

The Fife Neurodevelopmental Questionnaire (F-NDQ) Child Form Version 2 Guidance Document

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What is the F-NDQ?

The F-NDQ is a clinical tool designed to gather a single, exploratory, multidisciplinary developmental history applicable to all neurodevelopmental conditions, or where neurodevelopmental conditions are being considered as part of a formulation. It is a tool designed to be used in a healthcare context for children aged 18 and under.

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Part 1: Background and development of the F-NDQ

Rationale for the F-NDQ

“Neurodevelopmental disorders are behaviour and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, language or social function.” (ICD-11, WHO). These include Intellectual Disability (ID), Speech and Language Disorders, Dyslexia, Dysgraphia, Dyscalculia, Developmental Coordination Disorder, Autism, Attention Deficit Hyperactivity Disorder (ADHD), Foetal Alcohol Spectrum Disorders, Tic Disorders, and Stereotyped Movement Disorder. These conditions show significant overlap between each other (Gillberg, 2010; Hunt and Craig, 2015; Thapar, Cooper and Rutter, 2017), making assessment challenging. Gillberg (2010) estimates the total combined prevalence (accounting for overlap) at 7-10%, although this figure does not include Foetal Alcohol Spectrum Disorders.

Assessment of Neurodevelopmental Conditions “requires specialists from a range of disciplines (e.g child psychiatrist, psychologist, paediatrician, speech and language therapist and occupation therapist) and agencies (e.g health care and education)” (p340. Thapar, et al, 2017; SIGN 145, NICE CG128, NICE NG87, SIGN 156). Although essential, multidisciplinary assessment often means one child has multiple appointments with different professionals for one assessment. Siklos and Kerns (2007) found that for an autism assessment, parents saw on average 4.46 (S.D 2.42) professionals. Further, assessment services are often condition-specific (Gillberg, 2010, Hunt et al, 2015; Thapar, et al), meaning that if a presentation is unclear, or indicates co-occurring, multiple assessments with different teams may be required, leading to replication of information gathering (Kerry, 2017).

Recently, there has been a move towards ‘neurodevelopmental assessment pathways’. The Scottish Government’s National Neurodevelopmental Specification (Scottish Government, 2021) sets out that children and young people may require a neurodevelopmental assessment which takes into account their environment, experiences, and multiple areas of development (such as communication, attention, intellect, and movement). This allows those around the child to develop a shared formulation and understanding of a child or young person’s development, their

difficulties, and how they can be supported to fulfil their potential. It also highlights the need for multidisciplinary team working, and the possibility that as part of the neurodevelopmental assessment a child or young person may receive multiple overlapping diagnoses.

Guidelines and clinicians highlight the importance of a “structured discussion including a formal developmental history spanning preconception to present” (Hunt et al, 2015, p114; SIGN 145, NICE CG128, NICE NG87, SIGN 156) for neurodevelopmental differences. Several structured developmental history tools exist for specific conditions, such as the Autism Diagnostic Interview (Lord et al, 2000). These validated diagnostic tools predominantly gather evidence for or against a single diagnosis, and are therefore *confirmatory* assessments. While these are ideal for answering the question “does this child have this condition?”, they are less helpful in earlier stages of joined-up neurodevelopmental assessments where the initial questions are “what is contributing to this child’s presentation?” and “what further assessment does this child need?”, particularly in the context of mixed, complex, or inconsistent presentations.

Despite its importance, there is currently no quality standard or tool for developmental history taking for neurodevelopmental conditions more broadly. The Fife Neurodevelopmental Questionnaire (F-NDQ) is an exploratory tool which considers bio-psycho-social factors within a child’s development. This tool provides the necessary clinical history items to provide a basis for a comprehensive formulation of a child’s difficulties, and aid planning for future assessment or interventions as appropriate. It also supports clinicians who may be specialist in one neurodevelopmental condition to ask relevant questions about other possible conditions, and ensure evidence of absence is not confused with absence of evidence. For example, it is easy to assume that *other* clinicians have asked about alcohol use during pregnancy, and so one may assume that no mention of alcohol means there was none, when in fact nobody asked (indeed, a survey of Australian paediatricians indicated only 23.3% routinely asked about alcohol use during pregnancy; Elliot, Payne, Haan and Bower, 2006).

