



Special Needs Parents Network Donegal

A report on the stakeholder impact of the
Childrens Network Disability Team (CDNT) crisis.



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Introduction

Special Needs Parents Network Donegal were created on the 15th of September 2023, and are a group of parents who have children of all ages and disabilities/levels of additional needs that live in Donegal – currently over 570 members.

The purpose of the Special Needs Parents Network is to provide a forum for peer-to-peer support and to allow us to effectively advocate for our children. Our current focus is CDNT crisis, however our members are challenged with many other issues including CAMHS, and Respite. Since inception, the overwhelming feedback from our members, stakeholders and the local media is that of support.

Parents place huge value on the services of the CDNT teams and their clinicians who have a significant impact of children’s development, medical prognosis and in general, family life. From our discussions with parents and our research it is evident that there is huge frustration about the current service provision and how it has deteriorated since the implementation of the Progressing Disabilities strategy.

Our group was established due to recent communications to parents about the high vacancy rates in children’s disability services and the overall lack of meaningful consultation with parents about the crisis. Parent representative groups were elected at quarterly Family Forums however the direction from the HSE was that they should not be contacted by parents directly. We became increasingly concerned that the range of children’s needs were not being fully represented and as a result our children’s voices were not being heard.

The CDNT crisis

The Childrens Network Disability Teams around the country are experiencing extremely high vacancy rates and turnover rates. The overall national vacancy rate was at 34% at the beginning of September with several areas including CHO 4, 5, 7, 8 & 9 being highlighted nationally as a significant concern. In Donegal the vacancy rate is over 40% in the CDNT areas of Donegal North, Inishowen & Donegal East and Sligo South Donegal.

Donegal CDNT vacancy rates as of 1 September 2023

CDNT Area	WTE assigned	Current WTE	Vacancies	Percentage
Donegal East & Inishowen	26.6	11.7	14.8	55.64%
Donegal North	29.5	12.5	17	57.63%
Donegal South West	21	18	3	14.29%
Sligo South Donegal	38.21	22.83	15.38	40.25%
TOTAL	196.31	107.14	89.07	41.95%

It is clear to see that recruitment is a major issue of concern, however, the Special Needs Parents Network and the stakeholders believe that employee retention, staff morale, workload and job design are also critical issues that need to be addressed by the HSE.



Governance of the CDNTs has been highlighted in a HSCP professional bodies joint statement issued on the 9th of October 2023. The representative bodies of OTs, SLTs, Psychologists, Social Workers and Physiotherapists all voiced their concerns with regards to the ability of their members to deliver services to children with disabilities under the CDNT structure.

The HSE have communicated to us that they are working on workforce planning and recruitment – however, we are concerned about the lack of impact of these plans. We are dismayed that these are long term strategies that will not help our children in the immediate future nor in the short – medium term. The CDNT recruitment crisis has been in the news and spoken about at length at the Dail for over the last two years without any real change. Our children cannot wait any longer. High vacancy rates and plans for recruitment have been discussed at length at Regional Health Forums, Health Steering Groups etc with no real change seen on the ground. We are particularly concerned that statements from the HSE on how the services are being managed with prioritisation for children with complex disabilities and high medical needs isn't reflected in our members' experiences.

The Special Needs Parents Network Donegal have engaged with stakeholders to understand the impact of this crisis and the measures that could be put into place in the short to medium term to provide necessary clinical intervention and support to families. Based on this engagement and stakeholder input we are calling on the HSE to urgently provide **interim emergency measures** to support children and families as recruitment takes time and our children cannot wait.

Interim Emergency Measures

The measures suggested below have been developed with the input and assistance from our stakeholders. These include parents of children of all disabilities that are on the CDNT caseload, schools based in the county, staff who work for or have worked for a Childrens Network Disability Team and other healthcare professionals including public health and General Practitioners who see the impact of the crisis on a daily basis.

We are calling for:

Clear pathways for children to access essential equipment from the HSE

(e.g. AAC, wheelchairs and other postural management tools, orthotics).

These are normally assessed and managed through therapists. Families of children with complex needs in Donegal are not receiving regular therapy, support or timely access to equipment. There has been no indication given to parents on how this will be managed when there are no therapists on a team. This poses huge challenges to families from a medical perspective, and it is unclear whether appropriately robust risk management processes are in place to protect these children's conditions from deteriorating due to lack of intervention and appropriate equipment provision.



