

## Joint Briefing Document for the Oireachtas Committee on Education, Further and Higher Education, Research, Innovation and Science

### Introduction

This briefing document has been jointly drafted by AsIAM, Down Syndrome Ireland and Inclusion Ireland to portray the significant concerns expressed by almost 1500 families regarding the content of circulars issued by the Department of Education (Circular 0002/2024 and 0003/2024 – The Special Education Teacher (SET) allocation model and the calculation of the SET allocation for each school from the 2024/25 school year until further notice).

In the circular, it is proposed that the category of “complex educational needs” be removed as a criterion for allocating SET hours. The three organisations asked parents if this would affect their child. Almost 1,400 parents responded to express the devastating impact this change would have on their children with support needs. Last week in the mainstream media the teaching community also expressed significant concern with 700 principals signing a petition to demand changes on the allocation of Special Education Teachers.<sup>1</sup> It accompanies a survey revealing that 76% of primary principals do not believe they have enough hours to support children with additional needs.

Inclusion Ireland alongside with AsIAM and Down Syndrome Ireland highlighted the lack of consultation with families and schools on the implementation of this new measure.

This is a violation of article 4.3 of the UNCRPD which highlights that “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

Secondly, all policy should be ‘rights’ proofed and child centred. The single biggest theme we find in all of our work is lack of trust. Children need to trust that they will be welcomed and accepted exactly as they are in their local school. Families need to trust their child will get the support they need. Schools need to trust that they will get the resources they need to support all children in their community.

This submission shares the findings of our survey and brings family members and children with support needs into the Committee to on Tuesday the 5<sup>th</sup> of March. It also focuses on the importance of taking into account the complexity of support needs for some groups.

A consultation and engagement process has now begun with the Department of Education. We will need to be assured through this process that children with higher support needs are provided for appropriately. Whilst the department has ascertained that there will be no reduction in the allocation for children, the ramifications of these changes are still unclear.

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<sup>1</sup> See Irish Examiner article on the 2<sup>nd</sup> of March. Article available [here](#)

## Findings from the survey

### Context

The survey was opened for five days to the public and received 1,344 responses. This number attests to how critical this issue is for families.

The data below offers a snapshot of the level of dissatisfaction and distress felt by parents. It clearly triggered significant fear and concerns and highlights other existing barriers in the school system that children are facing.

### Findings

#### Quantitative data

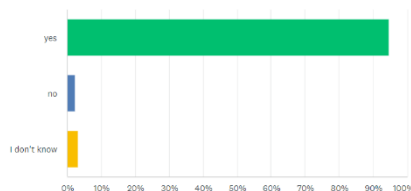
Many respondents to the survey (85%) are in receipt of support from a SET at schools. A small portion of respondents (2%) were unsure if they were in receipt of this support.

Q2

Customize Save as

Would a reduction in hours with your child's Special Education Teacher impact their ability to learn and participate in school?

Answered: 1,338 Skipped: 6



ANSWER CHOICES	RESPONSES
yes	94.62% 1,269
no	2.24% 30
I don't know	3.14% 42
<b>TOTAL</b>	<b>1,338</b>

When asked if a reduction in hours would impact on the ability of their child to learn and participate in school, nearly all of them (95%) responded 'yes' and a small portion did not know (3%). The remaining respondents (2%) did not feel it would impact their child.

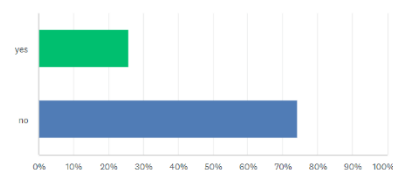
Another key concern is the accessibility of the information provided by the Department of Education. Many respondents (74%) felt that they did not have a good understanding of how the Department will allocate SET hours to schools. Only a quarter (26%) affirmed that they had a good grasp of the situation.

Q3

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Do you feel you have a good understanding of the changes made to how the Department will allocate Special Education Teacher hours to schools?

