



Down  
Syndrome  
Ireland

# RESEARCH REPORT

Parent's Perceptions of their  
Child's Education Journey

2024

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## Introduction

As Head of Primary & Post Primary Education with Down Syndrome Ireland, I am contacted by parents on a daily basis in relation to issues their children are experiencing in schools. In January 2024, to establish a more complete picture of the situation nationally, parents of children aged from 5 to 18 years at Primary or Post Primary stage were invited to participate in an internal Down Syndrome Ireland research project. In addition to providing data on their geographical locations; and the age and education stage of their children, parents were invited to express their satisfaction or dissatisfaction with their children's educational experience; and to identify areas for improvement. In early February 2024, circulars issued by the Department of Education relating to the Special Education Teacher (SET) Allocation model in both Primary and Post Primary Schools, advised schools of the process for calculating the educational profile for each school and the SET allocation arising from this for the school year 2024/25 and into the future. While our initial survey responses had been collected prior to the publication of the circulars, this report is both an overview of parent's perceptions of their child's education journey; and an additional commentary on those perceptions against the background of the revised SET allocations in 2024/2025 and into the future.

In addition to presenting this research project at the Down Syndrome Education International Research Forum, it will be shared with the Minister for Special Education, Officials in the Department of Education, the National Council for Special Education (NCSE) and the Oireachtas Committees on Education & Progressing Disabilities.

## Research Process

- Research was conducted internally in January 2024 with members of DSI on parent's perceptions of their child's education journey.
- A survey was issued to all members in the age range 5-18 years registered on the DSI database. Survey questions were used as follows:
  - a. Open-ended questions which provided the opportunity for additional feedback and more meaningful answers
  - b. Multiple choice questions giving the option of choosing a number of responses
  - c. Demographic questions highlighting the geographic location of the respondents
  - d. Closed-ended questions used to establish specific information

## Parent's Perceptions of their Child's Education Journey

### Survey Findings

#### ➤ Geographic Location of Respondents – Republic of Ireland – 26 Counties

	Respondents	%
Carlow	5	2.03
Cavan	4	1.63
Clare	6	2.44
Cork	40	16.26
Donegal	11	4.47
Dublin	40	16.26
Galway	17	6.91
Kerry	9	3.66
Kildare	11	4.47
Kilkenny	7	2.85
Laois	4	1.63
Leitrim	1	0.41
Limerick	9	3.66
Longford	2	0.81
Louth	5	2.03
Mayo	9	3.66
Meath	24	9.76
Monaghan	4	1.63
Offaly	4	1.63
Roscommon	1	0.41
Sligo	6	2.44
Tipperary	4	1.63
Waterford	6	2.44
Westmeath	7	2.85
Wexford	7	2.85
Wicklow	3	1.22
<b>Total</b>	<b>246</b>	<b>100%</b>

#### ➤ Current Education Stages (Responses 237)

Education Stage	Respondents	%
Primary Stage	147	62.03%
Post Primary Stage	90	37.97%

➤ **Current Enrolment/Setting (Responses 246)**

Setting	Respondents	%
Mainstream Primary School	99	40.24%
Special Class in Mainstream Primary School	13	5.69%
Mainstream Post Primary School	23	10.57%
Special Class in Mainstream Post Primary School	24	9.76%
Special School	83	33.74%

➤ **Dual Diagnosis of Down Syndrome & Autism (Responses 241)**

Setting	Respondents Yes	Respondents No
Mainstream Primary School	1 (1.03%)	96 (98.97%)
Special Class in Mainstream Primary School	5 (38.46%)	8 (61.54%)
Mainstream Post Primary School	1 (4.00%)	24 (96.00%)
Special Class in Mainstream Post Primary School	5 (21.74%)	18 (78.26%)
Special School	16 (19.28%)	67 (80.72%)
<b>Total</b>	<b>28 (11.6%)</b>	<b>213 (88.4%)</b>

➤ **Levels of Satisfaction with Children's Educational Experience by Setting  
(Responses 245)**