Urgent redeployment of therapeutic services from other areas into CDNTs

Redeployment of experienced and skilled resources from other areas needs to take place as soon as possible, with incentivization of roles within the CDNT if required. Other areas including Primary Care do not have the same level of unsustainable turnover and high vacancy rates. This will allow for prioritization of complex cases and will be necessary to support and train graduates/new entrants into CDNT.

Interim model to support children who need therapy and diagnostics to access it privately

Parents of children around the county are paying large amounts of money for private therapy. We are calling on the HSE to implement an emergency model to support access to private therapies when support and therapy cannot be provided by the HSE. Models like this already exist for e.g. private homecare grant, section 39, HSE's outsourcing of autism assessments from Lancefield Private Clinic, national treatment purchase fund and Cross Border treatment fund.

The regular provision of therapeutic support and guidance for schools

Schools around the county are providing high quality education to their students with additional needs and disabilities without the clinical support and guidance they need from the HSE. A school-based team is being hired for the special education schools of St Bernadettes and Little Angels however other schools will continue to rely on support from their local CDNT teams.

The stakeholder impact of the CDNT Crisis.

Since the establishment of our community, we have been engaging with the stakeholders of this crisis to learn where the issues are and understand what measures can be put in place to support them in the immediate and short – medium term.

Stakeholder 1 – Parents of Children on the CDNT caseload.

We have gathered extensive quantitative and qualitative data from the parents of children on the CDNT caseload. The survey feedback demonstrates that families and children are not receiving the therapy provision and support they require which is having a significant impact on children's development and family life. Families are concerned about equipment provision in the absence of therapists and regular therapy and those who have older children are stating that the services have deteriorated since the creation of the CDNT structure.

Parents are only too aware of the recruitment challenges and high vacancy rates but their children cannot wait any longer for clinical therapy and support. Special Needs Parents Network created an initial focus group to brainstorm which interim emergency measures could be put into place that would support families right now who are waiting for services and support and these suggestions were put to the survey respondents.



Parent Statements

Statement from a parent of a child with high medical needs and a complex disability based in East Donegal.

“My child is 11 years old and has a very complex disability including Quadriplegic Cerebral Palsy and Epilepsy. He has a moderate – severe intellectual disability, is fully peg fed, is non-verbal relying on an AAC device which he accesses with eye gaze technology. He relies on a highly supported moulded wheelchair along with other equipment items for postural support (such as sleep system, stander, AFO’s and other supported seating). He has severe scoliosis (80%) and is in pain and discomfort a lot of the time. He is potentially a candidate for spinal surgery to correct his scoliosis, but this is unlikely to happen and for it to have a successful outcome without the support of our local services. In particular we urgently need OT and physiotherapy to support preparations for such huge surgery and for after surgical care.

We strongly disagree that children with a complex disability in the county are being prioritised – our last SLT appointment was in November 22, and we last saw a physiotherapist in May 23. Our spinal team in Crumlin have contacted our local CDNT to request that our child gets the services he desperately needs urgently”.

Statements from parents who completed our survey:

“I had to tell a social worker for CDNT (whom i got talking to by chance) that i had thought about ending my child and myselfs lives at my lowest point, not long after i got psychology, but its behaviour therapy i need.”

“I would just love my child to be seen by CDNT. It's been 2 years of nothing since she moved to CDNT, just a letter to say she was now under them. Early intervention wasn't great, but we had more than what we do now. It's a total shambles that our children are missing out on vital therapies.”

“I pay 75euro a week for private therapy and I’m worried we won’t be able to afford it much longer.”

“My daughter is 8 years old, she fought so hard as a baby to be present in this world, she had open heart surgery at 16 weeks old. Her intervention team is practically now nonexistent. We worked hard to encourage her to eat and drink after no SLT was available in Donegal to help us wean her off her feeding tube. The Donegal Down Syndrome association were the support that helped us, feeding is a need for survival, and we had zero help from the HSE.

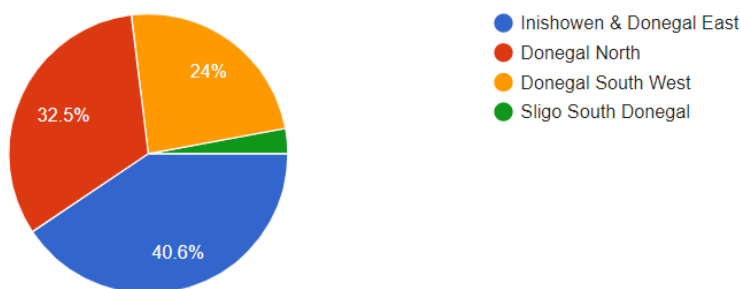


We issued a survey to parents of children on the CDNT caseload to understand their needs and what short – medium term interventions would support their families. This survey was distributed in a targeted, safe and ethical manner. Respondents were required to provide their email address to verify that the information was correct, and data could not be corrupted.