Answered: 1,341 Skipped: 3



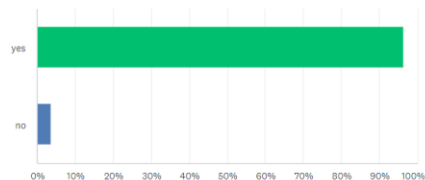
ANSWER CHOICES	RESPONSES
yes	25.88% 347
no	74.12% 994
<b>TOTAL</b>	<b>1,341</b>

Q4

Customize Save as

Are you concerned the removal of complex needs could see your child's school lose resources?

Answered: 1,340 Skipped: 4



ANSWER CHOICES	RESPONSES	
yes	96.34%	1,291
no	3.66%	49
<b>TOTAL</b>		<b>1,340</b>

## Qualitative data

### Concerns from respondents

#### Theme1: Children Struggling Even with Current Level of Resources

Respondents expressed that their children were already struggling with the current level of resources.

- *My child's needs are not currently met. The removal will have a direct effect in loss of set allocation.*
- *My son attends mainstream school. But he struggled and he has an amazing school who have geared his learning to where he is at. To reduce hours would only impact his learning and his progression. He already lost years pre-school and junior infants to Covid, so to reduce resources would be detrimental.*
- *Without the extra help my son is receiving, he would not be able to keep up with the class. He is now able to read as a result of his resource teacher. 6 months ago, he could not read.*
- *My child who is severely dyslexic gets 10 minutes one on one per week and four 20-minute small group sessions. It's not meeting his needs as it is, if this time was cut it would severely impact his standard of education*
- *Inadequate resources available to schools in the first place*

#### Theme 2: Impact of Reduced Resources on Children, exclusion from mainstream settings, and concerns for pre-schoolers.

A number of respondents focused their answers on the detrimental impact the new system could have on their children. Some expressed that the already low level of support will be impeded.

- *The removal of complex needs teachers or time with teachers is a huge step in the wrong direction. It will inevitably lead to reduced resources.*
- *Absolutely the difference in my child's ability to be educated or not depends on the support hours being available. Our class sizes are too big for 1 teacher to cater to the needs of all 30 children in her class. Kids with additional needs will be left behind again*
- *Children with complex needs will have to compete with less needy children for resources and will have no right to support. The available resources will be diluted even further, it will be impossible for these kids to remain in education. Maybe that's what our government want, out of sight out of mind.*

Finally, the quasi totality of respondents (96%) expressed their concern and associated the removal of complex needs criterion with a loss of resources for their child's school.

Those who responded yes to this question were asked in an open question 'If yes, why'. As nearly 1000 comments were received, the comments received have been populated under themes below, with a selection of quotes.

Many feel that reduced resources will **force children from mainstream classes/schools into special education settings.**

- *I'm concerned that the removal of complex needs will prevent a child from the choice and opportunity of attending mainstream school resulting in the loss of resources to the school and our young vulnerable children.*
- *I feel that this new model will serve to exclude children from mainstream schools as resources will not be available to allow them to be included. It will force parents to send the child to a special school rather than to their local school with other siblings.*
- *If there is a reduction in SET hours that could directly affect my son and the possibility that he would be forced into a special school, I'd have a large issue considering we are striving for inclusion in mainstream for children with additional/complex needs.*
- *I would be very concerned that children in mainstream will suffer and be made compete for limited resources. Things are bad enough. School is the only place the vast majority of children with additional needs are getting a screed of support. There should be a concerted effort to put in more resources, not less. I'm also very concerned that children are being forced into special classes in order to get a modicum of support. This is segregation and unfair to the children who genuinely need a special class placement*

Some parents who are in the process of preparing their children for school shared their **uncertainty for their child's primary school future.**

- *I am thinking of the future going forward as my child is not of school age at present. As a parent of a child with DS, I would be concerned that the removal of SET HOURS would affect my child's learning and development. This in turn would affect her chances of progressing with education in line with her peers. Any changes made would impact her chances of living an independent and autonomous life, as I feel in school, we learn all the skills to progress into adulthood. In addition, if my child is not supported at school, she may struggle socially and intellectually. This is a huge concern, as if she was not happy in school, it could have an impact on her mental health going forward.*
- *My daughter starts school in September, and I feel it will affect her education and development*

### **Theme 3: Schools Struggling with Lack of Resources**

Similarly to the first theme, a number of answers highlight the difficult situation schools find themselves in with the current level of resources.