F-NDQ aims

The Fife Neurodevelopmental Questionnaire (F-NDQ) is being developed as a tool to complement NHS Fife's move to more integrated neurodevelopmental assessment pathways. Its aim is to produce a single, exploratory, multidisciplinary neurodevelopmental history which:

- Identifies the priorities for person and their family
- Gathers information about a child's development across multiple domains
- Considers multiple bio-psycho-social factors which may contribute to a person's presentation
- Allows information key to different professions to be gathered at once in a core neurodevelopmental history, reducing the need for a similar history to be repeated by a different profession
- Allows professionals who are not specialists in neurodevelopmental conditions to gather relevant information to inform their judgement on referral to specialist services.

Summary of the development of the F-NDQ Child Form Version 1.0-1.3

The F-NDQ was developed in collaboration between the Paediatric, Clinical Psychology, Psychiatry, Speech and Language Therapy, Occupational Therapy, Dietetics, Epilepsy and Nursing services in NHS Fife, and designed by Dr Joshua Muggleton.

Version 1.0 & 1.1

Individual and group meetings with the above professions were conducted, focusing on those working in or closely with existing neurodevelopmental assessment pathways. These meetings established the key questions each profession asked when assessing different neurodevelopmental conditions, and their 'core' developmental history which they would always ask about regardless of context. These questions were then grouped, duplicates and (agreed) non-essential questions removed, and their wording simplified. The resultant prototype was tested first on staff (completing as parents) and then by contributing professionals with a small number of their patients. This led to clarifications of wording, and the addition of questions relating to adoption.

Version 1.2

In January 2019 the F-NDQ version 1.2 was released. In NHS Fife, it was used widely with new referrals to community paediatric services, ID and ADHD assessment services, and child psychology services. It was sent to all families waiting for an autism assessment to complete. Allied health professionals and CAMHS also had access to the F-NDQ to use when appropriate.

Version 1.3

The main criticism of the F-NDQ from parents and clinicians was its length (29 sides of A4 for version 1.2), due to covering so many domains of child development, and the variety of different information considered essential by different professions. To address this, and with the author's consent, questions from the ESSENCE-Q (Gillberg, 2012) were incorporated into the F-NDQ as 'gateway' questions. This lengthened the document, but also allowed parents to skip sections of the F-NDQ not relevant to their child. Additionally, most questions moved to forced choice, with space for elaboration if indicated, further reducing the writing required. Questions about developmental milestones were changed from asking for estimates of age they were achieved, to whether a child 'seemed late', in light of parent difficulties recalling this information precisely (Ozonoff et al, 2018). After consultation with Dr Shields (Clinical Psychologist within the Scottish Fetal Alcohol Advisory & Support Team, FAAST), the pregnancy questions were refined to better and more sensitively capture possible indicators of alcohol or substance use during pregnancy. Finally, with consent, the SNAP-IV (Swanson et al, 2001) was incorporated into the F-NDQ to better capture hyperactivity, impulsivity and inattention, further reducing the writing requirements in this area. Version 1.3 was released in the summer of 2019. A digital version of this, allowing parents and clinicians to type their responses directly into a PDF form, was released in spring 2020.

