

F.U.S.S Ireland

SHORT SURVEY ON
COMMUNICATION WITHIN
CHILDREN'S DISABILITY
SERVICES

February 2024



Families Unite for Services and Supports (F.U.S.S) Ireland have created this survey to capture the communication experiences that service users and staff have, within Children's Disability Services in Ireland as of February 2024. We take this opportunity to thank all our respondents for partaking in this survey.

Introduction to the Authors

F.U.S.S Ireland is an advocacy group run by volunteers who are family carers of children living with disabilities. We consist of a core national executive committee and official F.U.S.S sub groups in Cork, Tipperary, Meath and Balbriggan(Dublin).

Here at FUSS Ireland, we are driven by a single goal; to do our part in improving access to Disability Services and appropriate Educational Settings in Ireland.

Background to the survey

Since the reconfiguration of Children's Disability Services to a model called Progressive Disability Service in 2021,one of the biggest challenges service users and their families repeatedly report to us,is poor communication with their disability service provider.

This survey seeks to demonstrate whether this challenge had existed prior to the reconfiguration and whether there have been any changes in over two and a half years since PDS was rolled out.

Methodology

This survey was created on 13/02/24 and circulated online until 20/02/24 via our social media platforms.

It was open to family members of children with disabilities, service user themselves and to staff working within children's disability services.



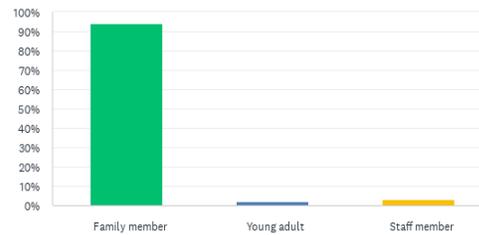
F.U.S.S.

Families Unite for Services & Support

Respondent profile

94.32% of the respondents are family members of children living with a disability, 2.27% are young adult service users and 3.41% are staff members of children's disability services.

Q1 Are you a family member of a child with a disability, young adult with a disability or a staff member of children's disability services?



Respondent Profile- Length of experience

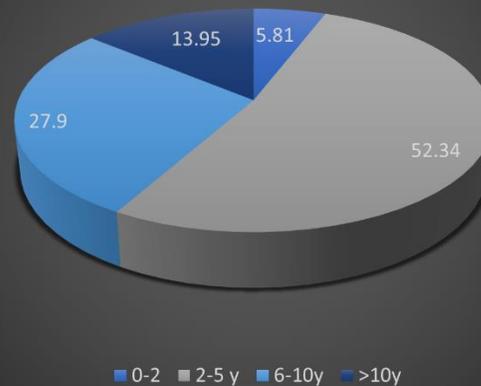
The length of time our respondents have been with children's disability services was categorized into four groups for ease of data sharing.

The largest group of respondents - 52.34% was in the two to five years of experience group, next was those who have been with the services less than two years which was 27.9%, then came the group that have between six and ten years of experience which made up 13.95% of respondents and finally 5.81% have over ten years experience.

71.5% of respondents have been with children's disability services previous to the reconfiguration to the PDS model.

28.5% of our respondents had no experience with children's disability services prior to the reconfiguration.

Length of experience

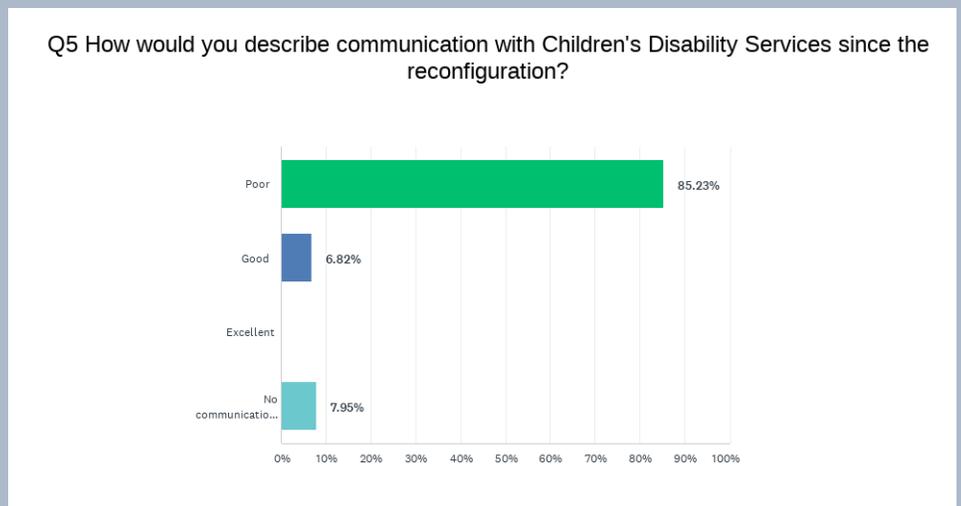


Communication Experiences

Respondents were asked to rate their experiences of communication with the services prior to and since the reconfiguration.

