
D12 campaign 4 Autism Inclusion



Margaret Jane Lowndes
Chairperson 087 672 2716

Helen Holmes
Vice Chairperson 087 7417590

Key Issues	4
Communication	4
Inconsistencies	4
Staff Resources	5
Waiting Lists	5
Recommendations	6
Summary	6
Reference List	8

D12 Campaign for Inclusion
Opening Statement Joint Committee on Disability Matters Thursday 26th May 2022

Good Morning Chairperson, Deputies and Senators.

Thank you for inviting the “Dublin 12 Campaign for Autism Inclusion” to present to the Joint Committee on Disability Matters today.

My name is Helen Holmes and I am a parent of a child with additional needs & the vice chair of the campaign. I want to acknowledge the input of our chairperson Margaret Jane Lowndes who worked with me on today's submission but is unable to attend.

The Dublin 12 Campaign was set up in 2018 due to the frustration of parents regarding the lack of school places & services in our area. We advocate for equal opportunities in education, services and to raise acceptance for our children with additional needs.

The Progressing Disability Services for Children and Young People model (PDS) is a HSE programme which aims to achieve a single national approach to delivering disability services. It is a fairer way to provide services for children with disabilities and the pooling together of all resources and the HSE specialist children's disability services in order to set up the Children's Disability Network Teams (CDNT).

A family centred model supported through an Individual Family Service Plan (IFSP), outlining what the goals of the child are and how best the teams can support the child and their family achieve these goals.

(Hse.ie April 2017)

While the above quotes read well on paper, the real experience of parents to date is very different.

In Dublin 12 we are under CHO7 and our CDNT's are split into 2 locations CDNT1 based in Dublin 8 & CDNT3 based in Dublin 12. Unfortunately our area was one of the last to be reconfigured and also was delayed further when the Covid-19 Pandemic hit in 2020. The delay with the reconfiguration left families with nowhere to turn for help or support. The most vulnerable in our society were forgotten about leading to extra stress in an already worrying and unprecedented time.

Based on our own personal experiences and those of many families in Dublin 12 (with whom we are in regular communication), the below sections detail key issues experienced and our collective recommendations on how the services could be improved for our vulnerable children who are currently suffering without these services.

Key Issues

Communication

Initial communication between the HSE and families detailing the dates for the reconfiguration was infrequent & a generic approach was used (i.e. no specific dates or details were provided), leaving families struggling with uncertainty. The communication was extremely inconsistent, with some families receiving correspondence while others did not.

Parents have reported last minute cancellations from CDNT's. A recent example, a family was waiting in a reception area with their child only to be informed that the appointment was cancelled. We would hope it does not come as a surprise that many of the children needing these services struggle with routine disruptions. An experience of this nature is very distressing for a child in these circumstances. The disregard for the impact on parents taking time off work to attend is also of note.

Family forums, as recommended by PDS, to be used to discuss issues within the CDNT's are still not established and will take another number of months to be set up. Parents need their voices to be heard now.

Inconsistencies

Different approaches are used depending on the CDNT that you attend.

- Some parents have been allocated key workers & attended an initial meeting with them. Others are inexplicably without this service.
- Some parents were asked to bring their children & others were told to leave them behind for meetings.
- Some CDNT's are offering play therapy and interventions for children while others are focused more on parent courses.
- One CDNT has a messaging system in place for appointments and reminders and the other does not.

A consistent approach, process and service is needed across the board.

Staff Resources

All teams in the area are suffering from lack of staff and this has been communicated as an excuse for the delays or lack of services. Staff recruitment & high turnover is a major issue. There appears to be no coherent plan to improve this trend. There is also a worrying trend of newly recruited staff leaving very quickly.

Currently the vacancies across the two teams are as follows :

- 3 x Psychologists
- 2 x Physiotherapist
- 2 x Speech & Language Therapists
- 1 x O.T
- 1 x Dietician

The primary reasons high turnover is a huge concern are:

- Lack of continuity in the process
- Services starting over to accommodate knowledge transfer to new hires
- Disruption of the relationship formed with the children who thrive on familiarity and routine
- Recruitment into the roles takes a long time

Staff illness and extended leave is not covered by anyone. Insufficient capacity is built into the teams to prevent the impact of staff absences.

Waiting Lists

Of the 25 parents we surveyed in April 2022:

- 20% have had an initial meeting with their key worker
- 8% are attending a parent course
- 16% have their children attending play therapy/interventions
- **56% families are waiting without services**

At present the wait time to access services as a 'new' case is two and half years. There is no respite or home help available during these extremely difficult waiting periods. In our survey, we also asked our parents if they had to privately bear the cost of therapies that their child required. The average cost per household per year to privately access services was €4000 for a single child and over €9000 for multiple children. As early intervention is so critically important, parents have had to struggle to find ways to fund services privately, including:

- Assessment of Need (AON)
- Speech & Language Therapy (SLT)

- Occupational Therapy (OT)

Private services have wait lists and, as many are over-subscribed, wait lists are often closed to new clients. Given the rising cost of living and inflation, many of the private services have recently increased in cost. Families are struggling and having to make difficult priority decisions between mortgage, rent, household bills and their child's needs. A very hard place to be as a parent.

Recommendations

1. A relief panel of therapists to be put in place to cover illness, long term and extended leave etc.
2. Automated text messaging system for confirming, amending and cancelling appointments to be consistently applied
3. O.T & SLT assistants to be trained up & sent into CDNT's to support therapists.
4. We need to look beyond Ireland to recruit expert staff and provide appropriate incentives to attract the required talent.
5. A system facilitating funded access to private services where public services cannot be provided within a reasonable timeframe should be implemented. This would not be dissimilar to the concept of medical card access to a private GP but would be applied to the required disability services.

Summary

On paper, the rollout of the PDS appears positive and was welcomed as a new modernised disability service. However, for many families it's a frustrating system to navigate.

As you know, the idea of it is to bring fairer access for each child and their families but the reality is that there are no therapies for children and the emphasis is put back onto parents to be the therapists for their child/children.

Parents are brought in for a meeting to set goals as part of the IFSP and you must decide your child's top 3 'issues' and they will be the foundations of the plan. Deciding as a parent is very difficult. You are left to appraise your own child and how can you choose when your child is complex and needs an array of help. We are steered away from requesting any direct intervention therapies for our children. As parents, we want to be empowered to support our children but we cannot do this alone. We need the expert therapists to do what they trained for and provide the services, frameworks and education necessary to families.

Children are left to regress and families left distressed. There is no one to step in and help us and you feel deflated as a parent that you have failed your child. Who supports parents' mental health as we continue to fight for what our children need?

Unless you live with a child with additional needs, you can never truly know the impact absence of services have on the child & family. I ask you all here today, what if it was your child? What would you do while you challenge the system and watch your child regress? Would you be happy for your 3.5 year old non-speaking child to wait until they are 6 years of age to be seen and supported?

Thank you for your time & the opportunity to speak today.

Reference List

HSE. (April 2017). *Tell me about PDS*. Available:
<https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/introduction/>. Last accessed 23rd May 2022