**Participant information leaflet**

**What is it all about?**

NHS Fife has been developing a new tool, called the Fife Neurodevelopmental Questionnaire (the F-NDQ). The F-NDQ is filled in by parents, and gives the healthcare professionals working with their child a detailed picture of their child’s development up to that point.

So far, we’ve had lots of feedback from professionals using the F-NDQ. However, it is really important we hear from parents, as it is parents who are spending their time filling it in and usually know most about their child. We would therefore like to gather feedback from parents (either on paper, or via an online interview) about what parents think about the F-NDQ and how we can improve it.

**Can I take part?**

We are looking for parents in Fife who:

* Have one or more children (aged 18 or under) **diagnosed** with a neurodevelopmental disorder (such as Autism, ADHD, Learning Disability, or Foetal Alcohol Spectrum Disorder) in their care.

**OR**

* Have one or more children **on a diagnostic pathway** for a neurodevelopmental disorder (ie the ADHD pathway or Autism Assessment Pathway)

**What will I be asked to do?**

If you would like to take part, please email us at [fife-uhb.f-ndq@nhs.net](mailto:fife-uhb.f-ndq@nhs.net) including

* Your name and postal address
* Your child age, diagnosis/suspected diagnosis, and gender.
* Whether you would like to feedback by written comments, or via an online interview

We want to capture a range of parent experiences. This means it is important we don’t have too many responses from only one parent group, and only one or two from another. Therefore, if we have already had feedback from parents of children of a similar age/diagnosis/gender to your own, we may no longer require your feedback. If this is the case, we will let you know *before* we ask you to do anything further.

If your feedback is required, we will send you a paper copy of the F-NDQ to complete for your child. The F-NDQ is a long document, and may take some time to complete. However, it is important that you attempt to complete the F-NDQ, as you may find the experience of *completing* the F-NDQ different to simply reading it. Some parents may have already completed an earlier version of the F-NDQ as part of their child’s preparation for assessment. However, this is an updated version of the F-NDQ and so will be slightly different, so we would still like you to complete it. We will also send you a brief document outlining some of the key questions we hope to answer with your feedback.

If you said you would like to feedback with written comments, we’ll send you a word document to fill in and email back to us with your feedback. If you elected to have a video call to discuss the F-NDQ, we will arrange a time that is convenient for you.

Often parents involved with parent-led organisations dedicated to supporting children with neurodevelopmental disorders from strong friendship groups. If you and a group of your friends would like to feedback collectively, via an online discussion (each via their own computer/phone to maintain social distancing), this can be arranged, provided all parents wish to take part, and have at least one child with (or waiting to be assessed for) a neurodevelopmental disorder.

Video calls will be made using Attend Anywhere. This is the same software the NHS uses for confidential remote appointments. It requires a phone, tablet or laptop with a microphone, speakers and a camera, and an internet connection that allows you to make video calls. This software is free for you to use, but be aware that this may use some of your internet data allowance. We anticipate video calls will last approximately one hour. During the video call, the interviewer will take notes on your feedback, but the interview will not be recorded.

Whether your feedback via a word document or an online interview, we will not record any personal information. Feedback will not be tied to any one person, but amalgamated into collective feedback about the F-NDQ. You will not be required to send back your completed F-NDQ, nor discuss any personal information in your feedback.

**Will I be paid?**

Unfortunately, we are not able to reimburse you for your time.

**How do I get in touch?**

The project is being run by Dr Joshua Muggleton, a Clinical Psychologist in the Child Learning Disability team. You can email him at [fife-uhb.f-ndq@nhs.net](mailto:fife-uhb.f-ndq@nhs.net).

If you have any complains or concerns about how the project is run which you do not feel you can address with Dr Muggleton, you can contact his manager, Dr Audrey Espie via the Learning Disability team secretary on 01383 565210