

PROGRESSING DISABILITY SERVICES FOR CHILDREN AND YOUNG PEOPLE

PARENT EXPERIENCE SURVEY REPORT FEBRUARY 2022



INCLUSION IRELAND

National Association for People with an Intellectual Disability



Article 23 of The Convention on the Rights of the Child:
“(assistance) shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development...”

**This document is written in font 12 Verdana in line with
Inclusion Ireland plain English guidelines**

Any images used in this report are for decorative purposes only and are not the children described in this report.

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INCLUSION IRELAND

National Association for People with an Intellectual Disability

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1. ABOUT INCLUSION IRELAND

Established in 1961, Inclusion Ireland is a national advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. Our work recognises persons with an intellectual disability, including children, as rights holders.

We are a campaigning organisation, informed by the lived experience of people with intellectual disabilities. We lead change for an inclusive society.

We are a membership organisation that holds Government to account.

We support families and the wider community as we work towards full implementation of the United Nations Convention on the Rights of People with Disabilities (UNCRPD). Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.



2. Key Messages/ Executive Summary

The development of the new teams throughout the country are an opportunity to get things right for children with disabilities and their families. Inclusion Ireland recognises and supports the values underpinning the model around fair access to services and family centred care. There is an opportunity with the collection of better data to plan for children by region over time and to work in trusting partnership with families. This can be done if the systemic issues within the services are addressed as a priority by Government and health services.

Whilst a child only has a right to an assessment but not the right to services, it will be a challenge for children to receive the support that they require. The Disability Act needs to be reviewed, hand in hand with the EPSEN act, to ensure that children's rights are front and central. This will be a challenge for the state, given the years of under resourcing of disability services, but it is imperative that children get the support they need, early and often in the years where it makes the biggest difference. In the wider context of disability rights, the optional protocol of the UNCRPD also needs to be ratified by the state. This will be a central part of Inclusion Ireland's advocacy over the coming year.

1. 1013 families responded to the Inclusion Ireland Progressing Disability Services Survey in February 2022.

- 60% of families who responded reported that their child has an intellectual disability, 44% reported that their child has autism.
- 16% of respondents have a child with disability under 5 years of age, 43% aged between 5 and 10 years.
- 29% of the children represented attend mainstream classes in primary or secondary school, 17% attend a special class in a local mainstream school and 28% attend a special primary or secondary school for children with intellectual disability and/or autism.

2. The three main issues identified by families needing services for their child were:

- Lack of services : 83% of respondents reported lack of services as one of their top 3 issues when surveyed. Many parents reported that their child spent a significant time on a waiting list for assessment or therapy intervention. 95% have waited more than 6 months to avail of services, 85% reported that they have waited or continue to wait for more than a year. 27 Families reported distress on receiving service statements which highlighted a need for intervention and the scheduled date for intervention often two years from the time of assessment.

- Communication: 48% of families cited difficulties with communications from the services as one of their top 3 issues with the service. Families describe a lack of clarity in relation to plans and time frames for Progressing Disability Services for Children.
- Quality of service: 19% families provided us with detail relating to quality of service in relation to progressing disability services in their top issues. This included only children who have received a service. Examples of the poor quality include lack of frequency, consistency and quality of interventions, difficulties with staffing and lack of joined up working with schools or other services.

3. Over 50% of the families of children with disability surveyed are not in receipt of any service. Less than 1/3 of families (28%) were engaging with Progressing disability Services through Children's Disability Network Teams (CDNT).

4. There is a lot of confusion about the assessment of need process amongst families. The Disability Act says the assessment of need shall determine whether child has a disability and shall determine the nature and extent of disability. However the HSE currently states that "the assessment of needs is a short screening assessment, it is not a diagnostic assessment". This needs clarity.

It is the view of families for whom diagnosis is important that having waited for assessment of need they should not have to be waitlisted a second time to receive diagnosis with further waitlisting for intervention. Without early assessment and timely access to therapies children can age out of Early Intervention without accessing critical developmental and educational supports.

5. Children and families need more support in the early stages post assessment/diagnosis. The source of most distress is the wait for assessment followed by a long wait for intervention. It is the view of some parents that if early-stage support was provided, the need for intensive support would diminish over time.

6. Families say that they want 1:1 intervention for their children. It is true that family training is a vital part of the package of supports for a child with a disability and can play a role in empowering the child's network of support. It should, however, only be viewed as part of a menu of supports and cannot replace the child's need for individual and team based direct therapy supports.

3. Methodology

In listening to our members and families who have reached out to us, we decided to survey families to gain a better understanding of the issues and to constructively make recommendations to the Minister and to the HSE around ways of improving matters. In this document, we are reflecting the lived experience of families and children who are struggling to get the help that they need.

Inclusion Ireland takes a rights-based approach in all of our work. In this instance we are looking closely at the rights of a child to get services and supports early and comprehensively so that he/she/they can thrive, flourish, develop emotionally, socially and physically and access their right to education.

Inclusion Ireland prepared a survey consisting of 12 questions. The survey was circulated to Inclusion Ireland members by email but also made available to all on social media for a number of weeks.

In total, 1013 responses were received to the survey. This high response level is indicative of the deep concern that many families feel and needed to express. While this survey cannot represent the totality of the unmet needs in Ireland, it can offer a clear overview and representative sample of the family challenges with regards to Progressing Disability Services.



