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Out of area placements in Ireland: a needs assessment

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Abstract

Purpose

To complete a needs assessment to enable the identification of quantitative and qualitative Information on social care and mental health funded service users placed out outside their area of origin in private placements. This would assist in the development of a robust pathway of care for children and adults with complex needs, and to assist managers to make informed commissioning decisions.

Method

The paper identified people funded by social care and mental health Health Service Executive divisions originating from the Republic of Ireland who were in out of area care, and collected data about them. The paper used reference groups to inform the analysis. Qualitative and quantitative methods were used.

Findings

307 people in out of area private services were all included in the analysis. In all,
74% were male and 26% female;
52 % had a learning disability;
Only a very small proportion had current very significant levels of complexity requiring significant levels of staffing.
Qualitative analysis on 251 of the cases showed them to be highly complex, and this in combination with unsuitable care environments and exceeding the capacity of family and formal carers is associated with frequent moves within Ireland and at times to the UK also.

Implications & Originality

Out of area care for this population is a major public health issue. Many are placed a long way from home. Local services should be developed, and there should be sufficiently robust "step down" places for people to be discharged to. There has been very little research into this issue in Ireland.

Keywords; Out of Area, private placement, complex needs

Introduction

In the Republic of Ireland, Current Community Operations expenditure on private out of area placements across Disability and Mental Health services makes up a significant percentage of the overall expenditure. There is a significant increase in numbers and expenditure year on year since 2014 across all Community Healthcare Organisations (CHOs, local regions in Ireland, of which there are 9 in total).

The purpose of the needs assessment is to examine Disability and Mental Health out of county residential placements with a view to ensuring that the Health Service Executive (HSE) is getting good quality person centered services at the most economical cost available. There is the requirement for a consistent approach for individuals whose complex needs span disability and/or mental health services placements, often at high cost. The cost does not merely refer to financial aspects. It also refers to being away from home, family, friends and oversight of local services. It is also worth noting that the financial cost of the placements impacts on being able to develop local services for service users with complex presentations.

Guidance and policy

Much of the guidance in this area comes from the UK and focuses on learning disability settings. In Ireland however a report on out of state care 'Excluded, expelled and exported' by Barry et al, 2011, describes the volume of remote placements as an unacceptable situation.

UK guidance

The Reed Report into services for offenders and those with similar needs (1994) recommended that people with learning disabilities requiring secure psychiatric services should be cared for as close to their local community as possible in conditions no more secure than warranted by their level of risk.

A survey of independent learning disability in-patient units (Healthcare Commission & Valuing People Support Team, 2004) identified the average distance from home for clients was 74 miles, with the furthest placement 385 miles from home

Commissioning Guidance for learning disability services from the Department of Health (Office of the National Director: Learning Disabilities, 2007) criticises this reliance on distant provision for services for people with learning disability. The guidance recognises that each local area will only need a small number of such beds. It suggests that local services work with neighbouring authorities to ensure that specialist inpatient services can be accessed without undue waiting or recourse to services a long way from home.

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There is further advice in the Best Practice Guidance, Commissioning care pathways through secure services for people with learning disability (Department of Health, 2008). Its stated aim was to promote a whole system approach to commissioning

This guidance stated that there was no consistent model for the provision of secure learning disability services. Patients remained in distant services longer than necessary and often could not be re-settled within their home area due to insufficient appropriate provision and a lack of continued involvement from local services to manage their safe return home

The 2009/10 Guidance on the Standard NHS Contract for Mental Health (Department of Health, 2010) is also relevant, and recommends the following;

- Care should promote recovery, social inclusion, independence and harm reduction. Carers should be appropriately involved in planning care and their needs should be assessed.
- Care should be provided as near to home as is reasonably possible.

Aims

- A standardized review process to take place.
- Complete assessments for HSE funded service users in the 3 biggest private providers nationally in Ireland.
- Use of findings to provide support to CHOs in decision making and build clinical capacity locally by sharing learning from the completion of the assessments.
- Develop a census matrix to represent all complex placements to reflect the following; CHO, Provider, location, risk issues, acuity/complexity of need, Full Year Cost and last review date.
- Describe current range of complexity of existing placements.

Method

2 senior executive officers worked on creating a master list of placements & liaising with providers. A placement improvement group was set up (see governance structure) to review assessment structure, agree communication strategy and oversee appointment of assessment team members.

A bespoke template was completed by the visiting assessor with a keyworker or residential team leader. Parts of the template had been used in similar projects in the UK and Ireland by the lead assessor. Significant support was acquired from a Disability Specialist to develop this into a bespoke project template, with 168 questions in total.

All assessors were employed in a National Placement Oversight & Review Team (Nport) and consisted of a consultant psychiatrist, two social workers and a clinical nurse specialist.
A tutor in the Department of psychology at an Irish university analysed anonymised qualitative sections of the template with supervision from a lecturer in clinical psychology.

A steering group agreed and reviewed an Algorithm created to determine levels of complexity (see appendix b)

Definition of relevant service users

We initially sought to include all adult and child service users residing full time in the 3 biggest private care providers in Ireland funded by the HSE. Due the Covid 19 pandemic the absolute majority were included but not all, and fewer qualitative analyses were carried out than quantitative ones as the process of anonymisation by executive administrative officers was impacted upon by lock down.