	Very Satisfied	Satisfied	Neither Satisfied Nor Dissatisfied	Not Satisfied	Very Dissatisfied
Mainstream Primary School	24 (24.24%)	48 (48.48%)	15 (15.15%)	10 (10.10%)	2 (2.02%)
Special Class in Mainstream Primary School	5 (35.71%)	5 (35.71%)	1 (7.14%)	3 (21.43%)	0 (0.00%)
Mainstream Post Primary School	3 (11.54%)	8 (30.77%)	7 (26.92%)	7 (26.92%)	1 (3.85%)
Special Class in Mainstream Post Primary School	6 (26.09%)	11 (47.83%)	4 (17.39%)	2 (8.70%)	0 (0.00%)
Special School	25 (30.12%)	37 (44.58%)	11 (13.25%)	8 (9.64%)	2 (2.41%)

➤ **Changes Necessary to Improve Children’s Educational Experience (Responses 218)**

<b>Changes in Necessary (in Order of Priority)</b>	
	<b>Respondents</b>
<b>Access to Assessment &amp; Therapies</b>	153 (70.18%)
<b>More Social Inclusion &amp; Friendship Development Opportunities in School</b>	86 (39.45%)
<b>Better Teacher Attitude Knowledge &amp; Training</b>	81 (37.16%)
<b>Better Understanding of Behavior Management by Teachers</b>	72 (33.03%)
<b>Better Differentiation of Work in Class</b>	67 (30.73%)
<b>Improved Home School Communication</b>	52 (23.85%)
<b>Higher Levels of SNA Support</b>	51 (23.39%)
<b>Improved Approaches to Home School Inclusion</b>	49 (22.48%)

Respondents were also given the opportunity to identify additional changes they felt were necessary. The following themes emerged from an analysis of the responses:

- The need of children with a dual diagnosis of Down syndrome & Autism must be properly addressed.
- Every mainstream school should have a Special Educational Need (SEN) class.
- Special schools intake is too limited by the ‘mild’ or ‘moderate’ criteria.
- Post Primary education need to be extended beyond 18 years for some students with Down syndrome.
- Increased opportunities for work experience to be provided throughout Senior Cycle.
- The involvement of parents in planning must be improved.
- Teacher shortages must be addressed.
- All teachers and school personnel should be trained in Lamh signing.
- Too much responsibility is given to SNAs by Class Teachers.

➤ **Additional Information Highlighted about Children’s Educational Experiences.**

The final question in the survey invited respondents to comment further on their children’s educational experiences. Themes emerging together with some quoted comments from respondents are outlined below:

○ **Mainstream Primary School**

❖ **Positive Experience**

- *Her school is outstanding. I shall be forever thankful to everyone there. They are all amazing.*

❖ **Too much Movement & Change in Teachers**

- *Teachers change every year as well as resource teacher and it's very frustrating as you have to start all over again with them on how to educate your child. Most don't have a clue and lots of time wasted starting all over again.*

❖ **Limited Support for Schools & Teachers**

- *Everyone in the school is doing their very best with the resources they have. However they do have very limited support in terms of training and resources to use when teaching / differentiating teaching to children with Down syndrome, from something as simple as using Numicon for maths, or the Reading and Language Intervention for teaching reading, or systems to teach typing. The school are expected to fund all of this when they don't have the finances to do so.*

❖ **Need for Children to be Challenged**

- *I think children in mainstream are being babysat not educated.*

❖ **Right to Attend Local Schools**

- *My child goes to her local school only because we fought for it at great sacrifice to our families' wellbeing. We need an Ombudsman for Education to protect our children's right to attend their local school. Government must enact EPSEN now, no more questionnaires to deliberately delay it.*

❖ **Issues with Assessment**

- *Get rid of these archaic psychological assessments and introduce something that is actually developed for children with Down syndrome*