The survey was live for over two weeks and a total of 308 parents on the CDNT caseload provided their information. The breakdown was as follows:

- 125 Inishowen & Donegal East
- 100 Donegal North
- 74 Donegal South West
- 9 Donegal South/Sligo

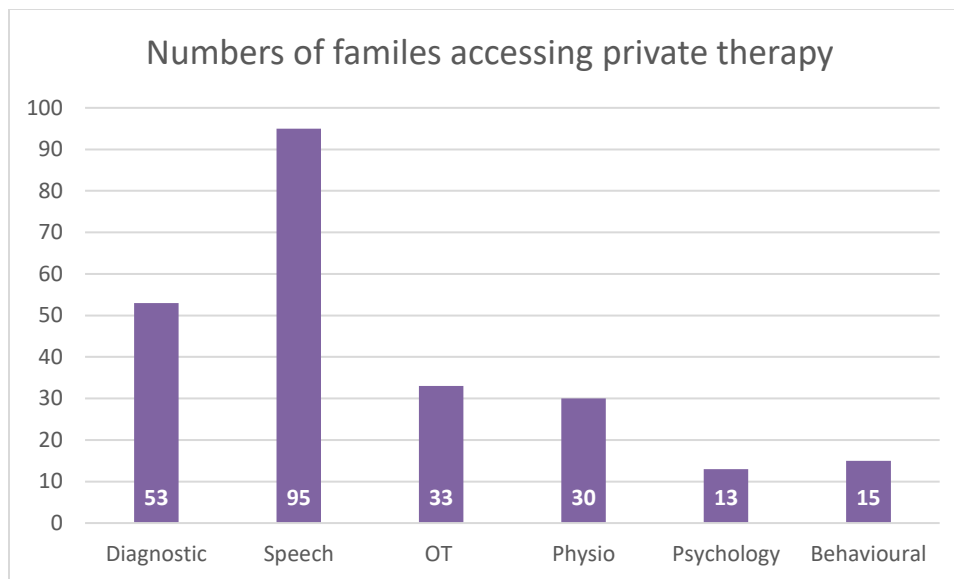
308 responses



Survey Analysis

- When parents were asked “how satisfied are you that the CDNTs are meeting your child needs” 87% responded that their child’s needs were not being met.
- When asked about the impact of the CDNT services on their child’s development 76% of respondents said the services have a high to very high impact.
- When asked about the impact of the CDNT services on their family life, 75% of respondents said the services had a high to very high impact.
- 30% of respondent’s children had various equipment needs and there was palpable concern from these as to how equipment provision would be managed without therapist availability and support.

It’s evident from the survey that parents are facing a huge financial burden from the lack of service provision from the CDNTs. Parents voiced that they have no option but to access private therapy, this was particularly clear for parents of children who have a physical or complex disability. There is huge fear that without any therapy provision their children will experience pain, regression and for many families this fear has been realised.



Families reported paying up to 400 euro a month on private therapy, which is putting significant financial burden on them. There's also the huge issue of inequality – families who cannot afford private therapy for their children, are having to go without, and these children will likely have poorer outcomes compared to children who can access private support. This is speaking to just the financial strain, many families also speak to the strain on their mental health, having to continually chase services, and the guilt of being unable to access what their child needs.

The survey asked for parent feedback on measures that could be taken by the HSE to support their child immediately and to short – medium term.

- Small Group therapy sessions – 44% of respondents felt this would be helpful. When we investigated this further, we noted parents are frustrated with the lack of one-to-one therapy provision and small group therapy wouldn't be a suitable solution for children with more complex needs.
- Travelling to another area for therapy – 56% of respondents felt this would be helpful. This number is potentially low due to the nationwide CDNT crisis.
- Support to access private therapy – 86% of respondents felt this would be helpful.
- Urgent redeployment of clinicians and other support staff from other areas – 90% of respondents felt this would be helpful.
- Extension of Cross Border Scheme to incorporate disability services – 83% of respondents felt that this would be helpful.