Complex financial arrangements

In order to identify relevant service users in the project team decided on approaching a wide variety of sources, described under 'data collection' below. This was to ensure that only mental health or social care funded cases were included.

Conflicts of interest

There were several potential conflicts of interest. For example, surveying patients in the independent sector for a needs assessment can lead to concern by providers about removal of patients. This could impact on the keyworker responses who may wish to portray a more positive image of their employer. Letters of explanation were written to private provider chief executives, with direct liaison and explanation where appropriate.

Confidentiality and Ethics

A needs assessment is essentially a survey and therefore ethics approval was not required. The NPORT staff responsible for data collection visited sites and recorded the responses of key workers/persons in charge information into a password protected laptop. Following data collection, all data was transferred onto a secure database on which each service user was allocated a separate ID.

Data collection

From previous experience of needs assessment, a core set of variables was identified that are crucial in considering the type of service that is appropriate to meet an individual's needs. They included basic demographics, legal status, forensic history, psychiatric history, clinical management data such as number of episodes of restraints, ongoing risks, mobility and level of learning disability.

The Project administrator identified relevant service users through HSE managers , direct contact with service providers and from knowledge in the project team of providers.

Some Information was held at national level in relation to the Disability residential emergency placements and for, from this information, a national database was developed which presented all placements in the following view:

- Service Provider
- Address of placement
- Service User initials
- Adult/Child
- CHO
- Service (disability/mental health)

- Yearly cost of placement

The collated information for each CHO was sent to the relevant Head of Service in Disability and Mental Health to populate the incomplete columns and validate the information contained within the template. The returns from the CHO areas were entered on the national database to ensure that it is up to date.

Contact was made with the heads of service of the private provider to organise the review dates and to ensure the information held on file was correct. Where there was a difference in details the relevant CHO was contacted and issues were resolved. All details collated were held on a national excel database which has a single view of where the individuals are residing, the cost, the CHO who is providing the funding.

Provider services were visited by Nport staff to gather information about each identified service user This was to ensure collection of valid and reliable clinical data.

Data Analysis

We used Microsoft Excel for the basic quantitative descriptive analysis for 307 cases, and a qualitative methodology, where a thematic analysis was conducted to explore the different service pathways of 251 cases.

Reference Group

A reference group met monthly to discuss the governance of the group and plan how the data shapes future service provision. It was also a forum to discuss a small group of service users whose trajectory was of concern and who required discussion with placing managers. Thus in order to use the existing patient group as a proxy for future service need it is vital to have a consistent approach to categorising that need in respect of the staffing level, care group and state of admission. The reference group methodology allows this. It relies on a group of professionals who have experience of specialist care. As can be seen from the reference group members (Appendix D), the clinicians have experience of specialist care, including for people with learning disability, both from perspective of provision and of placing and monitoring patients in specialist provision.

Anonymised information was presented in reference group meetings, leading to a brief case and whole residence discussion and updates on data analysis

A National Placement Oversight and Review Team (NPORT) was piloted for a period of 6 months and a number of assessments were planned (1 consultant psychiatrist, 1 nurse (CNS), 2 social workers (0.4 WTE). Placements in the 3 biggest private providers were reviewed during this period.

Results

Quantitative data

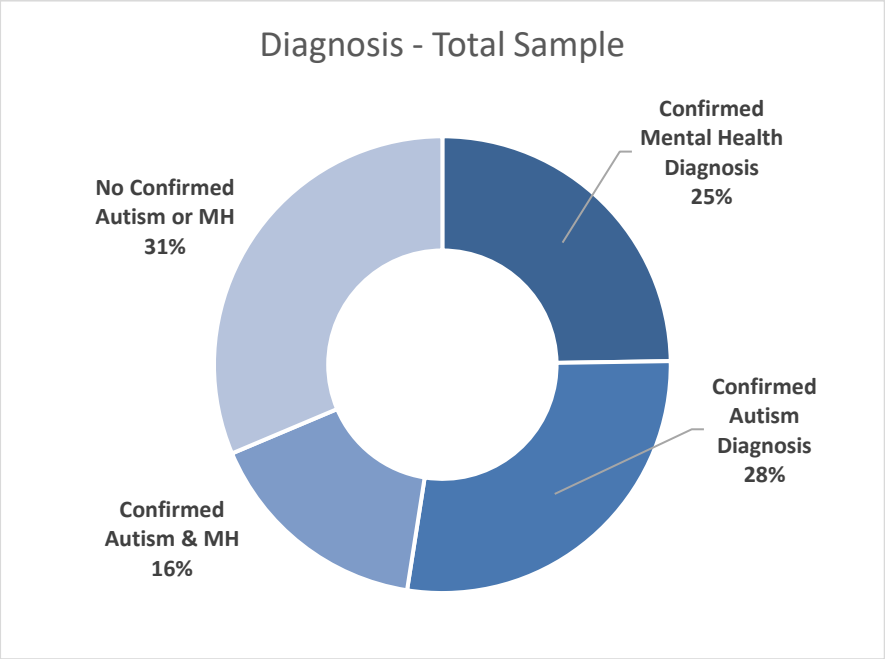
Male	74%
Female	26%

- 74% of service users identified were male, and 26% were female. 23.4% of Service Users were non-verbal. This is particularly relevant given the lack of oversight from services in families in remote placements.