- *It is a small school with low pupil numbers that already struggles with teaching resources.*
- *My child has ASD and dyslexia and the school can barely allocate a fraction of the time to him that he needs. He is a very hard working well behaved child that learns differently and is being discriminated against in the Irish school system. He has his ASD and dyslexia reports and diagnosis and the school still don't have the resources to allocate him the minimum hours*
- *Any reduction in resource allocation impacts a school's overall capacity*

#### Theme 4: Lack of Understanding or consideration re Complex Educational Needs

Many families in the comments express their anger at the lack of understanding or support for children with more complex educational support needs and how those needs cannot be simplified or overlooked.

- *I am concerned that DS will yet again just be lumped into "mild or moderate" without any understanding that many of our children have other issues like sensory, hearing, sight, that impact their ability to access the curriculum. Every child with DS has complex needs.*
- *My child has Down syndrome & global developmental delay, speech & language delay, OT & general organisational & health / safety needs among a plethora of medical issues. If allocation to SET does not allow for specific inclusion of children with complex additional needs, then how, with her level of required support, can she be included in Mainstream school alongside her peers?*

#### Theme 5: Issues with STEN Scoring

A number of comments underline several issues with STEN scoring (short for "Standard Ten").

- *My child scored a STEN of 5 in both her Drumcondra tests just from guessing the answers. Teachers were dumbfounded as they were expecting a STEN of 1. Under the new model, she would be entitled to no support but she struggles hugely in school. She is quiet and I fear that lack of support would lead to severe mental health issues over time.*
- *Our school would have quite high standardised test results so I fear that no special needs reflected in allocation can only result in less hours*
- *Hours are now calculated based on standardised test scores, not taking complex needs into account. When my child's school perform well in standardised tests they will have less hours overall to provide adequate support to my child. This will mean that some children will miss out and resources will be stretched.*

#### Theme 6: Reasons for Department Decision

Many families express their anger at the rationale for this change.

- *Because I know from experience that the Dept. only make these changes to save money. It's not for the benefit of any pupils.*
- *It appears to be a wholly cost management focus rather than an enhancement to the education of AEN children in our schools. We're still playing catch-up in many respects compared to other wealthy countries rather than reducing hours.*
- *The government want to cut costs and SET and resources should be allocated on a needs basis, not a general allocation*

#### Theme 7: Teacher issues

Finally, parents who are teachers shared their concern.

- *I am a special Ed teacher. Currently, cuts to SET allocation are going to have a detrimental effect on all children in primary education but in, particular, those most vulnerable and precious in our care.*
- *Our school has already lost resources, yet we have a greater level of complex needs than we've ever had. How are we to continue to support their needs, when the algorithm for providing hours was slowly based on literacy be numeracy? This is disgraceful. No mention of care for exceptional students (of which we have many) -they will fall through the cracks. We are already battling the aftermath of Covid school closures and still playing catch up. Now we've to contend with less support hours for a higher level of need. It is criminal.*
- *Teachers will be reduced. Schools will have less hours to divide out. Stupid shared positions in schools as a result. I'm a SET teacher as well as a parent with a child with needs. Shared teachers are ridiculous. I was in this position for a year and had half a day in one school. Crazy! In my opinion this is the DES way of coping with teacher shortages just cut the SET teachers, and means we won't have to admit there is a problem. Disgraceful! Also penalises schools that work really hard with students with needs and if they score STENs of 6 or over, are not taken in account for support allocation. Plenty of intelligent children need support*

#### Additional comments from respondents

The last part of our survey was a 'Comments' field. We received 500 comments. We have populated these under themes. While many different topics have been raised, the majority of them express anger with the Department of Education and anxiety for the future.

