

Title of the study:

Coping when your child has been diagnosed with an Autistic Spectrum Disorder (ASD): What are the views and experiences of parents in relation to coping with a diagnosis and receiving post-diagnostic support within Greater Glasgow?

A little bit about me:

My name is Mark Brownlie and I am an undergraduate student studying the BA (Hons) in Education and Social Services at the University of Strathclyde. In preparation for my dissertation, I have worked alongside Autism Network Scotland. I have always had a keen interest in developing an understanding of Autism and the means to which this can affect the family as a whole as well as the individual themselves.

I have worked with vulnerable people, as well as their families, for a number of years now – it is part of my long-term goal to contribute towards and influence the direction in which service provision is improved upon.

The purpose of this study and whom I am trying to reach:

I am conducting research on the importance of parental resilience – I believe it is important for future strategic development to ensure that the views and experiences of parents are heard. Throughout the Scottish Strategy for Autism there is a focus on improving the post-diagnostic services within Scotland, therefore it is vital to provide evidence as to how this may be improved in order to ensure that individual's with Autism *as well* as their families receive the right support if and when it is ever needed.

I would like to hear about your experiences as parents/guardians and the means to which a diagnosis of Autism within the family has had an impact on yourself and your family. I would like to gain an understanding as to what the overall experience of receiving a diagnosis and receiving post-diagnostic support has been for you and your family – particularly around the services that you have accessed for yourself or what services you feel would have improved the overall experience for you and your family.

Your views and experiences are valuable to improving upon the future of service provision to families in need of support, however this research is voluntary and you have no obligation to take part. If you do choose to take part then you may choose to withdraw at any point – this is entirely your choice. However, if you do choose to withdraw at the point of the focus group, as this is voice recorded, it may be difficult to ensure that your data is not included within any evidence or my final dissertation. If you do choose to take part, this will have no negative impact on yourself, your family or the services you may receive.

What I plan to do and the methods of doing so:

I would like to take a moment of your time and ask you to **please complete the following questionnaire (see link below)**. In doing so, this provides me with an overview of each participants experience and will then allow me to formulate an agenda for a focus group around the information gathered within each questionnaire.

You can complete this questionnaire online at:

https://hass.eu.qualtrics.com/jfe/form/SV_8p7mWXnijOM3bsV

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If you would like to be part of the latter stages of the research please put yes to the final question of the questionnaire and provide me with your preferred contact details so I can keep in touch and invite you along to the focus group.

What I plan to do with the information gathered and how will it be stored:

As aforementioned I plan to use the information gathered in this research to provide evidence as to what parents think is vital to ensuring that families have their well-being promoted – i.e. access to the right services at the right time.

The data will be stored electronically within a secured computer; **alongside this letter is a consent form, which I would appreciate if you could complete and return to the email address at the bottom of this letter.** You also have the right to withdraw your consent at any point within the research if you choose to partake in the focus group.

Ethical Considerations:

Anonymity – As this research will be documented as evidence as well as part of my final dissertation I would like to ensure you that I will be following a strict pseudo-anonymous formula. This means that if I document any particular quotes and or information it will be done so in a way that will protect your identity i.e. using a false name/location/age etc.

i.e. “I found that counselling really helped me during the process” Kate, 32, Glasgow. (false name and age)

To all participants of the focus group, as the focus group is likely to be held within the office of Autism Network Scotland, it is important to note that there may be a representative of Autism Network Scotland present. I will ensure that if this is the case that they are briefed on confidentiality and anonymity. I will maintain all data and no raw data will be made accessible to Autism Network Scotland, however once the research is complete I will provide pseudo-anonymised evidence, which may be of use to Autism Network Scotland.

Data Storage – As aforementioned, data will be stored on the university drives within a password-protected computer and will be destroyed upon completion of my dissertation. You will have the right to choose whether this data may or may not be documented in my final dissertation / evidence.

Are there any risks?

In completing the questionnaire as well as taking part of the focus group, this may include questions that require you to reflect upon your experiences. Some of these experiences may have been distressing or particularly difficult for you and your family. In addition, in particular to the focus group, you may witness other people expressing their experience, which again may have been difficult or distressing. Although there is a small risk that this research may cause some distress, please be assured that you do not need to answer all questions asked or discuss any difficult subjects if you do not wish to do so - you are also free to withdraw at any point.

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Please do not hesitate to contact me on the above email address with any questions or queries you may have.

Thank you very much for your time.