4. Progressing Disability Services (PDS): The Model

Services for children with disabilities developed historically in Ireland in an ad-hoc manner. As a result of this, there were parts of the country where children with disabilities received an adequate service and other areas where services were non-existent or poor. In some areas individual organisations were providing services and supports to children with a particular diagnosis or disability, whilst in the same region children with other profiles were not receiving any level of support. Following a review of these issues, The HSE decided to reconfigure all of children's services in a process called "Progressing Children's Disability Services".

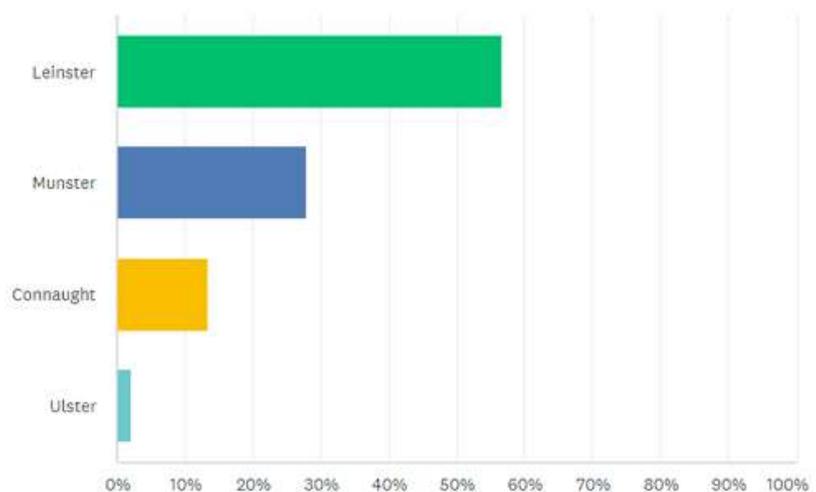
The vision for this change has been around fair and equitable access for all children in their locality and clarity for children and families around where to go to if they needed support for their child. The process involved an analysis of each region and the available resources (mainly therapy staff) that were employed in HSE services and HSE funded services. The next step was to bring all of these resources together into one team. The aim is for one team in each area comprising of therapists from multiple agencies, delivering on assessment and intervention for children.

PDS began the process of rolling out 11 years ago. Some parts of the country reconfigured quickly; others have taken a considerable period of time to do so. There has been an increase over the last two years of teams reconfiguring and coming together in the new model. Within the HSE the last of the 91 Children's Disability Network Teams was reconfigured by December 2021.

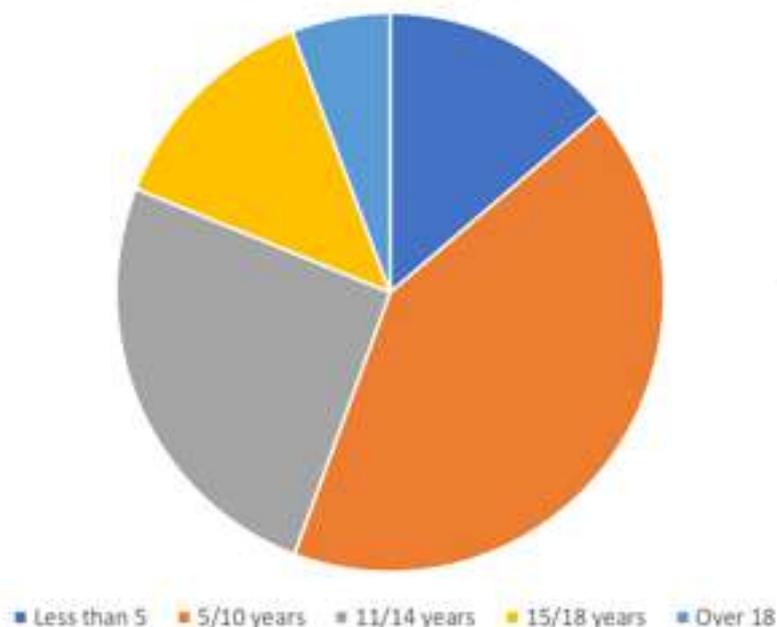
5. RESULTS FROM THE SURVEY

A. Who are the respondents?

Respondents to the survey mainly come from Leinster (57%), followed by Munster (28%), Connaught (13%) and Ulster (2%)