Primary Disability	%	No.
Intellectual Disability	52%	161

Over half of the service users had a diagnosed learning disability. Furthermore, almost a quarter of service users assessed had a diagnosed mental health issue. Slightly more had diagnosed autism, and a significant number had both diagnoses. There were also a significant number who neither and had either a diagnosis of learning disability on its own or other diagnoses such as an acquired brain injury.

Total Sample - Autism/MH/None	%
Confirmed Mental Health Diagnosis	24%
Confirmed Autism Diagnosis	27%
Confirmed Autism & MH	16%
No Confirmed Autism or MH	31%

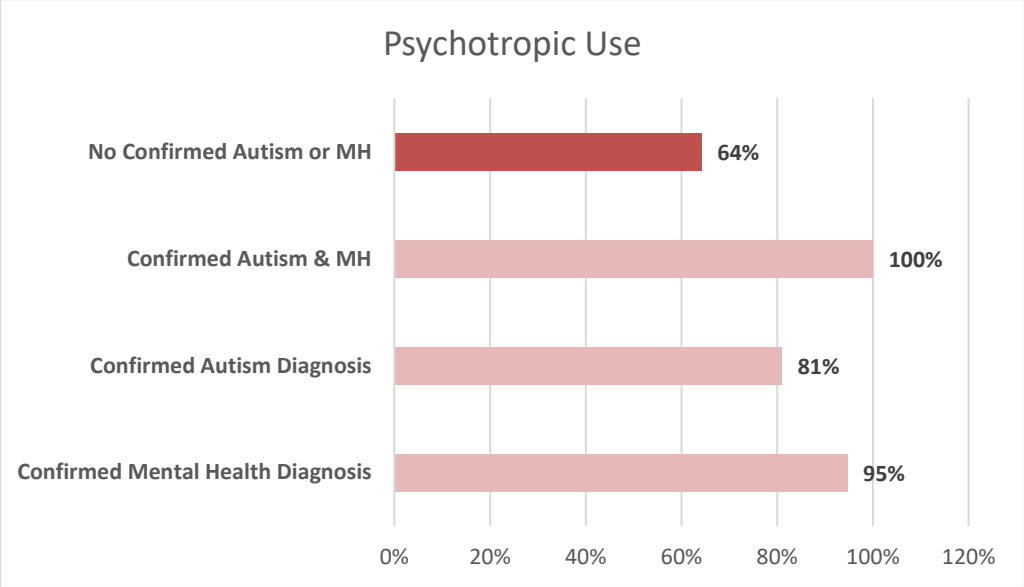


In those with physical and sensory disabilities, there were a plethora of co-morbidities in almost half of the cases.

Primary Diagnosis - P&S	%	No.
Confirmed Mental Health Diagnosis	36%	8
Confirmed Autism Diagnosis	5%	1
Confirmed Autism & MH	5%	1
No Confirmed Autism or MH	55%	12

In terms of psychotropic use, it is important to note that the 'no confirmed autism or mental health' group have the least evidence in terms of psychotropic effectiveness yet nearly two thirds had these prescribed these.

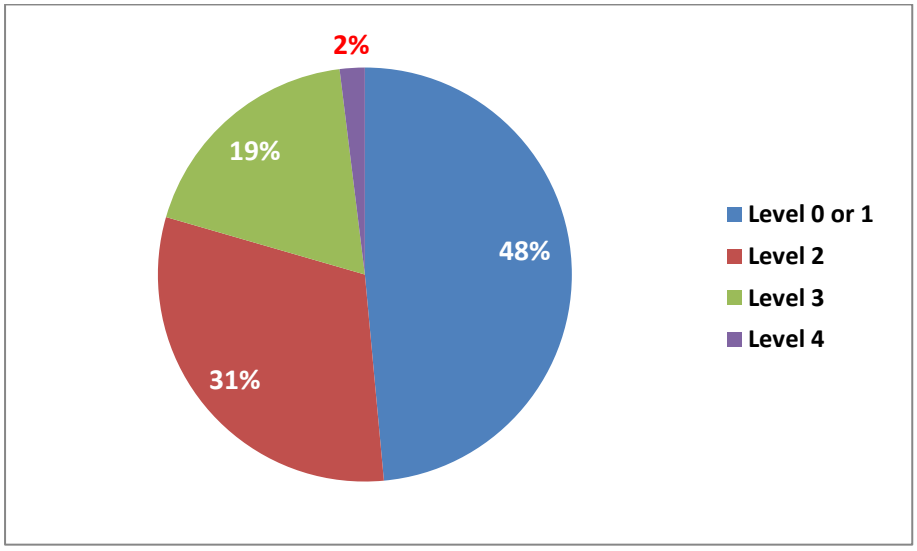
Autism/MH/None - Pyschotropics	%	No.
Confirmed Mental Health Diagnosis	95%	71
Confirmed Autism Diagnosis	81%	68
Confirmed Autism & MH	100%	49
No Confirmed Autism or MH	64%	61