❖ **Issues with Transition to Post Primary School**

- *I'm absolutely terrified about what happens for secondary school. My daughter is loved and celebrated in the mainstream she is in but will not thrive in main stream secondary and will need to move to special school. I fear I will have to make decisions sooner rather than at the appropriate time due to the shortage of spaces in special schools.*

❖ **Improvement in Teacher Attitude & Training**

- *Extremely poor uptake/acknowledgement of course information passed on to school by us e.g. DSI webinars. Very disappointed in this.*

- ❖ **Issues with Assistive Technology**
  - *I'm trying for months to get assistive technology for my son who has aggressive arthritis.*
  
- ❖ **Issues with the Provision of Therapies**
  - *My son has extensive speech delay and is using technology as a support. He/we/the school have zero access to any speech & language therapy to help him outside of technology (which he will not be able to use on its own, he needs SLT to compliment technology. I feel that we have been given the technology and abandoned since, without any supports other than training on the technology. I have met with his CDNT team but only to set a family service plan, he is not receiving any therapies which is essential for him to progress. I am worried that because he will be noted in the system as having a plan, that this will give the impression that he is receiving supports, which he has not. He has zero access to any therapies: SLT/Physio/OT/Psychological etc. I am unable to even access an assessment for his transition to secondary school, which he needs to gain access. It's extremely worrying and frustrating that our child is just left in the school system without critical input and supports. It's a very distressing, frustrating and lonely journey trying to get our child the support he needs to give him the opportunities he deserves. I'm sure it's against his human rights*
  
- ❖ **Issues with SENO / NCSE**
  - *Neither schools nor parents have anything positive to say about their SENO, there needs to be a full review of their role. NCSE advisors must provide feedback to parents.*
  
- **Special Class Mainstream Primary School**
  - ❖ **Positive Experience**
    - *We're very happy to have found such a good inclusive school.*
  
  - ❖ **Issues with Communication & Involvement**
    - *I would like more communication, and to be given the chance to be involved with my child's education needs, and know what he is learning. I know he is very capable, but I'm not convinced he is being pushed, or they are teaching him at his level, as he will act less intelligent than he is. If they get him at his level he will learn, and is learning outside of school. I'm finding it hard to measure what he is learning in school, and this is very frustrating, as I don't want his time being wasted again, as it was in a mainstream class, before I moved him this time.*
  
  - ❖ **Issues with Behaviour Management**
    - *My son is currently out of his school setting since October trying to get him in 1 hour a day. Teacher is not able to manage or hasn't much experience.*

## ○ Mainstream Post Primary School

### ❖ Positive Experience

- *Our son is in Leaving Cert Applied. We are happy with how it's going and are pleased that he does work experience one day each week.*

### ❖ Issues with SENO / NCSE

- *NCSE is totally redundant. Does nothing to support the educational needs of children with Down syndrome.*

### ❖ Issues with Free Classes

- *A lot of free classes going on over all the school.*

### ❖ Issues with Differentiation & Curriculum Adaptation

- *Secondary teachers in my experience don't know how to differentiate the curriculum, plus they don't have the time. It seems the default option now is for students with DS to automatically be referred to L2LP for JC rather than try some JC subjects with appropriate differentiation*

### ❖ Lack of Programme Availability

- *Leaving cert applied /L2LP is not available in the school which would really suit my son.*

## ○ Special Class Post Primary School

### ❖ Positive Experience

- *Her enjoyment of school is fantastic and it has been especially important to have the opportunity to attend the same school as her siblings.*

### ❖ Impact of Covid 19

- *COVID definitely had a huge impact and catching up is not easy.*

### ❖ Issues with Psychologists/ Psychological Assessments/Therapies/HSE

- *I was very lucky to have a good local secondary school willing to take my son. However the NEPS psychologist really pushed the Special School pathway which would have been further away and he would not have known anyone there. Please listen to the parents more. Also the psychological assessment spoke very negatively about what my son could not do, instead of focusing on his strengths. His primary school teachers were upset when they saw the assessment as they felt it did not capture his abilities, yet it was being used as the basis to make serious decisions. Finally there should be access to therapists in schools with a Moderate class. The CDNT services are a joke and provide no SLT or OT here. They tried to discharge my son as he did not have a complicated enough disability they said to qualify for their services! (Please note he has Down syndrome, serious breathing issues and balance problems etc.). Yet, I was told if he was in a special school he would get priority for these services. I tried to point out that the NEPS psychologist said he more than qualified for the special school and it was my decision to send*