Responses by age group

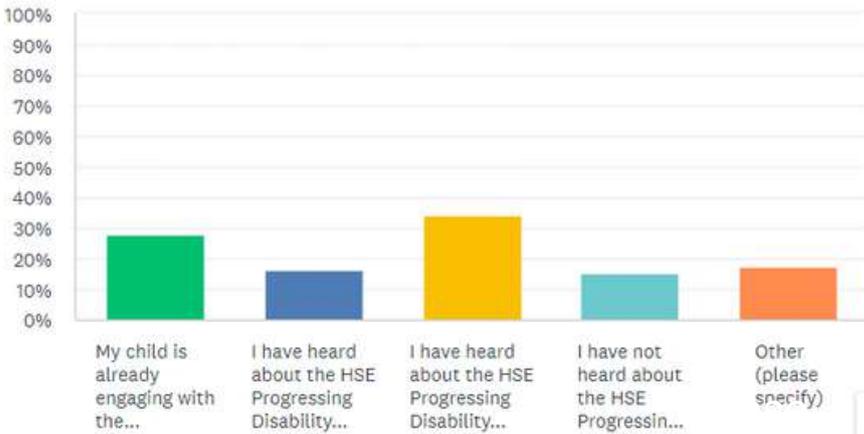
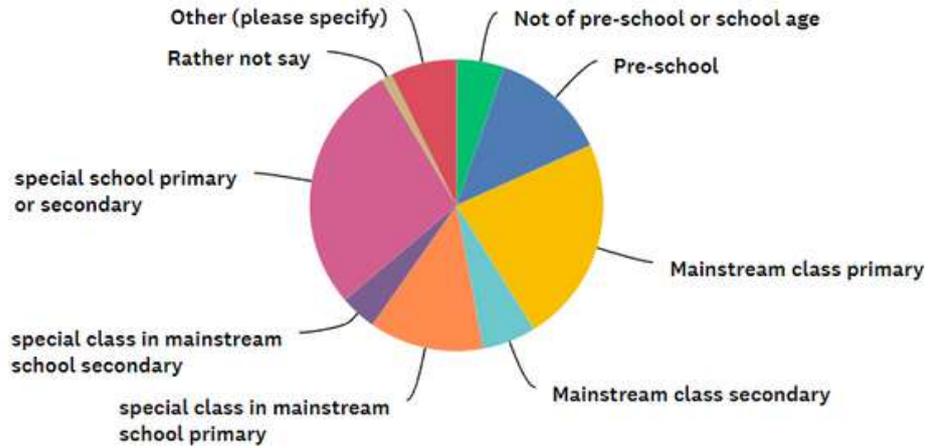


Most of the respondents have children with disabilities at a young age, less than 10 years old (56%). Children between 11 and 14 accounted for 25% of the answers. Finally, 13% of the respondents had teenagers between 15 and 18 years old. 8% of the families who took part in the survey reported the situation of young adults with an intellectual disability over 18.

60 % of the families who responded reported that their child has an intellectual disability. 44% told us that their child has autism.

A. Who are the respondents?

The educational situation of the respondents' children is pretty diverse: most are going to mainstream classes in primary and secondary schools (29%) and to special primary or secondary schools (28%) closely followed by those in special classes (17%).



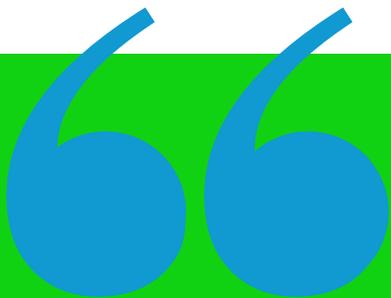
28% of respondents highlighted that they were engaging with the Progressing Disability Services (PDS) and a Children's Disability Network Teams (CNDT). 16% have heard about it and understand how it will work while 34% do not understand how it works. Finally, 15% have never heard of PDS. This proportion of families engaging with PDS falls to 25% for Munster and 20% for Connaught.

B. Main issues faced by families

When asked about the most important barriers faced by families when trying to access PDS the following were the main issues of concern:

1. Lack of services/difficulty accessing services

83% of respondents reported lack of services as one of their top 3 issues, which can significantly vary across the different counties and often referred to as the "Postcode lottery". Many reported that the services are understaffed and underfunded and that many team positions are not filled. A high number of answers highlighted the long waiting lists and delays in getting appointments. Finally, the lack of therapists (OT, SLT) was shared by many in the comments.



Direct quotes from families:

"On waitlist since 2017. Referred after AON"

"Waiting list - waiting 5 years now"

"It is based on a failed, fantasy model of "family centred" provision which involves provision of NO services to children with defined complex disabilities"

"Lack of therapists making us have a big waiting list

"They are moving us to another county from where I got all my child's services since birth"

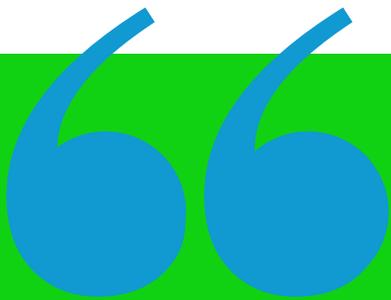
"Lack of therapies for my son as he's classified as "non-urgent""

"No service- not one session of physio since she was born and first 2 years are so crucial"

2. Lack of communication

48% of families cited difficulties with communication from the service as one of their top 3 issues. Many families in the survey regretted a lack of clarity on the plans and timeframes. Most of respondents found it hard to navigate into the new system and understand how it works. Many others reported no understanding around how the system works.

Responses also showed that many families do not receive consistent and regular information on services and appointments. Some felt that there was a lack of understanding and consideration from services about the circumstances families found themselves in. There was a perceived lack of flexibility in the appointments being scheduled, especially for parents working and with other children with disabilities.



Direct quotes from families:

“They don’t see parents as a part of the team.”

“Disjointed advice/understanding when working on behalf of child with other agencies/depts etc”

“Whilst we were informed in October what team we’re under, we still have no idea when we will receive services.”

“Don’t know if the new system will be any better than the old one. It still feels like there will be long wait lists.”

“No individual communication (all letters have been part of a mailing)”

3. Poor quality of services

19% of respondents pointed out specific issues with the quality of service. We must remember that only families who receive or received a service can give detail on the quality of service. Staff issues contributed to a poor quality of service.

