



# Thoughts and Experiences of PDS

The Perspectives of Service Users, Carers and Clinicians  
2023

*A Survey conducted by  
FUSS IRELAND*

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# Foreword

Dear Reader,

We are pleased to present FUSS Ireland's first publication since its inception in early 2022.

We wish to thank our volunteers for their time and effort in gathering this information and formulating the following report.

At FUSS, we hear daily from families, carers and professionals attempting to navigate disability services in Ireland.

Since the reconfiguration of PDS in 2021, accessing and providing services has become increasingly difficult. Media reports have become a daily occurrence with families forced to abandon their privacy to highlight the inadequacies.

We have spoken to clinicians at their wits end burdened with unrealistic caseloads and working on skeleton teams.

Disability Services have been an underfunded and under-resourced area for decades, long before the birth of our volunteers and their families.

In this report, we aim to highlight the perspectives of families, carers and clinicians.

We address the impact of re-configuration on CDNT and Primary Care teams as well as the changes for families, both positive and negative.

Most importantly, we look at moving forward by asking the vital questions. What do families actually want and need? Do families and therapists think the current model of service delivery is effective and if not, how can we change it?

The same themes echo throughout. The lack of funding, the lack of political will to drive change and ultimately the absence of accountability for multiple generations of children who have been failed by their government.

FUSS is a data and solutions driven team. We believe change is achievable with the correct supports in place. We will continue to liaise with families, therapists and government to advocate for equity.

#LetsMakeAFuss

Sincerely,

The Team @ FUSS

# 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 April 28<sup>th</sup> 2023 beginning at 16:00 and May 3<sup>rd</sup> 2023 ending at 16:00.

An invitation to participate was initially circulated to our 98 members and several hundred website subscribers. We swiftly extended circulation to our social media channels.

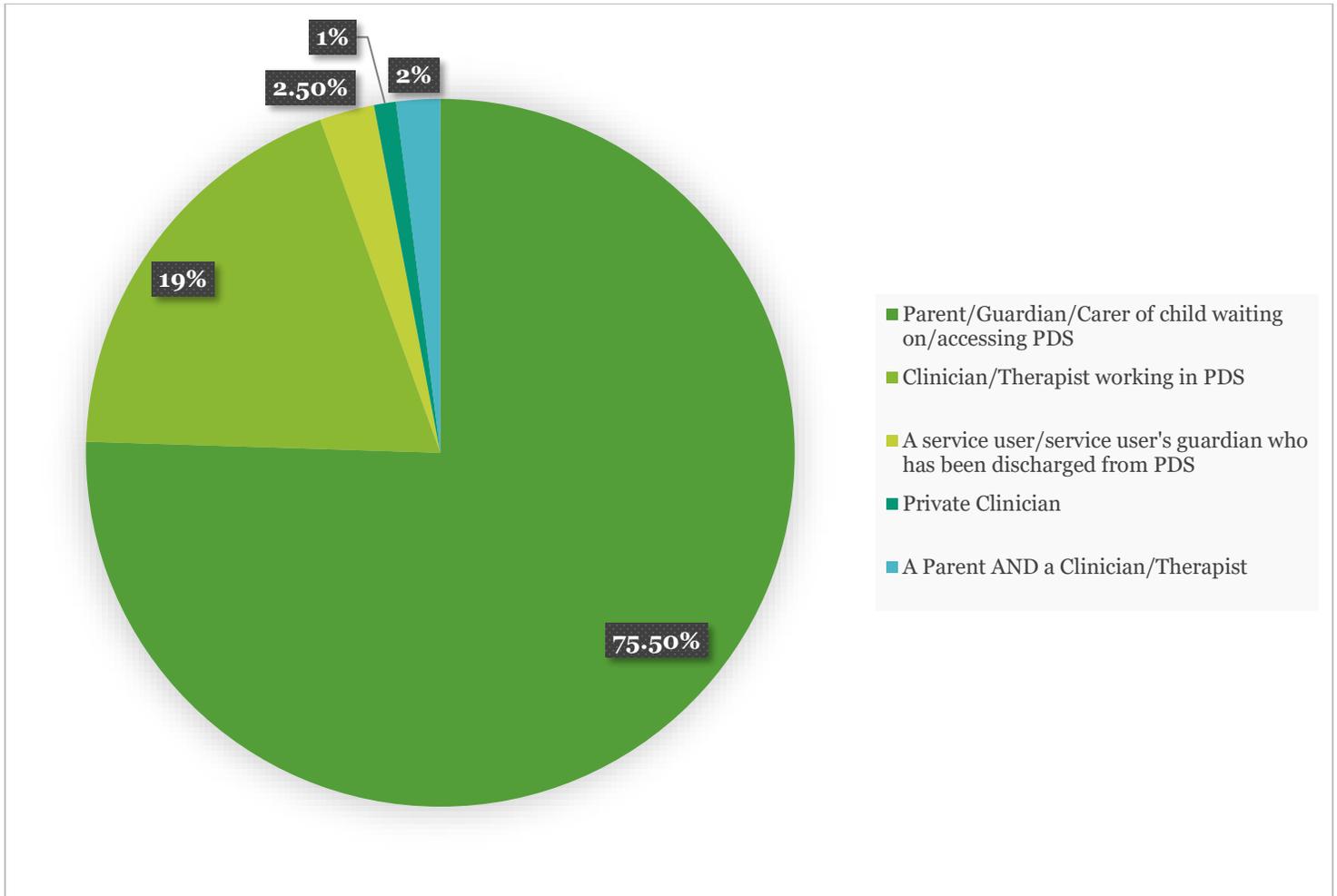
Given our status as unpaid volunteers and carers, we were forced to close the survey after 5 days due to the influx of responses. This decision was deemed necessary to ensure collation of the data was manageable.

# Summary

Several key issues emerged as concerns regarding Disability Services held by both parents/carers/guardians and clinicians/therapists.