*him locally. However the CDNT did not listen. Both my son's schools have been wonderful to him and have practiced genuine inclusion but he has been let down very badly by the HSE services.*

- ❖ **Issues with Transport**
  - *To make it easier for a student to get a school that meets their needs in their area. Not 22k away and then putting stress on the parents trying to find a school and then fight for transportation.*
- **Special School**
  - ❖ **Positive Experience**
    - *Her enjoyment of school is fantastic and it has been especially important to have the opportunity to attend the same school as her siblings.*
  - ❖ **Limitations on Student Progress & Learning**
    - *I don't feel he's achieved very much in school. The bar is set very low. Over the years, each teacher seems to be sick an awful lot, this has been a big problem. Even though he's in senior school, his school times have never changed 9.00 until 2.30 Monday to Friday. He has a very limited timetable and has done for years.*
  - ❖ **Issues with Access to Therapies**
    - *Child not getting the OT, S&L or physio supports he needs.*
  - ❖ **Lack of School Places**
    - *Lack of places in special needs schools both primary and post primary.*
  - ❖ **Issues with Resources & Supports**
    - *It is shocking that staff in schools, both special schools and mainstream) have to fight for resources and supports for children in their care. Lack of therapies in community and school is a huge difficulty for all.*
  - ❖ **Issues with Teachers & Curriculum**
    - *My son experiences challenges when he changes classroom and gets a new teacher. There is no handover and every time it's like starting again. I feel he has learned no skills in many years as the curriculum seems to involve puzzles and very little else. It's extremely disheartening and frustrating. And yet he couldn't manage a mainstream school.*
  - ❖ **Over Emphasis on Social Skills**
    - *Special schools focus more on social than education.*

Responses from this survey on parent's perceptions of their child's educational journey has highlighted both positive and negative findings at the time of analysis. While the majority of parents have indicated their satisfaction with their child's education in all settings, a number

of negative and concerning issues have been raised. As a result, it could be considered that while we have come a long way with the education of children with Down syndrome in this country, we still have a long way to go!

Only a matter of days after the analysis of the findings of this research had been completed, the announcement from the Department of Education on the revised SET Allocation in both Primary & Post Primary schools, gave rise to great concerns for both parents and schools. As a result, the findings from this research with specific reference to mainstream settings, as outlined above, must be reviewed against the background of the revised SET Allocation for both Primary & Post Primary Schools.

## **Changes to Special Education Teacher (SET) Allocation**

### **The Impact of Circulars 0002/2024 and 0003/2024**

#### **BACKGROUND**

As the national charity supporting thousands of Irish people with Down syndrome, Down Syndrome Ireland is gravely concerned by the content of two circulars issued by the Department of Education in early February 2024, proposing that the category of **complex educational needs** be removed as a criterion for allocating Special Education Teacher hours. The proposed change could have a potentially devastating effect on many pupils with Down syndrome and their educational attainment.

#### **INTRODUCTION**

Research has found that academic progress and achievements were better for those children with Down syndrome in mainstream school, with adequate educational supports in place, as opposed to those children educated in special school settings (Fox et al, 2004; Buckley et al, 2008; de Graaf et al, 2012). An inclusive society begins with inclusive education, but inclusion is much more than just physical presence. According to the UNCRPD, inclusion is a process of systematic reform embodying changes and modification in content, teaching methods, approaches, structures and strategies in education to overcome barriers and provide all students with an equitable and participatory learning experience. The majority of children with Down syndrome now enrol in their local primary school, with increasing numbers progressing to mainstream post-primary school. This is a welcome development and in line

with education policy. The EPSEN Act states that children with special educational needs should, wherever possible, be in an inclusive, mainstream environment with their peers. However, it must be noted that the nature of the disabilities and the differences in learning styles directly attributable to Down syndrome mean that additional teaching resources are needed in order to support learning and promote equality of opportunity.

