



Your Experience of Complaints Procedures in Disability Services

**The Perspectives of Service Users and
Parents/Guardians
2023**

Contents

Abbreviations	3
Methodology	4
Summary	5
Respondent Profile	5
Escalation of Complaints HSE	5-6
Resolution of Complaints	7-8
Perceived Consequences of Complaint	8-9
Transfer to other Services Post Complaint	9
Comments from Service Users	9-10
Conclusion	11

Abbreviations

AIMS- Access and Inclusion Model

AON – Assessment of Need

CAMHS – Child and Adolescent Mental Health Service

CDNM- Children’s Disability Network Manager

CDNT – Children’s Disability Network Team

CHO – Community Health Organisation

CORU – Multi-profession Health Regulator

DS- Down Syndrome

FCP- Family Centered Practice

FEDS – Feeding, Eating, Drinking, Swallowing Difficulties

HSE – Health Service Executive

IFSP – Individual Family Support Plan

KPI- Key Performance Indicator

MDT – Multidisciplinary Team

OT- Occupational Therapy

PBA – Play Based Assessment

PDS – Progressing Disability Services

PC- Primary Care

PCC – Primary Care Centre

SLT/SALT – Speech and Language Therapy

WTE – Whole Time Equivalent

Methodology

The data was collected via an anonymous survey between May 27th, 2023, beginning at 16:00 and May 30th .2023 ending at 21:00.

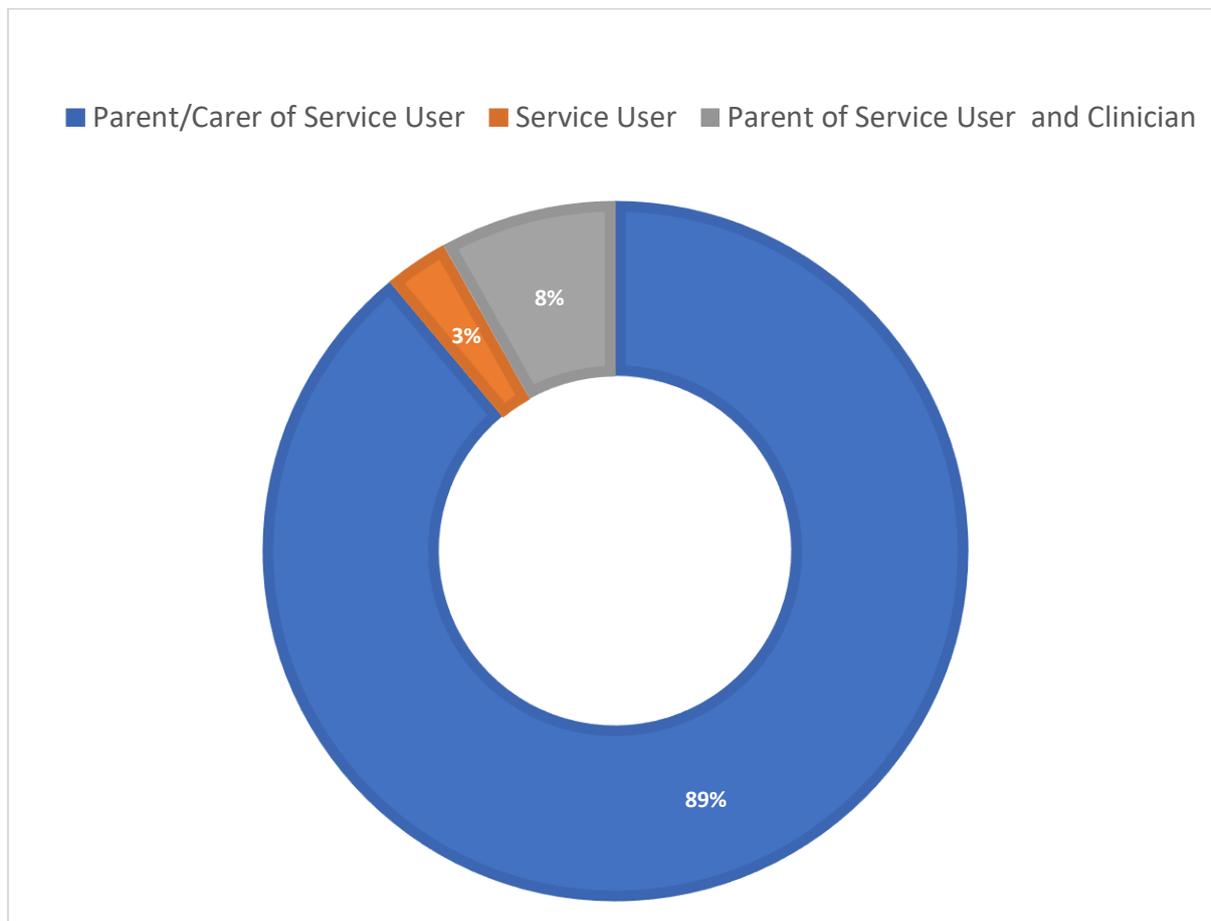
An invitation to participate was initially circulated to our 105 members and 529 website subscribers. We swiftly extended circulation to our social media channels.