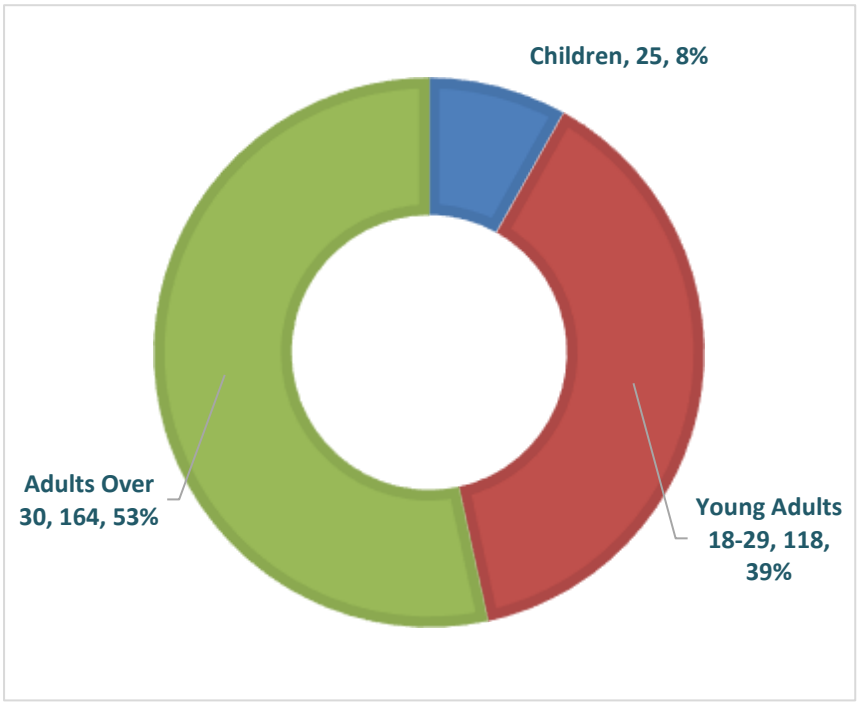


Only just over one third had contact with an extended family member, with the vast majority having no such contact.

Total Persons with contact with extended family
36.8%

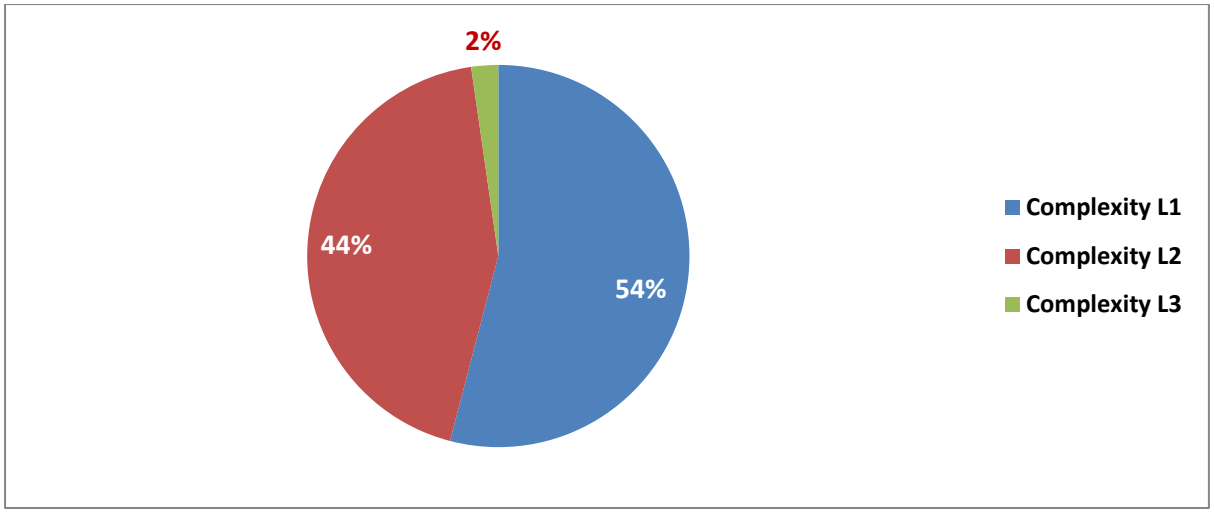
In terms of Behaviour intensity, only 2% per cent had current levels that can be classified as extreme requiring 2;1 or higher levels of staffing.