Prior to the reconfiguration, 52.27% described it as poor, 23.86% as good, 4.55% as excellent and 19.32% said they were not with the services before reconfiguration.

Since the reconfiguration respondents described communication with children's disability services as follows.



Of the 7.95% who have had no communication, two thirds of them are living in the South East. 42.5% have been waiting since 2021 for their first contact. 57.5% had been receiving a service but have heard nothing since the changeover, despite making contact themselves.

Observations: There has been a significant increase(33%) in the respondents choosing Poor to describe communication since PDS came into effect. What is disheartening is to find that nobody chose Excellent, a loss of 4.55%.

People were then asked to explain their rating of communication since the reconfiguration.

Observations: that while the lack of services came up in some of the **family member** responses such as;

*“No communication and no services for my children”
“Haven’t heard from them since August 2022.”
“Lost direct one to one access to therapies.”*

Families also reported communication difficulties in areas such as,

“Nobody can give a straight answer about anything, they just expect us to sit and silently wait.”

“Zero communication on when key workers leave, you’ve to chase reports, it’s a constant chasing situation!”

“Communication has always been poor - before the CDNT, it was Early Intervention I dealt with. With staff leaving, managers leaving, no update to parents on staff etc - I am constantly told to email the general email with any query and many times I do not get a reply.”

“Before reconfiguring, we used to have appointments issued in the post. Now my voicemails are ignored, there have been no appointments in years and written correspondence just spouts nonsense about staff shortages.”

“Our CDNT manager does not answer calls/emails and has made it so her phone no longer goes to voicemail. The call just goes dead. Our proposed respite service (through CDNT) simply ignores calls/messages to the point that we do not feel safe availing the service.”

Young adult service users made up 2.27% of our respondent profile, have been with the services since prior to the reconfiguration and would have previously described communication with service staff as good or excellent. All describe it now as poor and explained that nothing had been explained to them about the changeover and how it would affect them, also one young adult said-
“ Even post complaint, communication leaves much to be desired. Weeks to answer emails. Phone ring out and voicemail full”.

What **children’s disability staff members** described was internal communication difficulties, difficulties getting their own child seen by the services, feeling frustrated with “the system”.

Barriers to effective communications

From a staff point of view, they described the lack of adequate staffing levels as a significant barrier both to internal and external communication. They also feel more responsibility should be taken to address this by management.

Young adults blamed staffing levels also with one respondent saying,

" Very hard to know. Most people can't even get a response to an email. Surely that's what admin are for. Also, therapists are constantly changing. It's like a revolving door in our CDNT."

Family members are most of the respondents and there are a variety of reasons given as to what they thought were barriers to effective communication. **Nobody** mentioned the language used in communications from their service provider.

41% of them blamed staffing shortages are a barrier, but other reasons given included,

- A perceived lack of empathy
- Not a priority for staff
- Poor communication internally (this was mentioned by staff also)
- A lack of honesty/transparency
- Staff are completely overwhelmed with the caseloads.
- Not having the courtesy of being told when a staff member is leaving or has left.
- Not being told about the vacancies and having to hear it from other families or online.
- The lack of experienced staff causes a lot of upset on both sides (as inexperienced staff have nobody senior to turn to, which was also mentioned by staff outside of this survey)

What will improve communication according to respondents?

Recruitment and retention of staff

Transparency, staffing levels and where you are on the list.

Regular updates from the team even if little has changed, it is still communication.

Regular check-ins, even by phone a few suggested.

Hire more admin to let therapists provide therapies.

Response times to contacts made by families/service users needs to be significantly improved.

Key worker to provide one point of contact was mentioned several times.

More consequences for upper management as things are obviously very poor now.

