National Federation of
Voluntary Service Providers
Supporting people with intellectual disability (CLG)

Funding Crisis in Disability Services

Drivers and deficits in Intellectual Disability Services

Key Messages

An unprecedented crisis is occurring for people with intellectual disabilities and their families, many of whom are experiencing significant unmet need.

Many organisations who support people with ID are now **operating in deficit positions,** with the future continuation of their services at significant risk.

This crisis has come about as a result of several combined factors over the past 10 years

Successive **regulatory and compliance** frameworks have been implemented in disability services without requisite resourcing (e.g. HIQA; Fire Safety). This has taken place during a period of **sustained funding cuts**.

Major **policy and strategy** developments, which also require significant resourcing, have been introduced without sufficient funding for implementation (e.g. Progressing Disability Services for Children & Young People; New Directions; Congregated Settings).

There have been rising costs associated with **insurance, pay increments** and an increase in **complex and changed needs**.

The lack of an agreed, consistently applied **costing methodology** means that funding is apportioned based on historical allocation rather than present need. There is therefore a lack of consistency, equity or transparency in how resources are distributed to meet increased demand based on changing need and demographic pressures.

Urgent action is required to meet the needs of people with intellectual disabilities and their families and address the crisis in disability services.

Overview of Funding Crisis in ID Services

Funding Crisis in Intellectual Disability services

The cost of providing disability services has risen sharply in the past ten years. However, the **necessary funding has not been provided to meet these costs**. A number of key drivers has led to cost increases:

- Whilst some funding has been provided in relation to supporting people to move from congregated settings, there has been an absence of funding streams for planned residential supports to meet growing need in the community since 2009. This has led to those scarce residential supports that have been put in place, often being provided on an emergency basis;
- There has been an increase in the numbers of individuals presenting with complex need and requiring intensive support;
- Increased insurance costs;
- Unplanned, unscheduled care for children;
- Changing needs of older adults with intellectual disabilities;
- Pay restoration and increments;
- Increased cost of meeting compliance requirements without requisite funding;
- Policy implementation initiatives introduced without required funding.

Some additional factors exacerbating the crisis

- Significant unmet need for respite to sustain carers – resulting in distress for family carers and emergency entry into services;
- Deficits in the provision of multi-disciplinary supports for both children and adults and inequitable provision of the available multi-disciplinary resources;
- Whilst service providers have endeavoured to meet the need of school-leavers on an annual basis in partnership with the HSE, a lack of resources over a sustained period has meant that day services have been put in place without required multi-disciplinary supports, suitable buildings or facilities;
- Services are relying on an ageing transport fleet without appropriate allocation of funding responsibility at Government Department level.

Consequences of funding deficits

- Due to the lack of appropriate supports, thousands of individuals with ID are not being supported to live lives of their choosing, or to maximise their potential and live as independently as possible, as contributing active citizens.

- In addition to the personal cost, this is not compliant with the requirements of the United Nations Convention on the Rights of Persons with Disabilities, which Ireland has ratified.
- Families are forced to watch key milestones in their child's development pass without appropriate intervention due to waiting lists, a lack of supports and in the most distressing cases, children and young people moving into full time care on an unplanned basis.
- Older family members are trapped in unsustainable caring roles in the community due to the lack of investment in planned supports. Many parents are forced to provide significant support into their 70's, 80's and beyond, with no visibility or security in terms of planning for the future of their loved one.
- Many adults who require multi-disciplinary supports are on long waiting lists, with some experiencing consequent deterioration in their conditions (which also risks leading to further expensive care needs).
- **Many organisations who support people with ID are now operating in deficit positions, with the future of their services at significant risk.**