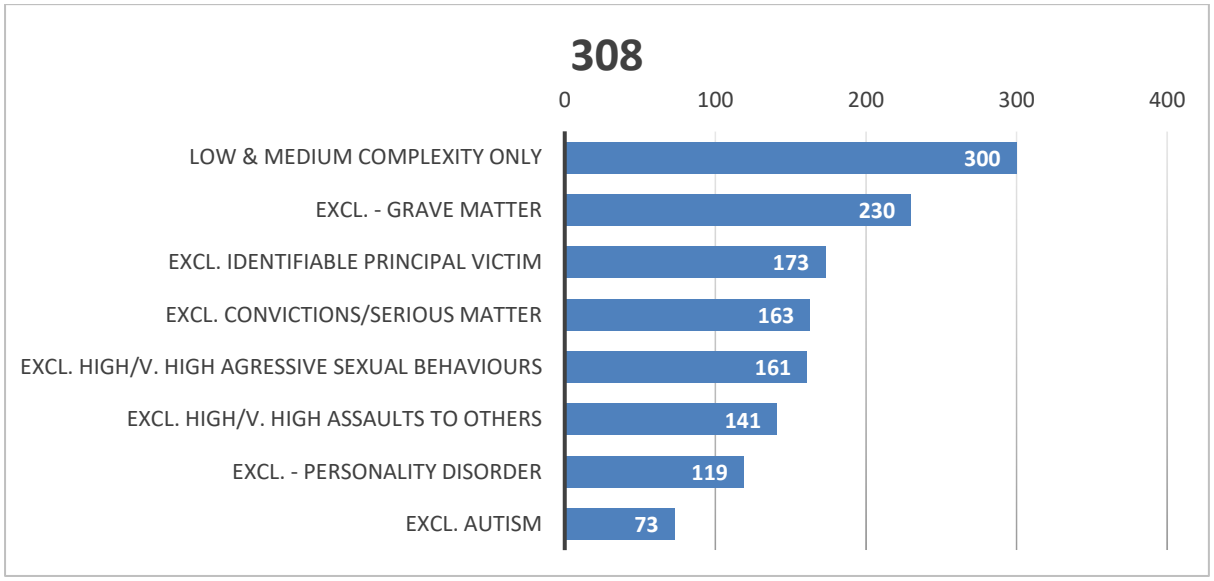


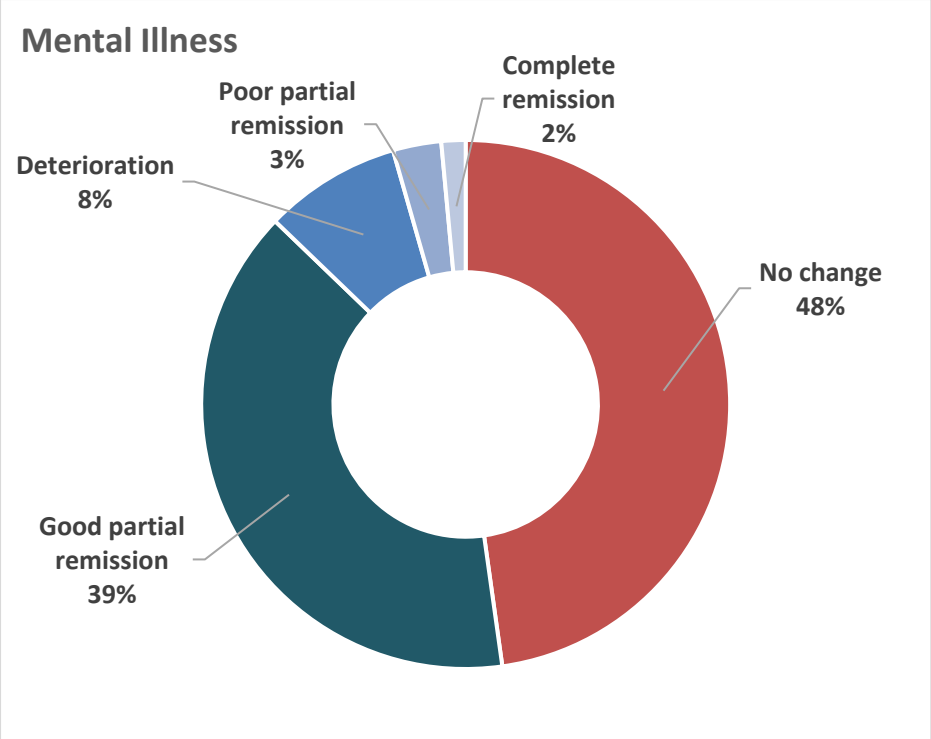
In terms of age profile of those out of county, approximately 2 out of 5 were in the 18-29 years of age group. 1 in 20 were children.

A Complexity algorithm was designed by the reference group. Only 2 per cent of individuals were rated as currently being in the highest acuity/complexity band.