Respondents mentioned:

- The high turnover of staff in services
- The lack of experienced staff
- The large caseloads per team was raised in the responses as not sustainable to provide a service of quality. As a consequence of this high demand on services, many reported the lack of frequency of appointments once the child reaches the top of the list for intervention. A lack of flexibility for families and lack of interagency working with school and other services were also issues relating to quality of service.
- There was frequent mention of the view that family /staff training was replacing direct 1:1 interventions.
- Many families pointed out the lack of continuity of services. Some of the respondents said that they lost/ experienced a gap in the services they were provided after the PDS reform. For others, the transition of services from primary to secondary school has been a challenge. Finally, a number of respondents experienced difficulties when transitioning from child to adult services

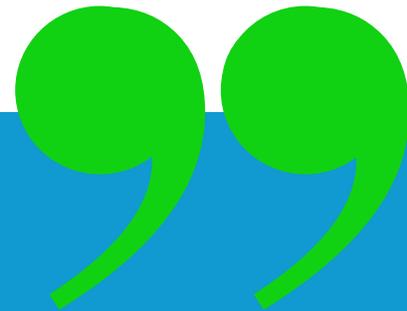
Direct quotes from families:

“They have seen me more than my child.”

“Caseload of 700 per team is not sustainable even if roles were filled.”

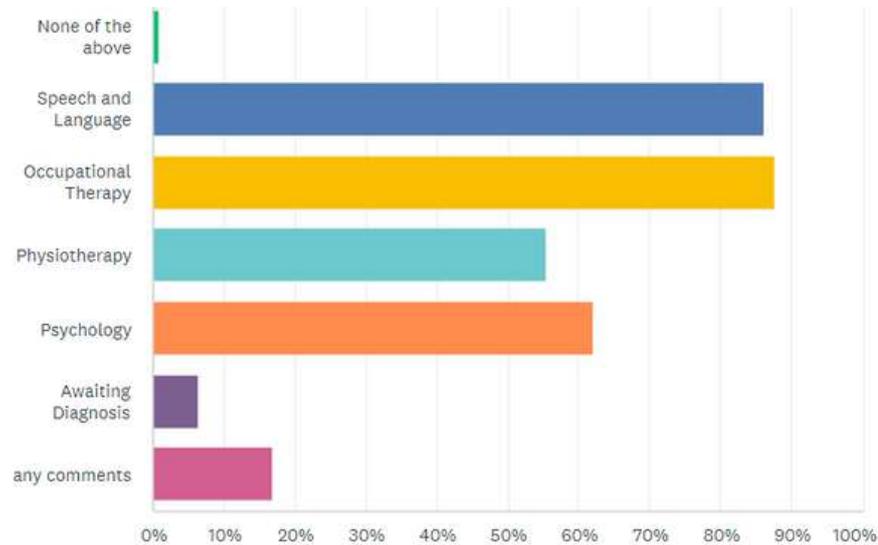
“No one on one therapy for child. Doesn't feel personal”

“Very experienced therapists are being used as administrators in a mammoth box ticking exercise and are no longer having any contact hours with children and young people, which has already led to low morale and skills deterioration, and means that new entrants to the therapeutic environment are not receiving the mentoring that is required to deliver anything to children with complex disabilities, particularly where there are both physical and intellectual disabilities”



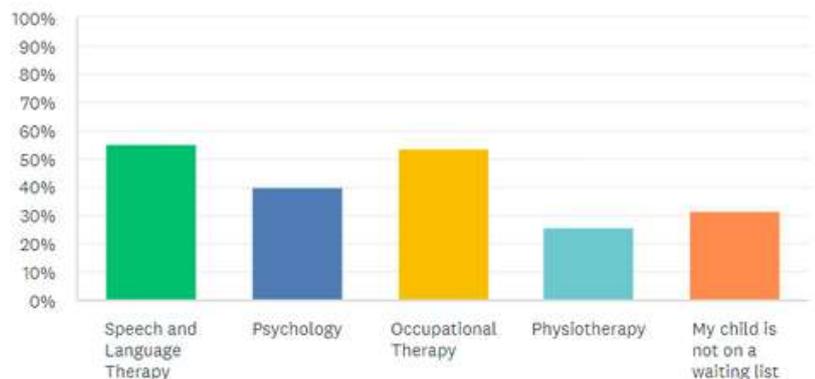
Accessing services

When asked about the type of services their children needed, families particularly pointed out that they needed Occupational Therapy (88%) as well as Speech and Language Therapy (86%). Psychology (62%) and Physiotherapy (55%) were also raised but to a lesser extent.