- 97% identified Staffing Recruitment and Retention as a vital threat to the success of service provision.
- 45% agreed that Staff Pay and Conditions play a major role in PDS inability to retain its current staff and entice more to join the workforce.
- 80% of respondents feel that PDS model and subsequent reconfiguration has failed while 16% remain unsure.
- An astonishing 40% do not understand the PDS model nor the purpose of reconfiguration. Thus, highlighting a common theme in this report, the lack of transparent and clear communication between teams and service users.
- 72% of participants feel that there is a lack of accountability by upper levels of management (defined as "Heads of Disability", "Service Managers and CEO", "CHO leads/heads of Disability Service", "National Level Directors", "HSE Chief Officers" and "Government, relevant Ministers".)
- Disability services have been described as disjointed, diluted and clinically unsafe for staff and users. There is a call for specialist and cohesive inter-agency working echoed throughout the replies.
- 4% of participants feel the PDS model is worth striving for but acknowledge that without adequate staffing and resources, it is an impossible feat.

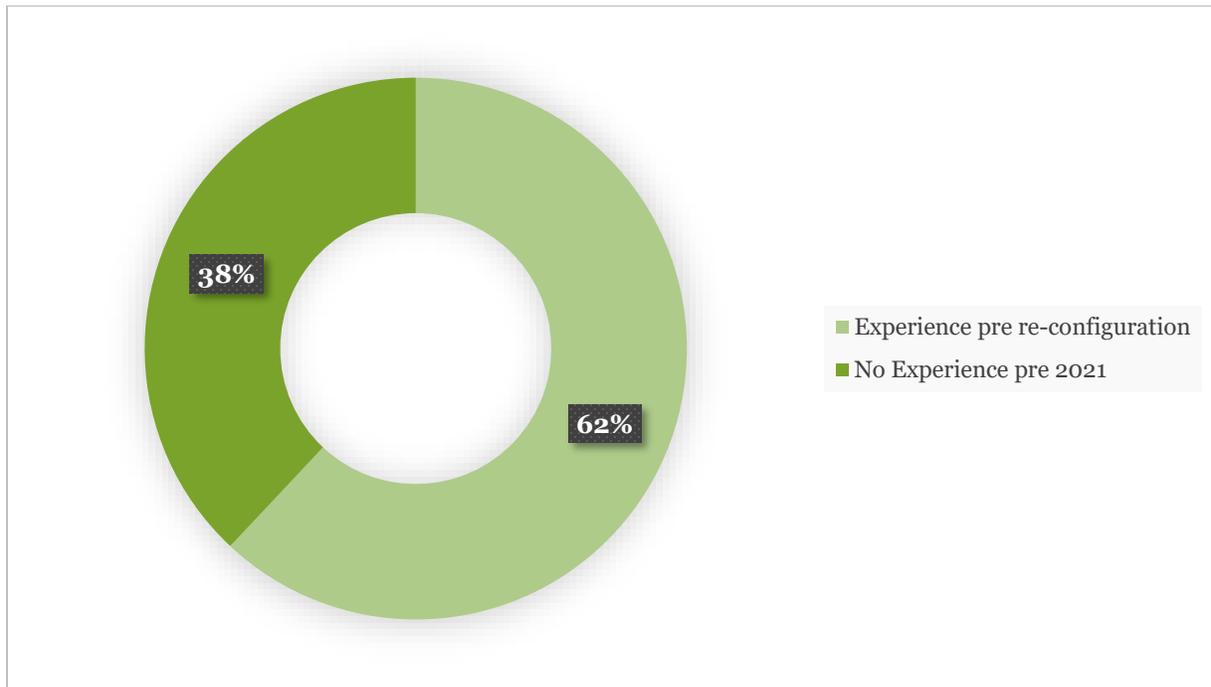
# Respondent Profile



The survey responses were majority Parents/Guardian/Carers of a child waiting on or accessing PDS. We gained significant insight into the Clinician/Therapists perspective on PDS given that 19% of participants are currently working in disability services while a further 2% identified as both parent and clinician. Additionally, 1% of respondents identified as a Private Clinician.

For Parents and Carer's who responded, 76% had 1 child who required access to disability services. The remaining 24% had multiple children in need of access to PDS. The age profile of the children was as follows: 34% aged 4-8 years, 32% aged 9-12 years, 16% aged 0-4 years, 14% aged 13-18 years and the remainder were 18+ years.

# Experience of PDS pre re-configuration in 2021



The 62% of participants with experience of PDS pre re-configuration were asked the following question:

Has your experience been positively or negatively impacted by re-configuration? Please describe and/or give examples.

(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 clinicians)

“Negatively, it barely functioned but now it's beyond repair”

“My experienced has been impacted on positively. Before PDS I was working with a large, overwhelming caseload that did not have the resources to work in a multidisciplinary manner and had ongoing staff turnover. Since PDS, I have had the opportunity to work collaboratively with my colleagues as PDS allowed us to re-structure a service that was previously failing our clients. I thoroughly enjoy working on the new CDNT and this has improved my work satisfaction.”

“Negatively - knew the system was not ideal but did not expect it to be so bad or such an unorganised transition...no top down, long term or national cohesive thinking! Everyone doing different things on different teams (even under the one lead agency under the same roof!!!!) which defeats the purpose of the “equity” for all service it’s supposed to be!!! Teams are disintegrating with staff leaving due to massive workloads, burnout, stress, lack of interaction with families which is why most clinicians became therapists (it’s most certainly not for the money!) leading to job dissatisfaction! Parents and families are understandably frustrated but taking it out on clinicians isn’t fair either...it’s the government/HSE should get the brunt of it but clinicians are the ones getting lambasted but we’re only doing our best in a broken system!!!!”

"Extremely negative. Higher caseload numbers, less colleagues per child to address a higher volume of varied and complex need. Had relationships with families built up over the years - all broken down over PDS. Constant stress, burnout, guilt. "

"Negatively impacted. We attended a specialist clinic in CRC for 7 years with trained therapists in this rare condition to then be put in Primary Care with therapists who have no experience or training so don't know what they are dealing with. They too are concerned. We are also not getting anywhere near the same number of appointments as we would have and should have and therefore a high risk of the disability worsening."