Requirements to secure ongoing future of ID services

1. There is an urgent need for the State and Voluntary Sector to work together to implement in full the recommendations of the Independent Review Group on voluntary services [1]. Its recommendations challenge all stakeholders and provides a framework for addressing the urgent challenges facing us.
2. There is a need for urgent financial investment on the part of the State to resolve the unsustainable deficit situation.
3. There is also an urgent need for a multi-annual investment programme to address the unmet needs outlined in this document and in the Working Group 1 report of the Transforming Lives Programme [2].
4. There is a requirement for an agreed programme of reform of the relationship of service providers and the State, accompanied by reform or change in the approach to the application of HIQA Regulatory compliance that moves from a position of "compliance focussed" to a model of "service improvement/ service user outcome measure focussed". This should include revision whereby there is a legal obligation to have regard to the financial resources available prior to compliance plans being developed and accepted.
5. The State and service providers must work together to innovate and develop new models of integrated service delivery, in line with Sláintecare [3] - harnessing the capacities of the community and voluntary sector in the provision of effective social care to people with disabilities.

Detail: Crisis in Intellectual Disability Funding

Residential Supports

Although funding has been provided over the past decade to support some people living in congregated settings to move to the community, **there has been a lack of funding for new *planned* residential supports for people living in the community, leading to significant built-up unmet need [2,4].**

- Funding cuts over the period[4] and the lack of new funding to meet demographic need means that those residential supports that have been put in place have often been met on an emergency basis[5,6].
- Many citizens living in the community who need residential support do not have access to appropriate supports and continue to live in situations that are not of their choosing or where families are experiencing significant unsustainable care responsibilities[2,4].
- Simultaneously, the (appropriate) closure of congregated settings means that previously available residential support options are no longer available as new need comes on-stream. Congregated settings have not been replaced with a sufficient pipeline of new, funded community-based supports for those coming into adulthood, or whose needs (or those of their carers) change and who now require residential support. For instance, in the period 2009-2014 there was a net reduction in the number of residential places provided[4]. This has contributed to a continually growing and urgent level of unmet need.
- Housing options have been made increasingly accessible to people with disabilities via the Housing Strategy for People with a Disability[7,8]. However, these cannot be accessed without corresponding health and social care supports. The potential benefits of mainstream housing allocation have not been realised for people with ID in terms of the numbers of allocations –e.g in comparison with people with physical and mental health disabilities [9]. This is in spite of the success and considerable quality of life benefits for indiviudals with ID who have been able to secure tenancy.[10]
- The pace of movement from congregated settings to community settings also remains slow[2,4] and leaves many people with ID living in unsuitable settings with people that they have not chosen to live with.
- In spite of rich evidence of the benefits, the opportunities of alternative supports such as Home Sharing have not been fully exploited for the benefiit of individuals with ID and their families[11].
- Article 19 of the UN Convention on the Rights of Persons with Disabilities requires the State to ensure that citizens with disabilities have access ‘to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation’[12].

Meeting residential support need in an emergency model is significantly more expensive than planning and maintaining vital natural supports which can then be supported with the appropriate level of paid resources needed for an individual.

Complex needs

Across the National Federation, member organisations have reported an increase **in individuals requiring support who have significant and complex needs**, particularly of young people in crisis who have behaviour support requirements and may require 24-hour support - as a key driver of cost[2,13]. The implications of these complex needs considerably affect the ways services are required in terms of day supports, residential supports, and the supports provided to families with whom the person is living, as illustrated in the case study included on page 10.

See Case Study 1, Page 10

Changing Needs

Census 2016[14] reports that 66,611 persons in Ireland have an intellectual disability, representing an 8.4% increase in population between 2009 and 2016. (During this period spending on disability services fell by 7%[2]). This demographic trend reflects an increase in the lifespan of people with intellectual disability, resulting in an expected **rise of 21% in the population of adults over 50 years of age between 2015 and 2025** [2].

As the lifespan of people with intellectual disabilities has risen – which is a hugely positive trend, there is a rise in the number of older adults with ID who have significant support needs[2], particularly in relation to their health[15]. The incidence rates for dementia in people with Down syndrome in particular, are multiple times higher than in the general population [15,16] due to the genetic effects associated with Trisomy 21. For instance in Ireland at age 60 there is 2% prevelance of dementia in the general population as compared with a 22.5% incidence rate in people with Down syndrome[15]. Cognitive health is just one area of support need for people with intellectual disabilities - along with areas such as mobility challenges, bone health and emotional health[15]. The changing needs of older adults results in cost requirements in day, residential and respite services.