Development of the F-NDQ Child Form Version 1.4

First draft

Development of version 1.4 started in Spring 2020. Since the release of version 1.3 in summer 2019, several points of feedback from multiple health boards had been received. While there were many specific points which users wished to address, common points included

- The need for questions on tics
- Better questions on alcohol use
- Better questions on attachment
- Shorter length

Version 1.3 was used as a basis for version 1.4. A section on tics was created, and further consultation with Dr Shields from the Scottish Foetal Alcohol Advisory Team was sought to further refine the pregnancy questions, which was given its own section separate from the child's medical history. After reviewing existing attachment tools, the section 'your child's relationships' was completely re-written, with attachment questions also imbedded in questions relating to a child's early history. Questions which tended to generate no or little useful information were highlighted for removal. Areas in need of development or refinement (e.g changing, re-ordering, re-wording, or removing questions) were identified. The resulting draft was sent to a range of multidisciplinary professionals (including Psychiatry, Clinical Psychology, Paediatrics, Speech and Language Therapy, Dietetics, and Nursing) from a range of specialities (neurodevelopmental assessment services, intensive therapy services, services for children who are looked after or accommodated, CAMHS, community services), within NHS Fife to ask for feedback and suggested changes. Interested parties from other health boards were also given copies to comment on.

Feedback was largely positive and specific points and suggestions were generally acted upon. There was, however, an exception to this:

One health board who use the F-NDQ as an interview (i.e not given to parents to fill in) has said they would prefer questions on attachment and difficult life events moved to the back of the F-NDQ as it is difficult to build enough rapport in time to

answer these questions. This was given careful consideration, but not acted upon. The majority of F-NDQs are given to parents to fill in independently, and then bring to the clinician to review in a session or over the phone. Consequently, it is noticeable that in many F-NDQs parents (understandably) write progressively less and less detail as they tire. Given the importance of detail in these sections, it was felt that making these the last two sections of the F-NDQ could result in poorer quality information. Further, questions on difficult life events and attachment are 'compulsory' sections (i.e do not have a gateway question which may enable the section to be skipped). All compulsory sections are at the front of the F-NDQ, and all 'gateway sections at the back. Placing these compulsory sections at the end of the F-NDQ, after completing 12 gateway where parents will have been able to skip some or all of those questions was felt to likely be demoralising for parents, and lead to a further reduction in detail.

As a compromise, the attachment and difficult life events sections were put as the last of the 'compulsory' sections to maximise time to build rapport, whilst keeping the clear divide between compulsory and gateway sections. Further, it is recommended that if clinicians are using the F-NDQ as a structured interview that they move between sections based on their clinical judgement, as the F-NDQ does not have to be completed in a specific order.

Second draft and service user evaluation

Based on this feedback, a second draft was compiled that represented the consensus feedback received from clinicians.

Permission had previously been granted to conduct a service user evaluation of the F-NDQ using focus groups. Due to COVID-19 lockdown, this protocol was revised and re-approved to gather parent feedback via email, telephone, and video conferencing. An advertisement for feedback was sent to Scottish Autism's One Stop Shop in Fife (who put it on their facebook page and website), a closed facebook group for parents who had completed the PINC ADHD Psychoeducation group in Fife, placed in the newsletter for Aberlour's McNally House, and through contacts within the Adoption UK Foetal Alcohol Hub. In this way, it was hoped to gather

feedback from parents with experience of Autism, ADHD, Learning Disability, and FASD.

The study initially aimed to recruit 20 parents. A total of 6 parents volunteered. One stopped responding to email contact after volunteering, and one volunteered after the cut off date. One was a parent of a child with autism, one of a child with ADHD, and two were adoptive parents of children with FASD. Additionally, feedback from a leader of a service supporting parents of children with FASD was given.

The feedback overall was very positive. Parents suggested several specific changes which were acted upon, but general points included:

- It took between 90 mins to 4 hours to complete, with the 4 hours being for a complex child and parents following the instructions exactly (digging out old photos, setting time aside to discuss, etc). Most families completed it in 2-3 hours
- Parents liked the F-NDQ. They felt it helped them communicate a clear picture of their child, and were delighted by the idea that this will stop them giving the same histories over and over
- Parents suggested they would like this in app form so they could take it with them, and would make it easier to fill in
- Parents mentioned they liked the fact that they could write about difficult subjects. This meant they knew what would be asked, could think about their answers, and that they didn't have to talk about such things in front of their child.
- Parents didn't feel the F-NDQ was overly negative, as they saw this as trying to identify difficulties. However, while they didn't feel the F-NDQ needed to add questions about strengths, they emphasised a final formulation produced by the clinician should do this.
- Parents really liked examples given on the questions, as this made it really clear what was being asked, and provided a reference for what is expected and what is unusual.