Less specific comments that could not be populated were also captured below.

- *I would need to seriously consider home schooling without the school support which will have a massive impact on our family. Just shocking that I only know about this through stumbling across a social media post. Concerned as my son's school hasn't mentioned anything about it.*

#### Theme 1: Children rights and UNCRPD

Many point to how this will push children out of mainstream settings, in violation of the UNCRPD.

- *Nothing of what is being discussed is thinking forward - children with extra needs are excelling in main stream settings ... look where society is today with general acceptance of persons with extra needs - integration and not segregation is obviously beneficial for all concerned. DOE needs to look at educating for all not while always keeping an open mind and always thriving to support those who need it most.*
- *While my son does not have complex needs, he has special educational needs, and regardless of the level of need, every child with additional needs is entitled to the support they require to fully participate in school. It's a fundamental human right. Making schools compete for additional special educational resources, or risk losing existing resources due to an arbitrary removal of the reference to level of need, is a direct infringement on the rights of children with more complex educational needs.*
- *With Irelands ratification of the UNCRPD article 24 which demands inclusion and equal access to education for any child regardless of disability, it is devastating that they are now bringing*



*in a model which can only serve to push children with disabilities out of mainstream and into special schools and classes*

- *When will this country catch up with the EPSEN Act and take education for additional needs seriously. We are supposed to be moving away from segregation for our children, yet special schools are those who are getting more resources and parents are being deterred from sending their children with additional needs to mainstream school. SNAs and SET are instrumental to the development and inclusion of our children in not just education but in their social future too.*
- *In our case, our son has Down syndrome and he needs can be identified and addressed. There are children that such needs are notices as they grow and develop through school. Their complex needs are not seen instantly. Children with any needs deserve the right for supports.*

## **Theme 2: Anger/Disgust with the Government**

A high number of comments referenced general dissatisfaction and anger with the Department of Education for this change.

- *As a principal, teacher and parent, I can confidently say that this government is a disaster for education spending colossal money on what can only be described as PR moves while neglecting the real needs that are not necessarily sexy enough to get them headlines. Hot Meals and Free Books are all well and good until your child is refusing to go to school because the necessary supports are not there to help them survive the noise and stimulation of a school day, never mind thrive in it. Yet another example of how our children are hung out to dry for a quick pat on the back from the media.*
- *I have 3 children with special education needs. My daughter aged 15 is no longer in school because of the lack of available support. I had to fight tooth and nail to get the right support for her brothers, the schools are stretched beyond capacity. They need more resource teachers, SNAs and a child with complex needs should not have to fight for support or to stay in school. Their government has failed my daughter, they'll end up supporting her for the rest of her life because they haven't supported her to remain in school.*
- *We get absolutely no state help, we go to private Speech and Language therapy, we attend our Rheumatoid Consultant in Crumlin Private after waiting 5 years on a public waiting list, all he receives from this state is his SET hours at school, to take away same is so disheartening and mean, I am disgusted at our Department of Education.*
- *It's unbelievable that the government can make this change in the Department of Education without prior consultation with families and relevant supporting organisations. It lacks clear vision for our children and it targets the most vulnerable of our society. Our children have complex care needs. Without relevant supports the results will be catastrophic for our vulnerable population.*
- *I feel already that the Government have taken away foundation level subjects at JC, making it harder for our kids to access the course - destroying their confidence, self- esteem, and self-worth. Why would the government take away SET hours for a student who is struggling already... why make it so hard for parents?*

### Theme 3: Teacher issues

The comments received from families who also happen to be teachers illustrate the disconnect of the Department of Education to children with support needs in school. They highlight the fight schools have to access limited resources.