## **DOWN SYNDROME AS A COMPLEX EDUCATIONAL NEED**

Children with Down syndrome are a unique category in terms of their specific cognitive profile, which impacts on their learning needs as they progress through the education system at all levels. A child or young person who has additional support needs arising from one or more complex factors or multiple factors (needs that are likely to continue for more than a year) is deemed to have ‘**complex needs.**’ When we look at children with Down syndrome, we must consider both the intellectual disability and the chromosomal disorder or disability.

The chromosomal disorder in itself has multiple factors:

- Chromosomal disorder affects all parts of the body, so a greater awareness of physical health needed
- Specific motor and sensory issues are common
- Significant additional impact on speech and language

The intellectual disability and chromosomal disorder both contribute to:

- Delayed motor skills, fine and gross – leading to clumsiness and manipulation difficulties
- Health issues
- Auditory and visual differences
- Speech and language disorder, over and above what would be expected
- Short term auditory memory / verbal working memory problems
- Consolidation and retention problems
- Difficulties with generalisations, thinking and reasoning.
- Concentration and attention can be a challenge

The combination of all of these factors must be considered complex needs for children with Down syndrome.

Down syndrome is one of the leading causes worldwide of Global Developmental Delay.

Global delay can be defined as **significant** delay in two or more developmental domains:

- gross and fine motor
- speech and language

- cognition
- personal and social development
- activities of daily living

**Significant** is defined as performance which is two or more standard deviations below the mean on developmental screening or assessment tests. (McDonald et al, 2006). The majority of children with Down syndrome have significantly delayed development in all of the areas above. All children with Down syndrome have significant delay in at least three areas, as the syndrome invariably affects muscle tone, and hence motor development; intellectual ability, and hence cognitive development; and speech and language development. This indicates that Down syndrome is a complex disorder which has many facets, not merely a cause of cognitive disability.

### **ADDITIONAL DISABILITIES FACED BY CHILDREN WITH DOWN SYNDROME**

As stated earlier, Down syndrome is a chromosomal disorder affecting multiple organ systems, and causing global developmental delay. Some of these disabilities are major and pervasive. Others can be milder, but the cumulative effect of multiple disabilities is a difficulty in accessing the curriculum and learning without additional teaching resources. Some of the specific disabilities faced by children with Down syndrome are outlined below:

- **Hearing**

89% of children with Down syndrome have some form of hearing impairment (Bull et al, 2011). Even a minor hearing impairment (thresholds of 30-35 dB) means that around one third of speech sounds are sub-audible. This could rise to half or two thirds of speech sounds in a noisy classroom environment. Between 50 and 70% of children with Down syndrome suffer from fluctuating hearing loss caused by otitis media or glue ear (Bull et al, 2011). This means that hearing can be adequate one week, inadequate the next. Long intervals between hearing tests mean that these fluctuating problems are often overlooked, although they can have a significant impact on a child's ability to access the curriculum.

- **Speech and Language**

As Down syndrome selectively impairs speech and language acquisition, all children with Down syndrome will have delays in these areas over and above what would be expected with a mild learning disability. Cleland et al (2010) found that individuals with Down syndrome present with deficits in receptive and expressive language that are not wholly accounted for by their cognitive delay. Martin et al (2009) also concluded that strong evidence suggests that phonology, expressive vocabulary, receptive and expressive syntax and some pragmatic aspects of language are impaired (in Down syndrome) beyond expectations for nonverbal cognitive level. Speech and Language impairments affect access to all areas of the curriculum, not just language tasks.

