In particular, the scholarship holder will be expected to:

- conduct a basic 'literature review' of the research and numerous official reports on this topic. This task includes searching for all relevant reports and research completed (mostly online resources) and summarising this information into one document. This is an important part of the project as it will inform our research and provide us with a foundation for the final report.
- to assist in the drafting of the Freedom of Information requests and supervising the pro bono students who will then send these and process the results;
- to liaise (with support from the project supervisor Sorcha McCormack) with the solicitors' firm and barrister(s) concerning the potential for strategic litigation;
- to help in the drafting of the final report on the research project;
- to take a leading role in the arrangements for a national conference in Leeds to publicise and disseminate the research findings;
- to work closely with local and national media concerning the progress of the research programme.

3. Principal academic outcomes/outputs to be generated by the scholarship holders' research

The scholar will achieve:

- (1) Enhanced research skills
- (2) Improved communication skills
- (3) Improved time management & organisational skills
- (4) Project impact skills
- (5) Social media skills
- (6) Presentation skills
- (7) Project impact skills
- (8) Editing and proof reading skills
- (9) Practical skills including conference attendance

4. Support and personal development

Miss Sorcha Mc Cormack will be the lead supervisor for the scholar. Weekly meetings will be arranged during the summer internship. Regular contact will also be made throughout the academic year to keep the student informed as to the progress of the project.

5. Resource requirements of the proposed research

The student will not require any additional resources. If any materials are needed for the experiments, they will be included within the grant budgets.

6. Who should apply?

The successful scholar should have the following skills, attributes and interests:

- be highly motivated and organised.
- have excellent writing **and** research skills.
- have good communication skills
- be interested in the area of disability law.
- be punctual and able to work to deadlines
- be aware of ethical issues
- be interested in the aims of the project