"Negative, less staff, less clinical governance, redevelopment of caseload, redistribution of experienced staff. EI, autism service and special school service is too great for the staff assigned. Not enough staff to meet growing demands. All different ways of working for each cdnts."

"Way less appointments we went from having physio every 2 weeks to not having physio in over a year"

"Negatively. Desperately miss being able to provide meaningful services to families. I agree with the concept of identifying and focusing on families priorities however what is being offered at the moment is absolutely not family centred. I feel very stuck as a therapist. I love working within the paediatric disability sector and do not want to leave that line of work for Primary Care, but being apart of a CDNT just feels so disheartening and honestly embarrassing at times."

"Negatively. 3 months in the National Rehabilitation Hospital as our daughter doesn't receive physio, ot, slt or any hands on therapies from PDS. Even if she were she needs to be on the Complex Neurodisability Pathway which is non existant. Neurodisability services are non existant within PDS so we end up in the NRH which costs the state a lot more."

"Neutral. Working in disability services has always had challenges. I'm not sure I blame reconfiguration for where we are at right now but I think the change on top of covid and the longevity of the impact that had on service provision has been significant."

"Negative. Largest caseload ever. Significant waiting list. Extreme staffing crisis where it is no longer safe. Expected to set up care pathways ect. Children missing out on assessments I.e children has their assessments completed prior to turning 6 and discharged from Early Intervention now lost in waiting lists with no diagnosis. Left alone only discipline involved with children... these children require team input. The NAP is highly subjective, not taking enough respect towards clinical opinion and referrals have significantly increased. Ultimately staff burn out, poor mental health. Never felt so unhappy in my job even though I work with a wonderful group of experienced people we are so over worked. Highly stressed families as a result of false promises PDS made."

"To be honest the service was/is pretty dysfunctional either way but the loss of a discipline-specific manager has been negative for me, as the line manager has less understanding of my role. However we never had psychology on the team before PDS and now we have fully staffed Psych posts which has been great"

"my son went for orthopaedic surgery without having any local physio support for his rehab. No follow up with SLT which was due Oct 2021. No in person OT sessions to work on fine motor skills which he was getting every 6 weeks. Increased wait times for equipment that would normally take maybe 5 weeks. We are currently waiting a year for a wheelchair. Still no sign of it. They had to remeasure for it after 6 months because it had been so long since the original measurements. They still didn't have the order in!"

"Both. Many things had been working well in the Early Intervention Team I worked on and little of that was maintained but reconfiguration has thrown light on all the service gaps and failings and while this makes for extremely challenging times, I continue to believe it will be a better service in the long run."

"More equality and transparency in relation to eligibility for services, regardless of postcode, school or diagnosis, which is highly important. However the poorly resourced teams and poor morale make day to day operations hugely challenging. The vacancies will NEVER be filled until we train more clinicians."

"Negatively - We were moved to a network that is an hour away. Previously services were accessed 10mins drive from our home. Now we would be expected to drive an hour away, hour appointment and hour drive back. And so this would be a three hour round trip for an appointment."

"Child with complex needs transferred from Enable Ireland in September 2021, after 13yrs with a fully functioning MDT. Child was triaged as a priority/no break in service. New team wasn't even set up, very few clinicians who didn't even have phones. One physio across two teams with 750 files on each team. 8 no break in service kids transferred to this from EI. No hands on therapy, prefab or rehab, postural and orthotic supports only"

The 38% of respondents with no experience of PDS were asked the following question:

How has your experience been so far? Please describe.

E.g. for Families: Are you accessing services or waiting? What have you accessed/not accessed? How long did/are you wait(ing)?

E.g. for Clinicians: How is your workload? Do you interact with families as often as you'd like? Has your health been affected positively or negatively? What do you like about PDS?

(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 clinicians)

"Workload insane. And no hope of any improvement. Can't interact with families as often as I'd like as its crisis management. Yes health negatively impacted suffering from burnout stress and recent onset of depression - myself and colleagues cry in work frequently as its all just negative experiences. The model works if there's resources to run it, I'd hate for it to be abandoned altogether without it having ever been given a chance but feel like families will never believe in it now"

"We are sitting languishing on a list - I have been able to access SLT and OT privately - I am paying €90 per week for SLT, OT assessment alone was €350. Awaiting private psychology assessment in June which will cost €1500. I have 4 children, Costs are high, I feel like we are absolutely killing ourselves to give our child the best chance in life. Barely contact from HSE, they don't give me any confidence or hope for a service"

"Extreme stress. Work life balance a huge issue. No job satisfaction. PDS model does not meet the needs of the children. We barely provide a service and we drown in databases, stats, waiting lists, IFSPs"

"Mainly filling out forms. Had 2 meetings in about 15 months for S&L. No formal assessment despite being months over statutory limit. All round has been no real benefit to us and felt I have wasted my time trying to engage."

"My workload is much higher with higher caseloads and less staffing, I interact with families much much less and days are consumed with planning and meetings, staff turnover is the highest I've ever seen along with stress leave and my health has been significantly affected due to stress and burnout."

"Access to physio and OT, preschool assistance, access to monthly sensory coffee morning, orthotics clinics. We are satisfied for the most part. Slow to start but once up and running access is in a form of groups. Physio and ot and wider team have met with the school prior to commencing Jr infants and prior to starting ecce. Providing support to the pre school teachers and the school"

"I feel we have been sold a total lie. The policies, procedures, and guidelines about how the services should be run on CDNTs is disingenuous, given that there isn't a team in the country that is anywhere near adequately staffed. I have been working as a clinician in Ireland and abroad for 15 years and have never encountered such a poor staff to child/young person ratio, and to think this is in a service for children with identified complex needs is outrageous. It is so disheartening as clinicians and CDNMs as we keep raising all the risks but seem to be getting no traction"

"Very very long waiting times for therapy, speech and language, OT, phycology, dietician etc. No contact is been made with me, lots of letters about the new disability network team but still haven't seen anyone. We have to seek private therapy which is adding to our financial strain. 3 years later and very little service received."