Stakeholder 2 - Schools

We have engaged extensively with schools to understand their needs and the impact of the CDNT crisis on their staff and the children at their schools who have disabilities/additional needs. Firstly, the overwhelming feedback was that the services provided by SLT, physiotherapy, occupational therapy, behavioural therapy and psychology are of immense value to schools in accessing and supporting children



with their education. Secondly it was noted by many schools that input and support from clinical therapists has declined significantly since the COVID-19 pandemic and the implementation of the Progressing Disabilities strategy. There is huge worry for families and schools that without therapeutic intervention and support children are unable to fully access the school system, and we have seen an increase of reduced hours for children with additional needs in schools, amongst other issues.

Here you will find a representative number of the statements that we received from our engagement with schools in Donegal.

Statement from mainstream school in East Donegal

"I am the principal of a small rural school in East Donegal. We currently have a number of children who are eligible to avail of the services of the CDNT –speech therapy, physiotherapy and occupational therapy services, among others.

These services are vital not only for the development of children who attend our school, but also to our teachers. For we are exactly that: teachers. We are not speech therapists; we are not physiotherapists, and we are not occupational therapists. We are teachers. And we, like the parents of our students, are crying out for help and guidance on programmes to help our students maximise their potential.

Our school fully supports the efforts of the Special Needs Parents Donegal Network Group in advocating for the needs of their children. We acknowledge the gaps and shortages that currently exist in the Donegal CDNT and we, like the parent's network, concur with the measures that are being called upon to ease the diabolical support system that is in place for children with additional needs or disabilities in Donegal at the moment".

Statement from mainstream school in Donegal South West with ASD classrooms.

"The CDNT play a vital role in supporting children with additional needs. It is also vital that CDNT liaises with all the stakeholders in order to provide the best possible support for children with additional needs. CDNT needs to firstly ensure it has adequate appropriately trained staff on its teams and secondly from a primary school's perspective it needs to improve the support it gives to schools who have children with additional needs enrolled.

The services for children with additional needs has deteriorated, not improved from my experience in dealing with CDNT over recent years e.g. children waiting over a year just to get a formal diagnosis before any support services may even to looked at being put in place. In this time schools are left to their own devices to try and cope"



Statement from mainstream school in Donegal North with ASD classrooms

"I commend the Special Needs Parents Network and the Parent Representatives in your work on behalf of children with additional needs in our county. The lack of services for special needs children is a cause of great concern for all involved in primary education. Schools require the specialist support of Occupational Therapy, Speech Therapy and Psychological Services in order to best meet the needs of our pupils. I have shared your poster with our parent body and urged those affected to take some time to complete the survey. I wish you well with your important campaign."

Statement from mainstream school in Donegal East with ASD classrooms.

"Our school has always welcomed children with complex needs to be part of our diverse and rich educational environment. A key component in allowing us to do this is knowing that children with complex needs are supported fully inside and outside of the school door. We have many children that rely on the services that should be provided under the Donegal East CDNT. These services ensure that we can help these children be the best that they can be and reach their potential. These services are crucial in supporting the staff of the school in providing education and support that is suitable for children with complex needs.

Currently with the CDNT not being resourced adequately, these children are being denied critical support including SLT, psychology, OT and physiotherapy. These professionals play a vital role in addressing the diverse needs of our students, including those with complex needs and developmental challenges. Children are being denied timely and comprehensive support they require to thrive academically, behaviourally, socially and emotionally. This affects their overall wellbeing, educational progress and social development. The impact to each child is profound.

The lack of services is also placing additional strain on our dedicated teachers and support staff, who are doing their best to fill gaps but are not trained or equipped to provide specialised therapeutic interventions necessary for these children. The staff in the school are left in an impossible and unmanageable situation, trying to support children with complex needs without the outside support that is needed. These children, more than ever deserve to have suitable supports in place, to allow them to thrive in our school, whether it be part of our autism classes or part of our mainstream classroom environment.

It is vital that emergency measures should be taken now to ensure the children have access to these necessary services as soon as possible"



Statement from mainstream school in Inishowen

“Our school has 11 additional needs classes, including a class for severe and profound additional needs and an early intervention preschool class. We’ve been operating for nearly 30 years. We are really struggling, and teachers are being asked to provide programmes for children that should be OT or SLT led with no training or guidance among other things. We feel we are being discriminated against because they are a mainstream school with an additional needs school attached. We also have had children in mainstream with profound physical disabilities that are getting no support either.”

