

## Participant Information Leaflet (DRAFT)

**Study title: Knowledge, attitudes and expectations of the ‘F-Words for Child Development’ in Children’s Disability Services in Ireland: A family perspective**

**Principal investigator’s name:** Yanlin Liu

**Principal investigator’s title:** Ms.

**Telephone number of principal investigator:** 087-4686002

**Supervisor:** Dr. Hazel Killeen

**Consultant co-supervisor:** Professor Agnes Shiel

You are being invited to take part in a research study by [Yanlin Liu and Dr Hazel Killeen](#) at [University of Galway](#)

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don’t feel rushed and don’t feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as ‘Informed Consent’.

You don't have to take part in this study. If you decide not to take part it won't affect your future medical care.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment you get in the future.

### **Why is this study being done?**

Over the last 20 years, there have been many changes in how we support children with disabilities and their families. Research from Canada has given us a lot of valuable information on how to best help children and families reach their goals. One approach that stands out is called the ‘F-Words for Child Development.’ This approach focuses on six key areas: Fun, Fitness, Function, Family, Friends, and Future. It aims to help families, children with disabilities, and the professionals who support them make the most out of daily life, both now and in the future.

We want to hear from you! Our study is interested in hearing about your experiences with family centre practice, specially for the ‘F-Words for Child Development’. We want to learn more about what you know about the ‘F-Words for Child Development’ and whether or not you like them! Don’t worry if you don’t know much about them, we can tell you more about them and you can let us know your opinions on them, and whether or not you would like to see them used in your health service. We’d also like to hear if you would be interested in more information and training on the F-Words.

Your opinion is really important to us. We will ask you about how much you value this approach and about your experiences using it with your children. This will help us determine if this approach could be a useful framework for others across the country.

### **Who is organising this study?**

The study is being completed by Yanlin Liu, Dr Hazel Killeen and Professor Agnes Shiel, all of whom are really interested in services being offered to families of children with disabilities in Ireland. The study has ethical approval from University of Galway.

### **Why am I being asked to take part?**

You've been invited to participate in the interview because you are a parent of a child with a disability aged 0-18 in Ireland. We are interested in learning about how you use the F-Words for Child Development framework, which includes Function, Fitness, Family, Friends, Fun, and Future. We want to understand how you are applying these concepts, what you think about them, and how they might be affecting the services your family receives.

Your input will be valuable in helping us see how the F-Words are working in practice and in guiding future, larger studies on this approach.

### **How do I join this study?**

Firstly, we ask you to read this leaflet carefully and contact us if you need any more information about the study. If you are happy to take part in the study, we ask you to follow the link <https://nuigalway.questionpro.eu/t/AB3uxmIZB3wEHC> (also included in the email). This will bring you to an online consent form followed by an online questionnaire. **You will not be identifiable in any way** from your questionnaire.

OR if you are interested in taking part in a follow-up interview (about 30 minutes), You will have the option to a link <https://nuigalway.questionpro.eu/t/AB3uxmIZB3wEG3> to leave your email or contact number. Alternatively, you can email us directly at [y.liu17@universityofgalway.ie](mailto:y.liu17@universityofgalway.ie).

#### **What can I expect if I agree to take part?**

- 1. If you are happy to take part in the study, we ask you to follow the link at the end of this document (also included in the email). This will bring you to an online consent form followed by an online questionnaire. You will not be identifiable in any way from your questionnaire.*
- 2. By the end of the questionnaire, if you are interested in taking part in a follow-up interview (about 30 minutes), You will have the option to leave your email or contact number. Alternatively, you can email us directly at [y.liu17@universityofgalway.ie](mailto:y.liu17@universityofgalway.ie).*
- 3. We will ask you to complete an once-off interview to discuss your experiences with family centre practice and the F-Words for Child Development framework. (If you already know something about the F-Words that's great, if not don't worry we will tell you about them!)*
- 4. One of the researchers will meet you at a time and date that suits either online via ZOOM or face-to-face, whichever is more convenient for you.*
- 5. The once-off interview will take 30-45 minutes to complete.*

#### **What are the benefits?**

By taking part in this study, you'll have a chance to reflect on a new approach to child development that's being used successfully in other countries. You'll also get to share your thoughts and experiences with the F-Words approach and whether you would like this to be included in your child's services.

Your participation will help us understand how the F-Words might impact the services you and your family receive. After we gather the results, we'll be happy to share them with you and the network teams, if you're interested.

#### **What are the risks?**

We understand that discussing the challenges you face in caring for a child with a disability can be sensitive and might be upsetting. Please only share what you feel comfortable discussing.

We also want to assure you that your privacy is important to us. Your personal information and opinions will not be made public. You will not be identifiable in any way.

#### **Is the study confidential?**

Yes. In this research, minimal identifying information will be collected. This information will be made anonymous and stored on a secure password protected, cloud-based, OneDrive in University of Galway.

<b>Data Protection</b>
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1. This study is being completed because of legitimate interests and for scientific research purposes – see Article 6 and 9 of the General Data Protection Regulation 2016. If you are unclear please contact the Data Protection Officer.
2. Only Yanlin Liu, Dr Hazel Killeen and Professor Agnes Shiel will have access to this data from this study.
3. Data collected via your once-off interview will be made anonymous. The data will be stored on a secure password protected, cloud-based, OneDrive in University of Galway in line with the Data Protection Act 2018 and deleted after 7 years.
4. You have a right to lodge a complaint with the Data Protection Commissioner.
5. *You have a right to request access to your data and a copy of it. Please note though, once analysed, as this interview will be anonymised and mixed with the results from other participants, there is no way of us withdrawing your information from the study as it will be merged with the results from other participants.*
6. *You have a right to restrict or object to processing of your data, however that would make it difficult to complete the overall research.*
7. *You have a right to have your personal data deleted, but again once analysed, your interview will be anonymised and mixed with the results from other participants, there will then be no way of us withdrawing your information from the study as it will be unidentifiable and merged with the results from other participants.*
- 8.
9. You have a right to data portability, meaning you have a right to move your data from one controller to another in a readable format.
10. There will be no automated decision-making or profiling of your personal information in this study. This means that we will not use your personal data to make any predictions about you.
11. Your information will not be processed for any other reason other than for this study. And it will not be transferred to any other country or organisation.
12. Your information will be held on a password-protected file storage system. Only the researchers have access to this.

<b>Where can I get further information?</b>
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If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect you or your child's access to services now or in the future. If you need any further information now or at any time in the future, please contact: [y.liu17@universityofgalway.ie](mailto:y.liu17@universityofgalway.ie) or [hazel.killeen@universityofgalway.ie](mailto:hazel.killeen@universityofgalway.ie) .

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