"Referred in august 2021, no services at all yet. Waiting on a proper AON. Being sent private for the assessment so we've been told but no date as to when that's going to happen. Don't hear from cdnt regarding anything. No updates. Nothing."

"Workloads are greater. No balanced in caseload. Crisis management. No cpd for staff, less staff, no cover for maternity leave. Development of a service from nothing. No carry over from previous services EI, autism and special schools."

"In new configuration we have had one session with physio who left. New physio states she hasn't the expertise to deal with my child. We have had 2 blocks SLT of 4 sessions each over the past two years. 2 sessions of OT. The psychologist refused to see my child even though she needed input to source a secondary school so we had to go elsewhere. We have had to request all services there was no contact from new provider when we transferred until I made contact

with them. My child's notes don't seem to have transferred with her even though our old provider stopped providing services months before transfer as they had to send the files to the new provider"

"The 10 principles of PDS are worth striving for. Equity, early identification of need, the biopsychosocial model, family centredness most evidently! It's a difficult environment to work in tho as it feels like we're always failing but we aren't failing for everyone. Also internationally it is very difficult to quantify caseload/workloads and this has been a major challenge"

"Daughter had PBA and assigned to CDNT in 2021. Main concerns are OT related. After FOIs/multiple complaints, she had one SLT app and an OT webinar."

"I like the PDS model and many of the policies. I like the idea that I can recommend universal, targeted or individual support according to my clinical judgement. I like the interdisciplinary approach and how it serves families in theory. My caseload is growing and growing and I cannot keep up with the reports, notes and follow up. Noone is attending groups that we spend hours organising because they don't trust the service. "

"My son is accessing services with the Kells Team. We were referred when he was discharged from hospital at 6 weeks old in November 2022. So far we have seen the physio and SLTs in our home multiple times. The OT and liason nurse are coming in May."

"We are waiting on services for over a year we had to go private for all assessments. My child is homeschooled now as there is no place for her within primary education. I have had to reduce my working hours to be at home with my child and my husband has had to change his days of working and cannot do overtime as someone needs to be with her 24/7. This has cause a massive financial strain on us. Our only saving grace was the asd parents support group who have arranged activities that is inclusive of our daughter."

"My workload is high but I work hard to make sure families needs are meet.I'm leaving my job because of how I'm treated by colleagues who shouldn't be in the helping profession,this is similar to social workers nationwide"

"Our child was refered before the age of 1 [July 2020) and was taken on by Enable Ireland immediately. Initial dealings were very positive. However, we have had very little input for the last year and a half. Empty promises from staff. Our dealings with Enable Ireland are a constant source of stress for us as parents"

"CDNT staff inexperienced & extensive training required to work with older children with complex needs. Some managers in CDNT inexperienced & unable to provide proper direction. Staff self selecting the less complex cases from caseloads as these are easier to work with eg large numbers of children who could be in primary care getting a service in CDNT while complex children left waiting. High levels of fear & anxiety amongst therapists & avoidance of complex "hard" cases. Some managers unwilling to deal with these issues & lack the experience to see what is happening. Children with complex needs are being discriminated against on these teams. KPIs more important to managers that actual meaningful intervention for children. Some staff on CDNTs have no child with ID active on their caseloads. Again "easy" primary care children being seen & complex children avoided."

"We have 'access' to the service but it's bare off minimum. We have to pay all private for physio and SLT. Inadaquate service is what we have. Extremely long period to ask for any supporting equipment and no one can tell me a thing except the parents who have done it before me. "

"In 28 month we had one meeting, parents only, and received an IFSP after that. Child has never been seen by anybody. Child 2 has been no contact other than the initial acceptance letter, and nothing since diagnosis 8 month ago."

"No sevices at all, 1 phone all from enable ireland manager to say child would be prioritised and that was over 14 months ago,1 email for Family Forum, we've been on a list for 2 years and 9 months for services,"

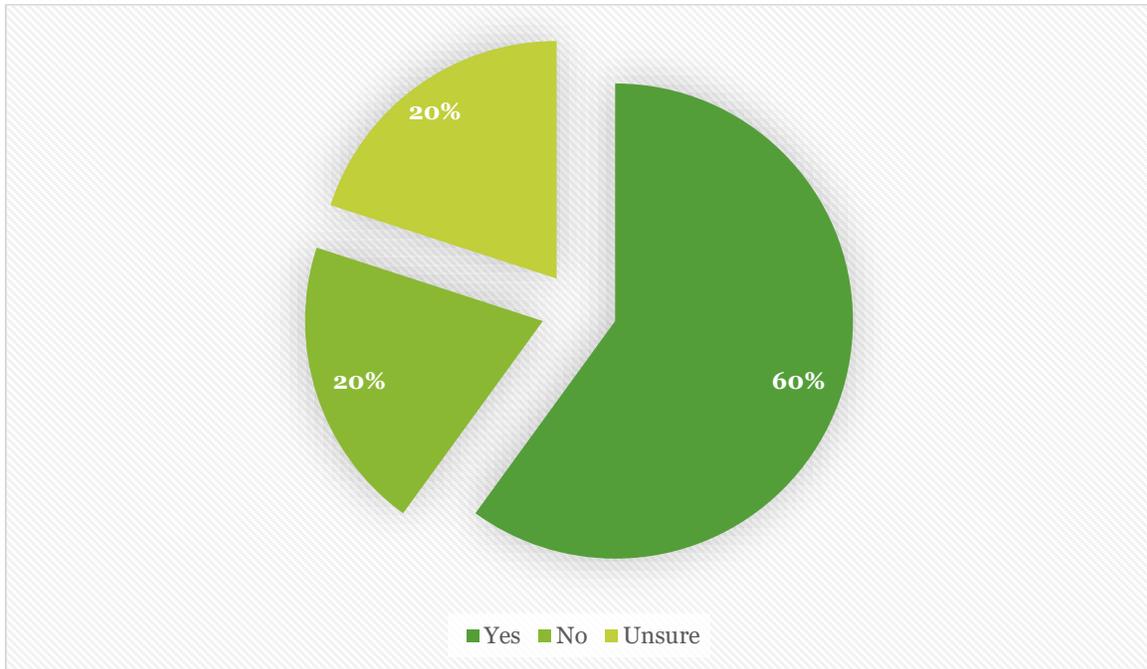
"Concerns not taken seriously fobbed off by everyone for a long time and only taken seriously when complaint logged due to delays. Since AON have actes fairly promptly and starting 2 parent courses but no 1 to 1 yet and frankly dont expect it we are sticking with private therapists"