- **Increased costs for residential support associated with changing need**
  - Individuals require increased levels of support to meet needs associated with dementia and cognitive decline;
  - Physical changes (mobility, bone health, falls risk, constipation); and
  - Emotional health (changed needs often bring with them significiant emotional disturbance both for the person themselves and for those sharing a home).

See Case Study 2, page 11.

- **Increased cost for day services associated with changing need**
    - There are additional costs when providing alternative support in the home setting for individuals who wish to retire or semi-retire from day services.
    - Individuals with changing need also require additional support in day service settings, and may no longer be able to or wish to attend some community activities (requiring a cost of support at the service setting whilst others are supported in the community activity).
    - Emotional and behavioural difficulties associated with changed need drives the cost of support in day settings.
    - No new funding for capital expenditure in day services (other than for school leavers) has been provided to support services to adapt to changing need reqirements.

CASE STUDY *See Case Study 3, page 12*

Example: In one service that supports 1200 people in day services, **250** chose to stay at home on at least one day per week with consequent support costs required in the home.

- **Increased unmet need for Respite associated with changing need**

  As needs change, family members are meeting significantly increased care needs and require more support (important for the family members, the individual and to avoid emergency placement)[4].

  However, in a period of time when the State has come to rely further on family carers, there has been a reduction in the respite supports available. In the period 2009 to 2019, family carers have experienced a deterioration in mental and physical health (increase of 70% in depression; 30% in anxiety; 40% of carers experiencing back injuries)[17]. During the same 10 year period, access to respite care has been substantially reduced with carers reporting that 71% have no access to respite and also reporting less access to support from the Public Health Nurse and GP[17].

Example: In one National Federation member organisation there are now **6** children on the waiting list for respite for every **1** child receiving support. There are **35** adults on the waiting list for every **1** adult receiving respite support in the same service. [18]

Older adults in unsustainable caring roles in the community

As a consequence of the lack of planned investment in residential supports, there has been a build up of **unmet need that is currently often being met by very elderly parents** in the family home. Many of these carers are now in older age themselves, with their own health needs and whose requirement for support will predictably and shortly lead to further emergency requirements for the adult they support[4].

Example: Across a sample of 18 of the 59 member organisations of the National Federation there are **473** individuals living at home with a parent who is between the ages of **70 and 79 years**. In these same 18 services there are **183** people supported by a carer who is **over 80 years of age**[19]**.** Many more parents between the ages of 60-69 are providing the primary care role in the home.

Unplanned, unscheduled care for children.

Families are currently experiencing a lack of required respite and in-home support, with access to respite for carers having reduced in the decade from 2009 to 2019 [17]. There is an urgent need for preventative measures to ensure that families are supported to meet the needs of their children with intellectual disabilities – particularly those with complex needs - and to avoid the catastrophic eventuality of abandonment, which is hugely detrimental for both child and family.

National Federation organisations have reported that in the past 3 years a number of children have been left in acute hospital settings and in children's respite services by families who are in crisis, and as a result the children have been taken into the full time care of the services. One organisation has had 15 children move into full time residential care since 2015.

Governance, compliance and regulatory costs - unfunded through central sources

A wide range of compliance and regulatory frameworks have been introduced in the past ten years, without impact assessment or requisite funding allocated. Instead, organisations have been required to find funding from within existing resources in order to meet the obligations of the various requirements, at a time of reduced funding within the ID sector. Some examples include:

- HIQA
- Fire Safety Requirements (often also linked with HIQA inspection)
- Internal Audit
- Data Protection
- Pension Authority/ SPSPS administration (particularly member benefit statements and increased cost of pension administration in general)

It is estimated that the cumulative spend on HIQA-related additional essential expenditure across the whole disability sector has amounted to c. **€82m over the period 2016-2018.**

Transport

Across intellectual disability service provider organisations there is an ageing fleet of vehicles which pose a safety risk and for which no funding has been provided for replacement to ensure the safety of the service users and staff. There is an urgent requirement for cross-Departmental engagement between the Department of Health and the Department of Transport to address this issue and the urgent funding requirements.