However, parents did highlight some issues:

- Several parents wanted more space to fill in the F-NDQ, although one noted that small space made her more concise which she found helpful.
 - As a result, while initially version 1.4 was the same length as 1.3, answer boxes have been expanded significantly which has made it 3 pages longer.
- The layout of the parents section was not at all appropriate for adoptive parents.
 - The parents section was completely re-written, following a format discussed with adoptive parents.
- There needed to be acknowledgement that for adopted children there may be limited information
 - Several sentences have been added in the introduction to the F-NDQ itself and to specific sections highlighting that adoptive parents may not have (or may legally not be able to share) certain pieces of information and that this is understood by clinicians.
- Some parents (both biological and adoptive) found the questions on pregnancy hard. Specifically:
 - One mum was "feeling frazzled" (her words) after a difficult day when she started completing this. She started to worry that because she went through a tricky time when she was pregnant with her child she might have caused her child's difficulties. She got panicky at this thought and called her mum and was calmed down. On re-reading the questions after this, she assured the examiner they didn't have the same effect, and she felt her response happened more because of her day than the questions themselves, which she said were very gently written. However, she pointed out that if parents are already tired/emotional, then it could trigger their worries running away with them.
 - Consequently, what had been a much longer paragraph discussing the thoughts and feelings that can arise during pregnancy and why it is important has been much reduced. It was felt that this paragraph was trying to be too 'containing' and may have a paradoxical effect for some parents. It was therefore made more factual and less about emotions.

Drafts 3-6

Following parent feedback, the F-NDQ was edited as outlined above (v1.4.3), and proof read (v1.4.4). Unfortunately, it became clear close to the proposed release date that the SNAP-IV could no longer be included in the F-NDQ so was removed. A possible replacement was identified (included in a draft version, v1.4.5) but was deemed not suitable. Therefore, qualitative questions were developed aimed at indicating if and *how* a child was showing signs of hyperactivity/impulsivity or inattention, rather than what level of difficulty they had, so as to help determine if these symptoms are likely ADHD in nature or if they could be due to other difficulties. This final sixth draft (v 1.4.6) became the F-NDQ version 1.4

Development of the F-NDQ Child Form Version 2

The author and NHS Fife agreed that, to increase accessibility and meet demand, it would be desirable to put the F-NDQ online free for anyone to access. As a result of this we have removed the ESSENCE-Q. Due to the demand, it was decided that version 2 would only be a minor update to 1.4.6, and so did not go out to service users for feedback.

Version 2 replaced the ESSENCE-Q questions with a statement asking parents to read the questions in a section, and if any might be applicable, complete all questions in that section. Titles of sections 9-20 were also updated, and references to the ESSENCE-Q removed.

In addition, some minor changes were made based on feedback

- Following feedback from LGBTQ+ parents, the parents section was updated to better reflect the diverse parenting dynamics. To accommodate this, parent fields were reduced from 6 to 4
- “Social naivety” was replaced with “social vulnerability” as this was felt to be kinder language.
- Instruction reminding users to fill in the ‘date completed’ added to the end of the form
- Minor typo fixes

- Following feedback from NHS Fife R&D, version number was updated to a whole number

Part 2: Using the F-NDQ Child Form Version 2

Clinical considerations

While most parents are able to complete the F-NDQ, some parents may find the language or interpretation of some questions challenging. Further, some answers may require additional detail or clarification. For both of these reasons, the F-NDQ should not be considered 'completed' until it has been reviewed by a clinician, with the opportunity to discuss parents' answers.