"3 years waiting 4 legal battles My child doesn't meet exceptional circumstances to move to another location"

"Most interaction through workshops and phone calls. Workload OK as reduced as lots of children were more fitted for primary care. Health 50/50 some parents don't have the cognitive to understand PDS so that's takes it toll and some parents done attend training especially tailored for their child- toileting, etc some parents will say they are goin to local tds about it all - I can't do anything I'm just trying to do my job"

# Understanding of PDS

Participants were asked: Do you understand the PDS Model and the purpose of re-configuration?



The 40% figure highlights a key issue undermining PDS which is the lack of effective, accessible, and easily understood communication between service users, families, and disability services.

This has potentially led to distrust between services users and providers, increased stress for all parties, unrealistic expectations of service provision/capacity and poor support by stakeholders.

# PDS Now: What's working and what's not working?

Respondents were asked: What do you feel works in relation to the PDS model? Please describe/give examples.

(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 clinicians)

"The multidisciplinary aspect and when the family forums do start I feel it will greatly help everyone"

"Tiered model of service. 1:1 direct intervention won't work / be enough for some kids so the other tiers are what's needed. Also the opportunities for mdt working are far better than I've had pre pds but it's not what it should or could be"

"There is an emphasis on interdisciplinary work. Resources don't really facilitate it but when it can happen it's positive. Families not having to travel far is a positive"

"Clear point of entry into service- everyone comes through same referral pathway so extent of numbers, needs etc clear from outset"

"That the service is based on complexity of need & not diagnosis. Parents are seen as key team members in the team supporting the child."

"Shared learning with colleagues on the new teams due to different past experiences and caseloads"

"The classes are good to know your not on your own, other parents are going threwh the same"

"Families should in theory be able to access services where they live and not have to travel long distances across the county to access services specific to their child's needs or disability"

"The values and principles of PDS. IFSP done well can be very positive Parent groups e.g post diagnostics with a neurodiversity affirming approach. Structures and clear communication with families."

"Identifying goals/skills that are important to families. Building on the young person's strength"

"Complex Cases get higher priority"

"The best part is I now have direct access to a social worker who regularly keeps in touch."

"I do think the three-tier model has some benefits. It is certainly beneficial for parents to have access to universal workshops on, for example, using visual supports, understanding sensory regulation, using language stimulation strategies, and it is certainly beneficial for children to have the opportunity to attend group interventions as this supports generalisation of skills as well as giving them an opportunity to meet other children in similar situations and with similar experiences. HOWEVER, this should be available as an adjunct to individual support. ALL children in CDNTs should be able to access 1:1 support and be seen by a therapist. It is accepted that

these children present with complex needs when they are accepted to CDNT waitlists, therefore they should receive substantial support from therapies.”

Respondents were asked: What do you feel does not works in relation to the PDS model? Please describe/give examples.

(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 clinicians)

“Dilution of the skills of staff, lack of speciality in terms of experience as a result of this new catch all method of disability Services provision. Unsafe caseloads and ever increasing number of children being referred to cdnts. The best will in the world it is not going to work”

“Lack of staffing. Inequality between PC and CDNT. No joined up thinking between PC/CDNT/CAMHS”

“Vacancies are too long empty and it's just a revolving door. In order to progress you've to leave your post. I'm just waiting for something to come up so I can leave. Communication with families about the model of service has been awful so we're ag the front line trying to explain it and families don't trust us. Costing me thousands in trying to upskill to stay on top of latest research and evidence base for such a broad caseload. Working out of hours constantly (obviously this is unpaid)”

“Service and resource led decisions are made and rarely clinically led decisions. I am constantly justifying why people need individual sessions. Targeted training does not meet the needs”

“Children referred into CDNT not automatically put on AON waiting list, instead was put onto another list not covered by statutory timelines. Ridiculous waiting times. Staff shortages obvious and staff turnover too high.”

“The managers at a high level are not from a sufficient clinical background and devise protocols that are not practical on the front line”

“Severe lack of clinical governance and staff with limited experience working without supervision. Loss of access to discipline specific managers.”

“Literally nobody tells me as the parent a thing I’m having to fish information out and mostly getting help from other parents.”

“Staffing is the main issue. And the difficulties that hse management describe about trouble recruiting don't really tell the whole story. People aren't interested in joining overworked, skeleton teams. What's needed is much more staff allocation so that clinicians can join well resourced teams. Also outsourcing to private clinics for assessments, and providing training for clinicians in these clinics, while not doing the same for clinicians in disability services is another example of poor and shortsighted management.”

“Communication is non existent. I leave voicemails and they are ignored. We have no support whatsoever, zero contact from anyone. I understand the different model of universal supports

but our last "universal support" was a link to a publicly available youtube video that did not address our specific situation."

"Too broad an umbrella. Too many children with non complex needs clogging up lists but they are not prioritised so will never get seen would be better served in primary care. PDS only supplied clinical services. Huge need for respite home support etc and it's outside of remit of PDS"

"The issues with PDS are systemic at the HSE. The HSE know what the problems are there is just no desire to change the status quo. Parents won't change a thing. PDS as a policy has failed"

"Everything! I'm not trying to be funny but it's a shambles and utterly dismaying and disheartening to be working in it. I used to love my job in early intervention 0-6 years giving a very good service to children and their families but now I dread going into work. It's just a job now get in get out get paid and that's not the therapist I am!"

"Apparent lack of awareness or insight into how bad things actually are on the ground, e.g constantly seeking figures and KPIs - for what? What is happening with the waitlist figures we send? What is happening with the risks we are highlighting?"