Overall, this survey had 136 participants.

Summary

- Of the 61% who made a complaint via HSE platform "have your say", 39% did not receive acknowledgement of their complaint in the 30-day time frame.
- A staggering 90% of those who complained stated that their complaint was not resolved by HSE's initial response.
- 49 respondents did not know that escalating their complaint was an option while 22 participants, 27%, who were aware of this option advised that this information was not readily available to them.
- 92% of participants who did escalate their complaint specified that their complaint was not resolved. A mere 2 respondents felt they had a resolution post complaint.
- The quotes from participants express concern regarding loss of service if a complaint was lodged or escalated.
- 63% or 81 participants have also complained directly to their assigned CDNT or PCC.
- Of the 81 participants, only 6 were provided with or directed to the Complaints Policy relevant to their CDNT or PCC.
- 33% of respondents were transferred to another service post complaint. 100% of those transferred did not receive any policy documentation regarding transfers.
- Only 1 participant was aware of their right to appeal this relocation.

Respondent Profile

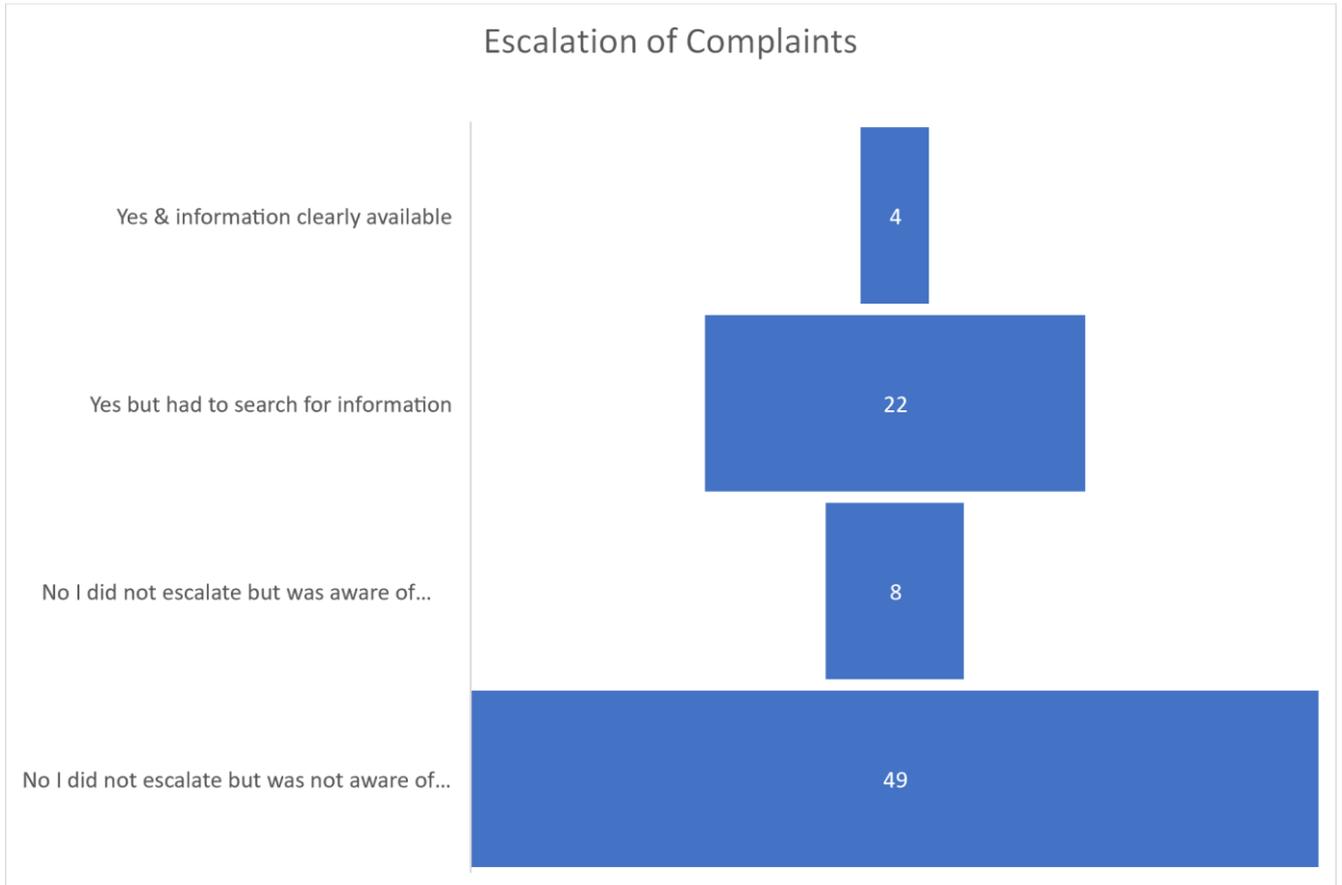


61% of respondents have made a complaint to the HSE via the “Your Say” platform. 61% received a response from HSE within the 30-day timeframe, leaving 39% who did not. 90% stated that the initial response from HSE did not resolve their complaint.

The 90% of respondents whose complaint was not resolved were asked the following:

Did you know how to escalate the complaint and was that information clearly available?
Please read options carefully.

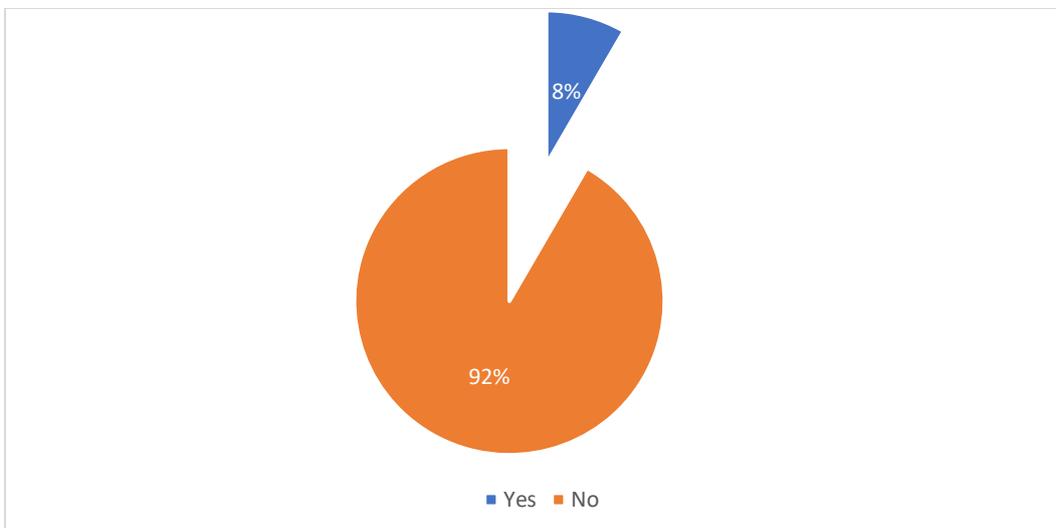
The breakdown is depicted in the following graph.