Average time families are waiting

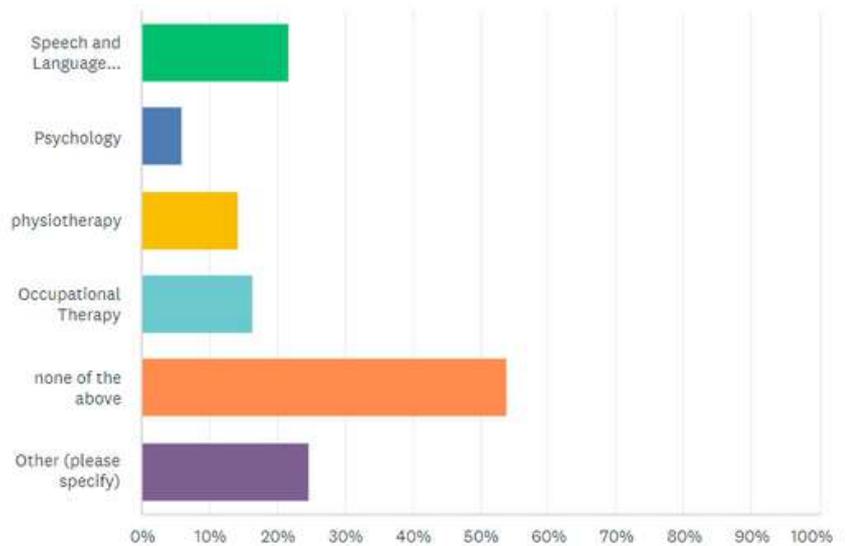
5% of children had to wait less than 6 months to avail of services, 85% mentioned that they had to wait/have been waiting for more than a year. Some answers highlighted situations where no services were ever provided to children who are now adults. Others reported waiting 4, 6 and 9 years. For those who are waiting a year or more or specified another timeline. 5% were waiting over 6 years, 16% 4-6 years and 27% 2-4 years.



When looking at the situation per region, it appeared that Munster had the highest proportion of families who had to wait more than a year for services (90%) in comparison with Leinster (82%) and Connacht (86%)

Services support received by children

When asking families what kind of support they were being provided with, more than half of them answered that they do not receive any services. This goes up to 55% for Leinster, 59% for Munster. However, it goes down to 44% for Connaught and 33% for Ulster



6. Key Recommendations

The key recommendations will be discussed under three headings, these were the most frequent issues highlighted by families. In total we have 9 clear recommendations for improvements to services for children .

A. Access to services

It is clear from the responses that access to services and supports is the main issue for families.

One of the major aspects reported in terms of access was the fact that many families report that their CDNTs are not complete teams and that there is a high turnover of staff.

Inclusion Ireland makes the following recommendations under “access”:

1. From analysis of the data we gathered; there is a serious issue with the workforce and one which requires creative and flexible recruitment and retention strategies. Advocacy organisations and umbrella groups can play a role in this plan in terms of telling the positive story of working with children with disabilities as there does appear to be a challenge in attracting therapists to the area. Even more fundamental issues around the number of University places and therapists qualifying annually need to be addressed if we are to avoid another generation of children waiting on lists to be supported.
2. Now that many teams have reconfigured, there is an opportunity to gather better data per region around access to services. Inclusion Ireland recommends that this data is used to form multi-annual improvement plans based on facts around the required number of therapists per team to ensure the wait list reduces significantly over time. It is clear from supplementary data we analysed as part of this process(see appendices), that there are inconsistencies across the country in terms of numbers of therapists per region. The issue with wait lists will not be “fixed” overnight but a clear, costed plan by region, based on justified and transparent criteria, to address the deficit would be welcomed by families and advocacy groups like Inclusion Ireland.

3. The families who are in contact with us advocate for Early Intervention post assessment/diagnosis. Inclusion Ireland concurs that this is absolutely essential for children with disabilities. We recommend that investment is made in Early Intervention supports for children and their families as an urgent priority. The effect of effective early intervention cannot be overestimated, is well researched and documented in terms of a child's development and their later access to their right to education.

4. School based support where needed: Many children with disabilities need support to access the curriculum in school and their right to education. Schools currently with therapists need to have these positions maintained.

We call on the HSE and Department of Education to work together on the development of school-based services for children who need it. The review of the EPSEN act this year is an opportunity to look at what resources children need in schools to thrive and access their rights to education. There is no "one size fits all" model, but a child centred approach which values each child as an individual and takes a rights-based approach to education is recommended strongly. There are many issues with children's rights to access education currently which could be improved by access to skilled professionals who can support the child in ways that uphold their rights. Reported practises including seclusion and restraint in schools are quite simply unacceptable in 21st century Ireland. With a skilled, child centred team working alongside educators, many such issues can be pre-empted and can be prevented.

2. Better communication with families.

The solutions we offer here are cost neutral or cost minimal and would go a long way towards building trust and better relationships with families. PDS as a model talks about being “family centred”. If there is a concerted effort in moving from “service led” to family led/ co-produced and designed supports , then some significant investment in communication and facilitation is required.

Inclusion Ireland makes the following recommendations under “communication”:

5. Many families report receiving letters from the CDNTs that were, in effect, system focused rather than child and family focused. Families do not want to know about internal processes and demands on service providers , they simply want clear information on when their child will receive services and supports. It is recommended that an external agency or parent steering group could “parent proof” letters and communication to families to avoid distress and confusion.

6. Inclusion Ireland has had many conversations with families about “family fora” and their effectiveness. It is our understanding that family fora are a core part of the PDS model and are a way of supporting the move towards co-produced and family centred services. Families report frustrations that they were asked to be a part of a forum or a local implementation group and soon after the group is disbanded without any progress being made. It is very clear that the establishment of these fora has been a challenge and at this moment in time, most are not functional in any meaningful way. It is our experience at Inclusion Ireland that independent facilitation and clarity of purpose is essential in terms of building trust. Co-design and partnership with families as allies will not happen by accident, it is a process based on transparency, openness and honesty. An independent facilitator could enable that process to commence meaningfully.

3. Better Quality Services

Families in receipt of services, reported dissatisfaction with the consistency and quality of the service.