Stakeholder 3 – Staff within the CDNT & ex CDNT staff

As mentioned above the HSE are experiencing critical and unsustainable vacancy rates, and recruitment has been an area of concern since the implementation of the Progressing Disabilities strategy. From engaging directly with ex CDNT therapists and clinicians the issues are not only recruitment; staff morale, health and wellbeing, and engagement are all major issues. Employee relations is also an area of major concern with Section 39 employees and clinicians engaging in industrial action throughout the country.

We have spoken to several therapists who have left the HSE CDNT teams. Burnout and stress are huge issues, and these issues are routinely dismissed due to the difficult working environment. The current model doesn’t allow for administrative support for therapists, and they had also a “Key Worker” responsibility (point of contact) role. Many of them stated that they would have to allocate days each week to administration and take work home with them at night. There is a huge level of frustration as this model takes valuable clinical hours away from them and children were losing out.

A clinician who works with CDNT teams in Dublin spoke to us about the scope of the issues:

“Shortages across all teams in Dublin...to my knowledge none of them ever had full staffing since launch and is haemorrhaging staff since – one whole team totally collapsed this summer (CDNM manager even left) The issue is not just recruitment (which is hard but not much evidence they are trying or there is a multi-year strategy) its retention and the PDS system does not allow people to do meaningful work”

An ex CDNT staff member spoke to us with the following statement.

“it’s very clear that this is a nationwide issue facing children’s disability services... it’s so disheartening as a staff member working on a CDNT team. I can see why number one, people aren’t expressing an interest in these posts and secondly why the HSE are struggling to keep the staff they have... As therapists we all went into these roles to provide children with therapy, yet we can’t do this. We spend so much of our time doing administrative duties... we now also have key contact roles which take a huge chunk of time away from our clinical work. Staff are burning out with the workload with no help



coming. One of the hardest things for staff is meeting kids and their families face to face, knowing you are not providing the services they deserve and need. The PDS model does not seem to be working and something needs to be done about it”

Stakeholder 4 - Public Health, GPs and Letterkenny Hospital representative.

Throughout our study we engaged with another group of stakeholders, that of other medical professionals. In their daily work they experience frustration at the lack of services in children’s disability care

Public Health

Public health nurses around the country are under significant pressure to get children’s developmental checks completed and are measured on the completion of such. They are gravely concerned that once a developmental delay has been identified there is nowhere that they can refer the child on to for support. They have spoken about families who are desperate to access a diagnosis, and therapeutic support but many going years without once the developmental delay has been highlighted by the public health nurse.

GPs

“As a General Practitioner it’s very upsetting to meet parents of children with additional needs with letters from the HSE saying that their child meets the criteria for x service but unfortunately there is no therapist available for their child. As a GP I often see their mood suffer as direct result. These parents simply don’t have the time to be constantly fighting for their children’s basic healthcare requirements. It is now much easier in some areas to be seen by a Physiotherapist, SLT, OT, Psychology if you have dementia, a stroke, back pain, a fall etc than if you are a young person with complex needs. Why are we allowing this to continue for children? Parents are being forced to pay money they often don’t have for private therapies as they are left with no access via the HSE to public therapies. This is increasing demand in the private sector and further decreasing the pool available to work in the HSE. Parents who don’t have the money to access private therapies often then feel a guilt that they are letting their child down. They often cannot work to get an income to pay for said therapies as they are needed at home to care for their child. They are in an impossible situation.

Retention in my opinion is a bigger problem than recruitment. This is one of the most rewarding areas one could work in, but staff need to be appropriately supported to do their jobs or they will leave. They shouldn’t have to work in isolation there should be a mentorship programme and incentives to encourage therapists to stay working in this area of need. They shouldn’t have to work into the night doing paperwork. This is not what they were trained at a large cost to the state to do.

Continuity of care is so important and don’t seem to be able to provide that for our most vulnerable children as evidenced by the huge turnover. We need to think outside the box



now for urgent solutions as time is of the essence for these children and because The CDNT appears not to be functioning in areas as evidenced by parents noting a worsening of access to services since the introduction. Primary care could share therapists with the CDNT where they have no therapists to try to provide some access rather than no access. Cross border initiatives need to be allowed. How is it possible for the HSE to pay for patients to access cataract surgery or hip surgery in the North but not physiotherapy to allow a child with complex needs recover from surgery or move their limbs? Please can we employ some of the same innovative solutions we employed during covid to help alleviate some of the suffering that this crisis has brought about. I am reminded of the words of Gandhi “the true measure of any society can be found in how it treats its most vulnerable members” Let’s bring some hope to these patients and their families by looking at workable interim measures whilst staffing is being managed”.