As depicted above, 59% of participants (49 people) WERE NOT aware of their option to escalate their complaint. 18%, or 22 people, of those who did escalate had to seek out this information themselves with a meagre 3% stating that the information was “clearly available” to them.

Participants were asked the following:

If you escalated your complaint, was it resolved?



Participants were asked the following:

Have you ever complained directly to your assigned CDNT or Primary Care Center (PCC)?

83 participants advised that they have complained directly to their assigned service. Of this 61%, the majority, 73 people, were not provided with the service's Complaints Policy nor directed where to source it. An additional 4% were unsure if they had been provided with a copy or not.

Furthermore, the 6 respondents who did receive a copy of their assigned service's Complaints Policy asserted that the response to their complaint DID NOT adhere to the timeline in the policy provided to them.

Participants were asked the following:

Do you feel your complaint (via any channel HSE/CDNT/PCC) was resolved? Why/Why not? Please explain.

(The following are direct quotes from the survey and contain the most common themes. We have not altered the language or abbreviations used. The views expressed are from both service users and parents/carers)

These are the most common themes identified.

"Complaint via CDNT was resolved as my child was seen for PBA by staff. Complaint to HSE was not resolved. Initially complained via have your say in Feb 2021. HSE asked for additional time to investigate in March 2021 and again in April 2021. They advised the investigation would be completed by June 2021. I have followed up numerous times with phone calls/emails. I escalated to regional complaints manager. Complaint still outstanding over 2 years later."

"No, we engaged in mediation but ultimately it required legal action"

"No. Complaint went in, got initial response to say its being looked at. Heard nothing back."

"I cannot comment fully as a file has been submitted to the DPP by the Gardai but the HSE, HIQA, The service provider, Ombudsman etc woefully failed and continue to fail my daughter "

"There should be an independent complaints procedure, the hse cripple you with policy and procedure while you are groaning under the weight of delayed diagnosis and or delayed intervention."

"Complaints sorted by TD's."

"Definitely not. Received a 'summary' of how they followed THEIR OWN policy I.e. they did nothing wrong,

"I directed it to your service and to the network manager, as well as the CHO office. To date I've had no response but missed the whole point of the complaint."

"No. Basically given all the usual recruitment problems, issues as reasons for failings."

"No, completely ignored. Example family plan sent to me full of errors, complained, edited document and returned it. Never updated or followed up on."

"Ombudsman for children intervened and pressured the HSE into resolving it"

"Yes- I received an apology, a contact email address (primary care being uncontactable part of complaint) and a timeline for service that they stuck to. I did not receive an adequate explanation as to why a service was uncontactable and why they supposedly never received or returned voicemails"

"I wasn't expecting it to be resolved. I was doing it more to make a point to the decision makers that the current system is not good enough and also to support the staff that are currently working in a broken system."

Participants were asked the following:

Have you ever faced negative consequences as a result of a complaint? Please explain.

(The following are direct quotes from the survey and contain the most common themes. We have not altered the language or abbreviations used. The views expressed are from both service users and parents/carers)

These are the most common themes identified.

"No really but I feel like I'm viewed as a nuisance or "that parent"

"I feel our family are seen as 'trouble makers', making big deals out of nothing."

"Yes, child was moved to another CDNT and never seen again as punishment"

"There is always a fear that the hse will make things harder in the future for your axis services cause you complained. Everyone has different entitlements even if in similar circumstances. Luck of the draw"

"Yes. Recently almost threatening to be sanctioned for my complaining"

"Yes. I've no access to wheelchair, disability aids."

"Not yet. Hard to have more negative consequence Than just sitting on a wait list with no sight of your actual placement on said list."

"No. But I'd never complain for fear of consequences or I'll be skipped over by therapist for a kid with 'less complex ' needs"

"When I broke down crying and questioned why our 4 year wait was to increase to 6 years I was told that if I kept complaining they wouldn't take my calls anymore."