We make the following recommendations under "quality":

7. We recommend that the reported issues around high turnover of staff as well as the "gaps" in service provision due to absences including maternity/sick leave be prioritised and resolved. Failure to replace staff has an impact on the child's development and ability to progress, measurable by risk assessment of failure to meet therapy needs. It has been reported to Inclusion Ireland that there are varying approaches to replacing staff who are on long term leave. Consistent, timely replacement of staff is essential to ensure that services operate at capacity meeting funded key performance indicators.

8. It is recognised that training is an important part of the menu of supports for families but it cannot replace the 1:1 support that children require. An evidence based approach to intervention is recommended and whilst this will require investment and further development of services, the need for intensive , transdisciplinary approaches for many children cannot be ignored. Frustrations with the quality of support stem mainly from this mismatch in expectations between the family and the services.

9. Confusion about AON /Diagnostic Assessments: many families report confusion and worry about the assessment of need/diagnostic assessment processes. We receive queries and concerns around families waiting for an AON, followed by a period of waiting for a diagnosis. The Disability Act says the assessment of need shall determine whether child has a disability and shall determine the nature and extent of disability. However the HSE currently states that "the assessment of needs is a short screening assessment, it is not a diagnostic assessment".

Not all children will need a full diagnostic assessment, but it must be available as part of the AON to those who do. The process and purpose of AON must be clearly explained to parents. The pathway to primary care therapy services and CDNT services must also be clear and efficient. Prompt access to therapy could reduce the demand for AON as we are aware over many years of advocacy and enquiries that many parents see AON as an alternative route to services rather than a key part of an integrated single pathway system that it is supposed to be.

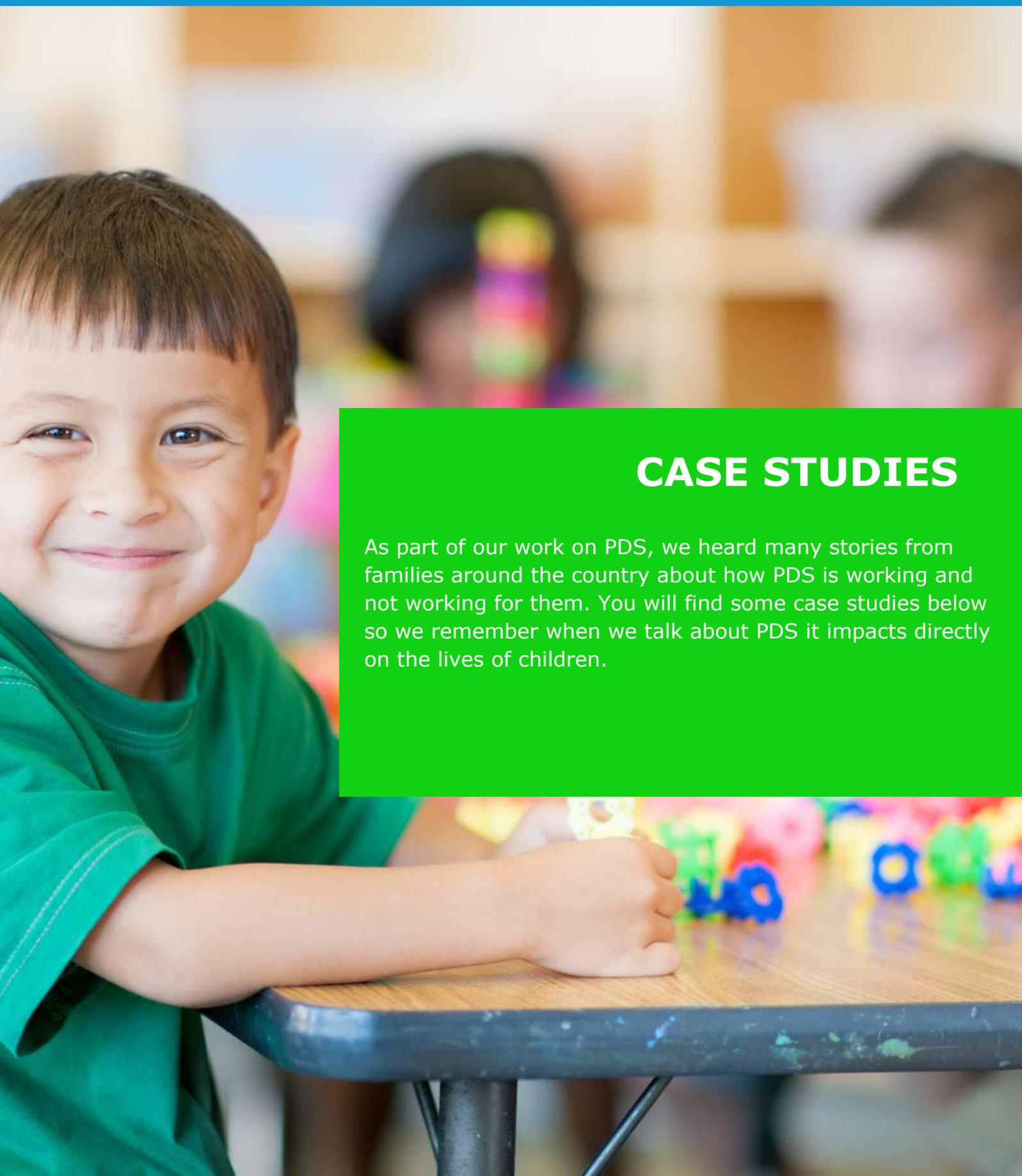


7. CONCLUSION

Inclusion Ireland has created this report to support the improvements in services and supports for children with disabilities. We have made nine key recommendations which we hope will enable the changes needed.