"The whole model, we need at least ten times the staff. We are losing staff and losing clinicians with huge experience being replaced by new graduates who need huge amount of support"

"Staffing numbers Expectations Thoughts that 1:1 blocks of intervention is the correct approach and that other interventions are somewhat less."

"We are travelling further for less services. Because the service is based on a generalist model the therapists lack the experience/skills to provide some of the interventions my child needs."

"The primary care component - CDNTs targeted for everything that is wrong regarding access to services. Staff not wanting to work in the area because of what they hear in the media and feeling unable to work with families. There are only bad circumstances shared, never good ones and there are absolutely children and families who are receiving what they need albeit, it is not everyone."

"Was on original PDS parent forum in 2009. Idea was to structure service similar to Enable Ireland and move away from HSE dysfunction. Opposite has happened. "

"Delays with equipment, trying to receive funding is difficult at times."

"CDNTs being asked to meet every whim of a minister - provide full teams to special schools overnight and cover failing AON process, training budgets non existent - offering sub par national training for 'gaps' hse have identified and hardly any specialist teams"

"Clinicians not held accountable to their decisions to ignore families requests for appointments/equipment. Managers not progressing complaints and ombudsman not resolving issues between families and the HSE."

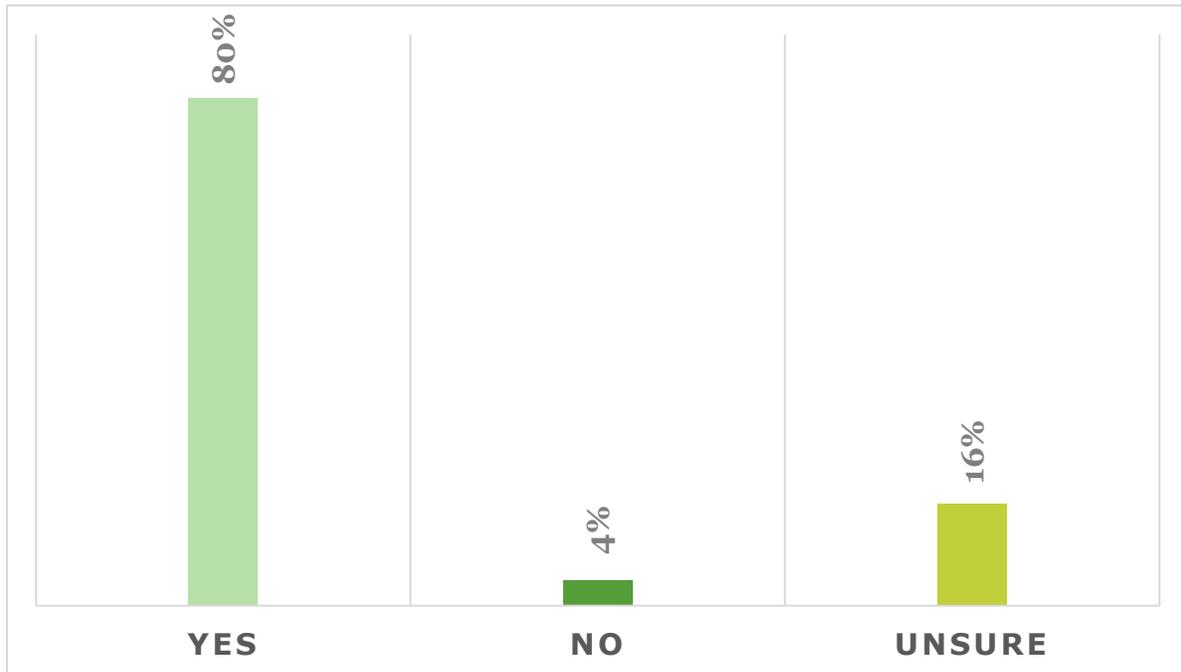
"I feel my daughter doesn't high levels of support all the time but there are times she needs help. There needs to be a part of the service for children to dip in and out when needed."

"Therapists need to maintain a professional standard of service delivery in line with CORU ethics. PDS has undermined the clinical safety standards for individual clinicians who are required to complete AON which were ruled illegal by the High Court more than a year ago and no guidance for clinicians from HSE has issued since-it is deplorable for families and clinicians alike"

"Every team does not appear to be having the same experiences and services continue to differ based off where you live."

## Has PDS failed?

Participants were asked the following: Do you feel PDS re-configuration has failed and its viability should be reviewed?



Survey participants were asked to elaborate on their answers. The 4% of participants who felt PDS has not failed are quoted below.

(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 clinicians)

“The theory and rationale of FCP is good but delivering this in practice requires staffing. The concept that intervention is blocks of direct therapy and anything else is somehow less valuable is particularly unhelpful.”

“It hasn’t been given a chance. At least 3-5 years is needed to bed down a change of this nature. To deliver a significant change in work practices whilst continuing to deliver services was a mammoth task and still it.”

“PDS is an ok model, the failure has always been there but some children with different diagnoses experienced a better service. The failure is in government and management within HSE”

“The principals of equity are sound The system can’t deliver without staff”

“I don’t think it has failed. I don’t think services were in a good place nationally before and if we give the new structure time and resources, I think it will serve our families needs a lot more ! Every team is different and some teams have been successful in improving service quality. This