Example: Across a sample of 33 National Federation member organisations, transport is provided to 6384 people to attend their service and community activities. In these 33 services there are **532 vehicles which are over 10 years old** and which require replacement [19].

There is also a need for the Motorised Transport Grant and Mobility Allowance to be reinstated.

Multi-disciplinary supports

There is a range of significant difficulties being experienced by children and adults with intellectual disabilities in relation to accessing adequate multi-disciplinary supports. Waiting lists in children's services are resulting in children waiting significant times to see Multi-Disciplinary therapists at a key time for the development of the child and when early intervention is crucial, with the system requiring an additional 300+ posts [2].

Therapy services for adults are also not appropriately resourced across the country and access to a range of supports including Primary Community and Continuing Care for people supported by services is currently inequitable[20]. The provision of multi-disciplinary supports to adults with ID is based on a system that is entirely inconsistent in terms of geographical provision. Furthermore, where therapy services to adults are available, some of these services have been negatively impacted by the introduction of Progressing Disability Services for Children and Young People (PDS). In areas where PDS has been implemented, therapists, who were previously split across both adult and child services, are now often aligned to children's services thus resulting in a reduction in therapy services to adults [21].

Long waiting times for essential Multi-Disciplinary support can lead to unneccessary deterioration in the conditions of the individual, with consequent effects on the quality of life of the person and on the costs to the state for supporting the person in the activities of daily living. The changing needs of older adults as described above and the resultant requirement for Multi-Disiplinary support is an additional factor creating pressure in relation to therapy posts in the ID sector.

Working Group 1 of the Transforming Lives Programme reports that based on unmet need recorded on the disability databases, provision of adult therapy services need to double from 2016 levels.

Insurance Costs

The State Claims Agency has recently completed a review of insurance costs across a selection of Section 39 agencies, overseen by a Value Improvement Task Group. The review aimed to analyse and make recommendations in respect of savings and efficiencies that can be achieved on insurance premiums. The draft report acknowledges the increasing insurance costs incurred by organisations over the past 5 years and makes a number of recommendations, including exploring the development of an affinity grouping to jointly purchase insurances, enhancing the buying power of combined organisations.

Recruitment and Retention

Organisations, particularly Section 39 agencies, are experiencing serious difficulties in recruiting and retaining staff who are critical to the provision of essential services. While there is a restoration of pay process underway for some Section 39's this needs to be extended to all affected agencies to ensure that they are in a position to attract essential staff and to retain existing staff members. In addition there are challenges being faced by agencies in recruiting and retaining senior staff members to oversee the effective development and delivery of services.

How deficits impact people and services on the ground

Case Study 1

Young adult with complex needs – full service requirement currently unmet

Rose lives at home with her parents and her younger sister. Rose is 20 years of age and has a diagnosis of a moderate learning disability, epilepsy and is blind. Rose has recently been diagnosed with severe depression and is presenting with significant anxiety following on from a number of traumatic events she has experienced in the past two years.

Rose finished in Special School in three years ago and commenced a transitioning to a 2-day per week service in the Day Service the following October. This transition was very stressful for Rose and she experienced several challenges during her time at the Day Service. It is felt that this transition impacted greatly on Rose's mental health as well as other significant life events such as a close family member passing away. Initially Rose's behaviours escalated at home and she began injuring herself and others, by kicking, biting, head-butting, hitting out and crying and shouting. Rose's sleep was also disturbed which impacted on the whole family as she wakes them at night. The placement at her day service broke down in 2018 and she commenced a 3-day week per day service with another service provider in October 2018 and then a 5 day per week-day service in January 2019. Rose also avails of 2 nights per week respite, however due to the impact her behaviours have on other residents it cannot be expanded beyond this.