- **Memory**

- **Auditory Memory**

Auditory memory and processing are also selectively impaired in children with Down syndrome. Laws (1998, 2004) found impaired phonological memory skills (memory for sounds and sequences of sounds) to be associated with poorer language comprehension, reduced mean length of utterance and reading difficulty in children and adolescents with Down syndrome. Frangou et al (1997) found that verbal processing deficits may be directly linked to atypical brain development, most notably a smaller planum temporal, and, as such, could be regarded as a primary phenotypic feature of Down syndrome. Wiseman et al (2009) found structural abnormalities in the brain (specifically in the hippocampus region) that are likely to contribute to deficits in learning and memory. Auditory processing and memory are important for all types of learning, not just specific memory related tasks.

- **Working Memory**

Working memory is a temporary storage system under attentional control that underpins our capacity for complex thought (Henry, 2012). Children with Down syndrome show specific difficulty with phonological short term memory and episodic memory beyond what would be expected given their overall cognitive functioning (Henry, 2012). The specific impairment in short-term memory for verbal information will make processing verbal information and,

therefore, learning from listening, especially difficult for children with Down syndrome (Hughes, 2006). Impairment in at least two of the main components of working memory mean that children with Down syndrome learn and remember skills and information in a different way to other children, and this needs to be taken into account in the classroom. Visuo-spatial working memory is relatively good, and so visuo-spatial information is likely to be conceptually easier, but children with Down syndrome also have major difficulties with visual acuity, as discussed below.

- **Vision**

Visual impairments (50% of children with Down syndrome wear glasses) may make it difficult to retain focus on written work. Usually, children focus very easily and very accurately on near targets and it is only as we approach middle age that we expect to experience difficulty in focusing at near. Over 70% of children with Down syndrome focus very poorly at near. They tend to under-accommodate by quite a large amount (Woodhouse, 2005). This is often not adequately corrected by wearing glasses. It is important for teachers to acknowledge that, even if children wear glasses (including bifocals) successfully, or if they focus accurately without glasses, their visual acuity will still be below normal. Thus reading materials, for example, do not look the same to a child with Down syndrome as they do to his/her classroom peers. The material does not appear to have the same level of detail. Enlarging the print may help the child to access print more easily, but does not restore a 'normal' appearance to the material (Woodhouse, 2005). Woodhouse further recommends that all children with Down syndrome, whether they wear glasses or not, receive input from teachers for the visually impaired, to ensure that classroom materials are adequate.

- **Motor**

One of the primary phenotypical features of Down syndrome is hypotonia (Wiseman et al, 2009). Low muscle tone causes delays in gross and fine motor development. Children with Down syndrome are likely to need both physiotherapy and occupational therapy support in order to participate in the classroom. For example, it may be difficult to maintain posture while sitting in a chair, or to manipulate a pencil while maintaining sufficient pressure to write and draw.

- **Medical**

Down syndrome affects multiple organ systems, leading to increased incidence of many medical conditions. Some of the major conditions are outlined below.

- Sleep apnoea affects 30-60% of children with Down syndrome. (Bull, 2011) This can cause poor growth, further delayed development, as well as concentration and attention problems. (It's difficult to focus when you are exhausted)
- Cardiac issues occur in 40-60% of children with Down syndrome. (DSMIG) These can also affect growth, development, and concentration. (Exhaustion can arise from poor cardiac function, as well as poor sleep)
- Hypothyroidism occurs in between 4 and 16% (rising in adolescence)
- Childhood leukaemia is around 20 times more frequent in children with Down syndrome than in mainstream children (Bull, 2011).
- Auto immune diseases like coeliac disease and inflammatory arthropathy are all considerably more common than in the general population (Bull, 2011).

Medical issues, which may not seem directly related to learning, are likely to lead to exhaustion and may increase vulnerability to minor infections. Absences due to minor infections and general exhaustion, along with frequent medical appointments (to monitor various conditions) lead to poorer school attendance than their peers, and hence fewer opportunities to learn.