Fundamentally, children with disabilities need and deserve to access comprehensive, consistent support from as early as possible for as long as they require. This support has to meet the child's individual needs and support their family in navigating their shared journey. Multi-annual planning per region is essential if things are to improve for this generation of children and the next. This plan needs to look at the systemic barriers in achieving quality supports for children and cannot shy away from tackling those issues head on if children are to be given the opportunity to flourish in Ireland today.

8. APPENDICES



CASE STUDIES

As part of our work on PDS, we heard many stories from families around the country about how PDS is working and not working for them. You will find some case studies below so we remember when we talk about PDS it impacts directly on the lives of children.

**Mum, CHO 8, Son, age 10, Attends a special school
Diagnosis at age 2 of Autism, non-verbal,
diagnosis through Children and Adolescent
Mental Health Services (CAMHS) of ADHD and
more recently of high anxiety**



The diagnosis/assessment of need our child received:

AON around age 2. Age 25 months seen by Early intervention(EIT) SLT; got services through EIT prior to AON in batches of 6; had home tutor age 2-4.5; OT was always accessible; SLT was never comprehensive. Paid private SLT going to school. Access to Psychology was good with pre-school assessment and to a parent course. At school age, he had a few therapy sessions, but the setting- an old institutionalised building- frightened her son and no alternative was offered.

About therapies

- Mum completed two Tusla Meitheal courses that opened doors to access with CAMHs
- Once her son moved into school Mum hired a private OT; this same OT is now on 0-18 team and she can no longer work with children on the attached to the team.
- The HSE OT offered sessions for parents online during Covid, but this did not meet needs of her son.
- Most pressing need is SLT. After issuing "Your Service, Your Say" Mum had a call from the SLT but SLT cannot go into the school as it is not his remit. A "programme" of four lines, four points, was issued to the parent indicating the work to be completed in the school, however there is not sufficient skill among teachers in the school for this programme to be implemented.

How CDNT worked for us

Received the first CDNT letter in November and the second letter last week. This re-structuring has little impact. It is talk about services with no service.

What we would like the HSE to know

Children in special schools need in school therapy. Staff need to be replaced when a therapist is out on maternity leave. Teachers need to be trained to run a programme. HSE Staff need upskilling in AAC programmes like Proloquo2Go.

**Mum, CHO 8,
Son, age 9, ASD diagnosis age 2 years, ASD
Class; Daughter, age 8, ASD diagnosis 2
years, ASD Class**



About therapies

- Son received 3 blocks (6 sessions) of OT and 2 blocks (6 sessions) of SLT under age 5 & transferred the School Age Team at age 5. Only one set of of OT sessions since then that was interrupted by Covid & lockdown. He has had a few PT sessions through Primary care and this is continuing.
- Daughter received 3 OT and 3 SLT sets of therapy sessions. Transferred to school aged team, at age 5 and since then offered online OT during lockdown, but this did not meet her needs. OT has gone into the school to meet with the class teacher and made recommendations.

How CDNT worked for us

Letters were received regarding the implementation of CDNTs. In the parent's view the communication has been poor.

What we would like the HSE to know

- Son needs SLT and he most likely has undiagnosed specific language disorders. Daughter needs sensory/emotional regulation guidance. Play Therapy, sought privately, was working until lockdown.
- Neither child sleeps well and day time respite is not provided unless there is a diagnosis of intellectual disability.

The HSE Disability Services need to provide services that are child centred, the whole child has to be considered, the building of relationships with therapists, and to create services that will make a difference.

Mum, CHO 1, Son age 8; Diagnosis age 3 of ASD and Intellectual Disability, Non Verbal; ASD 3rd Class



The diagnosis/assessment of need our child received

- AON was complete timely within 6 months at age 3

About therapies

- Within Early Intervention there were 2-3 blocks (six sessions) of SLT and OT while her son was in pre-school.
- A SLT went to the school, but nothing since in the last two years. Present SLT on maternity with no replacement.
- OT is working remotely, but no appropriate & accessible services for her son.

How CDNT worked for us

Received CDNT letters last March/April. No word from the network team nor indication of services/appointments.

What we would like the HSE to know

- HSE need to look again at services from the bottom up, ask why staff cannot be retained, be child centred.
- Mum completed a Tusla Meitheal course which has given her some clarity on how service ought to be delivered.

Mum, CHO 4, Son age 9; Daughter age 7



The diagnosis/assessment of need our child received

Mum went to court for diagnosis for her son- HSE outsourced diagnosis process and son diagnosed with Autism age 4. Daughter diagnosed with Autism within Early Intervention. Mum noted far superior HSE diagnosis than private diagnosis.

About therapies

Son received excellent services initially. Daughter received primary care OT, but this ended as the primary care team felt that she needed a MDT.

How CDNT worked for us

Letters were received and communication was great by the service provider. People were moved from initial team to a new team. Moved to the most populated area. She contacted the CDNT Manager many times with no contact or services.

What we would like the HSE to know

That children's needs do not go away after a diagnosis is given. I like the theory of PDS, but removing the existing relationships with therapists has been detrimental.

Mum, CHO 8, Son age 12



The diagnosis/assessment of need our child received

Son has Down syndrome and a heart complaint. Have not undergone AON.