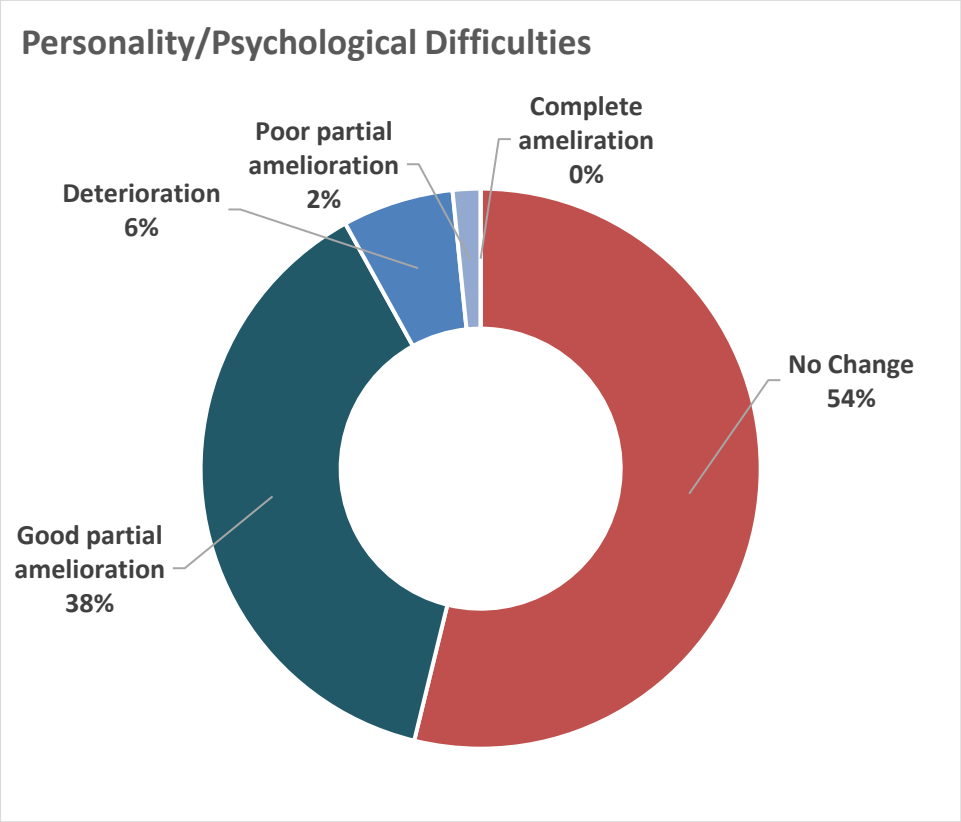


However, a breakdown of lower complexity cases shows that less than a quarter of medium and low complexity cases are genuinely ‘not complex’ due to the presence of significant historical or diagnostic risk factors.

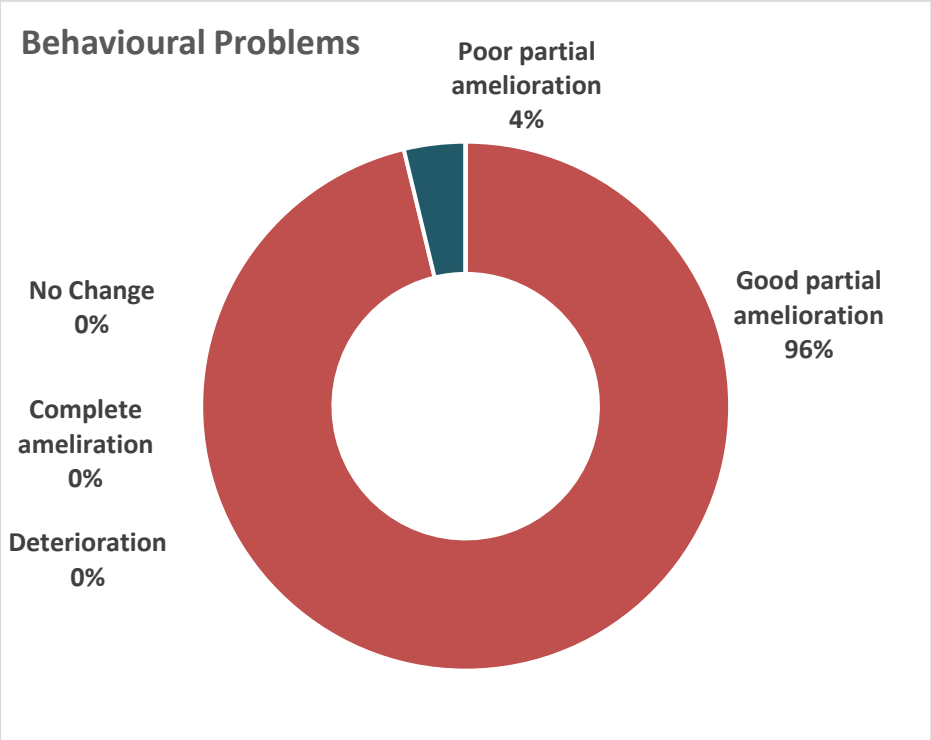




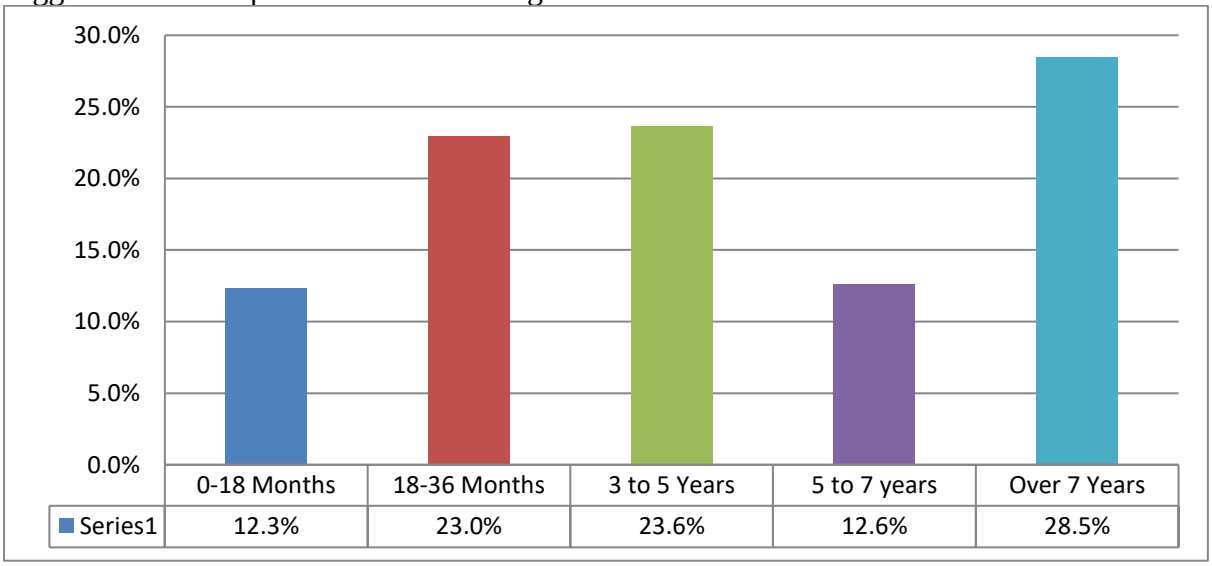
In terms of remission, there was a roughly equal split in terms of mental heath issues. 48% showed no change.