Rose continues to present with the above behaviours across all settings however it has reached and surpassed crisis point in the family home and they are now unable to manage the situation safely. Weekends are unbearable and her family are seeking a full-time residential placement. Rose is being supported by BSS and the MHID team however incidents continue to occur. Rose's parents are exhausted. Dad is under a huge amount of pressure trying to hold the family situation and maintain his work, which provides the family's only income.

Rose continues to shout, scream, hit out, bite, kick, pull hair and attempt to head butt her parents. Rose will self-injure during times of distress also. Rose's mother is covered in multiple bruises and scratches. The family report that this is continuous. In a recent incident of distress Rose went to hit out at her mother however she moved out of her reach and Rose ended up missing her and hitting a door which resulted in Rose breaking her finger.

There is concern that the situation will escalate beyond crisis point and Rose and/or her parents and 13 year-old sister will be seriously harmed. There are also huge concerns for the wellbeing and mental health of her parents and sister if they do not receive funding for a residential service.

Changing needs of older adults

Case Study 2

John is a 55-year-old man with Down syndrome who, in 2015 was residing with 5 other gentlemen (age range 55- 68 years) in a home in the community. The house required some physical adaptations in recent years due to the physical aging needs of residents. The staffing ratio in John's home at that time was 4.78 WTE to 6 gentlemen including a sleep over staff.

In 2016, John began to exhibit cognitive decline with changes evident for John in memory, orientation, general function and behaviour. This was evident in agitation, verbal aggression towards housemates and poor sleep pattern with risk behaviours at night. To meet this changing need, additional nursing support and a change from sleepover staff to waking staff was implemented. This increased the WTE to 5.25 staff to 6 gentlemen. Despite this, John's cognitive decline continued to have a severe effect on his mental health, behaviour and ability to attend his day service programme. This negatively affected his peers through aggression, interrupted sleep patterns and plans and staff who primarily focused on supporting John.

In 2018, John transitioned to a single occupancy dwelling with an individualised staffing model of 4.56 WTE. This resulted in a reduction in anxiety and improved quality of life for John allowing him to improve his level of functioning. Individually structured supports ensure John has a person-centred approach which has benefited his orientation and memory allowing him and his staff to concentrate specifically on John's needs and to adapt appropriately.

Johns previous housemates who have physical health needs associated with aging can now enjoy a slower pace in life and care that meets their individual needs without significant changes to their plans or disruption. They have no risks associated with aggression which positively impacts on their quality of life and sense of security. The staffing ratio has returned to 4.78 WTE in the community house.

Case Study 3

Niall is 53 years old. He received a diagnosis of late-stage dementia in 2013. He met 15 of the criteria on the Dementia Scale for Down Syndrome (DSDS). His assessment noted that changes in physical, emotional and cognitive abilities were observed from as early as 2006.

Prior to his diagnosis Niall enjoyed a relatively active life. Living in a community-based home with 3 of his peers in a lively town meant there was plenty to do. He had a part time job in the local church, attended his local day centre and enjoyed many social events with both family and friends. Staff ratio in his home was 1:4 (staff slept over in the house). He had a job coach while working. He was mobile, requiring no extra or specific clinical supports outside of the norm for a man with Down syndrome. In all reports Niall is described as an active, witty and sociable person. He spent time with his family and had annual holidays. His passions in life were music, sport, his family and food.

In the years prior and up to Niall's diagnosis, signs of increasing cognitive/physical and emotional changes included:

- Loss of skills around Activities of Daily Living;
- Apparent memory lapses when involved in tasks – requiring prompting to move on to next level of task;
- Loss of orientation at home - forgetting where a room/item was;
- Increased anxiety/ distress around noisy environments or people. This was presenting as aggression, shouting and anger;
- Regarding his epilepsy, seizures increased in frequency. These were in the form of drop-attacks which led to physical injuries;
- His swallow became a concern – choking was identified as a risk;
- His sleeping pattern became erratic, and as a result routine and scheduling of supports was difficult;
- From 2013 to 2015 levels of distress and anxiety increased;
- Increased sensitivity to touch was evident as was a sensitivity to water/bathing;
- Mobility became compromised which was a major change for him and his family.