Parents with significant literacy difficulties should be supported by a clinician to complete all stages of the F-NDQ. Where parents complete the F-NDQ independently without the opportunity to discuss their answers, they should be provided with the contact details of the issuing clinician and the ability to discuss any questions they have about completing it.

As the F-NDQ must be reviewed by a clinician before deemed 'completed' there is a time-cost to the clinician reviewing the F-NDQ. When done in person with parents, this is usually at least a one hour-long session, and possibly more for more complex cases. However, having seen the F-NDQ and thought about or written their answers prior to their appointments, parents are more readily able to answer questions, often with large parts or the whole F-NDQ completed. Furthermore, this is time saved for all future clinicians as it is a *shared* developmental history.

While more time consuming, a broader initial assessment of child development reduces the risk of confirmation bias by prompting the clinician to question areas they may otherwise miss, devote less time to, or not know how to effectively question. Further, the highly structured nature of the F-NDQ means that clinicians who are not specialists in neurodevelopmental assessment are able to complete it with parents, provided it is within the bounds of their professional competence. This has allowed the F-NDQ to be used in contexts other than neurodevelopmental assessment pathways, for cases where it is thought a neurodevelopmental condition may be present. For example, a child presenting to CAMHS who on further investigation is thought may have a Learning Disability. This also reduces consultation time between

services as key information will have already been gathered, and key questions about neurodevelopment and differential diagnosis will have already been answered.

The F-NDQ is not a diagnostic or screening tool, and does not produce a score or outcome pointing to a specific neurodevelopmental condition. It provides a structured developmental history of sufficient breadth and depth to highlight possible areas requiring specific diagnostic assessment, and factors potentially influencing a child's development. The F-NDQ therefore provides the basis for developmentally informed, bio-psycho-social formulations of children's difficulties, and the context for any further assessment findings.

User qualification

Clinicians using the F-NDQ are expected to have a professional qualification, supervision, and registration as a healthcare professional whose core training involves some degree of child development teaching. If a clinician doubts their competence in child development they are advised to seek the advice of a child development specialist (e.g. working in a neurodevelopmental assessment pathway) before using or interpreting the F-NDQ. Unqualified clinical staff (e.g. assistants and trainees) may administer the F-NDQ (e.g. ask questions and record answers) under supervision of an appropriately qualified clinician, and at the supervising clinician's discretion. Interpretation of the F-NDQ should always be made by qualified clinical staff acting within their area of competence and with consultation with specialist staff where needed.

Methods of administration

The F-NDQ is designed to be used as a form to be sent/given to parents to attempt to complete themselves and then review with clinicians. It can also be used as a structured interview for clinicians to complete with parents, or sent to parents to send back as part of an information gathering process for establishing onward referrals.

Parents complete and review with clinicians

The best way to administer the F-NDQ is to provide parents with a copy of the F-NDQ to complete what they can themselves (or with the help of family and friends) and bring to their next (or first) appointment. The semi-completed F-NDQ is then

reviewed in clinic with the issuing clinician. This enables the clinician to quickly see information and decide if further questioning/detail/clarification is needed, or whether the answer does not require any follow up. This also means that parents who have difficulty completing the questionnaire are not penalised as the clinician can assist in its completion. At the same time, more straight forward information (who lives at home, bed times, etc) can be gathered without significant clinician time.

Structured Interview

The F-NDQ can be used as a structured interview. Here, the clinician fills in the F-NDQ, asking parents questions and recording their answers. This is more time consuming, although allows for a greater level of detail to be captured, and supports parents with significant literacy difficulties. The order of questions in the F-NDQ is designed for parents completing the form initially independently, but clinicians may wish to change the order sections are administered in when used as a structured interview, based on the rapport with parents in the moment. Parents often find having a blank copy of the F-NDQ to look at, or being able to see it in advance to be helpful. Further, this style of administration can be therapeutic when parents are struggling to understand how their child's difficulties inter-relate, as it affords the clinician opportunities to make links in parents' narratives.