Conclusion

It is evident from this report that there is significant work to be done to improve the services provided by the CDNTs for children with additional needs and disabilities in Donegal. Throughout the past 3 weeks, we reached out and engaged with over 300 families, over a dozen schools, and many healthcare professionals to understand the impact of the situation we find ourselves in. Based on this engagement we have formulated several emergency interim measures that these stakeholders believe will provide short – medium term support for children and families.

It is clear to see that there is some work ongoing to managing this recruitment crisis, however the pace of change and impact on the ground is too slow for our children. The cost of this is to our children’s development, significant financial cost and a huge cost to the mental health of children, parents and families – it is impossible to quantify.

From here, we need to see a genuine attempt from the HSE and our elected representatives to make this happen. We need to see action; our children cannot wait.

We would like to sincerely thank all those who engaged with us in the development of this report, in particular the families of children who are on the CDNT caseload.

Josephine Corkery, Lisa Spelman & Aisling McCaffrey

Special Needs Parents Network Donegal



Appendix A – Local community support for our organisation

Highland Radio Interview: <https://highlandradio.com/2023/09/19/special-needs-parents-network-to-survey-service-users-ahead-of-key-meeting-between-tds-and-hse/>

Donegal News:



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**SABRINA
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Fresh Take

Giving a voice to those families who so often have to struggle silently

“The best activism is equal parts love and equal parts anger,” is a quote from American artist and activist Jackie Sumell whose work interrogating abuses within the US criminal justice system saw her collaborate with Herman Wallace, a member of the Black Panthers.

It struck me this week as I listened to two women from Donegal, both mothers of children with special needs. They have combined the love they have for their children with the anger they feel about the lack of adequate health services to create a movement and demand change for hundreds of children and young people with additional needs in the county.

A Facebook group, Special Needs Parents Donegal Network Group, created by Jo Corkery, Aisling McCaffrey and Lisa Spelman, is already a wonderful piece of activism. It is giving a voice to frustrated, loving parents, many of them who struggle silently, and many of whom have done so for years, to highlight the challenges they face in getting the appropriate care for their beautiful children. There are many heart-

breaking stories out there of parents who feel their children are being failed by the HSE and by government. But by enabling parents to come together and share their stories as well as giving support to one another, the group is showing that it can be a collective voice that's loud and strong and will be hard to ignore.

Failings in the provision of care for children with additional needs in Donegal reached crisis levels in recent months. In some part this is due to struggles around attracting and maintaining staff across a range of services including in social work, physiotherapy, speech therapy and psychology; there are currently 36 vacant posts within Donegal's three Children's Disability Network Teams in the north of the county, the east and Inishowen and south-west Donegal.

But in truth there have been issues around services for disabled children and those with additional needs for years and it's clear that the road to diagnosis and obtaining the correct care is a long one, fraught with many delays and heartache along the way. Letters sent to

parents at the start of this month alerting them to the fact that issues with recruitment and vacancies in CDNT would mean children may lose out on services, has led to families having to pick up the slack yet again, with many turning to other family members, their community and help via the internet to fill in the gaps created by insufficient service provision.

Regrettably, relying on others is not an option open to everyone. But even for those where outside support is available, it certainly shouldn't be a replacement for professional care on a long-term basis.

In addition to the problems within CDNT and its existing caseload, there are many children not receiving any assistance at all. There are families still fighting to get a diagnosis for their children, waiting endless lengths of time for an assessment and feeling so much frustration as they watch their children struggle and miss out on the help and treatment that would improve their quality of life.

Parents, however, are keen to point out that there are amazing

people working within the CDNT service and their fight is not with them but with the HSE and Government. Many also feel local politicians are not doing enough.

Ahead of a meeting in Letterkenny next month between the HSE and TDs, Jo, Aisling and Lisa want parents to contribute to a survey around service provision in Donegal. They hope the combined voices of all those involved will act as a loud and clear message about the sheer level of difficulties parents are facing and the kind of change they want to see.

Every child deserves a safe and happy childhood. It's a human right. Sadly though, as we've seen many times before, it often takes people power to get politicians and government to listen and for change to happen. If Jackie Sumell was right in her assertion that the best activism is love and anger in equal measure, the Special Needs Parents Donegal Network Group has everything needed to bring about change, because parents of children with additional needs in Donegal have both in bucket loads.

Appendix B Communications from the HSE