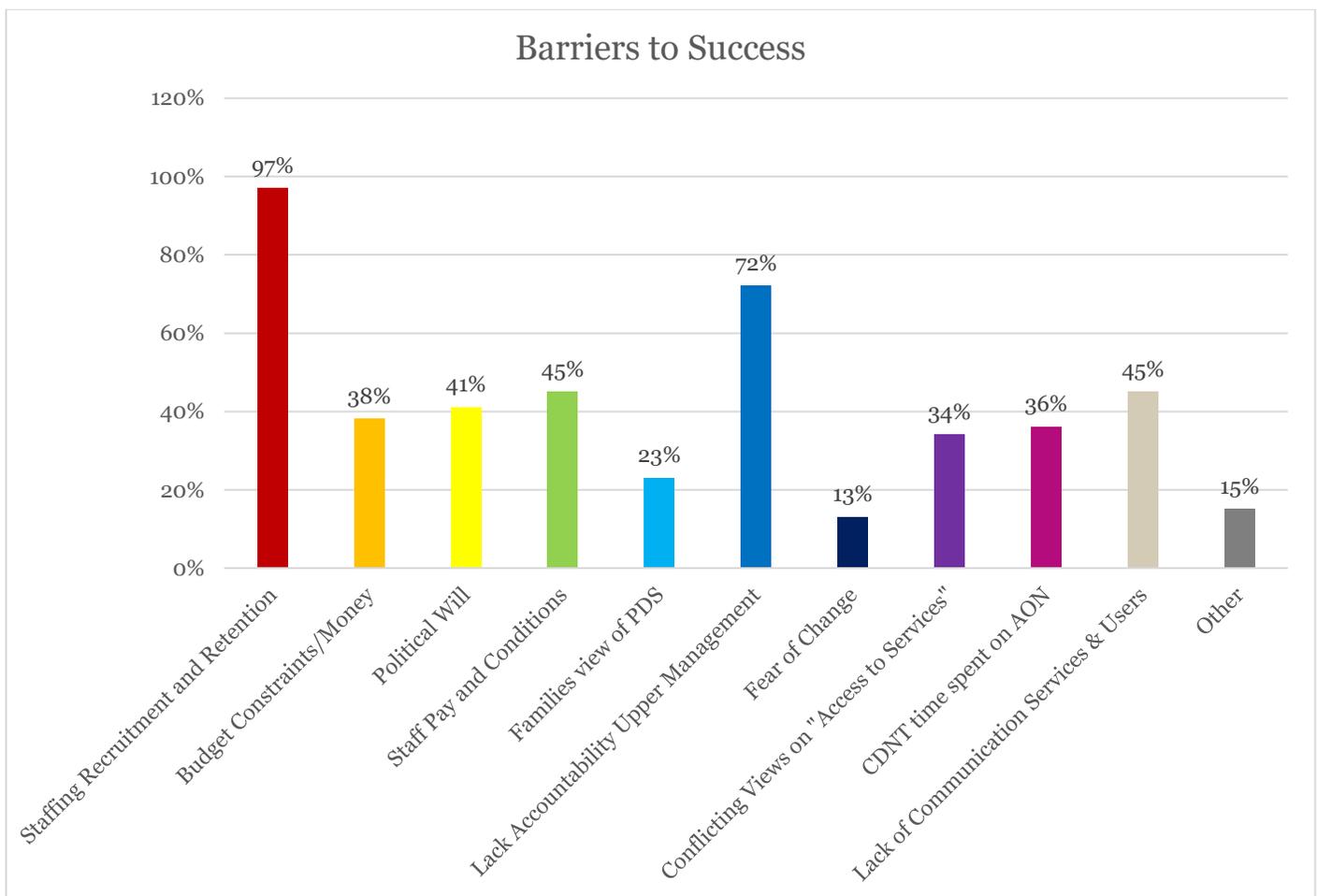
should be acknowledged and learning should be shared across teams. It's not all bad ! Let's talk about the positives and share them amongst each other."

"There were never enough resources and working in organisational silos led to huge inequities. Reconfiguration has shown it up for what it is. I don't understand it as the cause."

"As I've seen pre-2021, PDS has the capacity to be a great equaliser, offering based on needs, not based on diagnosis or geography. I saw family members navigate the old system that is now on a pedestal. It didn't work - unless you had a specific diagnosis on a specific geographic area. The issue is the number of staff to the caseload and demands from management."

## Obstacles to Success

Participants were asked the following: What is the biggest obstacle to PDS success? Responses were presented in a multiple-choice format with the option to select numerous answers, Additionally, an "Other" text option was available for participants to enter a barrier that was not listed.



For the purpose of this survey, participants identified "Upper Management" as "Heads of Disability", "Service Managers and CEO", "CHO leads/heads of Disability Service", "National Level Directors", "HSE Chief Officers" and "Government, relevant Ministers".

Responses to "Other" included:

(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 clinicians)

"Lack of vision/understanding as to what constitutes a good disability service"

"the biggest for me is clinical safety we do not have the tools to our jobs safely (supervision, governance, management, functioning and accurate database, prioritisation tools etc",

"Like everything else in the health service it's utterly disjointed. To much time spent trying to tick boxes to give the illusion help has been provided . No focus on outcomes."

"Not developing or implementing services based on child's needs"

"Impact of maternity leave, parents leave etc. we need to assume our CDNTs will require buffering int his regard and over resource them accordingly"

"HSE interference"

"Lack of specialism"

"Equity and Equality"

"Failure to support the implementation of the model among staff, failure to ensure retention of staff and recruitment of additional staff "

"Not just accountability - deliberate use of state resources to fight the child's rights, deliberate disenfranchising of the child, deliberate bypassing of Disability Act, deliberate institutional Psychological, Neglect, Gaslighting child abuse it"

"Teams are not choosing not to communicate with service users, they don't have the information to communicate with service users. "

"Complex children removed from PDS or a sub section for them working in tandem with Consultants. "

"poor management of time and resources."

# Moving Forward

When we discuss Disability Services, it is important to recognize that we can move forward. A key component in moving on and designing a functioning disability service is the involvement of service users, their families, carers or guardians and experienced front-line staff.

Survey participants were asked: What do you want Disability Services to look like going forward? How can we improve Disability Services?

(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 clinicians)

“Hire staff, treat them properly, more action, less talk about action.”

“The primary issue in disability services is not the model - it is and always has been a resource and staffing issue. Having said that, I don't think there will ever be an allocation sufficient enough to address the need given what is currently considered adequate.”

“From a clinician's perspective, It's difficult to say without sounding hopeless, as it feels as though we are so far into PDS that there's no going back. Going forward, more staff needed and within that, more support for existing staff is imperative as burnout levels are high. More cohesive working between CDNT, CAMHS, and primary care is also needed.”