Life over a number of years became increasingly stressful. Niall lost his job and had to move house when it became clear 24-hour supports were needed. In 2015 /16 he required several hospital admissions which included insertion of urinary catheter. Dental extractions and treatment were also undergone during this time. Staff supports during hospital stays were essential and required on a 24-hour basis.

Increased supports following diagnosis:

Clinical Supports:

Referrals were made to the interdisciplinary team requesting increased hours of support from the Dietician; Speech and Language Therapist; Physiotherapy; Occupational Therapy; Psychology and Psychiatry. In 2015, staff with a particular skill set were required to manage care and develop care responses to his changing needs. Options were explored and nursing hours were allocated to support Niall 12 hours daily 7 days per week.

The dual role of the nurse included the development of, and managing of care plans to meet Niall's changing needs. Nurses were also the liaison with medical professionals and sought resources when required. There was also an educational role in that existing staff could enhance their own skills and gain experience in a new way of supporting individuals with age-related conditions and changing needs. Staffing requirement became 24-hours with round the clock supervision. In terms of the increased likelihood of aggressive episodes around intimate care these tasks are carried out on 2:1 ratio. At times a third staff member was necessary on these occasions. Mobility supports means 2:1 for all transfers.

Equipment and Aids

Hi –Lo bed
Persona Chair
Motorised Chair
Commode
Changing trolley
Incontinence wear

Transport

Now must be accessible

Therapies

Music therapy
Sensory Equipment

Present Day: Life is less stressful for Niall now. He is enjoying many of his old pastimes. His sensitivity around touch/crowds/noise is diminished which means he likes to be out and about again. His physical needs have/are being met and he has a pain management /medication regime which works for him. All above lend themselves to a more enjoyable, healthier lifestyle.

Emergencies presenting to ID service providers that remain unfunded

Case Study 4

Carol is a 51-year old lady who lived at home with her elderly father. She hasn't had a day service since she left school at the age of 18. Carol came into emergency respite in 2016 after she pushed her mother which resulted in her mother sustaining a fractured pelvis and this was reported to the safeguarding team. Carol's mother has sadly recently passed away.

Carol has been living in emergency respite since 2016 and her support package is unfunded. Carol presents with high anxiety and behaviours that challenge, especially towards other service users whom she may see as vulnerable. Carol shares her living environment with 21 other people who use respite on a regular basis and up to 4 other people share her living space at any one time. There are two other people who are also emergency residential placements who use the respite service on a fulltime basis.

Living in a busy respite centre is a wholly unsuitable and inadequate living environment for Carol, as Carol requires consistency and predictability and really struggles with living with others with a disability. Carol has also trialled attending day services, however her difficulty with associating with other vulnerable people led to safeguarding concerns and a decision had to be made to provide her with an individualised day service, which is run from the respite centre.

Carol has not settled into living in the respite service and over the last year, there have been numerous peer-to peer incidents of a physically aggressive nature, which have resulted in 16 different safeguarding notifications and NF06 notifications to HIQA. These incidents have been aimed at more vulnerable or passive service users. One of the other service users who resides in the service as a further unfunded emergency placement has borne the brunt of many of these physically aggressive incidents.

Despite intensive intervention from Behaviour Support and additional staffing resources, physically aggressive incidents continue to occur as the behaviours are often opportunistic. This has led to a culture of policing interactions within the service, which reduces everyone's enjoyment of respite as well as creating a culture of fear for some of the more vulnerable and passive service users.

Carol's emergency placement in respite has been very vulnerable to breakdown for a considerable period of time and her continued placement there has significantly impacted others who reside there and who use respite and led to numerous physical incidents towards service users.

The urgent development of an individualised living arrangement for Carol is required as she is unable to live safely with other people with a disability.

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