The rates of remission in those with personality or psychological difficulties was rated as very slightly lower than those with mental illness. Rates of improvement in those with challenging behaviour were reported as very high



In terms of lengths of stay nearly 2/3 had been in remote placements for over 3 years, which suggests that these placements were being viewed as a home.



Summary of key findings

Despite considerable obstacles, 308 people were assessed in total.

- 74% of the total were male and 26% were female.

- Polypharmacy and limited communication significant issues
- Limited contact with family a significant issue, exacerbated in children.
- Only a small number of service users were requiring observation rates at a rate greater than one to one, however historical and diagnostic risks suggests return to localities not straightforward.

Qualitative data

Two underlying themes emerged from the data

Theme 1: Complexity/Uniqueness of Cases

This theme encapsulates the complexity and uniqueness of each case due to the high variability in backgrounds and living circumstances prior to attending a care service. Some service users had been homeless, or had recently been discharged from prison:

"came from prison following assaultive behaviour. Was homeless at time of offence."

"He was released from prison two months ago and is not linking in with the services since. He is now homeless, like his parents who are also in and out of prison."

The data indicated that a small number of service users had moved to Ireland from abroad, most commonly from the UK, in childhood.

"He lived with his family in UK where he attended a Special Needs School. He subsequently moved to Ireland with his family at 19 years of age. He was released from Prison in 2013 and absconded to the UK. He spent 3 years in a Forensic Unit in UK. He was then transferred back to Ireland where he was admitted to The Department of Psychiatry. A year later he was arrested, charged and remanded to Prison. He was transferred back to The Department of Psychiatry. He was released from prison. He was rearrested the same day due to the possession of a firearm. He was transferred to prison and was under the care of the prison Inreach Team."

In some cases, the service user had previously been referred to the UK for assessment or treatment.

"In 2000 he set fire to a house in the service provider. He was then placed in the UK where he stayed for two years."

"He was referred to the UK by CAMHS where was diagnosed with Conduct Disorder."

"He was Court diverted to care in the UK following this incident. In 2016 he was admitted to a location with service provider from the UK"

The data also included extremely unique cases, such as the following service user who was a child victim of war:

"She was born to Kurdisk parents in an Iraqi refugee camp. As a child a piece of concrete fell on her head during a bombing raid. She moved to Ireland in 2016 through the UN Family re-unification project."

Theme 2: Suitability of Environment

This theme captures the suitability of a service user's environment to meet his/her needs, whether it was the family home or a service provider. This theme includes the inability of parents or services to cope with challenging behaviours either due to the severity of the behaviour, or due to the physical environment not meeting the service user's needs.

Some patients were removed from their homes because their families were unable to cope with their extreme behaviour.

"Her family was unable to manage her challenging behaviour and aggression towards her younger brother."

In other cases, parents were unable to provide adequate support because of their own health issues.

"Her adoptive mother developed arthritis and had some difficulties caring for her."

"His mother had a fall and could no longer support him."

Some service users came directly from their homes following the death of one or both parents.

"Following the death of his parents in the 1990s, he tried to care for himself alone in the family home but became extremely neglected. He was attacked by dogs and also assaulted members of a gang. The house deteriorated with vermin and he was eventually admitted to Hospital."

"he was admitted to his current location from home where he lived with his sister due to the death of his mother."

"He lived at home with his parents until the death of his mother. He then lived with his father for a short time. He was unable to manage his behaviour."

In cases where service users had been moved from their previous service provider, the reason may have been due to challenging behaviour:

"He was admitted to hospital from a Nursing home where he was alleged to have caused a fire. As the Nursing home would not accept him back there, he then moved to another Nursing subsequently. He was admitted to the current service provider following a number of behavioural problems including threats to burn down the hospital, threatening suicide and assaults to other patients and staff members".

However, a service user may also have been moved due to the unsuitability of the physical environment:

"This placement broke down due to its close proximity to the family home as he would abscond and return to the family home."

"The physical environment did not meet his needs."

"came from HSE house following closure due to reported HIQA concerns about congregated setting"

Vignettes of residences highlighting issues in out of area placements

House 1 (children)

- All cases out of county of origin.
- Some with no family contact, others parent(s) only. None had contact with cousins/aunts/uncles etc.
  - All attending original schools with lengthy commutes. No local alternative.
  - No provider Camhs psychiatrist.
  - None stratified as having high complexity/behavioural intensity. .
  - Significant special rostering arrangements, yet SUs out of the house 6+ hours Monday-Friday term time.

House2 (adults)

- 6 service users
- Open service, very little in terms of complexity, incidents or challenges
- 2 SUs with no history of any behavioural issues ever, admitted due to death of carers
- All out of county, from the same county essentially
- Significant cost incurred by the HSE likely to exceed significantly the provision costs of a local service.
- No follow up from placing local services due to the low presentation complexities. No expectations to move into more independent settings.

Discussion

The three providers only provided residential services, with independent apartments essentially linked to 24 hour staffed accommodation. This means that there are likely to be significant Challenges in moving service users into independent living as out of area providers have not been commissioned to provide this type of service.