The combination of all of these factors must be considered complex needs for children with Down syndrome. And the very complexity of those needs must be the basis for the educational environment we provide for them. There is no possible "one size fits all" approach that respects and addresses those needs. Quite simply, many pupils with Down syndrome will not thrive educationally if their complex needs are not specifically addressed.

### **IMPLICATIONS OF CIRCULARS 0002/2024 & 0003/2024**

While we welcome the principle of all pupils, irrespective of special educational needs, being welcomed and enabled to enrol in their local schools, we have concerns in relation to the needs of our members with Down syndrome and Complex Educational Needs. We consider that the proposed allocations for 2024-2025 SET are fundamentally flawed as they fail to provide for the specific needs of this cohort of vulnerable children in the local context of their schools. Every year another 130-150 babies join the population of people with Down

syndrome living in Ireland. In the 1980's, average life expectancy for someone with Down syndrome was around 25 years. It's now around 60. The Department of Education, by failing to provide adequate teaching supports in childhood, are kicking the can down the road. They are not just impacting on the lives of children with Down syndrome right now, they are storing up social and economic costs for the future. Each child with Down syndrome has the right to attend their local mainstream schools with their siblings and peers from their local communities. However, the revised SET allocation has virtually taken the option of mainstream schooling off the table for some of our members. Without dedicated supports from Special Education teaching hours, pupils who could fare better in mainstream schools might not get that chance.

In response to the publication of the circulars in February 2024, we, together with our colleagues in Inclusion Ireland and AsIAm (National Autism Charity) issued a joint survey to members of all three organisations, to ascertain parent's concerns with the revised SET Allocation. Some of the findings in this joint survey indicated that:

- Children were struggling even with current level of support in schools.
- Schools & teachers were already struggling with lack of resources.
- The Department of Education had demonstrated a complete lack of understanding in relation to complex educational needs.
- STEN scoring is an inappropriate measure for children with complex educational needs.
- Revisions in SET Allocations will prevent attendance at mainstream school.
- Pre-School Children will be impacted before they ever reach primary stage education.
- Children's Rights and the UNCRPD are being violated.
- The allocations, against the background of the CDNT/ HSE Issues are completely detrimental for children.
- Parents were now having to consider a home schooling option.

In addition, we note that policy guidelines issued in January 2024 by the NCSE recommends that the Irish education system should continue to progress structures to enable students with special educational needs to attend their local schools. A system of inclusive schools will ultimately enable all students to receive their education in their local school, and to maintain links with their local communities. A system that includes all students with special educational needs in local schools will support a greater understanding of diversity and build respect for those in Irish society who experience exclusion and discrimination. An Irish education system

which includes all students in local schools, will foster a greater understanding of difference and perspectives, build greater empathy amongst young people, and help develop a more inclusive society. One must question how the proposed revisions in SET allocation align with this approach from the NCSE?

As one of a number of stakeholders in the education of children with Down syndrome, we were both concerned and disappointed with the complete lack of consultation between the Department of Education and the disability groups such as ourselves. While we of course respect the necessity for unions and boards of management to be a big part of the consultation process, organisations such as Down Syndrome Ireland have a wealth of knowledge and of members' experience to draw on. Had we been involved at an earlier date, the concerns we have would have been raised at a much earlier phase of the process; parents would have had more opportunity to reflect, respond and prepare, and would not now be in the position of urgently contacting public representatives to safeguard their children's educational future.

All in all, we consider this action of the Department of Education to be a very detrimental action for our members with Down syndrome. Every year another 130-150 babies join the population of people with Down syndrome living in Ireland. In the 1980's, average life expectancy for someone with Down syndrome was around 25 years. It's now around 60. The Department of Education, by failing to provide adequate teaching supports in childhood, are kicking the can down the road. They are not just impacting on the lives of children with Down syndrome right now, they are storing up social and economic costs for the future.

***Students with Down syndrome have the right to be educated in their local mainstream school. It is not unreasonable to expect that any additional training and resources required should be provided.***

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- Bibliography available on request