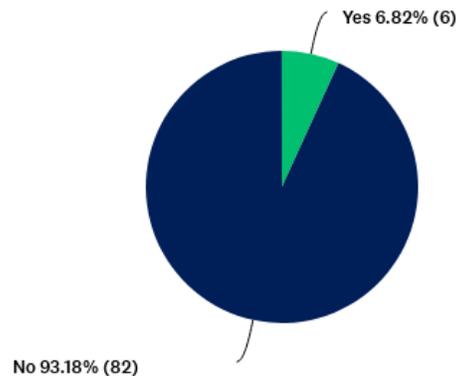
The Family Forums

The Family Forum provides an opportunity for families to discuss general issues and ideas about the children's disability services in the Network. The purpose/aim of these forums is to;

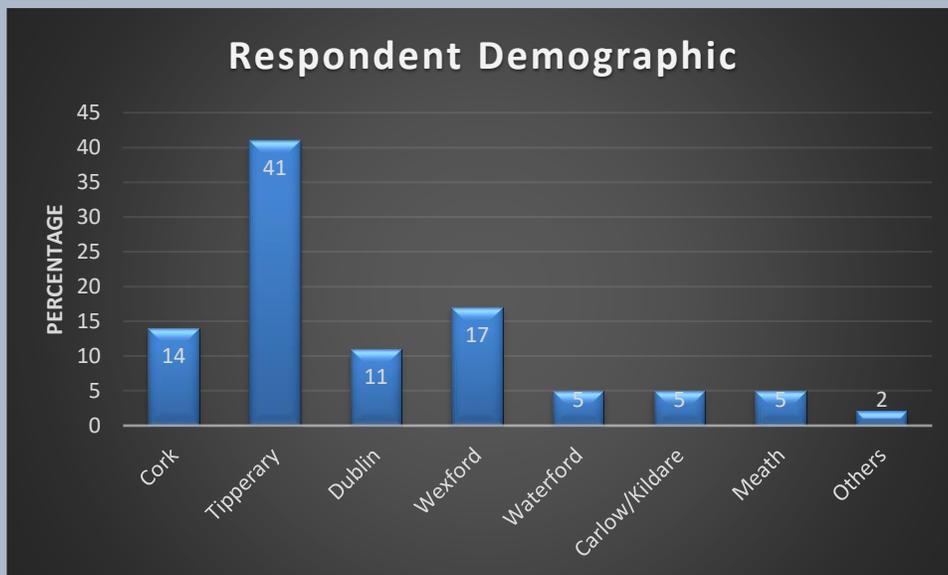
1. To involve families in the development of children's disability services in their local CDN.
2. To elect two Family Representatives who will meet the CDN regarding Network issues and ideas raised by the Family Forum and will join the Family Representative Group at area level.
3. To share information on:
 - Service provision, governance and access.
 - Community supports available.
 - Rights of the child and the family.
 - Other relevant topics of interest.To facilitate networking and sharing knowledge and experiences amongst families.

Family Forum Question: One of the serious issues raised at every family forum we at F.U.S.S Ireland are aware of, is poor communication and so we asked our respondents if communication had improved since their Family Forum took place. The following chart demonstrates their responses.

Q9 Every Family Forum has brought up poor communication as a serious issue. Has communication improved SINCE your family forum happened?



Finally, we asked respondents to list their county to provide us with a demographic of respondents. As the overall response was negative, we were unable to identify the better performing areas, as we had intended, when designing the survey. The chart below categorizes them by county.



Summary

71.5% of respondents have been with children’s disability services previous to the reconfiguration to the PDS model in 2021 and whilst their experiences of communication with service providers was never perfect, nearly 5% of them described it as excellent and are now describing it as poor. There has been an increase of 33% in people rating it as poor. Staff themselves admit that communication is poor internally and externally with service users.

Unfortunately, the move to progressive disability services has damaged the relationships built up over time between children’s disability services staff and the children. Many of those staff are no longer working in the service. Response times to contacts made by families needs to improve significantly. It is not a huge ask, to receive at a minimum, an acknowledgement of your query.

It is a matter of courtesy that a family or service user would be told, if a staff member they had been corresponding with, has left the team. A “bounce back” email is a completely unacceptable way to find out.

Whilst we all acknowledge that recruitment and retention are vital to the success of the new model. There must be a positive relationship between service users and service providers. Families and service users are the centre of this new model and effective communication and trust must be restored, in order for the model to be a success.

With this in mind we at F.U.S.S. Ireland are calling for a new national communication strategy to address the issues raised by staff and service users in children’s disability services. This strategy must be a high level priority before the relationships disintegrate further.

Signed
The Executive at F.U.S.S Ireland