- *I'm not a parent, I'm a teacher but you seem to be the only organisations showing up for all our pupils. Please, please highlight that the Dept do not have accurate information about the level of needs in our schools. They are purposefully not gathering the information because the actual number of pupils who are in need and being supported is far higher than they are willing to recognise. They say they can't get the information, but they can through the POD system. They just don't want to*
- *I am a teacher in a Junior Infant classroom. I am also a parent of a child in Junior Infants and 1st Class. I am teaching in a classroom where myself and the SET (well for the VERY, VERY limited access I have to her) are trying to be teachers, SNAs, psychologists, OTs and SLTs to the children in my room. I have at least 4 children in my class who have undiagnosed complex needs. Undiagnosed because they can't access any services. Their needs are far beyond what I can help with on my own while also trying to support the rest of the children in my room. These children are not getting the education that they are entitled too nor are the other children in my class as the vast majority of my time goes in trying to support these children. It is completely unfair firstly on the children themselves but also on staff. We are exhausted and at breaking point. Staff morale is at an all- time low because the guilt we have is awful. I feel so guilty that I can't do more but I am one person and there is only so much I can do on my own. Sometimes teachers are the only access to a professional that parents have and we try so hard to support parents too. Every single service is failing these children. It's heart breaking. I try my very best while I'm in there and come home and the task of trying to upskill in any way I can begins. We try so hard to do the very best for all of the children in our care but without the resources we need it is an impossible task. Please help us!*
- *From a teacher. In our schools we already have problems allocating SETs to children in need as there are not enough of them allocated. How can DoE say no child will be impacted?*

### Theme 4 Complex needs and STEN Issues

Additional comments reflect the inadequacy of indexing support based on the children's academic skills and the negative impact it will have on their school experience.

- *Children in the country are leaving primary education unable to read. This is horrendous in 2024. A child given resource hours based on STEN results is a system not fit for purpose. A STEN is not an accurate measure of a dyslexic child's level. Mainstream teachers have no specific Dyslexia training. Resource cannot be provided to meet child's need as currently school cannot provide adequate provision due to part time SET hours available. A number of children already cannot access the curriculum due to the lack of resource provided #your future generation enter secondary school unable to read.*
- *Complex needs are exactly what it says - complex. The child doesn't fit nicely in a box for literacy support or numeracy assistance- what about flight risk, sensory needs, movement breaks, melt downs, even more difficult in secondary school where there child meets between 6-9 different teachers a day with different expectations.*



- *Unless complex needs or Down syndrome is stated, I do not have confidence that our children will get the supports as required.*

### Theme 5: Misuse of SET hours by schools

Some comments highlight that a number of SET hours allocated are not used to support children who need it but instead are used to support the completion of administrative tasks.

- *Another big problem is although our kids are allocated hours, some are not getting them. In a lot of small schools principals are taking the SET roll and doing a lot of admin when they should be taking our children. They do not seem to be accountable to anyone. If our children are not able to tell us if they spent time or how much time they were with the teacher. Also, the set teacher is the first one put into mainstreams if there is someone out or gone to a school event.*
- *So much time which is allocated to schools for children with special educational needs is not given to them it is a joke and a disgrace. Teaching Principals are going into support roles and using these precious hours on school administration not related to these pupils. SEN staff spend half the time covering classes for absent teachers who are continually off to Blitzes, Communion / Confession / Confirmation classes, extra -curricular activities etc. Put real accountability in place. Give the parents an email outlining the hours their children did not get each week. It's an open secret that the hours are filled by inexperienced teachers in the main. Speech therapists and OTs need to be in schools and teachers properly skilled to meet the pupil's needs, not NQTs spending enough time to get permanence to take a career break and leave the school.*

### Theme 6 Questions addressed to the Department of Education

Finally, respondents posed questions seeking rationale for this change. Others seek reassurance that child will not be pushed towards a "special" education setting.