“- More Staff, better pay and conditions - Increased Budget to meet unmet need - HSE should be held accountable for their failures to provide basic adequate care. - Universal Interventions should be accessible immediately when accepted by service. Webinars recorded and online to view. - More Peer/ Community support encouraged by PDS teams. - We need something that functions.”

“Pay parity, reduce caseloads, reinstate hands on therapies especially prefab, rehab and priority for life limiting/palliative needs.”

“More joined up thinking with the best use of services available. For example if there's no dietician/Ot/physio in CDNT kids should be seen by PC dietician/ot/physio in order for the child to get the best outcome and possibly prevent further intensive intervention down the line”

“Revert to the old system, integrate more therapists into schools including mainstream schools. Improve teacher training and focus on creating a culture accepting of neurodiversity.

“Revert to the old system so that people with specific types of disabilities such as physical or intellectual disabilities are being supported by the organisations that have spent decades learning how to support people with those specific disabilities.

“Communication is key, everyone involving a child within the service should be on the same page. A website that is updated regularly with the on goings in the local service of workshops, talks, days out, upcoming meetings.”

"They need to integrate supports into schools and creches. There needs to be continuous support provided to children"

"Geography based teams with much larger amount of specialist services e.g motor management, FEDS etc Decision should be made at government level for one department to have full oversight rather than multiple government departments all passing the book to each other."

"Learn from implementation of PDS in other areas, using their already developed policies/procedures/guidelines and forms etc etc etc rather than spending lots of time trying to come up with prioritisation systems, new ax forms, report templates etc etc etc in each CDNT! Clinical specialisms are a must to keep clinicians motivated and keep their passion alive for the job!"

"Further clarity around who does what. - CAMHS , Dept of Education/NCSE - increased staffing"

"Policies to retain staff- wellbeing incentives, cpd money, flexitime, holidays, better communication with families and smaller caseloads, elimination of AON in favour of more posts for CDNTs"

"With as little admin and paperwork as possible! Maximising the time available to see young people and their support networks directly (either individually, group, or through school) should always be the top priority."

"Maybe have a kind of flexitime so early risers can be seen before 9 and others that need it after 5. Have a store of sensory equipment that can be given out like in primary care. Devise a system that suits the service users and the Clinicians best. Give clerical support to all the clinicians"

"Discipline managers need to have clinical and operational responsibility for each profession so clinical risks are escalated and decisions made to reduce or eliminate risk for staff and services. No therapist can practise safely if they are expected to have specific expertise in all areas of disability including physical, intellectual, ASD and behavioural issues from 0-18 years of age"

"More relaxed atmosphere, my Daughter hates the clinical/institutional feel of the office. Stop discharging kids because they aren't engaging, find a way to engage with them."

"Would love to see a team be assigned to a child following birth/diagnosis/concern. This team would meet with the parent to discuss the needs of the child and then assess the child. A care plan should be devised for each child to include parent support, therapies, social groups, parent training (behaviour management, Hanen, Lamh etc), education and school supports, life skill development, transition planning and support, healthcare needs "

"Appropriate staffing ratios consistent with international recommendations (ie. no whole time OT/SLT should have more than 30-50 to their caseload). Caseloads to be weighted based on complexity, not numbers, which would acknowledge the need rather than a headcount."

"Allow clinicians to respond to caseload needs, rather than adherence to "care pathways" which are decided by management. "

"Family Forums should include management of the teams and region to ensure visibility and accountability. Information regarding teams staffing should be available publicly and transparency across the board."

"Recruit from outside Ireland, use private companies to provide therapy and open more postgraduate courses to train more staff since we have such a dire shortage. An apprenticeship system might be worthwhile too"

"Disability services are an essential service and it is obvious from the decision of HSE management to redeploy Disability staff during COVID that they just don't get that"

"Post diagnostic counselling for families esp if neurodivergence identified, should consider pathway for parental assessment. "

"More college spaces to increase the amount of people who qualify each year. Lower the points for the courses. Better pay and conditions so they won't leave and go abroad after they have finished college."

"Provide clinical safety to staff! - Provide us with functioning databases, prioritisation too. - Provide management and leadership"

"Make the financial side more transparent & clear with how much money Gov puts in per year & where it is going."

"More funding for RAG aids and appliances and orthotics. Waiting times for funding always a cause of conflict between therapist and family even though therapists have no control over funding being granted once we have submitted our applications. Time spent communicating with families on this topic is huge and is stressful for both sides as it is the RAG committee who control this. Disparity between funding/wait times for these as well as what items are actually funded across counties (Cork one of the worst)"

"The Disability Act of 2005 should be reviewed so that disability services are a legal right"

# Conclusion

This survey received an overwhelming response from parents/carers and clinicians alike.

Unfortunately, it is clear from responses that disability services are in a state of crisis. The majority of participants listed numerous negative consequences of reconfiguration leaving few able to identify the positives.

It is evident that families feel they are deliberately held in the dark with 45% believing Poor Communication is an obstacle to service provision. They demand transparent and a clear, easy to access source of information. Many pointed to the lack of specialist pathways and the loss of experienced teams who understand their loved one's needs.

The following quote was a concluding comment by a survey participant:

"Communication is absolute key for moving forward and getting the PDS to work. Families want to work with the staff and service not against but unfortunately the HSE are working against the families."

Progressing Disability Services is described throughout as disjointed with teams "working in silos". The vast majority have concerns regarding the lack of governance and accountability regarding the thousands of children receiving little to no services. One participant is quoted as saying "I feel so stressed and disappointed with the lack of support available to us the only comfort I take is knowing we are not alone in this".

While collating this report, we, FUSS, were distressed to read the volume of clinicians experiencing stress, burnout and fear relating to management's failure to escalate clinical risks identified. One respondent is quoted below:

"I'm the future clinician workforce and I'm burnt out. My personal life has been irreparably damaged and this level of stress and workload demands isn't sustainable. I'll be leaving the profession as soon as it makes sense for me, if not sooner due to burnout."

The overriding feeling throughout this report is one of urgency. We ask that government, the Health Service Executive and relevant Health and Disability Ministers act with the same sense of urgency.

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

The team at FUSS



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