About therapies

Nothing in last three years. On Early Intervention MDT meetings were good. Since age 5 moved to school aged team only one OT appointment and 2 OT blocks of therapy sessions. Got more SLT appointments due to eating issues and coordination with Crumlin Hospital at ages 6, 7, 8 one round of four appointments.

How CDNT worked for us

Initial letter came and then second letter received October 2021. Supposedly still in the same locality, the same therapy team, but no word further to date.

What we would like the HSE to know

We are and families are crying out for therapies. We were fortunate to have Crumlin to source therapies. It is impossible otherwise. We are part of a family group who fundraise to provide services in the absence of the HSE

Mum & Dad, CHO 7, Son age 9



The diagnosis/assessment of need our child received

Autism, ADHD, Intellectual Disability, he has lots of words but limited functional language. Parents outsourced AON with no oversight of feedback etc and no multidisciplinary approach

Our therapies

Received 2 blocks of combined SLT & OT (4 of each for 8 sessions).

- There was and is no MDT approach. Following the receipt of his service statement and in subsequent interaction with the HSE we were advised that our child was not on a waiting list as there was no one in post to place him on the waiting list.
- Our son did receive some Physiotherapy and there have been one or two visits of therapists to the school about three years ago but nothing in his current school placement.
- Currently in receipt of no intervention and transferred to School Age Team.....

How CDNT worked for us

Two letters received informing of the delay to implementation of the CDNT. Dad rang the number on the letter only to be met by an answering machine message of not to leave a message and that a call would not be returned. Dad left a message and received a call back from a SLT. He was informed that there is no administrative support to work through the many files and that there is a 1-2 year wait list. SLT and part time OT are going through the files. No services exist.

What we would like the HSE to know

There are so few children receiving services that the change has little impact on families. The resourcing of this model is poor. It is devoid of leadership and accountability. Parents are exhausted and some are under extreme financial strain to source private therapies. The Therapists, too, are under extreme pressure to deliver as clinicians. The lack of a statutory obligation by the HSE to provide services needs consideration.

Dad, CHO 6, Son age 9



The diagnosis/assessment of need our child received

Autism

Our therapies

In Early Intervention received a couple of blocks of therapy.

How CDNT worked for us

Met in July 2021 with other parents and parents of another school to keep therapists in the school. Were told by Minister Anne Rabbitte that the implementation of the CDNT would be put on pause for special schools and that the therapists would remain within the school. However, since then we received letters asking us about which team we would select for our son and the therapists left and have not been returned to the school.

What we would like the HSE to know

The problem is pretending that there is a service., it The HSE Disability Services to Children ought to come out and say that "we are closed.", at least people would know where they stand. Time and again expectations are set for parents that are unreal, expectations about service delivery that will never be met. The change in the AON to a shortened process to get through the wait lists is disingenuous. It looks good for the purpose of reducing the waiting list, but in all it has sent those children who are truly in need of an adequate diagnosis through another process, removing their legal entitlement to a complete assessment, and creating another wait list and delay in diagnosis and intervention. There is need for legislation for children with support needs to get adequate and sustained care in Education, Health, and Care.

Mum, CHO 1, Son age 16



The diagnosis/assessment of need our child received

Child has Down syndrome.No AON. Consultant advised further assessment at 8. Diagnosed by at 9.5 with Autism and ADHD.

Our therapies

Early intervention was good from birth until age 5. Mum looked for services as behaviour concerns grew with her son. Help was refused. Consultant advised a diagnosis assessment at 8. Diagnosed by at 9.5 with Autism and ADHD. SLT visits special school once a month.

How CDNT worked for us

Lost faith in services long ago. Wait is far too long. Therapies are non-existent. Non-existent therapies have led to extreme stress in the family. Advocacy attempts in the past to attain services have only led to further stress.

What we would like the HSE to know

Would advise new parents to go privately, do not wait on the HSE. The amount of stress on a parent, on the family is damaging. Need skilled therapists available for children, not wait lists. The rights of my child have not been honoured, supported. Respite services are non-existent. Mum wanted someone to help her to plan for the future for her son. The well being of the whole family is rarely considered in the delivery of services.

Dad, CHO 8, son age 6



The diagnosis/assessment of need our child received

Trisomy 21, Global Development Delay, Tracheomalacia and Laryngomalacia, Hyperthyroidism

Our therapies

While in hospital my son was well cared for, but once transferred to the community my son has not received sufficient services. Under Early Intervention he had SLT once every six months, but it was not targeted or intense enough. He has seen the HSE Dietician twice. HSE OT on SAT for resources for school- good to source equipment, but takes too much time so that items measured for will not fit months later. HSE PT on SAT seen twice. Waiting on MRI- told could be 2-4 years- to assess his core to see about walking. Private PT drive to Galway 80 euro for 45 min session. No communication to follow up, to talk parent through resource and therapy needs.

How CDNT worked for us

Got letters regarding the change in October 2021- letter looked so amateur. No communication to date. Rang the manager and got a very vague reply and was pointed toward YouTube videos when asked about SLT.

What we would like the HSE to know

Need for proper online resource to provide advice. Parents are left in the dark. Would like HSE to take the needs of the child seriously. I realise there is extreme pressure. Managerial positions need to be turned into something practical to serve our children.



Thank you to the families who completed the survey and gave their time, their reflections and shared their stories.

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