"Yes many times, I wasn't listened to, I was told that my Son's "issues" were due to the breakdown of my marriage/separation' or my Mother's death"

"No but I'm nervous to complain too much for fear it will have a negative impact on my child"

Participants were asked the following questions:

If you were transferred to another service following a complaint, were you given access to the transfer policy?

If transferred, were you informed of your rights to appeal?

Twenty-seven respondents or 33% disclosed that they had been transferred to a different service provider following a complaint. Of these respondents, 20% were not informed of their right to appeal this decision. Only 1 participant acknowledged being aware of their right to appeal.

Participants were asked the following question to end this survey:

Any other comments regarding complaints

(The following are direct quotes from the survey and contain the most common themes. We have not altered the language or abbreviations used. The views expressed are from both service users and parents/carers)

85 participants answered this question. The key themes are quoted below:

"It's exhausting and with no resolution for us. It feels like no one is accountable."

"There seems to be no connection between places like St Joseph's/brothers of charity/enable ireland and the HSE. They all just do what they like with no accountability"

"Upon completing my complaint, when I did receive a letter it did not acknowledge that my son was negatively impacted upon due to reconfiguration. There was no offer of a key contact or review. The reply advised to contact the ombudsman for children."

"The CDNT manager decided to escalate my complaint and refused to give me the name of the person that my complaint was being escalated to, I asked in writing three times and she ignored the question."

"My complaint wasn't resolved because it was due to my son not getting an initial appointment with the CDNT. The manager told me that she couldn't give me a time frame for him to be seen, and if I wanted to, I could keep complaining because I was entitled to do so"

"I feel so sorry for therapists on the ground having to spend time responding to things that aren't their fault. The whole complaints procedure is as big a mess as the service itself."

"Right to complain is not emphasised and often discouraged as one believes that the minimal service received will be further diminished"

"Response was that the complaint was upheld and that was it. No resolution and this predates PDS"

"CDNT staff are spending an inordinate amount of time responding to complaints about lack of services, the cause of which is down to unequal pay across teams, lack of sufficient graduates in the required disciplines and not enough funded staff for teams. This is all outside of the control of the CDNT yet significant time that could have been spent on clinical work instead."

"My complaint was upheld (lack of AON) but not acted upon. So I have resorted to taking the HSE to court which is truly ridiculous. I also recognise as an educated English speaker, I am fortunate to be able to do so."

"You feel it's pointless making a complaint because nothing comes of it. You go through gaslighting and just made feel small then the child suffers from no appointments. You are labelled crazy or hysterical all because you spoke up."

"Complaints are a lot of effort and do not improve outcomes"

"Having submitted multiple complaints since 2021 via Your Service, Your Say, I have never received an adequate outcome. It is yet another frustrating and exhausting cog in the constant battle"

"Many phone calls begging for services left me in an extremely distressed state and as a family we made the decision not to pursue a complaint as all dealing with HSE were affecting my mental health"

"All complaints need an advocacy system and logged, fully reported, outcome with systemic changes if necessary"

Conclusion

Following on from this survey, it is important to acknowledge how convoluted and unclear HSE/CDNT/PCC complaints processes are. There is a requirement for a clear, accessible, and joined up "Complaints Pathway" for children's disability services.

Additionally, the role of the Ombudsman appears to be misunderstood among parents and clinicians. We would advocate that accurate, easy to understand information regarding the role and limitations of the Ombudsman for Children is communicated to families.

We would be remiss not to stress the toll the complaints process takes on families. The extra stress can affect many areas of their lives and is a strain that all service users and carers could do without.

It is evident from this report that service users and their families, 8% of whom are also clinicians, feel that complaints are not treated seriously. There is, as documented previously,

a need for transparency which includes the publication of data related to complaints.

Overall, communication and trust between service providers and families must be enhanced to achieve a functioning system.

Thank you to all who contributed and those who took the time to read this document.

The team at FUSS

Authored by Rachel Martin, Rebecca O'Riordan and Edwina McElhinney



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