- *Have the Dept provided an explanation for the removal and the basis for such, what is its agenda here and overall objective?*
- *Our school has already lost resources, yet we have a greater level of complex needs than we've ever had. How are we to continue to support their needs, when the algorithm for providing hours was slowly based on literacy be numeracy?*
- *Can the DoE guarantee my child won't be without this resource this coming September?*
- *My child is prioritised for SET allocation due to her complex needs- How will this impact her?*
- *Can the DoE guarantee this new approach won't push children/young people into special school's/classes? Where is the Choice?*
- *As a mum of two children that require two totally different supports that to "paper " is not complex but is complex when trying to transition in to mainstream and support them? How will this circular support them?*
- *Children should not be required to fail in order to get the appropriate supports they require. How can the Doe stand over this decision?*
- *Moving complex needs children to a general allocation totally disregards the often highly complex individual learning needs of children with multiple disabilities/ diagnosis. These*

*children are marginalised enough as it is and need a more holistic approach in order to meet their potential? How can the Department stand over this approach?*

- *Our school lost ten hours. In the last two years they have welcomed a number of children with complex needs but got no extra hours. They even did an exceptional review and got nowhere. What will make this new exceptional review any different?*

## Impact of the directive on different groups

### Children with Down Syndrome

#### **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. 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. 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. 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. Individuals with Down syndrome present with deficits in receptive and expressive language that are not wholly accounted for by their cognitive delay. 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. Impaired phonological memory skills (memory for sounds and sequences of sounds) is associated with poorer language comprehension, reduced mean length of utterance and reading difficulty in children and adolescents with Down syndrome. 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. 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. 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. 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. 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. 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. 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. 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. 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. 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.
- Auto immune diseases like coeliac disease and inflammatory arthropathy are all considerably more common than in the general population.

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.

### **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.

A recent internal survey conducted by Down Syndrome Ireland (January 2024 - prior to Circulars 0002/2024 and 0003/2024) indicated that 62% of those who responded were enrolled in mainstream schools. Many parents have since expressed their concern and their intention to move their children to a special education setting due to the removal of the category of complex educational needs for the SET allocation for 2024-2025. An earlier survey (2023) found that 35% of families who had already moved their child to a special school did so because the supports provided in mainstream were not adequate. If the supports provided then were deemed to be inadequate, how can any proposed lessening of supports improve the situation? These are going to get worse if resources are spread more thinly, as will be the case from 2024-2025 onwards.

## **Conclusion**

As highlighted by the survey and the multiple interactions between the three organisations submitting this briefing document and their members, the reform has triggered fears, anxiety and anger within the population. For many families, getting their children's right to education recognised is a constant fight. As the many responses received in the survey suggested, the removal of complex needs criterion and its replacements with more academic criteria has been unanimously met negatively. The way a child performs academically does not tell what this child needs in terms of support. Many families and schools are concerned that the scarcity of resources resulting from this reform will push children with additional needs out of the mainstream system towards special settings like special class or schools.

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. How do the proposed cuts in SET allocation align with this approach from the NCSE?

## About the organisations

**AsIAm** is Ireland's Autism Charity. Our purpose is to advocate for an inclusive society for autistic people that is accessible, accepting and affirming. We work to support the autistic community and our families to fully engage in Irish life and build the capacity of society to facilitate true inclusion. **Our vision is for Ireland to be a country where every Autistic person is accepted as they are. We are guided by and grounded in our living values. We commit to being: inclusive, rights based and empathetic.**

**Down Syndrome Ireland** supports people with Down syndrome and their families in their communities. We strive to provide consistent, high-quality advice, support and information to every person with Down syndrome, to ensure that, whatever their stage of life, they have a network to support them.

We work towards a society that enables all people with Down syndrome to participate to their fullest potential, as equal members with full entitlement as Irish citizens.

Our purpose is to create the environment for people with Down syndrome to achieve their potential, with a particular focus on health, education, employment, and life in the community. Down Syndrome Ireland is a confederation of local branches, who work together to ensure consistency, quality and a common approach which celebrates, supports, and advocates for people with Down syndrome.

**Inclusion Ireland** is a national, rights-based advocacy organisation that works to promote the rights of people with an intellectual disability.

We work towards the full inclusion of people with intellectual disabilities by supporting people to have their voices heard and advocating for rights under the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Established in 1961, Inclusion Ireland's work is underpinned by the values of Respect, Inclusion, Equality, Voice and Choice.