Sent out to parents to send a completed version back

This is the least time consuming way to administer the F-NDQ, as clinicians review the F-NDQ content without parents needing to be present. However, it is important that reviewing clinicians ensure they apply the same standard to the F-NDQ to ensure that the information is sufficiently detailed (see 'Reviewing the F-NDQ' below). Parents should always receive feedback on what the clinician learned from their F-NDQ. Further, when used this way, parents should be directed to specific sources of support for completing the F-NDQ. For example, a pre-existing arrangement with another service who can help them to complete it, or a phone number to call if they have any questions. The general sources of support detailed on the front of the F-NDQ are not sufficient.

Issuing the F-NDQ

The following components should always be present when issuing the F-NDQ:

- An explanation to parents as to why they are receiving the F-NDQ, and how it will support their child
- The benefits of completing the F-NDQ. In particular:
 - That it provides essential and important information
 - That it will save them repeating the same information to different professionals again and again in the future
 - That they will only be asked to complete it once for their child, although they might be asked to update it in the future
 - That this information will be placed on their child's electronic record, so involved clinicians now and in the future can assess the information.
- Parents should be warned that the F-NDQ often takes several hours to complete
- Parents should be advised of sources of support for completing the F-NDQ, and how to contact the issuing clinician if they have any questions about completing it.

These points summarised on the introduction page of the F-NDQ itself (except for why parents are receiving the F-NDQ, as this will be individual to the person), but should still be explained to the parent when giving them the F-NDQ.

F-NDQ Child Form Version 2 Structure

The F-NDQ Child Form Version 2 consists of the following sections

- i) Cover page*
- ii) Introduction
- 1) Family Concerns and Priorities*
- 2) Family History*
- 3) Pregnancy and Birth*
- 4) Medical History*
- 5) Educational History*
- 6) Tics*
- 7) Your Child's Relationships*
- 8) Difficult Life Events*
- 9) Daily Living Skills
- 10) Motor Skills
- 11) Sensory Processing
- 12) Communication Skills
- 13) Activity and Impulsivity
- 14) Attention and Focusing
- 15) Social Skills and Friendships
- 16) Routines, Rituals and Special Interests
- 17) Emotions, Behaviour, and Mental Health)
- 18) Sleep
- 19) Seizures, Convulsions, and Faints
- 20) Eating, Drinking and Weight

**Compulsory section*

Reviewing the F-NDQ

The purpose of reviewing of a completed F-NDQ is to

- Ensure that the F-NDQ has been completed fully
- Identify areas where information is lacking and follow up on this. For example, answers with a 'yes' or 'no' indicating difficulties but with little or no elaboration of these
- Identify any inconsistencies in the information given
- Ensure that parents answers are understood and legible
- Ensure that any 'leads' (disclosures that hint at a problem that is not fully explained) are questioned and sufficient detail provided

In addition, going through the F-NDQ can be an extremely important and helpful process for parents. Parents often come with a 'story', a narrative of the journey they have been on with their child that they may have told many times before, but may rarely have felt *listened* to. Taking the time to go through their child's story and ensure you understand the child and parents' journey can ensure parents feel (and more importantly, are) listened to.

Reviewing the F-NDQ with parents can also be helpful for the parent. When parents are struggling to understand how their child's difficulties interlink, or what their child's world is like, reviewing the F-NDQ provides the clinician with opportunities to guide parents to make links between different areas of development. It can also provide opportunities to offer brief points of advice, provided it does not detract from completing the F-NDQ.

Storing the F-NDQ

It is **essential** that all completed F-NDQs are uploaded onto a child's widely accessible but secure electronic health record once it has been reviewed. As clinicians, this is our part of the agreement we are making with parents, and the reason they are willing to complete such a long form. Each service will have their own place for the F-NDQ to be stored, which should be widely accessible (e.g not limited to a specific age or speciality). There should be clear local guidance on where

and how to store the F-NDQ electronically and securely, including how it is filed and labelled so it is easily found in the future.

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