It is important to note that stakeholders are not aligned in promoting a flow of service users into more independent settings. It makes little commercial sense for private providers to do this, and families may be very concerned about reduced supervision. Local services do not

appear to expect this from providers, and service users in the middle of this conundrum are significantly disenfranchised.

The placements were individually commissioned with no central oversight. Service users largely did not have locally commissioned group day services. Some placements were the result of limited local capacity (following the death of a carer) where emergency placements were required.

Lengthy placements had gone on for many years. Out of area placements are being viewed as 'home' as opposed to an emergency response

For cases where patients were moved from home following the death or illness of a parent, effective planning could ensure that patients enter a service provider in their own vicinity, close to their own social network, rather than being moved out of county. It must be acknowledged however that many of the service users presented with current or historical complexity which is significant. Unless care packages locally are equipped to deal with this level of complexity, remote private placements will continue to exist in significant numbers.

The significant improvements of behavioural presentations were encouraging.

Limitations of the project

Incomplete data collection; *Despite our efforts, the Covid 19 crisis meant we were unable to collect data on remaining private provider placements*

Reporting bias; It is inevitable that reporting bias may take place when information is collected via interviews with key workers and persons in charge. This type of information may lack objectivity, particularly if a staff member wanted to provide a particular impression of their service and the quality of care provided.

Successes of the project

Nevertheless the number of assessments carried out exceeded initial expectations by a factor of 2-3 in respect of the number of service user surveyed.

The project confirms the suspicion of the project team that out of area placements are a significant public health issue for the HSE.

A final note of caution, Time for action report (2016) states that people at risk of abuse tend to be Physically mobile, Aggressive, young, non-verbal, unsociable, self-injurious, lacking social skills, vulnerable, dependent, disenfranchised, powerless people. We noted a significant number of people in those categories in out of area placements.

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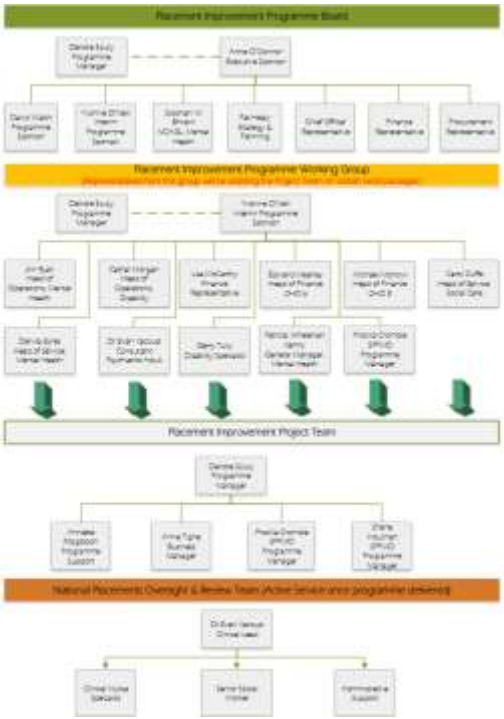

Appendix A governance structure

Physical Health complexities		
	Controlled	Uncontrolled
2.7. Epilepsy	0.5	0.5
	Yes	No
2.17. Cardiac Issues	0.5	0
Monitoring issues	Yes	No
2.20 Known to Safeguarding Team	0.5	0
2.22e Substance use	0.5	0
Forensic issues	Yes	No
3.12 Grave Matter	0.5	0
3.13 Convictions	0	0
3.17 Offences Against Children	0.5	0
Diagnostic complexity	Yes	No
3.19.2 Personality Disorder	1	0
Poor Treatment response	Yes	No
3.21-3.26 Deterioration or poor partial remission in any category	0.5	0
3.37 Absent engagement in treatment	0	0
3.40 b;	0.5	0

Treatment resistance		
Ongoing disturbed behaviour	More than 6	
3.29 More than 6 incidents in defined recent period	1	
Notoriety or legacy issues	Yes	No
3.40 f Stakeholder resistance to return to locality	0.5	0
3.39 specific victim issues	0.5	0

Complexity Judgement:	
Less than or equal to 1	**Low**
Greater than 1, Less than 4	**Moderate**
Equal to or Greater than 4	**High**

Appendix B complexity algorithm

Steering group and Nport staff members not on list of authors

- Ms Annette Fitzgibbons; executive Admin assistant
- Ms Deirdre Scully, Programme Manager
- Ms Yvonne O'Neill, Interim Programme Sponsor
- Mr Jim Ryan, Head of Operations, Mental Health
- Dr Cathal Morgan, Head of Operations, Disability
- Ms Lisa McCarthy, Finance Representative
- Mr Edward Meaney, Head of Finance CHO 6
- Mr Michael Morrow, Head of Finance CHO 5
- Ms Carol Cuffe, Head of Service, Social Care
- Ms Dervila Eyres, Head of Service, Mental Health
- Mr Gerard Tully, Disability Specialist
- Ms Patricia Whelehan, General Manager, Mental Health
- Ms Priscilla Crombie & Mr Shane Hoilan; SPPMO Programme Manager
- Ms Susan Wall; Interim director of service
- Mr Jesse Albertini & Mr Gerry Monaghan; Social work
- Ms Breda Sammon; Clinical Nurse Specialist;
- Bernard O'Regan; Head of Strategy; Social Care Division